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Keywords: medical futility, end of life, communication, critical care, intensive care unit, Edmund Pellegrino.

INTRODUCTION

Caring for critically ill patients at the end-of-life has been plagued by sometimes insurmountable difficulties. A persistent challenge concerns the significant communication gaps between clinicians and families in regard to treatment options. Often during the trajectory of a patient's illness, there is a point at which further medical intervention is believed to be non-indicated or inappropriate—either because it will be overly burdensome, or because it will be disproportionate in relation to the expected benefits. Clinicians hope, then, to redirect the goals of care so that the patient will be comfortable before an inevitable death. Many times, however, the patient, the surrogate, or the family does not agree with the medical team. Although attempts have been made to clarify and define medical (or clinical) futility and to show when it may be ethically invoked, this has been fraught with controversy. After more than twenty years of debate, there seems to be little or no substantive consensus on a definition or criteria for its use. Increasingly there has been a focus on procedural resolutions—either in the form of hospital policy, or in state legislation (such as that found in Texas). In this paper, I do not discuss the merits of these proposals; instead, I aim to identify lapses in good end-of-life communication between clinicians and patients (or their families), and argue that improved communication may mitigate intractable conflicts in regard to clinical futility. I have three objectives in this paper: first, to provide an overview of the medical futility debate; second, to outline several significant barriers to good communication in the end-of-life context; third, to re-orient the futility debate toward an improved focus on communication ethics. By acknowledging that ethical decisions at the end-of-life are at root shared decisions among physicians, patients, surrogates, and families, I demonstrate the desirability of authentic dialogue over value conflicts in medical decisions at the end-of-life.

DEBATE OVER MEDICAL FUTILITY

Today, the majority of American patients die in institutional settings (hospitals, hospice, nursing homes, and ICUs),¹ usually after an explicit decision to withhold, or withdraw life-sustaining medical treatment.² These decisions indicate that at some point a decision must be reached about medical limits. One way of describing these limits is in the language of clinical futility. In its common usage, the adjective futile means “serving no useful purpose: completely ineffective” and the noun futility is “the quality or state of being futile.”³ When applied to the medical context, futility determinations are judgments that a particular medical intervention will not achieve its intended goal—i.e., to cure, ameliorate, or reverse a disease process—given the medical circumstances, the trajectory of disease, and technological limitations. Determinations of futility have not been free of controversy, however. This is partly due to its unpleasant connotations—e.g., suggesting abandonment or a devaluation of the patient⁴—but also the worry that clinicians will apply the determination in an inconsistent way. Two questions in the debate have

¹ See, for example, Naoko Muramatsu, Ruby L. Hoyem, Hongjun Yin, et al., “Place of Death Among Older Americans: Does State Spending on Home- and Community-Based Services Promote Home Death?” *Medical Care* (2008) 46 (8): 829-38. See also Bob Winter and Simon Cohen, “ABC of Intensive Care: Withdrawal of Treatment,” *British Medical Journal* (1999) 319 (7205): 306-8. “About 70% of deaths in intensive care occur after withdrawal of treatment,” 306.

² See Edmund D. Pellegrino, “Futility in Medical Decisions: The Word and the Concept,” *HEC Forum* (2005) 17(4): 308-18.

³ See Merriam-Webster (on-line), available at <http://www.merriam-webster.com/dictionary/futile>, accessed September 7, 2011.

⁴ Pellegrino, op. cit., 309-10.

become paramount: First, are there medical interventions that we can label futile for a specific patient because the intervention will not be effective at curing, reversing or retarding a disease process, or restoring health and function? If so, are physicians ethically permitted to refuse to provide those interventions even if the treatment is requested or demanded by the patient or appropriate surrogate?

(A) GENERAL CRITERIA FOR INVOKING MEDICAL FUTILITY

The initial futility debate sought to resolve disputes by outlining contexts in which given therapies would be futile,⁵ with the implication that the medical team may withhold or withdraw the intervention unilaterally—i.e., against the wishes of the patient, surrogate, or family. In their review of the futility debate, Brody and Halevy have identified⁶ several general situations in which CPR would be ineffective. For example, an intervention will be physiologically (or scientifically or strictly) futile when it will not achieve its intended physiological effect or function.⁷ Alternatively, imminent demise futility means that regardless of the intervention, the patient will die in the very near future.⁸ Finally, lethal condition futility means that regardless of the intervention, the patient will die in the near future of an underlying lethal condition that the treatment cannot reverse.⁹

