

WHAT'S THE POINT?

Clinical Reflections on Care that Seems Futile

For

Charles McKhann MD

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Edited by: David H. Smith, Charles McKhann, Christiana Peppard,
Thomas Duffy and Stanley Rosenbaum

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What's the Point? Clinical Reflections on Care that Seems Futile

I. Introduction

David H. Smith

This collection of papers is about the awesome and painful decisions that often must be made when a life is nearing its end. The participants in these decisions include medical caregivers, family, and, when possible, patients themselves. Decision makers wonder whether further aggressive medical treatment is advisable; they think it may be futile or even harmful. Should the emphasis in care switch to providing comfort for the remainder of life, rather than continuing a struggle that cannot be won? That such a switch should be made has been conceded by almost everyone who has written about end of life care in the past forty years. Understandably, however, it is one thing to make this argument in a classroom or journal and another thing to act on it. We hope to describe the textures of decisions in seemingly pointless treatment in various care settings.

Pointless, Futile and Inadvisable Treatments: Why Should We Care?

The decision making issues in end of life care have been thoughtfully discussed in many ways in the past forty years. Some writers have stressed patient autonomy and the importance of deciding for oneself how one will die. But many people don't want to take that responsibility, are unable to take it, or use it in ways that seem destructive to themselves, their families, and perhaps to other patients and citizens. For that reason approximately a decade ago a group of scholars attempted to specify and clarify a notion of medical futility to describe treatments that parties should not be free to choose, since their likelihood of curative success was miniscule. "Medical futility" became a new buzz

word in the medical community, and debates raged over its proper definition and application. Inevitably, these debates were perceived as a morally misguided attempt to return power to physicians.¹ We do not want to resurrect that debate.

But we do contend that there are issues of substance at the end of life – of what care should be provided to persons as they are dying – that can not be reduced to questions of procedure, or medical politics, or of who should decide. In fact it is hard to expunge the language of “futility” from everyday speech, and hence from the decision making conversation and process. “Futility” was a word in ordinary conversation long before it began to be treated as a technical term, and no one disputes that some treatment choices may so inadvisable, so unlikely to produce a desired result, as to be futile in the sense of morally improper.

We want to renew the discussion of when curative treatments should not be continued, bracketing as far as possible the question of who should choose. When is a treatment highly unlikely to be in the interest either of the patient or those with whom her life has been enmeshed? This question holds regardless of who makes the decision, because we assume that the right decision maker can make a wrong decision, or vice versa. Thus, while who makes the decision is an important question, arguably the first question, it is neither the only question nor the central concern of this book.

Nor do we focus on primarily on rationing, a topic that is inevitably tied to discussions of futility. “Why do we waste the money on Aunt Edna when there are so many children needing basic care?” Rationing refers to decision making in situations of limited resources; we do not ignore the question. But our primary concern is with the

¹ See, for example, Susan B. Rubin, *When Doctors Say No* (Indiana University Press) 1998.

interests of patients themselves, and the ways in which pointless or futile treatments may run counter to those interests, however construed. We assume that is an undesirable outcome, whatever the larger community may conclude about rationing.

We want to describe the extent to which difficulty and ambiguity persist when we try to set boundaries to what is, or is not, pointless. General normative statements about treatment that is “futile” often don’t fit with the particular situations in which patients and families find themselves. Questions of futility or pointlessness deserve case-by-case attention. Failure by clinicians to recognize the particularities of a patient’s situation can seriously impact and impede the patient’s (and family’s) experience of the end of life; recognition by physicians of the particularities of the situation may enable enrichment and growth in the remaining period of life.

The Existing Literature on Medical Futility

In 1990, Schneiderman, Jecker and Jonsen proposed a notion of medical futility based upon quantitative evaluations of the efficacy (or, more precisely, failure) of various end-of-life medical treatments: If a treatment was not effective in more than 1% of the cases in which it was applied, then it could be considered futile.² They also proposed a separate, qualitative definition designating futile treatments as those that preserve permanent unconsciousness or fail to end dependence on intensive medical care. The quantitative element garnered the most significant response; a different quantitative approach was to define futility through the use of injury or disability scoring systems.³ Both quantitative approaches failed to account for the complexities of a given case.

² Schneiderman LJ, Jecker NS, Jonsen AR. Medical Futility: Its Meaning and Ethical Implications. *Annals of Internal Medicine* 112 (12), 15 June 1990: 949-954.

³ Knaus WA, Wagner DP, Draper EA et al. The APACHE III prognostic system: risk prediction of hospital mortality for critically ill hospitalized adults. *Chest* 1991; 100:1619-36.

A more qualitative definition required that a patient be brought to an acceptable level of functioning by the proposed treatment, such that the whole patient is or becomes aware of one's surroundings and is able to appreciate the results of treatment.⁴ Such criteria count as futile and therefore morally problematic attempts to seek high levels of recovery for those who are permanently unconscious, those who remain in the ICU in spite of treatment, those with severe dementia, and those whose underlying illness is expected to be fatal within a few days. Exceptions may be found to these rules.

Eventually, attempts at definitions and guidelines were replaced by methods for resolving conflicts when agreement proved difficult. Rules were replaced by methodology, criteria by process. In 2000 Helft, Siegler and Lantos categorized the literature on medical futility in four broad areas: first, "attempts to define medical futility;" second, "attempts to resolve the debate with the use of empirical data;" third, "discussions that cast the debate as a struggle between the autonomy of patients and the autonomy of physicians;" and fourth, "attempts to develop a process for resolving disputes over futility." The authors conclude that, despite the failure of many attempts to define it, medical futility remains an inescapable clinical issue, "the problem of making decisions about treatments that are of minimal benefit has not disappeared."

This last insight is crucial. While theoretical debates over medical futility (particularly the quantitative aspect) have waxed and waned, the end-of-life experiences of real people continue to be fraught with difficulty. Thus something like a qualitative concept of medical futility seems inescapable in the practice of modern medicine. For many people, a qualitative definition of futility seems too subjective: There is always the

⁴ Veatch RM, Spicer CM. Medically futile care: the role of the physician in setting limits. *Am J Law Med* 1992; 18:15-36.

danger, critics claim, that someone might err in making a determination of medical futility. And such an error is one of life or death proportions. Moreover one person's pointless life is another's final gift to be celebrated.

It seems apparent that judgments about futility or pointlessness must be contextual and will be just that, *judgments* made by responsible persons. There is no logarithm for avoiding the fact of judgment because the particularities of a patient's life are not just calculable from her bilirubin counts. If we are adequately to discuss "the problem of making decisions about treatments that are of minimal benefit," then we ought to look long and hard at the qualitative features of putative futility situations. The question then becomes what can be said in advance about futility so as to open the door for a dignified death that might otherwise be hard to achieve.

Listening to the Caregiver in a Complex Medical World

It is not only the uniqueness of each of us as persons that make it difficult precisely to specify what treatments are pointless. Medical and technological advances continuously expand the boundaries of medical possibility. Interventions that were beyond the limits of experience and even imagination twenty or thirty years ago are now accepted as standard practice. Premature infants who were formerly too small to survive now live, albeit at some risk. Adult intensive care units see their own share of seemingly miraculous recoveries. What once seemed futile, even to the most skilled physicians with the best technology at their disposal, now is routine. Yet despite all of this innovation and discovery, there continue to be limits on human life. We do not live forever, and most lives end with an interval of time in which attempts to cure seem pointless. This may be very brief and only theoretical, as in cases of sudden death from a heart attack or stroke.

Much more prolonged is the situation for many cancer patients, or those who die weakened from cardiovascular disease. Life for many Americans ends in slow motion.

We assume that patients and their families are the morally appropriate decision-makers at the end of life. Indeed, it seems clear that physicians are not necessarily the best judges of how patients perceive the quality of their lives or attribute value to their experiences. Physicians seldom know the particular hopes, goals and priorities that characterize a patient's life; families and patients themselves are often much more equipped to evaluate such things. But the other side of uniqueness is inexperience. Dying really happens only once for each of us; for patients and families the end of life situation is unique –obviously for the patient herself, and also (though differently) for the family or other concerned persons. Physicians and other health professionals, by contrast, see death frequently, often daily, and occasionally many times a day, depending on the setting in which they practice. Their exposure to end-of-life situations over many years produces one kind of relevant experience and expertise. Doctors do not speak with one voice; they disagree with each other and have their own ambivalences. Other voices need to be heard and rightly should cast the final vote. But without competent physicians who offer input and advice, decisions will be uninformed. Lack of information is at least as problematic as misleading information.

Hearing what physicians have to say in no way commits patients, families, hospitals, or other physicians to agreeing with them. But it can prepare persons (future patients, future families) for future conversations. Hearing what experienced physicians and caregivers have to say may also be instructive in professional education and influence the setting of policy.

Our Work

This collection grew out of a series of discussions of various aspects of medical futility carried out over a period of four years at Yale University's Interdisciplinary Bioethics Center, under the auspices of the Institution for Social and Policy Studies. Each chapter is written by someone who deals with medical futility on a regular basis. The book is divided into four main sections. The first comprises a set of observations by physicians who have seen many patients in situations that might seem pointless. The settings in which they practice vary from nursing home to intensive care nursery. This section is sub-divided by type of care: death early and fast; death after a major struggle; and death in the last act. The diversity of voices present in these chapters indicates the extent to which normative concepts of medical futility are strongly challenged by the multifaceted medical realities confronting physicians in a variety of care settings.

The section entitled "At the Bedside" describes the experiences of nurses and chaplains, who often see a different side of pointlessness than physicians. Nurses are on the firing line; they give few orders and make few decisions about the strategy of treatment, but they are the hands and hearts of medical tactics and care in the hospital. Being in close contact with patients and families, they are often asked the hard questions and expected to explain medical concepts and options. From this vantage point, nurses tend to encounter concerns over medical futility before the physicians do. This chapter includes the thoughts and writings of several student and graduate nurses based on their personal experiences in the hospital. Similarly, chaplains are full-time hospital employees who are trained to respond to the emotional and spiritual needs of patients, families and caregivers within the hospital. These concerns may be especially acute—whether explicitly religious, spiritual, or not—in situations of medical futility.

“Social Perspectives” consists of three essays that explore the ways in which economics, law and the slippery concept of hope affect situations of medical futility. These topics are usually discussed when the topic of pointless treatment comes up. It is said that admitting the failure of curative treatments will cause patients to lose hope—they will “give up.” Additionally, people worry that abandoning curative treatment will be somehow illegal or will hasten death prematurely; hence, although the law interacts with medical futility somewhat infrequently, noteworthy cases help to shape the way that Americans think about medical futility. It is clear from this chapter that the law is ill-equipped to deal with these complex questions of futility. Finally, the cost of care is a silent presence, even if it is not discussed. Financial aspects of futility fall into two areas: Those that relate to individual patients, and those that are more global and policy-oriented. Often the two domains come into conflict in situations of medical futility.

We include a section on religion. Religions play a central role in our culture and sometimes provide guidelines for medical care, particularly in end-of-life situations. They also affect the way people think about life and death. The United States, with its wide range of religious groups, has found it difficult to take a strong stand in management of the seriously ill and at the time of death (although the hospice movement has filled part of this void). This section briefly mines the resources of four major Western religious trajectories (Catholicism, Protestant Christianity, Judaism and Islam). Here as throughout we barely scratch the surface, but we think even a short summary report of a select few religious perspectives may be helpful for a reader trying to cope with decisions at the end of life.

The collection concludes with a case study and several commentaries that should speak for themselves.

Most readers of all or parts of this collection will think of other perspectives that might have been included, or other points that might be made. The number of voices and perspectives that could contribute to these discussions is as numerous as those who will encounter situations of medical futility -- which is to say, all of us. No one knows the limits of these essays better than their authors and editors, but our overall objective is to try to push discussion of the complexity of trying to choose when curing, perhaps even caring, seem pointless.

II. Clinical Observations by Physicians

Futility in the Newborn and Pediatric Setting

Mark R. Mercurio and John H. Seashore

A 42 year-old woman presents to the Labor and Delivery Unit in preterm labor. She has no living children, and a long history of infertility. This pregnancy is the result of *in vitro* fertilization. Based upon physical examination and clinical status, the obstetrician informs the woman and her husband that she will likely deliver within the next several hours. The neonatologist meets with the couple, and tells them that at this very early gestational age survival is very unlikely despite all medical efforts.⁵ Furthermore, if the child were to survive, it would only be after months of intensive care that would be a significant hardship for the infant and for the family, and there would be a significant risk of permanent injury such as mental retardation, blindness, and/or cerebral palsy. Therefore, the neonatologist informs them, he does not recommend that resuscitation or mechanical ventilation be attempted. Without these interventions, the child will almost certainly die of respiratory failure within minutes or hours after birth. Appropriate comfort measures and pain management will be provided. The parents, after hearing the physician's concerns and recommendations, insist that every possible attempt be made to save their child.

Physicians sometimes use the term "futile" to describe a proposed therapy, or an overall situation that has little or no hope of medical success. The concept of futility has been used by some as justification for refusing to provide a requested therapy.^{6, 7, 8} It

⁵ At the time of this writing, a gestational age of 22 to 23 weeks may be closest to this description, but a specific gestational age is intentionally omitted from the case for the purpose of the discussion. Though in the future this threshold of viability may move (as it clearly has in the past 20 years), there will likely remain some children born at or near that threshold, and therefore the dilemma will persist.

⁶ Luce, John M. "Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists." *Critical Care Medicine*, 1995: Vol. 23, No. 4, p. 760-766.

⁷ Schneiderman, Lawrence J., Jecker, Nancy S., Jonsen, Albert R. "Medical Futility, Its Meaning and Implications." *Annals of Internal Medicine*, 1990: 112: p. 949-954.

⁸ Wall, Stephen W., Partridge, John C. "Death in the Intensive Care Nursery: Physician Practice of Withdrawing and Withholding Life Support." *Pediatrics*, 1997: Vol. 99, No. 1, p. 64-70.

remains an important point of controversy in the field of medical ethics, and in the practice of medicine, particularly intensive care medicine. Although the issue of futility in pediatrics can emerge in the context of many illnesses and medical situations, this chapter will focus on the acute situation of the newborn intensive care unit (NICU). In the NICU, patients are extremely premature newborns, and the issue of futility is an ever-present reality. The most frequently encountered clinical situations in the NICU are with “pre-viable” newborns, felt to be so premature that survival is virtually impossible, and the “borderline viable” newborn, for which survival may be possible but remains very unlikely, and may be accompanied by severe disability.

It should be noted that futility in *any* pediatric situation brings unique and complex issues to medical decision-making. These difficulties relate to the status of children in our society as dependent people with hoped-for futures. Situations of medical futility, and especially the concomitant treatment decisions, can be agonizing to both parents and the health care team. Older children may be allowed to make life and death decisions for themselves, depending on the circumstances. Children are family members and people in society whose futures are open questions; they have not yet lived into their future lives. There is understandably strong resistance, and a heavy emotional burden, to the idea of “giving up” on curative treatment for a fatally ill child. Recognizing that the difficulties in pediatric futility situations will differ according to the age, history, and diagnosis of each particular patient, we take the NICU as but one instance of the range of futile situations for pediatric patients.

Can the physician in the above case refuse to resuscitate the baby on the basis of futility? Before we try to answer that question, we must be clear on our meaning of the word futility. Much of the controversy surrounding the concept of futility in medicine has

been centered around difficulty within the medical profession in reaching an agreement on the definition, and the subsequent overuse of the term.⁹ “Futile” is not an obscure medical term, but rather an English word long in common use, meaning “ineffectual” or “answering to no useful end.”^{10, 11} To say that a proposed therapy would be futile is simply to say that it cannot work. The term is best used with this common and straightforward definition in mind, particularly in conversations with patients and their families. It is essential to keep in mind that a proposed action could be ill advised, even a terrible idea, and still not be futile. Some actions, medical or otherwise, may result in a benefit (and therefore cannot be deemed futile), but a benefit that is far outweighed by the cost.

What is often lost in the discussion is that the question of whether a therapy would be futile cannot be answered until the goal of that therapy in a particular case is clearly established. Therapy that offers no reasonable hope of achieving goal “A” may easily achieve goal “B.” A determination of futility, therefore, is goal dependent, and it makes no sense (and is potentially misleading) to use the term without stating the goal. For example, it may become clear to physicians in the NICU that a certain child, currently maintained on mechanical ventilation, may survive but will surely have a very poor neurological outcome. They may conclude that continuing mechanical ventilation is futile. If the goal is survival with normal or near normal neurological function, then the statement of futility is reasonable. That is, ongoing mechanical ventilation cannot accomplish this. For the parents, however, survival (even with profound neurological

⁹ See Schneiderman et al., op. cit., and Helft, Paul R., Siegler, Mark, Lantos, John. “The Rise and Fall of the Futility Movement.” *New England Journal of Medicine*, 2000: Vol. 343, No. 4, p. 293-296.

¹⁰ Webster’s New International Dictionary. Second edition, unabridged. Riverside Press. Cambridge Mass. 1934. p. 1023.

¹¹ Webster’s 9th New Collegiate Dictionary. Merriam-Webster, Inc. Springfield. 1989. p. 500.

damage) may itself be a goal worth pursuing. With that goal in mind, ongoing ventilation may not be futile. Physicians should not assume without discussion that their goal and the parents' goal are the same.

Parents' goals for their infants usually involve a long and healthy future, even if that future is vaguely defined at the time of birth. Parents anticipate a lifetime in which they will watch their child flourish and help him or her develop into adulthood. Thus, when medical futility and the likelihood of death impinge on a child's life, it can be a horrifying event. While doctors also wish for the developmental flourishing of a child, they are better acquainted with some of the difficult problems of the newborn and pediatric period. Parents and doctors therefore often start out with very different hopes and expectations of medical treatment. For these reasons, not only is discussion of goals essential, but also sufficient time (when possible) for parents and families to evaluate those goals in light of their new medical information.

When confronted with a newborn at the borderline of viability, physicians often describe the situation as futile, and hence recommend (or insist upon) withholding resuscitation and intensive care. It is vague, and potentially misleading, to describe an overall situation as futile. It is clearer to consider a specific proposed therapy and desired goal, and then assess the chances of success relative to that goal. If the newborn is at a gestational age for which no survivors have been reported, and the agreed-upon goal is for the patient to survive and be discharged, then it would be appropriate for the neonatologist to say that resuscitation would be futile.

Many physicians and medical organizations have stated, in essence, that a physician is not obligated to offer or provide what would be a futile therapy.^{12, 13} In general, we concur with this statement, and we do not believe that a physician is obligated to provide resuscitation and intensive care at a gestational age for which there have been no survivors. There are some who disagree, and some hospitals may even have policies that require the physician to provide resuscitation in this setting. Regardless of hospital policy, when parents insist on a therapy that the physician believes futile, the physician needs to make every effort to help the parents understand the nature of the situation and the futility of the therapy. Communication and compassion will bring about agreement in most cases, and should be the cornerstone of the physician's approach. Unfortunately, the necessary time is not always available prior to the birth.

In the case outlined above, however, if the goal is survival to discharge, resuscitation could not correctly be deemed futile. The neonatologist, presumably based on personal experience and published data, called it "very unlikely" that the therapy (resuscitation and ongoing mechanical ventilation) would be effective. This could mean, for example, that only one in ten or one in twenty children born at this gestational age survive to discharge. From such data one cannot honestly conclude that survival would be virtually impossible. But the outlook is nevertheless quite bleak. This child would probably not make it home. Even if he were to survive hospitalization, he would require a long and exceedingly difficult NICU course and would probably have permanent, possibly quite severe, neurological damage. The emotional and financial stress on his

¹² See Luce, op. cit., and Task Force on Ethics of the Society of Critical Care Medicine. "Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill." *Critical Care Medicine*, 1990: Vol. 18, No. 12, p. 1435-1439.

¹³ Council on Ethical and Judicial Affairs, American Medical Association. "Medical Futility in End-of-Life Care." *Journal of the American Medical Association*, 1999: Vol. 281, No. 10, p. 937-941.

family could be enormous and could possibly continue for years into the future. The lives of his parents and/or siblings could be forever altered and possibly devastated.

If the neonatologist were to consider exclusively the interests of the newborn, as many say he should,¹⁴ he might conclude that the burdens of treatment outweigh the potential benefits. That is, it is in the child's best interest not to proceed with resuscitation. In such a case, the physician should frame his or her argument based on that assessment, rather than closing off dialogue with a misleading pronouncement of futility. But if he were to consider the interests of family members in addition, that balance may in his mind then be tipped even further against treatment. In either case, one can see why he might recommend no resuscitation or mechanical ventilation, and it could be reasonable for him to make that recommendation, carefully explaining the basis of his thinking to the parents. It might be easier, faster, and require less convincing, if he were simply to say that resuscitation would be futile, that it could not possibly work. It would, however, be misleading to do so. One reason why the use of the term "futile" remains controversial is that some physicians have used it in situations where they think, for any number of possibly valid reasons, that the proposed therapy is a bad idea. It thus becomes a way to limit or end discussion of a therapy the physician does not wish to provide.

One should not confuse "futile," which should be based on fact, with "ill advised" or simply "a very bad idea," which is an opinion, and may stem from the physician's values in addition to the available data. One may see a conflation of these two concepts, and hence the tendency of some physicians to fall back too quickly (and incorrectly) on the idea of futility as a justification for withholding therapy they feel should not be

¹⁴ American Academy of Pediatrics Policy Statement. "Guidelines on Forgoing Life-Sustaining Medical Treatment (RE9406)." *Pediatrics*, 1994: Vol. 93, No. 3, p. 532-536.

provided. This is not to suggest that every therapy should be pursued unless it would be futile. In our opinion there are clinical situations where a child is best served by withholding a certain surgical or medical therapy, even if that therapy would not (strictly speaking) be futile. The argument to do so, however, must in honesty be based on something other than futility. A more appropriate argument, for example, might be based on a long-term assessment of the benefits and burdens to the child.

It is quite appropriate for a physician to share his opinions with parents, provided he does not present them as if they were medical facts. Is so much effort, pain and suffering worth, for example, a 10% chance of being, or having, a healthy child? The answer to that question ultimately does not rest on any medical, epidemiological, or physiological evidence. Rather, it is a value judgment, and should be presented and discussed as such.¹⁵ While the values of the physician and other members of the clinical team are important considerations, in most cases the values of the parents should take priority.¹⁶

Clinical dilemmas at the edge of viability illustrate another fundamental point: a judgment about futility is, at best, only as good as the data upon which it is based. The edge of viability is a moving target, and somewhat blurred as well. At our institution (Yale-New Haven Children's Hospital), for example, there were no survivors at 23 weeks gestation from 1985 through 1991. For 2000 and 2001, however, survival at 23 weeks was 31%. It is easy to see how a physician might incorrectly conclude that resuscitation

¹⁵ The question of distributive justice might also be appropriately raised in this setting. That is, is a very low likelihood of a positive outcome worth the expense of limited resources that might better be put to use elsewhere? For the purpose of this discussion, however, questions of finance, cost to society and distributive justice are not considered. The only "costs" in this analysis are the pain and suffering of the patient, and perhaps the family.

¹⁶ American Academy of Pediatrics Committee on Bioethics. "Ethics and the Care of Critically Ill Infants and Children." *Pediatrics*, 1996: Vol. 98, No. 1, p. 149-152.

at 23 weeks is futile, if he were to base that judgment on data that, though relatively recent, are already outdated. Unfortunately, the presentation of therapeutic options to a woman with impending preterm delivery can still be based on obsolete data, particularly from an obstetrician or pediatrician with little recent experience managing extreme prematurity. Of course, even with current data, a physician might conclude that resuscitation at 23 weeks is ill advised. This conclusion may be based on a variety of reasons, such as the high mortality rate, the significant chance of disability if the child survives, or the burdens to the patient and the family. With the same data another neonatologist may come to the opposite conclusion. These are opinions, based upon value judgments, and it should not be surprising that they may vary among physicians. The question of futility, however, should be far less a matter of opinion, but rather a rational assessment based upon available data.

To further complicate matters at the edge of viability, the exact gestational age is often not known. In the case presented, the pregnancy was the result of *in vitro* fertilization, and therefore the dates are certain. In most cases, however, obstetricians base the gestational age on information that may be less precise, including last menstrual period, and estimates based on ultrasound. Depending on the reliability of the dates and the timing of the ultrasound (an ultrasound done very early in pregnancy is more accurate for assessing gestational age than one done later), the obstetrician may estimate the gestational age only within an accuracy range of one or two weeks. Depending on the nature of the information available, the wise neonatologist, when told the baby soon to be born is “at 22 weeks,” sometimes does well to hear instead “is probably between 21 and 23 weeks.”

The difference is quite important. At present, survival at 21 weeks at any medical center is virtually impossible, while at 23 weeks may be 30% or better!¹⁷ Furthermore, the published survival data are typically based on “best obstetrical estimate” of gestational age, which is usually subject to the same inaccuracies. After the child is born, the neonatologist will assess the gestational age based upon physical exam. This, too, will be at best accurate to within one or two weeks. For this reason prognosis is also based, at least in part, on birth weight survival data. Physicians need to keep the often-imprecise nature of the scientific data well in mind when counseling parents.

An understanding of the data is central to determining questions of futility, but good data, or even fairly good data, are not always available. The physician must then rely on an understanding of physiology and/or clinical experience. Sometimes this is enough; every decision regarding futility does not necessarily require data. Despite the absence of a relevant clinical trial or any extensive data, most physicians would feel confident in saying that amputation of a foot to cure brain cancer would be futile. As silly as this example may seem, some things physicians are asked to do make as much physiologic sense. Neonatologists are fortunate to have extensive survival data specific for each gestational age, both from the United States and elsewhere. Based on the potentially limited but nevertheless available information, physicians are often able to say that survival will not be possible.

There is, however, yet another important potential pitfall in the application of the data, which is most apparent at the edge of viability. If a given hospital has never successfully resuscitated a newborn below a certain gestational age, despite numerous attempts, a physician at that hospital might reasonably conclude – and communicate to

¹⁷ *Ibid.*

the parents – that resuscitation below that gestational age is futile. A more logical, and honest, conclusion, however, would be that resuscitation *at this hospital* is futile. There may be an accessible hospital that achieves 10% or 20% survival for this same gestational age. Regarding this second hospital, one could say that resuscitation is unlikely to work, or very unlikely to work, but one could not honestly say that resuscitation cannot work. If the physician is aware of another *accessible* facility where resuscitation has a reasonable chance of succeeding, there is no obvious justification for keeping that information from the parents. It would be dishonest, and therefore inappropriate, simply to tell the parents that resuscitation would be futile. The physician may feel that resuscitation is ill advised, for a variety of legitimate reasons, and if so should share his opinion and reasoning with the parents. While it may be faster and easier to tell them simply that it could never work, this would be more than a simplification or an oversimplification: it would be a deception. Even if the physician believed his recommendations were ultimately in the patient’s and family’s best interests, the ethical justification for such a misleading statement is doubtful.

Another potential source of error in assessing the futility of any therapy is the generation of a “self-fulfilling prophecy,” and this is clearly the case for extremely preterm newborns at the edge of viability. In major academic medical centers in the U.S., the survival of infants born at 24 weeks gestation is approximately 50% or better.¹⁸ Virtually all of these survivors would die without several weeks of intensive care. Familiarity with these data leads to the conclusion that the provision of intensive care for these patients cannot be termed futile, if the goal is survival to discharge. However, there

¹⁸ Lemons, James A. et al, “Very Low Birth Weight Outcomes of the National Institute of Child Health and Human Development Neonatal Research Network, January 1995 Through December 1996.” *Pediatrics*, 2001: Vol. 107, No. 1, p. e1.

may be some physicians who nevertheless consider it ill advised. What if there was a national consensus that infants born at 24 weeks or less should not be provided any intensive care measures? The justification might be, for example, the high cost of caring for these patients. Survival would fall virtually to zero. After several years of this, a neonatologist could honestly say to parents, “Of the past 500 babies born in this country at 24 weeks, none has survived.” It would then seem quite reasonable for the physician and parents to conclude that intensive care at that gestational age would be futile. But, of course, that would be incorrect. The source of the error would be the failure to ask, “How hard did you try?”

This self-fulfilling prophecy described above may be more than just a theoretical possibility, but rather could currently be the case for newborns at the borderline of viability in some hospitals. If one chooses not to try because the survival statistics are so low, the survival statistics remain low, and the cycle continues. The 14 participating centers of the National Institute of Child Health and Human Development Research Network recently reported 21% survival at 22 weeks gestation.¹⁹ Some centers have had no survivors at 22 weeks, and hence consider it futile to try. It may indeed be ill advised to try, but to deem it futile based on what may be self-perpetuating data is faulty reasoning. Another rationale for withholding support in this setting is needed. Once again, an assessment based upon benefits vs. burdens of therapy, for example, would be more appropriate.

An infant is born at 31 weeks gestation, weighing 1600 grams. He has a brief course of Respiratory Distress Syndrome requiring mechanical ventilation for four days. On day 17 he is on room air, and taking full

¹⁹ See American Academy of Pediatrics Committee on Bioethics, “Ethics and the Care of Critically Ill Infants and Children,” *op. cit.*

enteral feeding tube, with no obvious medical problems, but on that morning his clinical status rapidly deteriorates. He is noted to have significant apnea and bradycardia requiring reintubation and mechanical ventilation, as well as a worsening metabolic acidosis and grossly bloody stools. Abdominal x-ray reveals widespread pneumatosis intestinalis and portal air. Feedings are stopped, intravenous fluids begun, antibiotics are given, and the patient is emergently transported to a medical center approximately one hour away, where a pediatric surgeon is available. Upon arrival at the medical center the infant is taken immediately to surgery, four hours after the onset of symptoms, where laparotomy reveals necrosis of virtually the entire small intestine and much of the colon. The surgeon believes that if the necrotic bowel is not resected, the child may die from overwhelming sepsis, shock, and acidosis. If the resection is done, the child has a reasonable chance of immediate survival, but will not have adequate intestinal length for nutrition in the short-term or long-term.

The pediatric surgeon in this scenario faces a difficult decision. If he elects to do the resection, long-term survival is still unlikely, and would require: (a) survival of a critical post-operative course, (b) maintenance of adequate nutritional status and growth for months on total parenteral nutrition (TPN), (c) placement of central lines for the delivery of TPN, (d) successful treatment of infections likely to be encountered as a consequence of the TPN and central lines, (e) survival of compromised hepatic function that will result from the prolonged use of TPN, (f) availability of intestinal transplant, (g) survival of the transplant surgery itself, (h) lack of rejection of the transplant, and (i) survival of complications of immunosuppressive therapy. It is unlikely, but not impossible, that the child will survive all of these.^{20,21} Two questions are of central importance. First, is resection of the bowel futile? Second, what should the surgeon do?

²⁰ Vennarecci, G., Kato, T., Misiakos, E.P., Neto, A.B., Verzaro, R., Pinna, A., Nery, J., Khan, F., Thompson, J.F., Tzakis, A.G. "Intestinal Transplantation for Short Gut Syndrome Attributable to Necrotizing Enterocolitis." *Pediatrics*: 2000, Vol. 105, No. 2, p. e25.

²¹ Hwang, Sandy T., and Shulman, Robert J. "Update of Management and Treatment of Short Gut." *Clinics in Perinatology*, 2002: Vol 29, No. 1, p. 181-194.

If we assume that the goal is for the child to survive and be discharged from the hospital, then it cannot be argued that resection is futile. While survival to discharge is far from assured, it is clearly possible, and the resection has a chance of being useful toward that goal. If we assume a more ambitious goal, such as five or ten year survival, chances are much lower, but nevertheless it is possible. Though the odds are worse, resection may still have the effect of helping reach that goal, and hence cannot be termed futile. Finally, if the goal is a normal infancy and childhood, one could indeed argue that resection at this point would be futile. The infant, of course, has formed no goals of his own. His parents, as the acknowledged surrogate decision-makers, speak for him. An essential component of this dilemma is that the surgeon has not had the opportunity to speak at length with the parents.

Once in the operating room, the difficult decision of whether to perform the resection rests with the attending surgeon. If the clinical situation convinced him that the child would not survive the peri-operative period, regardless of therapy, then it would be reasonable to deem resection futile and to forgo the procedure. If, however, there is a chance of immediate survival, and some chance of long-term survival, then futility is not an issue. As with the previous case, this does not imply that therapy (resection) is the most appropriate choice, only that the decision to forgo it cannot be based on futility. Here the concept of “safety in numbers” comes into play, interpreted in two possible ways. “Numbers” may refer to having reliable data upon which to base the predicted chance of survival, and hence the assessment of futility if such data exists and can be applied to a specific case. It is noted that such data may not always exist, or be easily applied to a specific case. But “safety in numbers” may also be taken to refer to the wisdom of consulting with colleagues. The attending surgeon, if possible, should discuss

possible scenarios and appropriate actions with the neonatologist prior to surgery. Better still, the pediatric surgeons and neonatologists at the medical center (and possibly the referring hospital as well) should have previously discussed this scenario as a hypothetical issue, without the pressure of a case immediately at hand. Such preemptive preparedness might help the surgeon to discuss this and other possible scenarios with the parents prior to surgery.

In most cases like the one presented, futility should not be invoked as a justification for foregoing the resection. In a critical situation where success is unlikely but not impossible, the most appropriate approach would be to respect the fully informed wishes of the parents. Unfortunately, in this case, as in many emergencies, their wishes are not known. The decision of how to proceed, then, should be based on the best interest of the patient as viewed by the attending surgeon, after accessing all of the knowledge and judgment of individuals immediately available.

Another approach may be employed, which might be preferable from a logical and philosophical point of view. Assuming the surgeon is convinced that the infant will die imminently without the resection, he could perform the resection and return the child to the NICU. If the child survived the surgery, the surgeon and neonatologist would then meet with the parents to present the information and discuss therapeutic options. A decision could then be made, with appropriate parental input, as to whether to continue aggressive treatment anticipating possible transplant, or to withdraw support, while continuing appropriate pain management. There is no clear ethical difference between withdrawing mechanical ventilation, antibiotics, pressor support, and even intravenous fluids on post-operative day one, versus withholding the bowel resection in the operating room the day before. If it is ethically acceptable in some patients not to do the surgical

resection, then it may also be acceptable in those same patients to withdraw or withhold medical support the following day.

There are some clear advantages to postponing the decision in this way. First, the parents are included in the decision, as is generally felt to be their right. Second, the decision is not made as quickly, or under as much pressure. Lastly, this approach is consistent with commonly accepted medical practice. In general, when life-and-death medical decisions are to be made in the face of uncertainty about a patient's (or surrogate decision-maker's) wishes, the decision is made in favor of preservation of life.

However, there are at least two potential disadvantages of postponing the decision in this way. First, although it is generally felt that the parents have a right to strong involvement in such decisions, this approach could place an unfair burden on them. It could be argued that the surgeon would be abdicating his responsibility as a physician. This criticism revolves around a fundamental question of medical ethics, that of physician paternalism vs. patient/family autonomy. While it may indeed be difficult for the parents to act as the main decision-makers, it is nevertheless a role they have a right to play. It is a role they also have a right to refuse.

The impact that decision-making has on parents should never be underestimated. Parents' identities are intricately intertwined with care of their children; to "decide" against a certain treatment may well be seen as deciding to end their child's life. As one bereaved parent observed, the moment she signed her son's Do-Not-Resuscitate order was the moment she felt as if she had signed his death warrant.²² Many NICU

²² This statement was made at a conference held by the Initiative for Pediatric Palliative Care at the New York Academy of Medicine (November 5-7, 2003). A panel of bereaved parents discussed their experiences to physicians, social workers, chaplains and nurses. The theme that signing a DNR equaled signing a death warrant emerged for every single parent who had experienced the death of a child due to illness. While physicians, lawyers, and ethicists do not interpret the DNR as a "death warrant," this was

parents have said to the physician in such critical situations, “We’ll go along with whatever you recommend.” In such a case they were at least offered the chance to strongly influence their child’s care, and the physician is then free to act in what she perceives as the child’s best interest.

Should the parents choose a more active role in deciding the course of treatment for their infant, these situations can be managed in such a way that takes parental wishes strongly into account, without making the parents feel that the burden of decision is entirely on them, or that they alone “decided to let their child die.” Such cases, however, frequently require a significant amount of both time and communication skills on the part of the physician. It is surely easier for a physician to present the decision to the parents after the surgery has been completed, though this scenario is perhaps not ethically preferable.

The second criticism of postponing the decision is based upon the observation that ethical equivalence does not necessarily imply psychological equivalence. Though withdrawing support the following day may be ethically equivalent to withholding the resection (and we believe it is), it may be far more difficult psychologically for the parents as well as the medical personnel. Psychological difficulty may be ameliorated by communication with, and education of, both parents and staff, but it may nevertheless influence whether it is feasible to employ the postponed decision approach.

There is another point about postponing the decision in this way that may represent either an advantage or a disadvantage. If the decision is to be made in the operating room, a single physician will ultimately decide. If the decision is postponed, other

nonetheless a very real experience for parents. It is a striking illustration of how parents and physicians may interpret and experience a child’s medical situation in vastly different ways.

surgeons may weigh in on the question, as well as colleagues from neonatology. This may be an advantage, as it could serve as a check on the aberrant judgment of one physician. It could also be a disadvantage if several individuals disagreed with each other, since physician dissent can often lead to confusion for the parents. In general, however, it seems reasonable to assume that having the counsel of several colleagues would be more helpful than harmful.

If a decision is made in the operating room, whether or not others were consulted, it will ultimately be made by the attending surgeon. The point of authority is clear. But who will take the responsibility for deciding, with the parents, about withdrawal of support, especially if the question is deferred to the following day? Depending on the custom of the particular NICU, the point of authority may no longer be so clear. In some units the final authority will rest with the neonatologist, in others with the surgeon, and in still others it will be shared. This diffusion of authority may be problematic, particularly if the parents remain unsure and the physicians cannot agree. Nevertheless, it is both our belief and our experience that in the vast majority of cases the different perspectives and talents of the neonatologist and surgeon complement each other well, and consensus is achieved.

Sometimes when facing an ethical dilemma between option A and option B, the best answer is option C. In cases such as the one presented, a third option may be available and appropriate. The surgeon could close the abdomen without resection, return the patient to the NICU, and consider a “second look” surgery in 24 hours. This could allow time to consult with the neonatologist, and to discuss the situation and prognosis with the parents at length. The parents could then be a part of the decision to

withdraw support, or to go for a second look, with at least a reasonable understanding of the short and long-term implications.

In summary, these two cases illustrate difficult decisions in the newborn period when prognosis is poor. There are certainly times in the NICU when certain therapies would be futile. In general, we concur with the notion that the physician is *not* obligated to provide therapy that has virtually no chance of achieving the desired goal. However, it is essential to any discussion of futility that the goal be clear, and the data (or lack of it) be understood. The physician should make every effort to be truthful and thorough in communication with the parents. Simple honesty requires that the physician choose his words carefully; it is especially important that he not overstate the case for withholding treatment by misusing the term “futile.” As noted previously, there are times when aggressive treatment would not be truly futile but would nevertheless be inadvisable. One such situation (there may be others) would be when the benefits of therapy to the patient are clearly outweighed by the burdens to the patient. In such a case, the physician should frame his or her argument based on that assessment, rather than closing off dialogue with a misleading pronouncement of futility.

In situations of pediatric futility, communication about prognosis, hopes, and possibilities can define the experience of the child’s life and death. When physicians are able to facilitate communication and enable open discussion of goals and sorrows, the emotional devastation implicit in these difficult situations may be slightly eased. When pre-viable newborns enter the world, the ensuing moments of decision-making in the hospital will often define the parameters of family life for the parents. It is therefore

incumbent upon physicians and nurses to attend to these very difficult medical situations with care and compassion.²³

²³ The Initiative for Pediatric Palliative Care sponsors a training initiative for doctors who deal with terminal illnesses in pediatric patients and their families. Literature on this topic is burgeoning but still limited. For more information, see Browning D, "To Show our Humanness – Relational and Communicative Competence in Pediatric Palliative Care," *Bioethics Forum* 18 (3/4):23-28; see also Fleischman AR et al, "Caring for Gravely Ill Children," *Pediatrics* 94(4), 4 Oct 1994: 433-439; and American Academy for Pediatrics Committee on Hospital Care (Institute for Family-Centered Care), "Policy Statement: Family-Centered Care and the Pediatrician's Role," *Pediatrics* 112(3), 3 Sept 2003: 691-696.

Medical Futility in the Emergency Department

Karen Restifo and John Schriver

The determination that a clinical situation is “futile” and that medical intervention should be withheld or withdrawn is difficult under most circumstances, but the environment of the hospital emergency department (ED) renders such a determination almost impossible. The patient usually has no prior relationship to the ED staff or attending physician. The patient’s medical history is often unavailable, incomplete or inaccurate. The concept of a “family conference,” in which family members, personal physicians, social workers and perhaps even the institutional bioethics committee sit down and in a deliberate fashion discuss options and plans of action, is virtually always impractical in the ED. Because of the acuity of a patient's presentation to the ED, most decisions must be made rapidly, sometimes immediately. Thus, the most critical commodities in the determination of medical futility – namely, time and information – are usually in extremely short supply.

Superimposed on this already difficult situation is the legal system, particularly the concern of ED physicians about possible medico-legal exposure. According to the Hastings Center, from an ethical standpoint it is appropriate for an attending physician, acting in his or her best judgment, to withhold treatment that is unlikely to be of benefit to the patient.²⁴ There is also support for the judicious withholding of care in the policy statement of the American College of Emergency Physicians. This policy statement maintains that “physicians are under no ethical obligation to render treatments that they

²⁴ Iverson KL: Withholding and Withdrawing Medical Treatment: an Emergency Medicine Perspective. *Annals of Emergency Medicine*, July 1996; 28:51-54.

judge have no realistic likelihood of medical benefit to the patient.”²⁵ However, ethics and legality may diverge in the practice of the emergency physician.

In the absence of what seems to be a legally appropriate advance directive or “Do Not Resuscitate” order, or in the absence of clear evidence of death (such as rigor mortis), there may be among emergency physicians a tendency to attempt a “medico-legal” resuscitation even in a clearly hopeless situation. The absence of reliable predictors of futility and the inability of the physician to predict chances of outcome further underlie the tendency to err on the side of over-treatment. Although some cardiopulmonary arrest scenarios, such as traumatic arrest and unwitnessed nursing home arrest, have a hospital discharge rate approaching zero, these represent a minority of cases transported to the ED.

