Decision at the End of Life: The Use and Abuse of the Concept of Futility

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MODERN MEDICAL knowledge ameliorates, sustains, and postpones the natural course of dying in patients who, in previous years, would have died in a short time. These patients now become subjects of prolonged lives, recurrent episodes of acute complications, and of new superadded diseased. As a consequence, in almost every case other than sudden, unwitnessed death, some decision must be made about how vigorously to treat and about when it is morally permissible to withhold or withdraw life-sustaining measures. In the U.S. alone, 2.2 million deaths occur in hospitals annually and in 1.5 million of these an explicit decision is made to withdraw or to withhold treatment.

With remarkable prescience, His Holiness Pope Pius XII recognized this dilemma before it became the urgent problem it is today. On several occasions, Pius XII clearly set forth the foundations of Catholic teaching about care at the end of life. His teaching was based in the dignity of the human person, the sacredness of all human life, and the duty to use medical knowledge wisely, well, and within certain ethical constraints. He added that under certain circumstances, when treatments were "extraordinary" and excessively burdensome, they might licitly be withdrawn. ii

Distinguishing between "ordinary" and "extraordinary" treatments, Pope Pius enunciated a carefully nuanced approach to decisions to withhold or withdraw treatment within the context of the particularities of the patient's whole life. When all things are considered, Pius said, treatments can be discontinued if they are deemed to be "extraordinary," that is, excessively costly, dangerous, painful, difficult, or unusual when weighed against anticipated benefits. This teaching was reaffirmed notably in the Declaration on Euthanasia of 1980^{iv} and the encyclical *Evangelium Vitae*. In recent years debates have centered on the precise definitions of the terms "ordinary" and "extraordinary" and the

substitution of the terms "proportionate" and "disproportionate" in their place. vi As medical technology and capabilities expand, what was once ordinary is thought to have become extraordinary.

For Pope Pius XII, "ordinary" and "extraordinary" were ethical categories, not clinical or physical formulae for withholding or removing treatments. John Paul II has specifically rejected that kind of teleologism which determines the morality of human acts by weighing non-moral or pre-moral goods against harms. As an ethical norm, maximization of good and minimization of harms in order to produce a "better" state of affairs is a denial of the possibility of universal and absolute prohibitions against intrinsically wrong acts. Vii

Much of the difficulty in applying the concepts of ordinary and extraordinary relates to the determination of benefits and burdens in an actual clinical situation: "In the past, moralists replied that one is never obliged to use 'extraordinary' means. This reply, which as principle still holds good, is perhaps less clear today by reason of the imprecision of the term and the rapid progress made in the treatment of sickness."

In this essay I wish to suggest that the *proper* use of the term "futility"—not as a moral principle but as a means for prudential clinical judgment—can be a useful bridge between the ethical formulation of ordinary and extraordinary and the decision in a particular case at the end of life. Futility, taken generically, simply means inability to achieve stated purpose. Futility in the clinical sense simply means that an illness or disease process has progressed to a point such that a proposed medical intervention can no longer serve the good of the patient.

Today, in clinical and ethical parlance, *futility*, like ordinary and extraordinary means, has been the subject of very intensive debate. ix Futility is a very ancient concept clinically which is now being reinterpreted by secular bioethicists and given moral weight in decisions to discontinue treatments. Its validity for such decisions, who determines it, and where it fits in moral judgments are in a state of flux. Nonetheless, clarification of the use of futility criteria is important for Catholic Christians, since its use or abuse must be judged ultimately within the framework of Catholic principles of medical morality.

The fulcrum of this essay is the concept of futility for several

reasons: (1) Futility is an ineradicable fact in clinical medicine and its language is widely used by health professionals. (2) Futility is subject to morally proper use and abuse and these must be distinguished. (3) The idea of futility is implicit in Pius's teaching about ordinary and extraordinary means, but its explicit relationship to that teaching is yet to be fully examined. Properly interpreted, futility can help to recover some of the full moral import of the terms *ordinary* and *extraordinary*. (4) It can link the clinical with the medical and theological construals of *ordinary* and *extraordinary*. Properly and prudentially used, futility can avoid some of the dangers of automatic stigmatization and devaluation of the lives of certain vulnerable patients.

After a brief theological propaedeutic, this paper is divided into three parts: (1) delineation of the concept of futility, (2) delineation of its abuses in particular clinical decisions, and (3) definition of its proper use within the context of Catholic Christian anthropology and medical morality.

THEOLOGICAL PROPAEDEUTIC

Futility involves a prudential judgment about what is right and wrong behavior in deciding how vigorously to treat and when to desist from treatment in a given concrete clinical situation. It does not, and cannot, stand alone as a determining criterion. Although it has empirical dimensions, futility is not solely an empirical determination. Its morally responsible use must be grounded in our deepest perceptions about the nature of human beings and their existence as both material and spiritual creatures.

For the Catholic Christian, that deeper structure must be Christian anthropology and the moral principles that derive from it, that is, the recognition of human beings as creatures made in the image of God, endowed by Him with the gift of life and with a spiritual destiny beyond this world. From these elements flow the inviolable dignity of each human person, of the equal worth of all persons in the eyes of God, and the sanctity of human life in every stage of its development, from first to last.

