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THE BABY DOE REGULATIONS AND TRAGIC CHOICES AT THE BEDSIDE: ACCEPTING THE LIMITS OF “GOOD PROCESS”

Ellen Waldman*

INTRODUCTION

What is the significance of the Baby Doe Regulations, regulations that have now been on the books for a quarter of a century? Catalyzed by the well-publicized death of a Down’s syndrome baby whose parents declined routine intestinal surgery, the Regulations remain a subject of debate. Alternately portrayed as protective civil rights legislation for the handicapped and a ruinously meddlesome effort to constrict quality-of-life determinations for gravely ill newborns, the Regulations add to our ongoing deliberations regarding the concept of futility in medicine.

Promulgated in 1985, the Regulations threaten the withholding of federal funds if physicians treating infants less than one year of age “[fail] to respond to the infant’s life-threatening conditions” with treatment which, “in the treating physician’s . . . reasonable medical judgment” are “most likely to be . . . effective in ameliorating or correcting all such conditions.” Exceptions to this global mandate exist. Physicians need not treat infants suffering from life-threatening conditions in the following three circumstances: 1) “the infant is chronically and irreversibly comatose”; 2) the provision of such treatment would “merely prolong dying . . . or be otherwise futile in terms of the survival of the infant”; 3) the provision of such treatment would be “virtually futile in terms of the survival of the

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5. 45 C.F.R. § 1340.15(b)(1)-(2).
infant and the treatment itself under such circumstances would be inhumane." 6

The American Academy of Pediatrics and other commentators have interpreted the Regulations to allow for the exercise of clinical discretion. They point to the use of terms like "appropriate," "reasonable medical judgment," and "inhumane" to argue that the Regulations should not be read as requiring a full-court medical press in the face of unremittingly dire prognoses. 7 Critics, most markedly fellow symposium contributor Dr. Loretta Kopelman, counter that textual hints of flexibility are misleading. The rule's language, they argue, reveals a pro-life imperative that allows for little in the way of individualized, contextual decision-making. 8

As a matter of statutory interpretation, it must be said that Professor Kopelman and her fellow critics have the better argument. 9 The use of the phrases "futile in terms of . . . survival" and "virtually futile" and "inhumane" appear to require medical intervention, so long as the intervention sustains life and is not itself sadistic. Reading the text literally, the Regulations allow little room for qualitative assessments of the sort of life that awaits the fragile infant facing a phalanx of medical impairments.

But, from a conflict resolution perspective, the constricting nature of the Baby Doe language hardly matters. Had the regulations been written in more nuanced fashion, the practical import of the text

6. Id. § (b)(2)(i)-(iii).
8. See Kopelman et al., supra note 4. See also John Lantos, Baby Doe Five Years Later: Implications for Child Health, 317 NEW ENG. J. MED. 444, 447 (1987) ("The federal Baby Doe regulations had the effect of making neonatal intensive care an absolute right for every child in the land, and the provision of such care a legal obligation for every doctor and hospital.").
9. The Regulations' use of the phrase "futile in terms of the survival of the infant" suggests that they exempt from provision only those treatments unable to sustain biologic life. Respiratory support or artificial nutrition and hydration for a two-month-old suffering from multi-organ failure is effective in ameliorating imminently life-threatening conditions (in other words, the inability to eat or breathe). These interventions cannot, then, be said to be futile in terms of perpetuating the survival of the infant. Asking whether treatments are effective in sustaining physiologic life would appear to remove from consideration questions regarding the quality of the life sustained and precludes the more penetrating best interests analysis that would otherwise take place.
would likely remain the same. Even if the drafters had eschewed the language of survival\(^\text{10}\) and spoken instead of treatments that are medically ineffective,\(^\text{11}\) objectionable on the grounds of conscience,\(^\text{12}\) or more burdensome than beneficial,\(^\text{13}\) that phraseology would remain a significant barrier to the dialing-back of aggressive care. In a dispute between clinicians seeking to move to comfort care and parents who want everything done, it is likely that even the more ambiguous language of qualitative futility would be seen as affording parents a bargaining chip in their jockeying with resistant providers.

Despite decades of work, our futility discourse remains a muddle.\(^\text{14}\) Efforts to devise a working definition of futile treatment have come up empty. The only consensus to emerge is that no substantive consensus is possible. And because we are unable to inject substantive content into the concept of futile care, the conventional wisdom holds that all that is left to us is “good process.”\(^\text{15}\)

Attention has thus turned to alternative dispute resolution procedures as a means of coping with the clash of expectations at the bedside.\(^\text{16}\) When patients insist on care that clinicians deem futile,
mediation is thought ideally suited to bring parties to a middle ground. Anchored in precepts of procedural justice and disputant self-determination, "the talking cure" is considered the best tonic to calm inflamed passions and bring warring parties to a peaceable endpoint.

The truth, however, is that mediation's procedural power rests, in part, on the substantive content of background legal and ethical norms. Perceptions of prevailing law set the parameters of discussion. If clinicians believe that judges and juries support the withholding of care to gravely ill newborns on quality-of-life grounds, then they will bargain aggressively. Conversely, if they believe that legal norms support parental demands for all care that sustains biologic life, they will accede to such demands when pushed.

