

BIOETHICS MEDIATION AT THE END OF LIFE: OPPORTUNITIES AND LIMITATIONS

*Ellen Waldman**

I. INTRODUCTION

Medical advances in a wide variety of areas are helping more and more elderly people live longer. When hearts, lungs and kidneys failed in the past, death came swiftly and without discussion. Today, failing organs mobilize a sophisticated arsenal of medical technology designed to keep death at bay.

To have such tools at our disposal is both miraculous and problematic: Miraculous because sick, elderly patients can often be healed and delivered back to lives of satisfaction, dignity and meaning; problematic because where such deliverance is not possible, machines can nonetheless extend corporeal existence beyond sentience or awareness. This capability forces us to ask the question, “When does tending the body entail neglect of the person? When is it time to stop?” Death, in our modern medical age, increasingly requires a choice. Switches must be flicked, buttons pushed and tubes removed. It is a choreographed event preceded by discussion, debate, and not infrequently, conflict.

This choreography is particularly complicated because there are more characters on stage than formerly. Up until the 1960s, medical decision-making fell solely within the province of the doctors on the case.¹ With the advent of the patient’s rights and consumer movements, decisional authority shifted, in part, to the patient and her family.² In an effort to encourage advance medical planning, states enacted laws legitimizing living wills and proxy directives, and hospitals adopted policies granting such documents formal authority in the event of patient incapacity.³

* Professor Ellen Waldman has provided training and assistance to multiple hospital ethics committees and founded and directs the Mediation Program at Thomas Jefferson School of Law.

¹ See JAMES F. DRANE, *CLINICAL BIOETHICS: THEORY AND PRACTICE IN MEDICAL-ETHICAL DECISION MAKING* 121–26 (Sheed & Ward 1994).

² See NANCY N. DUBLER & CAROL B. LIEBMAN, *BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS* 5 (United Hospital Fund 2004) (“[b]oth the patients’ rights movement and the consumer movement have legitimized the place of the family and the patient in deliberations regarding medical matters.”).

³ See PRESIDENT’S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREAT-*

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Decision-making at the end of life, then, requires the inclusion of many voices. Patients speak directly or indirectly through their advance directives. Families assume the patient's voice where advance directives are absent or unclear, and clinicians speak from the podium of professional authority, urging those outcomes they believe to be most medically and ethically appropriate. The opportunities for conflict are legion.⁴

Grieving families immobilized by fear, denial, suspicion or grief may refuse to accept the patient's terminal condition and insist on treatments whose burdens outweigh their benefits.⁵ Clinical teams may disagree among themselves regarding the merit of a full court medical press and families may develop fractured interpretations of what an advance directive requires, or, in the absence of written guidance, what grandma would want if she could rise from the hospital bed and speak. These disagreements implicate profound value commitments and reflect divergent views about the importance of prolonging life, relieving suffering and conserving scarce medical resources.⁶

For nearly twenty years, bioethicists endeavored to bring some clarity to these disputes.⁷ Trained interveners would step into the medical fray in an effort to bring the parties' conflict to a mutually agreeable and ethically acceptable conclusion. Initially, these interveners were known as "ethics consultants," and the process was highly evaluative. Consultants reviewed the case, deliberated on the available options in light of universally accepted ethical principles, and rendered an opinion as to the proper medical course.⁸

MENT 1 (1983) [hereinafter PRESIDENT'S COMMISSION REPORT], available at http://bioethics.georgetown.edu/pcbe/reports/past_commissions/deciding_to_forego_tx.pdf.

⁴ One study found that conflict occurred in 78% of cases concerning the limitation of life-sustaining medical care. See John M. Luce & Douglas B. White, *The Pressure to Withhold or Withdraw Life-Sustaining Therapy from Critically Ill Patients in the United States*, 175 AM. J. RESPIRATORY AND CRITICAL CARE MED. 1104, 1104-07 (2007) (noting that disagreements between families and clinician on end-of-life care are commonplace in the United States).

⁵ Globalized distrust of medical motivation in the wake of managed care cost containment strategies may contribute to family unwillingness to acquiesce to clinical recommendations to withhold or withdraw life-sustaining treatment. See Thaddeus M. Pope & Ellen A. Waldman, *Mediation at the End of Life: Getting Beyond the Limits of the Talking Cure*, 23 OHIO ST. J. ON DISP. RESOL. 143, 164-65 (2007).

⁶ AMERICAN SOCIETY FOR BIOETHICS AND HUMANITIES CLINICAL ETHICS TASK FORCE, IMPROVING COMPETENCE IN CLINICAL ETHICS CONSULTATION: A LEARNERS GUIDE 32 (2003) [hereinafter LEARNERS GUIDE].

⁷ See Ellen A. Waldman, *Hospital Ethics Mediation Balances Life and Death*, 17 CPR INST. FOR DISP. RESOL. 14, 14-15 (Jan. 1999).

⁸ *Id.*; ETHICS AT THE BEDSIDE 6-7 (Charles M. Culver ed., Univ. Press of New England 1990).

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Ethics consultants functioned more like arbitrators or judges in a non-binding process.⁹

Over time, however, ethics consultation has morphed into a more facilitative process. This change is evident in the American Society for Bioethics and the Humanities' Task Force Report on Ethics Consultation Core Competencies, a report endorsed by the three major American bioethics trade organizations,¹⁰ and widely accepted in the field.¹¹ This report clarified that the ethics consultant's goal is not to tell the parties what to do, but to "identif[y] and analyz[e] the nature of the value uncertainty and facilitat[e] the building of consensus."¹² The report's suggested core process and interpersonal skills include the ability to resolve value uncertainty, engage in active listening, communicate empathy, and reframe positions.¹³ Although the core competencies identified mirror many of the skills central to effective mediation, the bioethics community continues to use the vocabulary of consultation, rather than mediation. It is only with the advent of Carol Liebman and Nancy Dubler's book entitled *Bioethics Mediation: A Guide to Shaping Shared Solutions*, that the term "bioethics mediation" has gained some currency.¹⁴

⁹ See Mark P. Aulisio, Robert M. Arnold & Stuart J. Youngner, *HealthCare Ethics Consultation: Nature, Goals, and Competencies*, 133 *ANNALS OF INTERNAL MEDICINE* 59, 60 (2009) (describing the authoritarian approach to ethics consultation, which emphasizes the consultants' role as the primary moral decision maker).