Schneiderman, Jecker, and Jonsen¹⁰ were the first to argue that the futility determination should be based on explicit quantitative and qualitative thresholds.¹¹ Other commentators have based the futility decision on different factors. For example, Bernard Lo and Ann Alpers have argued¹² that unilateral do-not-attempt-resuscitation (DNAR) orders are justified by physicians in some circumstances (in addition to cases in which maximal treatment or pathophysiological benefit fails patients), as long as there are safeguards against inconsistency and disregard for patient values. John Paris et al. have argued¹³ that the physician should describe the patient's diagnosis and prognosis, as well as offer a medical recommendation, but should not be compelled to undertake patient-proposed interventions. Stuart Youngner, by contrast, has argued¹⁴ that physicians are in the best position to assess the empirical facts of futility, but that almost all such determinations (except physiological futility and an absolute inability to postpone death) involve value judgments. His worry is that physicians “run the risk of ‘giving opinions disguised as data.’”¹⁵ This last concern—i.e., that the medical futility determination will be based on either the personal or professional values of the physician instead of the medical facts—forms the core criticism against unilateral determinations of medical futility.¹⁶

(B) MEDICAL FUTILITY: CRITICISM

A key concern of critics is that the determination of medical futility fails to consider the values and goals of patients and families.¹⁷ According to these commentators, the concept should be eradicated altogether. It has been described as elusive,¹⁸ an

⁵ Jeffrey P. Burns and Robert D. Truog, “Futility: a concept in evolution,” *CHEST* (2007) 132(6): 1987-93.

⁶ Baruch A. Brody and Amir Halevy, “Is Futility a Futile Concept?” *Journal of Medicine and Philosophy* (1995) 20(2): 123-44.

⁷ Adapted from *ibid.* Lo and Alpers provide an example: CPR will be physiologically futile if it cannot restore spontaneous heartbeat. See Bernard Lo and Ann Alpers, “When is CPR Futile?” *Journal of the American Medical Association* (1995) 273(2):156.

⁸ Adapted from Brody and Halevy, *op. cit.*

⁹ *Ibid.*

¹⁰ Lawrence J. Schneiderman, Nancy S. Jecker, and Albert R. Jonsen, “Medical Futility: Its Meanings and Ethical Implications,” *Annals of Internal Medicine* (1990) 112(12): 949-954.

¹¹ Quantitative futility is the probability that a given medical intervention has of being clinically ineffective such as “when physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of reported empiric data) that in the last 100 cases, a medical treatment has been useless, they should regard that treatment as futile” (*ibid.*, 951). Qualitative futility means that a life-sustaining treatment is futile when it does not provide a tangible benefit to the patient as a whole (i.e., cure, ameliorate the illness, or reduce pain and suffering in the patient): “any treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care should be regarded as nonbeneficial and, therefore, futile” (*ibid.*, 952).

¹² Lo and Alpers, “When is CPR Futile?” *op. cit.*

¹³ John J. Paris, Michael D. Schreiber, Mindy Statter, et al., “Beyond Autonomy—Physicians’ Refusal to Use Life-Prolonging Extracorporeal Membrane Oxygenation,” *New England Journal of Medicine* (1993) 329(5): 354-357.

¹⁴ Stuart J. Youngner, “Who Defines Futility?” *Journal of the American Medical Association* (1988) 260(14): 2094-2095. On this view, “Physicians should not offer treatments that are physiologically futile or certain not to prolong life, and they could ethically refuse patient and family requests for such treatments” (*ibid.*, 2095).

¹⁵ *Ibid.*, 2095.

¹⁶ For example, the decision that some treatments are not worthwhile is an altogether different kind of judgment than whether a particular treatment will work. Cf. Susan B. Rubin, “If We Think It’s Futile, Can’t We Just Say No?” *HEC Forum* (2007) 19(1): 45-65; p. 47: “[...] there are stark differences of opinion about the kinds of treatments that are appropriate and inappropriate and about who ought to be the ultimate decision maker.”

¹⁷ Cf., e.g., Rubin, “If We Think It’s Futile,” *op. cit.*

illusion,¹⁹ unnecessary and dangerous,²⁰ and too ambiguous and pejorative²¹ to be appealed to. Whereas some have noted its shaky foundation,²² others have stressed that its application to particular cases, as a unilateral trump to patients' claims to autonomy, offers only a partial solution to these disputes.²³ According to the American Medical Association's Council on Ethical and Judicial Affairs, the futility determination is "essentially subjective" and "A fully objective and concrete definition of futility is unattainable."²⁴ Still others believe the concept conceals various value-based assumptions about which there is no consensus—e.g., which medical interventions are "reasonable" to attempt and what quality of outcome is "worth" attempting to achieve. Arthur Caplan has labeled this the debate over "odds and ends."²⁵ As Robert Veatch and Carol Spicer have argued, "The real problem is with care that has an effect, but that clinicians believe has no benefit" since the latter "is not a judgment based on medical science" but rather "grounded in beliefs and values about which people inevitably disagree."²⁶ Similarly, Susan Rubin has argued convincingly that "One of the most significant mistakes" of the futility debate is "the mistake of imposing our [professional] views of a good death, of lives worth living, of battles worth fighting, or risks worth taking, or of suffering worth enduring uniformly across the patient population, a population which we know to be profoundly diverse."²⁷