Mediation, then, is a procedural echo chamber, reflecting and often instantiating regnant legal norms. For those who believe that providing treatment to hopelessly ill newborns is bad medicine, mediation will prove a disappointing palliative. Although useful in cases where impasse stems from poor communication or mistrust, mediation is unlikely to lead to withdrawal of treatment in cases where families and providers are animated by radically divergent values. In disputes where the family is driven by magical thinking or the conviction that life in its most compromised forms must be sustained biologic life, they will accede to such demands when pushed.

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20. Mediators, regardless of their professed stylistic allegiance, routinely confess to serving as the "agent of reality." In this role, mediators reference existing legal norms and question the parties' view of how those norms would be applied in their case. As agents of reality, mediators draw heavily on the frame that the law imposes on the parties' narratives. Thus, regardless of whether mediators admit to evaluating or passing judgment on the parties' claims, legal rules and their likely interpretation exert a significant influence over most mediation discussions.
prolonged, mediation will do little to moderate their demands. And, physicians, because they are risk-averse and feel disadvantaged in the litigation setting, are unlikely to press their case.

Hard-fought futility disputes inflict casualties. Clinicians experience a threat to their ethical integrity. Families feel betrayed by the very caregivers upon whom they have become dependent. Sadly, faith in mediation threatens to become the next form of collateral damage.

If we are not careful, clinicians’ disappointment with mediation’s inability to provide a suitable fix may curdle into broader disillusionment. Those laboring in the medical trenches may come to see mediation as yet another legal innovation that works poorly in the medical setting. This would be a shame. The problem with mediation in the futility context lies not with the process, but with the background norms that shape its course.

This essay seeks to rescue mediation from the threat of inflated expectations. Part I begins with a brief description of the mediation process and the mediator’s role in encouraging settlement. Part II takes up mediation in the context of futility disputes, detailing what can reasonably be achieved, while pointing out limits. By examining traditional mediator functions, this part seeks to explain why mediation’s reach in the end-of-life setting so often exceeds its grasp.

This essay concludes with two final points. First, relying on “good process” when clinicians and families disagree elides, but does not erase, the substantive decisions that result. Resort to mediation in many cases reflects a back-handed award of decisional authority to families and continued investment in care that cannot cure and


technology that cannot heal. This may be the substantive outcome we want, but we should acknowledge the choice. Second, if we acknowledge our normative choices, then perhaps we can revisit our earlier "Hail Mary pass" from substance to process. Unmasking the 'tragic choices' hidden under cover of 'good process' may prompt us to reinvigorate our quest for a workable definition of futility. Forging a consensus about the proper role of medicine at the margins of meaningful existence will not be easy; it is likely that no one conception will satisfy every constituency. Still, better to continue to forge ahead with this work then obfuscate the choices we do make and set mediation up as the "fall guy" for a problem not of its making.

I. BACKGROUND

A. How Mediation Proceeds

Mediation is a form of assisted negotiation. A third party with no ties to the dispute or disputants participates in a structured discussion designed to identify common ground and forge a mutually agreeable resolution.24 Modern-day mediation takes many forms,25 but most versions consist of at least four central stages: 1) Introduction; 2) Information Gathering and Exchange; 3) Problem Solving and Option Generation 4) Persuasion and Option Selection.26 In each stage, the
mediator choreographs discussion to overcome cognitive and affective barriers to agreement. The introduction is designed to establish rapport with the parties and set the stage for a “settlement event.” The mediator explains her role as third-party facilitator, sets the ground rules for interaction, discusses confidentiality and decisional authority, and invites the parties to talk and listen to one another in new and more productive ways. Importantly, at the end of the introduction, the parties should feel comfortable with and confident in the mediator and optimistic that a structured process can help surmount existing obstacles to settlement.

During information gathering and exchange, each party provides an uninterrupted narrative of the conflict from her own perspective. The mediator works in this stage to get a fuller picture of the underlying interests and pushes the parties to better understand their basic needs and long-term goals. The mediator constructs an agenda based on the issues identified and encourages the parties to tackle each issue systematically. In separate meetings, or in joint session, the mediator will explore and attempt to gain clarity on aspects of the dispute that may not have previously received attention but may be blocking forward movement.