¹⁰ The Task Force Report was commissioned and endorsed by three organizations: The Society for Health and Human Values (SHHV), the Society for Bioethics Consultation (SBC), and the American Association of Bioethics (AAB). These organizations merged in 1998 to form the American Society for Bioethics and Humanities (ASBH).

¹¹ AMERICAN SOCIETY FOR BIOETHICS AND HUMANITIES' TASK FORCE REPORT ON ETHICS CONSULTATION, CORE COMPETENCIES (1998) [hereinafter CORE COMPETENCIES]. In early 2011, a newly constituted task force organized by ASBH published a second edition of the Core Competencies. This edition expands and elaborates upon the central concepts of the first report, but does not fundamentally alter them. See AMERICAN SOCIETY FOR BIOETHICS AND HUMANITIES' TASK FORCE ON CORE COMPETENCIES FOR HEALTHCARE ETHICS CONSULTATION (2d ed. 2011) [hereinafter CORE COMPETENCIES 2].

¹² See Aulisio, Arnold & Youngner, *supra* note 9, at 61. See also CORE COMPETENCIES 2, *supra* note 11, at 3.

¹³ CORE COMPETENCIES, *supra* note 11, at 6–8. In the second edition of the Core Competency Report, the following classic conflict resolution skills are deemed "critical" to the successful functioning of a healthcare ethics consultant: "ability to listen well and communicate interest, respect, support, and empathy . . . Recognize and attend to various relational barriers to communication . . . elicit the moral views of involved parties . . . enable involved parties to communicate effectively and be heard by other parties."); see CORE COMPETENCIES 2, *supra* note 11, at 24.

¹⁴ DUBLER & LIEBMAN, *supra* note 2, at 5.

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Understanding the potential benefits and drawbacks of this sort of mediation can help lawyers advise clients who call with concerns about ill loved ones. This article explains the process of bioethics mediation and the situations in which it may arise.

II. WHAT IS BIOETHICS MEDIATION AND HOW DOES IT WORK?

Like mediation in many other contexts, bioethics mediation involves the interventions of a third party who seeks to help the parties learn how to talk and listen to one another in new, and more productive ways. The bioethics mediator seeks to clarify misperceptions, diffuse emotions, surface common interests, and encourage creative brainstorming.¹⁵ Many of the mediator's functions in the bioethics context are identical to those assumed by mediators in a wide variety of other venues.¹⁶ But, there are some roles and tasks that are *sui generis* to the health care arena and warrant elaboration.

III. ROLES AND TASKS UNIQUE TO BIOETHICS MEDIATION

A. *Pre-Mediation Groundwork*

Pre-mediation investigation or contact is not standard practice in mediating civil claims or community disputes, but is crucially important in the bioethics setting. The mediator must review the patient's medical chart, make a preliminary assessment as to whether patient capacity is a disputed issue, determine whether and which family members are available, and begin gathering the relevant medical facts. According to Dubler and Liebman, medical facts include "consensus agreements among the staff about the meaning of the medical narrative, the present data, and the observations of staff regarding the patient's improvement or deterioration."¹⁷ In addition, the mediator must attempt to gain mastery over the "de-

¹⁵ *Id.* at 39.

¹⁶ According to *id.* at 5, bioethics mediation proceeds in 7 stages: 1) Assessment and Preparation; 2) Beginning the Mediation; 3) Presenting and Refining the Medical Facts; 4) Gathering Information; 5) Problem-Solving; 6) Resolution; 7) Follow-up. As noted, many of these stages will be familiar to mediators who work in other settings.

¹⁷ *Id.* at 50.

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cision history” of the case.¹⁸ This would involve seeking answers to the following:

- Has this patient been in and out of health-care institutions for the past several years?
- Who has been the primary family contact throughout this period?
- Is there a clinician who has a long-term relationship with this patient and could shed light on her social and clinical history?
- Have there been any seminal events that have shaped the parties’ expectations and may be contributing to the current conflict?

The importance of gaining information about the narrative arc of a case is particularly evident when prior interactions between the patient and the health-care system have been unsatisfactory. In one case where a gravely ill patient had endured multiple hospital admissions, the mediator in a pre-mediation consultation learned that an unfortunate conversation between an insensitive specialist and a family member had led to a profound loss of trust between the family and that health care institution. The specialist, when discussing care for the patient, likened the hospital to “an extremely expensive hotel” and urged the family to think carefully about whether the expense of continuing to keep the patient in an ICU bed was “worth it.” Unsurprisingly, this conversation lingered in the family’s collective consciousness. When their loved one again required care, even with different clinicians in a radically changed factual scenario, the family could not contemplate the possibility that the clinical recommendations reflected anything other than the same old cost-cutting concerns. Obviously, the mediator’s understanding of the case history was crucial to any effort to restore trust.

Pre-mediation meetings with the clinical staff can surface any internecine conflict regarding the patient’s medical status and how future care should proceed.¹⁹ If clear differences emerge, the mediator can help the team decide how those differences should be framed and presented. Additionally, if significant areas of uncertainty emerge as a result of the clinical meeting, the mediator may

¹⁸ See *id.* at 51.

¹⁹ *Id.* at 52–53.

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work to supplement current medical understandings by bringing in additional medical experts, conducting a literature search, or eliciting additional support from outside departments.