(C) SUMMARY

Definitions of Medical Futility Have Suffered from Several Theoretical and Practical Limitations

No definition enjoys universal support among health professionals; All medical decisions to withhold or withdraw life-sustaining treatment have an irreducible value component; Proposed definitions often fail to distinguish between judgments of medical fact and normative judgments of value; Judgments from medical fact rest on probabilistic judgments that are uncertain and debatable; Normative judgments are variable from practitioner-to-practitioner and have not been endorsed by society as a whole; and there is little consensus on the decision question—i.e., who should decide when physicians and patients are at loggerheads?

Such persistent controversy indicates that definitional consensus will not be forthcoming. Furthermore, since there is little consensus on who should have the ethical authority to decide whether to withhold or withdraw interventions, many advocate procedural resolutions. Ultimately, because procedural approaches tend to skirt the substantive issues at the heart of the debate—issues that, I will argue, must be confronted head-on—I look to improved communication as a way of bridging the gap between conflicting values at the end-of-life.

From Procedural Solutions to an Ethic of Communication

As the previous sections have illustrated, the determination of futility is ultimately bound up with value judgments—it is a decision that, in addition to knowledge of the clinical facts, requires assumptions about reasonable benefit and potential outcome, and some articulation of the proper goals of medicine. As each of these elements to the decision has become controversial, many have looked to procedural resolutions.²⁸ Some call for hospitals to adopt futility protocols that would spell-out criteria by which

¹⁸ Robert D. Truog, Allan S. Brett, and Joel Frader, "The Problem With Futility," *New England Journal of Medicine* (1992) 326(23): 1560-1564.

¹⁹ John D. Lantos, Peter A. Singer, Robert M. Walker, et al., "The Illusion of Futility in Clinical Practice," *American Journal of Medicine* (1989) 87(1): 81-84.

²⁰ Alexander Morgan Capron, "Medical Futility: Strike Two," *Hastings Center Report* (1994) 24(5): 42-43.

²¹ Raanan Gillon, "Futility—too ambiguous and pejorative a term?" *Journal of Medical Ethics* (1997) 23(6): 339-40.

²² Brody and Halevy, "Is Futility a Futile Concept?" op. cit.

²³ Stuart J. Youngner, "Applying Futility: Saying No Is Not Enough," *Journal of the American Geriatrics Society* (1994) 42(8): 887-889.

²⁴ Council on Ethical and Judicial Affairs, American Medical Association, "Medical Futility in End-of-Life Care: Report of the Council on Ethical and Judicial Affairs," *Journal of the American Medical Association* (1999) 281(10): 937-941.

²⁵ Arthur L. Caplan, "Odds and Ends: Trust and the Debate Over Medical Futility," *Annals of Internal Medicine* (1996) 125(8): 688-689.

²⁶ Robert Veatch and Carol Spicer, "Medically Futile Care: The Role of the Physician in Setting Limits," *American Journal of Law and Medicine* (1992) 18(1-2): 15-36.

²⁷ Rubin, op. cit., 50. Rubin has published a more extensive critique of futility in her book *When Doctors Say No: The Battleground of Medical Futility* (Bloomington, Indiana University Press: 1998).

²⁸ For a useful breakdown of the history that led to this development, see Paul R. Helft, Mark Siegler, and John Lantos, "The Rise and Fall of the Futility Movement," *New England Journal of Medicine* (2000) 343(4): 293-6. See also Burns and Truog, "Futility: A Concept in Evolution," op. cit.

medical futility could be invoked.²⁹ Others have advocated increased legislation, modeled on the Texas Advance Directives Act of 1999.³⁰ Both of these aims are admirable, allowing for increased transparency at the organizational and judicial levels. Today if physicians believe that further aggressive life-sustaining interventions are inappropriate, they have new avenues in which to seek resolution—either through hospital policy or recourse to the courts.

