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The Dilemma of “Medical Futility”—A “Wisdom Model” for Decisionmaking

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The rise of the patient advocacy movement of the 1960s and '70s, along with the resulting advent of ethics committees and advance directives legislation, can be traced to growing concern over physician exuberance to employ life-prolonging technology in clinical situations considered futile by patients and family.¹ Requests that such therapy be withheld or withdrawn are now commonplace as a result of a large body of case precedents establishing the “acceptability” of abating these attempts to prolong life.² However, such widespread acceptance is far from solving the problems of overtreatment at the end of life. Daniel Callahan appropriately notes:

Doctors still do not, as a rule, talk comfortably and directly with patients about death. . . . A worry about malpractice, a zest for technology, a deep-seated moral belief in the need to prolong life, and the pressure of families and others still often lead to overtreatment and an excessive reliance on technology.³

In fact, a general acceptance of the “technological imperative” by the American public in the 1990s has led to the reverse problem of so-called medical futility, referring specifically to those situations in which patients or their surrogates request or even demand life-prolonging therapy that physicians are convinced is not medically indicated.⁴

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¹See, e.g., DAVID J. ROTHMAN, *STRANGERS AT THE BEDSIDE* 190-262 (1991).

²See Alan Meisel, *Legal Myths About Terminating Life Support*, 151 *ARCHIVES INTERNAL MED.* 1497 (1991).

³DANIEL CALLAHAN, *THE TROUBLED DREAM OF LIFE: LIVING WITH MORTALITY* 39 (1993).

⁴Robert M. Veatch & Carol M. Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 *AM. J.L. & MED.* 15, 15-16 (1992).

The Evolving Ethical Implications of "Medical Futility"

Callahan offers keen insight as to how such a problem could have developed so close on the heels of the patient advocacy movement, with its emphasis on the limitation of life-prolonging technology:

Futile medical treatment is indeed ordinarily not wanted, but useful treatment is wanted . . . except that 'useful' treatment is interpreted in such a broad fashion that it is often wanted even when its utility is highly marginal, and when the quality of life it provides is slight to vanishing. For practical purposes, it is this desire for useful treatment, however slight in value, that is most important, *not* the rejection of futile treatment. . . . Given the growing effectiveness of medical therapies at the margin of life and death, and the increased difficulty of pinpointing the line between living and dying, medical and lay ambivalence and uncertainty are necessarily intensified.⁵

Thus, while technology has greatly improved our ability to prolong life in the face of severe illness, it has also increased our uncertainty over when such life extension is *meaningful*,⁶ for often it is only one's *dying* that is prolonged by

[t]echnological brinkmanship . . . that is, pushing aggressive treatment as far as it can go in the hope that it can be stopped at just the right moment if it turns out to be futile. That brinkmanship, and the gamble it represents, can both save life and ruin dying; this is the dilemma it poses.

. . . We must reckon whether it is a good or a bad gamble, and how much we are prepared to accept a deformed dying as a result.⁷

Conflicts may arise when care providers do not agree with patients or their families that requested therapies are in fact "good gambles" and resist such requests on the basis of medical futility. Apparently, then, it is not the advances in technology *per se*, but rather difficulty discerning the expedient use of such technology, that has led to dilemmas of "medical futility." Such conflicts may even escalate to the level of a power struggle, especially when autonomy-based claims to the right to receive "futile" medical care are taken to court and pitted against efforts to protect the professional prerogative of physicians to restrict "acceptable" care to therapies that are "medically indicated."⁸ A line of cases is now emerging from such disputes and testing the scope of care physicians may be obligated to provide at the

⁵CALLAHAN, *supra* note 3, at 48-49.

⁶*Id.* at 42-48.

⁷*Id.* at 192-93.

⁸Veatch & Spicer, *supra* note 4; LAWRENCE J. SCHNEIDERMAN & NANCY S. JECKER, *WRONG MEDICINE: DOCTORS, PATIENTS, AND FUTILE TREATMENT* 35-50, 97-111 (1995).

"edges" of life when aggressive application of life-prolonging therapy seems medically futile.⁹

Prevailing Paradigms of "Medical Futility"

Two cases in particular—involving anencephaly at one extreme and the so-called persistent vegetative state (PVS) at the other—have underscored perhaps better than any other the high stakes involved in the outcome of the debate, as well as how divisive such power struggles can become. Baby K was born in October 1992 with anencephaly. Following prenatal diagnosis, the mother refused abortion, and her physicians initially agreed to provide full medical support at birth, including mechanical ventilation. Despite many subsequent attempts to convince the mother of the uniformly fatal outcome of anencephaly, she continued to demand full supportive care on the basis of firm religious convictions. Convinced that such care was futile, an ethics consultation team failed to resolve the dispute and advised the hospital to pursue legal remedies. Assisted by disability advocates, the mother secured an agreement with the hospital: After weaning from the ventilator, the baby would be transferred to a nursing home and allowed to return to the hospital for treatment of recurrent respiratory difficulty. However, with the third such readmission the hospital filed a proceeding in federal court to determine its legal obligation to render care. The court of appeals ultimately ruled that ventilatory support was mandated by the Emergency Medical Treatment and Labor Act (EMTALA), since respiratory arrest—a medical emergency—was the condition being treated, and not anencephaly. Baby K finally died in April 1995, thirty months after birth, the longest known survivor of this condition.¹⁰

Helga Wanglie was an eighty-five-year-old woman with lung disease who broke her hip and required mechanical ventilation. She was ultimately transferred to a chronic care facility, where she sustained anoxic brain damage after a cardiac arrest; this led to prolonged mechanical ventilation and other intensive care. Her husband was convinced that she would not have arrested if she hadn't been moved, and he resisted all attempts by physicians, ethics consultants, and even his own pastor to convince him

⁹See Bethany Spielman, *Bargaining About Futility*, 23 J.L. MED. & ETHICS 136, 136-37 (1995).

¹⁰*In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994); see also George J. Annas, *Asking the Courts to Set the Standard of Care: The Case of Baby K*, 330 NEW ENG. J. MED. 1542 (1994); Ellen J. Flannery, *One Advocate's Viewpoint: Conflicts and Tensions in the Baby K Case*, 23 J.L. MED. & ETHICS 7 (1995); Ellen Wright Clayton, *Commentary: What Is Really at Stake in Baby K? A Response to Ellen Flannery*, 23 J.L. MED. & ETHICS 13 (1995); Mary Crossley, *Infants with Anencephaly, the ADA, and the Child Abuse Amendments*, 11 ISSUES IN LAW & MED. 379 (1996).

that continued intensive life support might not be appropriate. Six months later, when it became clear that she would remain in a persistent vegetative state, the attending physician announced he was no longer willing to continue ventilator support. The husband invoked the sanctity of life and rejected proposals to transfer his wife, insisting that she had wanted full life support continued. When the hospital sought court appointment of an independent conservator to decide whether such treatment was beneficial, the family tried but could not find another facility that would treat her. Although the husband cross-filed and succeeded in obtaining the conservatorship himself, Mrs. Wanglie died three days later—despite continued aggressive care—fourteen months after her cardiac arrest.¹¹

There is growing apprehension that the outcome of these cases will unleash a proliferation of legally sanctioned “futile treatments.” One possible result of such “court-ordered” accession to requests for futile treatments could be to enable false hopes of cure that would only further aggravate the already pervasive loss of dignity in dying. Physicians worry, moreover, that an inordinate faith in technology, together with the growing consumerism plainly evident in evolving American health care, may threaten the integrity of the medical profession by preempting the physician's prerogative to decide if and when medical therapy is indicated.¹² Finally, societal unease is increasing over the skyrocketing costs of health care, which show no sign of abating in the absence of clear-cut guidelines for the judicious stewardship of health care resources,¹³ and concern is growing that expenses incurred in the proliferation of cases like *Baby K* and *Wanglie* will lead to an unfair redistribution of these resources away from benefits that should justly accrue to other contributing members of prepaid managed care plans.¹⁴

¹¹In *re Wanglie*, No. PX-91-283, slip op. (Cir. Ct. Hennepin County, Minn. July 1, 1991). See Ronald E. Cranford, *Helga Wanglie's Ventilator*, HASTINGS CENTER REP., July/Aug. 1991, at 23; Daniel Callahan, *Medical Futility, Medical Necessity: The Problem Without a Name*, HASTINGS CENTER REP., July/Aug. 1991, at 30; see also Steven H. Miles, *Informed Demand for "Non-beneficial" Medical Treatment*, 325 *New Eng. J. Med.* 512, 512-15 (1995); Nancy S. Jecker & Lawrence J. Schneiderman, *When Families Request That "Everything Possible" Be Done*, 20 *J. MED. & PHIL.* 145 (1995).

¹²See *supra* note 8; Miles, *supra* note 11; Tom Tomlinson & Howard Brody, *Futility and the Ethics of Resuscitation*, 264 *JAMA* 1276 (1990); Michael A. Rie, *The Limits of a Wish*, HASTINGS CENTER REP., July/Aug. 1991, at 24.

¹³See DANIEL CALLAHAN, *WHAT KIND OF LIFE: THE LIMITS OF MEDICAL PROGRESS* (1990); Donald J. Murphy et al., *Setting Limits in Clinical Medicine*, 154 *ARCHIVES INTERNAL MED.* 505 (1994); Robert A. Gatter, Jr. & John C. Moskop, *From Futility to Triage*, 20 *J. MED. & PHIL.* 191 (1995); Robert M. Taylor & John D. Lantos, *The Politics of Medical Futility*, 11 *ISSUES IN LAW & MED.* 3 (1995).

¹⁴See E. Haavi Morreim, *Moral Justice and Legal Justice in Managed Care: The Ascent of Contributive Justice*, 23 *J.L. MED. & ETHICS* 247 (1995).

These concerns have led some to call for societal or professional consensus on those conditions for which life-prolonging therapies can be considered futile,¹⁵ in order to justify instituting "futility policies" to limit such "medically futile" care.¹⁶ This article will elucidate the pitfalls of such attempts, as well as the inadequacies of the prevailing rights-based framework for decisionmaking in cases of medical futility.¹⁷ Just as in the *Wanglie* and *Baby K* cases, any exploration of the real motives at the crux of requests for medically futile care is subordinated to the issue of whose rights and which correlative duties should prevail. Consequently, we will explore an alternative framework that is capable of identifying and addressing the often obscured moral and existential issues that drive requests for futile treatment, as well as caregiver resistance to such requests.

Disparate Perceptions of Futility: What Futility? Whose Meaning?

A burgeoning literature has emerged over the last six years debating various definitions of futility and attempting to cover every possible nuance of futility that might be encountered clinically. Such definitions usually include both qualitative and quantitative criteria.¹⁸ Yet there remain significant conceptual barriers to an ethically sound way of arriving at legal, professional, and/or societal consensus over those conditions for which certain therapies may be considered futile and therefore withheld.