Pre-mediation meetings with the clinical staff can also be helpful to learn more about the psychosocial aspects of the case as well. The mediator should probe the team's understanding of the patient's capacity to make medical decisions, investigate which family members have been involved and the extent of their involvement, explore whether any other friends or family should be brought into the discussion, and elicit the team's sense of the family dynamics. If the team believes that sibling rivalry, spousal ambivalence or long-simmering filial tensions are shaping the family's response to clinical recommendations, it would be best for the mediator to know this before going into the actual mediation. After meeting with the clinical team, the mediator should try and set up a pre-mediation meeting with the patient, if possible, and the family.²⁰ If the patient is well enough, the mediator can inquire about her understanding of her situation and medical prognosis and speak directly about her preferences. More commonly, the patient is not functional enough to have this conversation, and the mediator will explore these issues with the family. Often the family is unclear about the patient's current status and likely prognosis, and a pre-meeting is a good time for the mediator to get a feel for exactly what the family knows and understands about the patient's current health and likely path for the future.

B. *Clarifying the Medical Facts and Managing
the Information Divide*

An irony exists with regard to the mediator's job of managing information. The mediator must encourage clear and comprehensive transmission of all relevant medical information, while at the same time conveying to the family the uncertainty that dogs any medical prognoses. Frequently, families' communications with various specialists have left them with an incomplete understanding of the patient's condition. The cardiologist may discuss what is happening with the patient's heart and blood oxygen levels; a renal expert may discuss the patient's kidney function and urine output; and a pathologist may report on the progress or regression of a

²⁰ DUBLER & LIEBMAN, *supra* note 2, at 53.

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tumor. These conversations, in isolation, may confuse the family regarding larger holistic questions about the patient's trajectory, her chances for improvement and the quality of life that lies ahead. Mediation is an ideal setting for a complete review of the medical facts, in language that the family can understand, and a candid big-picture discussion of the patient's likely medical outcome.

While attempting to paint a picture of the patient's medical status as a person, and not simply a collection of organs or metastatic systems, the medical staff must try, with the mediator's help, to convey that a medical diagnosis and its prognosis is a matter of playing with probabilities. Despite remarkable advances in scientific knowledge and know-how, efforts to predict how a treatment will work, what capacities a patient will gain or retain, and how much physical suffering lies in wait are unavoidably speculative. A mediator can help the family better understand how the clinical staff has arrived at its recommendations, what data points they consider relevant and how they have extrapolated from existing data to make projections about the future. In this conversation, family and clinical staff alike can get a better sense of what is known and knowable, and what remains a matter of best-guess-work. Creating a shared understanding regarding the risks, benefits and sheer uncertainty surrounding different clinical pathways is crucial in moving forward to a productive consideration of the options.

C. *Educating the Parties About Legal and Ethical Norms*

One of the most important ways in which bioethics mediation differs from mediation in other contexts is in its relationship to social norms. Mediation in many settings is a norm-generating process.²¹ That is, the parties are encouraged to view the negotiation setting as a normative tabula rosa and are invited to generate the rules and standards that will guide the resolution of their dispute. Existing social or legal norms are considered largely irrelevant to this process.²²

²¹ Ellen A. Waldman, *Identifying the Role of Social Norms in Mediation: A Multiple Model Approach*, 48 *HASTINGS L.J.* 703, 707 (1997).

²² *Id.* at 718 (In the "norm-generating" [approach to mediation], the mediator does not remove identified options from consideration simply because those options conflict with existing social norms.).

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In contrast, a competent bioethics mediator will identify the legal and ethical norms implicated by the dispute and urge their inclusion in any agreement the parties might wish to make. For example, considerable legal and ethical consensus exists regarding the appropriate standards for decision-making at the end of life. It is well established that legally competent patients have the right to refuse any and all treatment, even if the result of such refusal is death.²³ If the patient is no longer medically capable of making a choice, her autonomy is protected by honoring her living will or proxy designation, if such a document has been completed.²⁴ If no advance directive exists, family members are authorized to make decisions on the patient's behalf according to either a substituted judgment or best interests standard.²⁵ These mechanisms for respecting patient autonomy are deeply rooted in the law and guide all aspects of end-of-life care. The mediator's goal in this arena is to help forge agreements that meet the stakeholders' underlying interests while respecting these fundamental precepts. Simply working to surface common ground and forge an agreement that meets family and caregiver needs is not enough for bioethics mediation.²⁶

For example, imagine the following scenario: A bioethics mediation has been called to bring together the distressed family and clinical staff caring for an elderly patient suffering from advanced gangrene. The patient has refused amputation and stated unequivocally that he would rather die than lose the limb. As the patient's health declines, the mediation proceeds, with one faction of the family and all of the medical staff expressing their common desire to force amputation. A sole family member seeks to honor the

²³ *Schloendorff v. Society of New York Hosp.*, 105 N.E. 92 (N.Y. 1914) ("Every human being of adult years and sound mind has a right to determine what shall be done with his own body.").

²⁴ See PRESIDENT'S COMMISSION REPORT, *supra* note 3, at 1.

²⁵ *Cruzan v. Harmon*, 760 S.W.2d 408, 415 (Mo. 1988) ("[W]hen clear and convincing evidence exists that an incompetent patient would refuse treatment under the circumstances . . . the guardian may exercise a substituted judgment to achieve that end."). The best interests test arises "in the absence of clear and convincing evidence of the patient's wishes," but "it is clear that the burden of the patient's unavoidable pain and suffering outweighs the benefits of continued life." *Id.*

²⁶ See CORE COMPETENCIES 2, *supra* note 11, at 7 ("Suppose the consensus [at a bioethics mediation] was to override the clear and convincing evidence of an unconscious, dying patient's wishes, as expressed in a valid advance directive, absent any reason to doubt that the advance directive was an authentic expression of the patient's wishes. Such a consensus would fall outside the boundaries of widely accepted ethical and legal norms. . . . Thus, the pure consensus approach is an inadequate approach to HCEC [healthcare ethics consultation] because it fails to incorporate the importance of ethically justified norms or values.").

