

Medical Futility in the Natural Attitude

Barbara Bennett Jacobs, PhD, MPH, RN; Carol Taylor, PhD, RN, CSFN

Medical futility has a long history going back to Plato but continues to be a controversial topic. Patients, families, and health professionals are faced with decisions about which treatments and interventions may be futile, but such questions as who decides; how do competing values get resolved; what value is placed on human life; how are decisions balanced according to reason and, in some circumstances, faith; and who decides effect, benefit, and burdens of treatments are often difficult to answer. The naïve reality of medical futility is explored in the natural attitude to expose presumptions and facts related to both physiologic (fact-based) and evaluative (value-based) futility components. Highlights from the bioethical and clinical literature, a review of 3 landmark cases, and implications for nursing practice are presented. This natural attitude description could serve as what ought to be bracketed for a future phenomenology. **Key words:** *evaluative futility, medical futility, physiologic futility*

MILLIONS of people around the world witnessed, through extensive media coverage, the deaths of 2 persons who died within approximately 2 days of each other at the end of March and early April 2005.* At the first witnessing, we were the metaphoric peeping Toms, gazing through a hospice window into the *dying process* of one who was surrounded by love and hate, and despair and hope, where a challenge to human finitude was waged, where suffering was suffocating the survivors, and where death was undecidedly demoralized. Our second witnessing was, by invitation only, to the *event of death* of one who was surrounded by love and hope, where human finitude was embraced to segue into an eternal life, where suffering was a source of moral strength, and where death was divine destiny. The juxtaposition of these 2 deaths has challenged the general public

and the general *politic* to engage in both public discourse and political debate, a challenge that has at its focus, among other concepts, medical futility.

The Council on Ethical and Judicial Affairs of the American Medical Association has stated that “a fully objective and concrete definition of futility is unattainable.”¹(p938) Despite the idea that futility language might need to “retreat”² from the ongoing dialogue or be replaced with “more precise language,”³ the idea of futility has not been abandoned. Prendergast suggested 3 reasons for withholding or withdrawing life-sustaining treatments, one of them being “because the therapy in question has no hope of meeting long-term treatment goals.”⁴(p92) Is this language more precise because it relates a particular “therapy,” such as mechanical ventilation or artificial hydration and nutrition, to concepts of “hope” and “goals” or do such carefully chosen words confuse the concept even further? Whether one agrees that medical futility ought to be better defined⁵⁻⁷ or whether one agrees the phrase ought to be abandoned,¹ nurses, especially those working in critical care, hospice, and palliative care are subjects in the personal histories and narratives of patients, families, and physicians who often gather as moral strangers to

From the School of Nursing, University of Connecticut, Storrs, Conn (Dr Jacobs), and the Center for Clinical Bioethics, Georgetown University, Washington, DC (Dr Taylor).

Corresponding author: Dr Barbara Bennett Jacobs, PhD, RN, 37 Belknap Rd, West Hartford, CT 06117 (e-mail: Jacobs@uconn.edu).

*Theresa Schiavo, who died March 31, 2005, and Pope John Paul II, who died April 2, 2005.

decide the life and death issues that futility often poses.

MEDICAL FUTILITY AS A PHENOMENON

Futility, as a phenomenon or object in the world, cannot be adequately defined by an epistemic inquiry based on objectivism alone, nor can it have heuristic meaning based on an epistemic inquiry based on subjectivism alone. The epistemology of constructionism and the philosophical or theoretical foundation of interpretivism form a “scaffolding”^{8(p2)} for the philosophy of phenomenology, when object meets subject at “a point of contact”⁹ that “attempts to find objective essences in the very heart of subjectivity.”^{10(p688)} To go back to the thing itself (medical futility), *Zu den Sachen*, is to reflect on the phenomenon of futility in a phenomenologic attitude of critical realism that is mindful that phenomenology is an a priori or eidetic science where there are no facts but essences¹¹ and where there is “an intensified form of experience with pronounced ego-involvement.”^{10(p743)} This intentionality of a lived experience, *erlebnis*, is not just any experience in life that has taken place but an experience only available as perceived in a phenomenological attitude, bracketed or suspended from natural experience (*erfahrung*). A natural experience is “naïve living” in the world as it is “tacitly accepted as real.”^{12(p21)} Going from the empirical experience of facts (*erfahrung*) to the phenomenological experience of essences (*erlebnis*) is a “conversion” to retrieve meaning of a phenomenon and come closer to its reality, when “philosophical objectivity is tied into the consciousness of the subject” (R. Dell’Oro, personal communication, November 21, 2002). Table 1 contrasts natural everyday experiences with lived experiences by comparing the knowledge gained from each experience, the position or perspective from which truth is disclosed in each experience, and contrasts the objective science of the natural experience with the eidetic science of the lived experience. Medical futility is a phenomenon that

can be experienced in all its naïve reality and/or it can be consciously constituted by an intensified intuition of its critical reality. Asking those who experience medical futility to share their thoughts and feelings about medical futility (as they have experienced it) from their perspective in the natural attitude is not doing phenomenology. Such information derived from the natural attitude is not without use; it may be helpful information for those who have not had the experience to learn about it from others. Doing phenomenology as research requires the researcher to somehow transcend descriptions obtained in the natural attitude and analyze data using a phenomenological method that requires intentionality.