Qualitative Futility. Qualitative futility is tested when care providers judge whether a given outcome is *medically meaningful*—such as the restoration of cognitive function, transfer out of intensive care, or survival to hospital discharge—then whether such an outcome is *medically feasible*. Thus a given therapy is said to be futile either when the goal itself is not considered worth pursuing (such as prolonging life with ventilatory support in an infant with anencephaly like *Baby K*) or when it cannot achieve the

¹⁵Lawrence J. Schneiderman & Nancy S. Jecker, *Futility in Practice*, 153 ARCHIVES INTERNAL MED. 437, 440 (1993); SCHNEIDERMAN & JECKER, *supra* note 8, at 169, 171; E. Haavi Morreim, *Profoundly Diminished Life: The Casualties of Coercion*, HASTINGS CENTER REP., Jan./Feb. 1994, at 33.

¹⁶J. Chris Hackler & F. Charles Hiller, *Family Consent to Orders Not to Resuscitate: Reconsidering Hospital Policy*, 264 JAMA 1281 (1990); Donald J. Murphy & Thomas E. Finucane, *New Do-Not-Resuscitate Policies: A First Step in Cost Control*, 153 ARCHIVES INTERNAL MED. 1641 (1993); Tom Tomlinson & Diane Czlonka, *Futility and Hospital Policy*, HASTINGS CENTER REP., May/June 1995, at 28.

¹⁷A brief complementary analysis, based on the same two cases, may be found in C. Christopher Hook, *Medical Futility*, in DIGNITY AND DYING: A CHRISTIAN APPRAISAL 84-95 (John F. Kilner et al. eds., 1996).

¹⁸See, e.g., Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949 (1990); Albert R. Jonsen, *Intimations of Futility*, 96 AM. J. MED. 107 (1994); Baruch A. Brody & Amir Halevy, *Is Futility a Futile Concept?* 20 J. MED. & PHIL. 123, 126-28 (1995).

desired outcome (such as restoring cognitive function with CPR, should a patient with PVS like Helga Wanglie suffer a cardiac arrest). There is radical disagreement, however, over the lower limit of medically meaningful outcomes worthy of life support—that is, whether the threshold should be the restoration of detectable cortical function;¹⁹ presence of residual brain stem activity, to include spontaneous breathing;²⁰ the presence of any brain stem function at all;²¹ or just intact cardiopulmonary function.²²

Quantitative Futility. This designates a particular likelihood of achieving a given desirable outcome that falls below a certain arbitrary threshold of statistical probability, as in the low rate of survival to hospital discharge with CPR for certain kinds of patients or the very low probability of a patient with PVS ever regaining cognitive function after one year. There are multiple problems, however, with the concept of quantitative futility: Deciding which threshold of probability qualifies as futile depends on many variables, such as skewed physician experience, “disease” bias, and the variable willingness of the patient or surrogate to accept the suffering or other risks associated with therapy.²³ Moreover, for any given condition there is a relative paucity of reliable outcomes data on which to base a confident decision, and physicians are prone to take statistics that have been gathered from variable patient cohorts and apply them inappropriately to their own patients.²⁴ Finally, advances in technology often cause medical

¹⁹SCHNEIDERMAN & JECKER, *supra* note 8, at 17; Robert M. Veatch, *Brain Death and Slippery Slopes*, 3 J. CLINICAL ETHICS 181 (1992).

²⁰Amir Halevy & Baruch Brody, *Brain Death: Reconciling Definitions, Criteria, and Tests*, 119 ANNALS INTERNAL MED. 519, 524 (1993).

²¹See President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Guidelines for the Determination of Death*, 246 JAMA 2184 (1981); UNIF. DETERMINATION OF DEATH ACT, 12 U. L. A. 593 § 1 (1996).

²²Robert D. Truog et al., *The Problem with Futility*, 326 NEW ENG. J. MED. 1560, 1561 (1992).

²³See John D. Lantos et al., *The Illusion of Futility in Clinical Practice*, 87 AM. J. MED. 81 (1989); Robert M. Wachter et al., *Decisions About Resuscitation: Inequalities Among Patients with Different Diseases But Similar Prognoses*, 111 ANNALS INTERNAL MED. 525 (1989); Truog et al., *supra* note 22, at 1561; S. Van McCrary et al., *Physicians' Quantitative Assessments of Medical Futility*, 5 J. CLINICAL ETHICS 100 (1994); Lawrence J. Schneiderman et al., *Attitudes of Seriously Ill Patients Toward Treatment That Involves High Costs and Burdens on Others*, 5 J. CLINICAL ETHICS 109 (1994).

²⁴Kevin M. McIntyre, *Failure of "Predictors" of Cardiopulmonary Resuscitation Outcomes to Predict Cardiopulmonary Resuscitation Outcomes: Implications for Do-Not-Resuscitate Policy and Advance Directives*, 153 ARCHIVES INTERNAL MED. 1293 (1993); Brody & Halevy, *supra* note 18, at 134; Kenneth A. Ballew et al., *Predictors of Survival Following In-Hospital Cardiopulmonary Resuscitation: A Moving Target*, 154 ARCHIVES INTERNAL MED. 2426 (1994); Joanne Lynn et al., *Accurate Prognostication of Death: Opportunities and Challenges for Clinicians*, 163 W. J. MED. 250, 253-56 (1995).

indications to change rapidly and unpredictably, making previous statistical data obsolete.²⁵

Medical vs. Existential Meaning. However, the most serious problem with defining futility is that outcomes considered futile by *medical* criteria may well have valid *existential* or *moral* meaning for the patient or for others in the patient's community. Basically, this reduces to a wide variability of personal views on what states may be considered futile; for example, a patient with advanced AIDS and dementia may have a 20% chance of immediate survival with CPR after cardiac arrest, but less than a 1% chance of surviving to discharge—and even then with a high probability of residual anoxic brain damage. While a care provider may therefore conclude that CPR is futile both *qualitatively* (can't restore normal cognitive function) and *quantitatively* (provides very small chance of leaving the hospital), the family may for various nonmedical reasons be happy just to get the patient through the arrest for only two days, even in a coma.²⁶

We must conclude, then, that medical futility is a complex concept fraught with a high degree of subjectivity,²⁷ and it is therefore not surprising that the courts deciding the cases of *Wanglie* and *Baby K* resorted to a framework for decisionmaking that skirts such difficulties.

Ethical Individualism and the Inadequacy of Informed Consent

The Prevailing Ethical Framework. The disputes in these cases were settled according to a "contractual" model of decisionmaking based on an *ethical individualism* that emphasizes the predominance of rights, especially the right to self-determination. Therefore, the professional prerogative of exercising medical judgment was outweighed by the surrogate's right to exercise autonomous choice on behalf of the patient.²⁸ The contractual model is designed to guarantee such choice by requiring the care provider to fulfill certain correlative duties—most notably, informed consent—to

²⁵See Brody & Halevy, *supra* note 18, at 134-42; Erich H. Loewy & Richard A. Carlson, *Futility and Its Wider Implications: A Concept in Need of Further Examination*, 153 ARCHIVES INTERNAL MED. 429, 431 (1993).

²⁶Even Schneiderman and Jecker have acknowledged that there are situations in which it is reasonable to honor requests for "medically futile" therapy. See SCHNEIDERMAN & JECKER, *supra* note 8, at 166; Schneiderman et al., *supra* note 18, at 953.

²⁷See Stuart J. Younger, *Who Defines Futility?* 260 JAMA 2094 (1988); Kevin M. McIntyre, *Loosening Criteria for Withholding Prehospital Cardiopulmonary Resuscitation: Futility of Prehospital Cardiopulmonary Resuscitation: Like Beauty, in the Eyes of the Beholder*, 153 ARCHIVES INTERNAL MED. 2189 (1993); Mildred Z. Solomon, *How Physicians Talk About Futility: Making Words Mean Too Many Things*, 21 J.L. MED. & ETHICS 231 (1993); Howard Brody, *The Multiple Facets of Futility*, 5 J. CLINICAL ETHICS 142-44 (1994); Taylor & Lantos, *supra* note 13, at 3-9.

²⁸Veatch & Spicer, *supra* note 4, at 33-36.

ensure full disclosure of information necessary to make a truly autonomous choice:

At the heart of a contract is informed consent rather than blind trust; a contractual understanding of the therapeutic relationship encourages full respect for the dignity of the patient, who has not . . . forfeited his sovereignty as a human being. The notion of a contract includes an exchange of information on the basis of which an agreement is reached . . . [and] allows for a specification of rights, duties, conditions, and qualifications limiting the agreement. The net effect is to establish some symmetry and mutuality in the relationship between doctor and patient. It presupposes that people are primarily governed by self-interest.²⁹

It was just this emphasis on informed consent that clearly prevailed in our paradigm cases, but does informed consent perform as intended in cases of medical futility?

The Peculiar Role of Informed Consent. Some have argued that a robust process of informed consent is required to protect against care providers who invoke the concept of futility to avoid offering therapy in cases in which criteria for futility have not in fact been met.³⁰ However, the very notion of an informed request for futile therapy is ambiguous; what does it mean to consent to a therapy that is not being offered? Even though Katz³¹ and Brody³² have refined the definition and methodology of informed consent to ensure that authentic preferences are honored, the caregiver sensitivity, patience, and insight needed to achieve an accurate understanding of authentic preferences is lacking;³³ thus, even careful

²⁹William F. May, *Code and Covenant or Philanthropy and Contract*, in ON MORAL MEDICINE 83, 91 (Stephen E. Lammers & Allen Verhey eds., 1987). Perhaps the most outspoken contemporary proponent of contract in a "secular bioethics" and the primacy of informed consent ("permission") in medical decisionmaking is H. TRISTRAM ENGELHARDT, JR., THE FOUNDATIONS OF BIOETHICS 67-83, 122-28, 288-374 (2d ed. 1996).

³⁰See Lantos et al., *supra* note 23; Giles R. Scofield, *Is Consent Useful When Resuscitation Isn't?* HASTINGS CENTER REP., Nov./Dec. 1991, at 28-36; Schneiderman & Jecker, *supra* note 15, at 438-39. See also J. Randall Curtis et al., *Use of the Medical Futility Rationale in Do-Not-Attempt-Resuscitation Orders*, 273 JAMA 124 (1995) (providing evidence that such abuse is not uncommon).

³¹JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984).

³²HOWARD BRODY, *THE HEALER'S POWER* 83-119 (1992).

³³Robert M. Veatch, *Abandoning Informed Consent*, HASTINGS CENTER REP., Mar./Apr. 1995, at 5, 7-10; Marshall B. Kapp, *Medical Decisionmaking for Older Adults in Institutional Settings: Is Beneficence Dead in an Age of Risk Management?* 11 ISSUES IN LAW & MED. 29 (1995). But see the innovative model for consent recently proposed by Mark G. Kuczewski, *Reconceiving the Family: The Process of Consent in Medical Decisionmaking*, HASTINGS CENTER REP., Mar./Apr. 1996, at 30, 30-35.

documentation of informed consent does not necessarily reflect truly autonomous choice³⁴ nor shed any light on the reasonability of the request.