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patient's wishes, but is gradually being worn down. In mediation, he begins to move toward the rest of the family's view of the case. Regardless of this unanimity of opinion among the participants, the bioethics mediator would need to disregard those preferences in deference to the formerly competent patient's clearly stated wishes.²⁷ Legal and ethical precepts state that the patient's autonomy and decisional authority trumps the preferences of either clinical staff or family.²⁸

Similarly, in a mediation devoted to the care options for a terminally ill patient on dialysis, if the clinical staff and family resolve to discontinue treatment on the basis of the financial costs to the hospital and the social burdens to the family, the bioethics mediator could not ethically align herself with such an agreement. Instead, the mediator would need to focus the parties on the appropriate standards for decision-making. She would need to explain that neither financial strain on the hospital nor social stress on the family are appropriate grounds for treatment withdrawal.²⁹ She would need to explain that the preferred standard for decision-making is the substituted judgment standard, which requires surrogate decision-makers to make choices as they believe the patient would make them. Alternatively, if no useful information exists regarding the patient's preferences, then the parties must act in the patient's best interests. Decision-making oriented toward the family or clinical staff's satisfaction, rather than the patient's preferences or needs is legally and ethically illegitimate and should be rejected by the mediator.

IV. IMPLICATIONS OF THE BIOETHICS MEDIATOR'S ROLE AS NORM-ADVOCATE

A. *Mediator Must be an Expert in Bioethics Norms*

This bioethics mediation model can be called a "norm-advocating" model—and from this model several consequences flow: First, the bioethics mediator must be more than a master of process. She must also have a firm foundation in substance—in the legal rules and ethical concepts that represent the best thinking on

²⁷ DUBLER & LIEBMAN, *supra* note 2, at 36.

²⁸ *Id.*

²⁹ Financial concerns do play a role, but are best suited for policy discussions as a society, and should not be a factor at the bedside.

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bioethics dilemmas to date. The American Society for Bioethics' Task Force Report acknowledges this in its discussion of the knowledge base that ethics consultants should bring to the table. The Report explains that ethics consultants (aka bioethics mediators) should possess a strong background in:³⁰

- Moral reasoning and ethical theory
- Bioethical issues and concepts
- Health care systems, clinical context, knowledge of the local health care institution where consultation is occurring
- The local health care institution's relevant policies
- Beliefs and perspectives of the patient and staff population
- Relevant codes of ethics and professional conduct
- Guidelines of accrediting organizations
- Relevant health law

This knowledge base is critical in helping the mediator situate the bioethics dilemma she faces into its legal, philosophical, and political context. And it is crucial to the mediator's role, as norm-educator and advocate, in helping the parties understand the larger ethical issues at stake.

B. *Conflicts of Interest*

The bioethics mediator's role as "norm-advocate"—master of substance as well as process—has a second consequence concerning impartiality, often considered a standard requirement of mediators in other contexts. Mediators in civil or community disputes often comment that they are strictly impartial in that they have no relationship with either party and have no stake in the outcome. Thus, mediators typically present themselves as impartial both as to the parties in the dispute and as to the substantive contours of the outcome. Neither of these statements is entirely true for the bioethics mediator.

With regard to outcome, the bioethics mediator does have an interest in how the case gets resolved. As noted, she needs to be

³⁰ See CORE COMPETENCIES 2, *supra* note 11, at 26–31.

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sure that any agreement reached accords with universally accepted bioethics norms and principles. An outcome that contravenes these norms would represent a professional failure.

With regard to relationships with the parties, the bioethics mediator is often more aligned with the clinical staff than with the family simply because the staff and the mediator frequently share the same employer. Although some health care institutions bring in outside, unaffiliated dispute-resolution professionals, more often than not, the mediator works in-house and is seen as valuable precisely because of her familiarity with the political currents and rip-tides of the organization. As Liebman and Dubler write:

[t]he in-house person will be more efficient at the outset; more comfortable with the participants and the setting; more knowledgeable about the power politics and political camps; and able to write a chart note in the chart, alerting the rest of the care team to the discussions and the outcome, a critical ability. Furthermore, the fact that the mediator is part of the institution provides reassurance to the health care providers that he or she understands the complexities of the setting and the needs of the participants.³¹

For the family, however, the mediator's affiliation with the hospital, nursing home, or medical group is bound to create unease. The mediator gains some advantage if she is able to speak the clinical staff's language and navigate the institution's byzantine political byways. The price paid comes in her compromised impartiality and the loss of trust that it sometimes engenders. It is a trade-off currently accepted by practitioners and commentators alike³² but it is unclear whether bioethics mediation will remain an in-house function or whether healthcare institutions will move toward hiring outside consultants whose independence and impartiality is unquestioned.

³¹ See DUBLER & LIEBMAN, *supra* note 2, at 40.

³² This issue is addressed elliptically in CORE COMPETENCIES 2, *supra* note 11, under a section devoted to Conflicts of Interest. The Report does not state that ethics consultants employed by health care entities face a conflict by virtue of their employment status, but it does recognize the possibility that consultants may be subject to competing pressures. *Id.* The report notes, "There is a potential conflict of interest whenever the ethics consultant is employed by a health-care institution (whether the institution pays the ethics consultant specifically to perform HCEC services, or employees of the institution perform HCEC as part of their other professional activities). Giving advice or otherwise acting against what is in the institution's financial, public relations, or other interests will test the strength of the consultant's fiduciary relationship to the parties in the consultation." *Id.*

V. RESOLUTION AND FOLLOW-UP

Whether or not the mediation ends in agreement, the bioethics mediator will need to write a progress note in the patient's chart. The chart is both a medical device and a legal document. It contains every physician and staff member's notes on the patient, vital signs, diagnostic exams, psychological interviews, social work reports, specialist examinations—every piece of data developed on the patient. A bioethics mediator must “chart the consult,” meaning that she must report that a mediation took place, detail the issues that were discussed and document any decisions reached.

If no decision is reached, the mediator should tell the family what is likely to happen next in terms of the institution. It may be that the case will be brought before a full quorum of the ethics committee for review, if such a committee exists. It may be that the case is sent to the legal department to see if judicial intervention is needed. Each of these possibilities and their implications must be explained to the family.