The exchange segment of this stage is designed to help the parties see each other in more human terms. Conflict leads parties to demonize one another. It is part of the mediator’s task to reverse that process and help parties gain an appreciation of the other side’s experience. This is pursued through a variety of communicative techniques, including active listening, positive reframing, and role reversal. Parties are encouraged to take responsibility for their role in

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30. See LOUIS KRIESBERG, SOCIAL CONFLICT 69–72 (2d ed. 1982).
the dispute and to see resolution as a task requiring joint collaboration and accommodation.\textsuperscript{31}

When the parties demonstrate that they are able to work productively together, the mediator will initiate the next stage which is devoted to option generation and problem-solving. In this stage the mediator encourages the parties to make proposals designed to satisfy the interests that were earlier identified during the information exchange.\textsuperscript{32} Typically, the mediator will impose a no-critique rule, on the theory that creativity flourishes in an environment free of judgment or criticism.\textsuperscript{33} As part of the effort to encourage movement and dislodge parties from their entrenched positions, the mediator will engage the parties in a discussion of the likely outcome should the parties fail to reach agreement. This will usually entail consideration of the relevant legal norms and the probabilities of success or failure should the dispute proceed to litigation.\textsuperscript{34}

The final stage involves determining which of the proposed options is most viable and obtaining party commitment to those options. This may involve some persuasion on the part of the mediator. The mediator may point out to the parties that the options on the table represent the most advantageous terms they can expect, given the needs and interests of the other side. The mediator also might point out the benefits of the proposed options as compared to likely outcomes should the dispute proceed to other forums.\textsuperscript{35} If the parties are able to agree on a set or package of terms, the mediator

\begin{itemize}
\item \textsuperscript{31} See Mike D. Bennett & Scott H. Hughes, Art of Mediation 95–105 (2d ed. 2006).
\item \textsuperscript{32} See Nat’l Conflict Resolution Center, \textit{supra} note 28, at 48–52.
\item \textsuperscript{34} See Leonard L. Riskin, \textit{Mediator Orientations, Strategies and Techniques}, 12 \textit{Alternatives to High Cost Litig.} 111–14 (1994) (discussing the principal strategy of evaluative-narrow mediator, which is “to help the parties understand the strengths and weaknesses of their positions and the likely outcome at trial”). An elicitative, as opposed to a directive or an evaluative mediator, may refrain from opining on how legal norms would likely be applied given the relevant facts of the parties’ dispute, but would instead push the parties to consider and defend their understandings of how such norms would be applied. Either way, legal norms play a prominent role in the discussion. See Leonard L. Riskin, \textit{Decisionmaking in Mediation: The New Old Grid and the New New Grid System}, 79 \textit{Notre Dame L. Rev.} 1, 33 (2003).
\item \textsuperscript{35} See Marjorie Aaron, \textit{Evaluation in Mediation}, in \textit{Mediating Legal Disputes: Effective Strategies for Lawyers and Mediators} 267–305 (Dwight Golann ed., 2006).
\end{itemize}
will help them record those terms in a memorandum of agreement and formally conclude the mediation. If no formal agreement is reached, the mediator typically summarizes areas of common ground and suggests alternative pathways for the parties to pursue. 36

B. Mediator Roles and Functions

Mediators play a variety of roles throughout the process. They encourage, soothe, prod, probe, cheerlead, and persuade. Each of these functions can be viewed through a management lens. Mediators manage information, emotion, and expectations.

1. Managing Information

Parties in discord often wield information in ways that stoke continued conflict. They shield their vulnerabilities and obfuscate with aggressive oratory the more modest deal they would in fact cut to end the wrangling. Wary of being seen as weak, they hide their true interests under a swath of bellicose rhetoric. This behavior makes settlement difficult in two ways: first, it obscures the true bargaining range between the parties' "walk-away" points, 37 and second, it introduces inflammatory language into the negotiation, thus impairing the parties' ability to focus on the issues at hand. 38

Mediators manage information by encouraging parties to disclose their underlying needs and interests and then selectively revealing those interests to maximize the potential for agreement. 39 For example, in the classic case of two children fighting over one orange, the mediator would elicit from each child her reason for wanting the fruit and—having learned that one seeks to eat the pulp while the

36. See Nat'l Conflict Resolution Center, supra note 28, at 64–66.
38. See FRENKEL & STARK, supra note 26, at 45 (pointing out that when people are swamped by strong feelings of anger or fear they are "impaired in their ability to . . . express themselves dispassionately, without accusation, hostile attribution or threat").
other yearns to bake cake with the rind—encourage a division that maximizes each child’s goals. In short, the mediator assists in the development of a rich knowledge base about each party’s goals and strategically transmits information in ways that facilitate value-creating trades.40

Mediators also manage information by filtering out negative, unproductive critiques and attacks.41 They do this in two ways. In a joint session where all parties are present, a mediator will reframe a party’s statement to promote valuable data exchange and minimize inflammatory accusations or insults. Thus, the statement, “This hospital only cares about billing; it doesn’t bother with providing care to my dad at all” becomes, “You have some concerns that your father receive appropriate treatment while he is in the hospital.” In private caucus, the mediator would absorb much of the anger ventilated during one party’s private narrative and transmit to the other party only that information useful in advancing dialogue. Thus, a family’s rant regarding the attending physicians’ insensitivity to the patient’s pain levels may be lengthy and cutting. It might contain many demeaning characterizations of the hospital staff’s competence and humanity. In caucus with the caregivers, however, the mediator will merely convey the family’s fears regarding untreated pain and ask the caregivers what sorts of future proposals might be made to alleviate the family’s distress. By reducing each side’s exposure to belittling attacks on their behavior, motives or character, the mediator keeps the conversation on an even keel and moving in a positive direction.