Nevertheless, these resolutions are limited because they tend to skirt the substantive value conflicts at the heart of the debate in favor of procedures—procedures that must eventually acknowledge some notion of the clinical reality (i.e., futility) in order to bring closure to the debate.³¹ The worry is that such resolutions become a conversation stopper; the physician does not need to engage the concerns of the family if, for example, she can follow a step-by-step process to withhold or withdraw inappropriate life-sustaining treatment. For these reasons, I would like to suggest that a renewed focus on improved communication might bring further clarity to a discussion that is increasingly less about medical facts, and more about the underlying values of the medical profession and the individual family. The hope is that genuine conversation—not a transmission of facts, but a grappling together of the ethical values at stake—will reduce potential conflict and thereby mitigate recourse to ethics committees and legal resolutions. As the next sections illustrate, end-of-life conversations present real challenges to physicians and families alike; an ethic of communication therefore becomes essential to clarify and justify the values in these discussions.

(1) CHALLENGES OF COMMUNICATION

Burns and Truog have argued³² that the futility debate is often more about breakdowns in communication and trust than about intractable disputes over medical values. Recent empirical evidence suggests serious shortcomings in the communication that takes place in the end-of-life context. Cherlin et al. explain that “many family caregivers report limited and delayed communication about the incurable illness, life expectancy, and hospice as a treatment alternative.”³³ These authors continue, “Nearly 20% (n=38/183 or 20.8%) of the family caregivers reported that they had not been told by a physician that the patient’s illness could not be cured . . .” and furthermore, “Of the approximate 80% (n=145/183) who reported being told the illness could not be cured, about 60% (n=86/145 or 59.3%) reported that the physician also told them how long the patient had to live...”³⁴ Many times physicians do not know the treatment preferences of their patients³⁵ and recent studies have shown that although effective clinician communication is essential, discussion of meaningful end-of-life options is often offered too late.³⁶ Perhaps one reason for this is, as McPhee et al. note, “Too frequently, clinicians feel out of place negotiating the complexities of a family’s dynamics at a time when the integrity of the family is most at stake.”³⁷

Additionally, families frequently do not have an accurate understanding of the patient’s situation because clinicians often censor information in an attempt to protect them from difficult news. As Fallowfield and colleagues note, “A failure to give adequate information about test results, potential ways of managing symptoms with different treatments and the true therapeutic

²⁹ See, for example, Tom Tomlinson and Diane Czlonka, “Futility and Hospital Policy,” *Hastings Center Report* (1995) 25(3): 28-35. See also Peter A. Clark, “Medical Futility In Pediatrics: Is It Time For A Public Policy?” *Journal of Public Health Policy* (2002) 23(1): 66-89; Robert D. Truog and Christine Mitchell, “Futility—From Hospital Policies to State Laws,” *American Journal of Bioethics* (2006) 6(5): 19-21.

³⁰ For a discussion of the Texas Advance Directives Act (TADA), see Robert L. Fine, “Medical Futility and the Texas Advance Directives Act of 1999,” *BUMC Proceedings* (2000) 13(2): 144-7. For an excellent overview of the legal developments at the U.S. state level, see Thaddeus Mason Pope, “Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment,” *Tennessee Law Review* (2007) 71(1): 1-81. For a recent debate on the merits of the TADA, see Robert L. Fine, “Point: The Texas Advance Directives Act Effectively and Ethically Resolves Disputes About Medical Futility,” *CHEST* (2009) 136(4): 963-67 and Robert D. Truog, “Counterpoint: The Texas Advance Directives Act Is Ethically Flawed. Medical Futility Disputes Must be Resolved by a Fair Process,” *CHEST* (2009) 136(4): 968-71.

³¹ Pellegrino, “Futility in Medical Decisions,” op. cit., 314.

³² Burns and Truog, “Futility: A Concept in Evolution,” op. cit.

³³ Emily Cherlin, Terri Fried, Holly G. Prigerson, et al., “Communication between Physicians and Family Caregivers about Care at the End of Life: When Do Discussions Occur and What is Said?” *Journal of Palliative Medicine* (2005) 8(6): 1176-85; p. 1184.

³⁴ *Ibid.*, 1179.

³⁵ Susan Desharnais, Rickey E. Carter, Winnie Hennessy, et al., “Lack of Concordance between Physician and Patient: Reports on End-of-Life Care Discussions,” *Journal of Palliative Medicine* (2007) 10(3): 728-40.

³⁶ Timothy E. Quill, “Initiating End-of-Life Discussions With Seriously Ill Patients—Addressing the ‘Elephant in the Room,’” *Journal of the American Medical Association* (2000) 284(19): 2502-7; p. 2503. See also Cherlin et al., op. cit., 1179: “Approximately one quarter (n=34/145 or 23.5%) of the family caregivers who reported that a physician had told them the patient’s illness could not be cured said that they were told less than 1 month prior to the patient’s death.” Some of these caregivers received this information less than two weeks before the patient’s death.