Thus, human life is among the highest of goods, but it is not an

absolute good. As Pope Pius's and subsequent teachings indicate, there is a time when the natural history of a disease may be allowed to result in death. Death, too, is the natural end of life and an expression of human finitude. At some point, it must be accepted and surrendered to.

According to Gospel teaching, among human persons the sick and vulnerable have a special claim in charity on our solicitude. Healing, helping, and caring for the sick is an obligation shared by all Christians, for it is Christ as healer (*Christus medicus*)^x and Christ as patient and sufferer (*Christus patiens*) who is our model. His life gives meaning to our pain, suffering, and death—these things are not to be sought but, when they are inevitable, they have their place in God's ordering of the world and our individual human lives. Through the Incarnation Jesus entered into our suffering in order to give it meaning.

On this view, any intentional hastening of death by physician or patient would be morally inadmissible, even for what might appear to be beneficent reasons of compassion, mercy, and relief of suffering. Under all circumstances, man's stewardship of the gift of life demands that human life be nurtured, cared for, and protected. Other things being equal, there is the expectation that treatable disease will be treated. To violate that stewardship is to challenge God's sovereignty. On the other hand, not to accept the fact of human finitude and to prolong life when death is inevitable is, in its own way, a challenge to God's sovereignty and an act of hubris. Recognition of clinical futility is a crucial element in deciding the moral status of acts of continuance or discontinuance of end-of-life treatments. Catholics and other Christians are obliged therefore to interpret futility within the constraints of a Catholic Christian view of the meaning of human life and health care. xi

In this regard, it must be re-emphasized that the terms *ordinary* and *extraordinary* were not intended as purely technical judgments, although they have been misused in that way. Rather, they were proposed as moral judgments, that is, as criteria for a morally good or bad decision to withhold or withdraw treatment. Changes in medical technology since then do not change the moral impetus of the traditional language. If these terms are abused, they become morally problematic. This essay wishes to preserve the moral content of *ordinary* and *extraordinary* and to suggest

that proper use of the concept of futility can serve as a prudential hermeneutical device for linking traditional moral teaching with its application in a particular case. xii

FUTILITY-EVOLUTION AND THE DEFINITION OF THE CONCEPT Evolution of the Concept

Every clinician knows that, at some point in the natural history of any serious disease, further treatment is beyond the powers of medicine and no longer in the patient's interest. Sooner or later, this ineluctable fact becomes apparent to families and patients as well. That is why, from earliest times, the concept of futility has guided clinicians' decisions to treat or to desist. To treat under these circumstances violates the first principle of traditional medical ethics, that is, beneficence—acting for the good of the patient.

Futility was recognized as a clinical fact with medical and moral implications as long as 3500 years ago. The Smith papyrus, for example, cites fives cases of high trans-section of the cervical spinal cord in which, given the therapy of the day, treatment would have been futile. In the same papyrus there is mention of additional cases, and still others can be found in the Ebers papyrus. Later, the Hippocratic physicians recognized futility and advised against treatment when patients were "overmastered" by the disease. Patients were admonished not to expect treatment under those circumstances. The Hippocratics also urged physicians to ameliorate these diseases that were untreatable, to learn when they were untreatable, and to avoid harm by "useless" efforts.

Even in these ancient texts, the abuse of futility is evident. In several places, it seems that the physicians of the Hippocratic School were advised not to undertake treatment of incurably ill patients because they would die inevitably and tarnish the physician's image of therapeutic infallibility. This attitude was as condemnable then as it would be today.

Since those ancient times, physicians have used futility as a clinical criterion in unilateral decisions about prolonging life. But such decisions have always been fraught with moral consequences since medicine is, at heart, a moral enterprise. Still, the morality of futility determination did

not become a debated issue until a quarter of a century ago when the emergence of patient autonomy challenged the physician's authority. Emphasis on self-determination shifted the locus of all clinical decisions from doctor to patient or surrogate, or at least to some locus between them. The current trend to virtual absolutization of patient or surrogate autonomy in the U.S., and to a lesser extent in other countries, now makes the criteria of futility, and especially the way in which they are determined, a manner of the greatest practical moral significance since patients can demand overtreatment or undertreatment.

Futility, etymologically, means "inadequacy to produce a result or bring about a required end; ineffectiveness." In medical care, the required end, that is, the *telos* of the physician's activity, is the good of the patient. This is the moral center of the healing relationship. It is what patients seek and expect. It is what doctors promise implicitly by offering themselves as healers. When the good of the patient cannot be attained, treatment should not be offered, or, if in use, it should be withdrawn. To treat in the presence of futility is to act against the patient's good, and, if such treatment is burdensome, to act maleficently as well.

Futility is, however, not a moral principle. It is an empirical appraisal of probable clinical outcome, benefit, and burden. Thus it instantiates and specifies the principle of beneficence in a particular clinical event. It becomes a decision-making criterion because it offers a definable approximation of the patient's good. It is arrived at by use of our limited human intelligence and is fallible. Properly determined, the idea of futility helps us to attain the good of a particular patient, here and now, at the moment of a withhold/withdraw decision.