2. Managing Emotions

Negotiators are in a state of “perpetual emotion.”42 Positive emotions increase sensitivity to the possibility of integrative,

41. See Bennett & Hughes, supra note 31, at 101-03.
mutually advantageous resolutions, whereas negative emotions lead bargainers toward a narrower, more limited perception of what is possible.\textsuperscript{43} Intense negative emotion also impairs a negotiator’s ability to analyze, brainstorm and make rational, not retributive, decisions.\textsuperscript{44} Part of the mediator’s job, then, is to encourage optimism and help negotiators articulate, and thus dissipate, their anger, fear and paranoia.

Mediators help parties regulate emotions in various ways. First, they encourage emotional modulation by allowing time and space for ventilation. Mediators ask parties to describe their conflict with particular emphasis on its emotional impact. Giving parties an explicit opportunity to describe their turmoil, frustration, anger, or fear provides some measure of relief.\textsuperscript{45} Additionally, mediators are trained to listen attentively and reflect back the feelings they hear—techniques that help parties feel heard and induce calm.\textsuperscript{46}

Mediators also help parties sift through the cognitive fog engendered by strong emotion to better assess and advance their long-term best interests. Parties gripped by anger or fear may reject offers or pursue disadvantageous strategies in order to spite their adversary.\textsuperscript{47} Mediators help parties recognize the folly in “cutting off their nose to spite their face” and urge them, instead, to focus on pursuing their own gains as opposed to inflicting losses. Mediators also aid the communication process by helping parties interpret their


\textsuperscript{44} See Frenkel & Stark, supra note 26; Kenneth Kipnis & Anita Gerhard, \textit{Some Ethical Principles for Adult Critical Care, in The Variables of Moral Capacity} 156 (David Thomasma & David Weisstub eds., 2004).


\textsuperscript{46} See Gary Friedman & Jack Himmelstein, \textit{The Loop of Understanding}, in Menkel-Meadow et al., \textit{Mediation: Practice, Policy and Ethics}, supra note 24, at 225–28 (describing mediators’ efforts to understand each disputant’s experience and convey that understanding to the disputants).

\textsuperscript{47} See Frenkel & Stark, supra note 26, at 57–58 (discussing reactive devaluation, in which disputants view with disfavor substantively attractive proposals because the offer is made by an adversary).
adversary’s words and actions free of emotionally generated distortions. When parties’ “emotional flooding” threatens to devastate the path toward settlement, the mediator erects a system of dams and culverts to contain the damage and clear alternative routes for passage.

3. Managing Expectations

Disputants often enter into negotiations with inflated expectations. They focus on the facts and legal rules favorable to their position and shut their eyes to the less appealing aspects of their case. New information is interpreted to accord with existing over-confident prognostication.

New facts, if they are helpful, provide irrefutable proof that victory is inevitable. Unhelpful facts become inconveniences easily explained away. Disputants’ irrationally exuberant assessments of their negotiating alternatives lead them to adopt excessively hard-nosed positions at the bargaining table. This intransigence scuttles progress. One central task that the mediator performs is helping parties reach more realistic assessments of their options if settlement fails. This, in turn, eases parties into more reasonable negotiating postures.

Mediators help parties gain greater clarity regarding their best and worst alternatives to agreement in a variety of ways. They ask pointed questions about the strengths and weaknesses of various positions, pushing parties to think about where they might be vulnerable before a judge or jury. They highlight the transaction and opportunity costs of disputing. They ask about the likely investment in time, money, and emotional energy that continued conflict will

48. See BENNETT & HUGHES, supra note 31, at 86-89 (discussing barriers to effective receipt of messages in conflict situations); see also Lee Ross, Reactive Devaluation in Negotiation and Conflict Resolution, in KENNETH J. ARROW, BARRIERS TO CONFLICT RESOL. 28-29 (1995).


50. See generally Raymond S. Nickerson, Confirmation Bias: A Ubiquitous Phenomenon in Many Guises, 2 REV. OF GEN. PSYCHOL. 175 (1998).

51. See FRENKEL & STARK, supra note 26, at 235-41.
impose. And if they are comfortable taking an evaluative role, they offer predictions of what a court or other decision-making entity might do if the dispute is pushed onto an adversary track. 52

These interventions tamp down party expectations and curtail egocentric bias. They encourage a degree of self-interrogation and introduce some level of uncertainty into the parties’ thinking. When parties begin to entertain doubt regarding the rightness of their cause and the inevitability of success, they become open to more conciliatory and collaborative approaches. 53

II. MEDIATION IN FUTILITY DISPUTES—WHAT MEDIATION CAN AND CANNOT DO

Mediation can be usefully deployed in futility disputes, but it is important to be realistic about what the process can and cannot accomplish. In a large percentage of disputes, where strong emotion, information asymmetries, and inflated expectations distort families’ or caregivers’ assessments, mediation will likely reduce disagreement and bring about some resolution. In the smaller percentage of intractable disputes where family investment in continued treatment is unalterably high, mediation’s management strategies will likely not be successful in moving the family from its initial demand. More likely, the family will hold firm and clinical caregivers will capitulate. If we analyze the mediation of futility disputes through the lens of the mediator’s management functions, the limits of what mediation can accomplish become clear.