³⁷ Stephen J. McPhee, Michael W. Rabow, Steven Z. Pantilat, et al., “Finding Our Way—Perspectives on Care at the Close of Life,” *Journal of the American Medical Association* (2000) 284(19): 2512-13; p. 2512.

aim can leave patients isolated and scared that nothing can or will be done to help them.”³⁸ These authors also note that “Sometimes, doctors’ information is so ambiguous or incomplete that patients are not well prepared for what lies ahead.”³⁹ By discussing these options earlier and more systematically, physicians might enable patients to make more informed choices, achieve better palliation of symptoms, and focus on other important issues before the end arrives.⁴⁰ In theory, families equipped with such information might opt for less aggressive courses of care, thereby reducing requests for treatments deemed inappropriate. It is not surprising that, given lapses in crucial information, many families are unprepared to face a loved one’s death and therefore feel compelled to ask physicians to do everything possible—including initiating or continuing therapies believed to be futile.

(2) FACTORING PATIENTS’ PERSPECTIVES ON HIGH QUALITY END-OF-LIFE CARE

Some professionals believe high quality end-of-life care entails a primary focus on relieving physical and emotional symptoms. Others think it should give primacy to the patient’s previously stated preferences, such as those found in living wills and advance directives. For others still, high quality care should balance and address other factors: survival time, overall quality of life, and spiritual well-being. The burgeoning literature on the topic reveals, however, that these factors have traditionally been considered from the perspective of clinicians. Clinicians’ views of what they think their patients want are, as Fallowfield et al. note,⁴¹ often very different from what patients and their families actually want. According to Steinhauer et al., this underscores one of the true challenges of providing comprehensive end-of-life care: “attending to aspects of care that are not intuitively important to clinicians but are critical to patients and their families.”⁴² In one of the first studies to describe patients’ perspectives on this topic, Singer and colleagues⁴³ identified five key areas of concern: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones. Of this study’s 126 patients,⁴⁴ 77 of them (or 61.1%) identified avoiding inappropriate prolongation of dying as an important consideration at the end-of-life,⁴⁵ which was given the highest rating of all other areas of high quality care.

If the results of this study may be extrapolated—viz. that patients place a high value on avoiding inappropriate prolongation of dying—then this aspect of care provides us with a foothold from which to gauge how to facilitate good communication at the end-of-life. How clinicians broach these discussions has a direct bearing on the information conveyed to patients and their families. “Although poor communication may harm patients by leading to unwanted invasive procedures, generating unnecessary anxiety, or creating feelings of abandonment,” notes a recent commentator, “good communication can improve outcomes for patients and their families by promoting shared decision making and addressing patient concerns.”⁴⁶ If patients seek to avoid inappropriate prolongation of dying, frank discussion needs to take place between physicians and patients (as well as their families). Physicians need to be honest about those treatments that may not offer realistic hope or benefit—in other words, treatments that could be described as futile.

³⁸ L.J. Fallowfield, V.A. Jenkins, and H.A. Beveridge, “Truth may hurt but deceit hurts more: communication in palliative care,” *Palliative Medicine* (2002) 16(4): 297-303, 298-9.

³⁹ *Ibid.*, 301. These authors conclude their article (p. 302) with the following thought: “We believe that honest information about such things as prognosis represents an ethical imperative for the truly caring clinician. Patients need to plan and make decisions about the place of their death, put their affairs in order, say good-byes or forgive old adversaries and be protected from embarking on futile therapies.” (Emphasis added.)

⁴⁰ Quill, *op. cit.*, 2502. These discussions are also very important for family caregivers. As Cherlin et al. explain (*op. cit.*, 1180), “Most family caregivers indicated that communication from the physician was pivotal in their own understanding of the patient’s condition and of hospice as a treatment alternative.”

⁴¹ Fallowfield et al., *op. cit.*, 298.

⁴² Karen E. Steinhauer, Nicholas A. Christakis, Elizabeth C. Clipp, et al., “Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers,” *Journal of the American Medical Association* (2000) 284(19): 2476-2482, 2481.

⁴³ Peter A. Singer, Douglas K. Martin, and Merrijoy Kelner, “Quality End-of-Life Care—Patients’ Perspectives,” *Journal of the American Medical Association* (1999) 281(2): 163-8.

⁴⁴ *Ibid.* Perspectives from 48 dialysis patients, 40 people with HIV, and 38 residents of a long-term care facility.

⁴⁵ *Ibid.*, 165.

⁴⁶ Steven Z. Pantilat, “Communicating With Seriously Ill Patients—Better Words to Say,” *Journal of the American Medical Association* (2009) 301(12): 1278-9.

(3) WHAT CRITERIA MAKE UP THE DECISION?