Futility derives moral force from its status as a specification of the principle of beneficence—the first principle of clinical ethics. Beneficence is the first precept of the Hippocratic Oath. It recognizes the vulnerability, dependence, and need of the sick person as the source of the doctor's obligation to act always to optimize the welfare of the patient. In addition, when healing is pursued as a Christian vocation, ministry, or apostolate, it can become an explicit manifestation of God's grace. Then, beneficence and benevolence can become acts of loving

charity. Futility is then interpreted in the light of the Christian view of human life and its destiny. This construal of charitable beneficence is at considerable variance with the trend of contemporary bioethics, which often puts patient autonomy before beneficence or subverts that autonomy for utilitarian, economic, or social reasons. This divergence can best be delineated by looking at the most intensively debated questions: How is futility defined? Who defines it? How are competing interpretations resolved? How does futility as an instantiation of beneficence relate to competing principles of autonomy in three illustrative clinical situations (do not resuscitate orders, determinations of death, and care of the very young and very old)?

Definitions of Futility

As noted above, for most of the history of medicine, futility was taken to be an objective medical judgment which only physicians were qualified to make. This changed thirty or so years ago with the emergence of autonomy, which granted rights of decision and participation to patients and their valid surrogates. This movement began in the U.S. as legal right to refuse treatment.** It was strongly reinforced by a report of the President's Commision in 1983.** Since then, autonomy has less appeal outside the U.S., the American view of autonomy is beginning to be an issue worldwide.

In the 1980s, the major issue in professional ethics in America was the medical profession's adaptation to participation by patients and families in clinical decisions. The degree of authority which should be vested in patients or their surrogates through the instrument of informed consent increases in scope, even threatening the physician's moral integrity. In the 90s, that authority has come to include participation in the definition of futility as well as micro-management of bedside decisions.

As a result, futility is no longer defined solely in medical terms but also in terms of the patient's goals, values, and beliefs, that is, those things by which we determine whether the decision is indeed "worth-while" from the patient's point of view. A new debate now centers on who should define futility, how it should be defined, and what to do

when physician and patient or surrogate disagree on its definition. The range of the debate is wide and, in many cases, the opposing views are mutually incompatible. *xxiii* For example, there are those who argue that the moral weight of the patient's values is such that the idea of futility is no longer sustainable. The physician is thought to be so unable to disentangle his or her own values sufficiently from futility judgments that they should be abandoned. *xxiii* Another view is that the debate and the definition of futility are fatuous exercises in hair-splitting and detrimental to good clinical decisions. Some others hold that the idea should be retained only for obvious situations like total brain death or permanent vegetative state.

Opposing those views is the belief that the traditional idea of futility should be retained but refined by explicit criteria. One proposal suggests that a treatment should be considered futile if it has been ineffective in the last hundred cases, does not restore consciousness, or does not remove the need for intensive care. The increasing availability of studies of effectiveness and ultimate outcome of treatments like cardiopulmonary resuscitation, strengthen these suggestions. However, the potential shortcomings of objective criteria cannot be ignored (that is, errors or diagnosis, prognosis, and medical information, or the problem of applying statistics to individual cases). Newer, empirically based algorithms and models that predict outcomes are helpful in objectifying prognosis, but they too unavoidably include value judgments and thereby lose some of their objectivity.

To mitigate the influence of the provider's or third party's value judgments, to protect patient autonomy, and to avoid the potential abuses of unilateral judgments, some have proposed that the criteria for futility be institutionalized in hospital policy or ethics committees. There are, however, objections to institutionalizations, such as that institutions depersonalize the decision, that standards vary between institutions or committees, and that the very fact that a policy is needed implies a patient's right not only to reject but also to demand treatment.

Futility as a prudential guide

To obviate some of these difficulties, a combination of subjective and objective criteria and a joint determination of futility by physicians and patients or surrogates seems most reasonable. This approach strikes a balance between three criteria: *effectiveness, benefit*, and *burden*. This balance is not a mathematical but a moral calculation, based on clinical assessment, which gives a weight to each of these three dimensions in relationship to the other and, ultimately, to the patient's good.

Effectiveness: for each treatment intervention, an estimate of its capacity to alter the natural history of the disease or symptom in a positive way. Does the treatment make a difference in morbidity, mortality, or function? This is an objective determination, dependent upon outcome studies and within the physician's domain of expertise. Effectiveness centers on medical good and on measurable clinical data about prognosis and therapeutics.

Benefit refers to what is valuable to the patient as perceived by himself or his valid surrogate. This is a subjective determination and not within the doctor's domain but in that of the patient or his surrogate. Benefit centers on the patient's assessment of his own good—his goals and values in undergoing treatment. It asks the question:Is this treatment worthwhile for me, the patient? It is not quantifiable.

Burden refers to the physical, emotional, fiscal, or social costs imposed on the patient by the treatment. Burdens are both subjective and objective and within the domain of both the doctor, when factual, and patient, when subjective and personal. Burdens imposed on the medical team or society would, in certain rare circumstances, be considered as well as burdens on the patient. The question here is: What will effectiveness and benefits cost, not just in dollars but in their totality? Like benefit, burden is not readily quantifiable.