PURPOSE

Before any critical reflection in the phenomenological attitude can be achieved, the naïve reality, in the natural attitude ought to be explored. The purpose then of this article is to describe medical futility from the natural attitude as a method to expose assumptions, facts, and beliefs that are currently available in the literature related to the physiologic and qualitative components of futility. It is not within the scope of this article to describe futility as a *lived* experience from the phenomenological attitude, yet we anticipate *doing* such a phenomenology in the future. The future phenomenology will use a research methodology that studies the *object* of experience (in this sense the object or phenomenon will be medical futility) from the perspective of *subjects* experiencing the phenomenon, for example, either health professionals or surrogate decision makers. To achieve our purpose of explicating futility from a naïve reality, a brief etymologic explanation of futility will be given, followed by key highlights from both the reflective bioethical literature and the research-based clinical literature to describe futility’s fact and value components. In addition, 3 landmark cases that have focused the futility issue in

Table 1. Contrast of natural experience and lived experience

Type of experience and German word	Natural experience, <i>erfahrung</i> Spontaneous Empirical	Lived experience, <i>erlebnis</i> “[A]n intensified form of experience with pronounced ego-involvement” ^{10(p743)} “Life world is by no means immediately accessible as such to the average person in the natural attitude” ^{10(p145)}
Type of science	Science of facts; Science of realities—real events with real existence within subjects’ worlds in time and space (<i>omnitudo realitatis</i>); Empirical science	Science of essential being; a priori or eidetic science
Phenomena	Factual or empirical or real	Essential or universal or irreal
Knowledge gained	Natural knowledge of the world and facts	Eidetic knowledge of essences—no facts
Position or perspective	Natural attitude Not mindful of subject’s special relationship with reality—or reality of objects	Phenomenological attitude Mindful of special relationship with reality—noema for noesis—complete intellectual intuition of object
Truth	Objective reality; independent of human involvement	Truth is disclosure of meaning and value as consciously constituted
Words of description	Naïve realism Original; Prereflective or unreflective; Pretheoretical; Common sense; Presuppositions; Preconceptions; Prephilosophical	Critical realism Suspension of natural attitude (<i>epoche</i>); suspension of scientific, philosophical, cultural, everyday assumptions. The source of the phenomenological attitude is the natural attitude, but a reflection on it with the intentionality of a noema-noesis correlation

the courts will be briefly discussed. Futility has been labeled a debate^{6,13,14} and even a battleground,¹³ yet there are few in bioethics or in the health professions that would not welcome some consensus as to the criteria for determining futility in a way that respects liberty, self-determination, and autonomy of the patient and also respects the professional integrity and judgment of medical professionals. Neither ought to have privilege over the other so that their shared decision making balances power and allows for all voices to create a “moral shape”^{15(p32)} to the discussion of the

complex clinical, ethical, personal, and professional issues that the phrase *medical futility* engenders. The phenomenon of medical futility spans religious, spiritual, clinical, ethical, moral, and legal thought; beliefs; values; laws; and policies. We recognize the implications of all of these realms when medical futility is often at the center of end-of-life decision making; however, it is beyond the scope of this article to describe futility from all of these perspectives. Various views, however, are woven throughout the natural attitude description that follows.

GREEK MYTHOLOGY TO LEXICAL MEANING

Many¹⁶⁻¹⁸ recounted the connection of the meaning of futility to the Greek myth of the 50 Danaïds or daughters of Danaus (who was one of the sons of King Belus of Egypt). Danaus's brother, Aegyptus, had 50 sons, whom he ordered to marry the 50 daughters of his brother, a mass wedding that Danaus did not approve. Danaus instructed his daughters to murder their cousins on the night of the wedding; 49 committed the murders, and 1 daughter, Hypermenstra, did not (her husband, Lynceus, eventually murdered Danaus). Upon the deaths of the 49 daughters, the legend contends that they were punished in Hades by having to carry water continuously in containers that had holes.¹⁹ The Latin word *futilis* meaning vain or worthless is associated with the Latin word *fundere*, "to pour or melt"; hence carrying water in leaky containers is considered a futile act. The dictionary defines *futile* as "incapable of producing any result; ineffective; useless; not successful" and *futility* as "the quality of being futile; ineffectiveness; uselessness."^{20(p78)}

PHYSIOLOGIC FUTILITY

When considering futility in the context of medical interventions, the definition is not so concrete and straightforward. Helft et al²¹ tracked what they referred to as "the rise and fall of the futility movement" in medicine. They claimed that the discussion of the concept of medical futility was begun in 1987, waxed in 1995, and subsequently waned from 1996 to 1999. Although a more contemporary discussion of medical futility is waxing again, the idea of futility is found in Plato's *The Republic*, where there is a description of how legal and medical practice should be legislated by the state. Plato deemed it futile to medically support the unhealthy who have "a poor physical constitution" and advocated allowing them to die as well as suggesting that "those with irredeemably rotten minds [will] be put to death."^{22(p122)} Schneiderman

et al¹⁸ kept the debate about futility on center stage when they first introduced the dimensions of quality and quantity to the concept. They posited "medical futility refers not only to the quantitative probability of success or failure of a treatment but also to the qualitative results that treatment achieves for the patient."^{18(p949)}

With these 2 dimensions of futility defined, the authors proposed a method for physicians to evaluate the quantitative probability of medical interventions being of benefit to patients and supported these methods of probability in a subsequent article.²³ According to the principle of probability, if it is the best medical judgment of physicians that a certain intervention, "in the last 100 cases" of their experience with it, is "useless," then such intervention should be judged as futile. The same authors also proposed a method to evaluate whether a certain medical intervention has any qualitative use by considering whether the intervention or treatment "merely preserves permanent unconsciousness or fails to end total dependence on intensive medical care, it should be regarded as futile."^{18(p67)} Bernat agreed that

medical futility is defined as that situation in which a therapy that is hoped to benefit a patient's medical condition predictably will not do so on the basis of the best available evidence. The inability of the therapy to provide benefit to the patient may be either because it is highly unlikely to produce the desired physiologic effect or because it is likely to produce a physiologic effect but one that is not beneficial to the patient.^{16(p218)}

Schneiderman et al²³ responded to criticisms of their original work and clarified many of its aspects. Six specific criticisms, one of the more interesting being that even physiologic futility decisions are associated with value, are described in Table 2 along with the authors' responses. Swanson and McCrary²⁴ postulated that one of the more significant concerns with exploring definitions of futility is that all futility decisions are value-laden, in that physiologic medical futility is more than just a decision based on scientific fact. On

Table 2. Criticisms of the analysis by Schneiderman et al of medical futility with their responses to criticisms²³