Further, cultural expectations derived from widespread public cardiopulmonary resuscitation (CPR) education and television dramas that romanticize the heroics of resuscitation and emergency care lead to the public perception that everyone should be “coded” and that most patients will be successfully resuscitated. Younger physicians and those in training may be more enthused about the application of resuscitation procedures; they may also use the opportunity to gain experience or practice.²⁶ Thus, the momentum of the acute situation, and the feeling shared by medical and non-medical personnel that resuscitation “can’t hurt,” may conspire to make it difficult for the emergency physician to resist the application of resuscitation procedures, even under inappropriate circumstances. As a result, there is dire need for awareness about the issues inherent in resuscitation. It is essential that this education and preparation should occur well before

²⁵ Rosenberg NM, Klein E, Gittelman MA, Nozicka CA: When to start and when to stop. *Pediatric Emergency Care*, 2001; 17:126-129

²⁶ Abramson N, Rein de Vos, Fallet ME, Finucane T, Kettler D, Pepe P, Steen PA, Strobos NC. Ethics in Emergency Care. *Annals of Emergency Medicine*, April 2001; 34:196-200.

the patient is transported to the ED. This will require societal and cultural changes in attitudes toward death and the role of medicine – particularly resuscitation.

It is possible to debate the pros and cons of overly aggressive resuscitation. On the positive side, the twenty or thirty minutes spent on a futile resuscitation may meet family expectations and possibly help in the resolution of guilt (“everything possible was done”) as well as giving the family time to assimilate bad news. The actual procedural aspects of the futile resuscitation effort add valuable training opportunities that will assist in future patient care, although rarely will a “hopeless” resuscitation lead to survival and subsequent hospital discharge. Those “successes” tend to be remembered anecdotally (sometimes disproportionately) by physicians and nurses. These potential benefits are balanced against the risk of inducing a permanent vegetative or ventilator dependent state or prolonging a terminal patient’s suffering. Family members may object strenuously to what they feel is a needless extension of the patient’s misery. In the face of an advanced directive against CPR, a resuscitative effort may be construed (at least in theory) as assault and battery. In addition, the costs of resuscitation are substantial, and inappropriate expenditures are hard to justify in a cost-conscious medical environment. Finally, in a busy ED, the allocation of staff for resuscitation may detract from the care of other, more “salvageable” patients.

The ED often serves a triage function, and as such resources may be limited. Attention must be given, first, to those patients who exhibit the most need. A secondary consideration is the impact or outcome that treatment will have for the person’s lifespan and quantity of life. One factor that contributes to futility in the ED is the role of the ED as a “clearing house” for the deceased. In many communities, transport to the ED is often an unavoidable detour on the way to the morgue or funeral home. Simply put, the

prehospital care system is not designed to facilitate the appropriate disposition of the newly dead. A dead body at home or by the side of the highway is acutely uncomfortable for many involved, so the deceased is often taken to the ED for lack of an alternative course of action. An appropriate system would provide for determination of death by paramedical personnel in the field, often with “medical control” consultation with the emergency physician by radio or telephone, and with subsequent transport to the coroner or undertaker.²⁷

The role of the family may be magnified by the stress and tragedy of an emergency situation. Various family members may be present or absent, and familial conflicts or familial dysfunction may emerge as powerful forces in the decision-making process. Consider the case of an elderly nursing home patient with an unwitnessed cardiac arrest who arrives in the ED. To the ED physician it should be obvious that the chance of successful resuscitation is essentially zero. However, a family member may demand that “everything be done,” and the ED physician is placed in a difficult situation. The ED physician may feel compelled to “treat the family” – knowing that her intervention will have no effect on the patient – and carry out an otherwise inappropriate resuscitation attempt.

Even cases in which the patient’s wishes are known in advance, and in which the family concurs, may not be straightforward. For instance, a man with a painful terminal cancer attempts suicide by shooting himself in the abdomen. Does the fact that it was a suicide attempt raise the issue of state of mind or mental illness, and thereby render an advance directive invalid? Is the mental situation leading to the suicide attempt fixable?

²⁷ Portland, Oregon is one example of a community that employs this system.

The questions can be complex and multifaceted. Unambiguous conclusions are often elusive.

Indeed, medical futility in the context of the emergency department has a different meaning than in other parts of the hospital. Does the definition apply to the withdrawal of care that had been administered by pre-hospital personnel, or does it apply to the withholding of additional interventions? Some physicians have proposed a classification scheme that replaces the term “futility” with “clinically non-beneficial interventions” and further stratifies the interventions according to the level of risk as well as potential benefits to patients, families and society. They recommend that decisions be made after considering medical and non-medical benefits, the preferences of patients and families, and potential risks of intervention. Judgments should be based upon scientific data as opposed to personal biases concerning subjective issues such as “quality of life.” The more precise definitions of situations that they offer may make the futility debate more productive and consensus less elusive.²⁸

In summary, there are many factors that contribute to frequency and difficulty of determining medical futility in the ED. Deficits of time and background information, unrealistic societal expectations, fear of litigation and guilt-ridden family members are some of the causes of over-treatment in situations where there is no possible successful outcome. These convoluting factors are probably detrimental to society as a whole, because they perpetuate misinformed expectations and realities.

Possible solutions to the issue of medical futility as seen through ED resuscitation may derive from social policy, public education, national guidelines and increased

²⁸ Marco CA, Larkin GL. Ethics Seminars: Case Studies in "Futility" - Challenges for Academic Emergency Medicine. *Academic Emergency Medicine*, October 2000; 7:1147-1151. See also Marco CA, Larkin GL, Moskop JC, Derse AR. Determination of "Futility" in Emergency Medicine. *Annals of Emergency Medicine*, June 2000; 35:604-609.

utilization of advance directives. Until such a time, emergency physicians will need to rely upon their best medical judgment and call upon their best human qualities of insight, empathy and compassion.

Futility in the Intensive Care Unit

Mark D. Siegel, Stanley H. Rosenbaum and Heidi L. Frankel

Mr. C was an elderly patient, intubated in the Intensive Care Unit (ICU) with pneumonia and respiratory failure. He had survived multiple prior hospital stays but had recently been bed-bound in a nursing home with progressive dementia, coronary disease, seizures, renal insufficiency, and pressure sores. During this hospitalization, renal insufficiency progressed and he was unable to come off the respirator. Three weeks later, the ICU team had to consider possible tracheostomy and hemodialysis.

The physicians and nurses met with Mr. C's wife and sons, described his poor prognosis, and advised them that he would likely remain permanently dependent on mechanical ventilation. The team suggested foregoing dialysis and tracheostomy. Mrs. C., however, demanded that "everything be done," including dialysis, tracheostomy, and cardiopulmonary resuscitation should he have a cardiac arrest. The children deferred to their mother, confiding that they, not the caregivers, would have to live with their "angry Italian mother" should interventions be withheld. The team expressed discomfort with continued life-sustaining treatment (LST), which they felt would cause pain but no benefit.

This case illustrates a common dilemma faced by patients, families, and caregivers in intensive care units when treatment is failing. Difficult choices must be made, often quickly, regarding the benefits and burdens of initiating or continuing LST. Because most ICU patients are too ill to make decisions, the burden generally falls to surrogates (usually family) and members of the medical team, who may be ill equipped to determine patients' wishes. The complex decision-making process that follows involves prognostication and recommendations by the healthcare team, usually combined with decisions by the surrogates. In this chapter, we focus on the factors that influence the decision to withhold or withdraw life support in the ICU.

The Changing Face of Death in the ICU

Patients with terminal illness frequently end their lives in ICUs, often with pain and discomfort. Physicians may be unaware that many patients desire less aggressive care than they are actually receiving. Pain, dyspnea, restlessness, and agitation are frequent, even among those ordered to receive “comfort measures only.”

Inconsistent definitions and reporting make it difficult to estimate how many patients receive futile or inadvisable care, but the numbers are probably large. In a European survey, 73% of physicians indicated that they frequently admitted patients with “no hope of survival.”²⁹ Similarly, a study of critically ill Medicare beneficiaries found that 4.8% received “potentially ineffective care,” defined as dying within a short period of time despite high expenditure.³⁰ Such patients consumed 21.6% of all resources expended for the entire group. In one study, futile or inappropriate care was driven most frequently by the family.³¹

Caring for patients with little hope of survival imposes significant burdens on ICUs. When resources are limited, using critical care beds for hopeless patients may displace those with a better chance to benefit. Caring for such patients may also impose a psychological burden on the staff, who may feel demoralized by providing invasive, painful therapy to those who cannot benefit.

It has become common for ICU physicians to withhold or withdraw LST from dying patients. In one center, recommendations to withdraw or withhold life support

²⁹ Vincent JL. Forgoing life support in western European intensive care units: the results of an ethical questionnaire [see comments]. *Crit Care Med.* 1999;27(8):1626-33.

³⁰ Cher DJ, Lenert LA. Method of medicare reimbursement and the rate of potentially ineffective care of critically ill patients. *JAMA.* 1997;278:1001-1007.

³¹ Rivera S, Kim D, Garone S, Morgenstern L, Mohsenifar z. Motivating factors in futile clinical interventions. *Chest.* 2001;119:1944-1947.

increased from 51% in 1987-1988 to 90% in 1992-1993.³² Similar trends have occurred elsewhere in North America and Western Europe, so that most ICU deaths now occur after LST has been withheld or withdrawn.

The frequency and approach to terminating life support varies from country to country, hospital to hospital, and physician to physician. In Western Europe, the frequency of “do not resuscitate” (DNR) orders ranges from 8% in Italy to 91% in the Netherlands.³³ In North America, the frequency of withdrawal of life support varies widely: Some ICUs seem not to ever withdraw support, while others do so up to 79% of the time.³⁴ The frequency varies by hospital. Further complicating the issue, one study found that in hypothetical discussions of ICU case studies and patient care, individual physicians offer widely varying recommendations, ranging from comfort care to fully aggressive management. Taken together, these studies lead to the disturbing conclusion that local practice variation, rather than the features of a patient’s illness or wishes, are the most important determinants of care.

Futility and Ineffective Care: Definitions and Therapeutic Implications

The transition to withholding or withdrawing LST generally follows one of two paths. First, patients or surrogates may decide to forego potentially beneficial care due to personal values or beliefs. Alternatively, it may become apparent, usually to the medical team, that further therapy cannot achieve desired outcomes (i.e., it is “futile”) and therefore not warranted. It is widely accepted that competent patients may refuse

³² Prendergast TJ, Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill [see comments]. *Am J Respir Crit Care Med.* 1997;155(1):15-20.

³³ Vincent JL, “Forgoing life support...”

³⁴ Prendergast TJ, Claessens MT, Luce JM. A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med.* 1998;158(4):1163-7.

potentially beneficial care. In contrast, at least in theory, futile interventions should not be provided, even if requested. This, however, is often not the case.

Futility is the most commonly cited rationale for foregoing LST. Widespread disagreement and confusion exist regarding the definition of futility and when it should be applied, leading some to suggest that it be abandoned as a justification for withholding or withdrawing support.^{35, 36, 37} Yet the concept is strongly supported by those who argue that it is the physician's obligation to determine when further care is inappropriate.³⁸

Viewed simply, a futile intervention is one that cannot be reasonably expected to achieve an intended goal. Unfortunately, general agreement on the designation of futility is limited to extreme cases or narrow physiological concepts. Obvious examples include applying CPR to septic shock patients whose hearts stop despite drugs to support blood pressure; or the continuation of blood transfusion in patients with ruptured aortic aneurysms who are not surgical candidates.

In common practice, it is more difficult to agree upon what counts as a futile case. Attempts to identify futility are hampered by disagreement over thresholds, inadequate outcome data, poorly defined treatment goals, and confusion over usage, particularly among trainees. Schneiderman, Jecker and Jonsen suggested that futility may be identified when the chance of success is estimated to be less than 1%.³⁹ Unfortunately, this threshold can be applied reliably to only a minority of diseases in the ICU. Typical examples with predictably poor outcome include persistent anoxic encephalopathy,

³⁵ Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: Response to critiques. *Ann Intern Med.* 1996;125:669-674.

³⁶ Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications [see comments]. [Review] [38 refs]. *Ann Intern Med.* 1990;112(12):949-54.

³⁷ Helft PR, Siegler M, Lantos J. The rise and fall of the futility movement. *N Engl J Med.* 2000;343:293-296.

³⁸ Schneiderman, Jecker, Jonsen (1996).

³⁹ See Schneiderman, Jecker, Jonsen (1996).

cardiac arrest in the hospitalized elderly, acute respiratory distress syndrome (ARDS) with persistent multiple organ failure, and respiratory failure in bone marrow transplant patients with concurrent shock or renal failure. Furthermore, even studies showing predictably poor outcomes cannot exclude the possibility that, with larger cohorts, subsets might have been identified that do better.

For the concept of futility to have any value, there must be some level of confidence that a treatment cannot work. Using a rigid threshold to define futility is problematic because it is arbitrary and, because it is based on past experience, it does not account for newly evolving therapies. Furthermore, to some people, a less than 1% chance of success may justify treatment, particularly when the alternative is death. Recent reports of successful new therapies for ARDS, severe sepsis, intracranial hemorrhage, and cardiac arrest suggest that many traditional prognostic estimates may be obsolete. Similarly, the growing availability of trained intensive care physicians may be improving outcomes. When patients survive beyond caregivers' most dismal predictions, the difficulty of identifying futility becomes quite evident.

Improved survival from diseases previously considered hopeless, such as severe intracranial hemorrhage, suggest that past treatment limitations may have created "self-fulfilling prophecies" and overly pessimistic outcome predictions. Recent data from long-term ventilator weaning units suggest that patients willing to undergo weeks to months of therapy may eventually wean and survive.⁴⁰ It is important to strike a balance between foregoing futile care and being appropriately aggressive as technology improves.

⁴⁰ Scheinhorn DJ, Chao DC, Stearn-Hassenpflug M, LaBree LD, Heltsley DJ. Post-ICU mechanical ventilation: treatment of 1,123 patients at a regional weaning center. *Chest*. 1997;111(6):1654-9.

It is tempting to apply the term “futility” to include care that would fail to return a patient to an acceptable quality of life. Unfortunately, clinicians and families may underestimate what patients consider acceptable; therefore, application of this broader usage, however appealing, is problematic. It seems reasonable, however, to expect some minimum quality of life (e.g., some return to consciousness or the ability to survive outside intensive care) to justify continued life support. In addition, it seems reasonable to apply futility designations to therapies that cannot meet goals that would be acceptable to the patient.

In addition to futile therapies, others may be “inappropriate” or “inadvisable” because they are “extremely unlikely to be beneficial,” to be beneficial but “extremely costly,” or of uncertain or controversial benefit.^{41,42} In contrast to futile therapies, which probably should not be offered, the decision to discontinue inappropriate or inadvisable treatment generally requires approval from the patient or family after weighing benefits and burdens in the context of patient goals.

Decision-Making for ICU Patients

A critical principle in ethical decision-making in the ICU is recognition of the source of authority. Patients have the ethical and legal right to determine what health care will or will not be rendered. Unfortunately, such patients are often legally incompetent to render informed decisions, so appropriately identified surrogates are responsible in their stead. In this framework, physicians act as consultants: They evaluate patients and render expert opinions to be acted upon by the patient or

⁴¹ Anonymous. Consensus Statement (1997).

⁴² Luce JM. The art of negotiating. *Crit Care Med.* 2001;29(5):1078-1079.

surrogate(s). In our opinion, physicians should only render care if it is approved by the patient or their surrogate(s), except in emergency situations.

Most medical ethicists feel that substituted judgment is “the preferred method of surrogate decision-making because it follows from the respect for autonomy and relieves others of having to make decisions based on a perceived quality of life.”⁴³ Substituted judgment implies that a surrogate decision-maker can articulate the patient’s preferences and values to reach decisions that the patient would have made if he could. The alternative to substituted judgment occurs when decisions are then made according to the patient's “best interests,” which is a more objective and less personal approach.

Unfortunately, most ICU patients have not previously outlined their advance directives, designated a durable power of attorney for healthcare or executed a healthcare proxy. If there is no written document that outlines the patient’s wishes or appoints a surrogate decision maker, the ICU team must determine the closest next-of-kin. The usual order of priority is spouse, adult children, parents, and any living relative.

Conflict arises when no family members are willing or able to make decisions, when family members of equal standing (e.g. adult children) disagree or when the decisions of the surrogate contradict the recommendations of the ICU team. A court-appointed conservator can be utilized to address decision-making when there is no one else who is willing or able to make decisions. However, it may be difficult to identify an individual to serve in this role. The process of court-appointed guardianship is awkward, and courts often appoint individuals who are reluctant to forego any life-sustaining treatment.

⁴³ Tonelli MR. Substituted judgment in medical practice: evidentiary standards on a sliding. *J. Law, Medicine Ethics.* 1997; p23.

Determining the Goals of Care: Achieving a Consensus

The transition to withholding or withdrawing LST generally follows deliberation by the medical team and discussion with the patient, or, more commonly, the family. In North American ICUs, most decision-making follows formal discussions between physicians and the patient's family. Often nurses, social workers, and clergy are involved. In other parts of the world, the family plays a less central role. For example, in Western Europe it is more common for physicians to make decisions unilaterally. Admittedly, even in America physicians exert significant control over decision-making.

When care is truly futile (i.e. physiologically ineffective), the rationale for withholding or withdrawing LST should be self-evident and, at least in theory, asking the family to "make decisions" is not necessary.⁴⁴ One study reported that more than 80% of physicians withdrew or withheld care unilaterally in cases considered "futile," sometimes over the objections of, or without the knowledge or consent of, patients or surrogates.⁴⁵

Although some patients would allow their physicians to make independent decisions on the futility of LST, many would not. Legal support for unilateral discontinuation of LST is uncertain, although there is little precedent for punishing physicians acting in good faith and within professional standards.⁴⁶ To encourage well-considered decision-making, the American Medical Association has recommended a formal process to precede discontinuation of LST, in which unilateral decision-making

⁴⁴ Layson RT, McConnell T. Must consent always be obtained for a do-not-resuscitate-order? *Arch Intern Med.* 1996; 156.

⁴⁵ Asch DA, Hansen-Flaschen J, Lanken PN. Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes [see comments]. *Am J Respir Crit Care Med.* 1995;151(2 Pt 1):288-92.

⁴⁶ Anonymous. Medical futility in end-of-life care. Report of the council on ethical and judicial affairs. *JAMA.* 1999;281:937-941. For further discussion of this topic, see Stephen Latham's essay on this volume, which addresses the law and medical futility.

can be employed in only the most extreme circumstances. Further, formal policies regarding the discontinuation of futile care are being adopted in several communities in attempts to ensure that the process is appropriately deliberate, respectful of patients' and families' concerns, consistent, fair, ethically sound, and reflective of local values.

Although it is appropriate to discuss the rationale for withholding or withdrawing LST, there is no justification for asking surrogates to "make decisions" about further care when such care is accepted as physiologically futile. At the same time, identifying futility does not eliminate the need to communicate. It may take several days or longer for families to accept the futility of LST. Therefore, it is appropriate to allow time for them to grow accustomed to the transition to comfort care and, if possible, to allow the family to visit and grieve. Usually, with effective counseling, communication, and patience, families support the transition to palliation.

Truly futile cases, however, probably represent only a minority of those in which end-of-life decisions must be considered. More commonly, deliberations focus upon the relative merits and burdens of continued care. Factors considered include the likelihood of survival and return to independent function; these goals are counterbalanced by the likelihood of pain, prolonged immobility, dependence, and cost.

One significant difficulty in establishing medical futility is the inability to obtain a uniform interpretation of the patient's goals, willingness to face discomfort, and willingness to take medical or surgical risks. For this reason, end-of-life discussions should be initiated early in the ICU stay. Many, but certainly not all, seriously ill patients and their families welcome such discussions. Effective communication promotes a more timely transition to care that is satisfactory to both families and caregivers. One study, which investigated the efficacy of a multidisciplinary meeting after a patient spent 72

hours in the ICU, demonstrated that ineffective care decreased, the median length of stay decreased for dying patients, and bed availability increased for patients who were less ill.⁴⁷ Similarly, creation of a proactive ethics consultation team, which promoted communication about life support in patients requiring more than 96 hours of mechanical ventilation, resulted in decreased length of stay and more decisions to forego life support.⁴⁸

Effective communication is also critical to the resolution of ethical dilemmas. Patients and their families should be assured that they will be respected, heard, cared for and not abandoned. The clinical condition should be communicated in concise, simple language with attention to goals, expectations and prognosis.

Proper communication needs to occur among the primary physicians, ICU team, patient (if possible) and surrogate decision makers. Relevant specialists should be included in the discussion, but encouraged not to render organ-specific prognoses out of context or overall judgments beyond their expertise. Team members should appreciate that the content and context of discussions can have important, and sometimes unintended consequences, and should circumvent obstacles that may interfere with good communication. For example, it is not helpful to note that the “lungs are improving” if that is a clinically insignificant change in the course of progressive organ failure.

There are many obstacles to effective communication in the ICU, not the least of which is the impersonal and complex environment. This can be overwhelming. Further, the medical states of many patients may be hard for the untrained observer to differentiate. To the inexperienced physician, a brain dead patient on a ventilator, a

⁴⁷ Lilly CM, De Meo DL, Sonna LA, et al. An intensive communication intervention for the critically ill. *Am J Med.* 2000;109:469-475.

⁴⁸ Dowdy MD, Robertson C, Bander JA. A study of proactive ethics consultation for critically and terminally ill patients with extended lengths of stay [see comments]. *Crit Care Med.* 1998;26(2):252-9.

young person with transient multiple organ failure from sepsis and Mr. C. (from the case study above) may all appear about the same, and may even merit similar treatment – despite having vastly different prognoses. Furthermore, many patients in the ICU are admitted after emergency surgery or trauma, such that patients and families have not considered treatment preferences. Complicating this scenario is the fact that some patients and their families may not trust the ICU physicians because they have only just met. (In some cases, families may even attempt to “hide” an advance directive from the ICU team because of concern that its presence might lessen appropriate therapy or deny palliative care.) In addition, many ICU’s do not have adequate consultation space where the health care team and family can talk privately; health care providers may feel that there is inadequate time to spend with families and other team members; or ICU staff may be vastly overworked in caring for many patients with poor prognoses.

The lack of a relationship with the patient or family prior to their admission to an ICU also hampers effective communication. The intensivists often rely on a primary care physician or operating surgeon to have adequately discussed these issues with the patient previously, and to relay this information clearly and unambiguously to the ICU team. Finally, the patient, family and health care team may each be victims of their own hopes, whereby death is usually viewed as the enemy, and disease can and must be conquered.

Formal family meetings incorporate three key elements, including 1) a description of the patient’s medical condition and prognosis, 2) consideration of the patient’s presumed wishes, and 3) an attempt to reach a consensus regarding treatment goals and the merits of continued LST. It is essential to distinguish realistic from unrealistic expectations about outcomes and to be frank about the burdens of critical care, including pain and prolonged periods of dependency that follow most ICU stays.

Unfortunately, successful implementation of each element is challenging. For example, individual physicians vary greatly on estimates of prognosis. Severity of illness scoring systems, such as APACHE II, and past experience with similar diseases, provide uncertain guidance to physicians, particularly when unique patient characteristics, such as age, gender, and comorbidity are considered. Moreover, severity scores were never designed to make decisions about withholding or withdrawing care; thus they provide no guidance on extended survival rates or frequency of return to independent living. Only recently have studies focused on long-term outcomes in illnesses such as ARDS. Despite these uncertainties, the abilities of experienced physicians to provide reasonably accurate prognoses should not be underestimated.

In contrast to other settings, few ICU patients have the capacity to make decisions. Reasons include the effects of illness, sedation, pre-existing cognitive impairment, and delirium, particularly among those requiring mechanical ventilation. Lack of patient input is stressful for decision-makers. Although clear documentation of a patient's past wishes is required in some jurisdictions, formal proof of the patient's preferences is generally neither available nor expected.

Unfortunately, patients may not discuss their wishes with family before becoming sick, which makes it difficult to intuit their preferences. Advance directives are often unavailable and frequently fail to address key issues. Similarly, primary care providers rarely address end-of-life issues early enough or in sufficient detail to foster treatment decisions. Also, wishes expressed by patients when they are well may change as illness evolves. Hence, enormous reliance is placed on families to speak for patients.

Unfortunately, data suggest they may be inaccurate at predicting loved ones' willingness to accept life support.⁴⁹ Physicians and nurses are similarly inaccurate.

While many patients want less aggressive care than that being provided, most survivors of critical illness are glad to have received such care, even if it results in a diminished quality of life. In one study, survivors expressed willingness to undergo ICU care again, even for an additional one-month of life.⁵⁰ Willingness bore no relationship to age, quality of life, or life expectancy. Another study indicated that factors such as pain, age, current health, and concerns about the financial burdens of acute illness may influence survivors when asked if they would undergo mechanical ventilation again.⁵¹ In situations where standard choices of treatment remain an option, physicians should not make assumptions about patients' wishes, nor impose their own values.

For patients who are not doing well, it is essential that the medical team attempt to reach some consensus with family on the merits of continuing LST. When cure is no longer desired or possible, families must be given all necessary information on the burdens and benefits of continued LST as well as alternative treatment regimens, such as palliation, which could provide relief from pain, dyspnea, and other discomfort. Families rarely want to make decisions alone and most, but not all, welcome and count upon physicians' recommendations in making end-of-life decisions. In most cases, particularly with an appropriate investment of time, communication, empathy and support, consensus can be achieved and mutually satisfactory decisions made.

⁴⁹ Uhlmann RF, Pearlman RA, Cain KC. Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *J Gerontol.* 1988;43(5):M115-21.

⁵⁰ Danis M, Patrick DL, Southerland LI, Green ML. Patients' and families' preferences for medical intensive care. *JAMA.* 1988;260(6):797-802.

⁵¹ Mendelsohn AB, Belle SH, Fischhoff B, Wisniewski SR, Degenholtz H, Chelluri L. How patients feel about prolonged mechanical ventilation 1 yr later. *Crit Care Med.* 2002;30:1439-1445.

Failures to Achieve Consensus: Causes and Possible Solutions

Although consensus can usually be achieved, conflict between families and caregivers may prevent effective decision-making. Factors that contribute to conflict include mistrust, miscommunication, misconceptions about critical care, certain religious beliefs, and strife within the family.⁵²

Failure to build trust may lead families to doubt prognostic estimates and to resist treatment recommendations. Several factors may contribute to mistrust. First, true or not, families may question the quality of care being provided and whether all treatment options have been explored, in turn making it difficult for them to believe reports that treatment has failed. Second, families sometimes report past experiences in which patients survived after being told there was no hope, thus causing them to doubt subsequent prognostic estimates. Third, concerns about racial disparity may lead minority families to question the motivation to recommend withholding or withdrawing LST. Fourth, busy clinicians may delegate too much responsibility to inexperienced housestaff, whose opinions are less valued by the family. Other obstacles include frequent changes in the attending physician, perceptions of conflict among the staff, a perceived need to “free up” beds for other patients, and concern that the physician is not an enthusiastic advocate for the patient. Finally, families may be reasonably concerned that patients who made “do not resuscitate” (DNR) orders will have other interventions withheld.

⁵² Fins JJ, Solomon MZ. Communication in intensive care settings: The challenge of futility disputes. *Crit Care Med.* 2001;29(2 (Suppl.)):N10-N15.

Poor communication undoubtedly contributes to impasse. This is true particularly when meetings with families are delayed, poorly timed, or miss key issues. Important discussions are often left to housestaff, who may lack communication skills, neglect key issues (such as the likelihood of a response to treatment), or fail to elicit patients' goals and preferences. Additional specific factors that interfere with communication include the physician's use of technical jargon, her failure to listen, an excessive focus on specific procedures without sufficient discussion of the patient's status, and a perceived lack of empathy. Imprecise phrases, such as a request to "do everything," may cause confusion if not further defined.

It is enormously stressful for families to make "life or death" decisions about loved ones. If made to feel that they are being pushed to "pull the plug," many will balk, even if they would otherwise accept a recommendation to choose palliative care. Disagreement caused by strained relationships within the family may prove counterproductive when collaboration is needed. Although it may be tempting to identify a single family spokesperson, it is best to attempt to reach a consensus among loved ones, particularly those with a stake in the decision.

In addition, families may harbor misconceptions about the benefits of intensive care. For example, unrealistic expectations about CPR may result from medical television shows, where CPR tends to look far more glamorous than in real life, and survival rates greatly exceed that of reality. Given more realistic data about CPR, patients are less likely to request resuscitation, suggesting that education may steer decision-making in more appropriate directions. Consideration of intermediate treatments, such as limited attempts at resuscitation when potentially effective may be preferable to "all or nothing" options.

Many but not all religions condone withholding or withdrawing life support in patients who cannot benefit or who choose to forego treatment. Some groups may cite the potential for miracles, even in seemingly hopeless cases. In such circumstances, references to the burdens of care or the odds against survival are unlikely to influence decision-making in such circumstances. At times, however, religious arguments for continuing LST may simply be a way for families to avoid distressing but necessary conversations. In such cases a chaplain's assistance may be invaluable.

There are tangible benefits to effective communication. Stress levels of patients, family members and care providers can be lowered by clear discussion of expectations and projected course. End-of-life decisions can be made earlier, decreasing the frequency of unwanted care and utilization of scarce resources.⁵³ Fortunately, there are methods to improve communication. The health care provider must listen and deliver information in simple language with less attention to numbers and doses and more consideration to the overall situation. The ICU team should attempt to give the patient and surrogate decision maker a sense of control by respecting wishes based on informed consent. Physicians often spend too little time in the patient's room or sitting with family members in an environment conducive to listening and discussions. Summarizing the treatment course, setting tangible goals, asking questions and allowing families to express their understanding of the entire process are all vital practices. Indeed, a study of family members who received news of unexpected death from injury found that the attitude of the news giver was the most important feature (ranked most important by 72%) followed by the clarity of the message (70%) and knowledge (57%).

⁵³ Ong LM, de Haes JC, Hoos AM et al. Doctor-patient communication: a review of the literature. *Soc Sci Med.* 1995; 40: 903-918.

Discussions about withdrawing life support are particularly difficult. The Stanford University Medical Center Committee on Ethics recommends the following guidelines:⁵⁴

- 1) Talk with and seek unanimity among the various members of the healthcare team.
- 2) Vigorously solicit the patient's views regarding life support or seek any available evidence of the patient's wishes.
- 3) Be patient in working toward a unanimous decision.
- 4) Establish time-limited goals.
- 5) Allow the patients to express feelings of anger or mistrust.
- 6) Be understanding and avoid becoming defensive.
- 7) Seek facilitators, especially when conflict arises.

It is unfortunate that end-of-life decisions are so often first discussed in the intensive care unit setting, especially when patients who have chronic diseases could have had prior discussions with their primary physicians. It has been suggested that end-of-life discussions be initiated in the following settings whenever possible: Patients facing imminent death, or who talk about wanting to die; patients and families who inquire about hospice; patients recently hospitalized for severe progressive illness, or suffering out of proportion to prognosis; when physicians and patients are discussing prognosis, treatment options with a low probability of success, or hopes and fears about the illness and treatment; and when physicians do not expect patients to live more than one year. Such discussions should include the possibility of drafting an advance directive

⁵⁴ Christakis NA. Timing of referral of terminally ill patients to an outpatient hospice. *J Gen Intern Med.* 1994; 9:314-320.

and designating a health care proxy; clarification of do-not-resuscitate/intubate orders; discussion of other life-sustaining therapies such as nutrition and hemodialysis; and explanation of the value of palliative care.

In most cases, a consensus can be reached between the medical team and family regarding life support. It is rarely necessary or appropriate for physicians to withhold or withdraw care unilaterally. In general, effective leadership by the attending physician, good communication, demonstrations of empathy and patience, and assistance from clergy, social work, and nursing, can promote a mutually acceptable course of action.

When families insist upon continued LST against the judgment of caregivers, it is best to have a formal process that includes negotiation, second opinions, and the opportunity to transfer care before the decision is made to unilaterally discontinue LST. Assistance from the hospital bioethics committee may be helpful at identifying sources of conflict and clarifying issues to be addressed. In the few cases that have come to court, the rights of patients and surrogates to demand life-support have been generally upheld over the arguments of treating physicians.⁵⁵

In most hospitals, ICU teams can request consultations from expert facilitators to handle ethical dilemmas. Individual consultants who meet with the ICU team and surrogate decision makers may be more helpful than a formal committee convened at a remote site. Schneiderman et al. randomized 74 patients, plus their care providers and decision makers, to having ethics consultation or not. Mortality was not different between the groups, but ethics consultations were associated with reduction in life-sustaining treatments and reduced ICU stays (by nine days).⁵⁶

⁵⁵ Again, see the essay by Stephen Latham in this volume.

⁵⁶ Schneiderman LJ, Gilmer T, Teetzel HD. Impact of ethics consultations in the intensive care setting: a randomized, controlled trial. *Crit Care Med.* 2000; 28: 3920-3924. See also Schneiderman LJ et al., Effect

Finally, it is unrealistic to expect that many or even most conflicts will be resolved at a single family meeting. Physicians should expect to meet frequently with families to provide updates, allow trust to build, and allow time for surrogates to make decisions at their own pace without feeling coerced. In most cases, when families are not ready to accept predictions of a poor prognosis, a time-limited trial of continued intensive care may help them to accept the likely outcome.

Withholding and Withdrawing Life Support

There is no clear ethical distinction between withholding and withdrawing life support when the decision is made to forego LST. However, there may be a clear psychological distinction between deferring action and continuing LST by default, versus the proximate effect of withdrawal of LST and immediate subsequent death.

In contrast, there is a distinction between these decisions and euthanasia. The latter is not considered acceptable practice in most Western countries. Euthanasia denotes actively terminating a patient's life, while the withdrawal and withholding of life support are meant to forego care that is either ineffective or not desired, recognizing that the patient may die as a secondary consequence. Withdrawal of potential LST is always done within the implied context of the patient withdrawing consent for further care, which is always within the patient's right.

Any and all forms of life support can be withheld or withdrawn from dying patients, including vasopressors, intravenous fluids, dialysis, nutritional support, and mechanical ventilation. Specific decisions are subject to the preferences and practice

styles of individual families and physicians. With respect to mechanical ventilation, significant conflict exists regarding the appropriateness of tracheal extubation. Some authors express concern that families may be unnecessarily stressed by the sound of gurgling or the appearance of the patient after the endotracheal tube is removed. In our experience, such distress is exceedingly uncommon and extubation is well accepted, and generally preferred, by families who have been appropriately counseled. In almost all cases, palliation with narcotics and sedatives as needed will ensure effective symptom control. It is imperative that physicians continue to communicate and provide support to families, even as LST is withheld or withdrawn. In the end, decisions should be made on an individual basis, with respect for the wishes of the patient and family, recognizing that preferences may vary considerably.

Palliation in the ICU

A patient or proxy's decision to forego lifesaving therapy in the ICU through withholding or withdrawing critical care does not absolve the healthcare professional from providing any care. As practitioners in a setting where 10% to 20% of their patients will die, ICU physicians are charged with providing high quality palliative care for diseases not responsive to curative treatment. Palliative care includes removal or avoidance of unnecessary or uncomfortable therapies, pain and symptom management, and emotional and bereavement support.

Pain management is the essential component of palliative care. Objective assessment of pain through visual analog scales or observation of behavior and vital signs is important, because pain is experienced by 50% to 75% of ICU patients and inadequate

pain management therapy may accompany otherwise appropriate care.⁵⁷ ICU health care providers may fear that the administration of analgesics or sedatives for adequate palliative care may hasten death, though this concern is diminishing with the growth of palliative care as a specialty in its own right. Two U.S. Supreme Court decisions (Washington vs. Glucksberg and Vacco vs. Quill) affirmed that the state may “permit palliative care ... which may have the foreseen unintended double effect of hastening the patients’ death.”⁵⁸

The management of dyspnea is another important component of palliative care. A respiratory rate of less than 30 breaths per minute, and the absence of agitation, restlessness and grimacing are standard goals. Sitting the patient in a semi-upright position, plus the administration of opioids, sedatives and anticholinergic agents may be helpful. Finally, emotional and bereavement support for families of dying ICU patients is an important component of palliative care, to which end hospital chaplains, social workers, family clergy as well as physicians and nurses may be helpful. Unrestricted visiting hours in the ICU setting are similarly beneficial. Support groups or contact with the ICU staff after the patient’s death may be helpful to the family.

Conclusions

Critical care physicians frequently identify patients who are exceedingly unlikely to survive or benefit from continued LST. It is one of the ICU physician’s greatest challenges to recognize when LST should be withheld or withdrawn, and when palliation should be the exclusive mode of patient care. Such challenges will continue to be

⁵⁷ Nelson J, Meier D, Gei E, et al. Self-reported symptom experience of critically ill cancer patients receiving intensive care. *Crit Care Med.* 2001; 29: 277-282.

⁵⁸ Washington v. Glucksberg. US, 117S CT 2258, 138L. Ed. 2d 772, 1997; Vacco vs. Quill US. 117 Sct 2293, 138L Ed 2D 834, 1991.

dynamic due to the development of improved prognostic tools, more effective physician education in end-of-life care, and clarification of society's mandates regarding the appropriate use of scarce ICU resources. For those practicing in the ICU, the cultivation of trusting relationships with families, while fostering communication and respect for personal beliefs, is essential to ensuring treatment that best serves our dying patients.

Follow-Up

In Mr. C's case, an insightful chaplain recognized that Mrs. C's resistance to palliative care stemmed from a fear of living alone after her husband's death, particularly after years of devoted support and little contact with the world outside her home. Over time, gentle counseling allowed her to come to terms with the inevitability of her husband's death. She was encouraged to consider ways to re-enter the community and, after her husband passed peacefully without dialysis, she became a volunteer in the hospital's gourmet café, where she continues to contribute her time today.

The Withdrawal and Withholding of Dialysis

Robert Reilly

We (physicians) need to be more open minded to the patient and more realistic about what we can and cannot do... physicians need to teach themselves to recognize better the shadow line between prolonging life and prolonging dying and to understand that death should be a human act of dignity and not a prolonged mechanical failure that can be fixed with even more technology.⁵⁹

Introduction

The decision to withhold or withdraw dialysis is a difficult one for patients, families and nephrologists. Medical technology has advanced dramatically in the last several decades. In just forty years we have seen renal failure transformed from a uniformly fatal condition to one where a machine and medications now perform most of the functions of a native kidney well enough to sustain life. As technology advances, however, health care providers are increasingly confronted with the question: because we can do more, should we?

The issue of the withholding or withdrawing dialysis is a common one in the management of patients with end-stage renal disease (ESRD). In one of the largest studies to examine this decision, Leggat evaluated 116,829 deaths in the U.S. Renal Data System database between 1990 and 1995 and found that 17.8% of patients withdrew dialysis before death.⁶⁰ In general, patients beginning dialysis today are older and have more comorbid conditions than ever before. Further, the decision to withhold or withdraw

⁵⁹ Kjellstrand CM. Who should decide about your death? *JAMA* 267: 103-104, 1992.

⁶⁰ Leggat JE Jr, Bloembergen WE, Levine G, Hulbert-Shearon TE, Port FK. An analysis of risk factors for withdrawal from dialysis before death. *J Am Soc Nephrol* 8: 1755-63, 1997.

dialysis involves ethical and legal issues for which the majority of nephrologists have no formal training.

After providing a brief history of the ESRD program in the United States, the decision to withdraw or withhold dialysis is discussed from the viewpoint of the nephrologist and the patient. A review follows of the recently published guidelines from the Renal Physicians Association and the American Society of Nephrology entitled “Shared decision-making in the appropriate initiation of and withdrawal from dialysis.” I conclude with observations from clinical practice.

The End-Stage Disease Program

In the 1960s it became increasingly apparent that the lives of patients with kidney failure could be extended by renal replacement therapy (hemodialysis, peritoneal dialysis and kidney transplantation). These new forms of therapy were costly and, as a result, unavailable to the majority of Americans. From the perspective of the general public, the health care system was evolving into one where the rich survived and the majority died if they had the misfortune to develop kidney failure.

As a result, Congress amended the Social Security Act in 1972 to include an entitlement to Medicare for people with ESRD. An amendment to the bill grants disability status to patients with ESRD. At that point in time, however, there was neither adequate time nor sufficient data to accurately estimate the cost of the program. In 1972 approximately 10,000 people were on dialysis. Very few of them were above the age of 65, and cost estimates did not foresee that dialysis would be offered to patients above age 65. Further, the bill was adopted at a time when members of Congress felt that legislation regarding catastrophic health insurance would be enacted in the near future. Indeed, it

was viewed as a pilot program for catastrophic health care. Therefore cost estimates were seriously underestimated. The projected cost for the first year was \$75 million, growing to approximately \$250 million after 4 years, and with a several-fold increase in 25 years. However, by 1988, actual expenditures were already \$3 billion. In 1998, expenditures had risen to \$16.7 billion, with approximately 300,000 individuals covered in the program. Current estimates are that the number of patients in the program will double in the next ten years. Patient demographics have also changed dramatically. In 1973, 5% of patients were 65 or older and less than 10% had renal failure due to diabetes. In 2000, half of the patients starting dialysis were over the age of 65, and nearly half of all patients with ESRD had kidney failure secondary to diabetic nephropathy.

No one in 1972 could have foreseen the large growth in the number of patients on dialysis or with a functioning transplant. Since projections of the future use of any form of technology are necessarily based on current patterns of use, the government's predictions were dramatically lower than the eventual frequency of use. As the practice of dialysis advanced and familiarity with its use increased, the patient population grew. As its use continues to expand, the question of who should either start or stop dialysis becomes more complex.

The Nephrologist

Several studies have examined nephrologists' attitudes toward the initiation and withdrawal of dialysis. Data regarding the withdrawal of dialysis is much easier to obtain, because physicians must report these cases to the Center for Medicare and Medicaid Services. Prior to 1990 withdrawal from dialysis was listed as a cause of death on the Death Notification form that is required for all deceased ESRD patients. In 1990, a new

form was introduced for ESRD, in which withdrawal from dialysis was no longer considered a cause of death. In fact, the physician was required to specify another cause of death other than withdrawal. Up until 1990 withdrawal from dialysis accounted for 6-20% of all deaths. The new form drastically changed that statistic, though it does request information as to whether dialysis was withdrawn prior to death and the reason for withdrawal.

Moss analyzed the results of a questionnaire sent to the directors of 524 adult chronic dialysis units.⁶¹ Three hypothetical scenarios were presented: 1) to continue or withdraw dialysis at a competent patient's request to stop dialysis; 2) to start or withhold dialysis of a permanently unconscious patient; and 3) to continue or withdraw dialysis from a patient who had become severely demented. The results of the survey showed that 92% of the directors would withdraw dialysis at a competent patient's request, 83% would withhold or withdraw dialysis from a permanently unconscious patient and 32% would withdraw dialysis from a severely demented patient.