When the assessment of these three phenomena is favorable to the patient's good, other things being equal (*ceteris paribus*), treatment is morally justifiable; when it is unfavorable to the patient's good, the treatment in question is not morally justifiable.

This approach combines subjective and objective components and integrates the expertise and authority proper to each of the major

participants—physicians, nurses, patient, and surrogates. It cannot be a unilateral decision. It requires a joint determination and agreement if the total good of the patient is to receive the consideration it deserves. This approach also gives some concrete clinical expression to the terms *ordinary* and *extraordinary*. *Ordinary* treatment is effective, serves some beneficial goal of the patient, and/or carries burdens which can be outweighed by the effectiveness and benefit. *Extraordinary* treatment would be futile treatment as determined by the above criteria, that is, ineffective, not consistent with the patient's goals and values, and/or so costly, dangerous, painful, or otherwise so burdensome as to outweigh effectiveness and benefit.

On this view, *ordinary* treatment becomes beneficial treatment that can vary with current technological capability; in extraordinary treatment there would be little or no probability of a beneficial outcome for the patient. No matter how *high* the technology, the availability and non-availability of technology *per se* is not the determinant of what is ordinary or extraordinary. The meaning of ordinary and extraordinary thus is not tied to the state of technological progress. Technology is a means which is itself judged by its effectiveness, benefits, and burdens.

This approach should be helpful in actualizing the notions of *proportionate* and *disproportionate* as they are used in the Vatican Declaration on Euthanasia: "Thus, some people prefer to speak of *proportionate* and *disproportionate* means. In any case, it will be possible to make a correct judgment as to means by studying the type of treatment to be used, its degree of complexity, and comparing these elements with the result that can be expected by taking into account the state of the sick person and his or her physician and moral resources." xxv

Thus, on the definition of futility that I have suggested, a *dispro- portionate* means would be a futile means, remembering always the misuse of these terms by proportionalists as already noted above.

This approach to futility avoids the stigmatization and devaluation inherent in equating futility with any particular diagnosis, clinical condition, or category of patient. Too often, patients in a "permanent vegetative state," those with lethal genetic disabilities or mental "retardation" are relegated automatically to dangerous under-treatment or

neglect of remediable conditions. This schema also avoids automatic negative quality-of-life determinations or denials of personhood to brain-damaged infants, demented adults, or handicapped people generally. Instead, the focus is on the prudential interplay of effectiveness, benefit, and burden as they relate to the good of the patient with the spiritual good of the patient as the highest priority.

This schema recognizes that the *good* of the patient is a complex notion. As Thomasma and I have suggested, xxvi it includes at least four components, hierarchically arranged. The lowest good is the medical good, that is, the well-functioning of the human organism as organism. This includes psycho-social as well as physical functioning. This is the realm in which the physician has major expertise. The next level of good is the patient's own assessment of his or her personal good, a definition of the patient's preferences, goals, the kind of life he or she wishes to live. In this realm the patient or his or her designated surrogate is the point of reference. Next is the good of the patient as a human person, an assessment in terms of the natural law's grasp of what is proper to the life of humans as humans-this level of patient good is not defined by the doctor or patient. It is built into what it is to be human. Its point of reference is the natural law. Finally, the highest good is the spiritual good, that which derives from the fact that humans are created and destined by a personal God to a life beyond this world in union with Him. The point of reference here is Scripture, Church teaching, and tradition. These are not definable by patient or physician. This is the level entirely negated or ignored in secular bioethics despite the fact that every patient, physician, or surrogate will have some faith commitment or faith rejection.

MORAL DANGERS IN THE APPLICATION OF THE CONCEPT OF FUTILITY

Abuses of the concept of futility can be the result of a wrong or bad assessment of the balance between effectiveness, benefit, and burden. A wrong assessment could result from objective errors of observation, prognosis, probability estimates, incompleteness of knowledge of the patient's life context, or illogical reasoning. A bad assessment, on the other hand, would be the result of the erroneous moral, metaphysical, or

theological presuppositions about human nature, moral philosophy, or the nature of human life or its meaning. In the examples that follow, most emphasis will be put on the importance of the proper theological and metaphysical starting points. In the two examples, namely, cardiac resuscitation and brain death, the emphasis is on objectively wrong judgments. Usually the two forms of error will be intermingled and will have to be carefully disentangled in order for us to discern the sources and possible remedies for any specific instance of abuse of the concept.

Futility has been defined here as a prudential guide to moral assessment of the good of the patient and to the moral permissiveness of withholding or withdrawing particular treatments in seriously ill or dying patients. On this view, if a treatment is judged to be futile after weighing its benefits, burdens, and effectiveness, it need not, and ought not, be offered or used. However, like any prudential guide, there is a danger of misuse if the metaphysical, theological, and ethical presuppositions upon which the judgments are based are faulty.

This is often the case when secular bioethicists employ the concept in ways totally opposed to Catholic Christian medical morals. Thus, futility has been used to justify euthanasia; assisted suicide; refusing treatment to seriously handicapped infants, to the aged, and to the infirm in order to spare parents, families, or society the burdens of caring for such patients. Without a foundation in Christian anthropology and the Gospel vision of health care, such things as quality-of-life, economics, sacrifice for others, and spiritual belief are translated into terms of mere utility, economics, pleasure, or absence of all suffering.