Criticism	Response
Patient autonomy and power of self-determination is at risk if it is up to the physicians only to decide what is futile.	Standards of care and the physician's duty of beneficence, not power or whim, should inform him or her not to provide interventions without benefit to the patient.
There is no consensus in the professions or in society about futility.	Professional standards and values should be made known to the public to foster discussion and dialogue.
Broadening the concept of futility beyond physiologic futility is value-laden.	Even physiologic futility is not value-free.
Each patient is an individual and empirical data may not apply to every situation.	Karl Popper argued that there is always some tentativeness in all objectively determined, scientific, knowledge-based conclusions; willingness to say something is ineffective if so in 1 in 100 cases seems "reasonable." ^{23(p672)}
Medical futility does not take religious preferences into account.	Religious beliefs of divine intervention to help heal should not prohibit practitioners from practicing within a framework of professional values and standards.
Medical futility is a futile concept because the allocation of limited resources and rationing will prevail.	Rationing pertains to beneficial treatments, not futile ones; futility has a history as far back as Hippocrates; the goal of medicine is to achieve an end of healing and relief of suffering, and interventions should not be just a means without this end put into context.

the basis of a survey of 301 physicians, they concluded that there is no particular agreement among physicians as to the cut-off point (based on a percentage) of when a treatment should be considered successful. They coined the phrase "the elastic boundary of medical futility" to indicate the lack of consensus as to the percentage of probability of success that could be used to then say a particular intervention is futile. Most physicians reported that a 1% to 10% probability of success of any intervention would indicate that the intervention was really futile. Another 19% placed the percentage of probability of success at 20% or higher. An additional 20% said that even if there was absolutely no probability of success of an intervention, they would not consider that intervention futile—indicating to the re-

searchers that this group had "a posture of denial of the concept of futility."^{24(p323)}

Younger²⁵ related futility to physiology, length of life, quality of life, and probability. Miles²⁶ claimed different perspectives of futility, such as physiologically implausible, nonbeneficial to the patient as a person, unlikely to work, and nonvalidated. Brody and Halevy²⁷ defined 4 categories of futility: physiologic futility, imminent-demise futility, lethal condition futility, and qualitative futility. The definitional dilemmas that these explications produce have a common theme. There are 2 components to the definition of medical futility, one is that the medical futility of a certain treatment in a particular patient's circumstances is based on the judgment that the treatment or intervention in question just will

not work and, therefore, will have no effect or be physiologically futile. The other component, qualitative or evaluative futility, is discussed in the following section. Physiologic futility is typically based on scientific and empirical facts and on physicians' best medical judgments.

A hospital policy for *Withholding or Withdrawing Life-sustaining Treatments* from a large, urban, teaching hospital specifically addresses futility by defining it in terms of only "biomedical futility," that is, "the clinical judgment that it [intervention] is not physiologically possible, in the patient's current clinical circumstances, for the proposed intervention to achieve its biomedical goals. The proposed intervention, therefore, would not be medically indicated." The idea of physiologic futility, or having "no pathophysiologic rationale" is 1 of 3 circumstances that Lo suggested be reasons to designate a particular intervention futile "in a strict sense"; the other 2 circumstances he posited were when implementation of "maximal treatment" still does not prevent cardiac arrest, or when the intervention has previously been tried and failed.^{17(p73)} *Biomedical goals, pathophysiologic rationale, and physiologic goals* are not necessarily synonymous. An example is the patient who has been declared brain dead but whose lungs are being mechanically ventilated to preserve organ perfusion for eventual removal for future transplant. The biomedical goal of organ perfusion in this case is "possible," but if organ perfusion were not the goal, no one would argue that a corpse would not benefit physiologically or otherwise from mechanical ventilation. Pellegrino linked the word *effectiveness* not to the biomedical goal of the treatment (eg, the goal of hemodialysis being to regulate fluid and electrolyte balance and eliminate wastes) but to "an assessment of the capacity of the procedure to alter the natural history of the disease . . . an objective determination within the province of clinical knowledge of the physician."^{6(p1066)}

A deconstruction of the fact (physiologic)/value (evaluative) basis of medical fu-

tility and the objectivity stance of physiologic futility has been waged by Susan Rubin, a philosopher and bioethicist, in her book *When Doctors Say No: The Battleground of Medical Futility*.¹³ While Rubin sought to "challenge the presumptions underlying the standard approach to futility judgments,"^{13(p1)} it is our intent here to use her critical analysis specifically as it relates to physiologic futility.

Rubin challenged 3 presumptions about physiologic futility as interpreted in its current context using social constructionist theory. The first presumption is that truth (in this case the truth or fact of physiologic futility) is outside of the human mind and this objective reality is a source of knowing by way of epistemologic correspondence theory whether a particular treatment is physiologic futile; simply stated, what *is* is and that *is* is a fact not a value. She cited Kuhn²⁸ and Fleck²⁹ to substantiate her claim that positivistic thinking ought to be revisited in this context because "facts are not revealed phenomena but constructed ideas"^{13(p97)} within the minds of scientists in particular and within society as a whole. However, she did not reject the idea of objective truth per se, but did argue, "we do not have, and in fact never could have, direct and unmediated access to an objective medical truth or reality."^{13(p118)}

The second presumption, which supports the belief that physiologic futility as a fact is an objective reality in the purview of physicians to decide, is that knowledge about the futility of a certain procedure or intervention is autonomous knowledge and therefore "value-free, objective, dispassionate, context-independent, and free from outside controlling influences."^{13(p92)} If indeed the knowledge about whether or not a treatment is physiologically futile is derived from just the opposite, that is, values, passion, context, not free from outside influences, then such heteronomy would violate the "autonomy of knowledge credo."^{13(p92)} The idea that physiologic futility decisions are fact-based is not really a presumption that needs to be rejected. Schneiderman et al²³ claimed that physiologic futility definitions cannot be value-free, since

even physiologic futility ought not be limited to whether a treatment merely preserves organ function without considering whether such preservation is a patient-centered goal of medicine. Rubin's claim was that the pursuit of knowledge could never be value-free because values are part of the scientific and therapeutic enterprise, and are influenced by the values and perspectives of the knowledge seekers themselves and the communities in which they reside.