Several aspects of this study are surprising. First, 8% of dialysis unit directors would continue dialysis against a competent patient's wishes, despite the fact that all states recognize the right of the competent patient to self-determination and to refuse medical care even if that refusal threatens their life.⁶² A patient's right to autonomy was upheld by a California appellate court opinion in the case of a patient with severe cerebral palsy who wished to discontinue tube feedings. The court stated: "If a right exists it matters not what 'motivates' its exercise. We find nothing in the law to suggest that the right to refuse medical treatment may be exercised only if the patient's motives meet with

⁶¹ Moss AH, Stocking CB, Sachs GA, Siegler M. Variations in the attitudes of dialysis unit medical directors towards decisions to withhold and withdraw dialysis. *J Am Soc Nephrol* 4: 229-34, 1993.

⁶² Eiser AR. Withdrawal from dialysis. The role of autonomy and community-based values. *Am J Kidney Dis* 27: 451-457, 1996.

someone else's approval."⁶³ Second, 17% of dialysis unit directors would start a permanently unconscious or vegetative patient on dialysis if requested; yet there is broad ethical consensus that any life-sustaining therapy in this situation is futile.^{64, 65} Lastly, 68% of medical directors would continue to dialyze a severely demented patient, while 32% would not, which indicates a problematic lack of consensus on the issue.

Singer examined 118 New England nephrologists' responses to four hypothetical situations in questionnaire format.⁶⁶ The questions and responses were as follows.

1) Assume that a patient in your practice has asked to stop dialysis. According to a psychiatric consultant, the patient is competent. As the patient's nephrologist, you have discussed the request to stop dialysis at length with your patient, but the patient continues to request that dialysis be stopped. What would you do in this situation? *Only 2% of the respondents would choose to continue dialysis.*

2) Assume that the family of an irreversibly incompetent patient requests that dialysis be stopped. The family provides clear evidence that the patient had said he/she would not want to continue dialysis in his/her current situation. What would you do? *Again, only 2% would continue dialysis.*

3) Assume that the family of an irreversibly incompetent patient requests that dialysis be stopped. The patient had never discussed whether he/she would want to continue dialysis in his/her current situation. What would you do? *Although 63% of physicians would stop dialysis, there was less of a consensus on that decision, and 17% would seek legal advice.*

⁶³ Bouvia v Superior Court, Number B019134: Cal App 2d Dist, April 16, 1986.

⁶⁴ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Deciding to forego life-sustaining treatment. Washington, D.C.: United States Government Printing Office; 1983: 60-90, 171-196.

⁶⁵ Position paper. Withholding and withdrawing life-sustaining therapy. *Ann Intern Med* 115: 478-485, 1991.

⁶⁶ Singer PA. Nephrologists' experience with and attitudes towards decisions to forego dialysis. The End-Stage Renal Disease Network of New England. *J Am Soc Nephrol* 2: 1235-40, 1992.

Accordingly, the authors recommended advance directives as a potential mechanism to clarify the patient's wishes in this situation.

4) Assume that the dialysis team caring for an irreversibly incompetent patient feels that dialysis should be stopped. The patient had never discussed whether he/she would want to continue dialysis in his/her current situation. The family demands that dialysis be continued. What would you do? *The majority of nephrologists would continue dialysis if the family wished, even if the staff felt it was no longer beneficial. The possible legal ramifications of discontinuing dialysis in this setting may have motivated physicians' decisions.*

Several other interesting findings emerged from this study. Nephrologists reported that they withheld dialysis more frequently than they withdrew it. In the case of competent patients, the issue of whether to withdraw dialysis was raised by the patient 52% of the time and by the nephrologist or staff in 32% of cases.

Holley carried out a nationwide survey of nephrologists to determine factors that influenced their decisions to start or stop dialysis.⁶⁷ The two most important factors in the decision to start or stop dialysis were the patient's neurological and functional status.

These were followed by preexisting medical conditions, family wishes and age.

In summary, nephrologists frequently make decisions to start and stop dialysis. However, they have little formal training in professional ethics to prepare them for this decision. The topic is most often initially raised by the patient, and the neurologic and

⁶⁷ Holley JL, Foulks CJ, Moss AH. Nephrologists' reported attitudes about factors influencing recommendations to initiate or withdraw dialysis. *J Am Soc Nephrol* 1: 1284-88, 1991.

functional statuses of the patient are important factors in the decision to start and stop dialysis.

The Patient

Leggat examined the deaths of 116,829 patients in the U.S. Renal Data System database.⁶⁸ Almost eighteen percent were preceded by withdrawal from dialysis. Women were significantly more likely to withdraw before death than men. African-Americans and Asians were half as likely to withdraw from dialysis than Caucasians. After age 50 there was a progressive increase in likelihood of withdrawal before death. In patients starting dialysis at age 65 or older there was a 3% increase in the chances of withdrawal with each increase in year of age at death. Deaths from dementia, cachexia, malignancy and anoxic brain injury were more likely to be preceded by withdrawal. Death from cardiac disease, on the other hand, was significantly less likely to be preceded by withdrawal.

Mailloux studied 63 patients who withdrew from dialysis between 1970 and 1989.⁶⁹ More than half of patients withdrawing had either diabetes or atherosclerotic renal vascular disease as the cause of ESRD. Comorbid conditions and precipitating factors associated with withdrawal included weight loss and malnutrition, pain, decreased quality of life, dementia, cancer, and peripheral vascular disease with need for amputation or surgery. Most patients had more than one associated risk factor or comorbid condition.

⁶⁸ Leggat et al., "An analysis of risk factors...", op cit.

⁶⁹ Mailloux LU, Bellucci AG, Napolitano B, Mossey RT, Wilkes BM, Bluestone PA. Death by withdrawal from dialysis: a 20-year clinical experience. *J Am Soc Nephrol* 3: 1631-7, 1993.

Kaye distributed a questionnaire to 47 dialysis patients asking them to answer the following question:⁷⁰ *If your clinical condition were to deteriorate in a permanent manner so that you are unaware of your surroundings, are confused throughout the waking hours, are unable to be responsible for your actions and have become demented, do you believe it is reasonable to discontinue dialysis?* The results showed that 74% of patients would elect to discontinue dialysis, whereas 26% would continue.

Port studied 282 patients who elected to withdraw from dialysis in Michigan between 1980 and 1985.⁷¹ Factors that were statistically significantly associated with withdrawal included white race, increased age and the presence of diabetes.

In summary, a variety of factors are associated with withdrawal from dialysis. As expected, patients with chronic illness and diabetes withdraw more frequently. As age increases above 65 years, the chance of withdrawal also increases. In addition, some racial groups are less likely to withdraw from dialysis (African-Americans and Asians).

Renal Physician Association Guidelines

The Renal Physicians Association and the American Society of Nephrology, with representatives from other disciplines, formed a working group that developed a Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis.^{72, 73} The guideline included nine recommendations:

⁷⁰ Kaye M, Lella JW. Discontinuation of dialysis therapy in the demented patient. *Am J Nephrol* 6: 75-9, 1986.

⁷¹ Port FK, Wolfe RA, Hawthorne VM, Ferguson CW. Discontinuation of dialysis therapy as a cause of death. *Am J Nephrol* 9: 145-9, 1989.

⁷² Galla JH. Clinical practice guideline on shared decision-making in the appropriate initiation of and withdrawal from dialysis. The Renal Physicians Association and the American Society of Nephrology. *J Am Soc Nephrol* 11: 1340-2, 2000.

⁷³ Moss AH. Shared decision-making in dialysis: the new RPA/ASN guideline on appropriate initiation and withdrawal of treatment. *Am J Kidney Dis* 37:1081-91, 2001.

1) Dialysis decisions should be made through the process of shared decision-making.

Together patient and physician should come to agreement on a specific course of action.

If a patient lacks decision-making capacity then decisions should involve the patient's legal agent.

2) Physicians should fully inform patients about their diagnosis, prognosis and all treatment options. This should include available treatment modalities, the option of not starting dialysis, a time-limited trial of dialysis, and the option of stopping dialysis and receiving end-of-life care.

3) Discussion should address prognosis, including life expectancy and quality of life.

4) A systematic approach to resolve conflict is recommended. (Unfortunately, the authors provide no suggestions for how this might occur).

5) The renal care team should attempt to obtain written advance directives for all dialysis patients.

6) It is appropriate to withhold or withdraw dialysis in the following situations: Patients with decision-making capacity who refuse dialysis or request it to be discontinued; patients who no longer possess decision-making capacity but who have previously indicated refusal of dialysis in an oral or written advanced directive; patients who no longer possess decision-making capacity and whose properly appointed legal agent refuses dialysis or requests that it be discontinued; and patients with irreversible profound neurologic impairment such that they lack signs of thought, sensation, purposeful behavior and awareness of self and environment.

7) It is reasonable to not initiate or withdraw dialysis in a person with a terminal illness or whose medical condition precludes performing the procedure.

8) For patients who require dialysis but have an uncertain prognosis or for whom a consensus cannot be reached, nephrologists should consider offering a time-limited trial of dialysis.

9) All patients who decide to forego or withdraw dialysis should be treated with continued palliative care.

Clinical Practice Observations

In the past two years, I have participated in the decision to withdraw dialysis in eight patients. Five were women. Only two of the eight were African-American, despite the fact that the majority of patients in our dialysis unit are African American. Although I have been a practicing nephrologist for seventeen years, I – like many of my colleagues in the published literature – have had no formal training in ethics, nor did I receive any training during my fellowship that would prepare me to participate in such decisions. Many nephrologists gain and hone such skills only with years of experience.

No one can present an approach to the withholding or withdrawing of dialysis that will work in all situations. Until recently, there were no published guidelines in the renal literature that one could rely upon, although several excellent reviews have been written on the subject.^{74, 75, 76} Each of the eight cases I participated in was a unique learning experience. For patients who want to discontinue dialysis, my main focus is to determine the reasoning behind the decision, to gain insight into the patient's perception of their quality of life and to determine if it can be improved. This approach often involves

⁷⁴ Lowance DC. Withholding and withdrawal of dialysis in the elderly. *Semin Dial* 15: 88-90, 2002.

⁷⁵ Lowance DC, Singer PA, Siegler M. Withdrawal from dialysis: an ethical perspective. *Kidney Int* 34: 124-35, 1988.

⁷⁶ Neff MS. To be or not to be: the decision to withdraw or be withdrawn from dialysis. *Am J Kidney Dis* 33: 601-3; discussion 603-6, 1999.

several meetings with the patient and their immediate family. I attempt to discern whether potentially reversible factors such as depression or underdialysis might be playing a role in the decision. One difficulty here is that depression is very common in the dialysis population. Another difficulty may stem from perceptions of what it means to discontinue dialysis. For example, in one case a patient equated the decision to discontinue dialysis with suicide. Only after discussions with her pastor did she accept that the decision to withdraw dialysis was not the same as committing suicide in the eyes of the church. However, such conflict is rare when a competent patient decides to terminate dialysis.

Conflict arises more often when the nephrologist or staff feels that dialysis should be withheld or discontinued and the patient and their family wish to start or continue it. A time-limited trial with periodic and regular re-evaluation is one approach to this problem, and one might argue that it is the path of least resistance. In today's litigious society, most nephrologists will not withhold or withdraw dialysis against the wishes of the patient and/or family. But are we obliged to provide care if it is futile? The guidelines outlined above appear to state that we should do so, at least in the short term, if the patients or their families request it. The difficulty here, as in most medical situations, is that it is hard to define futility. Supreme Court Justice Potter Stewart, when asked to define obscenity, famously replied: "I know it when I see it." I suspect that most nephrologists know futility when they see it as well.

I repeat the simple question posed by Kjellstrand in the introduction to this essay: "Am I prolonging life or am I prolonging death?" If the answer is the latter, then I do not feel that it is appropriate to start dialysis. I explain to the patient and his/her family why I have come to that conclusion, and I ask them to consider the commitment they will have to make for an outcome that is unlikely to be of benefit. I also urge them to seek a second

opinion. In using this approach, I take a responsible position, while allowing the patient and/or the family to have the dignity of making an informed decision.

Futility in Transplantation

Amy Friedman, David Cronin and Marc Lorber

Solid organ transplantation is the medical embodiment of hope and optimism. For the person suffering from irreversibly failed function of one or more essential body parts, the dream of evading death or the absolute dependence on a mechanical replacement technology (as in the case of dialysis or an implanted artificial heart) is vivid. For society, the potential for a person's return to health is dramatic and, when fulfilled, truly exceptional. Unfortunately, as we celebrate the fiftieth anniversary of the first successful human organ transplant, it is more common to hear public laments over the limitations of transplantation, than to hear rejoicing in the accomplishment of still one more success story. With vastly inadequate resources, both fiscal and organic, serving as obstacles to the wider application of this life-saving therapy, the field of transplantation is now dominated by difficulties in determining and accepting circumstances of futility. In this context "futility" will be defined as an organ transplant that fails to result in sufficient organ function, patient quality of life, or longevity, and thereby fails to justify utilization of the invested resources.

Overview of the Organ Shortage

If high quality organs were readily available for all transplant candidates, the decision to proceed with or defer transplantation would rest principally on an assessment of the individual's current health and the associated risk/benefit ratio. Sadly, the supply of transplantable organs is so insufficient that the prolonged waiting time before organ allocation and the likelihood of progressive deterioration or death become important in

decisionmaking. The number of people waiting for deceased donor organs increased in the United States by 244% between 1993 and 2001.⁷⁷ At this writing, 84,150 candidates were awaiting transplantation of all solid organ types in the U.S., while only 12,133 donors had been available in the prior 11 months, the majority of whom (51%) were live donors.⁷⁸ With death as the most common reason for removal from the waiting list and an average of 17 people dying each day on the list (6,297 in 2003),⁷⁹ the transplant team must provide each candidate with a realistic appraisal of her specific chances of receiving an organ. For the patient awaiting transplantation, medical futility may be more a result of the scarcity of transplantable organs than a result of her medical condition.

The Unsalvageable Patient

Organ function is commonly lost slowly over time. A progressive disease process and predictability of the course of clinical deterioration may even permit the calculation of a specific score, modeled on observations from other patients. The Model for End-Stage Liver Disease (MELD) uses a 40-point score to predict pre-transplant mortality: each unit in the MELD scoring system is associated with a 22% increased risk for death.⁸⁰ Cumulative acquisition of objective criteria, or the rate of change in disease severity, allows transplant physicians and patients to quantify the mortality risk associated with continued waiting. While the exact significance in interpretation of the mortality risk is modified by patient- and disease-specific variables, the principle that one should use disease-based indicators in predicting a need for transplantation is widely

⁷⁷ http://www.optn.org/AR2003/103_dh.htm. 3/24/04.

⁷⁸ <http://www.unos.org/data/default.asp?displayType=usData>. 3/24/04

⁷⁹ <http://www.optn.org/latestData/rptData.asp>. 3/24/04

⁸⁰ Merion RM, Wolfe RA, Dykstra DM, et al. Longitudinal assessment of mortality risk among candidates for liver transplantation. *Liver Transpl.* 9(1):19-21. 2003.

applied. Similarly, use of such a validated system of quantifiable mortality risk may help define the appropriateness of continuing to offer transplantation in a situation of limited resources. When the likelihood of death becomes excessive, even in the face of successful transplantation, the procedure must not occur.

Organ transplantation should be undertaken when end-organ dysfunction has progressed to the point where the risk of transplantation is less than the risk of continued waiting, and before irreversible damage to other organ systems has occurred. For example, a patient with end-stage liver disease secondary to primary biliary cirrhosis who is experiencing symptoms of jaundice and refractory itching would be considered to have sufficient indications for liver transplantation. However, as the liver disease progresses – manifested by declining hepatic synthetic function with severe malnutrition, immunoincompetence, and the accumulation of ascites (intra-peritoneal fluid) – liver transplantation must be deferred because of the significantly increased mortality risk of transplantation. For some, intervening infection that fails to respond to antibiotic therapy can lead to the patient's demise. For others, clinical improvement occurs and transplantation may once again become a reasonable therapeutic option.

Ultimately, the decision that a specific patient's illness has reached a stage that makes survival impossible, is simply a human judgment based on available data and prior experience. Although there are some circumstances that absolutely preclude transplantation (Table 1), other scenarios are more difficult to predict. Thus, the teenager with fulminant liver failure caused by a second suicide attempt who has developed irreversible destruction of the brain due to severe swelling should not undergo liver transplantation. In this situation, the patient might receive intravenous sedation to prevent movement, hoping to minimize intracranial pressure and brain damage, but

pharmacologic suppression of intrinsic respiration and the prolonged circulation of these drugs (caused by impaired or absent hepatic metabolism of the drugs) would prevent the neurologist from using standard clinical criteria of death. Here, clinical determination of unsalvageability would be based on radiologic evidence of severe brain swelling, or measurement of very elevated and prolonged intracranial pressure; in short, it would be based on an expert judgment. Clearly, the retrospective diagnosis of brain death or profound neurologic injury would represent a delayed recognition of transplant futility.

In practice, most decisions to declare a state of futility are based on an assessment of cumulative clinical events. Although cirrhosis and coagulopathy, leading to severe intra-cranial hemorrhage, may represent an insurmountable obstacle to a geriatric transplant candidate, an eight-year-old boy who suffered a severe intra-cranial event may recover full function, with normal developmental parameters following liver transplantation. It is therefore critically important that experienced physicians provide guidance and decision-making support in such desperate situations. The consequences of these decisions have become even greater in the era of liver transplantation, largely due to the severe donor organ shortage. A decision regarding transplantation must be made to minimize delay in allocation of an available deceased donor organ: The United Network of Organ Sharing guidelines stipulate that an organ offer must be accepted or declined within one hour.⁸¹ As the individual psychological burden of making such decisions may be heavy, and difference of opinions likely, it is usual for a transplant center to rely on a multi-disciplinary team of experts to decide collectively, thereby protecting the individual physician from having to unilaterally deny a potentially life-saving therapy. In such

⁸¹<http://www.unos.org/policiesAndBylaws/searchResults.asp?fromPage=%2Fpoliciesandbylaws%2Fpolicies.asp&qu=organ+offer>

circumstances the overlap between clinical futility and a form of distributive justice may be blurred.

Since the designation of the futility of a specific organ transplant is usually a subjective process, it follows that disparate conclusions might be reached with the same information by different experts in the field. In fact, disagreement about patient suitability for transplantation occurs with some regularity. During the early days of kidney transplantation, for example, diabetics were considered too sick and unlikely to survive. Accordingly, many argued that it was not appropriate to undertake transplantation among such individuals. However, the vision of others, for example the transplant team led by Dr. John Najarian at the University of Minnesota, demonstrated the benefits of transplantation in this patient group, which led to a reversal of this consensus.⁸² Today, graft-survival is comparable between diabetics and non-diabetics, and the substantial increase in patient-survival among diabetics with kidney failure who receive a kidney transplant has made transplantation the renal replacement therapy of choice for this group.⁸³

Another, more contemporary illustration of changing perspectives on the question of futility is found when considering transplantation of patients infected with the Human Immunodeficiency Virus (HIV). Initial attempts to provide transplantation among HIV-infected individuals resulted in acceleration of the disease and shortened overall

⁸² [Najarian JS](#), [Sutherland DE](#), [Simmons RL](#), [Howard RJ](#), [Kjellstrand CM](#), [Ramsay RC](#), [Goetz FC](#), [Fryd DS](#), [Sommer BG](#). Ten year experience with renal transplantation in juvenile onset diabetics. *Annals of Surgery*. 190(4):487-500, 1979 Oct.

⁸³ [Brunkhorst R](#), [Lufft V](#), [Dannenberg B](#), [Kliem V](#), [Tusch G](#), [Pichlmayr R](#). Improved survival in patients with type 1 diabetes mellitus after renal transplantation compared with hemodialysis: a case-control study. *Transplantation*. 76(1):115-9, 2003.

survival.⁸⁴ However, in the modern era of HAART, in which viral replication can be controlled, cautious exploration of the risks and benefits of transplantation has been rewarded with success, and evidence now suggests that HIV infection should no longer represent an absolute contraindication to transplantation.⁸⁵ Accordingly, HIV infection seems to have joined the list of conditions once reflecting indicators of transplant futility that are now felt to be appropriate indications for application of this remarkable therapy (Table 2).

From the outset, organ transplantation has been a field where medical pioneers boldly challenged the established medical dogma, seeking to establish effective therapies and advocating on behalf of patients suffering otherwise fatal diseases. One might have considered Starzl's early attempts to accomplish liver transplantation as an exercise in futility.⁸⁶ Many patients died on the operating table as he struggled to find a solution to liver failure; but today his procedure is still conducted with virtually the same steps he painstakingly developed years ago.⁸⁷ Thus, successful experimentation can lead to rapid evolution of medical opinion, dramatically altering the perception of futility. These realities obligate transplant professionals to expeditiously share and adopt therapeutic advances with the entire community. In this regard medical futility should be considered a "moving target," and independent assessment for each person considered for transplantation must be applied.

⁸⁴ Rao TK, Filippone EJ, Nicastrì AD, Landesman SH, Frank E, Chen CK, Friedman EA. Associated focal and segmental glomerulosclerosis in the acquired immunodeficiency syndrome. *N Engl J Med* 1984; 310:669-673.

⁸⁵ Stock PG, Roland ME, Carlson L, et al. Kidney and liver transplantation in human immunodeficiency virus-infected patients: a pilot safety and efficacy study. *Transplant*. 2003; 76(2):370-5.

⁸⁶ Starzl TE. *Puzzle People: Memoirs of a Transplant Surgeon*. Pittsburgh, University of Pittsburgh Press, 1992.

⁸⁷ Klintmalm GB and Busuttil RW. The recipient hepatectomy and grafting. In *Transplantation of the Liver*. Busuttil RW and Klintmalm GB, ed. W.B. Saunders Company. Philadelphia. 1996. pp. 405-418.

Is Advanced Age an Indicator of Transplant Futility?

Accepting that life itself is a fatal condition, and every transplant recipient will have limited survival, one must also acknowledge that the resulting prolongation of life provided by transplantation reflects, in every case, a relative decision. Early in the history of kidney transplantation, patients older than 65 years were considered inappropriate candidates. In contrast, 11% of kidney transplant recipients today exceed 65 years, and they enjoy survival rates that equal or exceed those of younger patients as a group.⁸⁸ Expectations for these recipients are obviously impacted by their age. Although transplantation does not obviate the increased incidence of cardiovascular mortality, malignancy or other conditions associated with increasing age, optimistic hope for a post-transplant survival of 10 years has commonly been considered sufficient to justify transplantation. Clearly, the geriatric candidates who currently undergo transplantation can achieve a good quality of life, and the cost-effectiveness of their renal replacement therapy has been amply documented.

From society's perspective, a life of improved quality but abbreviated length might not seem to be the most prudent use of a limited cache of organs. Yet, one would be hard-pressed to consider this therapy futile. Addressing the appropriate allocation of increasingly scarce healthcare resources is a much broader issue. For the moment, it seems unreasonable to exclude geriatric transplant candidates solely on the basis of age, when such a practice would be out of context in a community that offers advanced abdominal surgery⁸⁹ and expensive cardiovascular interventions even to octogenarians.⁹⁰

⁸⁸ <http://www.optn.org/latestData/rptData.asp.3/24/04>.

⁸⁹ O'Hara PJ, Hertzner NR, Krajewski LP, Ming T, Xiong X, Beven EG. Ten-year experience with abdominal aortic aneurysm in octogenarians: early results and late outcome. *J Vasc Surg.* 1995;21:830-838.

⁹⁰ Lee JH, Swain B, Andrey J, Murrell HK, Geha AS. Fast track recovery of elderly coronary bypass surgery patients. *Annals of Thoracic Surgery.* 68(2):437-41, 1999

Coping With Futility In Transplantation

As in most other settings, delivering the news that transplantation would be medically inappropriate for a given person is a difficult task. This is especially true in transplantation, where the successful growth of this new field has, at times, been associated with unrealistic expectations. Accordingly, it is important for the transplant team to provide patients and their families with a progressively detailed education about the general indications, contraindications, risks and benefits of the specific type of transplant being considered. This process must begin with the initial encounter, and should provide a realistic picture of transplantation as it affects the specific individual. Thus, the patient with cirrhosis and hepatocellular carcinoma must understand that extra-hepatic tumor spread will preclude transplantation, even if it is only found intra-operatively at the time of organ availability.

When appropriately prepared, patients' emotions of frustration and, at times, anger that may result can be addressed constructively and compassionately. While other physicians may choose to evade opportunities to address these issues, the current healthcare environment requires the transplant team to adopt an open approach to sharing the provider's sense of futility, rather than pursuing a hidden agenda to which the patient is not privy (Table 3). This includes education about the magnitude and implications of the organ shortage, about physicians' obligation to use donor organs in a responsible manner, and about the individual's specific risk/benefit ratio. We believe it is also essential to undertake this process, especially when the medical setting may preclude transplantation, in a manner that leaves the patient (and family) with some amount of hope whenever realistically possible. This may be in the form of avoiding prolonged

pain, re-operation and hospitalization from a complicated transplant that fails to cure a malignancy (as in the case of the cirrhotic with advanced hepatocellular carcinoma); or it may simply avoid the side effects of pharmacologic immunosuppression. When faced with a desperate situation, patients and families frequently focus more on the quality than the quantity of remaining life.⁹¹

Patient Self-Exclusion From Transplantation

Many assume that the will to live drives all humans to grasp at any opportunity to prolong survival. However, in the specialized world of transplantation, organ availability is scarce and unpredictable; the outcomes are uncertain; and there is significant variability in the vigor of the host's immune response as well as side effects of the immunosuppressant medications. When these possibilities are shared with the patient and family, individuals do not always embrace the extraordinary technology that is being offered.

Hard data are not available on this issue, but perhaps the most common reason that candidates decline to pursue transplantation is advanced age. Many geriatric (over age 65 years) end-stage renal disease patients who seek initial evaluation for kidney transplantation later decline the opportunity to pursue the therapy. Whether deterred by the complexity of the process, the substantive medical interventions that may be required (e.g., coronary artery revascularization) or the potential loss of the psychosocial interactions gained through dialysis center visits, it seems that to some patients a

⁹¹ Bonanno GA. Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist* 2004; 59(1):20-28.

transplantation may simply be overwhelming and unappealing.⁹² We have also found that as many as 50 to 75% of our geriatric kidney transplant candidates decline offers of live donor kidney transplants from relatives or close friends. Typically, the older person near the end of her life expresses an unwillingness to subject another person to risk on her behalf.

Although religious reasons are commonly given for declining to *donate* organs, they are virtually never offered as a reason to decline transplantation. While it makes little scientific sense, even staunch Jehovah's Witnesses who refuse life-saving blood transfusion are usually willing to accept a solid organ, irrespective of the fact that passenger donor blood cells are simultaneously transplanted.

Patient Failure to Take Anti-Rejection Medications

On this matter reliable data are again difficult to obtain, but it is likely that many patients consistently fail to take prescribed anti-rejection medications; it is commonly believed that this is the etiology of reduced graft- and recipient-survival.⁹³ In one reported analysis, an average of 18% of patients skipped their daily dose of azathioprine (an immunosuppressant) for 4 or more days during the first 6 months following kidney transplantation.⁹⁴ Another report found that 48% of transplant recipients were less than

⁹² Rao SP, Lenkei S, Chu M, Bargman JM. The futility of pretransplant coronary bypass grafting in asymptomatic patients on peritoneal dialysis. *Peritoneal Dialysis International* 1998;18(5):485-8.

⁹³ Pascual M, Theruvath T, Kawai T, Tolkoff-Rubin N, Cosimi AB. Strategies to improve long-term outcomes after renal transplantation. *N Engl J Med* 2003;346:580-90.

⁹⁴ Nevins TE, Kruse L, Skeans MA, Thomas W. The natural history of azathioprine compliance after renal transplantation. *Kidney Int* 2002;60:1565-70.

fully compliant with their immunosuppressive medications by 12 months as judged by the prescription refill rate, even when the medications were fully paid for.⁹⁵

Greenstein and Siegal⁹⁶ divided noncompliant transplant patients into those who do so accidentally (47%), those who believed that they did not need to take their medications regularly (28%) and those who made independent decisions not to do so (25%). Regardless of the underlying explanations, it seems apparent that graft- and patient-loss due to medication non-compliance reflects a collective inability of the transplant team to avert the waste of precious organs, permitting procedures that become *de facto* exercises in futility. Unfortunately, it is difficult to establish reliable strategies or techniques for avoiding such frustrating outcomes.

Futility of Re-transplantation?

Re-transplantation represents a particularly challenging area because the high associated mortality rates might seem to define it as an exercise in futility. The issue of re-transplantation is rarely considered for lung or heart recipients because of the substantial technical challenges. Instead, the issue of re-transplantation arises much more frequently in the management of liver and kidney transplants. Currently, 13% of all waiting list registrations are repeat transplant candidates, with 89% of these seeking a second kidney.⁹⁷ If the first procedure failed because the organ simply did not work or a vascular thrombosis occurred, then the second transplant may be technically straightforward. This is frequently the case in kidney re-transplantation, and the only

⁹⁵ Chisholm M, Vollenweider LJ, Mulloy LL, et al. Renal transplant patient compliance with free immunosuppressive medications. *Transplantation* 2000;70:1240-4.

⁹⁶ Greenstein S, Siegal B. Compliance and noncompliance in patients with a functioning renal transplant: a multicenter study. *Transplantation* 1998;66(12):1718-1726.

⁹⁷ <http://www.optn.org/latestData/rptData.asp>. 3/24/04.

ethical discussion is resource utilization. However, liver re-transplantation incorporates a different set of issues (e.g. the possibility of recurrent Hepatitis C, a currently incurable condition; severity of disease progression, etc.). Unfortunately, in this circumstance, the patient usually becomes extremely ill from the combination of prolonged organ failure and sequelae from a major operation from which the patient never fully recovered. In addition to the risks of brain swelling (usually in liver failure) and acute renal failure, there is the grave risk of advanced infection. If urgent re-transplantation is needed, close communication with the patient (if possible) and the family is particularly appropriate. In many situations persons are unable to acquire a suitable organ before their situation becomes medically futile.

Delayed failure of an organ allograft may be caused by recurrence of the primary disease (e.g., Hepatitis C),^{98,99} technical complications (e.g., a hepatic artery thrombosis after liver transplantation may lead to bile duct necrosis),¹⁰⁰ or rejection. If no new intervention has been developed in the interval following the initial transplant, and if the causative agent is similarly likely to destroy another organ, then re-transplantation would be considered futile by many transplant teams.

Additionally, the adverse impact of immunosuppression and progressive patient debility must be factored into the difficult decision to utilize another organ. Uncontrolled rejection of an initial transplant is most common among kidney recipients. When preformed antibodies to Human Leukocyte Antigens (HLA) are produced, it may be

⁹⁸ Gopal DV. Corless CL. Rabkin JM. Olyaei AJ. Rosen HR. Graft failure from severe recurrent primary sclerosing cholangitis following orthotopic liver transplantation. *Journal of Clinical Gastroenterology*. 37(4):344-7, 2003

⁹⁹ Ghobrial RM. Retransplantation for recurrent hepatitis C in the model for end-stage liver disease era: how should we or shouldn't we? *Liver Transplantation*. 9(10):1025-7, 2003

¹⁰⁰ Guichelaar MM. Benson JT. Malinchoc M. Krom RA. Wiesner RH. Charlton MR. Risk factors for and clinical course of non-anastomotic biliary strictures after liver transplantation. *American Journal of Transplantation*. 3(7):885-90, 2003

virtually impossible to identify another allograft that will not be recognized and immunologically attacked. Although there are currently a variety of strategies designed to circumvent this problem,¹⁰¹ including plasmapheresis (deplete of antibodies),¹⁰² the long-term benefit of these high-risk transplants remains unproven. Hence, re-transplantation efforts are futile for the majority of these highly sensitized recipients who will never find compatible donors.

Summary and Conclusion

The renowned author James Michener developed renal failure at the end of his life. After an unsatisfying period of dialysis he determined that he had written his last book, consciously terminated dialysis and died within one week, at the age of 90. Had he, instead, preferred to pursue transplantation, it seems likely that his request would have been granted, even at his advanced age. Some might argue that had Michener sought a transplant, he may have received preferential treatment due to his world stature. However, others would argue that such a transplant could be done on many people in his age bracket and medical condition, citing good outcomes results even among patients of advanced age.

Society generally, and the transplant community in particular, will be challenged so long as the tremendous shortage of available organs for transplantation persists. The more straightforward situation of futility – when the risk of transplant failure is high – can, arguably, be managed well in the present environment. However, when the risk of

¹⁰¹ Duquesnoy RJ. Howe J. Takemoto S. HLAmatchmaker: a molecularly based algorithm for histocompatibility determination. IV. An alternative strategy to increase the number of compatible donors for highly sensitized patients. *Transplantation*. 75(6):889-97, 2003

¹⁰² Zachary AA. Montgomery RA. Ratner LE. Samaniego-Picota M. Haas M. Kopchaliiska D. Leffell MS. Specific and durable elimination of antibody to donor HLA antigens in renal-transplant patients. *Transplantation*. 76(10):1519-25, 2003

transplant failure is not excessive, decisions become much more challenging. Should transplantation be considered a right, so long as the risk/benefit ratio is to some degree favorable? Or should our community establish relative measures of worthiness for transplantation, perhaps judged by age, likely longevity, return to productivity, or likelihood of evading medical catastrophe in comparison to other potential candidates? Until a comprehensive societal approach to the overall distribution of these limited resources is developed, it seems appropriate that each patient should be considered individually by a balanced and objective team of experts, capable of making a human judgment of the relative benefit or futility of the undertaking. The relative needs of other waiting patients must be balanced in the context of individual need and urgency as these difficult problems are considered in an open, knowledgeable and compassionate manner.

Medical Futility and Inadvisability in Cancer: The Oncologist's Role

David Fischer and Dennis Cooper

Editors' Note: The two authors of this chapter differ in their concepts of the role of the physician in the management of cancer patients who are in the late stages of their disease. Since both approaches are commonly practiced, they are identified separately here. Both, however, are based on long-standing relationship between the oncologist and the patient and/or her family.

I. The Oncologist as Coordinator of Care

David Fischer

A friend reported that her father had pancreatic cancer, and was in great pain:

I took him to an oncologist, who was wonderful. He examined my father thoroughly, then asked him how much he wanted to know. My father told him to explain everything to me while he sat in the waiting room. The oncologist then told me that the pancreatic cancer was far advanced and incurable, and that he was afraid the pain would increase unless he gave my father some chemotherapy to slow the growth of the cancer. He explained that the chemotherapy probably would not shrink – and certainly would not cure – the tumor. The doctor said that his goal was to make my father's life as comfortable as possible at home and to avoid hospitalization, at least until the very terminal phase. The doctor opted to administer

low-dose, long-interval chemotherapy with the goal of pain reduction. To supplement the treatment, the doctor also prescribed pain medication. He called every other day to monitor my father's pain and adjust the dose of the medication. My father lived comfortably at home for six months, visiting the clinic every three weeks. He died in his home, peacefully and free of pain.

Ethical Considerations

The role of the physician and associated health professionals is to cure illness and preserve life whenever possible. Inherent in that role is also the relief of pain and suffering. Yet in the field of oncology, as in many medical specialties, these goals of extending survival and relieving suffering are often in conflict. A sensitive balance must be achieved between the efforts of the physician, the wishes of the patient, and even the constraints of the law. These decisions are frequently difficult and must balance ethical considerations, professional responsibilities, and mercy towards patients.

Oncologists recognize that there comes a time for many cancer patients when the quality of life begins to deteriorate. The choice of therapeutic options may become a selection of lesser evils. At that point, who should decide the course and trajectory of treatment: the attending physician, the family, or the patient himself?

In my opinion, the health care team should be consulted and the options discussed. Nurses, specialists and other health team members have often invested substantial time and interest in the patient, and they know the patient as well as the physician does, often in different ways. They can have very valuable input. In many cases, the family can accurately represent the patient's values and projected desires. Most important, the patient's own opinions and desires must be given the highest priority if

they are discernible, rational, and feasible. It remains true, however, that after all options have been discussed, the ultimate responsibility for care rests with the physician, so long as it is not contrary to the express wishes of the patient.

Always present in end-of-life medical decisions is the multifarious concept of autonomy – the notion that the patient’s wishes supersede all other considerations for treatment. While I respect autonomy very highly, there are competing values, such as the physician’s own autonomy, and the requirements of medical professionalism. A physician should be able to decide what treatment he is, or is not, comfortable administering in a given situation. No physician should be forced to render a service that he or she considers wrong or inappropriate. To accede blindly to all of a patient’s demands, especially those that may be personally or ethically repugnant, would be to serve as a licensed technician, but not as a professional doctor. Indeed, much of a physician’s responsibility – to both the patient and the profession – lies in his or her wise application of knowledge and experience. If a patient or family insists on a therapy that I consider excessive or inappropriate, I try hard to reason with them and talk them out of it. If that fails, I suggest that they see another oncologist, and I help them to do so.

What is Futility in Chemotherapy?

Futility, to some extent, is in the eye of the beholder. Acceptable definitions are elusive. In an attempt to be semi-scientific and quantitative, Schneiderman, Jecker and Jonson¹⁰³ suggest that if physicians conclude via personal experience, experiences shared with colleagues, or consideration of published data, that in the last 100 cases a medical

¹⁰³ Schneiderman LJ, Jecker NS, Jonsen, AR: Medical futility: its meaning and ethical implications, *Ann Intern Med* 112:949-954, 1990.

treatment has been useless, then the treatment should be considered futile. (That is, a treatment that has less than a 1% chance of success should be considered futile). This seems a little too simplistic for the complexity inherent in medicine. In real life, most physicians rely heavily on their own medical knowledge and experience and on their understanding of the desires and needs of the particular patient. After many years of oncology practice, I generally feel that I can recognize medical futility in cancer patients when I see it. If the situation is unusual and there is doubt, we can seek help from others who may have greater experience in the particular area.

Futility and Care

When a clear path of treatment is not possible, or when the disease is advanced and irreversible, the physician must be a good counselor to the patient. This can begin early in the relationship. Even during an early encounter a physician can ask, “How much do you want to know, when do you want to know it, and who else should be told?” The physician must then tell the truth, give as much or as little information as the patient wants, and minimize collateral harm. The aphorism of William Shakespeare is an instructive reminder about the value of compassion and mercy:

The quality of mercy is not strain'd
It droppeth as the gentle rain from heaven
Upon the place beneath. It is twice blest:
It blesseth him that gives and him that takes.¹⁰⁴

But if the course of treatment is unclear, how heroic should the therapy be? The answer is an emphatic, “it depends.” For a young patient with stage III Hodgkin’s disease and a serious infection, all possible therapy should be used, because current antimicrobial

¹⁰⁴ Shakespeare. *The Merchant of Venice*, Act IV, Scene 1.

therapy and cytotoxic chemotherapy make long-term survival and possible cure a likelihood, rather than a mere chance. Alternatively, an elderly patient with advanced pancreatic carcinoma with liver metastases has a poor prognosis with current modalities of therapy. Thus, if there is no response to a reasonable first course of chemotherapy, additional chemotherapy is probably not indicated, though palliation and pain relief certainly are. Two case studies will help to illustrate this point.

P.T. was a 17 year old, fragile looking Caucasian woman with a beautiful smile. She had presented with a lump in the axilla that had been biopsied and showed Hodgkin's disease. Standard workup required an abdominal exploration to remove the spleen and search for involved lymph nodes and to move the ovaries in order to give radiation therapy if the nodes were positive and at the same time to keep the ovaries out of the radiation field to preserve fertility. Her nodes were positive and extensive so that she had stage III disease. Palliative radiation therapy was planned. I was asked to see her in consultation. Knowing that patients with stage III Hodgkin's disease are incurable with radiation, I recommended chemotherapy with a newly developed regimen to attempt a cure. However, the surgeon told the family that cure was impossible with any modality or combination of modalities, and that chemotherapy would cause her to lose her hair, vomit, become infertile (not really a problem if already doomed to an early death), and have great pain from the drug injections into her relatively small veins. Accordingly, the family refused permission for chemotherapy.

I persuaded my friend, Father John, the Catholic priest in P.T.'s grandmother's parish to convince the grandmother to insist that the family allow the minor to make her own decision. At that point we were finally allowed to speak to the patient honestly and with full disclosure. Up to this point, we had been forbidden to discuss options with the patient because the family feared that she would become depressed. It turned out that she was an intelligent, spunky individual who was willing to fight to live. The parents signed the permission. With chemotherapy, she lost her hair, vomited, had pain at the injection sites, became amenorrheic and quite sad but not clinically depressed, and she never required antidepressive medication. Two years later, Father John officiated at her wedding, and I sat in the first row with her grandmother. The groom did not seem to mind that under the long black hair of the wig, his wife was just recovering from her baldness. The smile was back. When I last had contact with them, they were about to leave for Italy to celebrate their 30th wedding anniversary.

Why had the surgeon and I given contrary advice? Both of us were informed of the most effective procedures in *our* respective disciplines. However, the scientific progress that saved P.T.'s life was not yet in the surgical literature, though it was in the oncology literature. In this case, extensive measures *were* available and appropriate to prolong P.T.'s life. Dissent over what is "reasonably possible" in a given case underlies the entire debate about medical futility and medical inadvisability; it forces us to consider how much is allowable in the name of potential medical progress.

It is troubling to hear patients or their families say that they were told that "nothing more can be done," since all relevant specialties had run out of therapeutic options. When no further surgery, chemotherapy or radiation therapy can produce a significant change in the tumor, there are always ways to enhance pain relief and make the patient more comfortable, even though cure may no longer be possible. It should be noted that the possibility of narcotic addiction should not be of concern for the terminally ill patient; instead, pain control should be the paramount consideration. The second case illustrates this point.

Mr. B. was a 35 year-old married man with three young children when he developed acute myelogenous leukemia. He responded to the first chemotherapy regimen, but then relapsed. He had partial responses to several additional different chemotherapy regimens, but had 10 hospitalizations in 14 months. Finally, he was admitted for experimental therapy with "end-of-the-line" drugs. By this time he had internal bleeding, ulcerated sores in the mouth and anus and the experimental drugs only made them worse. He had lost 60 pounds, and though his leukemia was still not under control, he was mentally alert. He requested heavy sedation to allow him to sleep for a day without experiencing pain. After that he and his wife conferred with their spiritual advisor and were advised to "let God take charge." The next day he told me that the family had run out of insurance, that he was heavily in debt while waiting for approval of their welfare application, that his quality of life was so abysmal and the suffering inflicted on his family so immense, that he wanted increased doses of morphine to relieve his pain and suffering. He understood that it might accelerate his death by a matter of days or hours,

and he did not think that it was bad to die slightly sooner rather than later. His wife was consulted, and she reluctantly agreed. He was given morphine on a regular schedule and he died peacefully.