Even after the mediation is formally concluded, the mediator is not really done. She should follow up with the parties and provide support to both family and caregivers. If the outcome is to provide care that clinical staff feel is inappropriate, the staff is likely to feel moral distress, and the mediator should be available to provide a sympathetic ear or to make referrals to other departments that might provide assistance. If the outcome is to withhold or terminate treatment, then the mediator should similarly make herself available to the grieving family, to help them come to terms with the decision. Stopping treatment for a loved one, even when it is the right thing to do, is heart-wrenching for all involved and many commentators extend the mediator's role to include post-mediation efforts to help the family come to terms with the burdens of decision.³³

³³ See DUBLER & LIEBMAN, *supra* note 2, at 80–82.

VI. THE PROMISE AND LIMITS OF BIOETHICS MEDIATION:
A CASE STUDY³⁴

Mediation can prove to be a useful process in ameliorating conflict at the end of life. But, we should not oversell its potential. There are limits to what even the best dispute resolution process can accomplish, given the larger legal context in which it is situated. A case-study best illustrates mediation's promise and limits.

A. *Case Study*

Should Mrs. G. Get a Feeding Tube?

For well into their eighties, Mr. and Mrs. G. lived independently in their home, without assistance. When Mrs. G. started to experience some cognitive deficits that hindered her ability to cope with everyday chores and responsibilities, she and Mr. G. decided to move into an assisted living facility. Mrs. G. was seen by a neurologist and diagnosed with mild Alzheimer's Disease (A.D.) and both Mr. and Mrs. G. appointed their son, Steve, and their daughter, Deborah, to serve jointly as their health care surrogates.

Over the next few years, Mrs. G.'s mental status declined and she became more difficult to manage. She frequently wandered about outside her home and became confused as to her whereabouts. Assisted living staff pushed to have Mr. and Mrs. G move out of the assisted living units and into the nursing facility, where they would not be able to live together. Both Mr. and Mrs. G opposed this plan and the children split on what they thought should be done. Steve thought that his parents needed more medical support so he wanted to see them in the nursing facility; Deborah was also worried about her parent's safety but was inclined to follow her parents' wishes. Steve and Deborah are both stressed with their own families and responsibilities, and their involvement with their parents fluctuates, based on their careers and immediate family demands. Deborah manages to visit fairly regularly, whereas Steve's visits are more sporadic.

³⁴ The following material is derived largely from an article the author previously wrote and published with the Quinipiac Probate Law Journal. See Ellen A. Waldman, *Elegy for Mrs. G: Mediating Losses at the End of Life*, 23 QUINNIPIAC PROB. L.J. 411 (2010).

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Mrs. G's continued decline ultimately necessitates her move into the nursing facility. She is now in a moderate to advanced state of dementia. Mr. G., on the other hand, is mentally healthy but is deteriorating physically. His heart and kidney functions are failing rapidly. Steve and Deborah are both concerned about their parents' financial needs and the possibility that the money may run out. Over time, Steve has come to neglect his parents. Deborah has two very needy children and a demanding full-time job, though she does her best to visit. There has been no change to the joint surrogate status, but there is real concern regarding which sibling will take responsibility for the parents' welfare.

After several years, Mr. G. has died from heart failure and Mrs. G. has end-stage dementia. She has difficulty swallowing and, as a result, has stopped eating regularly and is often dehydrated. She recently developed a urinary tract infection, and has been admitted to the hospital. Hospital staff note that she has difficulty breathing due to recurrent aspiration, is dehydrated and malnourished, and manifests a variety of other typical but minor health problems associated with her age and condition. Mrs. G's capacity appears to wax and wane. Sometimes she recognizes her children and grandchildren and appears to be trying to communicate. Other times she appears entirely unresponsive. It is becoming increasingly difficult to get the children to show up for meetings with clinical staff to discuss their mother's care.

In light of her advancing dementia and disinclination to eat, the hospital staff discuss various treatment options, including offering artificial nutrition and hydration. Mrs. G's condition has worsened to the point that feeding by mouth is no longer an option. The treating physician tells Steve and Deborah that the remaining options for their mother's care are to put in place a gastrointestinal feeding tube or to do nothing except provide palliative care. Without the tube, Mrs. G. will likely die in several days. With the tube, she could live from another several weeks to 6 months. Steve wants to have the feeding tube placed. He says he once heard his mother say she "never wanted to be starved to death." Deborah is conflicted but is more inclined to "let nature take its course." Mrs. G., when asked about the tube, makes a nodding motion no, but it is not clear how much she understands or is responding to questions put to her. The hospital staff is reluctant to ignore the son's wishes.

B. *The Promise of Bioethics Mediation*

Bioethics mediation cannot reverse the tragedy of Mrs. G's decline, but it may be able to prevent the situation from disintegrating into an outbreak of hostilities. What bioethics mediation offers is a chance for Mrs. G's family to come together in a final effort to give Mrs. G. an end that is fitting to the life she has lived. And, mediation offers the possibility that the siblings might emerge stronger, rather than weaker, from the trauma of their mother's illness and impending death. The bioethics mediator in Mrs. G's case can help realize this promise by managing and clarifying the relevant information and helping the parties ventilate and diffuse emotion. Let us examine how this might work.

1. Managing (and Clarifying) Information³⁵

Often disputants enter into mediation with different understandings of what has led them there. In the case of Mrs. G, her son and daughter may hold different perceptions of who their mother was (and is), her core values, her current capacities, what she would likely want in terms of receiving artificial nutrition and hydration, and her short and long-term prognoses. Mediation is an ideal venue for surfacing and investigating these various understandings and building on shared perceptions and goals. We know that Mrs. G's daughter has, in recent years, spent more time with Mrs. G than her son. She may have had conversations and experiences with her mother that anchor her belief that her mother would not want a feeding tube. It is not clear that she has related those conversations or experiences to her brother. Mrs. G's son likely has his own experience of his mother that is shaping his current preference for aggressive treatment. It would be useful for the daughter—and perhaps clinical staff—to hear about those experiences. Daughter and son need to describe for one another the moments they shared with their mother that ground their current views on what her preferences would be, if she could clearly articulate them.