Decisions whether to initiate, withhold, or withdraw life-sustaining medical treatments depend on both medical facts and underlying personal values. Such decisions, then, must be shared decisions. Collaborative participation must be sought—among the team of physicians, the patient, the surrogate, and the family—as to the goals of care for a specific patient in specific circumstances. This requires, in turn, good communication. Because each member to the decision brings a unique perspective, expertise, and set of values to the discussion, we need to consider the criteria by which these diverse perspectives could be brought together, through dialogue, to constitute good—that is, ethical—communication and decision making. Following Pellegrino,⁴⁷ we divide this section into two parts: Who decides and by what criteria?

(3a) Who decides: To begin, patients with decision-making capacity—i.e., those who have the ability to provide authentic authorization for medical treatments—have the right to decide whether to initiate, withhold, or withdraw medical interventions.⁴⁸ Absent decision-making capacity, a valid surrogate is assigned—i.e., one who is “competent to make decisions [for the incapacitated patient], free of obvious financial or emotional conflict of interest, and [who can] give convincing evidence of knowledge of the patient’s values.”⁴⁹ Many times the surrogate is a family member. The moral authority to decide—either by the patient or the surrogate—is limited, according to Pellegrino, in the following situations: “(1) when the patient’s decision produces identifiable, serious, probable harm to identifiable others; (2) when the physician is asked to violate his or her personal and professional ethical integrity; (3) when the patient deliberately attempts to injure himself or herself; or (4) when the treatment requested is clinically futile or contraindicated.”⁵⁰

(3b) By what criteria? On what basis should the physician, patient, and surrogate decide to withhold or withdraw medical interventions? Whose values should ultimately guide the decision—those of the patient and family or those of the physician? As we have seen, these questions are controversial. Part of the reason for this is because the futility determination is based on objective components (i.e., the medical facts—such as the diagnosis and prognosis) and subjective components (i.e., the underlying values that inform the final decision). In order to bring further clarity to the discussion, we should note that the physician, patient, and family must first agree on the “end or purpose which an intervention is presumed to serve”⁵¹ and from there consider the various “medical-technical” (objective) and “personal-value specific” (subjective) criteria in relation to the end or purpose of the medical intervention. Following Pellegrino, the futility determination is an overall weighing and balancing of the intervention’s potential effectiveness, benefit, and burden. In this way, we can clarify the components to the decision and specify who is qualified to evaluate each aspect of the decision. Such an assessment is responsive to both the medical facts and personal values of physicians, patients, and families. According to Pellegrino,

Effectiveness is an assessment of the capacity of the procedure to alter the natural history of the disease. [...] it is an objective determination within the province of clinical knowledge of the physician. It must be based on as much evidence, outcome studies, and prognoses as possible. Benefit, on the other hand, is determined by the patient’s assessment of the value or desirability of the treatment’s result. [It] is in the province of the patient, helped by factual input from the physician. [...] Burdens are the cost, discomfort, pain, and inconvenience, of the treatment in question; it includes his or her quality of life assessment. “Costs” are both subjective and objective, financial and non-financial, and are, therefore, determined by both the physician and the patient or surrogate acting together.⁵²

For a decision of medical futility to be morally acceptable, it must be a shared decision, taking into account the two perspectives—that of the physician and that of the patient and family. To be ethical, the decision can never be made unilaterally by the physician—as some propose. Now that we have the theoretical framework in place, we must ask ourselves how an actual discussion over medical futility would look in normal circumstances.

⁴⁷ Edmund D. Pellegrino, “Decisions to Withdraw Life-Sustaining Treatment: A Moral Algorithm,” *Journal of the American Medical Association* (2000) 283(8): 1065-7.

⁴⁸ As Pellegrino notes (ibid., 1066): “patients with the capacity to give authentic authorization have both moral and legal authority that, within certain boundaries, overrides the wishes of the physician, the patient’s surrogate, and the family.” The criteria for decision-making capacity include the following: “the ability to communicate, to comprehend the nature and gravity of the decision, to make a reasoned judgment based on one’s own values, to persist in that judgment, and to do so in a manner consistent with previously expressed values and beliefs” (ibid.).

⁴⁹ Ibid.

⁵⁰ Ibid.

⁵¹ Pellegrino, “Futility in Medical Decisions,” op. cit., 312.

⁵² Pellegrino, “Decisions to Withdraw Life-Sustaining Treatment,” op. cit., 1066. (Emphasis in original.)

(4) WHAT WOULD THIS LOOK LIKE IN PRACTICE?

If physicians, patients, and family members are to make a good decision over whether to withhold or withdraw medical interventions, this presupposes that sufficient dialogue has taken place. All the relevant stakeholders to the decision—the team of physicians, the patient, surrogate, and family—need to speak truthfully about each component of the medical futility decision and assess together a proper course of action.