Mr. B. had “fought the good fight,” seeking a range of treatments and finally employing an experimental therapy that had a very low likelihood of success. He endured the pain and suffering; but he lost the battle to his leukemia because medical science and the current state of knowledge had nothing more to offer. In other words, he did not fail the therapy: the therapy failed him. Nor was his request for palliative morphine inappropriate. There was nothing more for him to do but endure more anal pain, more mucosal and buccal pain, more “heroic” interventions that would keep him alive for, at most, a few more days while his family descended further into poverty. His decision to end it all was, in some ways, simple. He recognized that at his stage of terminal disease, medical science must now bow to nature.

Occasionally, pain can be so severe and persistent that it resists all conventional drugs and doses. The only treatment to relieve such suffering is to sedate the patient, temporarily or even permanently. This should be done with understanding and permission from the patient and/or family. Employing palliative therapy in this way was, in the past, controversial because it was seen to hasten the patient’s demise, a phenomenon known as the medical “double effect.” If the primary effect of the treatment is relief of suffering but the secondary effect may be the suppression of respiration and earlier death, the treatment is acceptable; its intended purpose is to relieve suffering.¹⁰⁵ With the advent of palliative care as a medical specialty in its own right, more knowledge and discussion about drug titrations and effects has ensued. Most physicians and ethicists now find the

¹⁰⁵ See the chapter in this volume on Roman Catholicism, by Margaret A. Farley and Jennifer Beste, for further discussion of the doctrine of double effect.

“double effect” to be far less of an issue than ever before. Death is not always the greatest enemy. Unnecessary suffering is.

Relationships and Responsibility

The physician who has good rapport and the trust of the patient knows whether the patient wants extreme therapy. In most cases, this should be discussed quite explicitly as a “what if...,” long before the situation arises. In most instances the choice is clearly against heroic measures, and increasingly, people sign living wills early in the course of illness, or even when they are in good health. If the patient’s choice is not to undergo such treatment, it should be honored, and a “do not resuscitate” order written, so that the entire staff is aware of the preferred course. When the patient is unprepared or unable to discuss this decision, the next of kin should be engaged and given all the available facts and some gentle and compassionate guidance. It is important to instruct families not to call 911 when a patient who is expected to die at home is in the last moments of life. The emergency personnel who respond to such calls have been trained to attempt resuscitation, whether or not there is a living will or the next of kin requests that nothing be done. Instead, the physician or a qualified hospice nurse should be called. With appropriate authorization, the body can be removed with care and decorum, and not subjected to a useless and potentially desecrating event.

Oncologists usually have the opportunity to know their patients over a prolonged period of time, and even to know the family members most involved. They strive to know their patients so well that when the end approaches there is complete harmony between the patient’s wishes and the care that is planned. There should be no conflict, because

both are interested only in the welfare of the patient. In the worlds of Frances Weld Peabody,

The good physician knows his patient through and through, and his knowledge is bought dearly. Time, sympathy and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.¹⁰⁶

¹⁰⁶ Peabody FW: The care of the patient, J Am Med Assn 88:877-882, 1927.

II. The Oncologist as Custodian of Care

Dennis Cooper

Some oncologists feel that they should take significant personal responsibility for managing end-of-life issues and decisions for their patients. As the following cases illustrate, they see themselves as custodians of care. The basis for this is also the long term relationship that they have with their patients and families.

A 31-yr-old man with non-Hodgkin's lymphoma received salvage chemotherapy resulting in a partial response. He then underwent very advanced therapy, namely high-dose chemotherapy with autologous stem cell rescue. At the end of treatment, x-ray studies continued to show residual disease in the abdomen. He had radiation to the known site of disease but during the month of radiation treatment, the disease progressed throughout the abdomen. He was very frightened and uncomfortable because of abdominal swelling. However, he and his wife (who were often accompanied by their two preschool age children) insisted that he was not ready to die and that he had a lot to live for, with many people actively praying for him. His kidneys began to fail and his mental status deteriorated. I told the patient (who was now often confused) and his wife that I was not going to start dialysis but would try to keep him comfortable. Privately, I told the wife that he was going to die soon and that it would not be the right thing to support his breathing or blood pressure. He died the next day.

One of the major ideological changes in medical care over the past generation has been the focus on patient empowerment and autonomy in most aspects of care, including the choice of stopping anti-cancer therapy. Several studies in the 1990's found that patients continued to receive therapy that was not likely to be effective, even during the last few months of life.¹⁰⁷ The implication was that the *oncologist* was the driving force for futile treatment. Arguments denouncing oncologists' "inadvisable" treatment in the last few months of life ranged from financial incentives to the difficulties oncologists felt

¹⁰⁷ Study presented at 2001 meeting of the American Society of Clinical Oncology.

in discussing cessation of treatment options with their patients. Interestingly, patient expectation (“the deep desire not to be dead”) was not presented as a reason that oncologists might continue to administer treatment when pain management alone would be at least as effective as full-fledged therapeutic interventions.

In the case presented above, it was clear after the first two rounds of therapy that the patient was not making any progress. When his disease worsened during radiation, it was also clear that nothing was going to work and that the further chemotherapy would be fruitless. Should I have refused to give the last chemotherapy treatment even though I knew it was going to be ineffective? Would the patient have been better off knowing that the end was near, or should I have preserved his hope, misguided though it may have been?

In my practice of oncology, I often assume that patients who do not talk or ask about their prognosis are probably not ready to hear it. In fact, from the patient’s perspective, learning from the physician that you are terminal may be worse than just thinking it is a likely possibility. Indeed, the large number of patients who present to cancer centers with end-stage, treatment-refractory disease but who nevertheless request experimental therapy indicates to me that many patients desire to continue treatment. This may be is a major, even primary, factor in the administration of futile therapy at the end of life. Whether from denial on the part of the patient, an unwillingness to explore the meaning of treatment failure, or even inappropriate enthusiasm for new and experimental treatment on the part of the oncologist, many patients seem not to realize or accept the severity of their disease. As the saying goes, “desperate people do desperate things,” and the quest for a miracle cure is common among cancer patients.

An important aspect of this patient's last days of life is that I did not consult with the family about dialysis, mechanical ventilation, or blood pressure support. I made the decision myself not to employ these measures, and then I presented that decision to the family as our current approach to the patient's care. This is, of course, a blatant example of physician paternalism. However, I would argue that paternalism is occasionally warranted, especially when contrasted with the alternative of offering a false choice. The patient is not the doctor; the patient engages the doctor as an expert and custodian of care. Should our society require every physician to present every terminal cancer patient with the choice of life support? Or should patient autonomy trump all other principles to the extent that a physician is not able to execute his or her own autonomy or professional responsibility? What if patients, confronted with too many complex medical choices and too little professional advice, feel unmoored because they are not receiving the expertise for which they sought a doctor in the first place?

In practice, when a patient or family demands heroic measures, oncologists tend to acquiesce because of legal considerations or in order not to alienate the family. However, as oncologists we also generally have the advantage of knowing the patient and family for a considerable period of time, allowing us to establish trust and a working relationship. I feel that it is illogical to offer an uncomfortable, expensive treatment that has no potential benefit for the patient, while hoping that the patient/family will make the "right" decision to refuse that treatment.

The Living Will: Important Document, or Dangerous?

A 50-yr-old man with recurrent non-Hodgkin's lymphoma was treated with high-dose therapy and autologous stem cell transplant. He became septic four days after his stem cell infusion. He became

hypotensive and went to the intensive care unit where his family presented his living will. On the night of his transfer, his condition deteriorated and he developed rapid atrial fibrillation, low blood pressure and respiratory failure. I asked that the anesthesiologist be called to place the patient on mechanical ventilation. The nurse said that the patient had a living will and that he did not want to be intubated. I replied that a living will sought to prevent a patient from being put on life support if the situation was hopeless. I viewed this condition as fully reversible and moreover, I believed that I had an unstated contract to support the patient through his period of severe neutropenia. The anesthesiologist placed the patient on the respirator and he survived.

As the situation makes clear, nurses, doctors and other staff within the same hospital may have different conceptions of the living will. The ICU nurse in this situation interpreted the living will as saying that under no circumstances should the patient be resuscitated. Yet I interpreted that same document as intimating that the patient should not be resuscitated only if the patient's chances for recovery were abysmal. As a result of this episode, I have often discouraged patients from placing their living will in the chart – for fear that they will not receive aggressive treatment at all, even when a reversible problem demands it.

Too Much Autonomy Too Soon

After achieving remission, an 18-yr-old man with a high-grade lymphoma received high-dose therapy and autologous transplant in order to reduce his chances of relapse. Every day after receiving his stem cells he had high spiking fevers and on day five, his oxygen level deteriorated and a CXR showed bilateral pneumonia. As his platelet count was quite low and he was spitting up blood, we thought that he had alveolar hemorrhage. He continued to deteriorate and it became clear that he was going to require mechanical ventilation. The resident explained the procedure and then asked the patient whether he wanted to be put on the respirator. The patient was frightened to death of the rapid sequence of events and initially refused. I was called and was informed that the patient was a DNI – do not intubate. I explained the purpose and potential benefits of the procedure; the patient agreed.

I would have sedated this patient and intubated him even if he had not agreed. He had a reversible affliction and went on to recover. This was another case in which I valued my own expertise over the patient's autonomy. He had no understanding of his poor decision, knowing only that he had been very sick and frightened for the last several days.

Can patients really function autonomously, and make objective and informed decisions, when they are very sick? And what are the ethical implications of a process by which physicians can convince the patient to accept, or refuse, a procedure simply by the way we present it? Oncologists often emphasize different treatments for different patients in different situations. These suggested treatments directly reflect the physician's bias. As a result, informed consent is really "contrived consent": Doctors must necessarily choose which treatment options to present and which to omit.

Most physicians appreciate and embrace the primacy of a patient's wishes in all aspects of treatment, and they seek to explain alternatives so the patient can make an informed decision. However, the oncologist also has a responsibility as a doctor, and sometimes this responsibility comes into conflict with the patient's autonomy. I have presented two cases in which patient autonomy was trumped by my medical judgment. The issue of autonomy is rarely controversial when the patient refuses treatment. However, just as common – and much more difficult to deal with – is the issue of positive autonomy, i.e. when the patient requests therapy that is not indicated. I suspect that this "positive autonomy" is one of the major factors accounting for ineffective or futile treatment at the end of life. Much work remains to be done to examine and better define the limits of patient autonomy in this area.

Goal Setting and Futility in the Nursing Home

Margaret Drickamer

The concept “nursing home” evokes numerous different images and emotional responses. For many individuals, especially those less familiar with the scope of extended care, it seems that the “nursing home” suggests futility and is seen, literally, as the end of the line. I will argue that this attitude is based on misconceptions, restricted definitions, and a narrow frame of reference. On the other hand, I will also argue that the type of care that has been the traditional focus of medical care for hospital and ambulatory patients is, indeed, often futile for many nursing home patients.

The healthcare traditionally labeled “nursing home care” has evolved greatly over the past two decades. Today, nursing homes are often known by a variety of other names, such as convalescence centers, extended care facilities, rehabilitation and recuperation centers, and residential healthcare facilities. With the advent of prospective payment for hospital stays, a significant number of patients now go to nursing homes for short stays. That is, they receive short-term rehabilitation and medical care as they recover from an illness or procedure, and these patients do eventually return home.

How long patients stay in a nursing home, and their goals while there, varies significantly. Twenty-five percent of patients stay in the nursing home for less than three months, and only fifty percent remain for one year or longer. Those admitted for short-term rehabilitation have substantially different goals and prognoses than those needing long-term care because of chronic disabilities (cognitive or physical or, most commonly, a combination of both). Within the long-term patient population, prognoses and therefore goals vary as well.

Although some patients do come to the nursing home and remain there for the rest of their lives, the nursing home does not have to be viewed as a “dead end.” Twenty-one percent of patients live in the nursing home for five years or longer. During this stage of their lives, they may still grow, share of themselves, discover new interests and find enjoyment. This may occur even if they are no longer cognitively intact. New pleasures through music and ways of expressing oneself through art are common for both cognitively intact and impaired individuals. Disinhibition may bring an ability to express inner thoughts more clearly and to express the need for a hug or physical contact. Memories, revisited and reworked, become more precious and sometimes more real than the present.

As occurs in any life stage, the patient in a nursing home will develop new needs, new pleasures and new fears. She will remain a person with a very specific history, but her values and frame of reference may change. The goal of longevity may no longer be of primary importance, or it may indeed have been met! The desire to continue to live may be tempered by the need for quality of life and the fear of suffering and further dependence. Therefore, in decisions about medical care, the individual’s life stage and goals must be considered, along with the medical implications of a particular course of treatment and the likelihood of its success or futility. The following four nursing home patient cases highlight some of the critical issues and the depth inherent in decisions about treatment and futility in the nursing home setting.

Mrs. P. is a 68-year old woman with diabetes admitted for six weeks of antibiotics to treat a diabetic foot ulcer after revascularization of the vessels clogged by atherosclerosis in her legs. She is ambulatory and is expected to return to her baseline of complete independence after the antibiotics and short-term rehabilitation.

For a patient such as Mrs. P., decision-making would be very similar to that of an ambulatory outpatient. Cure is still very much the goal. Although she has chronic illness, at this point the major manifestation of this illness – her peripheral vascular disease with resultant foot ulcer and bone infection – can be cured or at least rendered inactive through medical procedures. Illnesses occurring in the interim are unlikely to be fatal, and most are easily treatable. If Mrs. P. were to suffer a cardiac arrest, her chances of survival with aggressive care (attempted cardio-pulmonary resuscitation and advanced cardiac life support) are somewhat less than for a totally healthy individual, due to her age and chronic illness. But Mrs. P.'s functional level is good, which is one of the best predictors of survival of a heart attack. Therefore attempting resuscitation would not be futile. She also has a good chance of benefiting from preventative health measures such as lowering cholesterol, managing blood pressure, exercising, and having regular mammograms, Pap smears, stool guaiac, and other tests. Her decisions will be based on values and preferences alone, not on the futility of intervention.

Mrs. S. is a 92-year old female in the end stages of Alzheimer's disease. She recognizes no one in her family and has limited language abilities. She makes sing-song noises, and will make transient eye contact. She is increasingly immobile and is incontinent of bowel and bladder. She has no other medical illnesses.

Mrs. S. is at the opposite end of the spectrum from Mrs. P. Although she does not have cumulative medical problems, she does have organ failure. Alzheimer's disease is a progressive condition that results in end-stage brain disease and, ultimately, death. As in most end-stage diseases, death will probably be due to infection. Her functional level is extremely low. She would not survive a cardiac arrest, even with very aggressive interventions. Hence, attempted resuscitation would be futile. Many would say that even treating infections is no longer relevant to any goal that she would hold for herself, and

that because she ultimately will die of an infection – even with aggressive treatments – antibiotics are futile. Preventative health measures should be aimed at maintaining comfort by avoiding skin breakdown and avoiding aspiration by positioning Mrs. S. appropriately. Other preventative health measures are futile, such as those aimed at detecting cancer; therefore, no action would be taken to screen for it. Similarly, preventing heart disease serves no purpose; it will not improve her quality of life or decrease her suffering. It might even create harm by pre-empting some of the more comfortable ways to die, leaving Mrs. S. to continue to degenerate and die of more complex problems.

Mr. R. is an 84-year old man who had been living with his elderly wife. Prior to admission he had become progressively demented and functionally impaired over a period of five years. He could still dress and feed himself, and he was able to walk until he fell down some stairs and fractured his hip. He was admitted for rehabilitation after a complicated hospitalization during which he was bedridden for almost one month. Now Mr. R. is having difficulty in following a two-step instruction and has lost the ability to complete simple tasks, such as sequencing muscle movement to rise from a chair. He is confused and sometimes agitated, especially with changes in his environment.

In this case, the patient is reaching a critical turning point. His needs are changing, as are the interventions required to address them. At this point, it is unclear if efforts to help him regain any of his lost function will be effective. His ability to cooperate with rehabilitation therapies and his cognitive abilities to re-incorporate learned sequences into his memory is questionable. At some point, continued attempts to help him regain abilities may be deemed futile. This, coupled with his high risk for further illnesses such as falls and infections, makes his future tenuous. Time will clarify some of these issues. For patients in this type of situation, the relative trade-off of interventions – that is, the amount of suffering they would have to endure – must be carefully weighed

against the probability of achieving desired outcomes. The outcome for attempted cardiopulmonary resuscitation would, by virtue of his decreased functional status, be futile, in the sense that it would not return to him even the limited cognitive and physical function that he has now. For interventions where desired outcomes are highly unlikely and the process is highly noxious, the trade-off between expected outcome and inflicted distress makes the intervention futile. Care providers would have a great deal of difficulty performing these interventions, knowing that they were making the patient suffer for a goal that was almost certainly unattainable.

One very important decision that will have to be made is when, or if, a patient should be sent back to the hospital. Transfer to the hospital can be highly traumatic. The chances for complications such as delirium, bed sores, use of restraints, hospital-acquired resistant infections, and further decrease in function are much greater in the hospital setting than in the nursing home. Many minor illnesses can be treated relatively aggressively in the nursing home; intravenous hydration and antibiotics are commonly used in the long-term care setting. Outcome for the treatment of pneumonia not accompanied by signs of sepsis is as good in the nursing home as it is in the hospital, if not better. Other interventions may not be as medically intense in the nursing home environment, but the gain in comfort and well-being may be worth the decrease in monitoring. For example, a patient with an acute arterial clot can be treated with subcutaneous anticoagulation with a low molecular-weight heparin, analgesics and close contact with nursing staff in the nursing home. The same patient, in the hospital, would receive a continuous intravenous anticoagulation with heparin, analgesics, and closer physician monitoring in the hospital. The difference is that the nursing home staff knows the patient better, understands the patient's needs and indications of pain and discomfort,

and is better able to keep the patient comfortable and deal with agitation than would the staff in the hospital. In view of these trade-offs, even if the patient is to be treated aggressively for intercurrent illnesses, it may be deemed that the individual should not return to the hospital, and a “Do Not Hospitalize” order will be written. This is, in essence, to say that the trade-off that hospitalization represents would make hospitalization futile for the patient.

Mrs. W. is an 87-year old widow who has been living in a nursing home for four years. She has Parkinson’s disease. She initially moved into an assisted living facility because she was no longer capable of maintaining her own home and cooking meals. Over time she felt increasingly unsafe living by herself without the round-the-clock availability of help, and not wanting to be a burden to her children, she voluntarily came to the nursing home. She remains cognitively intact. She reads avidly and corresponds with friends using a word processor. Her physical functioning has decreased slowly over time, and she is cognizant of the fact that it will only continue to get worse. She is becoming less able to tolerate the anti-Parkinson’s medications, and she is very afraid of living with diminished mental faculties, should that occur.

Mrs. W. will be able to develop her own definition of futility. She feels that being completely physically dependent and cognitively disabled would make life not worth living. Any procedure that would prolong such an existence would be futile. At some point in her disease progression, she would reject any interventions whose purpose was other than for comfort; the trade-off would be very clear. Even “health maintenance” procedures would have to be weighed, for instance, as to whether early detection of a cancer would make a difference in her comfort. The restriction of pleasures in order to slow the progression of vascular disease would be counter-productive. The difficulty would be deciding *when* in the progression of her disease these things would become futile. Early on she may decide that a low-cholesterol diet is meaningless to her, knowing the inevitable outcomes of her disease. Later, if the desired outcome shifts from

prolongation of life to acceptance of death, she may decide that a urinary tract infection should not be treated in pursuit of a cure (i.e., with antibiotics), but only to alleviate painful urination (with pyridium), leading to a possible death by urosepsis.

There are many concepts to be explored in the notion of futility in nursing homes, as evidenced by the cases of these four patients. First, *futility is a relative state*, dependent upon the physical condition of the patient, the efficacy of the intervention, the desirability of the probable outcome, and the noxiousness of the process. An intervention may be highly efficacious in one patient but futile in another. The patient's functional level is one of the most predictive features for good outcomes of interventions ranging from cardiopulmonary resuscitation, to chemotherapy, to surgical procedures, to pneumonia treatment. Almost by definition, a long-term resident of a nursing home has some degree of physical or cognitive dysfunction. Therefore the expectation is that aggressive treatment of all illnesses is more likely to be futile in this population than in a population of elderly persons who live independently.

Second, *futility is goal-dependent*. The most helpful questions I ask of any procedure I am considering for a patient – from drawing blood to prescribing medication to referral for major surgery – is, “What am I doing this for? What will be accomplished with this intervention?” And, most important, “Is that where we want to go?” If the result of a blood test does not provide useful information or point to an intervention that would help us toward our goal with a particular patient, then the blood test is futile. Similarly, I would not do a screening sigmoidoscopy in a patient for whom comfort is the goal; it is futile. While treating the symptoms of a patient with pneumonia, I might not give antibiotics if comfort and avoidance of prolonged death were the goals. On the other hand, if the patient's priority is comfort, and if intravenous antibiotics are not deemed

noxious, then treatment with antibiotics might be appropriate. This intervention might prolong the individual's life, but that is acceptable to the patient if comfort is guiding the decision-making process.

Finally, *futility will change over time*. Patients who are in a nursing home for short-term recuperation and rehabilitation may hold increased function and independence as their goals. These patients may thus be willing to tolerate a great deal of discomfort in the service of an attainable goal. Conversely, long term patients, for whom regaining independence is no longer possible, may posit comfort as the highest priority. And those patients whose health is rapidly deteriorating without significant possibility of improvement may choose avoidance of a prolonged dying process as the major goal. As we have seen, the range of conditions, prognoses and goals in the nursing home setting renders null any normative definition of "futility." Futility is a patient-centered reality. As the patient's medical condition, prognoses and goals evolve over time, so too should the definition of a "futile" intervention.

Futility and Appropriate Care in Hospice

W. Scott Long and Frederick Flatow

Hospice care has arisen in response to suffering in terminally ill patients and their families. The modern hospice movement has its origins in the mid-nineteenth century in Ireland and France. With the rise in medical technology in the last half of the twentieth century, hospice has in addition become an alternative to both further clinical intervention for cure and to the sense of abandonment when such curative efforts appear futile to patients, families and/or clinical caregivers. In the context of terminal disease, futility means for us that people (patient, family, clinician), faced with a clinical decision that may extend a patient's life, decide that the burden of the next specific intervention outweighs the expected benefit to the patient's quality of life. Often, it is only at this point that one begins to consider hospice.

Hospice entails the delivery of care to terminally ill patients and their families by an interdisciplinary team of clinicians, including nurses, doctors, social workers, those involved in pastoral care and the arts, volunteers, and others. Such teamwork recognizes that no one clinical service can adequately address all the needs, both tangible and intangible, of patients and families facing the end of a life. In hospice care, psychosocial support for both patients and families is usually more comprehensive than that currently found in most other medical settings.

The first American hospice was established in New Haven, Connecticut in 1974 to provide end-of-life care for patient and family in the patient's home. Members of the Yale community, concerned that care of the terminally ill was not adequately addressed by the medical community, patterned this program after the hospice principles developed

by Cicely Saunders in England. In 1980 a freestanding hospice was built to support its home hospice program with an inpatient unit.

In 1982 Congress passed the Tax Equity and Fiscal Responsibility Act, which placed hospice care on a more substantial financial base. Terminally ill patients 65 years old or older became eligible for hospice services under the Hospice Benefit of Medicare with fees paid for daily care at home and in inpatient programs. Eligibility for this coverage and admission to a hospice program required a prognosis of 6 months or less to live, estimated by primary physicians and the local hospice medical director. Subsequently Medicaid programs and some private insurers have also offered such coverage. This financial support strengthened hospice programs and contributed to growing availability of hospice care.¹⁰⁸

At present in the United States about 3000 hospices annually care for some 700,000 patients. Most hospice patients die at home (56%); but patients also receive hospice care in nursing facilities (19%), in free-standing hospices (12%), and the rest in hospitals, in hospice units located within hospitals, and in residential care facilities.¹⁰⁹

Home hospice is an important part of end-of-life care, as indicated by the fact that 56% of hospice patients die at home. Increasingly, people are able to live out their last days in the familiar setting of their homes (if they, their families, and the insurance providers so choose). Home hospice care usually entails visits to the home by hospice nurses. In addition, many people nearing the end of life need full-time care and medical support, which can be provided either by a hired nurse's aide or a family caregiver.

¹⁰⁸ Hoyer T. A history of the Medicare Hospice Benefit. In: Harrold JK, Lynn J, eds. A good dying: shaping health care for the last months of life. New York: The Haworth Press, 1998; 61-69. This article was simultaneously published in *The Hospice Journal* 13, 1998.

¹⁰⁹ National Hospice and Palliative Care Organization (2001). NHPCO facts and figures. www.nhpc.org, accessed 3 August 2002

There are significant ethical and emotional implications for family caregivers in end-of-life situations, particularly when some aspect of futility is involved. Little research has been done on this topic.

It is important to note that the term “hospice” is primarily applied to patients whose care is covered by Medicare or health insurance or who are able to pay out-of-pocket for hospice services, regardless of whether the care is received at home or at a hospice facility. However, a relatively large segment of the population does not have sufficient health insurance and cannot afford to pay out-of-pocket for hospice or end-of-life care expenses. When this is the case, female family members constitute the majority of end-of-life caregivers; they care for aging or ailing parents, relatives, spouses, and children. The difficulties encountered by family caregivers in all end-of-life situations have received more attention in recent years. Nonetheless, the burden on such caregivers far exceeds the social and financial support available to them. While we cannot cover this topic in greater detail, it is important to remember that hospice care is not even an option for many patients and families. We must therefore ask what our societal responsibility should be toward the dying *and* those who care for them.

Some extended care facilities (such as nursing homes) have policies supporting hospice care, but many such facilities do not educate or support patients and families in considering hospice. Developing better guidelines for hospice care entails education of administrative and clinical staff, honest but compassionate discussion of goals with patients/families, and the implementation of advance directives. Such policies allow terminally ill patients and their families the choice of either receiving hospice care in the residential facility or in a dedicated hospice setting – rather than a trip to the local

emergency room – or of being transferred to an acute care hospital. This can be spelled out in the patient’s advance directive.¹¹⁰

Cancer has historically been the diagnosis most often associated with hospice, and pain control is the prime concern. Cancer still accounts for the majority of hospice patients (57%), but skills learned in cancer care are appropriate for other diseases.¹¹¹ In recent years care of the terminally ill has received more recognition from the medical community with resultant increase in hospice admissions for non-malignant diseases, such as end stage lung, cardiac, renal, neurologic and infectious diseases including AIDS.¹¹² Some specialized hospitals and nursing facilities now include care of the dying among the services offered, and some hospice facilities exist specifically for AIDS patients.

The discussion in this chapter applies to all types of hospice (home, hospice facility, or unit within a hospital or long-term care center). However, the primary focus will be on futility within hospice facilities. We first discuss considerations of transfer to hospice as faced by treating physicians and patients/families in the context of “futility.” We then look at acceptance by hospice of patient and family, and what constitutes “appropriate care” there.

Futility and Hospice

¹¹⁰ Keay TJ, Schonwetter RS. The case for hospice care in long-term care environments. In: Matzo ML, Lynn J, eds. Clinics in geriatric medicine: death and dying. 2000;16:211-223; Zerzan J, Stearns J, Hanson L. Access to palliative care and hospice in nursing homes. JAMA 2000;284:2489-2494.

¹¹¹ Addington-Hall J, Fakhoury W, McCarthy M. Specialist palliative care in nonmalignant disease. Pall Med 1998;12:417-27

¹¹² National Hospice and Palliative Care Organization (2001). NHPCO facts and figures. www.nhpc.org, accessed 3 August 2002

The intersection of futility and hospice arises when patients/families and caregivers consider changing treatment from “cure-to-care,” as it is commonly stated, indicating a change in focus from treatment intended to *cure* the patient to treatment that seeks to *care for* symptoms without expectation of cure. We prefer the terms “cure-*and*-care” and “care only.” Every patient receives care. Decisions at this moment in a patient’s history often contain important subjective components that create differences of opinion about what next treatment is appropriate, advisable, acceptable and/or desirable. These differences occur within patients’ families, among clinical caregivers and between patient/family and clinicians. And they can provoke strong emotions. Even with evidence-based medicine, including statistical studies of therapeutic efficacy and extensive professional experience, any two clinical caregivers may disagree about the prognosis and/or appropriateness of a particular treatment, such as another round of chemotherapy for a given patient.

We believe the term “appropriate care” is both truer to reality and more helpful to patients and families than is “futility” during consideration of transfer to hospice. “Futility” implies that nothing more can be done for the disease, and may leave the patient feeling desperate and abandoned. When discussing the limitations of treatments that are more burdensome than beneficial, the conversation should progress to continuing care in a hospice environment. The possibility of continued support provides more comfort to patients and families than does mention of “futility.”

Transition to hospice care can be easy. In the most ideal transition, the patient and family accept a prognosis of less than six months, and they agree with the physician that the physical and psychosocial burdens of further curative therapy are not worthwhile.

The physician has determined that the patient is hospice-eligible, and all concerned (including the hospice medical director) agree that transfer to hospice care is appropriate.

In other situations, talking about transfer to hospice is much more difficult. This can occur if the physician and patient/family have not seriously considered an end to curative therapy, or a transition to hospice care, until it is unequivocally clear to the physician that further therapy is likely to produce more burden than benefit. Such “last-minute” discussions may be particularly difficult when resistance arises in patients or families, especially if patients/families are unprepared for the transition. Other difficult situations in patient transfer to hospice care include patients who are incompetent (unable to make conscious and informed decisions); patients without advance directives; patients in nursing homes without policies for terminal care outside an emergency room; or patients with repeated admissions to hospital for recurrent problems (such as aspiration pneumonia) without effective advance directives. These difficult discussions often require extensive conversations with families and administrators about the option of hospice as a means of optimizing the quality of a patient’s remaining life. And, of course, strong differences of commitment may exist between or within medical services, for example between a hospice team and an oncology team.

Several generalizations about discussing hospice care are worthwhile, referring specifically to discussions between clinical teams and patients/families. Some points may apply to conversations between clinical teams and other professional caregivers and administrators.

(1) *Open communication is paramount.* The patient/family must realize that the clinical team is listening as carefully as it is talking. Once again, we are convinced that the conversation is better served by talking about appropriate care, not about “futility.”

(2) *Such discussions should be had early in the patient's course of treatment, to give patient and family time to consider the issues. If advance directives do not exist, the patient and family should be encouraged to create a living will and to appoint a health care proxy after appropriate consultations. Discussion of hospice care may be started quite early after diagnosis if therapy is clearly "buying time" (if cure or lasting remission is acknowledged to be unlikely or impossible). In situations when some acceptable chance of cure exists, the physician can acknowledge the possibility of future hospice care while honestly discussing options of curative intent. This even-handed approach allows greater objectivity for the patient and family and a sense of collaboration with the caregiving team. Least desirable, but still much too common, is urgent transfer to hospice without sufficient time for discussion and reflection.*

(3) *Conversations about transition to hospice care should be individualized, private and conducted to encourage exchange between patient/family and clinicians. Discussion must be directed to the decision-maker, be it patient or surrogate, but should include others present. At times it may be possible to elicit from a patient a consideration of hospice care in response to simple questions, such as "How are you feeling?", "How are your spirits these days?", "How is your treatment going?", or "How do you feel about your therapy?", all framed in language appropriate for the patient or adapted for the patient's surrogate.*

(4) *The physician must know ahead of time that the patient meets the requirements for hospice. In some cases, this may involve prior discussion with the hospice's medical director.*

(5) *Ample and accurate description of local hospice care must take place in order to prepare the patient and family for the possible transition and to avoid the appearance*

of false promises. The patient/family must understand that transition to hospice care means continuation of good medical care, not abandonment. For example, the patient/family (and referring physicians) should understand that all clinically relevant medications presently in use will be continued and adjusted in hospice to maintain the patient's comfort (such as bronchodilators in a patient with COPD but dying of metastatic lung cancer). In some hospices, appropriate care may involve aggressive support measures for comfort, e.g. ventilators. Additional medication changes will be made as needed to maintain the patient's calm and comfort, e.g. titration of analgesics and anxiolytics.

(6) The referring physician should emphasize that the patient's family will also receive support in hospice.

(7) If the referring clinical team will not be following the patient in hospice, this should be clearly stated along with assurance that the referring team will transmit all relevant medical information to the hospice team. A realistic comment about the referring physician's involvement in hospice care should also be made, so that patients, families, and hospice clinicians know how to approach care decisions.

(8) Some hospices offer transition programs in which curative therapy, aimed at cure or lasting remission of disease as directed by the patient's referring physician, continues while the patient also receives palliative care from the hospice team. This can help patients and families prepare for a complete transition to hospice care. Similarly, care may begin in a home hospice program with later transfer to an institutional hospice, if such is available and desired.

Up to this point, we have written primarily about decisions made by caregivers and patients/families with regard to hospice care. However, the hospice must also be

willing to accept the patient and be able to provide appropriate care to each patient and family. Hospice Benefits, as articulated in the original Medicare legislation, require that (1) “the individual has a medical prognosis that the individual’s life expectancy is six months or less” as determined by the referring physician and the hospice’s medical director and (2) that the individual willingly gives up Medicare coverage for curative therapy in order to have hospice care (“management and palliation of a terminal illness”) covered by Medicare Hospice Benefit. Furthermore, the law requires that an interdisciplinary team - including a physician, a nurse, a social worker and a counselor - manage the patient and family’s care.¹¹³

The most difficult requirement for hospice admission is accurate prediction of remaining length of life. This becomes somewhat easier as one approaches the very end of life, i.e. hours/days rather than weeks/months, but it has never proved easy or infallible. Attempts to improve reliable estimation of survival timelines are extensive and ongoing. Many studies have involved modeling diagnoses, general functional abilities, physiologic parameters, lab tests, symptoms, psychosocial considerations, site of care, and clinical domain and experience of prognosticators. However, significant variation exists from study to study among the identified predictors. The most nearly constant predictive factor was general functional ability as measured, for example, by the Karnofsky or ECOG scales.¹¹⁴ These scales measure patients’ abilities to perform tasks requiring integration of cognitive, sensory and motor skills in ordinary tasks of daily life

¹¹³ Hoyer T. A history of the Medicare Hospice Benefit. In: Harrold JK, Lynn J, eds. A good dying: shaping health care for the last months of life . New York: The Haworth Press, 1998; 61-69. This article was simultaneously published in The Hospice Journal 13, 1998

¹¹⁴ Christakis NA. Predicting patient survival before and after hospice enrollment. In: Harrold JK, Lynn J, eds. A good dying: shaping health care for the last months of life . New York: The Haworth Press, 1998; 71-87. This article was simultaneously published in The Hospice Journal 13, 1998; Reuben DB, Mor V, Hiris J. Clinical symptoms and length of survival in patients with terminal cancer. Arch Int Med 1998;148:1586-1591.

like feeding, dressing, and toileting one's self. Dependence or independence in these large integrative tasks more accurately reflect patients' overall health status than do, for example, a symptom of dry mouth or a diagnosis of lung cancer or plasma bilirubin levels.

Overall, despite great variability in survival after diagnosis of cancer, accurate prediction of life expectancy is even more difficult in non-malignant diseases that do not show the more rapid decline in the last months of life found in cancer.¹¹⁵ In response, the National Hospice and Palliative Care Organization developed a set of prognostic guidelines for many nonmalignant diseases. These guidelines stress progression of disease, with specific emphasis on both general functional assessments and physiologic parameters.¹¹⁶ For example, criteria for end-stage pulmonary disease include (1) decreased functional ability, fatigue, dyspnea at rest; (2) *cor pulmonale* or right heart failure; (3) hypoxemia at rest on supplemental oxygen; (4) elevated carbon dioxide level; (5) other elements of poor prognosis including unintended weight loss of >10% over previous 6 months, and resting tachycardia above 100 beats per minute.

Although predictive studies produce estimates both overly optimistic and unduly pessimistic (with few accurate findings), physicians generally tend to *overestimate* survival time for dying patients.¹¹⁷ Timely referral to hospice spares patients burdensome and/or unwanted treatment and provides comprehensive support for patient and family.

¹¹⁵ Teno JM, Weitzen S, Fennell S, Fennell ML, Mor V. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? *J Pall Med* 2001; 4:457-464; Fox E, Landrum-McNiff K, Zhong Z, Dawson NV, Wu AW, Lynn J. Evaluation for prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. *JAMA* 1999;282:1638-1645.

¹¹⁶ Stuart B. The NHO Medical Guidelines for Non-Cancer Disease and local medical review policy: hospice access for patients with diseases other than cancer. *The Hospice Journal*. 1999;14:139-54, 1999. (A more accessible version, adapted from the 1996 NHO guidelines, is found in the reference of J Lynn); Lynn J. Serving patients who may die soon and their families. *JAMA* 2001;285:925-932.

¹¹⁷ Christakis NA. Predicting patient survival before and after hospice enrollment. In: Harrold JK, Lynn J, eds. *A good dying: shaping health care for the last months of life*. New York: The Haworth Press, 1998; 71-87. This article was simultaneously published in *The Hospice Journal* 13, 1998.

Late referrals due to over-optimistic prognoses may produce frustration, incomplete care and, in some patients/families, anger and feelings of abandonment. For the receiving hospice team, late referrals produce the stress attending all urgent care, as well as a feeling of diminished collegiality between referring and receiving teams of caregivers.

While emphasizing timely referrals, we do not mean here that every dying patient must be admitted to a hospice. Indeed, transfer of an actively dying patient is unfair and cruel. Furthermore, if a dying patient and family are receiving appropriate care where they are, such as in an ICU or at home with family and visiting nurses, then transfer to another institution may only complicate the situation.

Once the patient/family accept hospice, the issue of appropriate treatment is reframed. The goal of patient care is no longer prolongation of life. Instead, the goals become quality of life in the days remaining (for the patient) and general support (for both patient and family). Achievement of these goals can be difficult. Prominent obstacles include inadequate clinical and psychosocial information on transfer, incompetent patients without advance directives and without reliable or informed family, or unrealistic patient/family goals and disagreement among patient/family and clinicians about good symptom control.

Good information at transfer is important to initiating optimal hospice care. Sadly, the harried pace of most physicians' lives is probably the most frequent cause of poor transmission of medical information. Rotating physician coverage, hospital-based physicians who know little about patients/families beyond a patient's current hospitalization, and the occasional physician who thinks hospice offers minimal medical support and so discontinues all medicines except analgesia, all contribute to the problem. When, as a result of these factors, hospice staff does not receive a thorough report on

important psychosocial issues, the resulting problems may consume hours or days and cause unnecessary pain and delayed support for patient and family.

An advance directive, such as a living will, that is ubiquitously recognized as valid can be invaluable. The same is true for active participation of a person legally appointed power of attorney for health care matters for an incapable patient. With decreasing lengths of stay experienced by most inpatient hospice units, the presence of advance directives on admission is quite helpful, since time is precious.

Even when transfer of patient and family to hospice has seemed entirely appropriate and acceptable to all parties involved, misunderstandings may occur, particularly about the goals of therapy. Some patient/family goals are important but impossible to achieve, such as a patient's wish to walk freely even after aggressive but unsuccessful treatment of spinal cord compression. On the other hand, sometimes a patient states such a goal as a way to remain positive while facing the end of life. In these cases, support can be gentle; and no absolutes or hard truths need be forced on the patient. If the patient/family continue to insist on unattainable goals, education must be careful, unbiased, and firm – but not hurtful. Compromises, such as intermediate courses of treatment (such as physical therapy for patients with a longer prognosis), can often be found. Such interventions help the patient/family realize that we have not “given up” on them.

Appropriate Care

The issues of appropriate care most frequently discussed – and richest in conflict – for patient/family and hospice staff are (1) analgesia, (2) treatment of agitated confusion and (3) parenteral nutrition, especially intravenous feeding.

To begin: who defines “appropriate”? First and foremost, the patient’s condition guides the actions of hospice caregivers. These actions are then modified as necessary. Usually, but not always, staff and patient/family can successfully work out a plan of care acceptable to both parties.

The issue of appropriate analgesia illustrates the problems and difficulties in achieving consensus; it constitutes a major topic in the literature of hospice care. Up to 5% to 10% of patients tell us that they will tolerate some pain in order to remain alert, often to meet a specific goal. For many patients psychostimulants allow better analgesia by diminishing sedative side effects. On occasion, however, family members state clearly that the sedation observed in a patient is unacceptable; they often fail to understand or acknowledge a role for progressive disease. Clinicians addressing such concerns must themselves acknowledge the contributions of both medication and disease and then outline what options, if any, exist for improving awareness without allowing the return of distressing symptoms. Physician openness to these questions and comments is important, and family members must similarly trust a clinician’s good will and interest in their points of view. Persistent and detailed communication is crucial for resolution of these problems, as is acknowledgement of the family’s observations and questions. This forum for honest discussion in turn facilitates communication, relaxes defensive stances and promotes consensus for a plan to address the problems. Conversely, imposition of unilateral authority by physician, patient or family generally impedes the entire process.

The same clinical issues can cause dissent among hospice clinicians, most often between nurses and doctors.¹¹⁸ Nurses observe the patient's clinical condition over long periods of time each day, and their conversations with patients and families provide valuable psychosocial input. Physicians, on the other hand, see more patients, consequently spend less time with each, and often have a more medically focused exchange with patients and families. Due to a longer and more scientific training, doctors sometimes feel that they have a deeper understanding of the pathophysiology of patients' problems (especially their "physical" problems) and of their pharmacologic solutions than do nurses. Likewise, doctors will sometimes miss important psychosocial and clinical input from nurses, which leads the nurses to conclude that the doctors are intractable or obtuse. Resolution of these dilemmas between doctors and nurses involves mutual respect, sharing information, acknowledgment of personal and professional biases, and an honest effort at consensus.

Similar issues between patients, families and hospice caregivers arise during treatment of agitated confusion or terminal delirium,¹¹⁹ or consideration of treatment of hunger and thirst with parenteral nutrition and intravenous feeding.¹²⁰ We shall not go into these problems in detail, but it is worth acknowledging that clinical experience and studies continue to expand in both of these areas, sometimes with conflicting results. Further, these categories appear even richer in potential conflict than the question of analgesia. In clinical workup and effective treatment of agitated confusion, the issues of analgesia, confusion and intravenous feedings (IVF) are salient. It may involve not only

¹¹⁸ Frederich ME, Strong R. Physician-nurse conflict: can nurses refuse to carry out doctor's orders? *J Pall Med* 2002;5:155-158.