A. Managing Information

Families and caregiver often find themselves in conflict because earlier efforts at communication have been unsuccessful and the parties hold divergent understandings of the basic facts. Sometimes, families have received different information about the patient’s

52. See Riskin, Mediator Orientations, Strategies and Techniques, supra note 34, at 111–14.
53. See Korobkin, supra note 49, at 295.
prognosis from myriad specialists, and they remain confused regarding the true nature of the patient’s condition. The cardiologist may speak optimistically because the heart’s ejection fraction numbers are holding steady; the renal specialist gives encouraging news because urine output is stable and the neurologist is pleased that the intercranial bleed appears to be stage III and not stage IV. None of these specialists, however, has conveyed to the family that the patient lacks the ability to survive absent ministrations only available in an intensive care unit.

In these instances, the mediator’s efforts to broaden the information base can yield significant gains. Sometimes, when the family learns the complete medical picture, they decide that a full court medical press is not consistent with either the patient’s wishes or best interests. Sometimes, when clinicians discover the family’s underlying interests, they can find ways to accommodate those interests without forsaking either medical judgment or rectitude. For example, a family’s wish to keep a beloved patriarch or matriarch alive until an important event occurs (like a birth or the arrival of a distant relative) can almost always be accommodated. The timing of treatment withdrawal can also be modified to account for the family’s interest in achieving certitude regarding the patient’s future prospects. Once the family’s resistance to withdrawing care is properly understood, then efforts to satisfy those underlying concerns can begin.

In some cases, however, the mediator’s efforts to broaden the information base and alert each party to the other’s needs will not be nearly enough. In the most intractable cases, the family is impervious to the mediator’s efforts to fill out the medical picture. In these cases, even the most direct discussions about the patient’s condition do not shake the family’s conviction that recovery is possible. Some families are waiting for a miracle. Some maintain that the patient is “a

55. See, e.g., In re Baby K, 832 F. Supp. 1022, 1026 (E.D. Va. 1993) (“The mother opposes the discontinuation . . . because she believes that all human life has value . . . [and] that God will work a miracle.”).
fighter" and "will beat the odds." 56 Others simply do not trust the medical profession and the information they generate. 57

In other circumstances, families accept the medical picture presented, but disagree about the implications. Families may agree with clinicians that the patient is in a non-sentient state and will in all likelihood remain so—and yet still believe that withdrawal is not appropriate. These families typically hold that biologic life, in whatever form it takes, should be medically sustained. 58 A corollary belief is that withdrawing treatment would entail "taking life"—and that is a task for deities, not mere doctors, to perform. 59 Families and clinicians who hold different beliefs regarding medicine’s role in sustaining severely impaired life will continue to disagree, even when the mediator has successfully plugged information gaps and ensured accurate data transmission. Miscommunication can be a serious problem in end-of-life disputes. But, even when the mediator successfully clarifies the relevant facts, knotty value conflicts may remain.

Whether mediation "works" with value conflicts is a matter of debate. Some commentators contend that value conflicts can be circumvented by searching for practical solutions that do minimal damage to each side’s ethical commitments. 60 In the end-of-life context, however, if the family believes that withdrawal of life-support is murder, then little room exists for measures that pull back from aggressive care. And if clinicians feel that continued care is

56. See Clare Dyer, Doctors Need Not Ventilate Baby to Prolong His Life, 329 BRIT. MED. J. 995 (2004) (reporting that mother of terminally ill infant rejected medical advice because her baby was a "fighter" and "had lived longer than doctors had predicted.").

57. See Mary Ellen Wojtasiewicz, Damage Compounded: Disparities, Distrust, and Disparate Impact in End-of-Life Conflict Resolution Policies, 6 No. 5 AM. J. BIOETHICS 8, 8–12 (SEPT.–OCT. 2006) (discussing the distrust of the health care system by minority groups, especially African Americans).

58. See, e.g., Rideout v. Hershey Med. Ctr., 30 Pa. D. & C. 4th 57, 62 (1995) (parents refused to consent to removal of life support for daughter because of "religious belief that all human life has value and should be protected").

59. Emily Ramshaw, Children Fight to Save Mom: Carrollton: Hospital Seeks to End Care of Woman with Brain Injury, DALLAS MORNING NEWS, Aug. 18, 2006, at IB ("Ruthie Webster is deeply religious and believes only God should give and take life.").

medically and ethically inappropriate, then any agreement that prolongs the patient's life will lead clinicians to feel that they are violating professional norms. Where the family and medical staff hold fundamentally different values regarding the sanctity of life and the goals of medicine, even the most skillful efforts to facilitate information exchange will not provide a sufficient bridge to resolution.

B. Managing Emotions

Futility disputes catalyze an intense mix of emotions. Grief, guilt, anger and anxiety all typically play some role. For surviving spouses, children, siblings or parents, the patient's loss rips at the fabric of their individual and communal life. For many, the care of the patient—cooking meals, filling prescriptions, grooming, bathing, paying bills, and driving to doctors appointments—has become their sustaining life-task. The patient's death entails a disorienting loss of structure and meaning. Additionally, if the patient was the rock or glue of the family, then her absence heralds the neglect of family rituals or traditions and the disintegration of established networks.