Therefore, requests for therapy considered by the care provider to be futile raise legitimate questions about the reliability and true significance of such requests.³⁵ The issue seems not so much whether the patient/surrogate has been provided with sufficient information to make the decision; the "information" that the therapy is not medically indicated has already been rejected. Rather, what seems relevant is whether the *moral justification* supporting a request for such medically futile therapy is sufficient to override the *scientific justification* for the claim of medical futility.

The Noncapable Patient and Advance Directives. When the patient is not capable of rational decisions (as is often the case by the time medical therapy is deemed futile by the care provider), speculation over how prior expressed preferences should apply under current circumstances only increases the above-noted ambiguity of informed consent.³⁶ This in turn is aggravated by the frequently encountered uncertainty over prognosis when such decisions must finally be made.

To determine . . . that an illness is 'terminal' has always been difficult . . . But it is also growing harder to say that death is 'imminent' . . . [T]he principal reason for the failure of advance directives . . . has been medical uncertainty about when to invoke them . . . First, [such] judgments . . . are probabilistic in nature. . . . New . . . therapeutics . . . make it harder to predict that a disease will inevitably be fatal, and whether . . . death can be delayed to some significant extent. Second, the uncertain nature of the odds . . . makes termination decisions difficult and threatening. A physician can, reasonably, say that he is not certain a patient is 'dying'—until more efforts to save the patient have been made . . .³⁷

Given such uncertainty over both hypothetical preferences and prognosis, it is hardly surprising that care provider and surrogate

³⁴Veatch, *supra* note 33, at 6-11; see Kapp, *supra* note 33; Monica H. Schaeffer et al., *The Impact of Disease Severity on the Informed Consent Process in Clinical Research*, 100 AM. J. MED. 261 (1996).

³⁵CALLAHAN, *supra* note 3, at 49; see also Tomlinson & Brody, *supra* note 12; Hackler & Hiller, *supra* note 16; Martin L. Smith, *Futile Medical Treatment and Patient Consent*, 60 CLEV. CLINIC J. MED. 151 (1993).

³⁶See John A. Robertson, *Second Thoughts on Living Wills*, HASTINGS CENTER REP., Nov./Dec. 1991, at 6; Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?* 267 JAMA 59 (1992); Mark G. Kuczewski, *Whose Will Is It, Anyway? A Discussion of Advance Directives, Personal Identity, and Consensus in Medical Ethics*, 8 BIOETHICS 27 (1994). Diane E. Hoffmann et al., *The Dangers of Advance Directives or the False Security of Forms*, 24 J. L., MED. & ETHICS 5 (1996).

³⁷CALLAHAN, *supra* note 3, at 44-45.

decisionmaker often struggle over how and when to apply an advance directive,³⁸ or that advance directives legislation has so far largely failed to achieve its intended purpose.³⁹ Of even greater concern, however, by uncritically acceding to "prior expressed preferences," one can circumvent important dialogue about the moral propriety of the choices made and thereby neglect authentic interests.⁴⁰ Even when such discussion does take place, it can still serve the purpose of coercion⁴¹—whether overtly, as when invoking individual rights or a misperceived professional authority, or through more subtle manipulation and framing, as when one seeks to justify invalid futility judgments or prior preferences.

The "Best Interest" Standard. In the absence of an advance directive, decisions are usually made on the basis of the patient's supposed best

³⁸Jan Hare et al., *Agreement Between Patients and Their Self-selected Surrogates on Difficult Medical Decisions*, 152 ARCHIVES INTERNAL MED. 1049 (1992); David K.P. Lee et al., *Withdrawing Care: Experience in a Medical Intensive Care Unit*, 271 JAMA 1358 (1994); Lawrence J. Schneiderman et al., *Who Decides Who Decides? When Disagreement Occurs Between the Physician and the Patient's Appointed Proxy About the Patient's Decision-Making Capacity*, 155 ARCHIVES INTERNAL MED. 793 (1995); see John A. McClung, *Time and Language in Bioethics: When Patient and Proxy Appear to Disagree*, 6 J. CLINICAL ETHICS 39 (1995); David G. Smith & Sally Nunn, *Substituted Judgment: In Search of a Foolproof Method; A Response to Baergen*, 6 J. CLINICAL ETHICS 184 (1995); cf. Ralph Baergen, *Revising the Substituted Judgment Standard*, 6 J. CLINICAL ETHICS 30 (1995).

³⁹Ezekiel J. Emanuel et al., *How Well Is the Patient-Self-Determination Act Working?: An Early Assessment*, 95 AM. J. MED. 619 (1993); Rebecca Dresser, *Confronting the "Near Irrelevance" of Advance Directives*, 5 J. CLINICAL ETHICS 55 (1994); Jeremiah Suhl et al., *Myth of Substituted Judgment: Surrogate Decision Making Regarding Life Support Is Unreliable*, 154 ARCHIVES INTERNAL MED. 90 (1994); The SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 JAMA 1591 (1995); Special Supplement, *Dying Well in the Hospital: The Lessons of SUPPORT*, HASTINGS CENTER REP., Nov./Dec. 1995, at S1.

⁴⁰KATZ, *supra* note 31, at 125 ("[M]ere acceptance of patients' 'yes' or 'no' response to a proposed intervention may not express respect for their self-determination, dignity, or integrity."). See also Scofield, *supra* note 30, at 32-34; Kapp, *supra* note 33, at 36-37; Jaya Virmani et al., *Relationship of Advance Directives to Physician-Patient Communication*, 154 ARCHIVES INTERNAL MED. 909 (1994); Erich H. Loewy & Richard W. Carlson, *Talking, Advance Directives, and Medical Practice*, 154 ARCHIVES INTERNAL MED. 2265 (1994); Kuczewski, *supra* note 36, at 30-46; John F. Peppin, *Physician Neutrality and Patient Autonomy in Advance Directive Decisions*, 11 ISSUES IN LAW & MED. 13, 20-21 (1995).

⁴¹Morreim, *supra* note 15, at 35-36; KATZ, *supra* note 31, at 142-50; Peppin, *supra* note 40, at 21-25; George J. Agich, *Authority in Ethics Consultation*, 23 J.L. MED. & ETHICS 273 (1995); Edmund G. Howe, *Discussing Futility*, 5 J. CLINICAL ETHICS 91, 93-96 (1994); Bethany Spielman, *Futility and Bargaining Power*, 6 J. CLINICAL ETHICS 44 (1995); Robert D. Truog, *Progress in the Futility Debate*, 6 J. CLINICAL ETHICS 128, 130 (1995).

interests by means of a benefits/burdens analysis.⁴² While such a calculus only reduces to trying to maintain a positive balance between doing good and avoiding harm, at least it abandons the false pretense of preserving autonomous choice in an incompetent patient.⁴³ Even so, it remains a highly speculative and value-laden prospect.⁴⁴

Recent Attempts at an Elusive Solution. We must therefore conclude that informed consent is a misplaced framework for deliberating the merits of a therapy for which there is no apparent medical indication; it offers little hope of reconciling disagreements over what is futile or meaningful as death draws near.⁴⁵ It has been suggested that the traditional concept of informed consent be jettisoned altogether in favor of attempts to match the openly articulated values of physician and patient.⁴⁶ This makes sense as long as one's goal is limited to honoring patient preference, but if (as we expect) the issues driving requests for futile treatment are far more complex than simply ensuring autonomous choice, then an a priori matching of values—were it even feasible—may still be inadequate to deal with these issues.⁴⁷

These difficulties have led other commentators to propose that, rather than seeking a consensus on what constitutes futile therapy in order to bolster professional authority to make such judgments,⁴⁸ we should shift our attention to development of "ethically defensible systems for allocating scarce medical resources."⁴⁹ However, the appeal to limited resources offers yet another "default mode" to circumvent discussion⁵⁰ of the core issues

⁴²Rebecca Dresser & Peter J. Whitehouse, *The Incompetent Patient on the Slippery Slope*, HASTINGS CENTER REP., July/Aug. 1994, at 6; James F. Drane & John L. Coulehan, *The Best Interest Standard: Surrogate Decision Making and Quality of Life*, 6 J. CLINICAL ETHICS 20 (1995).

⁴³See Miles, *supra* note 11, at 513 (inferring this false pretense in the case of Wanglie); Kuczewski, *supra* note 36, at 36-39; Rebecca Dresser, *Dworkin on Dementia: Elegant Theory, Questionable Policy*, HASTINGS CENTER REP., Nov./Dec. 1995, at 32.

⁴⁴This dilemma is perhaps most challenging in patients with advanced dementia whose "selfhood" or "personhood" is in doubt, raising frustrating questions concerning what level of residual function remains "meaningful" or a "benefit" to continued life. See Daniel Callahan, *Terminating Life-Sustaining Treatment of the Demented*, HASTINGS CENTER REP., Nov./Dec. 1995, at 25; see also Younger, *supra* note 27, at 2094; Veatch, *supra* note 33, at 7-11; Taylor & Lantos, *supra* note 13, at 8-9; Smith & Nunn, *supra* note 38, at 185-86; Ralph Baergen, *Surrogates and Uncertainty*, 6 J. CLINICAL ETHICS 372 (1995).

⁴⁵See Veatch, *supra* note 33, at 7-11; Michael A. LaCombe, *The Quality of Consent*, 100 AM. J. MED. 258 (1996).

⁴⁶See Veatch, *supra* note 33, at 11-12; Baergen, *supra* note 38, at 32-37; Peppin, *supra* note 40, at 25-27; Morreim, *supra* note 15, at 38.

⁴⁷It is at best an elusive goal and virtually impossible in the setting of managed care. It may not even be desirable. See *infra* text accompanying notes 91-106.

⁴⁸See *supra* notes 15-16.

⁴⁹Taylor & Lantos, *supra* note 13, at 12.

⁵⁰See *supra* note 40.

that drive requests for futile treatment in the first place. Moreover, even sincere efforts by the caregiver to maintain the distinction between futility and rationing⁵¹ will likely fail in the face of economic incentives to limit care, so that "[w]hile the physician may regain some decision-making authority from patients, they [sic] may also lose a considerable amount to administrators."⁵²

Therefore, both rights-based and resource-based decisionmaking threaten to erode the professional autonomy of physicians, but they also fail to address the deeper issues that drive requests for futile treatments and physicians' willingness to provide them. The prevailing ethical framework has proved inadequate even to identify such issues, which must be addressed by any framework that purports to facilitate decisionmaking in these cases.⁵³ This should challenge the conscientious caregiver to respond to such requests in a morally appropriate manner, using an entirely different approach.

What Are the Moral Issues?

When one contemplates the factors that may have driven the demands for treatment in the *Baby K* and *Wanglie* cases, at least four moral issues can be identified that should be addressed by any proposed framework for decisionmaking in such cases.

The Quest for Meaning in the Face of Death. How do people really respond to the prospect of impending death? Isn't more involved in end-of-life decisions than the right to self-determination? What drives some patients or their surrogates to demand medically futile treatment, while others appear to calmly accept their medical "fate"?

The Role of Moral Justification in Requests for Medically Futile Care. When parties to a decision on whether to provide life-prolonging therapy disagree about the expediency of therapy deemed by the provider to be medically futile, who remains accountable for the decisions made, and how should they be justified?