Mrs. G's family may also be lacking important medical information that her caregivers could supply in the earlier portions of the mediation. We know that Mrs. G's son wants a feeding tube placed because he once heard his mother say that she didn't want to be "starved to death." But, if Mrs. G has stopped eating be-

³⁵ See *id.* at 417–20.

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cause swallowing has become difficult and eating generally lacks appeal, can we say that she is “being starved to death?” Is she “starving”—a condition associated with discomfort and distress—or is her body naturally taking in less fuel because it is in the process of shutting down?³⁶

We know that gravely ill patients who stop taking in nutrition begin quickly to dehydrate.

Dehydration increases drowsiness and catalyzes a process called ketosis, in which the body rapidly oxidizes protein and fat.³⁷ The ketones created as a result of this process are thought to have an analgesic effect. Hospice workers and experts in end of life care speculate that this process helps the dying “go more gently into that good night.”³⁸

By contrast, providing nutrients via a feeding tube can create serious medical problems. Tube feeding can cause skin breakdown due to leakage or infection, pneumonia, swelling of the arms and legs from increased fluid as well as constipation or loss of bladder control.³⁹ Additionally, if Mrs. G’s son aims to extend his mother’s life, existing data suggests that tube feedings are ineffective in achieving that goal.⁴⁰

Mediation can provide a safe environment for the presentation and discussion of this information. The son may think the placement of the feeding tube poses no risks to his mother’s physical welfare, and speaking with clinicians may offer a fuller understanding of what a gastronomy tube entails. At the same time, the daughter could learn more about the likely clinical course if mouth feedings are stopped and a tube is not placed. With the informational platform leveled, all parties can proceed to make informed judgments about the available options.

³⁶ See Dr. William Lamers, *Nutrition and Hydration*, HOSPICE FOUNDATION OF AMERICA, <http://www.hospicefoundation.org/> (under “End of Life” list, select “Pain and Pain Comfort,” then “Nutrition and Hydration” on the right) (last visited Apr. 11, 2010).

³⁷ Joan Teno et al., *Hospital Characteristics Associated with Feeding Tube Placement in Nursing Home Residents With Advanced Cognitive Impairment*, 303 JAMA 471, 544 (2010); DR. LAWRENCE J. SCHNEIDERMAN, *EMBRACING OUR MORTALITY: HARD CHOICES IN AN AGE OF MEDICAL MIRACLES* 8 (Oxford University Press 2008).

³⁸ SCHNEIDERMAN, *supra* note 37.

³⁹ See Thomas E. Finucane, Colleen Christmas & Kathy Travis, *Tube Feeding in Patients with Advanced Dementia: A Review of the Evidence*, 282 JAMA 1365, 1365–70 (1999).

⁴⁰ See Mark D. Grant, Mark A. Rudberg & Jacob A. Brody, *Gastrostomy Placement and Mortality Among Hospitalized Medicare Beneficiaries*, 279 JAMA 1973, 1973–76 (1998).

4. Managing (and Diffusing) Emotion

The effect of negative emotions on the ability to negotiate and problem-solve is well documented.⁴¹ Individuals inflamed by anger or paralyzed with grief or anxiety are vulnerable to a host of cognitive biases that impair deliberation and constrict creativity. These biases include:

- Catastrophizing - assuming that things are much worse, or will become much worse, than they actually are
- All-or-Nothing Thinking - assuming that only extreme options exist
- Overgeneralization - assuming that one negative experience can be broadly generalized to predict all other situations
- Unrealistic Demanding - assuming unrealistic expectations for oneself and the world⁴²

Mrs. G's son, if he is angry that clinicians are considering designating his mother a "DNR" and shifting to comfort rather than aggressive care, may be falling prey to some of these reductionist ways of thinking. He may impute overly dark motives to the assisted nursing home staff and his sister, and fail to see the care and love that underlies their approach. He may view his mother's future in Manichean terms, seeing life with a feeding tube as long and happy, and death without a feeding tube as grievous and painful. He may assume that having one or two difficult interactions with the staff means that all future interactions will be similarly unpleasant and unproductive and he may, propelled by righteous indignation, feel that he should get what he is asking for because he is the only one "watching out for mom."

Mrs. G's daughter, also angry and grief stricken, may find herself in a defensive and rigid stance. Her over-generalizing may lead her to despair of being able to "talk sense" into her brother and lead her to a strategy of avoidance rather than approach. Mrs. G's doctors and nurses may have labeled the son and daughter "difficult" and "dysfunctional" and feel resentful that, in addition to dealing with Mrs. G's deteriorating physical state, they have to cope with the emotional maelstrom the family presents.

⁴¹ See Clark Freshman, Adele Hayes & Greg Feldman, *The Lawyer-Negotiator as Mood Scientist: What We Know and Don't Know About How Mood Relates to Successful Negotiation*, 2002 J. DISP. RESOL. 1, 21 (2002).

⁴² ALBERT ELLIS & RUSSELL GREIGER, *HANDBOOK OF RATIONAL EMOTIVE THERAPY*, 126-27, 313 (1977-1986).

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Mediation provides a structured opportunity for emotional diffusion. Parties get a chance to say how they feel and to have those feelings acknowledged. At the same time, the mediator can help parties re-examine their reactions and separate out rational interpretation from responses tainted by cognitive and affective distortion. If Mr. G's son got a chance to talk about how angry he is that medical staff have "given up" on his mom, this would allow staff members to both express empathy for his difficult situation and also explain why they don't view their recommendations as abandonment. A mediator could help normalize and mutualize⁴³ the family's grief and help them start to see each other as possible help-mates in the task of planning their mother's care.