Guilt and remorse are also potently at work. It is an old story in hospital social work departments that the most ardent advocates for aggressive care tend to be the prodigal son (or daughter) recently returned from a lengthy siesta from their parents' lives. These estranged children, coping with their own unresolved issues and regrets, seek to prolong treatment to reinvent a relationship they never had. Bitter recriminations, buried yearnings, and squandered

61. See Barbara Given et al., Burden and Depression Among Caregivers of Patients with Cancer at the End of Life, 31 Oncology Nursing F., 1105, 1105–17 (2004).

62. With newborns, the context underlying the family's intense emotionality is different. Contemplating the death of a child is always tragic. But, for some families the tragedy is more profound. Some couples look to the birth of a child to save a crumbling marriage. Other would-be parents are looking to the care-giving role to ease some other existential pain—the loss of a parent, a professional failure or the like.

possibilities for reconciliation hang over the bedside. Those who are left crave absolution. For some, release comes only in assuming the mantle of crusader. The fight for more medical care becomes a way of achieving a solidarity elusive during healthier times, and maintaining a defiant position becomes a way of managing the intensity of the loss.

Families are frequently beset by anger as well. The indignity and decay of illness is infuriating. The stealthy ebbing of a life feels outrageous, and that sense of outrage colors their interactions with the health-care system. Even when content with the care being provided, families chafe against the lottery that has consigned them to the grieving role.

The situation is, of course, much more inflamed if the family suspects that medical mismanagement has played a role. Where the family blames the care team for iatrogenic harms, mistrust and rage increase exponentially. Even where bad outcomes in no way imply medical neglect, the family may seize upon caregiver inaction as the proximate cause of their grief.

For the care team, familial insistence on medically ineffective care engenders myriad responses. The most common responses are frustration, anger, and distress. Physicians do not perceive themselves as mere technicians but, rather, as professionals whose judgments are informed by an internally cohesive set of values and principles. When they are called upon to deliver care they deem inappropriate or worse, they feel a threat to these values and their own status as professionals. Clinicians have objected to demands for futile care on the grounds

64. Again, when a newborn, rather than an aging relative, is gravely ill, the guilt and remorse flow from a different psychological well-spring. A woman who delivers a very sick infant is at risk of blaming herself for the child’s fragile state. If the mother used fertility-enhancing drugs resulting in multiple births, she may feel that her ‘unnatural act’ led to the infant’s health problems. And, if she needed the fertility drugs because she delayed motherhood to pursue professional opportunities, she may feel that her selfishness lies at the root of her child’s difficulties. Delivering a premature and gravely ill newborn often feels like a cosmic punishment, and parents are adept at identifying past sins that demand terrible expiation. Klaus Hinde, Prematurity and Serious Medical Conditions in Infancy: Implications for Development, Behavior and Intervention, in HANDBOOK OF INFANT MENTAL HEALTH 176, 184 (Charles H. Zeanah, Jr. ed., 2d ed. 2000).

65. See Kenneth Kipnis & Anita Gerhard, supra note 44, at 156.
that “we are not medical vending machines.” That *cris de coer* represents a deeply-felt sentiment among physicians that their views regarding the proper aims of medicine deserve respect.

Mediation can make some headway in taming this emotional maelstrom, but its calming powers are not limitless. A mediator can help an agitated disputant consider an adversary’s actions from a less sinister perspective. She can point out alternative interpretations and nurture empathy where blame would otherwise reside. If family members come to the table crippled by hurts decades in the making, though, a mediator will not be able to knit those wounds. And where life has been built around the scaffold of another’s presence, denying death may be the only tool available to stave off collapse.

In her memoir, *The Year of Magical Thinking*, Joan Didion details how her daughter’s grave illness and husband’s sudden death plunged her into an *Alice in Wonderland* rabbit hole of fictional musings. She held on to her dead husband’s shoes on the chance that he would turn up and need foot-coverings, and she disliked public obituaries because they seemed to negate the possibility of his return. The reality of his passing seemed malleable, something that could change shape depending on the weather or angle of the sun.

Mediation is not long-term therapy; it is a short-term, goal-oriented intervention. It can lower the frustration that accompanies misunderstanding and soften resentments engendered by casual disregard. It cannot, however, rationalize magical thinking or surmount rigidly maintained psychological defenses. Denying death may be the last life-affirming act left to a bereaved relative. Mediation cannot (and perhaps should not) be tasked with breaking through that denial.

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C. Managing Expectations

Mediators manage expectations by pointing to existing legal norms and suggesting that the parties’ anticipated recovery in a court of law is likely more fictive than real. She will highlight the costs of pursuing litigation and point out each side’s legal and factual vulnerabilities. In settings where legal norms are relatively clear and where both disputants experience some degree of risk aversion, this tactic successfully encourages settlement.