Rubin's third presumption to repute was the fact basis to physiologic futility, being related to the pure scientific method as the gold standard of scientific investigation and inquiry. The scientific method is valued if it is not contaminated or biased by what Rubin called "contextual values,"^{13(p93)} such as those found in the social, political, or economic landscape. However, she contended that these values cannot be avoided, because, for one reason, there is no one scientific method. Different disciplines use different methods, and those methods are constructed from contextual values that represent the particularism-based beliefs of not only the researchers themselves but also the particularism-based characteristics of the objects under study, and the relationships of those objects.

To accompany her deconstruction of these 3 presumptions, Rubin claimed that the problems with "interpretation" (ie, the probability of success or failure of an intervention set of 100 cases) and "uncertainty" (there can be no absolute certainty) and the fact that physicians "make errors" all contribute to her^{13(pp104–08)} assertion that physiologic futility is "an insufficient ground for physician unilateral decision making . . . to refuse to offer, provide, or continue treatment based on their opinion that the treatment in question is futile."^{13(p115)} It is to be emphasized that Rubin's rejection of the current framing of medical futility is centered on her belief that the futility debate itself is about power, the power of physicians to make unilateral decisions to not offer, provide, or continue treat-

ment. The rejection of the fact/value, or will it work/will it be worthwhile, distinction is to render this practice (unilateral decision making by physicians) unacceptable. Rubin does offer an alternative for physicians to use to refuse treatments that patients demand, an alternative that begins with discarding medical futility as it is currently defined because the presumptions are indefensible for the reasons cited; because such decisions are not based solely on empirical facts, errors can be made, and certainty cannot be guaranteed. The alternative is to use social constructionist epistemology—social discourse and consensus, social justice and contract theory—and establish public policy that establishes justifiable limits of medical interventions.

QUALITATIVE FUTILITY

Previously, we linked physiologic futility to what is often referred to as the fact distinction—the fact based on scientific and empirical evidence that a certain treatment or intervention will not achieve its biomedical goal, or will not alter the natural course of the patient's disease, or just makes no clinical sense (eg, doing a craniotomy to treat acute tubular necrosis). Qualitative futility is not about facts but about values, values that lead the patient or his or her surrogate decision makers to conclude that the treatment has no benefit according to those values. Pellegrino⁶ posited that patients make determinations about "benefit" when they subjectively decide whether a certain treatment has value. Benefit determinations are patient-specific, but often the patient's values are unknown, leaving the burden of deciding benefit to family members and other surrogate decision makers. Although benefits may be a patient-centered value decision, "burdens" of a treatment, claimed Pellegrino, could be "the cost, discomfort, pain, and inconvenience of the treatment in question; it includes his/her [patient's] quality of life assessment. Costs are both subjective and objective, financial and non-financial and

are, therefore, determined by both the physicians and the patient or surrogate acting together.^{6(p1066)} An interpretation of this definition of *burden* is that if the burden is related to a fact, then it can be decided to be a burden by the physician; however, if the burden is subjective and personal, it is to be decided by the patient or surrogate decision makers.⁷

The value of life in a persistent vegetative state (PVS) poses one of the greatest moral (and legal) dilemmas in clinical practice and, despite the legal precedents and decades of moral and theological reflection, there is a continued lack of consensus in public discourse on whether such a life does or does not have value. Keown,³⁰ in his book on euthanasia, articulated 3 perspectives of the value of human life that may serve as a philosophical foundation for why some choose to take actions that lengthen or prolong life for patients in PVS and others take actions that shorten life. The first perspective is that all human life, no matter in what condition or circumstances, has absolute moral value and no action ought to be taken to shorten it. The second perspective reflects the inviolability of human life, in that, because of one's intrinsic dignity or worth and the rational capacity (not ability) to make choices, such life ought not to be violated. The difference between these first 2 perspectives is that the inviolability of life perspective does not necessarily mean that life ought to be preserved at all costs as in the vitalist perspective, but that each treatment being considered will be accepted or refused on the basis of an analysis of the benefits and burdens of that treatment. The third perspective relates to an assessment of not only one's quality of life as related to the worth of a specific treatment, but also the worth of the patient's life as a whole, what Keown called "Quality of life," with a capital Q. There is a line that certain persons are not willing to cross to lengthen their lives, if his or her life does not meet the standard of a life worth living.

Rubin¹³ stated that value cannot be ascertained unless one knows the goal or goals that

a particular treatment is to achieve as cited in the previous description of artificially ventilating a brain-dead patient. To bolster this important point, she cited 18 different goals, found in the literature, that authors have associated with futility, for example, if a treatment does not postpone death, does not benefit the patient, or does not restore consciousness, then a treatment can be determined to be futile according to the values associated with those goals. The "worth it" component is not limited to the worth to the patient or his surrogate decision makers and family. An example makes this point. A patient's husband does not accept brain death as a reason to declare his wife dead and, according to his Asian cultural beliefs, insists that certain nonpharmacological substances (suggested by a traditional Eastern medicine) be administered to his now-brain-dead wife through a nasogastric tube while her body is mechanically ventilated, her heart still beats, and while nurses care for her body in an intensive care bed. The treatment suggested must be administered over 6 days. The worth to the dead woman's husband is that, because she is not really dead, she may recover; a value he bases on his religion, culture, and personal beliefs. The worth question to the staff and to the hospital is one of respecting cultural values and beliefs, utilizing scarce intensive care resources for a dead body, and asking nurses to administer nursing care to a body that has no chance, with certainty, of experiencing any therapeutic benefit or effect. In essence, nurses would be expected to deliver 6 days of postmortem care for the benefit of the patient's husband. The nurses' caring interventions would not be justified by the principle of beneficence, since a corpse cannot appreciate such beneficence, and many would argue that the nurses' caring interventions could not be justified by non-maleficence simply because one cannot harm a corpse in the first place (in the sense of harm that a corpse could appreciate). However, in this case, the nurses were not permitted (by administrative edict) to administer the substances (the husband administered them)

but did continue to administer other more conventional medications. Interestingly, in this case, the patient was “pronounced dead” on the sixth day and “allowed to die” when the ventilator was discontinued despite the fact (or is it a value) that she was dead 6 days earlier according to criteria supported by state statute for declaring death.