¹¹⁹ Breitbart W. Diagnosis and management of delirium in the terminally ill. In: Bruera E, Portenoy RK, eds. *Topics in palliative care*, vol 5. Oxford, Oxford University Press, 2001:304-321.

¹²⁰ Huang Z, Ahronheim JC. Nutrition and hydration in terminally ill patients. In: Matzo ML, Lynn J, eds. *Clinics in geriatric medicine: death and dying*. 2000;16:313-325.

changing medication (including rotation of opioid analgesia), but also initiation of IVF or other forms of hydration.¹²¹ To further complicate issues, some hospice clinicians do not consider these interventions, especially IVF, part of hospice care.

Other interventions once considered inappropriate for hospice patients but now used in some palliative settings include surgery,¹²² radiation therapy,¹²³ intravenous medication and fluids (e.g. some bisphosphonates and antibiotics), chemotherapy,¹²⁴ hematologic support¹²⁵ and ventilatory support devices.¹²⁶ In some cases standard admission guidelines may be temporarily set aside to admit patients on life-supporting therapies (such as peritoneal dialysis, mechanical ventilation, or nutrition by various non-oral routes), in order to support patients and families in their consideration of eventual cessation of these treatments. Before accepting these patients/families, it must be explained in a non-threatening way that hospices are not merely nursing homes with especially attentive clinical care. If the patient or family insists on continuing aggressive life-support therapies, they may be discharged to community care.

¹²¹ Fainsinger RL, Tapper M, Bruera E. A perspective on the management of delirium in terminally ill patients on a palliative care unit. *J Pall Care* 1993;9:4-8.

¹²² Arbit E, Bilsky MH. Neurosurgical principles in palliative care. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford textbook of palliative medicine*, 2d ed. Oxford, Oxford University Press, 1998:414-42; Ball ABS, Baum M, Breach NM et al. Surgical palliation. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford textbook of palliative medicine*, 2d ed. Oxford, Oxford University Press, 1998:282-297.

¹²³ Hoskin PJ. Radiotherapy in symptom management. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford textbook of palliative medicine*, 2d ed. Oxford, Oxford University Press, 1998:267-282; Galasko CSB. Orthopaedic principles and management. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford textbook of palliative medicine*, 2d ed. Oxford, Oxford University Press, 1998:477-487.

¹²⁴ Osoba D, MacDonald N. Principles governing the use of cancer chemotherapy in palliative care. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford textbook of palliative medicine*, 2d ed. Oxford, Oxford University Press, 1998:249-267; Nicum, S; Cullen, M H. Chemotherapy versus palliative care in non-small cell lung cancer. *Anti-cancer drugs* (2000);11:603-607.

¹²⁵ Turner AR. Haematological aspects. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford textbook of palliative medicine*, 2d ed. Oxford, Oxford University Press, 1998:769-774; Turner R, Anglin P, Burkes R et al. Epoetin alfa in cancer patients: evidence-based guidelines. *J Pain Symptom Manage* 2001;22:954-965.

¹²⁶ Claessens MT, Lynn J, Zhong Z et al. Dying with lung cancer or chronic obstructive pulmonary disease: insights from SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments). *J Amer Geriatrics Soc* 2000; 48(5 Suppl):S146-53; Neudert C. Oliver D. Wasner M. Borasio GD. The course of the terminal phase in patients with amyotrophic lateral sclerosis. *J Neurol* 2001;248:612-6.

In some situations, however, use of aggressive treatments indicates a broadening definition of hospice care. This is due to three factors: a deeper understanding of how to improve quality of life for patients/families; a wider range of diagnoses admitted for terminal care; and an increasing use of hospice as a temporary venue for symptom control, such that the patient returns to another care setting until terminal care is needed. Some of these short-term, symptom-alleviating treatments may potentially change the course of disease by prolonging it, as in the case of hormonal or radiation therapies for bony metastases in prostate and breast cancers. In such short-term, symptom-management contexts, the physician must address issues of palliative interventions fully with patients/families (employing the guidelines mentioned earlier) so that the implications of both symptom control and prolonged survival therapies are understood. Discussion with other members of the interdisciplinary team in providing such interventions is necessary, but responsibility for the decision belongs to the physician and patient/family.

Conclusion

In summary, hospice care is an alternative to persistent therapy with curative intent, once its burden becomes weightier than its benefit. We prefer to avoid talk of “futility” and recommend using “appropriate care” in discussing transition to hospice care. In hospice, comfort and quality of life remain worthy, appropriate and realistic goals, while unnecessary prolongation of life is neither appropriate nor realistic. We believe that hospice care embodies a philosophy and practice of humane clinical care, often more comprehensive than traditional medicine because of its constant concern for

symptom relief and psychosocial support not only for patients but for their families as well.

III. At the Bedside

Medical Futility From a Nurse's Perspective

Linda Honan Pellico and Annette Milliron

Amelioration of suffering continues to be a primary goal for nurses, who are in a unique position to assess the day-to-day reality and viability of a patient. Nurses are the ones who treat the wounds, the pain; who see the patient at all of his/her acute and mundane moments. What knowledge can we lend to assessments of medical futility? This chapter presents experiences and journal entries of nurses and student nurses in an acute care institution. The themes that emerge are poignant and important to an examination of the appropriate goals for patient care.

A forty-year old woman comes to the Emergency Room because she cannot breathe well. She had her gallbladder removed in our hospital a year ago without any difficulty, but now she is clearly in trouble. She is so hypoxic that she gets intubated. A thick plastic tube is inserted into her windpipe and a bag attached to push in oxygen. With a few puffs, the panic subsides; her breaths become slower and deeper and her color improves. Now the search begins: Why did this happen?

As clothing is removed, some with scissors, one problem becomes obvious. Her left breast is huge and full of lumps, like craggy rocks inside. My God, how long has she had these lumps? How long has she ignored them? And – the most critical question of all – were they there a year ago, when this presumed-healthy woman had her gall bladder removed?

From the ER she is wheeled up to the Intensive Care Unit, where a battery of tests are done that confirm the worst suspicions: breast cancer with metastatic lesions in the liver, the lungs, and the brain. By the time the prognosis is determined, her plastic breathing tube has been replaced with a permanent opening in her neck. Despite the staff's best efforts, she is quickly disintegrating; and ulcers have developed on her coccyx and her heels. Treatment will be a bleach solution that will burn the deep, gooey, tender crevices. A catheter is inserted into the large blood vessel in her neck so three different treatment options can be provided: to put liquid food in, to draw blood out, and to provide pain relief. It seems odd, almost as if we can't decide which route to take.

We are her nurses. As we watch her fade away, we sense that she is still in pain. The morphine is increased, the liquid nutrition continues, the ulcers grow larger. We know we are losing her and that the food, the suctioning, the bleach solutions do not help – in fact, they hurt. When we suction her lungs, we watch her shake, lose her breath and gasp, eyes wide with fright, desperate for air. We see her wince when the bleach solution for her ulcers, designed to heal, burns the fragile nerves now exposed along with her bones. It feels wrong. We know it is time to stop.

A team meeting is called. When faced with our observations, medicine and social service all concur. There are no arguments, no arrogance, just a moment of clarity. That is all it takes. It is time to call a family meeting. We – the nurses, doctors, and care team – need to be clear that we have no magic left; there is nothing that surgeons or medicine can do to restore this woman to health. The family understands and acknowledges that they have watched her drift away to somewhere between here and not here. All have been trying to avoid the inevitable. We have actually been prolonging her suffering. The futility of our care has indeed been an elephant in the room.

The decision is made to remove the respirator, continue the pain medication, and let nature take its course. Yet the treatment on the ulcers has been overlooked and is to continue. Why? To what end does it make sense that a stinging, sterile solution that can kill any organism on the planet should continue to irritate the now numerous cavities? At last it is a nurse who insists, “We will use a soothing, moist dressing from now on.”

There is no point to this treatment any longer. Nothing is to be gained by aggressive treatment in a decaying body.

Unfortunately, even agreement about futility in the big picture does not necessarily translate into good care at all levels. The events described above represent one such case. As the others that follow indicate, there is no single representative example. Rather, each case points out the limits of medical technology and the limits of human life. How willing we are to recognize and accept these limits, and accordingly to find the boundaries of appropriate and humane clinical practice? In the case described above, if we did not recognize the futility of our efforts, we would have continued the treatment regimen. So something happened that opened our eyes to the patient's prognosis. What was it? Could we hasten our recognition of medical futility? Perhaps more importantly, what was the context that finally corrected our myopic vision?

Time is a crucial factor in assessments of futility. Clearly, providers need to come to know the patients, their desires and their diseases before coming to a decision. We understand that over a period of hours, days, sometimes weeks and months, the goals of care can change from living well to dying well. But sometimes the time required for caregivers to recognize such a goal shift results in needlessly prolonged suffering for patients and their families. Can patterns be detected to alert us earlier, so the suffering can be mitigated?

Several themes emerge from the nursing experience that relate to medical futility. The first theme is the omnipresence of nursing. Nurses are always there, twenty-four hours a day, seven days a week. They maintain the bedside vigil that is intimate and personal. When one is always there, the experience of providing care is real, concrete,

and naked. Treatment options have immediate meaning. It is far different to write an order for blood work every six hours than it is to search in vain for a vein every six hours. Nurses are constantly observing the response to the prescribed therapy, not from the bleachers but from the field. Take, for example, this poem written by a nursing student, John Leopold, when caring for a patient on the trauma unit.¹²⁷

Chronic Vegetative State

Name: CP

Age: 34

Sex: Male

Race: Caucasian

Admission Date: August 1, 1999

I spoke with him

Or was it at him?

“Just in case.” I told myself.

Just in case he was afraid.

Just in case he was confused.

Just in case he needed to hear his name.

Just in case the cough when we suctioned him was more than reflex.

Just in case he knew how fucked up he was.

Just in case there was someone behind the Duratear glazed eyes who was

Hovering

In my nightmare, unable to scream,

Claw,

Kick,

Cry,

Or reason his way out of it.

Just in case my voice or words could comfort him.

Inflicting the pain of interventions – like suctioning the windpipe – earns nurses the badge that allows them to judge benefit versus cost. What appears at first glance to be a simple action can often carry profound ramifications. Turning a patient with bone cancer is not a simple procedure; suctioning a patient with tenacious secretions is not a straightforward task. The nurse’s job is both

¹²⁷ All student journal entries are from *Do you see what I see? GEPN Student Journal Entries* (2002), Yale University School of Nursing.

procedural and artistic. Thus nurses, always present, may indeed be the first to understand when the inevitable is simply being prolonged. They may be the first to realize when we have moved from medical therapy to medical futility, when our obligation shifts to relieving suffering, and when it is time to step forward onto that new path.

A second theme emerging from nursing experience has to do with the philosophical foundation of health care. Virginia Henderson's definition of nursing articulates that "[t]he unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge."¹²⁸ This philosophy stands in contrast with the philosophy of Western medicine, which promotes "interventions" and "cures" for "diseases" and "pathologies." One profession's focus is to temporarily fill the patient's needs so that the patient can return to her own state of balance, while the other implies that an action is required from outside to alter the patient's current state. The focus of nursing is on care. Nurses have witnessed the profound success of medicine and surgery, but they have also seen its failures. Nurses acknowledge the exponential growth of technology and can attest to its time saving aspects but also to its ability to interfere with meaningful patient-caregiver relationships. This puts nurses at an advantage when considering medical futility. They do not recognize a peaceful or good death as failure; it is simply another goal, a continuation of the holistic journey and experience of the patient at the center of care.

The writing of Kira M. Showalter, Yale School of Nursing (YSN) Class of 2003, illustrates this perspective.

Death is a natural part of life, and there is a beauty in death that parallels that of birth. As a future midwife, I can't help but make the connection. I believe that mothers and families have the right to a normal, nurturing, intervention-free birth at a place where they feel comfortable and are surrounded by people who love and care for them. Why should death, for a person who has lived a long life or has decided that they do not want to bear the suffering they are enduring, be any different?

When I walked into his room at the end of the hall, I could feel the suffering and pain in this man as if it were an actual substance – little droplets in the air. He is starving himself, and he has pulled out his tracheostomy tube on multiple occasions. He wants to die. He is finished with this, he wants to move on. Yet he cannot talk. He cannot communicate this to his family and his doctors in a rational or clear way. So he is trying the best he can to tell everyone his wish. But instead of listening, they tie his arms down to the bed. He is agitated, in pain at all times. He has a pleural effusion, pulmonary embolism, and countless other problems.

We give him a bath, we comb his hair, change his dressings, try to make him comfortable. We take off his restraints as long as we're in the room. I spend a lot of time just holding onto his hand, and looking at his eyes. I know I am not imagining it. He is pleading with me. He locks onto my eyes and I get uncomfortable, look away. I still can't grasp it, really. This isn't the way it should be. It makes me so angry, so filled with pain and confusion. *Why?* I want to scream, cry, let it out. I want to find Dr. Death so, finally, he can help this man let go.

It is essential to realize that futility occurs at different times for all individuals involved. Sometimes nurses recognize the hollowness of efforts, sometimes other members of the team, sometimes the family members or loved ones – but, as the above testimony demonstrates, often the patient knows or at least senses it. The patient may simply need the medical team to confirm what he already understands: that life is ending.

¹²⁸ Henderson, V. (1964). The Nature of Nursing. *American Journal of Nursing*, 64(8), 62-68. Quote from page 64.

Ultimately, we must hold sacred the patient's sovereignty in this situation. It is important to remind ourselves that despite extraordinary success in healthcare, death remains inescapable.

Another theme from the nursing experience is connectedness.¹²⁹ Earlier, we explored the omnipresence of nursing staff. However, just being in attendance on a patient does not equate to effective care. Connectedness is viewed in nursing theory as central to all dyad relationships, whether they involve teacher/learner, nurse/patient, nurse/physician, or novice/expert. Connectedness is the ability to transcend the roles, positions, content and context to truly connect with the other person. It has been described as a "central human longing."¹³⁰ The nurse remains constant in caring, listening to and focusing on the patient. It is clear that the ability to communicate is central in actually connecting with a patient.

From the inception of the profession of nursing, leaders such as Yale School of Nursing's first Dean, Annie Goodrich, have delivered a clarion call to "be master of two tongues, the tongue of science and that of the people."¹³¹ Simply put, nurses speak of treatments in understandable language (not the hospital "medicalese"); they strive to break down complex biological functioning or treatment modalities. As a result, they are approachable. They acknowledge that medical jargon limits dialogue, and that clear, direct language facilitates communication. When real communication occurs, patients and families will often entrust nurses with their fears, their hopes, and their secrets. They can ask nurses the scary questions. This is true of any medical professional who can

¹²⁹ Schubert, P., & Lionberger, H. (1995). Mutual Connectedness- A study of client-nurse interaction-using the grounded theory method. *Journal of Holistic nursing*, 13(2), 102-116.

¹³⁰ Resnick, M., Harris, L., & Blum, R. (1993). The impact of caring and connectedness on adolescent health and well being. *Journal of Pediatric child health*, 29(suppl.1), S3-9.

¹³¹ Goodrich, A. (1932). *The Social and Ethical Significance of Nursing, A Series of Addresses*. Macmillan Company, New York. Page 14.

listen and engage with the patient in his/her language – nurse, doctor, technician, or chaplain. Conversely, inaccessible language can stultify and terrify the very patient we are seeking to treat, which stunts attempts at connectedness. Ashley Weycer, a YSN student, gives life to the meaning of connectedness in this excerpt from her journal:

I met Grace this morning a few minutes before her doctor entered her room. She was frightened, lonely, and hungry for human contact. I was stroking her hand when her doctor came in. He was babbling on about more tests and procedures, asking her if her pain was being controlled by the morphine she was receiving. Fairly well controlled, she claimed. Somehow into those queries and comments he mentioned that she had cancer. That it had proliferated throughout her entire body. That they would be doing chemo and radiation. That they would be serving pancakes for breakfast and Have a Nice Day. He was gone before Grace could speak. She asked for some more morphine. Her pain was suddenly much worse, she said, worse than it had been, the worst pain she had ever felt. We gave her some more morphine.

When I came back into the room with the medication, Grace grabbed my hand. Clinging to it, she began to talk. She does not want chemo, could her doctor actually make her take it? I explained to her that it was her body and her choice. She asked about morphine addiction, she said she didn't want to die an addict. I assured her that she wouldn't. She asked me to stay and hold her hand.

Grace began to cry. And talk. She spoke about her childhood, and all of the places she had visited over the course of her life. She described all of her children, her grandchildren, and her great grandchildren. She told me about the beautiful house on the lake that she and her husband had built by hand...about her son's house in Maine, the town she grew up in, and her ninety-seven year-old mother who is still alive. Grace recounted a lifetime of joys and sorrows and hopes. She spoke of her fears of leaving her loved ones, and the sadness of no longer being able to experience the seasons. She discussed her refusal to burden her husband and children with these fears and thoughts, of how isolated she suddenly felt, and alone. She loves life, she said, too much to lose it. "Please don't leave me alone," she pleaded, "there is too much pain when I am alone." So I let myself cry with her, right there in front of her, and she looked at me and smiled. "I'm not alone," she said, "I see that you understand me, and I'm not alone."

Grace talked and reminisced, hoped and feared, felt and cried for most of the six hours that I was with her in her room. But the more she shared and grieved, the more she smiled too. "You understand me, I'm not alone, you understand," she kept repeating, "you understand." I promised her that others would understand too, that her family would understand too,

that they would find it a blessing and an honor to share her life, every aspect of it, with her (I hope they do).

At post-conference I talked about how I felt that I had helped a patient far more today than in all of my other days as a student nurse combined. I feel like I have finally experienced the reason I chose to become a nurse in the first place. Nursing to me is an opportunity to take care of the *whole* person, not just their aching, sore, infected, cancerous parts. I felt like a “real” nurse for the first time. Ironically, I’m afraid that it is “real” nurses who don’t have the time to do “real” nursing.

Unfortunately, Ashley Weycer’s fears are well-founded. Experts have written of the palpable moral distress that is sensed on nursing units when nurses are unable to provide the care they believe patients deserve.¹³² In an era when reimbursement and funding mandate that providers across the United States do more with less, with steadily increasing patient-to-nurse ratios, it becomes increasingly difficult to offer patients the personal support they deserve. It is more difficult still to find support for using limited resources on non-curative care. Take, for example, the patient with whose story we began this chapter. Once the decision was made to discontinue the respirator but continue to provide “comfort measures,” the team encountered pressure to release her ICU bed to another patient in critical need. Nurses in Intensive Care Units often do not want to transfer dying patients out to units where the nurses do not know the patient or the family. The ICU nurses often want to honor already-established relationships with a patient’s family members by staying committed to the care of the dying patient. But when critical-care beds are tight, it is a hard battle to fight. Described eloquently and succinctly by a nurse in the ICU, “we stand in this wave of want.” As a result, nurse-patient (or nurse-family) relationships are often severed during a patient’s dying process.

How can we translate the themes that emerge from patient situations into pertinent lessons about medically futile circumstances? First, we can learn that the work of caring is as important as the work of curing. Nurses do much of this important work, and the hospital infrastructure needs to allow them to do that work. We need to look at the systems that are in place to maximize time at the bedside, not in front of the computer screen or in the boardroom.

We need to advocate for our patients, and we need to work together to hear their voices. Since nurses are specially positioned to understand the daily situations of patients, they can be excellent advocates. But an *a priori* requirement for advocacy is empowerment. Nurses must be viewed as important members of the team. A vision of comprehensive treatment is only broadened by encouraging several medical opinions. The buck does not stop in medicine or surgery or nursing. We must communicate within the care team by sharing our knowledge, perceptions, and recommendations.

We should also communicate with families as a team. It is in these family meetings that we can try to alter the imbalance in power that exists between “professionals” and “patients.” The health team has the medical data, and many times the family needs to be

¹³² Aiken, L.H., Clarke, S., Sloane, D., Sochalski, J., Silber, J. (2002). Hospital Nurse Staffing and Patient Mortality, Nurse Burnout, and Job Dissatisfaction. *JAMA* 288(16), p.1987-1993. Corley, M. (1995). Moral Distress of Critical care Nurses. *American Journal of Critical Care* 4 (4), p. 280-285. Jameton, A. (1993). Dilemmas of moral distress: moral responsibility and nursing practice. *AWHONNS Clinical Issues in Perinatal & Womens Health Nursing*. 4(4):542-51. Lutzen, K., Cronqvist, A., Magnusson, A., Andersson, L. (2003). Moral Stress: Synthesis of A Concept. *Nursing Ethics*, 10 (3), p.312-322.

educated about what the information means. The family, however, has the advantage of knowing the patient's history, their desires, regrets, spiritual needs, and cultural norms – all rich sources of learning and necessary resources for care planning.

Finally, we must provide anticipatory guidance for death. Families benefit from a health care team that admits that we don't exactly know when death will come. At the same time, we must be clear that we will provide the best care for the patient and family's goals until that point, and – as best we can – beyond. We can educate families about the realistic limitations of therapy, as well as what to expect in the dying process. For example, many families believe that when life support is removed death will be swift and certain, only to find minutes turn into hours, days, and sometimes weeks. Through sensitive communication, we can help to minimize the misperceptions and make the transition out of life realistic, meaningful and dignified. In situations of futility, our ultimate aim is a comfortable, dignified death.

We conclude with a story from the nurses on the oncology unit of Yale-New Haven Hospital.

This patient is a quiet man in his late 60s who emigrated from Korea. He is a husband and father of three, and although he speaks English extraordinarily well, he cannot read the written word in anything but his native language. Despite his healthy appearance and optimistic nature, there is an insidious disease invading his body, acute myelogenous leukemia. He is admitted for chemotherapy; later, a needle is inserted deep into a bone to obtain some marrow cells and determine whether the chemotherapy that was pushed into his veins has arrested this cancer. No such luck: this cancer is a fugitive. The team explains the results of the test and the need for more rigorous therapy. The treatment will be difficult, side effects will be considerable.

The patient and the family concur and additional toxic drugs begin to course through his bloodstream. Six weeks go by and in this time period, the optimistic strong man becomes weak, pale, feverish, and swollen. His family maintains a constant vigil, believing that their loved one's side effects are directly related to a deficit of care. If we doctors and nurses were better, his white count would improve; if we were smarter, his hands and feet would not burn. We all try our best, but it is not good enough this time. This cancer is advancing and we are losing our grip. Another needle gets tunneled into the deep recesses of his pelvis and this time, no cells. Is it time to celebrate or too premature to know? The family chooses to believe the former; the team prefers the restrained response. The treatments continue.

Two more weeks go by and now this patient feels he has waged a long enough battle and is ready to surrender. He has had enough. He just does not know how to tell his family or his doctors, and so he tells his secret to his nurses. They tell him it is his body, it was his choice to begin this treatment, and it is his choice to end it. They tell him he has fought valiantly. He tells the nurses that together his family made the decision for treatment, and that he is distressed thinking of the implications of renegeing on the plan. The nurses encourage the patient to talk to his family and pray that their advice is wise. The family acquiesces and together they inform the doctors that the battle is over. The physicians are furious. It is much too early to know for sure whether all is lost. A family meeting is called, all state their cases, and ultimately, the patient chooses. Treatment is stopped, comfort measures are instituted, good-byes are said, and the patient peacefully dies surrounded by his family.

In the end, medicine has not lost, nor has nursing won. The reality is that the patient died, and a family is changed. Ultimately, there will be no prescription for avoiding medical futility that fits all patients, and there is a danger in advocating such a procedural list. Each case will differ in both obvious and subtle ways. But care providers can accept the challenge of accountability to something far more tenuous than guidelines, but also far more palpable: the patients themselves.

The Chaplain's Role
Margaret Lewis and Christiana Peppard

“Serious illness, like other significant life challenges, forces us to rethink what it is that really matters.”¹³³ For many people, part of what “really matters” has to do with spirituality and/or religion. Repeated national polls have shown that 94-96% of Americans say that they believe in God and pray frequently. It is not surprising, then, that a great majority of patients in the hospital are also concerned about ultimate values and the sacred, which in Western traditions is often named as God. Some patients may not identify with an explicitly religious worldview but may nonetheless experience pressing questions about the meanings of illness, life and death. Chaplains are the members of the health care team in a hospital who are immersed in the spiritual, relational and religious dimensions of life. As such, they are resources who can provide opportunities for patients and families to express and explore important dimensions of illness, change, hope and loss.

The Mission of Hospital Chaplaincy

In general, hospital chaplains seek to help patients and families navigate the difficult spiritual and emotional terrain that comes with a person's hospitalization for a serious illness.¹³⁴ Hospital chaplaincy is primarily a service of support for the patient –

¹³³ Joanne Lynn, M.D. *Handbook for Mortals*. New York: Oxford University Press, 1999. Page 28.

¹³⁴ Hospital chaplaincy in its modern form emerged during the 20th century to address the spiritual needs of patients and families, and today hospital chaplains come in many stripes. Some local religious leaders or representatives can serve as chaplains to members of their congregations who are in the hospital. Some hospitals employ local clergy on a part-time basis. But there is an important subset of ordained or commissioned ministers who are employed full-time by the hospital and whose “congregation” is exclusively the transient population within the hospital: patients, families, friends, and staff members.

that is, chaplains try to work within the belief systems and life-defining contexts of the patient and family. The patient's spiritual view, as well as his sense of need, dictates the type of spiritual support offered. Unlike a pastor who gives sermons, or a rabbi who advises about religious behaviors, the hospital chaplain's only agenda is to provide spiritual support for the person *on the individual's own terms*.

In this way, the hospital chaplain is first a listener. A chaplain does not necessarily follow a specific rubric in her pastoral visits, though there tends to be an internal logic to the encounter. Chaplaincy is a responsive discipline; it does not seek to approach patients with an agenda. Instead, it grants agency to the patient and family to express the type of support they desire. In this way, only after she has grasped the individual's orientation and concerns does the chaplain become a responder, offering spiritual support in ways appropriate to that individual.

Whether it is patients or staff who experience spiritual need, chaplains can help clarify values, as well as witness to (and sometimes help contain) emotional and spiritual responses to a wide range of situations. Further, chaplains seek to provide spiritual care

In many hospitals, chaplains are accredited by the Association of Professional Chaplains. To be an accredited chaplain, individuals must have a graduate degree in theology and ministry; be ordained or commissioned by their denomination; and have had at least one year total of full-time supervised experience in hospital pastoral care. Because a hospital chaplain's "congregation" is the hospital population, most chaplains are interdenominational: that is, they are trained in interfaith care, and are able to support the spiritual needs of each individual patient (as defined by the patient), whether or not the patient and chaplain share a faith tradition. Most hospitals with chaplaincy programs strive to support the increasingly diverse spiritual and cultural needs of the population within the hospital.

Many chaplaincy departments offer services similar to the four listed below:

- Pastoral ministries to the ill and their families and friends at times of crisis and life transitions
- Spiritual care of the staff
- Quality education and training for students of ministry and health care providers
- Community outreach

In this way, chaplains are available to anyone in the hospital who needs them. High-priority visits include those requested by patients themselves, either through the medical team or through a Spiritual Assessment; those requested by nurses or physicians; visits requested by the patient's local clergy person; and events such as trauma or end-of-life situations.

for individuals with professed religious beliefs of any tradition or denomination, or for those with none at all. The chaplain must therefore be respectful of and conversant with various religions and notions of spirituality. When hospitals are able to employ chaplains from a variety of faith traditions, this diversity allows chaplains to better serve a broad religious population within the hospital.

Hospital Chaplaincy in Cases of Medical Futility

In cases of medical futility, a major issue is the way in which patients, families and the interdisciplinary health care team agree or disagree on the goals and methods of care. We offer two case studies that describe the varied terrain of medical futility, although we recognize that the range of experience between these two extremes is vast and varied.

Case 1

The first case study is an example of agreement over prognosis, goals and methods of care. Such a situation usually evolves over the course of time. In these situations, the patient, family and clinicians have come to a shared understanding that curative treatment is medically futile – it offers little or no benefit to the patient and cannot cure the disease – and that the medical emphasis should primarily be on alleviation of symptoms (palliative care). This shift in goals is not “giving up” on the patient; instead, a shift in goals – from cure to comfort – recognizes the medical reality of the situation and reflects consensus on how best to proceed. Such agreement is not always easy to attain. It can also be hard for families to accept, because a switch to palliative care as the only mode of treatment is a sign that death looms. Nonetheless,

when there is agreement over the goals of care, patients and families have an opportunity to live fully in the precious time that is available.

Over Sarah's several admissions to the hospital for active treatment and for symptom management of a metastatic gynecological cancer, the health care team concluded that Sarah's lifespan was very likely a limited one. Over time, the health care team had acknowledged that the treatments were no longer effective. At a family meeting, the team shared their assessment of the poor prognosis. One of Sarah's sisters concurred with the assessment and shared her own observations and concerns about the burden of continued treatment. She also expressed concern over her sister's unrealistic hopes for recovery.

Eventually Sarah was able to comprehend that she was nearing the end of her life. During this stay at the hospital, Sarah processed the news of her impending death with many different caregivers. Drawing upon the resources of the health care team who knew her, Sarah repeated the story of how she had come to her new knowledge and her sense of loss – in all of its dimensions. This storytelling was accompanied by a new focus: she began to make plans for how to use the time that was remaining. Her first priorities were to help her daughters prepare for her death and to support them in their grief, by arranging for them to meet with counselors, getting home to share time together, to create memories, and to take pictures together. She let her friends and work colleagues know of her situation so that they could visit with her and share goodbyes. She continued to practice the rituals of her faith and spoke about her expectations of an afterlife. The content of her hope as expressed in her prayers shifted explicitly to the anticipation that she would live long enough to be with her children and family through Christmas, and that they would be sustained by knowledge of her love and God's eternal grace.

During this time, Sarah received support from the hospital's palliative care nurse as well as from hospice home care nurses, all of whom sought to manage her pain and symptoms so that she could have meaningful time with the people she loved. Sarah was able to stay at home with her family, without re-admission to the hospital, through Christmas. On the 26th of December, Sarah was admitted to in-patient hospice. She died nine days later, having had the opportunity to evaluate her priorities, express her ultimate values, and live accordingly.

The chaplain was one of Sarah's listeners and prayer companions as she made the transition into accepting and living into the end phase of her life. The chaplain's role included helping Sarah process the spiritual dimension of her life's ending, her grief at all that she was losing, her concern for her family, and her hopes for their future and her

own. The chaplain's role also entailed sharing her perspective of these dimensions of Sarah's life with the rest of the health care team – sharing that included relevant (though not confidential) information, a sense of emotional connection, and prayerful intention.

Part of what makes Sarah's story compelling is that her life was lived out on her own terms. The medical team was able to communicate their best assessment of her prognosis, and Sarah eventually incorporated this information into her own thinking. Members of her family and the medical team were aware of Sarah's hopes, values, and decisions throughout her illness. The chaplain offered spiritual care throughout the stages of Sarah's disease, from hope for cure to acknowledgement of imminent death. As death neared, there was ultimate agreement on Sarah's prognosis and the goals of care, which freed Sarah and her family to attend to other matters of living.

As this case study indicates, an important component of a hospital chaplain's ministry is to offer his presence as patients and families begin to question or integrate new medical, emotional and spiritual changes; as patients and families revise goals and hopes; or as they begin to construct entirely new life stories, new hopes and new prayers. Such spiritual presence tends to occur within a shared acknowledgement between chaplain and patient (or family, etc.) that the transcendent and sacred – however defined, understood, or experienced – are important elements of human life.

Case 2

Unfortunately, it is not always possible for patients, families and the health care team to navigate smoothly the difficult emotional, spiritual and physical transition into end-of-life care. Sometimes this is the result of disagreement within the health care team. More often, communications among family members or between family and the medical team are fragmented and, at worst, contentious. When this occurs, family members and

clinicians can become polarized and suspicious of each others' motives and values, despite the fact that both sides are often trying to act in the patient's best interests. Indeed, the health care team and family members may have very different ideas about what the "best interests" of the patient are, and they may envision vastly different ways to attempt to meet those ends. This case describes a conflicted situation of the sort frequently associated with medical futility, and in which the chaplain's role as listener takes a different form.

Eve was no longer able to speak for herself. When she had been able to communicate she had agreed with each of her daughters about the goals of treatment. The problem was that one daughter was devoted to keeping her mother alive as long as possible, while the other was devoted to not letting her mother suffer. Each daughter felt that her religious faith supported her conviction and her promise to their mother. They were angry and distrustful of each other and of the medical team. The daughter who was devoted to "doing everything" had also provided home care for her mother, and she was the most recently named health care proxy.

The care team evaluated Eve's advanced disease and concluded that she was beyond effective curative treatment. They were concerned that were she to enter cardiac arrest, attempts to resuscitate her would cause significant harm (i.e., crushed ribs as a result of her severe osteoporosis) without offering medical benefit. They were also concerned that Eve be adequately medicated for her pain and symptoms, since the daughter who was the health care proxy had requested a reduction in her mother's pain medication, because she hoped that her mother might wake up and speak with her.

Several different chaplains spent time with both daughters. These chaplains and members of the ethics committee also spent time with staff members: listening, clarifying values, and facilitating communication in order to support the work of the healthcare team.

Eve died with the family still divided. Each daughter remained convinced that she had been the sole advocate for her mother's best interest. There was no comfort of communal consensus between the two daughters, or between the daughters and the health care team. As a result of this double conflict, the family as a whole was fragmented. Each daughter grieved in her own way but without the support of the other, and the sisters were not able to find opportunities for reconciled relationship and for shared grief.

In such situations, family members and the healthcare team can become entrenched in their opposed views. For instance, the daughter who had cared for her dependent mother responded to the medical staff in her perceived role as protector and advocate for her mother. In this sense, her own future and self-definition were in doubt, as was her mother's. What would be the meaning of her life if her mother were to die? What about the bargains she felt she had made with God? She experienced many dimensions of loss and of hope. The chaplains who listened and prayed with her tried to encourage her to explore the many aspects of her fears and hopes and sought ways to stand beside her in her suffering.

Complicated Terrain

The transition from an emphasis on curative treatment to an emphasis on comfort care is difficult, as this second case study indicates. It involves significant shifts in terms of goals, hopes, and expectations. Yet these are complex emotional and spiritual situations that evolve, not simple cognitive assessments that snap cleanly into place. Time is therefore an important factor as clinicians and family members come to agreement over the efficacy of certain treatments and the goals of care. Not surprisingly, the patient, family, and individuals on the health care team experience this transition in very different time frames. For example, nurses may be alert to certain prognostic indications before physicians; physicians may feel that they have clearly communicated the medical issues and recommendations to a family; but a patient and family member may be unable to internalize and accept those statements.

Ideally, patients, families and the health care team would have unlimited time to discuss the relevant issues and work through their concerns. This does occur, as the first

case study indicates. Yet it is also true that many medically futile situations end with the patient's death and a high degree of discord among family members and/or clinicians, as the second case study attests.

Conflict and the Chaplain's Role

In addition to hearing the concerns of patients and families, chaplains also listen to the observations, sorrows and discouragements, and joys of the hospital staff. Indeed chaplains are called to support the spiritual and emotional needs of *all* individuals in the hospital. The difficult situations encountered in the hospital both challenge and affirm the staff's professional values and life assumptions.

In a situation such as the second case study, it is possible for a chaplain to respect the spiritual and emotional needs of individuals who disagree. Indeed, a chaplain may be uniquely positioned to serve as a liaison among these dissenting persons. This is not to say that chaplains are professional arbiters, that they should be called in only in times of conflict, or that their primary utility is as a source of "insider" information. Quite the contrary: Because their job is to support the spiritual and emotional needs of people in the hospital, chaplains can honor and represent the concerns of one involved party (for example, the family) to another (clinicians, or other family members).

When the chaplain serves as a liaison among concerned individuals, she can preserve confidentiality while communicating general issues of concern to relevant parties. In some cases chaplains can represent these concerns in a way that places the responsibility for decision-making and agreement within the larger context of the individual's expressed faith tradition or orientation. This is an important point, for while a chaplain can support and communicate the needs of distressed individuals, it is *never*

her job to arrive at a judgment. Instead, chaplains attempt to facilitate communication and, if possible, reconciliation; but all decisions about treatment and relationships must ultimately come from the family members or the care team themselves. If reconciliation is impossible and a death occurs, chaplains have the important duty of aiding individuals in their suffering, struggles and grief.

Hope

When medical intervention is deemed futile it is often associated with the loss of hope. However, both futility and hope are terms that are necessarily defined by their contexts.¹³⁵ When chaplains ask patients what they are hoping or praying for, the responses are varied and nuanced. While many patients are hoping to get better, their prayers are also that they find the courage to get through whatever lies ahead, that they know the companionship of God, or that their families be sustained through illness and loss. Their hope is seldom only about medical outcomes, but encompasses relational and spiritual values and goals. Given the multi-dimensional range of hope, communications about medical futility and hope must be precise and appropriate to a shared understanding of the goals. For instance, a particular medical intervention may be futile in terms of providing a cure or returning function, but it may not be futile in terms of sustaining a life long enough for loved ones to gather and say their goodbyes, as indicated in the first case study. Similarly, when a medical intervention is no longer effective toward containing a disease process, continued treatment may be futile both relative to medical goals and also to relational goals, as indicated by the second case study.

¹³⁵ For an extended discussion of the relationship between hope and futility, see Jennifer Beste's essay, "Promoting Authentic Hope," in this volume.

As death approaches, spirituality and the transcendent nature of that which is sacred also become important components of many people's expressions of hope. Such hope may be expressed as belief in an afterlife, but it is also often expressed by prayers on behalf of family and community, or sentiments of deep gratitude for the life that a person has led.

Conclusion

Medical futility is not a "one size fits all" situation. Each situation is unique and difficult in its own way. Further, each human has a distinct bodily, emotional, and spiritual history that affects her experience of a serious illness. These values exist independent of the health or illness of a person, but they often come to the fore in important ways when the question of death looms on the horizon. Frequently, these values are played out not just with doctors and nurses, but with family members, friends, and even within oneself.

As a hospital employee, the chaplain is part of the care team who interacts with physicians and nurses and has access to medical records. But as a minister or representative of a faith tradition, she is also a spiritual resource for patients and staff. Because of this dual identity, the chaplain is often engaged as a neutral, or "transitional," person with whom patients and families can explore concerns about new and unfamiliar medical, emotional, or spiritual territory. In this way, chaplains can offer an important component of care for patients, families and the healthcare team. This becomes particularly relevant in cases of medical futility, for ultimately the chaplain seeks to affirm who the patient was in the past, is in the present, and will be in her uncertain future.

IV. Perspectives

Promoting Authentic Hope

Jennifer Beste

This essay explores how dominant assumptions about hope in American culture often exacerbate the practice of pursuing medically futile treatments. By way of introduction, I will briefly examine the meaning of hope and its significance for people confronting a life-threatening illness. The Webster Dictionary defines hope as follows:

Hope *n* **1:** Trust, reliance **2a:** desire accompanied by expectation of or belief in fulfillment **b:** someone or something on which hopes are centered **c:** something hoped for.¹³⁶

Quite distinct meanings emerge from these two definitions. The latter definition – construing hope as a particular object or outcome – is perhaps most familiar. Consider 13th century philosopher and theologian Thomas Aquinas’ formulation of this meaning of hope:

What we hope for has four distinguishing characteristics: it is good (not bad, like what we fear), future (not present, like what we take pleasure in), challenging and hard to achieve (for hope is an aggressive emotion, not simply an affection for future good, like desire), nevertheless able to be achieved (not unachievable, like what we despair of)... So hope is movement of our appetite towards what we perceive as a good [that is] difficult, but possible, to achieve in the future.¹³⁷

In this essay, I wish to explore in greater depth what hope might mean for patients if it is construed more broadly, as an overall sense of trust or reliance. Some have

¹³⁶ Webster’s Seventh New Collegiate Dictionary. Springfield: G&C Merriam Company, 1967.

¹³⁷ Thomas Aquinas, *Summa Theologiae*, Volume II.q.40.a.1.

described this meaning of hope as “an awareness and inner confidence that there is a way through one’s difficulty,” the feeling “that we as human persons can somehow handle and manage internal and external reality, and that there are solutions.”¹³⁸ Several researchers interviewing palliative care patients found that hope was described as “an inner power, that can enrich the lives and enable individuals to look beyond their current pain, suffering, and turmoil.”¹³⁹

Why Is Hope So Important?

According to contemporary medical literature, hope provides several important benefits to patients. The first, and most debatable, claim is that hope offers direct therapeutic benefits for patients. These therapeutic benefits may resemble placebo effects for patients and may facilitate recovery. Second, there is widespread consensus that hope enhances one’s overall coping process when confronting the uncertainty of a future marked with a life-threatening illness. Hopeful patients report less anxiety and depression, and are more motivated to pursue and attain goals. On a related note, care providers report that hopeful patients are more compliant with treatment regimens and recommendations. Finally, researchers have found that hope enhances one’s quality of life, enabling persons who are even in the terminal stages of their illness to live life as fully as possible.¹⁴⁰

While the significance of hope for patients experiencing life-threatening illness may appear to be self-evident, the literature is less clear as to what hope exactly means,

¹³⁸Gabriel Marcel, *Homo Viator* (Chicago: Henry Regnery Company, 1951), 34.; William Lynch, *Images of Hope*, (Notre Dame, IN: Notre Dame University Press, 1965), 32.

¹³⁹ Kaye Herth and John Cutcliffe, “The Concept of Hope in Nursing 3: Hope and Palliative Care Nursing.” *British Journal of Nursing*, Vol. 11 (14) 2002, 977-983.

¹⁴⁰K. Wilkinson, “The Concept of Hope in Life-Threatening Illness.” *Professional Nursing*. 11(10) 1996: 659-61.

what form it takes, and how care providers can best promote authentic hope for their patients. During an eighteen-month clinical ethics internship on a bone marrow transplant unit at a university hospital several years ago, I observed how certain assumptions about hope actually fueled the pursuit of medically futile treatments and resulted in greater despair for patients who did not respond positively to treatment. My conclusions are based on observations and discussions with patients and their doctors and nurses, as well as other research findings from contemporary medical literature.