Each of the three elements of the relationship, that is, effectiveness, benefit, and burden, must be judged within a moral context, that is to say, within the context of treatments that are not intrinsically wrong. Thus, abortion, tubal ligation, or assisted suicide could, on purely secular grounds, be classified as *effective*. A patient might see euthanasia or assisted suicide as highly *beneficial*. A marginally painful but highly effective treatment might be judged as *burdensome*. These three variables are to be judged clinically but always within the boundaries of the morally permissible. Futility assessments, thus, are prudential judgments about specific clinical situations to assure that the moral

judgments of *ordinary/extraordinary* and *proportionate/disproportionate* are grounded empirically.

Let us look briefly as some examples of the misuse of futility, recognizing that *abusus non tollit usum* and that Catholics need not abandon the idea of futility because it is misused so often in secular bioethics. Indeed, secular misuse of the futility criterion imposes an obligation on Catholic moralists to "rescue" the term from its misuse. To abandon the term is to surrender it to secular definition solely.

Quality of Life

One frequent misuse of futility is to interject the observer's quality-of-life assessments into the judgment, especially with infants, children, and those who cannot express their own views. Usually, the argument is made that the projected disabilities or discomforts are so severe that no one would want to endure them or ought to have to endure them. Out of compassion and mercy, it is insisted that treatment should not be considered since the possibility of a satisfactory life is futile. This is a particular danger with neonates, the retarded, or the comatose patient.

Quality of life, however, is an infinitely malleable term. No two persons have the same definition of a satisfactory life. No one is qualified to make a quality-of-life decision for another, especially for an infant or a child who has had no opportunity to experience life. In Christian charity and morality, there is no such thing as *Lebens unwertes lebens* nor metaphysically wrongful existence.

Quality-of-life for those who cannot assess that quality for themselves is not a consideration in a Christian view of life which bestows dignity on every human being, regardless of physical or intellectual limitations. Who among us can discern God's intent or provide initial purposes for any human life or for those in whose midst that life may be placed? Whether a person is a "useful" or "contributing" member of society does not affect his or her dignity or the sanctity of that person's life. Human dignity is intrinsic, conferred by God, and therefore not "lost" or "gained" by human judgments. Indeed, the very disabilities so many fear may be the occasion of spiritual growth among the family or friends called to raise a disabled child. None of this denies the

difficulties or suffering that may accompany years of caring for a mentally or physically disabled person. It is to insist, however, that in a Christian view of human life, no life is so disvalued as to be *per se* futile or "worthless." Confusing the futility of treatment with the futility of a life itself is a serious offense against human dignity and God's providence in our daily lives.

Even a mentally competent person must make a decision to refuse life-saving or effective treatment on grounds of the quality of that life with the utmost care. There are clinical situations in which the burdens of treatment are so heavily fraught with physical, emotional, and fiscal burdens, and the benefits are so remote that conscious refusal can be justified.xxvii However, this is not the case with persons in the early stages of chronic illnesses which may be disabling, painful, or fatal in the future. Some patients refuse treatment or seek euthanasia and assisted suicide in anticipation of future changes in the quality of their lives before it is clear what those changes will be or how they will respond to them. There are reasonable limits to how much additional burden or suffering one must assume. But the extent and weight of those burdens must first be known before a decision can be made.

The most opprobrious abuses of the quality-of-life argument are being advanced to justify experimentation with humans in permanent vegetative states. Here futility, the impossibility of returning to "meaningful" social relationships, is taken to devalue this class of humans as non-persons. Some moralists give such persons less claim on life and respect than anthropoid apes. The same devaluation of persons because of the futility of attaining a *quality life* leads some ethicists to speak of disabled infants as "biological remnants" to be mercifully euthanized. The same fallacious reasoning lies behind the distinction between *having a life* (biological life) and *being alive* (having a biography), which is used to justify euthanasia and assisted suicide. XXXX

Similar reasoning leads to devaluation of the lives of the frail and the aged. Young people may fail to see any *quality* in a life restricted by the infirmities of age. Medical treatment cannot return a young person's estimate of quality-of-life to the aged. But all treatment is not, on that account, *futile*. As with infants, underlying this abuse of the futility

concept is a contradiction of the Christian teaching about the value and dignity of all lives. It also reflects an unwillingness to accept any sacrifice of one's own pleasures, pursuits, or resources in corporal works of mercy.

Economics and Futility

Ours is an age obsessed with economics and with the *drain* on society of caring for those whose lives are socially devalued. To accept that devaluation is to risk the next step, that is, to limit care, undertreat, and accelerate the deaths of those who are an economic burden on society. This is a special danger in countries like the U.S., in which managed care in its commercialized form is taken to be an economic necessity. To be sure, no plan at present openly advocates withholding necessary life-sustaining care, but the temptation to do so is not negligible. Moreover, the definition of *necessary care* is manipulable when money is the issue. *Economic futility* is justified usually by the presumed deprivation of resources for the young and those with better prognoses. Again, to reach such a conclusion is to devalue the lives of a whole segment of society. A stronger denial of the Christian respect for the dignity of each person regardless of disability cannot be imagined.