The aforementioned description of evaluative futility turns on values, values typically of the patient but also values of society. The description of physiologic futility, however, has suggested that there are other values other than those of worth to the patient that are associated with such determinations. Because a person has a particular value, ought that value be absolute and nonnegotiable? Ought medical professionals be obligated to respond to all personal values even if these values are perceived to force them to provide care that is not medically indicated, may not be in accordance with their medical knowledge, or somewhat fraudulently deceitful because it is given with the knowledge that it will not benefit the patient? Having certain values ought not to justify certain actions just because a certain value exists in someone's mind; it could be that some values or beliefs are just too outrageous to justify actions in a medical context. These values, to be defined in public discourse and in conversations with individual patients as Rubin¹³ has suggested, are goals and values that ought not to be confused with ends. An end in the sense of the Greek word *telos*, according to Pellegrino and Thomasma, “is that for which a thing exists, that which an act is designed to bring about. Ends are rooted in the nature of things themselves. Today, discussion of ends has been replaced by discussion of values and choices. The rights to choose and to value have become the warp and woof of bioethics, rather than a search for the good of individuals and society.”^{31(p22)} The end of the relationship a patient and his or her family may have with a health professional, according to an essentialist view, is right and good healing, meaning that this end of the encounter is grounded within the nature and

philosophy of medicine or nursing and not external to them.³² A more detailed contrast between socially constructed values and essential ends is beyond our scope; suffice it to say that the *telos* or end of the clinical encounter has phenomenological interest for our future phenomenology of medical futility.

LEGAL CASES

The Quinlan case

Three precedent-setting legal cases have highlighted the concept of medical futility. Ms Karen Ann Quinlan lost consciousness in 1975 at the age of 21 after returning home from a bar where she had been drinking. After suffering a cardiopulmonary arrest, she was placed on a ventilator. After the first 6 months of being ventilator-dependent, her parents requested that the ventilator be removed since there was every indication that their daughter would never regain consciousness. Because her physicians refused to remove a ventilator from a live patient for they were concerned about their liability,³³ the case went to the New Jersey Court, which appointed a guardian *ad litem* to make healthcare decisions. The guardian did not agree with Ms Quinlan's parents and supported the decision to continue mechanical ventilation.

The Quinlan case points out the struggle that ensues when family members and healthcare team members cannot come to agreement on what is futile or what is in the best interests of the patient. The legal battle that resulted from the disagreement of Ms Quinlan's parents, the guardian *ad litem*, and the physicians resulted in the New Jersey Supreme Court reversing the ruling of the lower court and appointing her father as her guardian for medical decisions and allowing the ventilator to be removed. Ms Quinlan survived ventilator weaning and lived for 10 more years in a nursing home, where she eventually died of pneumonia.

The reason given for why the parents considered the ventilator treatment futile and why they continued artificial hydration and

nutrition for their daughter was that they perceived that the ventilator caused her suffering and the other intervention did not.³⁴ Devettere objected on moral grounds to the weaning procedure used to remove the ventilator because it ultimately “brought no good to the patient, was not consistent with the desires of the proxy, and imposed a decade of expensive and useless care on a vegetative body.”³⁴(p207)

The Baby K case

The case of Baby K was a futility-based case also.^{18,34} When she was born in 1992 by caesarean section, her mother already knew from prebirth examinations that the infant was anencephalic and at the time refused an abortion. Despite the doctor's suggestion that ventilatory life support be discontinued after it had been initiated immediately after the birth, the mother insisted on continuing support. After being discharged to a nursing home, Baby K returned to the same hospital where she was born on several occasions when she sustained respiratory distress requiring reintubation. The hospital requested the federal court to rule against the mother's decision to continue the cycle of intubation-ventilator-extubation-discharge-respiratory distress-reintubation on the grounds that such care was futile and did not follow the standard of practice of care for an anencephalic infant.

Robert Veatch, a bioethicist, presented a moral analysis of the Baby K case on 2 different occasions (R. Veatch, lectures, June 2000 and April 2004). Veatch described 5 criteria that, if met, obligate a physician to deliver a service even if it violates that physician's judgment that such service is futile. The 5 criteria are as follows:

1. the physician has the skill to deliver the service/intervention;
2. the service delivers the effect the patient or surrogate decision maker is expecting—a normative effect or fundamental interest, for example, prolonging life or relieving pain and suffering;

3. there is available, equitable funding either from an insurance plan, independent funds, or a charity;
4. there is an existing ongoing patient-physician relationship;
5. there is no competent colleague willing to take the case.

The Baby K case and Dr Veatch's analysis demonstrated that what appears as a professional integrity case is really not a case of dispute in medical science but a case of what normative effect means and whether it provides reason enough for a court to order treatment as compulsory even if there is no moral obligation for the physician to provide such care. As Veatch described, physiologic futility is relatively simple to explain. It would obviously be physiologically futile to perform an amputation of a leg in the hope that it would achieve healing a diseased heart, but it is not physiologically futile to provide ventilation to an anencephalic infant if the goal is for ventilation to achieve its biomedical goal of ventilation.

However, normative futility or subjective futility may be when a certain intervention achieves a particular goal sought by the patient or surrogate decision maker but the goal is not perceived by the physician as worth pursuing. In this case, the mother of Baby K did not view treatment for her infant as futile—her desired goal was not necessarily to have her daughter cured of anencephaly but to preserve the infant's unconscious life.