The Mentality of Instilling Hope

I first met Susan during daily clinical rounds when she was thirty days post-transplantation in the bone marrow unit. What struck me most vividly then and during the following weeks was how bright-eyed, cheerful, and upbeat she always seemed. She had just been through one of the most aggressive medical treatments possible, was besieged with distressing side effects,¹⁴¹ yet she always greeted the medical team with a smile. As Susan's symptoms of serious graft versus host complications increased over the next few weeks, her medical team grew more concerned as they spoke in the hall outside her room. Certain nurses even confided to me that they had never seen someone survive a transplant with her particular degree of graft-versus-host symptoms. Interestingly, despite having little expectation for Susan's survival, one nurse specifically referred to herself as Susan's cheerleader and said she would not abandon the practice of offering Susan hope. Other nurses and physicians shared the same mindset. Entering her room each morning, I noticed that they all consistently exhibited an upbeat, positive

¹⁴¹ These side effects included severe physical pain, physical exhaustion, nausea, diarrhea, constipation, insomnia, graft versus host disease, organ failure, and the possibility of death.

attitude about how she was doing and did not mention their concerns. Susan continued to display cheer and positivity, and her care providers habitually praised her fighting spirit. Patients who had fighting spirits, they used to tell her, were those who survived. One simply “couldn’t walk out of here” without such spirit and hope.

I was profoundly struck by the emphasis that care providers placed on a positive attitude and hope, particularly given my privileged information about their own concerns about her prognosis. Could a patient’s attitude really influence medical recovery and survival? If so, to what degree, and under what conditions, was this possible?

I was away from the hospital for three weeks. When I resumed clinical rounds, I learned that Susan had developed pneumonia before Christmas and was eventually placed on a ventilator. She died several days later, while I was still away. One of the nurses mentioned that Susan had been withdrawn and anxious even prior to contracting pneumonia. Two of her nurses expressed anger that Susan had been treated for so long and not been given the chance to go home since no one else had survived her series of complications.

As the weeks went on, however, I observed (with some amazement) that the fact of Susan’s death – in spite of her courageous hope and fighting spirit – neither altered nor challenged the discourse of hope that pervaded the bone marrow transplant unit. Care providers continued to focus tremendous energy on positive encouragement and optimistic forecasts. Incredibly, they still hid their doubts about recovery as they exhorted patients who were experiencing serious post-transplantation complications about the necessity of hope for recovery.

In what follows, I will draw on this case and similar experiences to analyze three dominant assumptions of hope that influenced communication between care providers and patients about patients' medical condition and prognosis. I will also argue that dominant beliefs about hope in contemporary oncology often function to fuel and perpetuate the problem of medical futility in American oncology practice. This failure to discuss patients' decreasing chances for survival and the prospect that aggressive treatment has become medically futile is ethically problematic because it denies patients the right to self-determination – informed choice about whether to continue aggressive treatment or reassess their options. Lastly, in order to increase respect for patient autonomy with terminally ill patients, I offer a revised understanding of hope that promises resistance to entrenched practices of those physicians who continue medically futile treatments and patients who desperately pursue them.

As demonstrated by the interactions between Susan and her care providers, the first prevalent assumption operating on the unit was the belief that a patient's hope and overall psychological state greatly influence his or her physical recovery and survival. Consider, for example, statements of two nurses on the unit:

Nurse P: The attitude they bring affects how they get through it, their disease process, whether they engraft. I don't know if that's directly related, but the way they handle it is different. We're like pieces of driftwood in a flood and these are drowning people and they grab onto this piece of driftwood called a bone marrow transplant and some make it to shore and some don't...[Hope] makes them kick harder to shore, if you want to keep with that analogy.....

Nurse C: I think a patient knows that they're going to make it. A patient has to have that feeling. We have several new patients who came here last week [who] have a very poor prognosis. They begged the attending physicians to do the transplant, to give them time with their small children. They are very pitiful people; they're very scared. Their day never goes right. They have this pending doom when you walk in the room. It's very uncomfortable taking care of them because they're always down. Patients

that come in with the attitude that they're going to make it, they usually make it. They're going to do whatever it takes to make it. They're going to make it no matter what. *99% of recovery is attitude.* ...I guess my whole belief is that the mind is very strong. The mind causes illness. I usually ask patients, "Did something happen a year to six months before you were diagnosed? Some say "No," some say "Yes," but after I meet them the second or third time they often say, "You know, I've been thinking about that and you might be right." It's usually a death of a loved one, a divorce, a bankruptcy. It's something they cannot fix, something they can't get over because they have no control over it, and they get sick from it. So, if that can make you sick, then why can't attitude make you well? Because mind over body – it's very true. If you have the flu or pneumonia or any kind of virus, it was probably a very stressful time. It suppresses your immune system, just from worrying. If you come in here knowing that you're going to do well, doesn't the body fight more? If it fights less when you worry, can it not fight more if you're happy?

The belief that a person's will and attitude can positively or negatively influence recovery was not, I discovered, confined to this particular bone marrow transplant unit. This attitude is frequently expressed in contemporary oncology and sociological literature as well. Sociologist Mary Jo Good observes that American oncology, relying upon cultural meanings of hope, is grounded in popular American notions regarding the relationship between mind and body, and the belief that an individual's will can change the course of one's disease and facilitate physical recovery.¹⁴² The popularity of Norman Cousins' books *Anatomy of an Illness* and *Head First: The Biology of Hope*, which profess the power of the will and human spirit to overcome physical disease, testifies to the American public's fascination with the idea that hope gives some degree of control over one's physical illness.¹⁴³

Given this mindset that hope and a positive attitude influence one's ability to recover from cancer, care providers assume that *they* are responsible for instilling hope

¹⁴² M.J. D. Good, B. J. Good, C. Schaffer, & S. Lind, "American Oncology and the Discourse on Hope." *Culture, Medicine, and Psychiatry* 1990; 14: 61.

¹⁴³ Interestingly, there is a glaring lack of substantive evidence that hope actually does influence survival.

into their patients; hope, then, is something a care provider can give a patient.¹⁴⁴ One physician expresses this sentiment in the following way: “I think just by offering therapy... [we are] offering hope.” Another states: “They come here to buy hope.”¹⁴⁵

Corroborating this in her 1993 study, Naoko Miyaji found that most U.S. physicians think that whether a patient loses hope or not is the physician’s responsibility – “a lonely burden to bear.” Mary Jo Good similarly found that physicians intentionally view themselves as giving hope to their patients in stages throughout the course of a life-threatening illness:

As with disclosure, hope is staged, given in calibrated, achievable and realistic bits...information is tailored to the clinical task, to maintaining the hierarchy of the physician-patient partnership, to the efficacy of biomedical treatments, and to the goal of instilling hope.¹⁴⁶

This responsibility to be the dispensers of hope leads to a third central conviction concerning hope: care providers often perceive that, when a patient’s medical condition and prognosis worsens, the duty to instill hope can conflict with the duty to respect patient autonomy and tell the patient the truth. In such cases, they often argue that the duty to instill hope trumps the duty to be completely truthful. In one study, Miyaji found that 50% of the doctors interviewed reported that, if medical information is perceived to threaten hope, they would continue either to withhold or “soften” the information.¹⁴⁷

¹⁴⁴ See N. Miyaji, “The Power of Compassion: Truth-Telling Among American Doctors in the Care of Dying Patients.” *Social Science and Medicine* 1993; 36: 249–264; E. Gordon & C. Daugherty, “‘Hitting You Over the Head’: Oncologists’ Disclosure of Prognosis to Advanced Cancer Patients.” *Bioethics* 2003; 17: 142–168; N. Christakis, *Death Foretold: Prophecy and Prognosis in Medical Care*. Chicago, IL. University of Chicago Press, 1999; M.J. D. Good, B. J. Good, C. Schaffer, & S. Lind, “American Oncology and the Discourse on Hope.” *Culture, Medicine, and Psychiatry* 1990; 14: 59-79; E. Kodish & S. Post, “Oncology and Hope.” *Journal of Clinical Oncology* 1995; 13: 1817–1822.

¹⁴⁵ Christakis 1999, 160.

¹⁴⁶ Good, 72-75.

¹⁴⁷ Miyaji, 255.

Why do physicians perceive such a conflict? The difficulty arises reasonably from their basic assumption – a premise that may unfortunately be flawed – that hope and a positive attitude give a patient the best chance for the best possible outcome. If bad news threatens hope, causes fear, anxiety, and/or depression, would blatant truth about a prognosis not destroy a patient’s hope and compromise chances for recovery? Bruhn most dramatically expresses the fear of truth compromising recovery:

To withdraw or reassess hope can have grave consequences for the patient.... *Hope turned sour can hasten death.* Most patients expect the caregiver to remain hopeful, even if they are not. Therefore, if the caregiver expresses a loss of hope, this can contribute to despair that the patient may already feel.¹⁴⁸

Consistent with this mindset, physicians frequently use violent imagery when describing what it is like to tell patients bad news or a worsening prognosis. Gordon, for example, notes the following statements from physicians:

I don’t want to *hit someone in the face* with it.

Sometimes to out and out *force it down their throat* is really gonna undermine the physician-patient relationship.

It’s probably not the best strategy to just *hammer them* with it.

...You do your best to sort of give an opinion, but you can’t *beat people over the head* with that.¹⁴⁹

¹⁴⁸ John Bruhn, “Therapeutic Value of Hope,” *Southern Medical Journal*, 1994, 217, emphasis mine.

¹⁴⁹ Gordon, 155.

Christakis' commentary on physicians' violent metaphors is telling, for it highlights the underlying belief that truth-telling harms patients on some level.

The militaristic expressions used by physicians – such as “hitting,” “dumping,” “hammering,” “bludgeoning,” “crushing,” “battering,” “bombing,” and even “oppressing,” “imposing,” or “dooming” – capture physicians' belief that communicating prognoses in this way may be injurious to patients' composure and optimism.¹⁵⁰

For reasons that include the desire not to harm patients or compromise recovery, many oncologists and other physicians tend to avoid discussing prognostic information altogether. In his work *Death Foretold*, physician and sociologist Nicholas Christakis documents the widespread phenomenon of physicians' reservations in this regard:

Physicians avoided prognostication, both consciously and subconsciously, because they did not want to deal with its unpleasant aspects or to think about the limits of their ability to change the future. But they also avoided it because they wanted to deceive themselves about death, as if in not predicting death they could avoid causing it or witnessing it.¹⁵¹

Overall, he discovered that physicians (somewhat superstitiously) believe that giving patients bad news about prognosis will thwart positive medical outcomes through some kind of self-fulfilling prophecy.¹⁵² Other research, which confirms this trend to avoid prognostication, associates this practice in part with the desire to preserve hope.¹⁵³

Despite their tendency to avoid prognostication, there are situations in which most physicians are more likely to share prognostic information: when patients ask specific questions about prognosis and repeatedly demand answers, when therapy is clearly

¹⁵⁰ Christakis, 110. v b

¹⁵¹ xii.

¹⁵² Christakis, 110.

¹⁵³ See footnote 4 (above) for references.

failing, or when patients have extremely unrealistic expectations, etc.¹⁵⁴ In these cases, Christakis and other researchers find that most physicians develop a “ritualistically” optimistic attitude when speaking about the future, and at times offer false hope to patients. For instance, one physician expresses optimism by qualifying statistics:

Many times they actually come to me already knowing what the median survival of the disease is. And I always try to temper that with, “Again, that’s lumping everyone together. That’s not necessarily you.” And I always try to say, “You know, you have a better chance than that.” Although in reality, many patients have a worse chance than that.¹⁵⁵

Physicians also report that they allow patients’ needs and their own expectations about recovery to guide how they present the prognosis.¹⁵⁶ Two oncologists whom I interviewed expressed the following:

Dr. F: It all depends on how you in a sense sell the disease, [or] paint the picture, and I think physicians, myself included, are often guilty of providing false hope for people. But it’s a fine line to walk, as far as trying to be realistic. You don’t want to [always] hammer home...the facts of the illness—that you aren’t going to live long. . . . False hope is something that physicians are often either not aware of [giving] or won’t admit to... I think it’s in part that you really want the patients to do well and you want them to live long.

In response to a question about what one should say to a patient who is not doing well:

Dr. X: It depends on how it’s going to influence them. You try to tell people what’s going on... You have to be appropriate. Someone said, “When do you tell people something?” and the best response is, “When they ask the questions.” When they are willing to verbalize the question, it means they’re more likely to be responsible. If they’re not verbalizing it, they might not be ready to hear the answer... You try to understand what the patients want to hear and what their needs are.

[You have to discuss] what’s required, but again the patient has to understand. Ultimately, you’re responsible for giving accurate and timely information. How you do that depends on the patient’s situation: intellect, emotional stability, understanding, physical well-being.

¹⁵⁴ Christakis.

¹⁵⁵ Christakis, 111.

¹⁵⁶ Miyaji

Researchers find that, in order to preserve hope, physicians also use ambiguous language, emphasize the uncertainty in any prognosis, and disclose information in stages.¹⁵⁷ In her research, Good finds that, during conversations about diagnosis and prognosis, physicians deliberately blur horizons of what the future holds. From the beginning, physicians attempt to manage the time horizons for their patients by delaying information about prognosis in favor of sharing information about possible cancer therapies. Clearly, their strategy for providing hope entails avoiding the topic of uncertain ends, for example, the possibility of dying. Good notes that, when patients do bring up questions about the future, intimating that they want to know about their chances, oncologists frequently side-step the issue and return to treatment options.¹⁵⁸

Thus, it is clear that in some cases physicians offer overly optimistic prognoses, or avoid prognostic information altogether, in order to instill hope. Given this practice, it is not surprising that care providers often continue aggressive therapies even when they suspect the therapies have become medically futile, for it is difficult to broach the possibility of medical futility if no prior context is established for open communication about a realistic range of future possibilities. In one study of over 1,400 physicians and nurses in five different hospitals, 50% of the nurses and almost 75% of physicians reported that they had acted “against their conscience” in pursuing aggressive treatments on terminally ill patients.¹⁵⁹

What are the consequences of offering overly optimistic prognoses or avoiding the issue of prognosis altogether? While there are many negative effects, both individually and societally, of continuing medically futile therapies without an honest

¹⁵⁷ Christakis, xvii.

¹⁵⁸ Good, M, “Cultural Studies of Biomedicine: An Agenda for Research,” *Social Science and Medicine* 41 (1995): 858.

¹⁵⁹ [[citation forthcoming]] See 176, footnote 1.

appraisal of outcomes, I will focus on the negative consequences for patients. During my time on the bone marrow transplant unit, I began to see a pattern for those patients who did not survive their transplants. I noted that physicians did not discuss how the patients' debilitating medical condition worsened their prognosis and their chances for survival. As a result, care providers continued treatments that were no longer benefiting the patients, and patients died in isolation on the unit, often without having the chance to put their affairs in order, attain closure with family members, and resolve religious or spiritual issues. Withholding adverse prognostic information thus robbed patients of the opportunity to make an informed choice about whether to continue aggressive therapy or choose palliative care and possibly return home. I also observed that silence about patients' changing medical condition and pressure on them to remain cheerful and optimistic – even through increasing suffering and deterioration – often led to a greater sense of hopelessness and despair for patients.¹⁶⁰ From his own research and experience as a physician, Christakis also argues that offering patients optimistic (but unrealistic) prognoses or none at all harms many patients:

As a result of a failure to prognosticate, let alone prognosticate accurately, patients may die deaths they deplore in locations they despise. They may seek noxious chemotherapy rather than good palliative care, enroll in clinical trials of experimental therapy that offer more benefit to researchers than to themselves, or reassure loved ones that it is not yet time to pay a visit—only to lapse into a coma before having a chance to say good-bye. ... Cogent and compassionate prognostication, I believe, could decrease the prevalence of bad deaths in our society.¹⁶¹

¹⁶⁰ For more description about how the mentality of instilling hope can create despair, please see my article, "Instilling Hope and Respecting Patient Autonomy: Reconciling Apparently Conflicting Duties," *Bioethics*, forthcoming.

¹⁶¹ Christakis, xiv-xv.

How precisely does this mentality of instilling hope by withholding news of a worsening medical condition result in greater suffering and “bad deaths”? From my observations on the bone marrow transplant unit, I can suggest several reasons. First, there is a lack of consensus on the meaning of “hope.” It is important to understand what care providers and patients meant by the word hope. From the very beginning of patients’ diagnosis of cancer, the meaning of hope for patient and care providers was narrowed to hope-for-recovery. When recovery from the transplant no longer became likely, both care providers and patients were faced with despair.

Second, care providers’ failure to acknowledge a patient’s worsening medical condition – or outright denial of it – did not preserve hope: instead, patients experienced decreased trust towards their care providers and greater alienation and anxiety. The message that patients must remain cheerful and optimistic also placed unfair pressure on patients and discouraged them from expressing the full range of emotions and thoughts they were experiencing.

Third, withholding information about worsening prognoses denied patients any semblance of what little control they could still exercise over their lives. They were deprived of the chance to reassess their options and possibly choose palliative care, which – with its focus on alleviating suffering – would have offered perhaps a more humane, meaningful dying process for patients and their families.¹⁶²

¹⁶² Contrary to many physicians’ expectations, research studies have shown that information about patients’ medical conditions increases patients’ hopefulness because it gives them some sense of control over their lives. See J. Peteet, et.al., “Presenting a Diagnosis of Cancer Patients’ Views.” *Journal of Family Practice* 1991; 577; A. Sardell & S. Trierweiler, “Disclosing the Cancer Diagnosis.” *Cancer* 1993; 3355–3365; and Shelley Taylor, *Positive Illusions* (New York: Basic, 1989).

Re-envisioning a Concept of Hope that Does Not Lapse Into Futility

If I am correct that these three prominent beliefs about hope exacerbate the practice of medical futility, what are we to do? Obviously, an adequate response will not dismiss or caution against patients' need for hope. To preserve hope in contexts of end-of-life situations, we must instead work toward a revised understanding of the concept itself. Drawing on various philosophers and theologians, I argue that *authentic hope*, which is not vulnerable to despair, must have three features: it must be realistic; it cannot be reduced to a specific object of desire; and it is dependent upon interpersonal trust and support.

First, authentic hope, which involves a desire for that which is not yet in our grasp, must nevertheless be realistic. As Thomas Aquinas argues, what one hopes for is difficult to attain, but if it is not ultimately plausible, it is not hope.¹⁶³ Many philosophers and theologians follow suit by emphasizing that authentic hope is limited to what is realistic. For instance, theologian William Lynch vehemently rejects the idea that one's hope can be an object that is impossible to realize. Realistic hope has limits: if a person hopes for the impossible, she or he inevitably ushers in hopelessness and despair since that object of hope cannot be fulfilled. As we have seen, this insight is confirmed by the experiences of many cancer patients, who, with their care providers, often confine their hopes to remission or recovery even when those outcomes are practically impossible. Unfortunately, though, eschewing truth in favor of false hope and continuing medically

¹⁶³ Thomas Aquinas, *Summa Theologiae*, (New York: Benziger Bros., 1948), 1a2ae q.40.1.

futile treatments merely sows seeds of despair and all but guarantees painful disillusionment and greater suffering at the end of life.

Authentic hope is quite distinct from the ritualistic optimism expressed by many physicians when formulating a prognosis. Phenomenologist Gabriel Marcel portrays the optimist as one who has a vague feeling that “things will turn out for the best.” Marcel claims that the optimist “always relies upon an experience which is not drawn from the most intimate part of himself, but, on the contrary, is considered from a sufficient distance to allow certain contradictions to become alternated or fused into a general harmony.”¹⁶⁴ According to Marcel, hope mysteriously involves a relaxation, the taking of one’s time to go through the trial: “I develop in connection with the event, and perhaps above all through what it makes of me.”¹⁶⁵ In Marcel’s view, hope is related to our most intimate selves and our sense of fulfillment. Similarly, Lynch depicts hope as an awareness and inner confidence that there is a way through one’s difficulty, “that we as human persons can somehow handle and manage internal and external reality, and that there are solutions.”¹⁶⁶

In addition to recognizing the limitations of hope, I contend that authentic hope must be distinguished from “what is hoped for;” it cannot be reduced to a specific object of desire, such as the hope for recovery from an illness. To characterize hope as a single object of desire reduces and distorts hope by making it conditional and causing the one who hopes for something to be vulnerable again to a despair when the object of desire is unfulfilled. As Marcel argues, “A particular hope is nothing more than an illusion that

¹⁶⁴ Gabriel Marcel, *Homo Viator* (Chicago: Henry Regnery Company, 1951), 34.

¹⁶⁵ *Ibid.*, 38-40.

¹⁶⁶ William Lynch, *Images of Hope*, (Notre Dame, IN: Notre Dame University Press, 1965), 32.

turns into an expectation, a right that one demands.”¹⁶⁷ Authentic hope, by contrast, which does not give way to despair, concerns the broader horizons of what matters most to persons and gives their lives meaning.

A third and final feature of authentic hope is its dependence upon relationship with oneself and others. As Lynch argues, the assumption that hope is an inner resource that “strong” people possess can be self-destructive: “The sick, who have reached the limit of their interior resources, are often told to hold on to this completely inward kind of romantic hope. Medically or spiritually, it is nonsense and harmful.”¹⁶⁸ Thus, care providers undermine the possibility of authentic hope when they expect the sick to draw solely on their inner resources to maintain a positive attitude. Support from family, friends, and care providers will effectively help patients use their imaginations to envision new possibilities of hope. Fostering trust, empathy, and a sense of partnership is obviously essential for communicating a genuine sense of support. Thus, there *is* a way for care providers to promote authentic hope, but the goals of such hope will not necessarily be tied to attaining a certain medical outcome.

Having outlined three key features to authentic hope, we need to question how – or whether it is even possible – to nurture this conception in contemporary American oncology. Unfortunately, there are significant barriers to appropriating and fostering this more holistic understanding of hope for patients and care providers within the current healthcare culture in the United States. Such barriers actually stem from more entrenched philosophical presuppositions about the overriding objective of medicine. Currently, a dichotomy exists between 1) the dominant objective in healthcare to eradicate disease and

¹⁶⁷ Marcel 1951, 45.

¹⁶⁸ Lynch 1965, 31.

prolong life and 2) the secondary goal of palliative care to attain the best possible quality of life. Under the dominant medical paradigm aimed at curing disease, care providers and patients both tend to view any outcome other than a cure as a personal defeat and failure. With all hope directed towards hope-for-a-cure, they are psychologically and spiritually ill-equipped to cope with any other outcome. As palliative-care specialist Eduardo Bruera states: “Within this health-care culture, palliative care is typically viewed as a second-rate alternative, apologetically presented to patients when no other options are available.”¹⁶⁹ It is no wonder that within this dominant medical paradigm, many terminally ill patients refuse to hear bad news about failing curative therapies and desperately insist on pursuing yet another round of futile, aggressive treatment. Typically, such treatments are accompanied by severe side effects that further physically debilitate patients and exacerbate the suffering and despair at the end of their lives. In efforts to maintain patient hope under almost any conditions, most physicians tend to postpone telling patients that all efficacious curative therapies have been exhausted. The majority of physicians offer palliative care when patients are only a few weeks or days from death, if palliation is offered at all.

Clearly, a revised framework concerning the very objective of healthcare is needed to decrease the needless suffering of terminally ill patients and foster an ethos in which a meaningful dying process is possible. The alternative, I propose, is a radical overhaul of the *status quo* in medicine – unrealistic expectations about the curative potential of modern medicine – a *status quo* that fails its patients and their families precisely as it succeeds in extending the hours of their lives. Instead, the overarching goal of oncology (and health care in general) ought to be ensuring the best possible

¹⁶⁹ Eduardo Bruera, "Organizing Palliative Care," *World Health Organization*, Nov. 21, 2001.

quality of life for the patient as a whole person. Quality-of-life concerns will encompass weighing the side effects of treatments and their impact on a patient's identity, her relations, and her overall sense of well-being. This emphasis on maximizing quality of life, of course, does not mean an abandonment of advanced treatments and research; the goal to cure disease by choosing aggressive curative therapies would simply not be absolutized. Instead, the desire to prolong life would be viewed as one important factor among many impacting the patient's quality of life.

To explore why this is the case, it is helpful to define briefly what is meant by "quality of life." Such a term, which has many evaluative and normative meanings in medical ethics, is generally defined in terms of an individual's overall assessment of her own well-being, of her overall sense of satisfaction with life. An important factor that influences one's sense of well-being is the desire to be able to anticipate a future – to look forward to coming events and envision the fulfillment of particular goals and dreams. For many people, then, the value of trying to prolong life will play a significant role when discerning how to attain a high quality of life. In these cases, the benefits of a curative treatment outweigh resulting burdensome side effects and will represent the best way to maximize their quality of life. However, when aggressive treatments offer extremely low odds for prolonging life and do not provide the patient with reasonable hope for anticipating a promising future, other palliative options that promise greater symptom control may be the best choice for living life as fully as possible in one's time remaining.

Under this rubric, the meaning of hope from the very beginning of diagnosis will be intrinsically related to the overarching goal of maximizing patients' quality of life as they negotiate their way through the quagmire of therapeutic options. This goal will

convey to patients that, although there are limits to medical technology, physicians have enormous capacity to support their patients and help them strive for a high quality of life. If this goal is stated early in the illness process, patients will be better equipped from the very moment of diagnosis to formulate hopes that are not solely contingent upon eradicating their disease. While a patient obviously does hope for this outcome, she also remains aware of broader hopes that give her life meaning. For instance, she may hope to become closer to her children throughout her “trial”; she may hope that she can get through her cancer treatments without experiencing unbearable depression and that her increasing pain can be managed and tolerated. Another patient might hope that that he can die believing that his life has had significance and has positively affected others. For a patient who has an explicitly religious understanding of life’s meaning, hope may include being reunited with a Divine Being. Thus, there are innumerable hopes that are broader than hope-for-a-cure that can offer meaning during times of trial.

Situating hope within this larger narrative of quality of life may well make terminally ill patients less vulnerable to crushing disappointment and hopelessness. Ultimately, this understanding of hope may enable patients to experience an end-of-life that reflects their personal identities and makes the very most of their last days of life.

The Law and Medical Futility

Stephen R. Latham

This section is currently being revised.

Financial Aspects of Futility: Global versus Individual Issues
Attilio V. Granata

A 26-month-old girl, momentarily left unattended in her bathtub at home, was found lying submerged and unresponsive by her babysitter. She was immediately taken out of the tub and given CPR, and when paramedics arrived the child was found to be pulseless, cyanotic, and without spontaneous breathing. She was in ventricular fibrillation, and was defibrillated into a normal and stable sinus rhythm after appropriate medications and electrical countershock. Her blood pressure was 90/60, and her cyanosis resolved. She still had no spontaneous respiratory efforts and remained unresponsive.

On arrival at the hospital, the child was placed on a ventilator and transferred to the pediatric intensive care unit. Her neurologic exam revealed findings consistent with diffuse cerebral anoxia, which did not improve over several days of observation. Laboratory tests revealed no evidence of metabolic, infectious, or toxic causes for her unresponsiveness. Over the next several days, two different pediatric neurologists confirmed the impression of brain death.

The child's parents, extended family, and members of her church group reject your explanation that the child is dead. They explain that in their faith, irreversible cessation of heart and lung function defines death. Since the patient has a spontaneous heartbeat, she is clearly not dead even if a machine is required to support her breathing. While they understand that the child is critically ill, the family insists she should be given every opportunity to recover, for as long as required.

Is it futile to continue providing "heroic" supportive measures for this patient?

How might one reconcile apparent differences in the perceived degree of futility from the points of view of the treating physician, the patient or surrogate unit, and the payor?

What role, if any, should futility play in decisions to finance health care, individually and collectively?

As ethicists, policy planners, and clinicians continue to discuss the quality, accessibility, and cost of health care in the U.S. system, they must constantly remain aware of the important distinctions between absolute futility and other, less precise, uses of the term.¹⁷⁰ Absolute or “physiologic” futility is characterized by any situation in which the likelihood of a beneficial, desired clinical outcome is exactly zero.¹⁷¹ For example, in an extended care facility during morning nursing rounds, an elderly patient was found unresponsive, pulseless, and cyanotic. Nursing staff had last seen her about 8 hours ago, just prior to her bedtime; currently the patient’s body is already in an early state of rigor mortis. In light of these facts, any attempt at resuscitation will be futile in the term’s most precise sense – the patient is dead beyond any doubt, and such a patient (who has not experienced hypothermia or drug toxicity) cannot be resuscitated. That type of situation is quite straightforward.

The much more commonly used interpretation of futility, “probabilistic futility,”¹⁷² is more subjective. In probabilistic futility, the probability of clinical amelioration is very small but greater than zero. The essence of the issue is whether it may or may not be “worth” attempting treatment. For example, a 73 year old male patient with end-stage congestive heart failure due to multiple myocardial infarctions is alert, but he requires a ventilator and an intra-aortic balloon pump with multiple vasoactive medications. He is not a cardiac transplant candidate and has had ventricular tachycardia or fibrillation five times in the past three days, with successful defibrillation from each occurrence. He and his wife will celebrate their 50th wedding anniversary in 11 days.

¹⁷⁰ Zawacki BE. The “futility debate” and the management of Gordian knots. *Journal of Clinical Ethics* 6(2):112-27, 1995.

¹⁷¹ Jonsen AR, Siegler M, Winslade WJ. *Clinical ethics: a practical approach to ethical decisions in clinical medicine* (5th edition). New York: McGraw-Hill, 2002.

¹⁷² *Ibid.*

Each wants to share that day with the other, if at all possible. “A physician’s judgment that further treatment would be probabilistically futile does not justify a conclusion that treatment should cease; instead, it signals that discussions of the situation with patient and family are mandatory.”¹⁷³

The wide range of levels of probabilistic futility provides a basis for better understanding the interactions between futility and health care financing. We will consider these relationships at two levels – first for the entire population and second for the individual patient.

Financial Decisions for Individual Patients

The principal health care payors in the United States include the federal and state governments (for government employees and for recipients of Medicare and Medicaid), and private employers (for those with private health insurance, either via insurance companies or self-insurance by the employer itself). Providing health care services collectively as well as responsibly for a large population requires some understanding of the global resources one can allocate to such services, as well as clinical and economic evidence of the value of potential services to be covered.^{174, 175} In choosing among clinical interventions, two factors must be considered – the probability of a successful outcome, and the value, or utility, of that outcome to the patient. The product of these results in an “expected value” for the decision-maker; such concepts are used commonly in the field of clinical decision analysis.

¹⁷³ Ibid.

¹⁷⁴ Escalante CP, Martin CG, Elting LS, Rubenstein EB. Medical futility and appropriate medical care in patients whose death is thought to be imminent. *Supportive Care in Cancer* 5:274-80, 1997.

¹⁷⁵ Granata A, Hillman A. Competing practice guidelines: using cost-effectiveness analysis to make optimal decisions. *Annals of Internal Medicine* 1998;128:56-63.

The cost-effectiveness of a specific health care service is its “value” – the dollars paid for the service per additional amount of “extra health produced.”¹⁷⁶ Since health consists of both quality and length of life, health economists and clinical epidemiologists have developed measurement scales such as “dollars per year of life added,” or “dollars per quality-adjusted year of life added” to assess the value of existing and competing clinical technologies. In the latter type of assessment, one attempts to estimate a more accurate measure of cost-effectiveness, known as cost-utility, by assessing both additional length of life, and the quality of that life as assessed by the patients themselves. Thus, an additional 10 years of life, the quality of which is rated at 5 on a scale of 10, will be defined as 5 quality-adjusted life years (QALYs).

Schneiderman, Jecker and Jonson discuss the importance of considering the probability of an outcome apart from its utility (quality of life).¹⁷⁷ Either a low probability or a utility value below a certain threshold may justifiably lead to withholding therapy based on the notion of futility. A very unlikely outcome of high quality of life, or a likely outcome of poor quality of life, may lead one to forego therapy. However, the mere incorporation of utility (quality of life) into the formula demands that the patient or surrogate become involved in the decision: “[P]hysicians may recommend termination of the intervention on the grounds of probabilistic futility, but they lack the ethical authority to define the benefit as such.”¹⁷⁸ Such authority resides in the autonomy of the patient or

¹⁷⁶ Granata A. Risk alignment in health care quality and financing: optimizing value. *Physician Executive (American College of Physician Executives)* 1998;24(1):22-25.

¹⁷⁷ Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. *Annals of Internal Medicine* 122:949-54, 1990.

¹⁷⁸ Jonsen AR, Siegler M, Winslade WJ. *Clinical ethics: a practical approach to ethical decisions in clinical medicine* (5th edition). New York: McGraw-Hill, 2002.

surrogate decision-maker, who alone can assess the potential impact of an outcome upon quality of life.¹⁷⁹

Quality of life decisions should reside primarily at the bedside, and have little role in global policy planning. While countless authors have assessed the “cost-utility” of various clinical interventions, such exercises are useful only as general guides towards assessing the comparative values of differing clinical services. No author would argue that their cost-utility analysis, insulated from all other clinical data, should be used to make the decision for a given patient without first understanding the patient’s own expectations, fears, and goals.

Population-Based Financial Decisions

How do payors decide what to cover for their patients? Ideally, health insurance companies, medical specialty societies, and technology assessment organizations should use well-defined analytic methods¹⁸⁰ to review the medical literature, and then regularly assess the merits of new technologies and interventions. The goal is to decide to cover a new technology or intervention based on:

- Evidence-based documentation of the benefits and risks of the intervention, from the published peer-reviewed medical literature
- Assessment of whether the intervention presents an overall net benefit - do benefits outweigh the risks?

¹⁷⁹ McCrary SV, Swanson JW, Youngner SJ, Perkins HS, Winslade WJ. Physicians’ quantitative assessments of medical futility. *Journal of Clinical Ethics* 5(2):100-105, 1994.

¹⁸⁰ Eddy DM. *A Manual for Assessing Health Practices and Designing Practice Policies: The Explicit Approach*. Philadelphia: American College of Physicians; 1992.

- If there is a net benefit, how does this intervention compare with existing treatments already available for the same kind of condition? Specifically, how do the net benefits and net costs compare?

Health policy decisions for a population, therefore, should not involve inferences about the quality of life resulting from covered interventions. Instead, one should expect that clinical coverage policies of health care payors permit coverage of most or all of the services that may have some benefit, and exclude from coverage those not proven to have any benefit. Interventions in which the probability of any type of beneficial medical outcome is exactly zero should not be offered for coverage; those in which there is potential for benefit should be offered to the extent that resources are available. It would be the responsibility of the individual patient and physician to select the most appropriate intervention from those offered. In this setting at the bedside, and in this setting alone, one may and should take into account quality of life issues, and therefore elements of probabilistic futility.

In real life, evidence suggests that this is often the case. For an individual patient, appropriate discussion of options that might lead to a decision of probabilistic futility would usually exclude from consideration a variety of treatments that are indeed generally covered by the payor. Such interventions might include artificial ventilation, chemotherapy, surgery, and even organ transplantation. Any decisions by the payor not to cover such common services usually result from data showing no benefit in a particular group defined by specific, evidence-based clinical criteria.

However, the question always remains as to whether an intervention is actually of no benefit, or whether the data is so limited that it cannot account for progress in further

knowledge of the treatment's efficacy.¹⁸¹ For example, in the early 20th century, certain types of childhood leukemia were considered absolutely incurable – there was nothing to do but provide comfort and relieve pain. The advent of chemotherapy, radiation, and bone marrow transplantation has now rendered many of these malignancies not only treatable but often curable. Thanks to technological advancements, attempts to treat such diseases have progressed from the physiologically futile, to the probabilistically futile, and now to the current standard of care. Thus it is worthwhile to consider allowing some degree of coverage for interventions showing promise and verifiable benefit.

Even as policy planners attempt to provide as many beneficial treatment options as possible to a population, global budget constraints will require some degree of planning and rationing.¹⁸² It was only when a child in Oregon died after being unable to get funding for an expensive but potentially life-saving cancer treatment that the issue of clinical benefit and effectiveness – as well as cost – became of paramount importance in designing health care benefits for large populations. Oregon then reorganized its health payment rules by listing the priority of covered services in descending order by cost-effectiveness, which would be covered as far down the list as a given year's budget would allow. The people of Oregon decided that an expensive treatment should merit consideration for coverage as long as it had potential to treat or reverse a life-threatening disease for which there was no other treatment. No longer was an expensive but worthwhile treatment considered probabilistically futile, i.e., not “worthy” of coverage.

With regard to futility at the population-wide level, the major instrument used by health payors is formulation of clinical coverage policies. This employs a variant of the

¹⁸¹ Rubenfeld GD, Crawford SW. Withdrawing life support from mechanically ventilated recipients of bone marrow transplants: a case for evidence-based guidelines. *Annals of Internal Medicine* 125:625-33, 1996.

¹⁸² Kissick WL. *Medicine's dilemmas: infinite needs versus finite resources*. New Haven: Yale University Press, 1994.

“physiologic futility” rule, often referred to by a term such as “not medically necessary.” Almost always, such rules simply serve to carve out those technologies, interventions, drugs, and other services that the evidence-based literature shows to provide no benefit to certain patients. The problem is that such services are then eliminated from the entire covered population. When some subgroups of patients but not others could benefit from a specific intervention, payors develop criteria-based coverage policies, again using the evidence-based literature to assure that such services go to where they will provide the most benefit. Investigational and experimental technologies, which have yet to be of proven benefit (the probability of a beneficial outcome is unknown), are usually not covered until accepted by licensing or regulatory agencies and/or the specialty that will be using them. Lately, some state legislatures have required that insurance companies cover some patients in experimental studies, especially if their illness is life-threatening and they have exhausted all other treatment modalities.

One problem resulting from the application of a strict physiologic futility definition (i.e. treatment of zero value) to populations is that much policy-setting is homegrown at each insurance company, tediously detailed, and often redundant. Except for Medicare there is no national mandate for what must be covered, or how, in any basic insurance package for each patient. A given company’s policy seeks to address futility primarily by refusing to cover interventions felt by the company to be totally ineffective (or purely cosmetic), while covering a larger selection of treatments of proven benefits. However, not all of the coverage choices made are based on good science. Companies need to keep track of politically sensitive issues that might have been legislated into coverage, or of a recent single, noteworthy care denial whose appeal is now saturating the media and placing the company’s stock price at risk. Because many large health insurers

are publicly held for-profit companies, their first duty must, of economic necessity, be to their shareholders. Their duty to patients and members is secondary.

The existence of a wide range of policy coverage guidelines in a society in which there is no universally defined health insurance benefit for all citizens means that too much money is probably being applied to administration and profit, with too little going directly toward care. Most insurance companies are privately owned, for-profit institutions, so that a very significant amount of money is withheld from actual patient costs and care. Such lack of foresight for society as a whole is problematic, especially when coupled with financial incentives that often tempt physicians to think beyond the welfare of their patients. It is therefore important to note that a critical element for the proper functioning of an evidence-based, outcomes-oriented health care system is *trust* between patient and physician. Increasingly, this trust is lacking. As Arthur Caplan notes:

When patients do not trust what physicians say – not for want of evidence about prognosis and benefit but because patients do not believe that physicians are their advocates, because physicians do things that are racially or culturally insensitive, because physicians show little or no interest in their patients' religious beliefs or because physicians simply seem to be too distant and removed from the living experience of their patients - the prognosis for trust is poor. When patients have no health insurance or cannot meet the requirements for copayment, they have reason to doubt a physician who says that nothing else can be done. When the prognosis for trust is poor, so are the prospects for guiding treatment by means of data about medical futility.¹⁸³

The case at the beginning of this section seemed to describe a clear case of physiologic futility, one in which brain death had been proven. However, from the point

¹⁸³ Caplan AL. Odds and ends: trust and the debate over medical futility. *Annals of Internal Medicine* 1996;125:688-89.

of view of the child's family, culture, and religion, her clinical state could have been classified as probabilistic futility, since in their view the child's physiologic state had not yet become irreversible due to continuing heart and lung function. How might one approach a situation in which a clinical definition of physiologic futility contradicts the value set of the patient and family, who still believe in continuing care based on such a hope?

This case was modified from an actual case several years ago, which was reviewed carefully by the insurance company covering the child's care. The company's medical director and nurse reviewer agonized over the case, concerned on the one hand about using significant resources to keep alive indefinitely a brain-dead child who, technically and legally, was no longer an insured member because she was dead. However, the family's religious concept of death was not far removed from other notions of death in the 20th century. Coupled with evidence that brain-dead patients on life support usually develop irreversible cardiac and pulmonary deterioration and progress to natural cardiac arrest, it became evident that indefinite resource allocation was not a major issue here. The nurse case manager was able to find a high quality ventilator-care facility near the acute care hospital to take the child for the remaining part of her life, at a cost less than in the acute care hospital. The patient was transferred and given good care for approximately 6 weeks until irreversible cardiac arrest occurred, and the family began their bereavement process.

Conclusion

In a world of finite resources, it is unethical to provide or promote unnecessary care, just as it is ethically imperative upon any health care system to promote more

efficient use of resources, more effective outcomes, and to encourage research in benefits and outcomes.¹⁸⁴ For the individual patient, futility issues should be left at the bedside by patient and physician. The role of the health care financing process is to ensure that as many appropriate treatments as possible, however probabilistically futile for a specific patient, are available for the use of all physicians and patients when appropriate. Another role is to remove from coverage those treatments where there is no evidence of clinical utility – treatments, for example, that are still undergoing clinical trials, or those in which net risks outweigh net benefits.

It is a role of the health care system, including its financing mechanisms, to “clear the land” around a given patient, giving the physician and patient time and room to discuss options about building the most appropriate and ethical therapeutic plan for the patient. As long as any clinical option has a reasonable and scientifically verified chance of providing benefit, it should be covered and made available for the patient. When for reasons of population-wide cost-effectiveness a specific option may not be funded (even though it may be the most beneficial choice for a specific patient), it may be because planners believe the monies saved by providing the patient with a less effective option provide more benefits elsewhere in the population (and/or more profit for the health insurance company). Economic models for such scenarios suggest that releasing more funds directly for patient care will enable the system to provide more patients with their best treatment options.¹⁸⁵ To facilitate optimal decision-making about futile as well as useful care, health care’s administrative costs must be reduced and the profit incentive must be eliminated, so that more resources are available for the care of every patient.

¹⁸⁴ Edmund Pellegrino, M.D., personal communication.

¹⁸⁵ Granata A, Hillman A. Competing practice guidelines: using cost-effectiveness analysis to make optimal decisions. *Annals of Internal Medicine* 1998;128:56-63.