On the Christian view of economics and healing, there must be a concern for solidarity, for the mutuality of our responsibilities to each other as members of the human community. This is properly expressed in a positive, rather than a negative, way as the responsibility to assist each other in time of need. We are all expected to use common resources wisely, but also to make sacrifices for the most vulnerable among us. In times of war, famine, or pestilence, rationing of resources might be unavoidable. But, even then, allocation must be on the basis of respect for all humans and a personal willingness to sacrifice some part of one's own resources for others more needy.

Obviously, the same abuse of futility can be directed against lifesustaining care among the poor. Here clinical futility is equated with non-clinical futility. The unlikelihood that a poor person will become self-sufficient or a contributing member of society is used to justify the withholding of all or of expensive treatments. This abuse is in direct contradiction to Christian charity, which gives preferential option to the poor.

The disturbing aspect of economic influences on futility determinations is that they are so evident in affluent countries in the absence of any demonstrated economic emergency. The fear seems to be that expenditures for the aged, the poor, or the handicapped infant will compromise or limit discretionary spending for luxuries, recreation, or personal pleasure. Such an attitude contradicts the idea of a society founded on Gospel teachings, or the social encyclicals of the modern pontiffs.

Abuse of the futility concept does not preclude morally proper considerations of economics in health care decisions. Competent patients can, out of consideration of charity, refuse treatment for themselves to spare others the expense of their care or to protect an estate for children, for example. Patients anticipating the loss of competence to make their own decisions can instruct their proxies or surrogates or prepare a living will to impose economic restraints on their terminal illness. The treatment in question, however, must be of marginal effectiveness or benefit. Refusal could then be an act of charity in the interest of one's family or to society at large.

Futility and Autonomy

In American bioethics, autonomy has become the dominant ethical principle. In a short period, it has evolved from a negative right to refuse treatment into a positive right to participate in treatment choices. In the last decade, many have come to demand treatment in the name of autonomy or even to "micro-manage" clinical decisions at the bedside. Some would argue that, in the name of autonomy, patients have a right to *demand* that "everything be done," even when treatment is judged futile by the definition we have suggested.

On philosophical grounds alone, one can argue against such a demand since it would force physicians to practice irrational medicine. This violates even the ancient notion of futility as simply medical futility. It also imposes economic burdens unjustly on others without a proportionate reason and without their consent. A Christian patient

should not make such a request because it would be selfish and uncharitable. It would offend against the acceptance of finitude and the sovereignty of God who calls us to Him when He wills. To ask for repeated resuscitation and for futile employment of the full panoply of medical technology when death is inevitable is an act of pride.

There are times, however, when a treatment may be futile in the long term but of benefit to the patient in the short term. A patient dying of disseminated carcinomatosis might desire to live to see a grandchild born or graduate from college or to say a final farewell to his family. He might ask that dying be prolonged by antibiotic treatment for a pneumonia or dialysis for renal failure. Treating pneumonia or using dialysis would be futile in curing the cancer, but not in attaining a benefit for the patient, like having time to complete unfulfilled religious or personal obligations. For similar reasons, a patient might ask to be resuscitated or given transfusions.

Continuing treatment could also be justified in order to allow young parents to adjust to and to accept the inevitable death of a newborn baby. Or, it may be justifiable to some extent when patients or families genuinely believe in and pray for a miracle. Pastoral counselors should be given time to help patients who hope for miracles to comprehend the burdens they may be imposing on a terminally ill, comatose, infant or adult.

In all these instances, treatment does not satisfy the full notion of futility since there is some benefit, at least as seen by the patient or his family. Moreover, futility, like any other consideration in decision-making, must always be applied humanely, sensitively, and with discretion. Some argue that a treatment judged futile should never be initiated or, if initiated, should be stopped immediately. Applied too rigorously, the futility concept could ignore the obligation to help the patient live the last days of his or her life as serenely and satisfactorily as possible.

In these cases, patient autonomy cannot override a physician's conscientious moral objection. This would be absolutizing the patient's right of self-determination. Patients cannot expect physicians to provide treatments that they take to be medically futile. Physicians are persons

too and are entitled to respect as such. Like patients, physicians are moral agents bound to follow their consciences and are accountable for failure to do so. Neither doctor nor patient is empowered to impose his will on the other. A civil and courteous discontinuance of the relationship may sadly be the only answer when moral and religious commitments are mutually incompatible.

In any case, a Christian view of autonomy would be based in respect for others as brothers and sisters in Christ. Physicians and patients would recognize their mutual obligations in charity and work together to negotiate the establishment of treatment goals, the conditions of futility, and the time-lines for re-evaluation periodically of those definitions. Autonomy modulated by charity is an obligation of Catholic Christian patients, families, and health professionals.

RESUSCITATION AND BRAIN DEATH

Do not resuscitate decisions involve the concept of futility very intimately. Cardiopulmonary resuscitation is a treatment like any other. It was developed for sudden cessation of cardiac function usually as a result of failure or disorder of electric activity of an intact myocardium. Under these conditions CPR is very effective if done promptly—within 2-5 minutes, that is, before cessation of cerebral blood-flow has irretrievably damaged the brain.