In her discussion of the futility debate, Susan Rubin offers a helpful reflection on what shared decision making would mean in practice. Based on the influential study by Imbus and Zawacki, Rubin considers a four-step SOAP (subjective, objective, assess, and plan) method as a way to facilitate shared decision making at the end-of-life.⁵³ The “S” is in reference to the subjective information as reported by the patient. The clinician would consider the following: Who is the patient? What is the patient saying? What is s/he experiencing so far and how does the patient understand the clinical situation? What are his/her beliefs, goals, values, and preferences for treatment? Next, the clinician would consider the various objective (the “O”) components of the patient’s situation, such as the information gleaned from examinations, lab tests, and diagnostic procedures. Third, the clinician would assess (the “A”) the subjective and objective data in light of the patient’s diagnosis and prognosis and consider those goals that are reasonable to pursue. The fourth aspect would be to develop a plan (the “P”) based on the previous discussion. The clinician would evaluate the available treatment options, their corresponding benefits and risks, and make a recommendation to the patient that obviously could be accepted or refused.⁵⁴

On the basis of such a genuine conversation—understood not as a mere transmittal of facts (as already legally required by informed consent), but as a process for articulating and addressing the various concerns from the perspective of the professional and family—all members involved would attempt to come to consensus. Physicians would describe the potential effectiveness of the proposed treatment, along with an explanation of the potential harms and benefits. If, for example, CPR has a 5% chance of being physiologically effective in a given situation—i.e., effective at restarting cardiac circulation—physicians would need to discuss a possible DNAR order with the family. In this context, physicians would explain their worries about providing a treatment that is likely ineffective and might inflict further suffering (e.g., broken ribs or the pain of defibrillation).⁵⁵ Patients and families, as co-members to this dialogue, would articulate their goals⁵⁶ and express their deeply-held values.⁵⁷ They would evaluate the 95% chance that the intervention has of being ineffective and consider the likely benefits and burdens. For example, some patients might consider saying last goodbyes a worthwhile goal and, on that basis, elect for CPR with only a 5% chance of being effective. The ultimate decision of whether the intervention is worthwhile would be based on this conversation.

Of course, sometimes patients and their families will have unrealistic assumptions and hopes. The physician must, to the best of his/her ability, correct any unrealistic views, especially if the family is in denial about the patient’s approaching death.⁵⁸ When there is a divergence of opinion with regard to the values that shape the decision, using Pellegrino’s algorithm, the goals and values must be assessed together, thereby addressing the concerns of all parties. If an aggressive medical intervention is clearly futile (its effectiveness is nearly zero), but the patient or family persists, physicians would need to explore the potential benefits and harms of the intervention—from the perspective of the patient. Perhaps the patient has a short-term goal: he or she would like a final chance to say goodbye to a distant relative. In such a case, the physician may decide to make a compassionate exception.⁵⁹ If the intervention, however, violates the physician’s professional integrity and conception of the best standard of care,

⁵³ Rubin, *op. cit.*, 50. Her discussion is in reference to this study: Imbus and Zawacki, “Autonomy for burned patients when survival is unprecedented,” *New England Journal of Medicine* (1977) 297(6): 308-11.

⁵⁴ *Ibid.*, 50-1.

⁵⁵ Timothy Quill provides several useful questions for physicians to ask patients: “If you were to die suddenly, that is, you stopped breathing or your heart stopped, we could try to revive you by using CPR. Are you familiar with CPR? Have you given thought as to whether you would want it? Given the severity of your illness, CPR would in all likelihood be ineffective. I would recommend that you choose not to have it, but that we continue all potentially effective treatments. What do you think?” See Quill, *op. cit.*, 2506.

⁵⁶ *Ibid.* Physicians should ask patients (or surrogates) the following: “Given the severity of your illness, what is most important for you to achieve? How do you think about balancing quality of life with length of life in terms of your treatment? What are your most important hopes? What are your biggest fears?”

⁵⁷ *Ibid.* Questions that might be helpful for exploring patients’ values: “What makes life most worth living for you? Would there be any circumstances under which you would find life not worth living? What do you consider your quality of life to be like now? Have you seen or been with someone who had a particularly good death or particularly difficult death?”

⁵⁸ Sally Norton and Barbara Bowers describe this as shifting the patient’s or proxy’s “big picture” to help them recognize more realistic goals and palliative treatment options. See Sally A. Norton and Barbara J. Bowers, “Working Toward Consensus: Providers’ Strategies to Shift Patients From Curative to Palliative Treatment Choices,” *Research in Nursing & Health* (2001) 24(4): 258-269.