Morally Appropriate Care in the Face of Denial of Death. In those cases when it becomes obvious that demands for medically futile care are based—

⁵¹Nancy S. Jecker & Lawrence J. Schneiderman, *Futility and Rationing*, 92 AM. J. MED. 189 (1992).

⁵²Glenn G. Griener, *The Physician's Authority to Withhold Futile Treatment*, 20 J. MED. & PHIL. 207, 221 (1995).

⁵³See Jecker & Schneiderman, *supra* note 11, at 152-60; Lawrence J. Schneiderman et al., *Beyond Futility to an Ethic of Care*, 96 AM. J. MED. 110 (1994); Nancy S. Jecker, *Medical Futility and Care of Dying Patients*, 163 W. J. MED. 287, 290 (1995); Rosemarie Tong, *Towards a Just, Courageous, and Honest Resolution of the Futility Debate*, 20 J. MED. & PHIL. 166, 181-88 (1995); Amir Halevy & Baruch A. Brody, *A Multi-Institution Collaborative Policy on Medical Futility*, 276 JAMA 571 (1996).

at least in part—on some manifestation of existential dread, rather than on authentic values and interests, how is the caregiver to respond to those who persist in such demands?

The Pursuit of Legitimate Hope in the Face of Uncertainty. Given that such decisions are so often encumbered with medical and moral uncertainty on the part of the caregiver and others who represent the interests of the severely compromised patient, how do we decide what states of "residual life" should receive life-prolonging therapy?

The Wisdom Model and "Medical Futility"

I recently proposed a framework for decisionmaking derived from the biblical books of Job and Ecclesiastes—the "wisdom model"—as a preferable alternative to the contractual model for identifying and addressing certain key moral and existential concerns that underlie requests for assisted suicide.⁵⁴ Requests for assistance in suicide reflect many of the same moral issues as requests for futile treatment; I therefore propose to apply this wisdom-based framework to cases of medical futility and consider whether it can similarly provide a reliable basis for morally appropriate decisionmaking.

A "Wisdom" Paradigm—Existential Dread, Denial of Death, and Moral Justification

The following narrative from the life of Solomon relates his resolution of a dilemma that was in many ways analogous to the *Baby K* case and poignantly illustrates the existential concerns that may drive at least some requests for medically futile care and bring the resulting dilemmas to the attention of the courts:

[T]wo women who were harlots came to the king, and stood before him. And one woman said, 'O my lord, this woman and I dwell in the same house; and I gave birth while she was in the house. Then it happened, the third day after I had given birth, that this woman also gave birth. And . . . there was no one with us in the house, except the two of us . . . And this woman's son died in the night, because she lay on him. So she arose in the middle of the night and took my son from my side, while your maidservant slept, and laid him in her bosom, and laid her dead child in my bosom. And when I rose in the morning to nurse my son, there he was, dead. But when I had examined him in the morning, indeed, he was not my son whom I had borne.' Then the other woman said, 'No! But the living one is my son, and the dead one is your son.'

⁵⁴James S. Reitman, *The Debate on Assisted Suicide—Redefining Morally Appropriate Care for People with Intractable Suffering*, 11 ISSUES IN LAW & MED. 299, 305-06 (1995).

And the first woman said, 'No! But the dead one is your son, and the living one is my son.' Thus they spoke before the king.⁵⁵

The insufferable dread that led the woman who inadvertently killed her baby to seek restitution, even at the expense of the other woman, was not obvious to those in Solomon's court. The motivations behind the two women's respective claims were further obscured by the fact that both women were known harlots, which raised the question of the moral justification of their pleadings before Solomon.

And the king said, 'The one says "This is my son, who lives, and your son is the dead one"; and the other says, "No! But your son is the dead one, and my son is the living one."' Then the king said, 'Bring me a sword.' So they brought a sword before the king. And the king said, 'Divide the living child in two, and give half to one, and half to the other.' Then the woman whose son was living spoke to the king, for she yearned with compassion for her son; and she said, 'O my lord, give her the living child, and by no means kill him!' But the other said, 'Let him be neither mine nor yours, but divide him.' So the king answered and said, 'Give the first woman the living child, and by no means kill him; she is his mother.'⁵⁶

Solomon's wisdom was able to generate a moral dialogue that was capable of ferreting out the underlying motivations, which in turn supplied the moral justification for the decision made.⁵⁷ Unfortunately, most dilemmas of medical futility do not yield so readily to the application of wisdom; yet the demonstrated need for moral justification should generate an approach that is capable of assessing the motivation for such requests in ways that autonomy-based jurisprudence has not, indeed cannot, if we take the examples of *Wanglie* and *Baby K* to be the prevailing paradigms.

The Framework for Decisionmaking

The book of Ecclesiastes was written to address the question⁵⁸ "What is the point of continuing to struggle in life when it appears so meaningless?" Since requests for life-prolonging therapy provoke this exact question in the caregiver who is convinced that such care is futile, the author's reflections and conclusions on this question should be relevant to

⁵⁵1 Kings 3:16-22. Unless otherwise indicated, all biblical citations are from THE HOLY BIBLE, NEW KING JAMES VERSION (1982).

⁵⁶1 Kings 3:23-27.

⁵⁷This narrative has been cited as a paradigm of moral justification for ethical dilemmas in general. See, e.g., ROBERT D. ORR ET AL., LIFE AND DEATH DECISIONS 13-14 (1990).

⁵⁸James S. Reitman, "What Profit Has a Man . . . ?" *The Structure and Unity of the Book of Ecclesiastes*, 154 BIBLIOTHECA SACRA (forthcoming 1997) (establishing this premise regarding the book's purpose).

the moral issues raised by dilemmas of medical futility. By applying this framework of decisionmaking to the four moral issues raised in cases of medical futility (and handled so poorly by the contractual model), we will develop four important priorities for caregivers: (1) the need for careful attention to the role of existential dread and despair in driving requests for futile treatment as death approaches; (2) the value of sensitive and timely efforts to morally justify requests for medically futile treatment, as well as the refusals to provide it; (3) the critical role of community and of wise advocacy in facilitating authentic mourning when demands for futile treatment are driven by existential dread and the denial of death; and (4) an existentially based definition of death and phenomenology of dying that can help delineate sources of hope in the face of continuing clinical uncertainty over prognosis.

The Quest for Meaning

Why do some people react to the prospect of impending death with a panic-stricken pursuit of futile treatment, while others seem to calmly accept their medical condition?

Death's Inevitability and Existential Dread. The narrative from the life of Solomon illustrates the profound effect that the perceived absence of a future had on one woman when she lost her baby. This response reflects a universal truth about the crucial importance of man's concept of personal future in this life:

Our singular self . . . has the potentiality for a future. We are, in that sense, our possibilities, not simply what we happen to be at any given moment. . . . Time is our hope as well as our enemy. It provides the continuity for us to fulfill and develop as selves, as well as the entropy that will deprive us finally of our selves. Death may be understood as an evil just because, with it, all possibility ends; there is no future, only a past, and even the memory of that past is to be taken from us.⁵⁹

According to Wisdom, man's inevitable mortality also leads him to contemplate his future after this life, which is typically characterized by existential uncertainty:

[W]hat happens to the sons of men also happens to beasts; . . . as one dies, so dies the other. Surely they all have one breath; man has no advantage over beasts, for all is vanity. All go to one place: all are from the dust, and all return to dust. *Who knows whether the spirit of the sons of men goes upward, and whether the spirit of the beast goes

⁵⁹CALLAHAN, *supra* note 3, at 164.

downward to earth? . . . [W]ho can bring him to see what will happen after him?⁶⁰

We are not normally forced, however, to face the implications of our inevitable death until the possibility of future void is thrust into consciousness by unexpected loss in life. For those whose concept of personal future is undeveloped, vague uncertainty can suddenly escalate in the face of death into a terrifying existential dread. When this dread continues to evolve to the point of paralyzing fear, it may powerfully constrain the sufferer to desperately pursue any promise of forestalling death, even if this pursuit is morally questionable.⁶¹ This was certainly true of the harlot who deceitfully appropriated another woman's live baby to appease her own existential dread, and such dread may have played some role in the demands made by the mother of Baby K or Helga Wanglie's husband. If people were fully convinced of the ever-present potential for sudden loss of life,⁶² they might well take a different (and less desperate) approach to the future in the face of approaching death.⁶³ Unfortunately, the prevailing ethical framework on which these decisions were based completely neglects this critical role of one's concept of future and how it helps to shape suffering and dread.⁶⁴

The Despair of Meaning. The author of Ecclesiastes goes on to delve more deeply into the basis for this existential dread and determine why it

⁶⁰Ecclesiastes 3:19-22. (The asterisk denotes an alternative textual reading incorporated from footnote 4 in THE HOLY BIBLE, NEW KING JAMES VERSION (1982)).

⁶¹STANLEY HAUERWAS, SUFFERING PRESENCE 51 (1986) ("[I]ncreasing technological power is an attempt to maintain . . . moral coherence . . . in a morally incoherent society—that is, medicine gains its moral coherence by drawing on the fear of death, the one thing people have in common."). This "bondage" is well portrayed in Hebrews 2:14-15: "He likewise shared in [flesh and blood], that through death he might destroy him who had the power of death . . . and release those who through fear of death were all their lifetime subject to bondage." See also Allen D. Verhey, *Faithfulness in the Face of Death*, in DIGNITY AND DYING: A CHRISTIAN APPRAISAL 56, 63-65 (John F. Kilner et al. eds., 1996).

⁶²Ecclesiastes 9:12 ("For man also does not know his time: Like fish taken in a cruel net, Like birds caught in a snare, So the sons of men are snared in an evil time, When it falls suddenly upon them.").

⁶³CALLAHAN, *supra* note 3, at 25-30; see text accompanying *infra* notes 100-01.

⁶⁴Cassell states the following:

The model persons of archetypal ethics (and apparently, the law) . . . appear devoid of an enduring past or an extended future. [This] clearly provide[s] an inadequate basis for ethicists to do their work . . . Persons could not suffer if they did not have a past and did not anticipate a future.

Eric J. Cassell, *The Importance of Understanding Suffering for Clinical Ethics*, 2 J. CLINICAL ETHICS 81 (1991). This insight applies equally to the future of others in the patient's moral community—like the surrogate decisionmakers in the Wanglie and Baby K cases—who request futile therapy.

can so powerfully constrain such choices and lead to the panic-stricken pursuit of any future at all: "If a man begets a hundred children and lives many years, so that the days of his years are many, but his soul is not satisfied with goodness, . . . I say that a stillborn child is better than he . . ." ⁶⁵ It is not as much the threat of loss of life per se that is so abhorrent to the one who must face death as the perception that life to this point has yielded no real "goodness" or *lasting meaning*—under such circumstances even a stillborn child seems more fulfilled. ⁶⁶

"*Better Living through Technology*. Unlike the harlot who could not bring her baby back, we have the promise of modern technology to help forestall death and the need to think about lasting meaning as death approaches: Medical resources now available in the setting of serious illness—when applied as they were in the case of Baby K or Helga Wanglie—seem to extend the opportunity for meaningful life. ⁶⁷ Medical technology can even become conflated over time with the meaning of life itself, for

in many ways [medicine] is constantly tempted to offer a form of salvation that . . . may come close to idolatry. . . . Too often it is tempted to increase its power by offering more than care, by offering in fact alleviation from the human condition . . . [T]he fault lies with those of us who pretentiously place undue expectations on medicine in the hope of finding an earthly remedy to our death. ⁶⁸

Even though the impressive advances in modern technology may hold the promise of forestalling death, the resulting extension of personal future must ultimately expire, leaving us face to face with existential dread.