Cardiopulmonary resuscitation is, however, of dubious, marginal or no value when used in patients dying of some underlying fatal disease or when the heart muscle itself is seriously damaged. It is now known, for example, that patients with massive intracerebral bleeding, disseminated carcinomatosis or chronically ill and aged patients with simultaneous failure of three organ systems (cardiopulmonary, renal, pulmonary, or hepatic) do not survive to leave the hospitals even if cardiac activity can be restored. Indeed, they are apt to end up in a permanent vegetative state even if cardiac function is restored. Cardiopulmonary resuscitation is therefore not intended for every patient who dies. It must be regarded as a treatment with proper and improper clinical use. **xxxii**

For a Christian Catholic patient or his or her surrogate to demand repeated cardiopulmonary resuscitation in the face of its futility as a treatment would be morally wrong. It would, again, be to deny the fact of human finitude and impose unnecessary effort, expense, and emotional trauma on the patient and on others. One may believe in the power of prayer and miracles without resorting to repeated futile resuscitations. If God wills a miracle, He will intervene in His way and on His time, so long as we do not cease treatment when it is still effective or beneficial.

In passing, it must be said here that the so-called *slow* or *chemical* code is not justified morally. Here, physicians go through the motions of resuscitation with no intent to succeed. Physicians may wish to please or comfort the family by these incomplete faux resuscitations. But they are acts of deception and, in the end, betrayals of trust. For the Catholic Christian, there is either a *full* code with the intention to resuscitate if possible, or no code at all. Cardiopulmonary resuscitation should be withheld when it is not indicated, that is, when it is futile.

Another clinical situation in which the notion of futility is crucial is total brain death. **xxiii* Here the whole brain (cortex and entire brainstem) is irreparably destroyed and recovery is not physiologically possible. In such a situation, treatment could not be effective; no benefit could accrue; resources in personnel time and effort would be used to no discernible purpose. To continue to treat or repeatedly to resuscitate such a patient would be to no spiritual or material purpose and a wrongful intrusion on the natural process of dying.

In this essay, we need not confront the debated question of whether a person is dead when the brain is dead. This question deserves reexamination since its metaphysical implications are highly significant. XXXIV Indeed, it is critical when it comes to organ transplantation. The temptation here is to declare *death*—or futility—hastily in order to procure a needed organ. This abuse is a constant danger in secular bioethics where utility, and not the dignity of the human person, is the dominant criterion. Catholic and secular clinicians and moralists differ on the moment at which death of the person occurs. Year For the purposes of clinical decision—making, as long as it is clear objectively that recovery is not possible, a prudential judgment of futility is defensible and the patient may be allowed to die as a consequence of the natural history of his or her disease.

The situation is different, however, with partial brain death, *e.g.*, death of the cortical function but retention of mid-brain function—the so-called *permanent vegetative state*. Here the patient is unquestionably alive. The patient can no longer enter into *meaningful* relationships with other humans or achieve any of his spiritual or physical goals. Some ethicists even argue that the patient is no longer a person, erroneously making a metaphysical judgment not determinable by the clinical state of the patient. This is an especially dangerous conclusion if it is factored into a futility judgment since it puts many vulnerable persons—infants, the demented, the brain-damaged—at risk.

These conclusions are objectively wrong, and they lead to morally bad decisions by imposing metaphysical categories beyond the scope of medicine to determine. Patients in a permanent vegetative state should be approached as seriously ill human persons. Decisions to withhold or withdraw life-sustaining treatments should be made on the basis of whether such treatments will be effective and beneficial or whether the burdens are so great as to be disproportionate. The presumption, as the American Bishops have stated, is to provide "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."

All of these problems are compounded in the case of infants and children. Here, determinations of cortical function, future prognosis, and intervals beyond which recovery is impossible are much more difficult to assess empirically. Prudence in the evaluation of empirical data is an essential moral precaution. This is especially true in cases of trauma or in prognostication of future defects in intelligence.

With infants, we must be especially cautious in applying the criterion of futility. We cannot know what the infant now, or in later life, would take to be the "benefits" of treatment. We can ascertain what the effectiveness of treatment may be in terms of mortality and morbidity. We can also, to some degree, assess the burdens to the infant. In an age driven by utility, economics, and the unwillingness of some parents to "accept" anything less than a perfect child, "futility" can be grievously

misapplied.

Lacking the infant's participation, the physician is under special moral obligation to protect the welfare of the infant, even in the face of the parents' wishes. Parent "autonomy" is often misinterpreted erroneously as giving absolute dominion over the life of the infant. "Benefit" in these situations cannot mean intentionally accelerating death, involuntary or non-voluntary euthanasia, or neglecting effective treatment which carries little burden. Nor can benefits or lack of benefit to society–economic or relief of social burdens–be considered. If they involve intrinsically immoral acts, they can never be factored into futility determinations.

Both in brain death and resuscitation, there is an integration of objective clinical data (making the technically right decision) and the metaphysical and moral principles (making a good decision). These distinctions can, perhaps, help in clarifying what is "ordinary" and what is "extraordinary" treatment.