As one of the attorneys of Baby K stated, the distinction of subjective futility vis-à-vis physiologic futility was central to the court's decision.³⁵ To the mother, whose fundamentalist religious belief was that all life is a precious gift from God, her daughter's life was worth living. She once was quoted as saying “I believe in God for a total miracle that she'll be a living testimony to the world.”³⁶ Devettere,³⁴ in his moral analysis of this case, agreed that the care the mother was demanding was futile; however, the care caused no harm to the infant and was being requested on the basis of religious beliefs. That the physicians offered treatment at the time of

the infant's birth, since such treatment is not in accordance with standards of treatment for anencephalic infants, has been cited as a criticism.¹⁶ Some suggested that the issue of resource allocation should have been considered.^{16,34} In this case, the physicians contended that resource allocation was not an issue nor was the insurance company unwilling to pay, and was not named in the legal proceedings.

The federal district court ruled in favor of the mother's religious belief, the right to life, and the Emergency Medical Treatment and Active Labor Act (EMTALA) that requires emergency care be given to all patients regardless of their ability to pay. Other statutes considered during the court's proceedings were the Rehabilitation Act of 1973, the Americans with Disabilities Act, the Child Abuse Amendments of 1984, and the Virginia Medical Malpractice Act.³⁵ The favorable decision for the mother of Baby K was appealed to a 3-judge panel of the Fourth Circuit Court, where the federal decision was upheld. Further appeals to the Federal Appellate Court and the US Supreme Court were denied. The child died in 1995 at the age of 2½, the longest recorded life of an infant born with anencephaly.³⁷ Bernat¹⁶ is quite clear in his belief that no physician is under *moral* obligation to provide what they consider to be futile care. The American Medical Association in its Code of Medical Ethics states, "Physicians are not ethically obligated to deliver care that in their best professional judgment, will not have a reasonable chance of benefiting their patient. Patients should not be given treatments simply because they demand them."^{38(p13)} Bernat posed the following in his discussion of the Baby K case:

Whether a child's mother has the right to insist upon a treatment regarded by all physicians and by society as futile . . . a strong argument could be made that it is an irrational wish, particularly given the reasons she holds it. She is hoping for a miracle to cure her daughter. Relying on this wish as the only basis for choosing aggressive therapy is irrational. Such a wish is not simply highly improbable; it is impossible. Although the baby's mother

may be a sincere believer, religious faith in miracles alone cannot justify the irrationality of her wish.^{16(p228)}

However, the mother did not hold out a cure for anencephaly and even perhaps recognized the physiologic futility of providing life-sustaining treatment in the hopes that such treatment would benefit her daughter or change the natural course of her disease. The mother had a fundamental interest that had nothing to do with physiology but everything to do with the religious belief that all life is precious and that miracles can happen. Others have posited that the Baby K case was not a case about futility at all because ventilation was keeping the child alive and, therefore, was a benefit as determined by her mother and was not futile.³⁹ Despite it not being a case of futility, Clayton contended that the court was wrong in making Baby K's medical care compulsory. Her 3 reasons were that it is "appropriate to decline to provide medical interventions to individuals who will never (re)gain consciousness . . . we cannot and ought not pursue biologic existence at all costs. . . it is too much to require health care providers to provide ventilatory assistance, other sorts of ICU care, or even organ transplants for patients who will never (re)gain consciousness."^{39(p14)} These comments demonstrate the debate about medical futility—who decides, based on whose values and preferences; what value is placed on human life; are there criteria for determining whose life is worth living; how are these decisions balanced on the basis of reason and in some circumstances faith; and who decides effect, benefit, and burdens. There is a disagreement about the answers to these questions and there are those who would argue that only the patient and his/her surrogate decision makers know what would be in the patient's best interest. But this often-indefinable, elusive phrase, "in the patient's best interest," is a burden that frequently incapacitates family members to make decisions. It is quite clear, these decisions to respect the patient's best interests cannot be made

without the caring, compassionate, prudent, and intellectually honest input from health professionals. From our own clinical experiences, we have witnessed personal patient narrative after narrative when patients' families, amid the existential pain, tears, and agony of decision making, ask us, "If this was your mother, what would you do?"

The Theresa Schiavo case

As Annas³³ has pointed out, there is nothing particularly different in the circumstances of the Schiavo case either legally or ethically from the Quinlan or the Cruzan case. Nancy Cruzan's parents petitioned the US Supreme Court in 1990 to allow the removal of their daughter's gastrostomy tube after she sustained injuries in a car crash that left her in a PVS in 1983. Of interest, however, is the similarity in the facts of these 3 cases: all women were in their 20s at the time of their illness/injury; all were diagnosed in PVS; all were receiving artificial/medical hydration and nutrition; all 3 lives and deaths had profound impact on the issue of medical futility; all centered on whether there was clear and convincing evidence of their wishes; and all were being cared for in healthcare facilities by nurses. The Quinlan case led to states' enacting living will legislation and hospitals' embracing the merits of ethics committees. The Cruzan case immediately preceded the enactment of the federal Patient Self-Determination Act in 1990. The interest of the Schiavo case was the involvement of elected politicians both at the state and the federal level as well as the involvement of President George Bush.³³ Yet, what seems most compelling to viewers was the spectacle outside the hospice unit on the streets of Florida. This was not the typical battleground of medical futility between doctors, patients, and surrogate decision makers, but between values, religion, and the role of the US government in private healthcare decisions. Such a debate about values is exactly what Rubin is suggesting as an alternative to the current conception of medical futility, albeit it is unlikely that she perceives what hap-

pened in Florida as a "focus group" between the medical profession and the general public.

Views on artificial hydration and nutrition

What did happen in Florida was the exposure of competing values about life in a PVS and whether or not there is *evaluative worth* in continuing to nourish these patients through artificial means, and there is little doubt that artificially feeding Ms Schiavo *physiologically worked* in the sense that it provided her cells needed nutrients but it would not alter the natural course of her disease.