Illusions of Control and Certainty. Our author attacks the conceit that may well lie behind such requests for futile treatment:

Whatever one is, he has been named already,
For it is known that he is man;

⁶⁵Ecclesiastes 6:3-4.

⁶⁶This realization can lead to such despair that the suffering patient may be moved to request assistance in suicide. See also ORR ET AL., *supra* note 57, at 162-64; cf. Reitman, *supra* note 54, at 307-12.

⁶⁷Callahan states the following:

By changing our bodies and their prospects, medicine changes the self and its expectations as well. I know that I am likely to live a longer and healthier life than my grandparents, and when I become sick I will have a better chance of surviving. Medical powers and possibilities have become the constant companion of the self in its effort to live with mortality.

CALLAHAN, *supra* note 3, at 25.

⁶⁸HAUERWAS, *supra* note 61, at 68; see also Mary Midgley, *Visions, Secular and Sacred*, HASTINGS CENTER REP., Sept./Oct. 1995, at 20; Verhey, *supra* note 61, at 57-58.

And he cannot contend with Him who is mightier than he . . .
 For who knows what is good for man in life, all the days of his vain life
 which he passes like a shadow? Who can tell a man what will happen
 after him . . . ?⁶⁹

To think that one can forge one's own meaning out of life is absurd, because regardless of our intent, the outcome is not really under our control ("he cannot contend [with God]"); moreover, one cannot even be certain which intended outcomes will end up being meaningful for him anyway ("For who knows what is good for man in life?"). Callahan applies these autonomy-based illusions to our demand for medical technology:

The demand for control, the unwillingness to accept death as it might present itself . . . has become a passion for many.

. . . [H]owever, . . . two massive illusions . . . mark [this] change One . . . is the naive belief that the watchful self . . . can master the body by means of carefully controlled medical technology. . . . The other illusion complements the first: that we can know ourselves . . . well enough to manage ourselves . . . as if we can come to know ourselves and our inner world with the same clarity, and the same mastery, that technology gives us over the outer world.⁷⁰

While requests for life-prolonging technology *may* be valid, the prevalence of this illusion that we can know what is best for us—and then control our dying in order to make it happen—should lead us to question the propriety of such requests.

The Role of Moral Justification

How can we tell whether demands for medically futile treatment reflect the presumption described above or simply represent a reasonable choice among valid options in the face of life's uncertainty? Why not simply avoid the risks of probing the motivation behind such requests by acceding to autonomous preferences or by invoking professional consensus on futility or the need to conserve scarce resources?

The Need for Moral Accountability. Caregivers are enjoined to judge the expediency of all choices made in the face of man's suffering and mortality:

[F]or every matter there is a time and judgment,
 Though the misery of man increases greatly.
 For he does not know what will happen;
 So who can tell him when it will occur?

⁶⁹Ecclesiastes 6:10, 12.

⁷⁰CALLAHAN, *supra* note 3, at 36-37; see also H. Jochemsen et al., *The Medical Profession in Modern Society: The Importance of Defining Limits*, in *BIOETHICS AND THE FUTURE OF MEDICINE: A CHRISTIAN APPRAISAL* 14 (John F. Kilner et al. eds., 1996).

No one has power . . . to retain the spirit,
And no one has power in the day of death.⁷¹

Although there is an appropriate time for everything that happens, we cannot tell ahead of time when death will occur.⁷² However, once death has declared itself as imminent and unavoidable, it is presumptuous (and futile) to continue to marshal the power of modern technology to cling to life. Even in the setting of intractable suffering ("Though the misery of man increases greatly"), we are accountable for our choices ("there is judgment"); indeed, wisdom would dictate, just as in Solomon's case, that all parties to the decision be held accountable for the choice(s) ultimately made.⁷³

Irrational Hope for Cure. The author of Ecclesiastes reveals the foolishness of acceding to such demands when expressed out of determined anger or bitterness over the above-described inability of man to control the circumstances of health and life:

The end of a thing is better than its beginning,
And the patient in spirit is better than the proud in spirit.
Do not hasten in your spirit to be angry
For anger rests in the bosom of fools.
Do not say,
'Why were the former days better than these?'
For you do not inquire wisely . . .⁷⁴

The stylized plea quoted at the end of this text perfectly exemplifies the impatient emotional response that drives some demands for futile treatment: Like the harlot who inadvertently killed her baby, a patient or family member may rage unwisely at the unfairness of a lot characterized by premature loss of life or erosion of health and demand restoration of that loss by whatever means necessary. When caregivers resist such demands, such a disposition may only be further entrenched and lead to an escalation of technological attempts to control dying.⁷⁵ Thus, the pursuit of legal

⁷¹Ecclesiastes 8:6-8; see also *supra* text accompanying note 37.

⁷²See *supra* text accompanying note 37.

⁷³See, e.g., 1 Kings 3:23-28; Katz states the following: "The process of thinking about choices can only be effectively carried out if physicians and patients are expected to take responsibility for their conduct and if both affirm that they must be allowed to carry out this responsibility in their own ways and must accept responsibility for their own mistakes." KATZ, *supra* note 31, at 154; see also Reitman, *supra* note 54, at 315-16; Tong, *supra* note 53, at 186-88; Erich H. Loewy, *The Ongoing Dialectic Between Autonomy and Responsibility in a Pluralistic World*, in *TEXTBOOK OF HEALTHCARE ETHICS* 59, 59-78 (1996).

⁷⁴Ecclesiastes 7:8-10.

⁷⁵Compare the risk that such a rights-oriented approach may aggravate the similar demand for control behind requests for assisted suicide. Reitman, *supra* note 54, at 312-13, 319.

remedies to resist the surrogate's demand to maintain control in the cases of Helga Wanglie or Baby K may have also been "unwise."⁷⁶

The caregiver must not assume, however, that all requests for medically futile treatment represent an inappropriate demand for control. Even if characterized by some contention, requests for futile therapy can reflect caregiver insensitivity to legitimate sources of meaning for the patient or family⁷⁷ and may therefore be influenced more by the fear of abandonment than the illusion of control, particularly under the alienating circumstances of hospitalization with life-threatening illness.

If medical decision-making focuses solely on whether to attempt a particular life-saving treatment, a patient who is not offered such treatment might reasonably wonder: Does the physician deem me unworthy of further attention and concern? Am I being discarded? Understandably, the patient might respond with a desperate plea to be kept alive at all costs, insisting on any treatment no matter how unlikely its chance of success or how undesirable the outcome.⁷⁸

The Need for Moral Justification. Since the rationale for requests for futile treatment may be unclear, the caregiver who is challenged with such a request should attempt to clarify the motivation for the request, as Solomon did with the two harlots.

If one ought to do the morally defensible action in the contested case, then the final appeal cannot be solely [the] preferences of someone or some group. Preferences or agreements may be unworthy because they result from prejudice, self-interest or ignorance. In contrast, moral justification requires giving and defending reasons for preferences The evolution of contested cases often illustrates the pitfalls of failing to take the time to clarify people's concerns, problems, feelings, beliefs or deeply felt needs, or even to consider if people are treating others as they would wish to be treated.⁷⁹

By contrast, a single-minded focus on justifying futility claims seemed to undermine this kind of discussion in the Wanglie and Baby K cases; for example, in the latter case

⁷⁶See, e.g., Annas, *supra* note 10, at 1543; Steven H. Miles, *Interpersonal Issues in the Wanglie Case*, 2 KENNEDY INST. ETHICS J. 61, 63-67 n.2 (1992).

⁷⁷See sources cited *supra* notes 23, 26-27.

⁷⁸Schneiderman et al., *supra* note 53, at 112. This fear of abandonment often also drives requests for futile treatment by family or others in the patient's community on behalf of an incompetent patient.

⁷⁹Loretta M. Kopelman, *Conceptual and Moral Disputes About Futile and Useful Treatments*, 20 J. MED. & PHIL. 109, 117-18 (1995).

[the ethics subcommittee] seems to have discussed nothing ethical at all. Composed of two physicians and a minister, it gave advice on medical practice and legal strategy, concluding that if the physicians could not reach agreement with the mother, the hospital should seek judicial relief. The subcommittee should have insisted that discussion with the mother continue until a resolution was reached, and it should have tried to facilitate this communication.

The hospital's administration and attorney seem also to have overreacted Instead of . . . encouraging further discussion with the mother, they decided to go to court, because they saw Baby K's ventilatory support as a legal issue that might affect the institution, rather than an issue of medical practice or medical ethics.⁸⁰

The Priority of Moral Dialogue. The perceived need to protect professional integrity and the resulting pressure to establish institutional futility policies or appeal to limited resources risk circumventing the very conversation called for to resolve such issues.⁸¹ Ironically, rights-based *opposition* to such strategies only further truncates such discussion: By insisting that the only purpose of discussion should be to unmask the authentic preferences of the decisionmaker,⁸² decisions like *Wanglie* and *Baby K* have a trump-like effect, virtually stifling further consideration of the critical moral and existential concerns that drive requests for medically futile care.⁸³ Once the disputes in contested cases like *Baby K* and *Wanglie* reach the point of litigation, legitimate attempts at moral justification of this kind are all but impossible, thus preempted by the need of both sides to justify their respective legal interests.

Angry requests for futile treatment should therefore prompt caregivers to respond by engaging in moral conversation patiently over time ("the patient in spirit is better than the proud in spirit"⁸⁴) with increased

⁸⁰Annas, *supra* note 10, at 1543.

⁸¹See *supra* note 40; Bruce E. Zawacki, *The "Futility Debate" and the Management of Gordian Knots*, 6 J. CLINICAL ETHICS 112, 116 (1995) ("[C]alls from both sides of the debate for some form of compassionate and caring discussion . . . have gone largely unanswered in the literature, even by those calling for it Only now there appear to be increasing efforts to cut through this knot by stopping or at least discouraging discussion.").

⁸²Cf. KATZ, *supra* note 31. (This is the foundational premise of the entire book.)

⁸³Zawacki states the following:

[T]he consent-based paradigm has become associated with a . . . winner-takes-all, and loser-is-silent decision making by the patient [M]any house officers believe that after they have presented a 'menu' of options to a patient, that they must accept, without comment, any choice the patient makes about any intervention as a discussion-stifling 'last word.'

Zawacki, *supra* note 81, at 116-17 (citation omitted).