C. *The Limits of Mediation*

Although mediation has a valuable role to play in end-of-life conflict, its powers should not be overstated. One or two multi-hour sessions can help clarify misperceptions, smooth out the ragged edges of prior conversations and, often, allow the parties to move forward. But in the most intransigent cases—involving the provision of so-called "futile treatment"—the talking cure will not work. Here are two reasons why:

1. Some Emotions Resist Management

The emotional currents coursing at the end-of-life run strong and deep. As Mrs. G's family scenario indicates, filial behaviors may reflect long-standing family dynamics that are difficult to decipher. The children themselves may not fully understand what motivates them. The son's distance from his parents and sudden desire to be his mother's "white knight" may reflect long-buried feelings of ambivalence. Resentment and guilt may twine together to inspire his end-game zealotry. The daughter's confidence that she is in the better position to know her mother's preferences may reflect her sense that she was always the more nurturing and best-loved child.

Even in families free of these internecine rivalries, the sheer weight of grief and loss can fuel "magical thinking." Joan Didion,

⁴³ MIKE D. BENNETT & SCOTT H. HUGHES, *THE ART OF MEDIATION* 21 (2d ed. 2006) (discussing mediation goals of mutualizing and neutralizing).

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in her memoir of the year following her husband's sudden death and daughter's mysterious illness, writes how these twin shocks:

[C]ut loose any fixed idea I had ever had about death, about illness, about probability and luck, about good fortune and bad, about marriage and children and memory, about grief, about the ways in which people do and do not deal with the fact that life ends, about the shallowness of sanity, about life itself.⁴⁴

She found herself “thinking as small children think, as if my thoughts or wishes had the power to reverse the narrative, change the outcome.”⁴⁵ She ordered an autopsy of her husband, thinking that perhaps if she learned what went wrong, “they might still be able to fix it.”⁴⁶ One of the most clear-eyed, flinty-eyed writers of our generation found herself holding on to her dead husband's shoes in case he came back in bare socks, and shying away from a public obituary because it implied a permanence she didn't feel.⁴⁷

End-of-life disputes often involve family members who are similarly in a war with the reality they face. They are waiting for a miracle and in active rebellion against the fixedness of their loved one's condition. Mediation is not psychoanalysis. It is a short-term, goal-oriented intervention. It can clarify misunderstandings, lessen frustration, and give voice to sadness and regret. It cannot, however, rationalize magical thinking or surmount rigidly maintained defenses. Denying death may be the last life-affirming act of a bereaved relative. Mediation cannot (and perhaps should not) be tasked with breaking through this denial.

2. Unclear Law and Ethics Regarding Futile Treatment Creates Lopsided Bargaining

A second limit to the power of mediation stems from the lack of a legal or ethical consensus surrounding the proper handling of “futility” disputes. Clear law and even clearer ethics exist regarding a competent patient's right to withhold or withdraw treatment, and equally clear law and ethics exist regarding standards of decision-making for incapacitated patients. But, increasingly, the most challenging and contentious bioethical conflicts center on the provision of so-called “futile” care. In this arena, legal and ethical guidance remains murky.

⁴⁴ JOAN DIDION, *THE YEAR OF MAGICAL THINKING* 34–37 (2005).

⁴⁵ *Id.* at 35.

⁴⁶ *Id.* at 37.

⁴⁷ *Id.* at 35–37.

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The Uniform Health Care Decisions Act (“UHCDA”), formally adopted in six states and informally tracked in another four, authorizes physicians to decline to comply with patient or family requests for “medically ineffective” health care or for “reasons of conscience.”⁴⁸ Yet, it remains unclear what sort of care falls into this category: Is a ventilator that perfuses the body of a permanently comatose patient “futile” or “medically ineffective” care? Is cardio pulmonary resuscitation for a patient who will never unplug from intensive care unit machinery “futile”? Can a physician refuse, as a matter of conscience, to provide treatment that will keep a patient’s heart and pulse beating while the mind and soul stay forever asleep? Is the extension of life, by definition, a benefit—or can a treatment extend life yet still be “non-beneficial?” Do we mean to make or avoid making quality of life judgments when considering a physician’s right to say no?

Despite decades of work, our futility jurisprudence remains a muddle. Common law and statutory text suggest that physicians need not offer futile treatment, but efforts to devise a working definition of futility in this setting have come up empty.⁴⁹ The only consensus to emerge is that no substantive consensus is possible.

Consequently, when physicians or one segment of the family seek, over the objections of others, to limit treatment on futility grounds, it is not clear what legal or ethical authority exists for them to do so. Some cases appear to support the right, but others push in the opposite direction.⁵⁰ Statutes like the UHCDA are fa-

⁴⁸ Uniform Health Care Decisions Act §§ 7(f), 7(e), 9 U.L.A. 93 (1993), *reprinted in* 12 *ISSUES L. & MED.* 83 (2006); *see also* *Health Care Decisions Act*, UNIFORM LAW COMMISSION <http://uniformlaws.org/Act.aspx?title=Health-Care%20Decisions%20Act>; *see also, e.g.*, CAL. PROB. CODE § 4734; TENN. CODE ANN. § 68-11-1808(c).

⁴⁹ *See* PR Helft, et al., *The Rise and Fall of the Futility Movement*, 343 *N. ENG. J. MED.* 1575, 1577 (2000); Jeffrey P. Burns & Robert D. Truog, *Futility: A Concept in Evolution*, 132 *CHEST* 1987, 1987–93 (2007); Glenn Cohen, *Negotiating Death: ADR and End of Life Decision-Making*, 9 *HARV. NEGOT. L. REV.* 253, 262 (Spring 2004) (reviewing case law that attempted to distinguish between “ordinary” and “extraordinary” treatment, and noting the difficulty courts face).