Expectations are not easily managed in futility disputes, and efforts to point out the risks of litigation do not push both parties equally toward settlement. Rather, when mediators play “the agent of reality,” families are emboldened and clinicians are cowed. This is so for a variety of reasons.

First, the law (and ethics) surrounding physician’s rights to terminate treatment over familial objections is unclear, and this lack of clarity makes it hard to tamp down familial confidence that they would prevail in court. Some cases appear to support the right, but others push in the opposite direction. A number of states have passed statutes that affirm physicians’ right to withhold care that is “medically ineffective” or offends the conscience, but those terms are fatally vague and leave much room for challenge. As a result, mediators cannot offer the statutes as a “safe harbor” and physicians find no sanctuary in their text.

70. See Patrick Moore, Note, 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, 451 (2007) (discussing cases in which physicians sought to withdraw or withhold aggressive treatment over surrogate objections and concluding that they “send an inconsistent, if not incoherent message to healthcare providers about how to handle these end-of-life situations”); but see Thaddeus Mason Pope, Involuntary Passive Euthanasia in U.S. Courts: Reassessing the Judicial Treatment of Medical Futility Cases, 9 Marq. Elder’s Advisor 229 (2008) (arguing that a close review of the futility cases from 1983 through 2008 reveals that “courts have generally neither prohibited nor punished the unilateral refusal of [life sustaining medical treatment]”).
Because the statutory and common law surrounding futility disputes is so murky, all mediators can do is tell both clinicians and family that a decision to litigate entails a bold roll of the dice. In the face of this information, families are inclined to “hold ’em” while clinicians are likely to “fold ‘em.”

Asymmetries in risk tolerance explain this divergence. 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 war 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. Given the current fragmentation of care, it is unlikely that the clinician troubled by current levels of treatment has a “thick,” long-standing relationship with the patient. More likely, the objecting physician has “rounded into” what she experiences as an ethical dilemma, but can look forward to “rounding out” in the near future.

72. The phrase “know when to hold ‘em and know when to fold ‘em” comes from a Kenny Rogers song, “The Gambler.” The song, in the best country tradition, talks about poker as a metaphor for life. A good poker player holds cards that seem good enough to win and folds—meaning quits the round—with cards that don’t seem good enough to best the competition. KENNY ROGERS, THE GAMBLER (United Artists 1978).

73. A “thick” relationship would be one in which the participants knew one another well enough to be able to interpret isolated statements and behavior into a larger intelligible context. Clifford Gertz famously argued for “thick”—rather than “thin”—ethnographic descriptions in which social actions were understood and informed by a larger cultural vocabulary. As Geertz wrote, the test of whether a particular cultural analysis counts as “thick description” is whether it “sorts winks from twitches and real winks from mimicked ones.” Clifford Geertz, Thick Description: Toward an Interpretive Theory of Culture, in READINGS IN THE PHIL. OF SOC. SCI. 222 (Michael Martin & Lee McIntyre eds., 1973). In a thick relationship, the doctor would have a knowledge of the patient over time and a sense of the narrative arc of the patient’s life. A thick relationship would allow physicians greater confidence in assessing the patient’s and families preferences as well as the patient’s best wishes. Additionally, a thick relationship would increase the physician’s emotional investment in ensuring an ethical (and compassionate) outcome. Where the physician is new to the patient and the family, it is difficult to separate out the twitches from the winks, and harder to find the energy to care about the distinction.

74. The primary physician—the caretaker with the most long-standing relationship with the patient—is often not consulted after hospital admission. Instead, hospitalists and specialists, newcomers to the patient-as-person, take over.

75. In many hospitals, interns and residents work for several days or a week with the same patient before moving to a different part of the hospital. Specialists may issue a consulting opinion and provide
Even if the physician anticipates having to care for the patient over an extended period, providing medical treatment that she finds distasteful remains preferable to buying a front row seat at counsel’s table.

Legal commentators have difficulty grasping the full extent of physicians’ aversion to the adversarial judicial system. Physicians do not want to be sued, even if they are sure to win. Avoidant impulses only increase with the possibility of an adverse judgment. Even the task of obtaining a declaratory judgment is viewed with dread. The transaction costs of litigation are simply too high; even in the face of real moral distress, most clinicians prefer the distress of dispensing what they view as “bad medicine” in the clinic to the distress they anticipate experiencing in the courtroom.

CONCLUSION

Although disputes over futile treatment are agonizing, time-consuming, and ever more frequent,76 bioethicists have written off the pursuit of substantive clarity as a dead letter. Our societal reluctance to acknowledge limits at the end of life paralyzes efforts to identify acceptable stopping points on the treatment horizon. But though the creation of substantive standards appears out of reach, we remain hopeful that “good process” can ameliorate these conflicts.

There are two things to say about this move. First, abandoning substance for process is itself a substantive choice. As explained above, asymmetries in risk afford families considerable leverage in informal bargaining. In cases of intractable conflict, families negotiate aggressively while clinicians respond timidly. Most often, vocal and insistent families get the care they want. The move to process, then, is, in effect, a move to empower families to successfully resist physician efforts to limit treatment.

limited coverage, but they do not constitute an ongoing presence. They do not care for the patient consistently or continuously; they do not see the arc of the patient’s struggle or decline.