⁵⁹ See Lawrence J. Schneiderman, “Defining Medical Futility and Improving Medical Care,” *Bioethical Inquiry* (2011) 8(2): 123-131; p. 127. Schneiderman is careful to distinguish a compassionate act from an obligatory act.

he or she could, for example, refuse to participate in such interventions.⁶⁰ In this case, “the physician must inform the patient or the patient’s surrogate and ask to be relieved of responsibility by transfer of care to another physician.”⁶¹ The hope is, with improved communication, such a decision will be rare.⁶² Although resolution is ultimately available for intractable conflict through hospital policy or the courts, at least a segment of the intractability has the real possibility—through improved communication—to become mitigated.

(5) FINAL REFLECTION: A PATIENT IS NEVER FUTILE, ALTHOUGH MEDICAL TREATMENTS MIGHT BE

Before concluding, it is important to emphasize several caveats to the medical futility decision. As previously mentioned, the language of futility is controversial due to its negative connotations. Patients, families, and surrogates often worry that if a treatment is deemed futile, all supportive measures will then cease. Fears of being abandoned or devalued come to the fore. This would, however, represent an abuse of the concept of futility.⁶³ Although particular treatments may be futile, the patient is never futile,⁶⁴ and must be cared for until the moment of death with attention to comfort, relief of pain, and personal needs.⁶⁵ The futility decision, then, signals that a shift should occur in regard to the goals of care—i.e., from curative to palliative treatments—in order to achieve a good death.⁶⁶ Attention to caring for the whole person—thus recognizing and respecting the inherent good and dignity of the patient—represents the ultimate criterion for providing optimal medical care at the end-of-life.

CONCLUSION

Caring for patients at the end-of-life is extremely difficult, and the communication lapses between physicians and their patients present real and persistent challenges. Because they are clearly value-laden, decisions whether to initiate, withhold, or withdraw life-sustaining medical treatments have become intractable—but they need not be. In order to carry ethical weight, these decisions must be based on a model of shared decision making—a genuine conversation must allow the underlying values of all to have a voice. One commentator has noted that the principle of medical futility “stands too ready to serve physicians as a ‘conversation stopper,’ that its apparent moral authority can too easily divert physicians from engaging in the time-consuming, emotionally stressful and seemingly ‘unprincipled’ business of negotiating about treatment alternatives with frightened, grief-stricken patients or family/surrogates.”⁶⁷ The process of communication begins when physicians believe that a given medical therapy is futile. By articulating, exploring, and grappling with the underlying fundamental values at stake, physicians and their patients, along with their families and surrogates/proxies, initiate a relational dialogue thereby crossing a new threshold—the threshold of true ethical communication at the end-of-life.

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⁶⁰ See Robert D. Truog, “Tackling Medical Futility in Texas,” *New England Journal of Medicine* (2007) 357(1): 1-3; p. 2. See also Pellegrino, “Decisions to Withdraw Life-Sustaining Medical Treatment,” *op. cit.*, 1066.

⁶¹ Pellegrino, “Decisions to Withdraw Life-Sustaining Treatment,” *op. cit.*, 1066.

⁶² Cf. Rubin, “If We Think It’s Futile,” *op. cit.*, 62.

⁶³ Pellegrino, “Decisions at the end of life: abuse of the concept of futility,” *op. cit.*, 5.

⁶⁴ Schneiderman, “Defining Medical Futility and Improving Medical Care,” *op. cit.*, 128. Cf. Pellegrino, “Futility in Medical Decisions,” *op. cit.*, 309, for a different formulation: “Care, comfort, pain relief of suffering, however, are never futile. Care is a continuing moral obligation, while continuation of medical interventions may not be.” He continues (p. 315): “A diagnosis of futility *per se* is no warrant for automatic discontinuance of food, hydration, respiratory assistance, or of pacemaker support of cardiac rhythm.”

⁶⁵ Pellegrino, “Decisions at the end of life: abuse of the concept of futility,” *loc. cit.*

⁶⁶ See Norton and Bowers, “Working Toward Consensus,” *op. cit.*, 262: “A good death was characterized by all providers in a similar way as one that includes time to resolve personal business, time to reconnect with family, time to forgive and be forgiven, time to achieve important goals, and time to say goodbye to loved ones, while maintaining good pain and symptom control. A difficult or bad death was characterized by not being able to say good-bye; having unfinished business, unresolved conflict and anger, and difficulty grieving; undergoing futile treatment, creating bad memories for the family; and having poor symptom and pain control.”

⁶⁷ Robert A. Burt, “The Medical Futility Debate: Patient Choice, Physician Obligation, and End-of-Life Care” *Journal of Palliative Medicine* (2002) 5(2): 249-54

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