⁵⁰ Patrick Moore, *An End-of-Life Quandary in Need of a Statutory Response: When Patients Demand Life-Sustaining Treatment that Physicians Are Unwilling to Provide*, 48 *B.C. L. REV.* 433 (2007) (discussing the varying case law that supports or rejects the provision of treatment physicians deem futile); Thaddeus M. Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 *TENN. L. REV.* 1, 58 (2007); Pope & Waldman, *Mediation at the End of Life*, *supra* note 5, at 186 (proposing statutory “safe harbors” for health care providers should they wish to refuse to provide inappropriate or futile treatment at the request of patients’ families).

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tally vague and leave much room for challenge.⁵¹ Mediators cannot offer them as “safe harbors” and physicians find no sanctuary in their text.⁵² When one faction says “withhold treatment,” and the other threatens a lawsuit, all mediators can do is tell clinicians and family that a decision to litigate entails a bold roll of the dice.

According to classic mediation theory, this indeterminacy should encourage settlement. Neither party can be confident who will win were a judge to apply law to fact, and so, to avoid the gamble, each finds reason to agree in mediation. But, this theory assumes parity in risk aversion. What if one party is vastly more risk-averse than the other? Intolerant of even a small risk of litigation, that party will bargain tentatively and concede readily. The preferences of the more risk-attracted party will govern.⁵³

Where family members are pitted against the physicians caring for their relatives, the risk asymmetry is particularly extreme. Families are willing to take the chance of a court ruling against them because “winning” is the only thing that counts. Their loved one’s life is at stake and no cost is too high, no risk too great. They are locked in a life or death struggle and the possibility of pursuing victory in another venue is no deterrent (it is also true that ample numbers of plaintiff’s attorneys will take high profile futility cases on contingency).

From where physicians sit, the risk calculus looks much different. Although clinicians may feel that they are being forced to administer “wrong medicine,” their moral distress is not so dire that they will risk becoming defendants in a malpractice case.⁵⁴ Although the law is not entirely unsympathetic to clinical efforts to avoid futile care, medical professionals perceive it to be, and in a negotiation setting, perception is all.⁵⁵

⁵¹ See Pope, *supra* note 50, at 58 (noting that a healthcare provider does not receive any immunity for complying with the UHCDA regarding the unilateral decision-making power of the patient; and also that courts do not like to get involved in end-of-life decisions).

⁵² The one exception to this textual uncertainty is the Texas Advance Directive Act, (TADA) statute, which clearly grants physicians the right to unilaterally withdraw treatment they deem medically futile so long as certain procedural steps are taken. See TEX. HEALTH & SAFETY CODE 166.046. However, this statute has come under substantial criticism and shows no sign of becoming the model for futility cases throughout the country. See Robert Truog, *Tackling Medical Futility in Texas*, 357 N. ENGL. J. MED. 1–3 (2007), and Thaddeus M. Pope, *The Growing Power of Healthcare Ethics Committees Heightens Due Process Concerns*, 15 CARDOZO J. CONFLICT RESOL. 425 (2014).

⁵³ See Pope & Waldman, *supra* note 5, at 181.

⁵⁴ *Id.*

⁵⁵ See Pope, *supra* note 50, at 49–52.

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Where the primary disagreement exists between family members, it is often the relative seeking to continue care that pursues her preferences most tenaciously. They are confident they are fighting the good fight, and this conviction fuels tenacity. Those seeking withdrawal of care are often more ambivalent and unwilling to take the battle to another forum where the stakes and aggression will increase.

Ideally, the mediation process helps parties identify integrative solutions that meet both parties' needs by identifying new and inventive options for mutual gain. Mediation proposes that if one party wins, the other doesn't have to lose—creative brainstorming can unearth novel approaches that satisfy everyone.⁵⁶

If this is mediation's promise, then we must admit it is only imperfectly realized in the "futility" context. In the really tough futility cases, there are winners and losers. The party asking for continued aggressive care typically wins, and the party seeking that treatment be withheld steps aside. This may be an acceptable—even desirable—outcome, but we should not label it a "mediated outcome" where positions do not change, integrative agreements are not reached, and the result is predictable from the outset.⁵⁷

VII. CONCLUSION

Bioethics mediation is an important tool in the armament of any professional working to mitigate the conflict that attends tragic end-of-life choices. It is a tool that should be kept at the ready and burnished with energy and tenaciousness. Where formulating a care-plan for a grievously-ill loved one threatens to fracture families and unsettle caretakers, the intervention of a trained professional can clarify miscommunications, help supply needed data, diffuse emotion, and surface common interests and needs.

But, while embracing mediation as a useful palliative, we should try and avoid magical thinking. Mediation cannot obviate the need for choice or elide life's finality. Where family members are driven by complex subterranean forces, a short-term intervention can do only so much. Additionally, indeterminacy in the legal and social norms governing medical obligations at the end of life

⁵⁶ See Carrie Menkel-Meadow, *Toward Another View of Legal Negotiation: The Structure of Problem-Solving*, 31 *UCLA L. REV.* 754, 818 (1984).

⁵⁷ See Ellen A. Waldman, *The Baby Doe Regulations and Tragic Choices At the Bedside: Accepting the Limits of "Good Process"*, 25 *GA. ST. U. L. REV.* 1023, 1039 (2009).

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gives considerable bargaining power to the more risk-attracted party. Clinicians and family members seeking to withhold care will find themselves at a disadvantage because their BATNA (best alternative to a negotiated agreement) and WATNA (worst alternative to a negotiated agreement) remain murky. Until we as a society get clearer on what sort of quality of life determinations are acceptable at the end of life, mediation will likely temper but not transform the bald exercise of power that the less risk-averse party enjoys.

But to say that mediation cannot eliminate the tragic choices that await life's end is not to deny its obvious uses. The inevitability of death doesn't lend itself to win-win outcomes and any process that can mitigate the trauma should be tried with tenacity. But, bioethics mediation is not for the faint of heart. It is a complex, highly specialized form of dispute resolution, requiring not only acutely developed process skills, but mastery of a discrete and complex body of knowledge. It is the equivalent of mediative brain surgery and should only be undertaken by those who have pursued extensive training in both conflict resolution and medical ethics.