76. See Gordon DuVal et al., 175 J. MED. ETHICS 24, 25 (July 2001).
This may be the substantive outcome that we want, but we should transparently acknowledge our choice. There are reasons to yield compassionately to family demands for treatment that physicians find inappropriate. Some have argued that part of a clinician’s job at the end of life is to “treat the family”—and there may be situations where providing treatment that can do the patient little good, but helps the family is the right thing to do.

Adopting a policy of always giving in to family demands, though, is suspect. Treating the family by continuing to treat the patient can yield very bad outcomes. First, the treatment may be painful and may cause the patient to suffer. Second, the treatment may be undignified and despoil a memory that the patient herself wanted to preserve. Third, the treatment may entail an expenditure of health care dollars that could be much better deployed elsewhere. In an era where health care spending continues to spiral to dizzying heights, decisions to allocate intensive care unit (ICU) beds, nursing services, and other hard and soft resources to patients who will never recover sentience requires careful thought.

A common objection to the quest for a substantive definition of futile treatment lies in the term’s radical subjectivity. We cannot say that a given treatment is futile for a given patient, because that would require we agree on what sorts of medical effects are worth pursuing. This would require us to consider what investments should be made to sustain biologically functional but nonsentient existence and how much “quality of life” we should demand for the cost. These are questions of value and implicate vastly divergent moral commitments. Physicians, it is said, have no special expertise in moral reasoning or judgment. Consequently, their claims regarding “futile treatment” should, it is thought, enjoy no greater weight than those held by the general public.

This may be a compelling argument against granting physicians’ exclusive authority to craft enforceable definitions of futile treatment. But it does not entail wholesale abandonment of the definition-crafting project.
Our society is continually confronted with the challenge of crafting definitions in areas where individuals’ moral intuitions radically diverge. When are media so graphically sexual that state censorship is justified? Which types of religious practices deserve accommodation and which must yield to our rigorously pluralistic concept of the state? Most contentiously, when does life begin and how should moral obligations to the fetus be balanced with concerns for maternal autonomy? These are all questions of value and yet we continue to work on content-laden rules to which we advert in situations of conflict. Why is futility so different?

It may be the futility debate has stalled because advocates for a substantive definition have attempted to move too far and too fast.77 Ruling out a treatment because it has not worked in the last 100 cases strikes some as too draconian and defeatist. Medicine is unpredictable. Who can say that the 101st time will not be a charm?

Ruling out a treatment because the burdens outweigh the benefits seems too vague and indeterminate: too much hangs on the whims of the decision maker. Some hospital or institutional policies rule out treatments that will never release the patient from the tubes and drapes of the ICU. But some will say that life in the ICU remains worthwhile, if family can still visit and feel connected to an afflicted loved one.

What if our quest for substantive consensus were more modest? What if we began with the proposition that hospitals and doctors will not sustain individuals in permanently nonsentient states beyond a certain time period? The medical profession could propose a set

77. Our distinctly American unwillingness to acknowledge or talk about limits at the end of life has been showcased in the recent hysteria surrounding the Obama administration’s health reform bill. The bill contains a provision that would provide Medicare financing for optional consultations with physicians about hospice care and decisions to pursue aggressive treatment or comfort-care. This provision has been presented as the first step toward state-sponsored euthanasia. Opponents of reform have successfully aroused public fear and condemnation with inaccurate references to bureaucratic “death panels.” As the media have pointed out, whipping up public mania by suggesting that proposed legislation will result in government-controlled rationing at the end of life is a tried and true political tactic. Given our national aversion to setting limits and big government, linking the two is sure to inspire quick and fierce objection. See Jim Rutenberg & Jackie Calmes, False ‘Death Panel’ Rumor Has Some Familiar Roots, N.Y. TIMES, Aug. 14, 2009, at A1.
period of time—three months perhaps—and solicit reactions from the lay community. After a period of time working with this norm, the medical profession could propose additional content, perhaps addressing the problem of aggressive treatment in the context of irreversible multi-organ failure. Again, the profession could propose a norm and solicit input and response from patient groups, disability activists, elder law attorneys, and other groups. Over time, in step-by-step progression, we might as a society grow more comfortable with limits.

Good process is essential. The process we should be focusing on is a measured dialogic process of norm formation—a process crafted to engage the widest swath of society possible. We all have loved ones who will die, and we will all experience the dying process ourselves. Moreover, we all contribute to and partake in a health care system with limited resources. We should, then, encourage and participate in a national conversation about when, in the medical context, enough is enough: what sort of life is worth preserving and at what cost.

Until we collectively agree that the formation of substantive norms is possible and desirable, we will continue to look to mediation as the magic bullet for disputes at the end of life. When mediation fails in this context, it is important to remember the structural constraints that dictate its course. In the long run, perhaps these failures will push us back on the road toward thinking about substantive standards. Perhaps then we can link good process with sensible substance—a "win-win" outcome that mediation would applaud.