⁸⁴Ecclesiastes 7:8b.

attentiveness to underlying needs and motivation.⁸⁵ Katz elaborates further on these benefits:

If the process of thinking about choices is attended to with care, the problem of a total stand-off between physicians and patients may turn out to be a rare event. . . . [I]n the face of disagreement both may discover through conversation that their 'irreconcilable' differences have merit if viewed from the other's perspective and that both views deserve respect.⁸⁶

Moral dialogue thus offers an opportunity for each of the various parties to the decision to openly examine the bases for their differing preferences. Thus clarifying the underlying existential issues holds out hope of actually resolving ethical dilemmas and remaining accountable for those preferences,⁸⁷ thereby avoiding the presumption inherent either in blind accession to requests for futile treatment or in various forms of coercion—whether overt or subtle—to which any of the parties to the decision may be prone.⁸⁸

Morally Appropriate Care in the Face of Denial of Death

But what if such gentle, even altruistic, attempts at moral justification are met only with a redoubling of persistent demands for futile treatment? How can discussion continue with individuals such as the mother of Baby K, especially if it eventually becomes clear that such demands are unjustified; in other words, how do we approach what may be the denial of death driving such demands? Can we positively influence such requests without interfering with autonomous choice and thereby becoming vulnerable to the charge of coercion? Is there a role for unilaterally imposed

⁸⁵See Kopelman, *supra* note 79; SCHNEIDERMAN & JECKER, *supra* note 8, at 51-64; Jecker & Schneiderman, *supra* note 11, at 152-60; Schneiderman et al., *supra* note 53; Halevy & Brody, *supra* note 53; Zawacki, *supra* note 81, at 116-25. Philosophical justification for such moral engagement is provided in Richard M. Zaner, *Medicine and Dialogue*, 15 J. MED. & PHIL. 303 (1990) and Jonathan D. Moreno, *Ethics Consultation as Moral Engagement*, 5 BIOETHICS 44 (1991).

⁸⁶KATZ, *supra* note 31, at 154.

⁸⁷See Kopelman, *supra* note 79; Tong, *supra* note 53, at 182-86; see also Jacquelyn Slomka, *The Negotiation of Death: Clinical Decision Making at the End of Life*, 35 SOC. SCI. MED. 251 (1992).

⁸⁸Howe, *supra* note 41, at 93-94; Nancy S. Jecker & Lawrence J. Schneiderman, *Judging Medical Futility: An Ethical Analysis of Medical Power and Responsibility*, 4 CAMBRIDGE Q. HEALTHCARE ETHICS 23 (1995); Jonathon D. Moreno, *What Means This Consensus? Ethics Committees and Philosophic Tradition*, 1 J. CLINICAL ETHICS 38, 40-41 (1990); cf. text accompanying *supra* notes 15-16, 41, 48-52. A "coercive" appeal to legal precedent or remedy may, however, be required in some instances to redress a marked disparity in power. Cf. Spielman, *supra* note 9, at 139-40; Spielman, *supra* note 41.

"futility policies" to cover situations analogous to those of Baby K and Helga Wanglie?

The Critical Role of Community. Whether the request is driven by a demand for control or the fear of abandonment, the Wisdom Model assigns heavy moral weight to early supportive involvement by those with moral standing in the patient's community:

There is one alone, without companion:
 He has neither son nor brother.
 Yet *there* is no end to all his labors . . .
 Two *are* better than one,
 Because they have a good reward for their labor.
 For if they fall, one will lift up his companion.
 But woe to him *who* is alone when he falls,
 For *he* has no one to help him up.⁸⁹

As the passage implies, the clear benefits of depending on community are forfeited by the alienating effect ("without companion") of insisting on one's own way.⁹⁰ Probably the most common mistake in arriving at some judgment about requests for life-prolonging therapy that seems futile is the presumption that the responsibility for deciding whether it is futile necessarily rests on a single set of shoulders.⁹¹ This error may be perpetrated as much by the paternalistic caregiver who steadfastly resists shared decisionmaking⁹² as by the patient or surrogate who insists on radical autonomy. How then can members of the patient's moral community help to "lift up his companion"?

Wise Advocacy in the Midst of Suffering. Caregivers should be fully aware of the tendency for suffering to rob the decisionmaker of the capacity for sound reasoning necessary to make wise decisions:

Sorrow is better than laughter,
 For by a sad countenance the heart is made better.

⁸⁹Ecclesiastes 4:8-10.

⁹⁰Reitman, *supra* note 54, at 320.

⁹¹Loewy & Carlson, *supra* note 25, at 430 ("Who then decides what is futile? . . . [S]uch decisions are legitimate decisions that can profitably be decided by the community (with critical collaboration and advice by physicians, but not merely by physicians)."); see also John Hardwig, *What About the Family?* HASTINGS CENTER REP., Mar./Apr. 1990, at 5, 9-10; Slomka, *supra* note 87, at 255-56; Kuczewski, *supra* note 33, at 31-32, 35-36; Kuczewski, *supra* note 36, at 39-48.

⁹²Virginia P. Tilden et al., *Decisions About Life-Sustaining Treatment: Impact of Physicians' Behaviors on the Family*, 155 ARCHIVES INTERNAL MED. 633 (1995) ("Behaviors that made families feel excluded or increased their burden included postponing discussions about treatment withdrawal, delaying withdrawal once scheduled, placing the full burden of decision making on one person, withdrawing from the family, and defining death as a failure.").

The heart of the wise is in the house of mourning,
 But the heart of fools is in the house of mirth.
 It is better to hear the rebuke of the wise
 Than for a man to hear the song of fools. . . .
 Surely oppression destroys a wise man's reason,
 And a bribe debases the heart.⁹³

Given that "oppression destroys a wise man's reason," the "rebuke of the wise" may well be needed to restore wisdom to the decision-making process.⁹⁴ When requests for futile treatment appear to signify a foolish demand for technological control, this kind of wise advocacy may entail actually *challenging* such requests in a timely and appropriate (caring) fashion.

Sometimes . . . it seems easier to submit to unreasonable demands than to challenge them. But what are patients or, more often, their families really asking from health care workers? . . . [They] want [them] not only to be skillful masters of the science and technology of medicine, but also wise counselors who respond compassionately to patients and understand something about the human condition.⁹⁵

The risk that such a challenge would just reduce to plain coercion or harassment is minimized when such decisions are attended by a caregiver who has already established credibility as an integral member of the patient's moral community.⁹⁶

However, an even greater risk is posed in the text for the sufferer who rejects the constructive encouragement of "wise rebuke": Whereas the wise response when confronted with mortality is to engage in authentic "mourning," which edifies the heart,⁹⁷ the "song of fools" functions like a

⁹³Ecclesiastes 7:3-5, 7.

⁹⁴Jay Katz, a psychiatrist, provides a cogent discussion of this need from a psychological perspective in KATZ, *supra* note 31, at 121-25, 159-63.

⁹⁵Jecker & Schneiderman, *supra* note 11, at 152-53 (citation omitted).

⁹⁶See *supra* notes 91, 94. The qualities of moral engagement and sustained presence essential for the caregiver to establish credibility as a wise advocate within the patient's moral community are described in Reitman, *supra* note 54, at 318-26. This does not at all require the caregiver to be a close personal friend of the patient—a social stranger can gain such credibility, whereas lifelong friends can fail miserably. *Id.* This concept of advocacy is developed at length by the present author in *A Wisdom Perspective on Advocacy for the Suicidal*, in Gary P. Stewart & Timothy J. Demy, eds., *SUICIDE AND THE CHRISTIAN COMMUNITY* (forthcoming 1997), (illustrating the abject failure of such advocacy by Job's three older friends, while wise advocacy is epitomized by the younger, enigmatic Elihu). Regarding the potential for coercion, see *supra* text accompanying note 41.

⁹⁷Authentic mourning "edifies the heart" by ultimately leading to patient hope. *Cf. infra* note 107 and accompanying text. This concept of authentic mourning certainly does not reduce to mere resignation to one's fate under such circumstances. The process is described

"bribe," in that it *appeases* the threat of suffering. In the case of requests for futile therapy, this bribe is embodied in the elusive promise of life-extension—the Faustian lure of technological salvation⁹⁸—that only "debases the heart" by subverting authentic mourning, the very process by which "the heart is made better."

The challenged decisionmaker thus has two choices: He/she can listen to the wise advocacy of others and mourn, or foolishly succumb to the illusory bribe of technology. While futility policies⁹⁹ could help limit such inappropriate therapy, they could also undermine the mourning process that helps to restore wise decisionmaking to responsible moral agents—the dying patient and members of his/her community.

Wise Stewardship in the Face of Death. By facilitating the mourning process, wise advocacy may enable the patient to exercise optimal stewardship of the time and opportunities that remain in life, which is the final thrust of Ecclesiastes against the backdrop of man's impending mortality:

However many years a man may live,
let him enjoy them all.
But let him remember the days of darkness,
for they will be many.
Everything to come is meaningless.
Be happy . . . while you are young,
and let your heart give you joy in the days of your youth.
Follow the ways of your heart and whatever your eyes see,
but know that for all these things God will bring you to judgment.
So then, banish anxiety from your heart
and cast off the troubles of your body,
for youth and vigor are meaningless.
Remember your Creator in the days of your youth,
before the days of trouble come
and the years approach when you will say,
"I find no pleasure in them."¹⁰⁰

These verses encourage the process of mourning in order to reorient the individual who is gripped by the fear of death to pursue authentic meaning in his/her remaining choices in life. The exhortation underscores the

further in Reitman, *supra* note 58 ("Mourning entails an honest and patient willingness, first to acknowledge one's inability to avoid suffering or to forge one's own meaning in life, then to submit . . . to God's sovereign purposes and face one's ultimate accountability for stewardship before God . . .").

⁹⁸See *supra* text accompanying notes 67-68.

⁹⁹See *supra* note 16.

¹⁰⁰Ecclesiastes 11:8-12:1 (THE HOLY BIBLE, NEW INTERNATIONAL VERSION (1978)).

importance of appropriating a concept of personal future, before the opportunity to exercise wise stewardship in view of that future has expired with the inexorable erosion of one's vitality.¹⁰¹

Although the passage presupposes a theistic worldview and thus raises questions about the moral probity of an advocacy that might involve influencing religious beliefs (or the lack thereof),¹⁰² it certainly supports the wisdom of an advocacy capable of assisting patients to remember their responsibilities as moral agents in the face of death.¹⁰³

[W]e have had trouble considering how we should care for the dying because we have not thought enough about what kind of responsibilities the one who is dying should have. . . . [T]he dying person has obligations to the living that are important for us to understand in the care of the dying. The attempt to determine the moment of death may be an attempt to avoid determining when it is time to die.¹⁰⁴

This difficulty in deciding when it is time to die in turn raises the question of how caregivers and decisionmakers should then measure the remaining hope for meaningful life as death draws near: Thanks to the ever-improving capabilities of modern technology to prolong life, we are often left even more uncertain over the timing of the day of death.¹⁰⁵ Moreover, the resulting ambivalence over whether to apply life-prolonging therapy is only compounded by the risk of caregiver presumption, i.e., of projecting one's own views and preferences on others to justify a premature judgment of futility.¹⁰⁶

Balancing Hope and Uncertainty—Meaningful Criteria for Dying and Death

How then do we assess when it is "time to die"? Given that such decisions are so often encumbered with medical and moral uncertainty on the part of the caregiver and others who represent the interests of the

¹⁰¹See *supra* text accompanying notes 60-64; see also Verhey, *supra* note 61, at 63-65; ORR ET AL., *supra* note 57, at 133-34; DAVID SCHIEDERMAYER, PUTTING THE SOUL BACK IN MEDICINE 91 (1994).