The fact that certain cases of futility are referred to the legal system for final decision means likely that the healthcare team and those persons who are making the decision for the seriously ill or dying patient cannot agree on the course of medical action nor do they agree on the appropriateness or inappropriateness of the means to achieve the healing end of the relationship with the patient. The pendulum of futility can swing in 1 of 2 directions. The family or surrogate decision maker may perceive that a certain intervention is not futile and request that it be implemented (as in the Baby K case and according to the parents in the Schiavo case), or a family perceives that a certain intervention is futile whereas the healthcare team perceives it should be implemented (as in the Quinlan case).

The Ethical and Religious Directives for Catholic Health Care Services specifically states,

A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community. There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient.^{40(p31)}

This is the guide for Catholic hospitals and is based in Catholic moral theology. What

surfaced in Florida was not particularly a debate about a futile medical treatment but a debate about (1) whether or not artificial hydration and nutrition is a medical treatment as is mechanical ventilation, (2) whether or not such feeding is an ordinary or extraordinary means of sustaining life, and (3) whether or not it is ever morally permissible to discontinue its use. Conservative believers opine that medical hydration and nutrition is an ordinary means of survival, and once removed does not simply allow the patient to die from his or her disease (as does removal of a ventilator) but leads to “death, not because of the illness, but because of our omission to provide adequate nutrition and hydration, . . . whatever the medical condition of the patient, artificial nutrition and hydration have to be continued.”^{41(p12)} Even though Iscara⁴¹ made this statement, he did acknowledge that in the case of certain patients in particular terminal conditions, certain burdens may change the status of such feeding from something ordinary to extraordinary and, therefore, too burdensome to continue.

Cahill, in her analysis of the writings of moral theologian Richard McCormick, specifically in his article “To Save or Let Die”⁴² printed over 30 years ago, sums up the importance of life, its quality, and its value:

Quality of life makes a difference. The highest value in human life, the one for which biological life is given, is love of God and neighbor. When life does not or can no longer serve as the condition for experiencing this higher, more important good, then life has ceased to be a commanding value for the undoubtedly valued person. Death may be permitted to arrive, even by withdrawing technological measures that make it possible to go on.^{43(p134)}

Cahill explained that McCormick did not believe that living in a PVS had any benefit or value to the person in such a state.⁴³ Conservative and liberal views span politics, religion, medicine, nursing, and ethics as demonstrated by these views of life in a PVS and the use of artificial hydration and nutrition to sustain it.

POLICY/GUIDELINE INTEREST

There is professional interest at the policy and guideline level regarding medical futility. The Ethics Committee of the Society of Critical Care Medicine⁴⁴ has 5 recommendations for policies that address futility (Table 3). Lo, a physician, suggested 3 “safeguards” for physicians to implement when they believe a certain intervention is futile: (1) “establish explicit guidelines on futility,” (2) “obtain a second opinion,” and (3) “discuss the intervention with the patient or surrogate.”^{17(p77)} The American Medical Association has suggested that the following 7 steps be used if there is disagreement regarding futility: (1) attempts should be made in advance to come to agreement with patients or their surrogates and physicians as to what constitutes futile care, (2) use joint decision-making models to negotiate any conflicts or disagreements, (3) use consultants if needed to negotiate conflicts and disagreements, (4) use an ethics committee consultation if needed, (5) transfer the patient to another physician if the institutional review supports the patient yet the physician “remains unpersuaded,” (6) transfer the patient to another institution if the institutional review supports the physician but the patient “remains unpersuaded,” and (7) “if transfer is not possible, the intervention need not be offered.”^{1(pp937–941)} Transfer to another institution as the final step in this facilitative approach to a conflict may not be possible if it depends on a facility and another physician being willing to accept such a patient.

Table 3. Recommendations for futility policies from the Society of Critical Care Medicine⁴⁴

- Discussed with and be available to the general public
- Reflect acceptable moral values
- Not exclusively dependent on prognostic scoring systems
- Include description of an appeals process
- Recognized by the court system

In 1999, a patient with amyotrophic lateral sclerosis was admitted to the Massachusetts General Hospital. Although the hospital and its medical staff petitioned a Family Probate Court Judge to intervene in the best interests of this patient to discontinue what they judged as futile care, that is, mechanical ventilation, the patient's daughter insisted that her mother would want such care based on her conversations with her mother prior to her losing the capacity to voice her own preferences. On March 11, 2005, while still hospitalized since 1999, it was decided in court that the ventilator be withdrawn by June 30, 2005 (the patient died just days prior to that date).⁴⁵ In 2003, Blue Cross and Blue Shield of Massachusetts declined to continue to pay for the patient's "custodial care not covered under her policy, leaving the hospital to cover the cost of her treatment at least \$1000 to \$2000 a day."⁴⁶ It has been our experience that in circumstances such as these, for example, a patient has no insurance coverage, a long-term need for mechanical ventilation, is receiving artificial medical hydration and nutrition, and there is no hope of recovery, many institutions flatly refuse to accept such patients. So although the American Medical Association's approach sounds reasonable, the social structures of institutions define policies and practices that often make such implementation impossible. If one institution, even with the sanction of its ethics committee, refuses to provide futile care to a patient, it is naive to think another institution would be willing to open their doors to such a patient. Suggesting transfer of such a patient is in and of itself morally questionable in light of knowing one would be transferring the burden(s) of care to another institution.

The American Trauma Society perceived a crisis related to the issues of manpower shortages, the increasing demand for intensive care unit beds that often necessitates hospitals to divert ambulance patients to other facilities, an aging population, the needed integration of palliative care into trauma care, and the rise in the sophistication of medical technologies. The crisis is so pressing and important

that they convened a national panel of experts in 2003 to address these issues. This Trauma Leadership Forum, titled "End-of-Life Issues: Quality, Availability, and Ethics,"⁴⁷ outlined specific recommendations for the utilization and availability of intensive care and for the integration of palliative and trauma care. Simultaneously with the conduct of this forum, the new *Guidelines for Withholding or Termination of Resuscitation in Pre-hospital Traumatic Cardiopulmonary Arrest* were being promulgated in the literature.⁴⁸ These guidelines clearly have medical futility as an underlying construct.