V. Religion

A Jewish Paradigm

Rabbi Michael Whitman

*Even if a sharp sword rests upon a man's neck, do not desist from prayers for mercy.*¹⁸⁶

A paradigm for a Jewish approach to issues of medical futility is conveyed by this Talmudic statement, which contains (at least) three layers of meaning.¹⁸⁷

Layer One

The first lesson implicit in these words is humility. Just because the situation appears futile, it may not be so. Life is in God's hands, while doctors are God's instruments. No human can fully *know* when life is at an end. Even the term "futility" wrongly implies certainty. The more that medical knowledge increases and technology advances, the more we must insist on medical humility – recognizing the boundary between what we know and what we cannot know.

Very good doctors can fail to make this distinction. A doctor who mistakenly thinks s/he controls life, and decides death; a doctor who, through the arrogance that comes with his/her enormous skill, loses the humility to recognize what isn't certain. We would do well to recall the well-known doctor's lament: "My victories can only be temporary. My defeats are always final."

¹⁸⁶ Babylonian Talmud, Tractate Brachot, 10a.

¹⁸⁷ For a more detailed presentation of these issues, see Rabbi Zev Schostak, "Ethical Guidelines for Treatment of the Dying Elderly," *The Journal of Halacha and Contemporary Society*, Volume XXII.

Layer Two

The second layer of meaning is that the Talmudic statement does not promise a desired outcome. Prayer is advocated even in the face of imminent death, but not because there is a statistically significant chance of a miraculous cure. Such is, empirically, not the case. Rather, the statement conveys that even the last moments of life, with death imminent, can be imbued with infinite spirituality and meaning through prayer. Even if incapacitated, even if unconscious, even if of fleeting duration, life is valuable. And life's value is never determined by its productivity.

The Talmud also makes it clear that this value of life applies to *every* moment of *every* life: “He who closes the eyes of a dying person (thus, perhaps, hastening death by even a moment) is a murderer. This may be compared to a lamp that is about to go out. If a man places his finger upon it, it is immediately extinguished.”¹⁸⁸

The consequence of these sources for our subject is cogently expressed by Rabbi J. David Bleich: “Human life, regardless of its quality and, indeed, of its potential for even the most minimal fulfillment of *mitzvot* (good deeds), is endowed with sanctity.”¹⁸⁹

Classical Judaism asserts that every soul has a mission or purpose for which it is brought into this world. For some, that purpose may be for itself, the actions it will perform during its life. But for others, the mission may be to elicit something from others, such as love, caring, or perhaps prayer. Thus, from God's point of view, the unconscious

¹⁸⁸ Babylonian Talmud, Tractate Shabbat 151b.

¹⁸⁹ Rabbi J. David Bleich, *Judaism and Healing* (Ktav Publishing House, 1981), p. 25.

last moments of life can be as spiritually meaningful as the greatest human accomplishment.¹⁹⁰

Based on this, Jewish medical ethics requires the use of aggressive effort of known, proven therapies when there is a good chance of saving life,¹⁹¹ even when the process is painful. When therapy is itself dangerous and carries risks, it must be analyzed whether the level of risk makes the therapy prohibited, permissible, or mandatory. An important application of this principle is the case of persistent vegetative state (PVS). Such a patient may retain brain stem function and not be terminally ill. Therefore, all medical treatment must be provided. Though such a case is tragic for the patient and the family (more on this below), on this issue there is broad consensus among Jewish medical ethicists to value this life like any other.

The murkier question is, “When is a therapy no longer a therapy?” In a case of terminal illness, when our best judgment is that the patient will die soon (without miraculous intervention), when should we say that a therapy or intervention becomes meaningless, or even harmful?¹⁹² On one view, even in this case, any action taken to shorten life is prohibited: “From the hand of man – even from the hand of a man’s own brother – I will demand an account of every human life.”¹⁹³

From the repetition of the term “man”¹⁹⁴ in this verse prohibiting murder we can detect two distinct motivations covered by this grave sin. Murder can be an act of anger

¹⁹⁰ I heard this idea expressed by Rabbi Yitzchak Breitowitz in a public lecture. For a similar concept, relating to the death of a child, see *Igros Moshe, Even HaEzer* Volume I, #62.

¹⁹¹ See *Igros Moshe, Yoreh De’ah* Volume II, #58, and *Choshen Mishpat* Volume II, #73, 74, 75.

¹⁹² The definition of this state is also somewhat murky. In this section, let us assume we are discussing a patient whose disease is known and is irreversible and who is expected to live only a short time. Jewish medical ethicists differ widely on how long this time may be – ranging from about 3 days to about 30 days.

¹⁹³ Genesis 9:5.

¹⁹⁴ In the context of this Genesis quotation, we take “man” to indicate “humankind.”

and hatred, or murder can be an act of brotherhood and caring – euthanasia. Taking this interpretation of the verse, both murder and euthanasia are forbidden.¹⁹⁵

Jewish law, in contradistinction to some other systems of ethics, distinguishes between action and remaining passive. While active euthanasia is always prohibited, situations exist where we can withhold or stop treatment. In other words, a patient can reach a stage where aggressive treatment ceases to be treatment.

There are several approaches to this among Jewish medical ethicists. Rabbi Moshe Feinstein's discussion is based on a poignant narrative in the Talmud concerning the death of Rabbi Chananyah ben Tradyon (second century C.E.) at the hands of an executioner.¹⁹⁶ Rabbi Chananyah's body was wrapped in a Torah scroll and set on fire. Wet cloths were placed over his heart to keep him alive longer so the torture would be more intense. His students who were watching this horrible scene asked him to open his mouth, allowing the flames to take his life more quickly. He replied, "Let Him (God) Who gave me my soul take it away, but no one may take their own life." Here we see the traditional prohibition of active euthanasia even under the most painful circumstances, with only minutes of life left, accompanied by unimaginable suffering. Then the executioner asked, "Rabbi, if I take away the wet wool which is over your heart [in other words the wet wool was a treatment that would not lead to healing or even comfort, while removing the 'treatment' would lead to death and release from torture coming more quickly] will I merit reward in Paradise?" To which Rabbi Chananyah responded, "Yes."

Rabbi Feinstein holds that medical treatment can be withheld or stopped when the following three conditions are met:

¹⁹⁵ HaKesav V'HaKabbalah, loc. cit.

¹⁹⁶ Babylonian Talmud, Tractate Avodah Zarah 18a.

1. The patient is terminally ill (based on the definition indicated earlier; see note 7).
2. The patient (and not the family) is in terrible pain – physical or emotional.
3. The patient asks that the treatment be withheld or stopped.

This would allow, when the above conditions are met, for a “Do Not Resuscitate” (DNR) order, as well as for refusal of painful procedures or medicines with unwanted side effects. However, even under these dire circumstances, it is not permissible to withhold that which is needed by all humans to sustain life – oxygen (if necessary) and nutrition/hydration. Rabbi Feinstein does distinguish between the involuntary provision of oxygen and nutrition/hydration, which is required, and forced feeding, the anxiety produced by which may adversely affect the patient.¹⁹⁷

To remove a terminally ill patient from a respirator, even under these circumstances, may hasten death. However, if such a patient is conscious and agitated, it may be preferable to remove the tube to calm the patient.

A common issue for a terminally ill patient is the use of morphine to control pain in a dose that begins to suppress respiration, thus perhaps hastening death. Here, the overwhelming majority of Jewish medical ethicists support the notion of the double effect of a therapy. As long as the dosage is appropriate to the individual patient’s pain management, the second effect of suppressing respiration need not be considered to prevent its usage. A higher dosage, however, would be prohibited as active euthanasia.

Layer Three

¹⁹⁷ Igros Moshe, Choshen Mishpat Volume II, #73:5, 74:3

At the same time, there is a co-existing, even contradictory attitude. We realize there are circumstances in which a person could legitimately prefer death to life – a life of severe pain, loss of control, or anguish. The Talmud portrays the passing of Rabbi Yehudah HaNassi, known as Rebbi, who lived in the second century C.E.. At the end of his life, he suffered great physical pain. His many students gathered outside his home to pray for his recovery:

Rebbi's handmaid climbed to the top of the roof of his home and prayed, "Angels want Rebbi to ascend (to Heaven), and mortals want Rebbi to remain (alive). May it be God's Will that the mortals overpower the angels." When, however, she saw how much pain Rebbi was suffering, she changed her prayer to, "May it be God's Will that the angels overpower the mortals."¹⁹⁸

This narrative indicates that there are times when the compassionate and legitimate response to suffering is to pray that God end that suffering. This, then, is the third layer of meaning of the Talmudic statement quoted at the beginning. In some cases, mercy may be the restoration of health. In other cases, God's mercy – unlike man's mercy – may provide a quick end to life, which releases the person from suffering. That is a gift from God, however, and God alone.

As a rabbi, I have occasions to be present at the passing of life. Sometimes it feels exceedingly tragic. Sometimes it feels overwhelmingly fulfilling and sadly beautiful. I will never forget the passing of my friend, "Menachem." Menachem was a survivor of the Holocaust who demonstrated superhuman strength and resilience by coming to

¹⁹⁸ Babylonian Talmud, Tractate Kesuvos 104a.

America, raising a family, working hard, and maintaining his faith in God alongside his anger and bewilderment at what had happened to his people. He attended every prayer service and every Torah class – we came to love and respect each other. At the end of his life, he suffered numerous illnesses. He developed kidney failure and began to experience multiple organ failure.

I was with Menachem, together with his two sons, as the doctor tried to maintain his blood pressure, which was falling despite his efforts. It seemed clear to us that his end was near. We stood around his bed. In traditional Jewish fashion, Menachem's sons and I began to recite aloud the familiar words of Psalm 121, words which Menachem had uttered innumerable times during his life: "I lift my eyes to the mountains to see from where my help will come? My help comes from God, creator of heaven and earth...." We reached the last verse and we said the words, "God will protect your going out and your coming home..." when Menachem clearly stirred himself and, with his last breath, hoarsely whispered the conclusion of the verse, "...from this time and for all eternity." He then closed his eyes and passed away.

We may wish to pray to merit such a death when our time comes. But we must remember to distinguish between what actions or inactions are permitted to us, and what must be left to God.

Roman Catholic Perspectives on Medical Futility

Margaret A. Farley and Jennifer Beste

A Theological Framework

There has been longstanding concern in Catholicism, centuries before end-of-life decisions were complicated by contemporary technological advances, about the limits of the obligation to preserve life. Two fundamental religious and theological convictions ground the need for discernment in cases where someone can be kept alive against all odds, or allowed to die.¹⁹⁹ First there is the traditional affirmation that life is a sacred gift from God, which is based on an interpretation of the Bible and on what reason can discern regarding God's plan in the workings of creation. There is in human experience a drive for self-preservation and an intuition of the claims of our neighbors to have their lives preserved as well. Both Old (Hebrew Bible) and New Testaments bear witness to the sanctity of human life – whether through prohibitions against killing or commands to protect human life. Human life is truly given, yet is held as a gift between uncreated giver and created receiver. As such, the meaning and value of human life is not determined solely by human persons; it is a gift that embodies an obligation. Life is ours to receive, nurture, and care for; but it is not ours alone to do with as we please. The obligation to respect, even to reverence, human life is itself grounded in the belief that the

¹⁹⁹For a fuller consideration of these questions, see Margaret A. Farley, Issues in Contemporary Christian Ethics: The Choice of Death in a Medical Context. The Santa Clara Lectures. Santa Clara University, 1995.

human individual is made in the image and likeness of God, made to respond to God's call to fullness of life in relation to God and neighbor.²⁰⁰

The Catholic tradition also holds a second conviction – namely, that human biological life in this world does not constitute the total end or purpose of humanity; it is a relative, not an absolute, good. In the words of Pius XII, “Life, death, all temporal activities are in fact subordinated to spiritual ends.”²⁰¹ Physical goods are relative to, and may conflict with, spiritual goods; though this does not mean that they will ultimately be lost. Since human persons are destined to life after death, either in “another world” or ultimately in this world “transformed,”²⁰² the whole meaning of an individual's life is not limited to life before death in this world. Even biological life will be incorporated, resurrected and transformed, into the wholeness of communion with God and all human persons. This belief and hope on the part of Roman Catholics does not make life in this world unimportant. Indeed, the significance of life “on earth” derives from its place in a larger redemptive process, one that includes all creation. What individuals are called to do in this life is to respond to the divine offer of this destiny, to say “yes” to God's self-communication of eternal life. The response must come in the form of love of God expressed in love of neighbor.

²⁰⁰Roman Catholic theology also insists that the unconditional value of the human person is discernible by human reason and in the experiential encounter of one person in relation to another.

²⁰¹ Pius XII, Acta Apostolicae Sedis 49 (1957): 1031-32.

²⁰² Catholic tradition affirms a belief in the resurrection of the body. Most Catholic theologians today favor the view that embodied life after death is ultimately not in an ‘other’ world but in this world, transformed and perfected. This view has become more and more important as the Catholic tradition has taken seriously the value of all creation, not only the creation of human persons.

Limits and Distinctions

In this world, however, the preservation of human physical life may conflict with other goods: one's faith commitments, the common good of self and neighbor, liberty, and so on. Hence, Roman Catholic theologians have acknowledged limits to the obligation to preserve and sustain human life. As Richard McCormick put it, the Catholic tradition has consistently sought a middle ground between vitalism, which seeks to preserve biological life at all costs, and a medico-moral pessimism, which seeks to end life whenever it becomes painful, dull, or useless.²⁰³

Given the two-fold Catholic affirmation that human life is a fundamental good, yet not an absolute one, we turn to methods of reasoning in which this insight is put into practice in end-of-life decision-making. Though there is not complete unanimity among Roman Catholics regarding what the limits to the obligation to preserve life are, the following provide good examples of types of circumstances in which the value of human life can be relativized.²⁰⁴

1. *Personal integrity*: When fidelity to beliefs cannot be sustained without risk of one's life, one is allowed to remain loyal to one's faith commitments. This is true even if the cost of such loyalty is death.

2. *One life in conflict with another*: There are situations – for example, self defense, justifiable armed conflicts, or even a fair distribution of scarce life-saving resources – that can allow limits to the preservation of one's own or another's life.

²⁰³Richard A. McCormick, "To Save or Let Die: The Dilemma of Modern Medicine," in How Brave A New World? (Washington, D.C.: Georgetown University Press, 1981), 345.

²⁰⁴See Farley, 5-6.

3. *Personal or communal autonomy*: Sometimes values such as freedom are considered so important that loss of life can be risked to maintain them. While such an example can be subsumed under the previous two limits, there is a particular sense in which it is unique. That is, just as our society recognizes the legal right of individuals to refuse medical treatment, which then limits the obligation of caregivers to provide treatment, so the Catholic tradition respects the moral right of persons to make their own decisions, at least in some circumstances, to forego or to cease lifesaving procedures or technologies.

4. *Quality of life*: Though this is a more controversial limit than others, nonetheless the Catholic tradition has long recognized that the obligation to prolong life can be limited when the burdens of procedures or of the life that is sustained become significantly greater than the benefits of continuing to live. This limit is what is behind considerations of, for example, the use or refusal of “extraordinary means” to preserve life.

*The loss of present and future awareness, of the ability to relate with others, of the possibility of a life free from intractable and personality-changing pain, etc., may relativize the value of ongoing sheer biological existence and limit the obligation to preserve one’s own or another’s life...*²⁰⁵

5. *Medical futility*: This, of course, is the contested term we are dealing with in this volume. There is a sense in which it correlates closely to the “quality of life” limit above, yet it deserves particular identification – if only to point up the debates that surround it. We use it here as an application of the “quality of life” limit but specifically

²⁰⁵Ibid, 6.

focus on cases in which no benefit whatsoever seems to be possible from the continuation or initiation of treatment. Hence, the Catholic tradition would recognize this for treatments that cannot serve the goals of care (curative, sustaining of biological life, or comfort).

Some of these limits play significant roles in end-of-life decisions in medical contexts. In order for them to become operative, however, further considerations are necessary. In the Catholic tradition, these limits must be combined with analysis and interpretations of actions (or decisions not to act) before adequate ethical discernment is possible. The limits may provide reasons for actions (or nonactions), but only for certain kinds of decisions. Making distinctions between kinds of action is another longstanding method and resource in the Catholic tradition of moral theology and church teaching. These distinctions have been incorporated into contemporary secular medical ethics, but not without serious opposition, as we shall note.

Active vs. Passive

One distinction that is fundamental in the Catholic tradition is the philosophical distinction between actively taking life (or killing) and passively allowing someone to die – in other words, the distinction between decisions to act and decisions not to act – to cease, or refuse to initiate, action. This distinction is challenged, from within the community of Roman Catholic theologians and from secular medical ethicists and theologians in other traditions. The challenge is based on at least two objections. First, it is argued that decisions to forego or withdraw treatment may involve actions, as in pulling a plug. This objection can be obviated by the traditional Catholic view, which

holds that every decision itself is considered to be an action – whether or not it involves a physical movement. Hence, there is always an action, but an action of “commission” or “omission.” In either case, the decision and the action require ethical justification.

A second objection is not so easily addressed. Opponents of the passive-active distinction frequently argue that when it is used to justify not doing something (as opposed to doing something), it is specious. An agent is not absolved from responsibility for either action or nonaction; both are bad, and the active-passive distinction is simply wrong insofar as it implies otherwise. Often an example is used wherein a person wants another person to die in order to gain something – as when one allows an uncle to drown in order to gain an early inheritance.²⁰⁶ In the view of many Catholic theologians, however, this objection does not undermine the usefulness of the distinction. No one who favors the distinction thinks that it absolves anyone from the requirement for ethical justification for one’s decision. Both a decision to act and a decision not to act require justification. In particular, both a decision to actively take the life of a patient and a decision to withdraw and forego treatment require justification. The decision, for example, not to save one’s drowning uncle (if one is able to do so) is not justifiable.

But what is the ethical difference between on the one hand taking life and on the other hand letting it go? For those who continue to find the distinction morally significant, there are marked differences between the two possibilities. The first is intent. To let someone die need not be to intend or desire the death of that person. In the case of the rich uncle, to allow him to die in order to gain an inheritance is indeed to intend his death. But to allow him to die only because one is unable to save him, or only because

²⁰⁶ James Rachels offers a provocative situation similar to the one described here. For his argument, see James Rachels, “Active and Passive Euthanasia,” *New England Journal of Medicine* 292 (2) (January 9, 1975): 78-80.

one cannot save him as well as oneself or others, is not to intend his death. Here, of course, we are in the midst of a philosophical quagmire. For sometimes when a decision is made to refuse medical treatment, death is – if not intended – at least welcomed, perhaps under difficult circumstances of prolonged dying. And almost always in such a choice, death is at least foreseen. Hence, there is a sense in which death falls within one's intention, though not one's direct intention. When a decision is made to let someone die, and the circumstance is that the patient is in the process of dying, then it is accurate to say that what kills the person is an underlying disease, not the withdrawal of treatment that can no longer help (or respect) the person. The decision to withdraw treatment is the "occasion" of death, but not in the strict sense the "cause." Intention is involved, but it is not the sole determinant – not even the direct and primary determinant – of death.

The descriptive difference between active and passive "euthanasia" is not trivial. In each case, the person dies; and in each case a justifying reason for the decision is required. But in the latter case, our experience is of a very different sort. It is experienced as, yes, accepting death, allowing it and providing an occasion for it by removing (or not initiating) unreasonable barriers. However, it does not violate the value of human life – it neither disrespects a divine gift, nor counters a fundamental human desire to live, nor takes into one's own hands a decision that may harm the community. It can be described, rather, as accepting the inevitable process of dying that is a part of human living. On the contrary, to choose directly to take someone's life with, say, a lethal injection, is seen as violating the person by overstepping one's duty to respect and reverence life.

The Principle of Double Effect

There is another medical situation in which ethical analysis in the Catholic tradition appeals to the distinction between direct and indirect intention. This is the clinical situation in which a patient in serious pain can be given medication to alleviate her suffering, even if there is some reason to suppose that the pain medication (usually morphine) will hasten slightly the death of the patient. If pain is alleviated by medication that also suppresses respiration, a patient may die somewhat sooner than if she were not given the medication. This decision, unlike the ones we have been considering to withdraw or withhold treatment, is a decision to do something – i.e., to give medication. The intention is precisely and directly to take action to alleviate pain. It is not to kill the patient. Yet if the patient is suffering a great deal, it is ethically justifiable to treat the pain without intending, though foreseeing the possibility of, the patient's death. This decision, too, is patient-relative. For some patients the hastening of death may not be justified – since the patient has some likelihood of recovery, or the patient requests not to be medicated, etc. Apart from such circumstances, however, it may be a failure of good care to leave patients in great pain just because they might die a bit sooner than otherwise. Actions in cases like these are assessed with the help of the traditional Catholic principle of “double effect.” This principle states that if one action (giving pain medicine) has two effects (the alleviation of pain and a possibly hastened dying), only the first effect – the effect in the service of quality of life, i.e. alleviating pain - is directly

intended. The second effect is accepted and allowed, even though not wanted and not directly intended.²⁰⁷

An important external factor is involved in the distinction we have been addressing. Social policy sets boundaries around the populations that can be candidates for decisions for death. If the only decision that can be justified on society's terms is a decision to forego or withdraw treatment, then only those who are already in the process of dying, or about whom it can be said that there is no point whatsoever in sustaining biological life, can be considered candidates for a decision for death.

Ordinary vs. Extraordinary

From the preceding discussion, it is clear that decisions to allow death must be ethically justified. An additional distinction in the Catholic tradition is between what have traditionally been called "ordinary" and "extraordinary" means. Because of the ambiguity of these terms, even Catholic theologians and medical ethicists have sometimes substituted alternative terms such as "obligatory" and "optional," "medically indicated" and "not medically indicated," "beneficial" and "excessively burdensome," "proportionate" and "disproportionate." Whichever terms are used, the point is to assess a concrete situation in terms of whether or not there is an ethical obligation to treat in a particular way. What is important about this distinction is that it does not refer to what is usual or unusual, nor does it provide labels for general categories of kinds of treatments

²⁰⁷ It should be added that a full explanation of the principle of double effect is more complex than we provide here. It probably also should be added that patients not given pain medication may sometimes die sooner from the gravity of the pain.

(as in organ transplantation, ventilation, antibiotics, dialysis, etc.). Rather, the distinction can only be applied to the needs and circumstances of a particular patient. For one patient, dialysis may be “extraordinary”; for another it may be “ordinary.” In other words, “extraordinary” does not simply refer to rare, expensive medical interventions, and “ordinary” does not simply refer to basic medical care. Prognosis, individual pain thresholds, psychological and spiritual resources to cope with suffering, familial support: all of these and more are involved in the application of these terms. The Catholic tradition has even emphasized that, should the suffering resulting from medical treatment threaten a person’s spiritual integrity and faith, such treatments are likely to be disproportionate and extraordinary. As Pius XII observed, it is unwise to insist that people must use extraordinary means in their medical treatment: “A more strict obligation would be too burdensome for most [persons] and would render the attainment of a higher, more important good too difficult.”²⁰⁸ The distinction, therefore, is finally between what in a specific case is an acceptable benefit and what is an excessive burden, and whether the proportion between benefits and burdens weighs more significantly on the side of benefit.

Given varying judgments about benefit and burden, this distinction yields different decisions regarding end-of-life care. What is excessive for one person may only be difficult for another. In the Catholic community there has been a consistent affirmation of the right of conscience of the individual in such matters.²⁰⁹ Yet, the need

²⁰⁸Pius XII: 1031-32.

²⁰⁹“Moral conscience, present at the heart of the person, enjoins him [sic] at the appropriate moment to do good and to avoid evil.” Catechism of the Catholic Church (Washington, D.C.: U.S. Catholic Conference, 1994) 1777. Thus, it is imperative that a person “not be forced to act contrary to his conscience. Nor must he be prevented from acting according to his conscience, specially in religious matters.” Ibid., 1782, citing the Vatican II document, Dignitatis Humanae.

has become all too frequent in our society (and perhaps also within faith communities) for at least minimal commonly agreed upon criteria for weighing benefits against burdens. Traditionally, general criteria for the assessment of burdens have included such factors as medical prognosis, expense, gravity of risks and harms, small likelihood of success of treatment, and adverse quality of life achievable through treatment. Criteria for assessment of benefits have included benefit not only for a patient's physical existence but for the person as a whole, impact on family and community, the value of prolonging life for a particular duration for a particular purpose, and so on. One might note also that, although Catholics do not discount the possibility of miracles, neither do they think that miracles depend on extraordinary medical treatment; buying time for God to work a miracle seems to involve a conceptual contradiction.

Artificial Nutrition and Hydration: Extraordinary Means?

Controversy has erupted within the Catholic theological community over the issue of providing artificial nutrition and hydration to patients with poor prognoses.²¹⁰ Cases

²¹⁰For a helpful overview of this debate, see Richard A. McCormick, The Critical Calling, (Washington, D.C.: Georgetown University Press, 1989), 369-88; McCormick, Corrective Vision (Kansas City, MO: Sheed & Ward, 1994), 210-32. Even among church leaders there is not always agreement on this issue. For example, in 1992 the bishops of Pennsylvania published a document arguing that the fact that nutrition and hydration are provided "artificially" is not sufficient to justify withdrawing these from a patient in a persistent vegetative state. Pennsylvania Bishops, "Nutrition and Hydration: Moral Considerations," Origins 21 (Jan. 30, 1992): 547-51. Yet soon after this, the U.S. Bishops' Committee for Pro-Life Activities released a carefully nuanced statement maintaining that while withdrawal of nutrition and hydration should "not be viewed as appropriate or automatically indicated for the entire class of PVS patients," nonetheless, artificial nutrition/hydration can be withdrawn if they offer no hope for sustaining life or if they pose excessive burdens. Moreover, this statement argues that the primary decision-maker in such cases should be the patient or, when and if the patient is unable to make decisions, the patient's family. Committee for Pro-Life Activities, "Nutrition and Hydration: Moral and Pastoral Reflections," Origins 21 (April, 1992): 705-712. For this same position, see also, U.S. Bishops, "Ethical and Religious Directives for Catholic Health Care Services," Origins 24 (1994): 459. For helpful commentaries on such documents and on the Catholic tradition of theology regarding these questions, see Kevin O'Rourke & Jean deBlois, "Removing Life Support: Motivations, Obligations," Health Progress (July-August, 1992): 20-27; Kevin O'Rourke, "Evolution of Church Teaching on Prolonging Life," Health Progress (Jan-Feb, 1988):

of patients in irreversible coma provide some of the most stark questions, as do cases of patients who are in a persistent vegetative state (PVS). What these cases have in common is that the individual cannot, at least according to the best medical assessments, return to conscious awareness. In PVS cases, although the patient may seem to be awake, she or he will not (or very likely will not) return to conscious awareness. In both kinds of cases the patient will not have a reflective, rational, cognitively informed affective possibility of relating to other persons or anything else. The question is, then, what is the “point” of sustaining the lives of such patients?²¹¹

The debate within the Roman Catholic community of leaders and scholars represents a lack of full consensus on whether so-called artificial nutrition and hydration are simply forms of giving food and water, such that providing these basic needs to persons is a part of normal care; or whether artificial forms of feeding in a clinical context are medical interventions that must be evaluated just like any other medical treatments. They are “normal/ordinary” or “extraordinary” only in relation to benefits or burdens for the particular patient who may need them.

To better understand the (now majority) position that acknowledges the possible nonobligatory nature of artificial nutrition and hydration, it is necessary to focus on the center of the controversy: namely, that the belief that human physical life in this world is valuable, but its value is relative. It is relative to all the values that constitute possible

28-35; John J. Paris & Richard A. McCormick, “The Catholic Tradition on the Use of Nutrition and Fluids,” *America* 156 (May 2, 1987): 356-61; James J. McCartney, “Catholic Positions on Withholding Sustenance for the Terminally Ill,” *Health Progress* (October, 1986): 38-40.

²¹¹It must be underlined that the kinds of cases referred to here are all characterized by a complete lack of even a potential for conscious awareness. Hence, the same question (about the “point” of sustaining such lives) cannot be asked, for example, in regard to other intellectually disabled persons such as those with Down Syndrome. The issue is not the degree of intelligence, nor the quality of conscious affective relationships.

limits to our obligation to preserve bodily life. But something more must be said.

Human persons (as understood in the Roman Catholic tradition) are essentially relational beings. The very purpose of human life is lodged in the possibility of relationships at a conscious level. The argument here is that there is no point to an existence that is without any possibility of conscious awareness of and affective relationships with what is knowable and lovable. When physical life in this world reaches the point where there is no present capacity to relate to others and no potential to retrieve or to grow into such a capacity, then the purpose of this physical life is gone.²¹² Without a capacity to relate to God, one's neighbor, and one's own self, there is no "point" to a human life.

To say that there is no "point" to continued physical existence in this world, however, must be understood in the context of the ultimate belief that the embodied person is still and forever unconditionally valuable. There never comes a time, in the Catholic view, when there is not an obligation to respect, care for, even love, a human person. But precisely out of respect, caring, and love, the obligation may become one that allows the bodily existence of the person in this world to be let go—even if this means to cease or not initiate life-saving measures (including medically provided nutrition and hydration). The individual person still has a future – but not here and now in this world. Without espousing a philosophical or theological dualism, the person is affirmed to have a future that includes embodiment. Once embodiment in this world no longer provides the condition for knowing and loving, for freedom of choice, for saying "yes" to the life

²¹² McCormick argues that since the goal, the raison d'être, of human persons is to accept God's offer of communion and friendship, when the potential for moving toward this in this life no longer exists, then physical life in this world has achieved whatever potential it has. McCormick, How Brave a New World, 349. See also O'Rourke, "Should Nutrition and Hydration be Provided to Permanently Unconscious and other Mentally Disabled Persons?" Issues in Law and Medicine 5 (1989): 5.

of God communicated in nature and through grace, then there is indeed no point in continuing to preserve this present form of embodiment.

Despite this trajectory of Catholic moral reflection on end-of-life situations, a recent statement by the late Pope John Paul II raised the question of artificial nutrition and hydration in ways that, according to most Catholic bioethicists, are not necessarily commensurate with all of the principles described above. John Paul II suggested that “the intrinsic value and personal dignity of every human being do not change, no matter what the concrete circumstances of her life.” This affirms traditional Catholic teaching. However, John Paul II further claimed that artificial nutrition and hydration are “*natural means* of preserving life, not a *medical act*,” and that “[i]ts use...should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory.”²¹³ This latter statement seems to be a deviation from the bulk of Catholic moral teachings.

While John Paul II was explicitly concerned about the dangers of euthanasia, his statement tends to contradict and in some ways obfuscate significant Catholic moral tradition leading up to this point. Unresolved are issues such as what the determinant of morally obligatory action is: Is an action morally obligatory because of its medical status and use, or is it obligatory with reference to the particular patient? Further, it is unclear how this statement is to stand in relation to the tradition of Catholic teaching on life issues: Should it be considered equal in stature to *Evangelium Vitae*, for example?

Thomas Shannon and James Walter opine that while the Pope has rightful purpose in

²¹³ Pope John Paul II. “Address of John Paul II to the Participants in the International Congress on ‘Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,” Saturday, March 20, 2004. Accessed at the Vatican website, http://www.vatican.va/holy_father/john_paul_ii/speeches/2004.

protecting “patients in persistent vegetative state and to curb the movement toward euthanasia,” this statement does not quite achieve that goal.²¹⁴

All of the reasons for not directly killing such a person remain in place, however. A hand may not be raised to take the life of this person, but it may be raised to remove the artificial barriers mounted by medical technology – barriers that prevent the person from yielding to God in death and from gaining the new freedom of a life transformed. The prohibition against direct killing of innocent human persons is not lifted in medical situations such as the ones we have been considering. Permission and sometimes even obligation to let persons die in such medical situations can, however, be affirmed. As an individual faces death in such circumstances, it is a time for remembering (in so far as this is possible) and sharing the meanings of life and death, call and response, love and loss, present sorrow and future joy. It can be utterly significant to consider the meaning of letting go, surrendering into God’s hands, supporting each person in the consummation of her or his history in this world, while removing the non-beneficial barriers that keep such a person from the “absolute future which is [her] goal.”²¹⁵

Protestant Christianity and Medical Futility

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²¹⁴ Shannon, Thomas and James Walter. “Artificial nutrition, hydration: Assessing papal statement.” *National Catholic Reporter* (April 16, 2004), pp. 9-12.

²¹⁵This is a paraphrase of Karl Rahner, “Theological Considerations Regarding the Moment of Death,” in *Theological Investigations* v. 11 (New York: The Seabury Press, 1974), 319.

The Protestant tradition is undeniably diverse. In light of this, it is probably impossible to give a complete account of Protestantism's views on medical futility. It is worth noting that the diversity of the Protestant tradition on this issue contrasts markedly with that of the Roman Catholic tradition. Where Roman Catholicism is characterized by a strong magisterial voice and a generally coherent history of interpretation regarding issues like medical futility, Protestant Christianity has a more piecemeal history of interpretation. In this light, my strategy will be to paint with a broad brush in hopes of capturing some distinctive aspects of Protestant Christianity on medical futility.

In general, Protestantism holds to an ethic of *imitatio Dei*. Christian living is an attempt to embody and reflect *agape*, or the love of God, in the world. Agapeistic ethics, that is to say ethical reflection upon how God's love is normative for human beings, is one example of how the Protestant tradition reasons ethically; we can identify features of God's love exemplified in the world, and we are to imitate this love in our lives. In this light, Christian ethics "takes depictions of love in the Bible as its point of departure."²¹⁶ Our own efforts at Christian love "[aim] to correspond and attest, on our own level and with our own limited capacities, to God's [love]."²¹⁷ In thinking about decisions over courses of treatment – especially decisions regarding the futility of medical care – we want to offer God's love, or an approximation of it, in particular ways to patients in particular circumstances.

²¹⁶ Outka, Gene. "Agapeistic Ethics," in *A Companion to the Philosophy of Religion*, eds. Philip L. Quinn and Charles Taliaferro. Oxford: Blackwell Publishing, 1997.

²¹⁷ Ibid.

Another significant theme in Protestant Christian thought is the relationship between freedom and responsibility. Daniel McGee, a Protestant theologian who speaks out of the Baptist tradition, argues that in America we often opt for one of two inadequate moral stances in the face of increasingly overwhelming medical options – the “humble stance” or the “heroic stance.” The humble stance “resists the impulse to take into our hands new responsibilities,” and the heroic stance “promotes the virtue of courage and calls for bold and adventurous action.”²¹⁸ The humble stance gets caught up in the weight of responsibilities while the heroic stance revels in freedom.

In McGee’s opinion, the biblical image of the “faithful steward” offers a far more helpful way of understanding how to approach the concomitant demands of freedom (options) and responsibility (use and discretion) in the medical setting; we should resist the inclination to shirk responsibilities on the one hand and the inclination to become overly self-reliant and aggressive on the other hand. Both have relevance for discussions of medical futility. McGee offers an interpretation of the faithful steward, which can shape how we think about medical futility within the Protestant tradition. On the one hand, we need to appreciate the importance of taking risks and being bold in the medical care we give, while on the other we need to appreciate and acknowledge our limitations. Faithful stewards ought to steer a course between humble and heroic “with a sense of sober hope that in using our new freedoms we can serve the people who share our time and place in history.”²¹⁹

In this essay, I will first articulate what I see as (at least) two related assumptions embedded in Protestantism, which undergird a traditional understanding of medical

²¹⁸ McGee, Daniel. “Euthanasia and Physician Assisted Suicide: A Believers’ Perspective,” in *Must We Suffer Our Way to Death? Cultural and Theological Perspectives on Death*. Eds. Edwin R. DuBose and Ronald P. Hamel, 306. Dallas: Southern Methodist University Press, 1996.

²¹⁹ Ibid, 306.

futility: (1) that God allows all creatures to die, which suggests that death is not itself an evil; and (2) that the most faithful response to those among us who are dying is often acceptance and acknowledgement of collective finitude in an attempt to embody God's love in the world. Taken together, these two assumptions reflect the tradition's perspective that there are times when medical futility is a very real phenomenon. And when it does obtain, we are called to caring recognition of finitude.

I conclude by reflecting more specifically upon this second assumption of acceptance and knowledge. It is especially important with regard to how we ought to embody God's love in our care for the dying, and especially in our care for people for whom medical interventions may have become medically futile. The caring recognition required by situations of medical futility ought to compel us to offer especially meaningful and enduring presence to those who are dying.

I. Embedded Assumptions

(1) God Allows All Creatures to Die

Our tradition understands God to be the ground of existence. God has power both to create and destroy life. Given that all creatures die, therefore, we can say that God allows all creatures to die. What does this claim mean? Does the fact that God allows all creatures to die cause us to question God's love? In order to answer this question, we can distinguish between two different kinds of death – natural death and tragic death. Natural death is death that comes at the end of a relatively long and normal lifespan. A tragic death is one that cuts a life short when there is still much promise and experience to be had.

Within the Protestant tradition, an account of God's role in natural death can be articulated as follows. God has ultimate power over life and death. Additionally, all human beings are subject to a natural life cycle, which includes birth, life, and death as instituted by God. That a human life ends in death, therefore, does not mean that God is unloving or that God is a perpetual murderer. In general, we do not think about the natural life cycle as an evil. Rather, Protestant Christianity traditionally sees life in itself (birth, death, and all) as pure gift, even in a world shaped by human sin.

That God lets humans die does not call God's love into question. Karl Barth, a Protestant theologian who wrote during the mid-20th century, suggests that "the blessing of life is a divine loan unmerited by [humanity]. It must always be regarded as a divine act of trust that [humans] may live."²²⁰ The fact that God allows all creatures to pass out of existence offers important insights into the ways in which God acts in our lives and in our world – God gives us the gift of life, God sustains this life, and God allows this life to come to its natural end.

A traditional account of God's role in tragic death is more difficult to accept than an account of God's role in natural death, but it leads to a similar conclusion. Few would argue against the claim that sometimes people dear to us die and the death is altogether tragic, unjust, and enraging – as when a child is struck dead at the bus-stop by a speeding commuter on his way to work. That God wields power as the sustainer of life and yet allows us all to die in whatever common or uncommon way (whatever natural or tragic way) does not mean that God is unloving. Our tradition says that God accepts the reality of creaturely life. In allowing death, God acknowledges and accepts our finitude as creatures. A few questions emerge from these observations about human finitude and

²²⁰ Barth, Karl. *Church Dogmatics*, III/IV, 336. Edinburgh: T&T Clark, 1957.

God's love, which I will mention now and return to in a later section of this essay. If letting die is consistent with God's love, how should we act in light of this love? Does Christian love impel Christians to imitate God in this respect? What does this mean for Protestant understandings of medical futility?

We have seen that finitude is a condition of human life. But is death *bad*? By death, both natural and tragic, I mean physiological death. Medically, this can mean cardiopulmonary death, or it can mean brain death. (Brain death is the current medical and legal standard for death in the United States, though other cultures and religious traditions consider cardiopulmonary death to be primary.) I will consider Karl Barth's theology of death as representative of the Protestant tradition in this respect. I want to raise two questions: (1) What is the function of death in human life? and (2) What happens to human beings after death?

Barth says that all people *perceive* death as a threat – as a moral evil. Death threatens us because we do not like knowing that we lack ultimate control over our destinies. We act pridefully when we try to pretend that our lives are not finite; this pride is a type of sin. Therefore Barth claims that our perception of death as evil is the result of sin – of our revolt against dependent nature. If not for sin in the face of God, death would not strike us as threatening – it would merely strike us as a fact of the gifted lives we live as fully dependent beings. Thus, like the fact of human finitude, death in itself is not evil according to Barth. Death is a natural event – an event that is coherent with our anthropological condition as finite creatures; death is non-moral. Death simply is, and its function in human life is that it provides a definitive end to finite, creaturely existence.

Barth is reluctant to say very much about what comes after death. Nonetheless, like many Protestant thinkers, he maintains a commitment to realization of an

eschatological promise made in Jesus Christ – the promise of eternal life in unity with God – that lies beyond the grave. What is certain is that “God is [humankind’s] beyond.”²²¹ God is creator, sustainer and redeemer. Death is the anthropologically conditioned end to human life as we know it, and God’s eschatological promise – extended concretely to us in Jesus Christ – offers enduring hope both for this life and the next.

The Protestant tradition generally understands God to be the sustaining power of all existence. Given the reality that death affects all creatures, God can be understood as allowing death to occur for all. But death should not be seen as an evil. Rather, it should be seen as a fact of existence. Our tradition interprets this fact as an indicator of the unavoidability of finitude in human life on the one hand and God’s willingness to accept us, even into infinity, despite our finitude on the other. This understanding of finitude and death has moral valence for end of life care – particularly in discernment of the futility of certain medical interventions.

(2) Caring Recognition of Finitude

The assumption that God allows all creatures to die as both acknowledgement and acceptance of finitude suggests that death is a morally neutral phenomenon. This leads to a second assumption: There are times when we ought to, like God, accept finitude and acknowledge its inescapability in allowing our family members, patients, and friends to pass out of existence – to die. In other words, there are times when a patient’s circumstances require caring recognition of finitude. Determinations of medical futility can be part of this process of caring recognition. I explore the question of why this kind

²²¹ Barth, Karl. *Church Dogmatics*, III/II, 633. Edinburgh: T&T Clark, 1957.

of recognition is important in this section, and then I reflect upon how this kind of recognition can take place in the next.

In his famous book *The Patient as Person*, the Protestant theologian and ethicist Paul Ramsey raises the question of “whether with the [irreversible] process of dying...there does not arise the duty only to care for the dying, simply to comfort and company with them, to be present to them.”²²² The Protestant tradition would seem to answer Ramsey’s question with a resounding “yes.”

There is an important analogy between God’s love and human love with respect to the importance of allowing someone to die – of acknowledging the futility of certain kinds of medical care when death is either unavoidable or inevitable. Determinations of medical futility offer us formal procedures for accepting finitude and shifting our focus from medical cures to meaningful companionship for those among us who are approaching the end of life. As I have said, presumably God lets us die because we are finite creatures. In end-of-life care decisions, we have the ability to offer this same sort of affirmation – to join those who are dying in coming to terms with the fact that we will all inevitably pass out of temporal existence.

At the very least, we should make efforts to avoid denying finitude. For example, unnecessarily prolonging treatment or undertaking medically futile procedures can be a denial of finitude. Ramsey’s Protestant ethic (and many contemporary Christians with him) suggests that sometimes the most faithful response to the dying may be to let someone die. This is not to say that medical treatment is always superfluous. But in certain situations when treatment is no longer effective, beneficial or appropriate for the patient’s current situation and disease prognosis, it may be proper to allow a person to

²²² Ramsey, Paul. *The Patient as Person*, 125. New Haven: Yale University Press.

encounter her finitude. Discernment of when this becomes the case is a difficult and highly particularized matter, as this book attests.