¹⁰²Edmund G. Howe, *Influencing a Patient's Religious Beliefs: Mandate or No-Man's Land*, 6 J. CLINICAL ETHICS 194 (1995). Compare Verhey's approach, *supra* note 61, at 58-63, and the recent proposal of Russell B. Connors, Jr. & Martin L. Smith, *Religious Insistence on Medical Treatment: Christian Theology and Re-Imagination*, HASTINGS CENTER REP., July/Aug. 1996, at 23 (the latter article is of particular relevance to the cases of *Wanglie* and *Baby K*).

¹⁰³This was precisely the intended impact of Solomon's wisdom in 1 Kings 3:23-28.

¹⁰⁴HAUERWAS, *supra* note 61, at 94; see also Hardwig, *supra* note 91, at 8-10.

¹⁰⁵See *supra* note 71; see also Thomas E. Finucane, *Choosing Resuscitation Late in Life: Problems with the Paradigm*, 100 AM. J. MED. 126, 127 (1996).

¹⁰⁶See *supra* note 41.

severely compromised patient, how do we decide what states of "residual life" should receive life-prolonging therapy?

Patient Hope in the Face of Uncertainty. In view of such ambiguity and uncertainty those accountable for choices about therapy are advised by wisdom to adopt a disposition that patiently accepts the "hand that one is dealt," regardless of the apparent success or failure of those choices.¹⁰⁷ Unfortunately, the caregiver is not likely to encounter this disposition in the face of impending death:

This is an evil in all that is done under the sun: that one thing happens to all. . . . [M]adness is in their hearts while they live, and after that they go to the dead. But for him who is joined to all the living there is hope, for a living dog is better than a dead lion.¹⁰⁸

Such "madness" (impure motivation and a profound lack of wisdom) can lead angry or fearful patients or their surrogates to make unwarranted demands for clearly futile treatment when faced with mortality. By the same token, however, this tendency may also influence an inexperienced, fatigued, resentful, or presumptuous caregiver to arrive at an invalid futility judgment and refuse potentially meaningful care.¹⁰⁹

There is increasing evidence to suggest that seriously ill individuals characteristically rate their quality of life as greater than it would be rated by their physicians,¹¹⁰ and that such ratings are not particularly durable over time, tending to improve as death approaches.¹¹¹ This reinforces the impression that advance directives are hardly reliable guides to patient preference concerning life-sustaining treatment when the patient is no

¹⁰⁷*Ecclesiastes* 7:14 ("In the day of prosperity be joyful, But in the day of adversity consider: Surely God has appointed the one as well as the other, So that man can find nothing that will happen after him."). This text illustrates how the patient hope that issues from authentic mourning differs from mere resignation. Cf. *supra* note 97.

¹⁰⁸*Ecclesiastes* 9:3-4. My application of these and the following verses, *infra* note 117, in the context of medical futility has been previously cited in SCHNEIDERMAN & JECKER, *supra* note 8, at 113.

¹⁰⁹See *supra* notes 23, 30.

¹¹⁰Marion Danis et al., *Patients' and Families' Preferences for Medical Intensive Care*, 260 *JAMA* 797 (1988); Richard F. Uhlmann & Robert A. Pearlman, *Perceived Quality of Life and Preferences for Life-Sustaining Treatment in Older Adults*, 151 *ARCHIVES INTERNAL MED.* 495 (1991).

¹¹¹See M. Powell Lawton et al., *The Quality of the Last Year of Life of Older Persons*, 68 *MILBANK Q.* 1 (1990); F. Russell Kellogg et al., *Life-Sustaining Interventions in Frail Elderly Persons: Talking About Choices*, 152 *ARCHIVES INTERNAL MED.* 2317 (1992); Robert M. Walker et al., *Living Wills and Resuscitation Preferences in an Elderly Population*, 155 *ARCHIVES INTERNAL MED.* 171 (1995); Joel Tsevat et al., *Health Values of the Seriously Ill*, 122 *ANNALS INTERNAL MED.* 514 (1995); Neil Abramson, *Quality of Life: Who Can Make the Judgment?* 100 *AM. J. MED.* 365 (1996).

longer competent.¹¹² Given this human fallibility in surrogate decisionmaking, our text clearly infers that it is expedient to err on the side of life whenever the outcome is uncertain, thus providing a cogent rationale for negotiating time-limited trials of therapy.¹¹³

What Constitutes a "Living Dog"? Is there a way then to determine when it is no longer expedient to continue such therapy, especially when patients are incompetent? There is evidence to suggest that seriously ill "incompetent patients are far more likely than competent patients to have life-sustaining treatment withheld" and that "[m]ost decisions are made by a consensus of physicians and family surrogates, and major conflicts rarely occur."¹¹⁴ How do we decide whether this situation is as it should be? When faced with the choice of whether to provide life-prolonging therapy for a patient who is no longer capable, those who must decide may benefit from wise counsel about reasonable limits of hope for meaningful life.

Considering the wide variation of opinion over physiologic states worthy of life-sustaining therapy,¹¹⁵ physiologic definitions of death have met with very limited success in delineating the boundaries of life¹¹⁶ when there is uncertainty or disagreement over the meaning of continuing life support for a given patient. By contrast the author of Ecclesiastes provides us in the next two verses with a (non-physiologic) phenomenological definition of what is meant by the "hope" of the "living dog"; it is a guideline that helps define a living existence with some remaining potential for meaning:

For the living know that they will die;
 But the dead know nothing,
 And they have no more reward,
 For the memory of them is forgotten.
 Also their love, their hatred, and their envy have now perished;
 Nevermore will they have a share
 In anything done under the sun.¹¹⁷

I call these capacities the living dog criteria: According to the text, life is worth supporting as long as there remains the capacity for cognition, "rewarding" relationship, emotional expression, and/or volition,¹¹⁸ or the

¹¹²See *supra* note 111; cf. *supra* notes 36-42.

¹¹³See Slomka, *supra* note 87.

¹¹⁴Laura C. Hanson et al., *Impact of Patient Incompetence on Decisions to Use or Withhold Life-Sustaining Treatment*, 97 AM. J. MED. 235 (1994).

¹¹⁵See *supra* notes 19-22.

¹¹⁶ENGELHARDT, *supra* note 29, at 241-53; see Jeff McMahan, *The Metaphysics of Brain Death*, 9 BIOETHICS 91 (1995).

¹¹⁷Ecclesiastes 9:5-6.

¹¹⁸Reitman, *supra* note 54, at 314.

potential to develop these capacities.¹¹⁹ Consider Callahan's very similar assessment from a nontheistic perspective—

I . . . define full selfhood as the capacity to have feelings and to be aware of them, to reason and be able to make decisions, and to enter into relationships with other persons. A person who has even one of those capacities can be said to have a self, even if limited and impaired.¹²⁰

The use of such criteria for potentially meaningful existence ("selfhood") may be more productive than debating societally acceptable criteria for personhood in cases of seriously compromised or not-yet-developed individuals¹²¹ and then maintaining the pretense of exercising autonomous choice on their behalf in decisions about whether to prolong life.¹²² Loewy's suggestion that the primary criterion should be the capacity to suffer may provide one way to translate the living dog criteria into clinically useful guidelines for decisionmaking in these difficult borderline conditions of existence.¹²³

Implications for Quality-of-Life Considerations. The use of phenomenologically oriented criteria in such decisions would appear then to bring quality-of-life considerations into play. The question of how much weight to give such quality-of-life criteria in decisions over whether to employ life-sustaining therapy in incapable patients has provoked a vigorous debate over the definition of meaningful life, with supporters of the sanctity-of-life principle historically denying any significant role for quality-of-life criteria.¹²⁴ However, a growing number of conservative commentators have begun to qualify the sanctity-of-life stance on this question, such that there now appears to be some room for consideration of quality-of-life criteria in the abatement of life-sustaining therapy for some individuals who may not

¹¹⁹Erich H. Loewy, *The Role of Suffering and Community in Clinical Ethics*, 2 J. CLINICAL ETHICS 83, 85-86 (1991).

¹²⁰Callahan, *supra* note 44, at 26.

¹²¹See, e.g., ON MORAL MEDICINE 273-304 (Stephen E. Lammers & Allen Verhey eds., 1987); ENGELHARDT, *supra* note 29, at 135-54; P. Goube de Laforest, *An International Workshop: Life Sciences and the Concept of Person—Impact of Individual Opinions on the Respect for Human Personhood*, 12 ETHICS & MED. 10 (1996).

¹²²See *supra* notes 40, 43 and accompanying text; Callahan, *supra* note 44, at 26.

¹²³Loewy, *supra* note 119, at 85-86 ("[P]atients who retain the capacity to suffer continue to have primary worth However, once the patient becomes permanently insentient and loses the capacity to suffer, a relationship (except a symbolic one) is no longer possible").

¹²⁴See Jerome R. Wernow, *Saying the Unsaid: Quality of Life Criteria in a Sanctity of Life Position*, in *BIOETHICS AND THE FUTURE OF MEDICINE: A CHRISTIAN APPRAISAL* 93 (John F. Kilner et al. eds., 1995).

satisfy criteria for whole-brain death yet retain no meaningful existential capacities.¹²⁵

In fact, the living dog criteria actually honor sanctity-of-life concerns by avoiding the "slippery slope" or "wedge" concerns about quality-of-life criteria raised by some advocates of the sanctity-of-life principle.¹²⁶ By focusing on the presence of specific vestigial existential capacities, these verses do not leave nearly as much leeway for judgments of futility as recently proposed, broader-ranging quality-of-life criteria.¹²⁷ Monitoring the residual presence of living dog criteria would facilitate maximizing the meaningful exercise of whatever capacities may remain at the time¹²⁸ and thereby help forestall premature judgments of futility on the part of family or care providers.

It would appear on first inspection that applying these living dog criteria to patients like Helga Wanglie and Baby K would suggest no remaining potential for meaning in those patients, who retain no cognitive, emotive, or volitional capacity. In practice, however, it may take some time for borderline conditions such as PVS or advanced dementia to declare themselves, as decisionmakers struggle over how vigorous an approach to take; moreover, there may well be some latitude in understanding "the memory of them" and "no further reward."¹²⁹ Thus it is natural for loved ones and care providers to experience ambivalence over the meaning of

¹²⁵*Id.* See also HAUERWAS, *supra* note 61, at 87-98; ORR ET AL., *supra* note 57, at 139-50; KENNETH E. SCHEMMER, TINKERING WITH PEOPLE 99-113 (1992); ON MORAL MEDICINE 107-49, 273-304 (Stephen E. Lammers & Allen Verhey eds., 1987) (discussing the wide range of sanctity-of-life positions).