IMPLICATIONS FOR NURSING

Redman and Fry reported the most prevalent theme of ethical conflict described by nurses working in intensive care units was "harm/good of life-prolonging aggressive therapies."^{49(p6)} Fry and Riley⁵⁰ reported that the second most disturbing ethical issue to 521 surveyed nurses practicing in 6 New England states was "prolonging the living/dying process with inappropriate measures." Moral distress is the subject of an official position statement of the American Association of Critical Care Nurses.⁵¹

At the level of clinical nursing practice, one of us (CT) has challenged nursing to be a major negotiator when there is conflict between the medical physician and the family as to the best treatment plan for the patient.⁵ There are 3 options that can be laid out when such conflict arises. Either the patient or his or her surrogate is considered the one who ultimately decides whether an intervention is futile, but not be the ones to decide physiologic futility, or all futility decisions are left to the physicians to make, or there be a "*compromise*" that results from shared decision making. There are often underlying reasons that families may request care that the medical team has decided is futile. Such reasons are listed in Table 4. Suggesting that the third option of shared decision making be pursued

Table 4. Possible reasons for surrogate decision makers to request futile care^{5(p303)}

- Faulty reasoning, belief that doing the loving or right thing for the patient means doing everything that is medically possible
- Denial and guilt
- Unrealistic expectations
- Inability to trust professionals to act in the patient's best interest
- Religious conviction that life is to be preserved at all costs
- Economic considerations
- Entitlement mentality

highlights the special value of the relationship nurses can have with families who are being placed in the position to make difficult and serious decisions. The challenge is for nurses to be advocates and mediators because they are the ones who can determine the values patients and families hold as important, because nurses have formed relationships with patients and their families, and because nurses have the knowledge and skills of communication to mediate conflicts. It is unacceptable to wait for futility conflicts to reach a crisis level or wait for physicians or social services to initiate family meetings to discuss goals of care and treatment options. Few would disagree that resorting to hospital policies or the legal system are not the most satisfactory methods of resolving conflicts that center on futility. "If patient care conferences that include patients and families are not routinely scheduled for critically ill patients, a nurse's first task is to convene such a conference."^{5(p305)}

Any approach to conflicts related to futility should stress the importance of establishing trusting, fiduciary, and caring relationships as a means to prevent such conflicts and resolve those that already exist, the basis of the ethics of care. In addition, an institutional ethics committee or ethics consultation service will prove fruitful in making recommendations or advising the healthcare team on how to resolve such conflicts.

There is a plethora of published work in the area of medical futility as it relates to moral philosophy, reasoning, and discernment, withholding and withdrawing of life-sustaining treatments, palliative care, and end-of-life care. The wave of professional/clinical position statements, guidelines, and best practices related to medical futility has for the most part been in the disciplines of bioethics, medicine, and law. This brief review was designed to capsule some of the more pertinent issues and add to nurses' familiarity with the concept to enhance and encourage their role while at the same time describe the concept within the natural attitude.

David Hume, the 18th century empiricist who refuted radical rationalism, introduced the idea of the naturalistic fallacy meaning that "propositions about what ought to be the case can never be derived from propositions about what is the case."^{52(p198)} If the naturalistic fallacy is to be followed, then whatever medical futility ought to be cannot necessarily be derived from what it is. If, however, one believes that the naturalistic fallacy in and of itself is a fallacy, then phenomenology holds promise of using the lived experience as the point of truth by bringing forth a normative claim (the *ought*) from the *is* of such experience. However, applying the philosophy of phenomenology to a methodology of research has met with some criticism from both within nursing and outside.⁵³⁻⁵⁵ The philosophical underpinning of phenomenology, particularly to describe (or interpret) the experience of medical futility, ought not to be abandoned because of methodological controversy. We suggest that this natural attitude description of medical futility is insufficient to embrace the meaning of futility as it is experienced and that phenomenology as a research method holds promise to consciously constitute its essences in a way that will be potentially useful for nurses. What this article has attempted to do is to provide the facts and descriptions that could be bracketed prior to a phenomenological reflection as a first step in a phenomenological explication.

CODA

In describing the case of a woman in her 80s who resides in a nursing home after suffering multiple complications from diabetes, hypertension, atherosclerotic heart disease, and dementia, and was bedridden with multiple decubitus ulcers, Brannigan⁵⁶ uses the phenomenological attitude to address the ethical conflict between her legal guardian's request to have her feeding tube removed and her physician's refusal. Brannigan poignantly wrote,

[P]henomenology reminds us that we cannot in essence split apart the illness itself from the patient's own experience and understanding of that illness. Phenomenology requires that we approach the illness within the entire context of the illness. And in considering this entire context, particularly the patient's overall condition, experience, and preferences, we refrain from focusing primarily upon the treatment modalities. Phenomenology reminds us that illness is not simply a physiological event. It is an existential impairment, an assault upon the patient's world and meaning-giving-activity. If her medical feeding is medically futile and without substantive benefit in her world, then there is no morally sound justification to continue to provide such

treatment. All this needs to be assessed within the entire context, bodily and personal, of the patient.^{56(pp452-453)}

Is access to the patient's world, even if the patient has no capacity to rationalize or make choices, possible through phenomenology? Using the interrelational intersubjective philosophy of an ethics of care, both Gadow⁵⁷ and Parker⁵⁸ believe that access to the patient's world is possible even if that patient is unresponsive.

We suggest that this explanation of medical futility in the natural attitude is what should be bracketed so that the essences of this phenomenon can be described using a relational ethics of care and the philosophy of phenomenology to go back to the thing itself, to go back to the experience of the phenomenon of medical futility. We anticipate that such an inquiry holds promise for "seeing" medical futility in a way that it has not been seen before—unencumbered with facts—where there is objectivity for subjectivity,⁵⁹ recognizing that, "we cannot think away experience and retain the reality of the world, but we can think away the reality of the world without changing the structure of experience."^{60(p71)}

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