Judicial use of the futility criteria avoids stigmatization and the resulting devaluation of brain-damaged patients by confining the decision to a deliberative balancing of effectiveness, benefit, and burdens. Proper use (empirical and moral) of futility criteria would forbid automatic cessation of life-support in patients simply because they are classified as being in a permanent vegetative state, frail and aged, or, as infants, faced with what some would judge as lives of poor or reduced "quality."

THE MORALLY APPROPRIATE USE OF FUTILITY

The criterion of futility is today working its way into secular clinical parlance as a component of the ethical decisions to withhold or withdraw treatments. It will undoubtedly attract the interest of Catholic physicians and health professionals since it has strong roots in clinical tradition and empirical observation. Properly interpreted as a prudential guide within specific moral constraints, it can help to recover and explicate the continuing importance of the traditional terms *ordinary* and *extraordinary*, *proportionate* and *disproportionate*. These terms are central to the teaching of Pius XII on end-of-life care, and they have strongly influenced subsequent Catholic approaches to end-of-life

decisions.

Some of the requirements for the morally proper use of a notion of futility can be formulated as follows:

- 1. Every determination of futility must be made within the set of beliefs and commitments that inspire all Catholic health care with the dignity of the human person, the sanctity of life, and the ministry of Jesus as healer and suffering servant. Life can never be willfully ended simply because treatment may be *futile*.
- 2. Each judgment of futility must take all aspects of the patient's total life into account–physical, mental, spiritual, preferences, and lifegoals included. Futility is not an isolated, empirical, yes-no test. It demands prudential assessments for a particular person in a particular experience of illness and within a particular metaphysical and theological content.
- 3. Care, comfort, pain relief, amelioration of suffering must always be provided. Futility does not mean abandonment of care.
- 4. Efforts must continue to discover genuine cures or treatments for diseases now considered incurable. Futility is not a justification to limit the progress of medicine for certain vulnerable groups, including the very young, the very old, the disabled, those in permanent vegetative states. Indeed, properly used, the criterion of futility avoids the stigmatization of this group of patients whose lives, rather than their treatments, are too easily regarded as *futile* by others.
- 5. Futility determinations cannot be made unilaterally. They are always a cooperative enterprise in which each participant has a defined area of authority; the doctor is best equipped to determine effectiveness, the patient is the authority on benefits, and the doctor and the patient together share the assessment of burdens. Anticipations and working together will prevent the conflicts that arise when decisions are urgent and communication has been lacking.
- 6. The concrete judgment of futility must not be so rigorously applied that it precludes prolongation of life in order to meet religious obligations, to see family and friends, and so on. As always, futility must be interpreted within a Christian context of life, death, illness, suffering, and the spiritual destiny of all humans. Charity, not utility, is the final

principle and ultimate virtue of care for the dying.

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Anticipating futility loss of decisional capacity. Statement of wishes. Specificity within value context. Treatments. Outcomes. Credibility. Motives. Intentions. End-of-Life Decisions Patient has right to accept or refuse medical treatment Even if the treatment is lifesustaining Includes all treatments, whether. Unit 4 Chapter 22: Caring for People who are terminally ill. Advance Directives Ethics Champion Program Carol Bayley, PhD VP Ethics and Justice Education Catholic Healthcare West. A To use this website, you must agree to our Privacy Policy, including cookie policy. I agree. Ads by Google, Maryland Law Review, The Futility of Futility?: On Life, Death, and Reasoned Public Policy. A ("The use of a mechanical ventilator to assist breathing is not 'futile' or 'inhu-mane' in relieving the acute symptoms of respiratory difficulty." (emphasis omitted)). 12. The Fourth Circuit explained: [The Hospital] maintains that a requirement to provide respiratory assistance would exceed the prevailing standard of medical care. A Because many futility decisions involve individuals who have disabilities, 29 one's pointing out, for example, that an infant without disabilities would not need ventilator support would simply provide no guidance for deciding which treatments would be futile in a whole category of cases. 3 Ű. Consider an AIDS patient who accidentally injures her foot. (2) Futility is subject to morally proper use and abuse and these must be distinguished. (3) The idea of futility is implicit in Pius's teaching about ordinary and extraordinary means, but its explicit relationship to that teaching is yet to be fully examined. Properly interpreted, futility can help to recover some of the full moral import of the terms ordinary and extraordinary. (4) It can link the clinical with the medical and theological construals of ordinary and extraordinary. that proper use of the concept of futility can serve as a prudential hermeneutical device for linking traditional moral teaching with its application in a particular case.xii. FUTILITY-EVOLUTION AND THE DEFINITION OF THE CONCEPT Evolution of the Concept. 7 End-of-Life Decision-Making. Euthanasia, medical futility and double effect. introduction. A Substituted judgement = the principle used by surrogate decisionmakers and HCPs to make decisions for the non-competent patient based on what the patient would have wanted if he were able to decide for himself.A Leon Kass criticize the concept as philosophically and legally groundless logically incoherent by considering what is a "right" is and what right "to die" would entail rights language is inappropriate for activities involving killing others three problems if society accepts a "right to die" Hardwig considers whether a duty to die is rightly generated by the significant burdens of illness or injury