¹²⁶Wernow, *supra* note 124, at 95, 99.

¹²⁷See, e.g., Drane & Coulehan, *supra* note 42.

¹²⁸This is the main point of the argument in Wernow, *supra* note 124, at 100-07. See also HAUERWAS, *supra* note 61, at 94-98.

¹²⁹*Cf.* *supra* note 117 and *supra* text accompanying note 123. Loewy's discussion of decisionmaking regarding limiting treatment—including fluids and nutrition—in states of advanced dementia, acognition, or anhedonia is to be commended for its sensitivity to these concerns. Loewy, *supra* note 73, at 174-83.

In enunciating grounds for making the decision to limit treatment, our obligation to refrain from causing suffering and to prevent harm . . . as well as our obligation to sustain life must be considered. . . . [A]t least four considerations are appropriate: (1) the immediacy of the threat, (2) the relievability of the suffering caused by the disease, (3) the suffering entailed in the treatment, and (4) the patient's ability for sustained understanding of and cooperation with treatment.

Id. at 175.

residual life¹³⁰ and consequently find the need to negotiate the potential meaning of continued therapy.¹³¹

Negotiated Meaning and Negotiated Death. Linda Emanuel has proposed a practical methodology—the "asymptotic model"—which avoids black and white definitions of death and is flexible enough to allow for a broad range of *prima facie* views on meaningful states of existence: The so-called bounded zone definition of death facilitates the kind of moral dialogue that may eventually be needed to grapple honestly with the uncertainty which characterizes decisionmaking for residual states of life.¹³² It becomes much easier within such a framework for care providers and decisionmakers over time to negotiate the resolution of perceived differences over the potential meaning of proposed therapeutic interventions.

In clinical decision making involving the dying patient, physicians, patients and families bring various perceptions and interpretations to the situation. These different realities must be negotiated in order to define the meaning of the situation and the meaning of various medical technologies.

... [A]n illusion of choice in medical decision making, as offered by the physician, begins a negotiation of meanings that allows a sharing of moral responsibility for medical failure and its eventual acceptance by patient, family and physician alike.¹³³

At first blush the use of terms such as *negotiation* may seem crass and "illusion of choice" disingenuous; however, these phrases merely reflect the initial language of moral dialogue¹³⁴ as applied to those residual states of existence fraught with high levels of ambiguity and uncertainty. Ideally, a language more apropos of the unique narrative that has characterized the patient's existence will develop over time as the deeper issues of meaning surfaced by dilemmas of medical futility are explored and interpreted by the patient's moral community.¹³⁵ It is lamentable that, the more modern health care with its attendant advances in medical technology continues to evolve,

¹³⁰See Linda L. Emanuel, *Reexamining Death: The Asymptotic Model and a Bounded Zone Definition*, HASTINGS CENTER REP., July/Aug. 1995, at 27.

¹³¹Slomka, *supra* note 87; Loewy, *supra* note 73, at 191-92.

¹³²See Emanuel, *supra* note 130, at 31-34; cf. sources cited *supra* note 116.

¹³³Slomka, *supra* note 87, at 251 (quoting from abstract); see also Jecker, *supra* note 53, at 288-89.

¹³⁴See *supra* text accompanying notes 79-87.

¹³⁵See Hardwig, *supra* note 91; McClung, *supra* note 38, at 42-43; Kuczewski, *supra* note 33, at 33-36; Valerie Swigart, *Recognizing and Respecting Family Judgment*, 6 J. CLINICAL ETHICS 85, 86-87 (1995); Robert Lyman Potter, *The Hermeneutical Process and Clinical Ethics*, 6 J. CLINICAL ETHICS 88 (1995).

the less available seem to be the time and patience required to fully engage this process.

Conclusion

Requests by patients or their surrogate decisionmakers for life-prolonging therapy that care providers believe is futile raise significant questions about the moral propriety of acceding to such requests. However, since all parties to the decision are morally accountable for their preferences, the moral justification for the eventual decision should entail efforts toward understanding the unresolved existential issues that drive requests for futile therapy, as well as caregiver resistance to those requests. By contrast, a preoccupation with determining patient preference and defining futility may only circumvent the moral dialogue needed to elucidate the motivations underlying these preferences.

Wisdom suggests that requests for futile therapy are often driven by uncontrolled existential dread, expressed as a fear of abandonment or the illusion that life-prolonging therapy may allow one to control death and dying. When it becomes clear that a persistent demand for futile treatment is attributable at least in part to such unresolved existential dread, wise advocacy undertaken over time with sufficient patience may allow for the *desperate* pursuit of any future at all to be replaced by the *purposeful* pursuit of meaning in spite of progressive personal disintegration, when

the purposes of the suffering individual are no longer subsumed under an organized unity. This loss of unity is why suffering persons are *not* autonomous and *not* free and cannot clearly articulate what is in their best interests Like all who are very sick, they require the help of others to represent themselves, but it is the nature of this assistance that is key. The suffering person is being helped, through the process of interaction and probing by the caregiver, to make decisions (to pursue purposes) that are authentically coherent with the pattern of purpose that has characterized his or her previous life. This is, in fact, the function of medicine—to enable sick persons, within the constraints of fate, to continue to live true to themselves.¹³⁶

Thus, in resolving dilemmas of medical futility the attention of those in the patient's moral community is most productively focused on the pursuit of authentic meaning while life remains,¹³⁷ and the relational and communication skills of the caregiver are often more important than the

¹³⁶Cassell, *supra* note 64, at 82. Recent evidence supports Cassell's contention regarding the autonomy of seriously ill persons. See Schaeffer et al., *supra* note 34; cf. KATZ, *supra* note 31, at 121-25, 159-63.

¹³⁷See Abramson, *supra* note 111; Michael Lipson & Abigail Lipson, *Psychotherapy and the Ethics of Attention*, HASTINGS CENTER REP., Jan./Feb. 1996, at 17.

rationalistic skills of prognosticating survival or protecting the patient's right to self-determination.¹³⁸ When caregivers lack such skills, or caregiving is compromised by expectations that have been conditioned by negative past experiences, the ensuing relational tension or power struggle may provide an occasion for clinical ethics consultation and/or pastoral care to attend within the context of the patient's moral community, with the hope of morally reorienting the sufferer "toward increasing alertness to the people and meanings of the world."¹³⁹

While such advocacy does involve the potential for subtle coercion, and attempts at influencing the patient's concept of future as death approaches might thus be construed as proselytizing,¹⁴⁰ this may encourage the continued development of mechanisms of accountability¹⁴¹ to ensure that the risks of wise advocacy are still outweighed by the potential benefits, which are considerable, according to the Wisdom Model. By the same token, attempts at wise advocacy that are consistently rebuffed over time may signify the decisionmaker's refusal to mourn and stubborn insistence on radical self-determination, rather than incompetence or failure on the part of the caregiver.¹⁴²

Whether it is the dying patient or a member of that patient's moral community who struggles to find meaning in the patient's dying, wise advocacy does not shrink from encouraging the authentic mourning that

¹³⁸In this regard see the persuasive argument of Sally Gadow, *Aging as Death Rehearsal: The Oppressiveness of Reason*, 7 J. CLINICAL ETHICS 35 (1996).

¹³⁹Lipson & Lipson, *supra* note 137, at 22. See also Cassell, who states the following: It is only necessary that persons be known well enough to lend assistance in their decision making. Unfortunately, that much cognizance of another individual demands a certain degree of skill that most physicians and clinical ethicists do not possess. When clinical ethicists realize what they must do to meet the needs of suffering patients, they will seek the necessary proficiency.

Cassell, *supra* note 64, at 82; see also Mary Beth West & Joan McIver Gibson, *Facilitating Medical Ethics Case Review: What Ethics Committees Can Learn from Mediation and Facilitation Techniques*, 1 CAMBRIDGE Q. HEALTHCARE ETHICS 63-74 (1992); Reitman, *supra* note 96.

¹⁴⁰See *supra* note 102.

¹⁴¹See *Defining Quality in Ethics Consultation: First Steps*, 18 QUALITY REV. BULL. 1 (1992); John C. Fletcher & Diane E. Hoffmann, *Ethics Committees: Time to Experiment with Standards*, 120 ANNALS INTERNAL MED. 335 (1994); see Bette-Jane Crigger, *Negotiating the Moral Order: Paradoxes of Ethics Consultation*, 5 KENNEDY INST. ETHICS J. 89 (1995); Linda L. Blank, *Defining and Evaluating Physician Competence in End-of-Life Patient Care: A Matter of Awareness and Emphasis*, 163 W. J. MED. 297 (1995).

¹⁴²In such cases there might then be some moral justification for appeals to futility policies, conservation of scarce resources, distributive justice, or even legal recourse; however, it is still not clear how such measures would then be appropriately implemented. See the thoughtful mechanism proposed by the Houston City-Wide Task Force on Medical Futility (cited in Halevy and Brody, *supra* note 53).

may be necessary to pursue that meaning when confronted with the impotence and uncertainty of approaching death:

Death is both a friend and enemy. It is a friend in that without it we would not be forced to value one thing in life over another. . . . [D]eath creates the economy that makes life worthwhile. But . . . [death] also becomes our enemy, for what we come to value and love we want to continue to value and love.

* * *

It is important, then, that the one who is dying exercise the responsibility to die well. That is, the person should die in a manner that is morally commensurate with the kind of trust that has sustained him or her in life. . . . [I]t means that we should die in such a manner that others see that they are sustaining us and that correlatively due credit is given to God as the ultimate giver of life.¹⁴³

As an authentic and abiding future ultimately begins to emerge over time for the dying patient and for those in the patient's community, ambivalence and dread then give way to growing confidence in that future, and difficult decisions can finally be made.¹⁴⁴ Once issues of meaning become the focus of attention as disintegration continues, phenomenological descriptions of dying may be much more helpful than physiological criteria for death in addressing the question of the timing of death, even when prognosis remains uncertain.

¹⁴³HAUERWAS, *supra* note 61, at 96 (citation omitted); *cf. supra* notes 97, 107.

¹⁴⁴See *supra* note 101; see also STANLEY HAUERWAS, NAMING THE SILENCES: GOD, MEDICINE, AND THE PROBLEM OF SUFFERING (1990); Thomas R. McCormick & Becky J. Conley, *Patients' Perspectives on Dying and on the Care of Dying Patients*, 163 W. J. MED. 236 (1995); Paul B. Bascom & Susan W. Tolle, *Care of the Family When the Patient Is Dying*, 163 W. J. MED. 292, 293-95 (1995); Robert R. Fleischman, *Death: An Enemy? Reflections on 1 Corinthians 15:26*, 11 ISSUES IN LAW & MED. 411 (1996); Abramson, *supra* note 111; Nancy Day Adams, *Going Fishing*, 100 AM. J. MED. 475 (1996); Connors & Smith, *supra* note 102, at 25-29; DIGNITY AND DYING 181-242 (John F. Kilner et al. eds., 1987).