Protestant conceptualizations of *agape* can bear on this situation as well. In terminal situations at the end of life, we are exhorted by *agape* to bear with people who suffer. Bearing with those who suffer may require us to acknowledge finitude (and futility) and embrace death. Prolonging life in dire circumstances, or failing to accept the futility of medical care in certain kinds of circumstances, takes focus away from the patient who suffers. The whole person, not just the disease trajectory, ought to be the focus of our attention. If the patient is treated only as a constellation of medical symptoms, not only is the patient marginalized but the professional in charge of caring is distanced from the suffering patient. The patient is not treated for who she is at her very core (child of God, irreducibly valuable), but rather for how the provider may feel (terrified, unwilling to face death).

Consciously or unconsciously, a refusal to let a person die – to acknowledge the futility of medical care – may be a covert way of avoiding the hard work of suffering with a patient (and/or a family member). Denying finitude dehumanizes, violates respect, and thwarts any meaningful ability to company with the suffering. Embracing finitude in letting die offers a patient respect in the form of honesty, and it enjoins a caregiver (and/or a family member) to company with the patient by identifying with and acknowledging the suffering person's deepest needs, which are probably comfort, solidarity, and presence in the face of imminent death.

As attested by Karl Barth, Protestant Christianity sees all of life as a gift. Death, whether natural or tragic, is a feature of creaturely life that God accepts. Furthermore, that God allows all creatures to die suggests that death itself is not evil. Rather, death is

perceived as evil because of sin. Because death is not evil and because it is unavoidable, Christians are sometimes called to caring recognition of finitude, which can manifest in determinations of medical futility in care for the dying. As Ramsey suggests, a duty sometimes arises *only* to care for the dying, not to attempt to cure them.

II. Presence with the Patient

Some contend that futility is a dangerous term because it implies hopelessness. Acknowledgment of finitude and futility, however, does not mean either hopelessness or abandonment of dying people. At least within the Protestant tradition, determinations of futility should lead to the opposite. As Ramsey explains, “the chief problem of dying is how not to die alone. To care, if only to care, for the dying is, therefore, a medical-moral imperative; it is a requirement of us all in exhibiting faithfulness to all who bear a human countenance.”²²³ Recognition of finitude and futility should be coupled with a commitment to be present with dying patients. I maintain that when caring recognition of finitude is necessary, there is a special obligation to offer compassionate presence to the dying.

The obligation to acknowledge and accept finitude is shaped by the concomitant demand of Christian ethics to care for the vulnerable. One need not look further than Jesus’ words in the Sermon on the Mount to perceive a heightened Christian obligation to love and care for the vulnerable. People who are at the very end of life are indeed some of the most vulnerable among us, and the obligations we have to care for them are especially great. In end-of-life care, sometimes the only real care that we can offer is comfort and compassionate presence at the bedside. When we acknowledge futility, we

²²³ Ibid, 134.

acknowledge and accept the reality that our lives are not ultimately under our own control and that our existence is finite. Because our options may be limited, however, does not mean that our caring should be any less deep.

The contours of this compassionate presence can be articulated by an example. In her play *Wit*, the playwright Margaret Edson tells the story of an aged though yet uncompromised professor of English named Vivian Bearing who is struck with ovarian cancer in the midst of a successful and still promising academic career.²²⁴ Edson offers numerous clinical episodes that capture the great needs of sufferers and the many ways in which these needs can be neglected by uncaring professionals, useless (futile) procedures, and relentless attempts to control suffering that cannot be controlled.

However, Susie Monahan, one of Vivian's caregivers, offers a model set of responses to Vivian's suffering. After initiating a discussion over whether or not Vivian would like to add a do-not-resuscitate order to her chart, Susie and Vivian sit together in knowing silence, sharing a popsicle. Susie and Vivian have a relationship that has developed over the course of countless episodes of extreme pain and suffering in which Susie has been present with Vivian – holding her hand, holding a bowl to catch her vomit. In this particular silent moment, Susie expresses solidarity with Vivian in her suffering. Susie cannot make the suffering go away. She cannot explain why it has befallen Vivian. But she *can* sit with her.

Later in the play, when Vivian has lost consciousness, and she is nearing death, Susie enters Vivian's room and hovers over her bed. First, she brushes Vivian's hair. Then, she slowly applies baby oil to Vivian's dry, cracked hands. Susie clearly acknowledges and accepts the reality of Vivian's impending death – and the futility of

²²⁴ Edson, Margaret. *Wit*. New York, New York: Faber & Faber, Inc, 1993.

much of the care Vivian has received. And Susie's honesty in the face of Vivian's impending death causes Susie to draw even more near to Vivian. This is the kind of caring response that our tradition hopes for.

Conclusion

I have suggested that the Protestant tradition has a particular way of understanding death. First, death is part of a natural life cycle that is pure gift. God allows death to occur. Second, our tradition maintains that God's role in death does not implicate God in death but rather highlights God's willingness to accept and affirm our reality as finite. In this light, death should not be understood as evil. Death is simply a mark of creaturehood. As people seeking earnestly to imitate God's love in the world – in patterns of faithful stewardship and as people living at the bedsides of patients who are dying – sometimes we are called to caring recognition of the realities of others as finite; sometimes we are called to allow patients to die. Careful discernment of determinations of medical futility can offer just this kind of caring recognition. But the call to accept finitude brings with it a call to an even deeper commitment to company with the dying – the responsibility to offer patients stable presence as they live out their last days on earth.

An Islamic Perspective
Nour Akhras

Prolonged care of the terminally ill patient is a relatively recent phenomenon, with the advent of ventilators and other technological advances found in most intensive care units across the United States. As such, it has become incumbent upon religious scholars to address questions of medical futility, extrapolating from religious texts that were compiled hundreds of years ago. Islam is not exempt from this obligation. Medical futility did not need to be addressed over 1400 years ago, when the Qur'an and the teachings of the Prophet Muhammad were established. Muslim legal scholars have also had to draw from the basic principles of Islamic legal theory to answer such questions. Consequently, there are no clear-cut answers that can be made on the issue of medical futility; each case has to be looked at individually and decisions must be made on a case-by case basis.

It is also clear that certain principles must be laid out in attempting to come to a decision for an individual patient. One of these is that in order for the patient to make an informed decision, he needs to have available to him all of the medical information pertinent to his disease. In addition, the patient should know the ramifications of his decision from an Islamic religious perspective. In order for this information to be evaluated, the medical team, including the ethicist and chaplain, needs to clearly explain all feasible options within the medical and religious context to the patient and/or his family.

The general aim of legislation in Islam is to protect and guarantee five basic values for all human beings: preservation of life, the right to practice religion,

preservation of intellect, protection of family life and lineage and the protection of wealth. These five basic values are deemed “The Necessities” in Islamic Law. They are to be protected in that particular order of importance, with life being the most essential. Therefore, when two basic values, such as life and religion, come into conflict, Islamic Law judges that the person may and should preserve his life at the expense of his religion. The principle of prioritizing preservation of life over religious duty pertains to one’s own life and to human life in general.

The hierarchy in the value system in Islam makes it appear that life takes precedence above all other things. However, there are exceptions to the rule; sanctity of life is not always the ultimate consideration. For example, a proven murderer may be punished by the death penalty in order to prevent destruction of nations or other individuals. This punishment reflects a societal attempt to preserve the sanctity of life for all humanity.

This does not in any way diminish the reverence that the Islamic tradition gives to life. Every second of a person’s life is a great gift and an irreplaceable opportunity to elevate one’s spiritual state and refine one’s character in order to become closer to God. There is a great sense of responsibility placed on the human being for every precious second that he has been given. Life on earth is revered because human beings were placed on this earth to live their lives as the vicegerents of God, an honorable but difficult role to carry out (Qur’an 2:30). And in various other places throughout the Qur’an, God instructs the human being about the purpose of life: “I have only created ... [humanity] that they may serve Me” (Qur’an 51:56). The definition of serving God is essentially through serving creation. And as such, every human being has great potential to serve God, regardless of his/her position in society as long as the human being intends to serve

God. This does not dismiss the fact that a person can spend part or all of his life in worship, praying, fasting or even merely contemplating the wonders of God's creation and he would have fulfilled the covenant to serve God. This is a crucial point for the chaplain when he counsels his terminally ill patient because it essentially means as long as the human being can still think about God, even if he can do nothing else, he is acquiring good deeds and improving his station with God.

Next we turn to issues that require medical attention in the context of Islamic Law. Since there is one ideological camp which supports the notion that rejecting medicine and accepting God's decree is a sign of closeness to God, the medical team should be particularly adept in addressing this issue when counseling terminal patients.²²⁵ A person can refuse medical treatment believing that God can cure him at any moment God pleases. Even the Prophet Muhammad was known to have refused medical treatment at a certain stage of his life. Refusing medical treatment may be seen as a sign of one's contentment with what God has planned, with recognition that patience has very great reward in the Afterlife. On the other hand, there is a strong and well-known saying of the Prophet Muhammad that impels people to seek medical treatment when they fall ill: "God ... has not created any illness without creating its cure except for one illness and that is old age." It is also historically related that the Prophet Muhammad himself sought medical treatment during other instances of his life. It is thus asserted that a Muslim will be rewarded in the Hereafter for seeking medical treatment if she does so with the intention of emulating the Prophet Muhammad. This teaching not only indicates the permissibility of seeking medical treatment but it can also be understood to compel

²²⁵ This ideology derives from a story in which the Prophet Job resisted supplication to the Lord for healing (Qur'an 21:83). All Qur'an citations are from *Qur'an: with meaning translation in English*. Damascus: Dar-Al-Maarifah, 2001.

the sick patient to do whatever he can in his power to search for a cure for his disease. It implies that the Prophet is giving hope to people who have diseases that supposedly have no cure by the standards of modern day medicine. In fact, his words can be the basis upon which one would promote scientific research to look for cures for all diseases. If modern day scientists say there is no cure, it is only because we as human beings, in our limited abilities, have not yet discovered the cure. Consequently, this teaching can be used as a basis for the decision of a patient who has what is deemed an incurable cancer to try an experimental chemotherapy protocol.

Since both views, seeking and refusing medical treatment, are valid in Islamic tradition, the decision is left up to the patient. However, it must be clear that the intention behind either of the actions taken must be good because an absolutely fundamental principle of Islamic legal thought is that all actions are judged by God according to intention. For example, a patient cannot refuse medical treatment because he is suicidal, since suicide is a grave sin in the Islamic tradition. He can, however, refuse medical treatment because he believes that God does not need for him to swallow a pill in order to cure him.

In the Islamic tradition, there is a strong belief in the temporality of this world and that life does not end with the death of the human body. The human soul will live on forever in the Afterlife. Human beings are essentially spiritual beings who are confined to our human bodies. In the Afterlife, if one lived a virtuous life, the spirit will attain the highest form of pleasure in Paradise, which is living forever in the majestic and glorious company of God. Life on earth is considered a time of investment and the fruits of this investment are reaped in the eternal Afterlife. That being the case, it may be necessary for the chaplain or physician to remind the terminally ill patient or his family of these

teachings in an attempt to console and bring solace to the hearts of these individuals who are experiencing agonizing times.

Historically, Islamic legal scholars have defined life as that which is contrary to death. A being is said to be living if it has a structure (or body) which is composed of elements, (e.g. cells) without which the body cannot be formed. Legal scholars, in turn, divided life into two categories: vegetative life and animal life. Vegetative life is defined as a group of functioning cells that can acquire nutrition and grow but does not necessarily have to have a spirit. This declaration was made in the Sydney declaration of 1968 which stated “Existence of life in an organ or a group of cells does not necessarily mean that the organism itself is alive.”²²⁶ An example of this is an organ transplant. When an organ donor dies, his heart is harvested before it is transplanted into the recipient. The heart itself is biologically alive. However, it does not have a spirit that allows it to perform any voluntary actions. Consequently, a body or group of cells can be organically alive before the spirit is breathed into it and can still be organically alive after the spirit has departed. In the Islamic tradition, it is believed that the spirit is breathed into the body of the human being as a fetus.

Animal life, on the other hand, is defined as a body that possesses a spirit which allows it to perform voluntary actions. In contrast to vegetative life, animal life ceases to exist when the spirit departs. Using the approach of Imam al-Ghazali, the prominent Muslim scholar of the 12th century, the organs are like a machine and the spirit is like the operator of the machine. Death occurs when the body ceases to function as an operating

²²⁶ Qalahji, Mohammad Rawas. “Determinant Time of Death and Removing Resuscitative Equipment from the Patient” *Contemporary Jurisprudence Research Journal*. 24th ed.: 32-41, 100-116, Jan-Mar 1995.

machine. Therefore departure of the spirit occurs with the departure of the animal life but not necessarily the vegetative life.

The questions then still remain: where in the body does the spirit reside and how does one know if the spirit has departed from the body? According to Dr. Mohammad Rawas Qalahji, a professor at King Saud University, the spirit resides in the brain.

...the center of the spirit is the brain because any organ of the body other than the brain...may be amputated and the person does not lose his/her life. Hence, the heart, the lungs the liver and the kidneys can be removed and replaced by other human or artificial organs and life still continues without hindrance. As for the brain, it cannot be removed and replaced by another, as well as, its damage causes the creature to die.²²⁷

According to modern medicine, the brain dies within 4-6 minutes after blood perfusion and oxygenation cease. Hence, the brain requires functioning circulatory and oxygenation systems, whether functioning naturally or artificially. Consequently, according to the Islamic Jurisprudence Academy, a person is legally dead if one of two signs occur: 1) the heart and lungs completely and irrecoverably stop functioning. 2) All the functions of the brain irrecoverably come to a complete stop. Both criteria must be decided by an experienced physician.²²⁸

According to Dr. Qalahji, four requirements must be fulfilled in order for a patient to be declared brain dead:

1. The patient must be in a coma which is not induced by drugs or due to a disease caused by organs (other than the brain), such as kidney failure
2. Absence of electrical activity on the EEG (electroencephalograph)
3. Cessation of spontaneous breathing

²²⁷ *Ibid.*

²²⁸ *Ibid.*

4. Absence of brain stem reflexes.

The Islamic Jurisprudence Academy concluded that in the case of brain death “it is justifiable to remove the resuscitation apparatus from the patient if some organs such as the heart [are] still functioning due to the use of the apparatus connected to the patient.”²²⁹

Many legal ramifications stem from the death of a human being. While it is comforting to know that there are general guidelines which one should abide by when one is dealing with end-of-life issues, the reality of the situation is that the law, whether that of the American judicial system or that of the Islamic legal system, dictates that a stance must be taken regarding removing resuscitative equipment from a patient and a decision must be made as to at exactly what point a human being is declared dead.

The final scenario to consider is the patient who is in a persistent vegetative state (PVS) and is kept alive by total artificial nutrition. According to the 1994 Multi-Society Task Force on PVS,

The vegetative state can be diagnosed according to the following criteria: (1) no evidence of awareness of self or environment and an inability to interact with others; (2) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; (3) no evidence of language comprehension; (4) intermittent wakefulness manifested by the presence of sleep-wake cycles; (5) sufficiently preserved hypothalamic and brain-stem autonomic function to permit survival with medical and nursing care; (6) bowel and bladder incontinence; and (7) variably preserved cranial-nerve reflexes (papillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes.... A wakeful unconscious state that lasts longer than a few weeks is referred to as a persistent vegetative state.²³⁰

Based upon this definition, it is easy to see why some people say that it is ethical, and in fact necessary, to withdraw artificial nutrition and hydration from a patient in a PVS,

²²⁹ *Ibid.*

²³⁰ Multi-Society Task Force on PVS, Medical Aspects of the Persistent Vegetative State: Second of two parts, *New England Journal of Medicine*, 330 (22): 1572-1579, 1994.

such that the patient is “allowed to die.” However the definition is problematic. From time to time people who were diagnosed with PVS have recovered. If we decide that it is ethically acceptable to withdraw total artificial support from all such patients, how do we resolve the issue that a certain unknown percentage of them may have emerged from this state had we not “allowed them to die”?

Another argument for withdrawing total artificial support from PVS patients is that they have lost all cortical function. Such a person, it is argued, has lost the ability to think; thus, he no longer possesses the differentiating quality that makes him human. Such a person does not display any evidence of awareness or perception of pain. Drs. Young and Pigott, authors of “Neurobiological Basis of Consciousness” state, “Consciousness is complex and represents more than the sum of its parts, but when disordered, it is best to resolve which components are affected. The term impaired consciousness is too vague to be clinically useful.”²³¹ It is possible that the PVS patient can think, and can think about the signs of God for that matter and, thus from the Islamic perspective, has not lost the ability to fulfill the covenant to serve God. I do not think that we, as a medical and religious community, should deprive human beings of nourishment and hydration if there is any element of uncertainty.

One may argue that by keeping the patient alive by such measures, we are only prolonging his pain and suffering. We cannot be sure that this is the case, just as we cannot be sure that the patient would not experience pain and suffering if starved to death. Consequently, I – as a physician and Muslim - would rather err on the side of safeguarding myself from even the remote possibility of being the cause of pain,

²³¹ Young, GB and Pigott, SE “Neurobiological Basis of Consciousness” *Archives of Neurology* 56(2): 153-157, 1999.

suffering and death. This is particularly true in the case of a fellow human being, in whom God planned to keep his brain alive. We have benefited tremendously from medical research. But we also find ourselves in ethical predicaments that humanity never had to face previously. There will continue to be vast areas of unexplored territory that we must discover. Regardless of how far science and technology advance, we must also recognize that some things will remain mysterious and only in the knowledge of God. As the Prophet Muhammad was instructed to declare to humanity: “ ‘The Spirit cometh by command of my Lord: only a little of knowledge ...of it is communicated to you, oh men!’ ” (Qur’an 97:85).

Case Study with Commentaries

Uncertainty and Futility: A Case Study

Thomas P. Duffy

Joseph, accompanied by his wife, Helen came to see me in January 2004. They had been married for fifteen years and had no children. He was a computer specialist. She sold antique jewelry in a small store on the outskirts of a nearby town. They appeared to have a rich life together. Joseph was in his late forties suffering significant temperature elevation; his general practitioner had referred him to me; early laboratory results showed that he had severe anemia.

The general practitioner had been unable to identify the cause of Joseph's ailment. Between his visit to the general practitioner and me, Joseph had developed significant enlargement of his spleen. I recommended that he undergo a splenectomy, which would provide a tissue sample for biopsy, but which also had the possibility of being therapeutic since it could potentially ameliorate his decreased blood count and anemia. The biopsy revealed that Joseph had a histiocytic sarcoma, an extremely rare malignancy. At that time there were only eleven cases of this disease described in the entire world literature.

Uncertainty exists in all care of patients, even from the physician's vantage point. True, physicians are trained and expected to know as much as possible about a given disease and its possible treatments, but in some cases that knowledge is simply not available. In this circumstance there was unusually great uncertainty within the world of medicine over how the disease proceeds and how best to treat it, since only a few people worldwide had been diagnosed with this particular disease. In such situations, physicians are in a bind. On the one hand, they must know the limits of their knowledge. Yet on the other hand a physician must command, to the best of his ability, what knowledge there is—after all, patients expect and deserve expertise from their physicians.

After contacting several centers throughout the country, other specialists agreed that this was indeed a histiocytic sarcoma, but there were no new suggestions about

useful therapies. In fact every therapy that had previously been used had ended in failure. One regimen of a relatively simple chemotherapy drug did seem to evince slight temporary improvement, so I recommended this therapy to Joseph. I also suggested to Joseph that a second opinion was necessary.

At this point, I was a complete stranger to Joseph and his wife Helen. We had met only twice. We were about to embark upon a journey which would end with Joseph's death in approximately one year. Joseph and Helen could not and did not anticipate the medical problems that eventually arose. So instead of telling Helen and Joseph immediately about the outcome of the eleven known cases—all of which were fatal—I opted to lay more groundwork first.

If the patient were to ask, “Could anybody—has anybody—survived this disease?” then the physician must be truthful and tell what he knows from the data. Joseph did not ask that question, and I chose not to volunteer this information to him. Instead, I said that we really didn't know what the outcome would be, because there were new drugs available to us. This is a true statement. But it also evaded the distressing data of survival post-diagnosis.

Truth is important, but it is not always clear how, when, and by whom truth should be articulated. At first pass, several questions arise: “How much truth must one burden a family with? How soon should a physician disclose everything he knows about the disease trajectory?” Such queries might seem to be simple or merely rhetorical, but they are not. In many medical situations, a physician's delivery of too much information too soon can be devastating to a patient and his family. Hearing and processing difficult news takes time: In most cases of terminal diagnosis it will probably take more than one visit to communicate the facts of the situation to the patient, let alone to begin to discuss

treatment options.²³² Some people maintain that it is absolutely essential to be brutally honest about outcome statistics at the first diagnostic meeting. My guess is that someone who lobbies for this “brutal honesty” has never sat at the bedside of a patient and recognized that in destroying their hope, whatever life they will live from that point on is somehow going to be lessened.

This quandary raises the question of hope. Many physicians, especially those who work with patients with terminal illness, see themselves as the unwitting wardens of a patient’s hope in the first moments after a diagnosis has been given. Some physicians feel, as I did, that even if they are unable to provide a clear medical cure, they must not allow the patient to abdicate hope.²³³ This is not to say that a physician should provide vain hope—hope against hope, hope against all rational knowledge, hope manufactured solely for the psychological benefit of the patient. But, strangely, it may also be the physician’s responsibility not to eliminate all of the patient’s hope in one fell swoop. Sometimes patients need a while to get used to the idea of having a new condition—a new identity—before they can think about what this means and how to proceed.

From February to September 2004, Joseph returned to work. Although he and Helen lived under the threat of the current disease, his symptoms were limited during that particular period of time. Unfortunately, this period of relative health may have given

²³² A story may best illuminate this situation. One of our family’s closest friends underwent surgery that was thought to be relatively simple. In the course of it the surgeons discovered an advanced malignancy. The patient was our very close friend, and we felt a responsibility to help her through this. I accompanied her when she went to her physician to discuss the diagnosis. We sat down, and the physician did a wonderful job of introducing the terrain of her illness. He told her threatening knowledge: She had an advanced malignancy. He then proceeded to discuss with her, in detail, what this diagnosis meant. When we returned home, and I sat down with this very intelligent woman, it was apparent that she had not heard anything beyond the initial diagnosis. Her receptors had shut down after she heard that she had cancer. Sometimes a lot of information at once, especially threatening information, is too much for a patient to receive in the initial visit. The best a physician can do is to introduce the terrain and return, time after time, to the conversation: “Do you have any questions about what it is we spoke about?” and “Tell me what your understanding is of what it is that we’re embarking upon.”

²³³ For an in-depth discussion of this situation, see the essay in this volume by Jennifer Beste.

Joseph an unrealistic sense of his disease prognosis. It wasn't until September, when Joseph reported a return of fever and anemia, that I knew that curative treatments had failed. However, the locus of the tumor remained a mystery. A month later, in October, repeat scans revealed that Joseph had lesions in his vertebral column and liver. Pain followed. His quality of life changed; he required very aggressive support for pain management.

Given the relatively rapid expansion of his tumor, Joseph's need for narcotics increased. We had already removed his spleen. We had treated him with chemotherapy that failed to curb the spread of the sarcoma. Our options were severely curtailed, and Joseph seemed to understand this. Helen, however, pointed out that there had been seven months when he had few symptoms. She wondered whether it would be appropriate to return to the original regimen of chemotherapy.

Medically speaking, if someone receives a course of chemotherapy that fails within an interval of approximately one year, it is usually not worthwhile to repeat a course of the original drugs. However, Joseph and Helen decided to attempt chemotherapy once more. Joseph entered a new course of combination chemotherapy, which raised the ante because it is highly toxic.

High toxicity has significant physiological effects. Joseph's appearance changed. He lost his hair. He developed problems in his gastrointestinal tract. The prednizone made his face swell and elevated his blood pressure. Whatever normal bone marrow was still remaining was knocked out, creating a high risk for infection. Fevers that may once have been solely correlated to the malignancy now indicated infection. The whole complexion of his life had changed, and he was no longer able to work, although he attempted to do what he could with his laptop computer in the hospital. He increasingly

required significant pain medication. At this point, he had not “given up,” but more importantly Helen was even further from capitulating. She expressed her great love for her husband and her great need that he stay alive for her.

In discussions about treatment options, Joseph and Helen presented a united front: All interventions should be pursued if they could possibly cure the disease. This was unusual; most people in a situation like Joseph’s opt to limit their types of treatment. This round of chemotherapy failed, and additional tumors emerged within his vertebral column.

Throughout all of this, Joseph began to suspect what the outcome was going to be. He was withering visibly in body, and he seemed to wither in spirit as well. For many patients the dying process often includes a slow deterioration, during which period of time many patients are extraordinarily alive. Eventually, the dying process tends to accelerate. How and when the dying process is recognized, and what treatment options should accompany that process, becomes a central concern for the physician and patient.

At any rate Helen—more than Joseph, though they were always unified in their decisions —wanted to resist that dying process as long as possible. She wanted Joseph to repeat once more the chemotherapy trial that had worked in the past. Joseph agreed, so we gave him a third round of chemotherapy. He began spending much more time in the hospital, and he required larger and larger amounts of narcotics.

Should I have agreed to all these courses of chemotherapy that were only making Joseph’s life worse? Should I have offered very direct advice and kept my own opinions out of the discussion? Should I have flatly refused to grant the third round of chemotherapy on the grounds of professional experience? In short, when does a certain type of medical treatment become pointless?

The couple's choice of a third round of chemotherapy may well have been inadvisable, even pointless, and therefore morally problematic. However, it is difficult (if not impossible) to quantify systematically the success rate of a given treatment for a given individual. A purely quantitative approach to the patient, his disease, and his life situation does not acknowledge the importance of other factors such as the patient's family, his social situation and life values, and his physiological particularities. Some critics of physicians say that futility is in the hands of physicians, and hence the term is inherently subjective and physician-controlled. And the critics are right, in a sense: Futility is a subjective, situation-specific reality, and physicians are in a position of authority. But they are not always the only decision-makers. In this case, Helen didn't see a third round of chemotherapy as futile and, as long as it was not going to hurt Joseph, she wanted to see if it would work. The trouble is—it *did* hurt him.

Would Joseph have gone through the three courses of chemotherapy if his wife hadn't pushed it? He likely would have undertaken two, but possibly not three. Yet Joseph was definitely a partner to the enterprise, for he and Helen decided on his treatment trajectory as a couple and always presented a united front. I therefore felt it impossible to discuss the concept of futility when Helen and Joseph insisted on the third round of chemotherapy. To say to a patient, "I believe that it's unlikely that this is going to work," is a difficult task for physicians. It is the rare patient to whom you can say those words. Thus, most physicians acquiesce in the face of a patient's or family member's fervent unwillingness to "give up" on the possibility of effective curative treatment.²³⁴

²³⁴ There are boundaries, of course; if Helen and Joseph had asked me to perform CPR and put Joseph on a respirator, then the discussion would have gone differently; I would say to them, "We are now at a stage in

When the third round of chemotherapy failed, we had a lengthy discussion as to whether or not it was appropriate to say that the tumor was overwhelming him. Helen and Joseph had reached *their* subjective judgment on the pointlessness of further treatment. They were in agreement that further curative treatments should be avoided due to the harm that they caused Joseph's present life.

Joseph left the hospital with the desire to spend some time in his own home, but shortly thereafter he was readmitted to the hospital with fever and infection. At that point he claimed that the hospital staff should not attempt to reverse the infection. Instead, he requested that he would like to die simply, without any more aggressive intervention. Joseph died, at home, shortly thereafter. I spoke to Helen after Joseph's death. She was candid about her grieving process and said that she was only beginning to emerge from the experience.

Between a patient's terminal diagnosis and his eventual death, much has been shared between a patient, his family, and the physician. Yet the contemporary American medical system is organized almost exclusively around the medical needs of the patient, not around the long-term needs of the family. This puts the physician in a quandary: Once the patient dies, contact between the family and the physician tends to cease. Some physicians go to patients' funerals; others write a letter of condolence; others do nothing. As a physician who has accompanied many patients to the edge of their dying, I feel that it is important for physicians to acknowledge what we have witnessed—to pay tribute to the life that has been lived and to those people who are left behind.

your illness where I and the whole healthcare team would agree that doing those interventions, which are fundamentally broader than the particular disease itself, is inappropriate.”

First Commentary

Medicine and Moral Balance: The Art of Disclosure

Robert A. Burt

If the practice of medicine is an art as much as a science, the interaction with patients—especially where they are suffering from imminently life-threatening diseases—is almost all art. Tom Duffy’s essay masterfully conveys this proposition. He identifies principles that must guide this interaction: truth-telling, deference to the patient’s right to choose his treatment, the physician’s obligation not to inflict harm through clearly futile treatments, the physician’s responsibility to safeguard the patient’s emotional as well as physical well-being. But as Duffy shows, these principles are not self-defining and, indeed, are frequently in conflict with one another.

One of the most intriguing dilemmas that Duffy highlights is the problem of identifying exactly who the patient is. Duffy observes that Joseph and Helen made treatment decisions “as a couple and always presented a united front.” Duffy thus appears to have viewed both husband and wife together as “the patient” in deference to their vision of themselves. It is apparent from Duffy’s account, however, that the propriety of this deference was poignantly forced into doubt by the question whether to embark on a third course of chemotherapy. The failure of the prior courses and Joseph’s terrible suffering as a result of the second round had, as Duffy describes it, “withered” Joseph both in body and in spirit. It was also apparent to Duffy that Helen wanted to undertake a third round and to “resist the dying process ... more than Joseph.”

But Duffy was unwilling to interfere with the united front that this couple had consistently maintained. Duffy recounts that he found it “impossible to discuss the

concept of futility,” that he kept himself cautiously and respectfully outside the boundaries of this intensely committed marriage and refused to intervene in a way that might bring into visibility any latent conflict between Joseph and Helen about the desirability of the third course of chemotherapy. Duffy only laconically observes that “the third round of chemotherapy failed”; but we might deduce from his vivid account of Joseph’s suffering from the second course that the third course was also agonizing, and perhaps even worse for Joseph. After the failure of the third round, Duffy states, “we had a lengthy discussion ... [and] Helen and Joseph had reached *their* subjective judgment on the pointlessness of further treatment.”

Would it have been appropriate for Duffy to act on his close observation of the decision-making dynamics of this couple by talking to Joseph alone before the final decision to embark on the third round? Would it have been appropriate for Duffy to raise the futility issue with Joseph and discuss the possibility that his wife was clinging to unrealistic hope that Joseph himself might be ready to forego? My own impression, based on the spare account that Duffy provides, is that this course might have been appropriate—but that it was not ethically obligatory. The only ethical obligation that I see in this circumstance is that the physician must explicitly examine the possibility that this intervention would best serve Joseph—and perhaps even Helen—in living the imminent last days of his life. The answer to this question depends on multiple considerations—considerations that cannot be reduced to any formalistic calculus.

This is equally true of the other questions that Duffy’s account raises: Tell the truth; but how to tell it so that the patient is prepared to understand it? Defer to patients’ choices; but who exactly is the patient making those choices? Avoid the infliction of pointless suffering through futile treatments; but when is there good reason to endure

suffering even though cure seems out of reach? The only ethical obligation that seems to me clear-cut and readily applicable in making these complicated calculations is that physicians must not see themselves as isolated decision-makers, that they must seek out opportunities to consult with others, both within and outside the health care professions. Both in individual cases and in general discussions (as exemplified in the pages of this volume), this is the best means to assure that the full range of complex considerations—the entire palette, one might say, of medicine’s art—is brought into view. Such consultations are also the best way for individual physicians to find the support necessary to keep their emotional and moral balance in confronting the poignant and often tragic circumstances endemic to the practice of medicine.

Second Commentary

Truth, Futility, and the Importance of Relationships:

A response to the case of Joseph and Helen

Mark R. Mercurio

This case raises many important questions regarding the care of the dying patient, among them truth, futility, and the role of family members. Dr. Duffy acknowledges the importance of being truthful, but then points out that patients sometimes need time to absorb the truth. Too much information too soon can sometimes overwhelm patients, which can not only cause them added distress, but may actually impair their ability to make decisions. Thus the paradox, that immediate complete disclosure of all the information can actually compromise a patient's autonomy.

Dr. Duffy suggests that those who endorse "brutal honesty" in these situations have never had to be the one giving the information. His point is well taken; there is a certain credibility that can come only from direct experience. Surely the clinicians that have cared for these patients have insights that others do not. However, in some circumstances, our experience that brings insight might also potentially impair our judgment. When one has long held a certain opinion, it is sometimes difficult to recognize that it is flawed. This recognition becomes even more difficult, however, if one has *acted* on that opinion, as the clinician must. In such a case, he must not only recognize that he thought wrongly, but also that he acted wrongly, which may be a far

more difficult psychological task. In this way, those who have never managed dying patients may in some ways see things more clearly or objectively than we can.

Perhaps the most important thing that can be said about truthfulness here is that a physician (like everyone else) must be truthful first and foremost *with himself*. The desire to avoid a difficult situation presents a risk of self-deception. We might convince ourselves that withholding certain information is done for the patient's benefit, when the real motive is avoidance of the unpleasant task of giving grim news. In the case presented, however, self-deception does not seem to have played a role. Dr. Duffy seemed painfully aware of, and primarily concerned with, the impact of his words on Joseph's remaining days.

Was the chemotherapy in this case futile? Given the scant data available, it is hard to say. It does not seem right to say something is impossible, or virtually impossible, based on such limited experience. It therefore seems reasonable to offer the chemotherapy if the informed patient wants to try. However, if a physician feels it is unlikely that a prescribed treatment will work, I believe the patient should be told, as difficult as that is. To remain silent on the likelihood of success risks misleading the patient. When a physician prescribes a treatment, a patient might reasonably assume it has a good chance of working unless told otherwise. Still, Dr. Duffy's concerns about not wanting to take away Joseph's hope are well taken. Words must be chosen carefully. "Unlikely" does not necessarily dash hopes as soundly as "impossible."

One does get the sense that ongoing chemotherapy seemed futile by the second course, and even more so by the third. How, then, can we justify it? The answer might reside in the recognition that Joseph's relationship with Helen was an essential part of his life and well-being. A more absolute devotion to patient autonomy might have led one to

explore the possibility that, without Helen's input, Joseph might have chosen to forgo the third course of chemotherapy. However, Dr. Duffy seems to have concluded (and I agree) that Joseph's interest was best served by keeping Helen inside the decision-making process and onboard with the plans.

There is valid concern that the third course of chemotherapy, which may well have been futile, caused harm to the patient. One could likely have fashioned a strong argument for withholding the chemotherapy on that basis. However, it is important to consider the potential benefits of the treatment as well. It might have benefited Joseph to do it for Helen, and might have benefited Helen herself, possibly even after Joseph's death. One aspect of our respecting relationships is the acknowledgement that serving Helen's interest could be a benefit to Joseph.

Patients like Joseph seem to call for attention to so many sometimes conflicting considerations, such as their right to know, ability to understand, need for hope, and right to control their situation as much as feasible, as well as our obligation to spare them needless suffering. Each of these must be weighed within the context of their lives, which for most means primarily their relationships. Joseph's medical management represents a struggle to balance all of these. While I think Dr. Duffy could have justifiably refused the third course of chemotherapy, I do not think he was obligated to refuse, and I can see the wisdom in his care of Joseph and Helen.

Third Commentary

Navigating the Terrain of Compassion

James Swan Tuite

Thomas Duffy's "Uncertainty and Futility" raises several interesting and important questions about the limits of meaningful and futile interventions. His case summary enjoys unique qualities in its deft ability to illustrate the multifaceted complexities of medical practices through the compassionate narration of his *involvement* with his patient Joseph and Joseph's wife Helen. In part, I take it that Duffy's narrative success flows from his choice to track the itinerary along which he, Joseph and Helen traveled together during their year-long effort to treat Joseph's histiocytic sarcoma. For his remarkable case description, I applaud Duffy. For example, when he acknowledges his worry that blunt truth-telling, though satisfying the literal requirements, can harm, Duffy acknowledges his depth of concern for his patient—an *involvement*—that typically escapes case summaries.

One issue raised by this case is what we could label "compassionate harm." Such harms involve failures of compassion where efforts to heal or ameliorate suffering inappropriately contribute to or add additional sufferings. It is not clear to me that this case qualifies, but cases involving futility, uncertainty or both frequently raise the likelihood of compassion going awry. To clarify the dangers of compassionate harms and particularly with regard to futility judgments and uncertainty, it is important to recognize that within the medical context compassion is multidimensional and involves both care and respect. Even a brief survey of consensus norms in medical ethics, such as the Georgetown principle approach (autonomy, nonmaleficence, beneficence, and justice),

indicates our conventional interest in respecting individual decision-makers, avoiding harm, and the desire to aid patients in their suffering. Generally speaking, compassion transgresses the borders of the principle approach by adding a relational dimension often implied but not made explicit in the principle approaches to medical ethics.

On the one hand, a caregiver (doctor, nurse, or chaplain) aims to ameliorate a patient's suffering within the limits of the caring role. We might even say, following Margaret Farley, that compassion consists of a caring disposition to ameliorate suffering, the caring response to suffering, and the specific healing effort(s). On the other hand, care involves respect for the subject of care—which is why we use, however clumsy for human relations, instruments such as informed consent in an effort to elicit patient interests and wishes that ultimately ends in a sharper or more refined picture of patient needs. Thus, genuine compassion in health care is multi-dimensional and it is consequently subject to potential failures in each dimension.

Caregivers may care too much, too little, or inappropriately. They can mistake the sufferings of their patients and misdirect the helping efforts. With regard to futility judgments or in cases where extended and difficult treatments yield no change in prognosis, futility concerns are typically expressed in the form of a question: Should *this* treatment regimen continue? Such cases, as critics of futility argue, raise acute worries about compassion by virtue of its potential to put the interests of patient, doctor and medicine at permanent odds with one another. But as Duffy's case summary suggests, futility and uncertainty raise an even greater likelihood of compassionate harm.

Futility and uncertainty tend, in a particular and perhaps unavoidable way, to threaten the integrity of health care practice, because such cases exceed the limits of medical knowledge and therefore pose the possibility of blurring our sense of appropriate

care. A physician might, as Duffy notes, fail to recognize the complexities of communicating futility and uncertainty with patients and opt for blunt honesty or maybe even withhold information because it is believed such withholding is in the patient's best interest. Further, in cases where medical knowledge offers no relative certainty, the object of care shifts toward a deeper and more sensitive dimension of personhood. I think this shift is expressed when Duffy asked whether Joseph would have opted for a third round of treatment were his wife Helen less encouraging. I think it is precisely in this acknowledgement that Duffy raises a warning of compassionate harm as well as the inter-subjective complexities that accompany futility and uncertainty.

Fourth Commentary

Minimally Beneficial Treatments and the “Revealed Subjectivity” of the Patient

Constance T. Donovan

The process for making decisions about minimally beneficial treatments is influenced by such factors as: the decisional capacity of the patient; the availability of information about the wishes of the patient; the time frame of the need for a decision; the patient’s physiological status and the potential outcomes of the proposed treatment; and the type of relationship between the clinician and the patient.

While most of these factors have been widely discussed in the literature, considerably less attention has been given to the clinician-patient relationship, and especially to the potential that certain kinds of relationships have for making more transparent the patient’s subjective views and experiences. This case offers the opportunity to consider a physician-patient relationship in which there is engagement and dialogue with an adult, decisionally-competent patient and his wife. It also offers the opportunity to pay attention to the revealed subjectivity of the patient as he reaches decisions.

Consider, first, the early days of their relationship when they were strangers. The physician had not yet had the opportunity for in depth, engaged conversations or for the kind of observations of behaviors and attitudes which might reveal the patient’s meanings or ways of coping. Yet, a decision had to be made about whether to share the survival data in the course of informing the patient about the first proposed treatment. To reach a decision, the physician could have simply employed a detached objective approach, which applies ethical principles such as truth telling, without consideration of particular

situations. Clearly, the physician rejected this “distanced” approach and did not tell the patient the “brutal” truth about survival. Instead, the physician chose a nonlinear, contextual process; he considered ethical principles but also included at least two other dimensions. First, he sustained a genuine effort, even in this early stage of the relationship, to view the situation from the inside and to take into account certain subtle messages, such as the patient not asking about survival even when open communication provided the opportunity for such questions. Second, he considered insights gained from similar oncology cases—notably, the observation that since patients often need time to adjust to a new condition and find meaning, they can be harmed if disclosures at the time of diagnosis remove all hope. This more complex approach requires not only commitment to and involvement with the patient and family but also a willingness to tolerate uncertainty and ambiguity.

Turning now to the decisional process regarding the third round of chemotherapy, it is apparent that the physician is deeply immersed in the patient’s and his wife’s subjective beliefs and values. Their subjective perspective of the good was to continue any potentially effective curative treatment. Yet, the objectively determined medical benefits were viewed as not only minimal but potentially harmful. The physician struggles with what is the “right” choice: Should he use a “distanced” approach and unilaterally decide not to treat because it would be both pointless and harmful? Does he attempt to influence the patient and his wife’s subjective perspective of the good (pursuing curative treatments) by providing information and helping them to reconsider their perspective? Or does he simply respect the subjectivity of the patient and proceed with treatment?

Ultimately, the physician chose the third option and rejected the “distanced” approach. Most interesting is the physician’s decision to not influence the patient’s subjective perspective. It would seem that the physician-patient relationship, at that particular time, did not allow for reconsideration of the previously established good, which was pursuing curative treatment.

There was, however, another dimension to the situation which was not explored and which might have been helpful. Given that the patient was in the hospital and most likely on an oncology unit, it seems reasonable to assume that other professionals (nurses, social workers, chaplains) had committed and involved relationships with the patient and his wife. The context and the interactions of these professionals plus their views of the patient’s subjective perspective are likely to have differed from that of the physician. For example, in the context of a nurse-patient relationship, where the nurse would actually be giving physical care and providing emotional support to this man who was suffering from significant pain, deterioration of his body, and disintegration of his life, it is not difficult to imagine that the patient might indicate in some way a readiness to explore what it might mean to him and his wife if he did not pursue treatment. If the nurse is sensitive to this readiness, knowledgeable, and provides only the information that the patient wants, the patient and his wife might begin the process of reframing their subjective perspective.

This hypothetical possibility raises the question as to whether a fuller understanding of the patient’s and his wife’s evolving subjective perspective might have emerged if the physician and other involved professionals had entered into a dialogue. With a fuller understanding made possible by communication among different members

of the medical care team, the physician's dialogue with the patient and his wife might have led to a different decision regarding the third course of chemotherapy.