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Hope, Uncertainty, and Lacking Mechanisms

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Something is not working in ethics consultation: in certain situations, relationships within families and with careproviders and surrogates have become so emotionally charged and destabilized that attention is dominated by conflict and misunderstanding, foreshadowing a loss of dignity and hope. In a compelling, urgent article in this issue of *JCE*, informed by events in the *Schiavo* case, with examples from the literature on theory, practice, and outcomes, Caplan and Bergman address this situation: redirecting our attention to what they see as "a lack of effective mechanisms" for dealing with a "painful class of disputes in which families disagree with one another, or with doctors, about the care of those who cannot communicate."¹ It is no small matter that many of these cases are situated in the immediate, intense environment of end-of-life decision making.

How might we understand these encounters, and their limits? What can we hope? Following the tack of Caplan and Bergman, I will extend the discussion of the complex relationships between patients, families, surrogates, and physicians, and "hope for consensual resolution," offering a somewhat different account of what is lacking. While Caplan and Bergman foreground an apparent irreconcilability of appeals to competing biomedical principles as what is lacking, I will suggest that a "salient characteristic" among participants, what Caplan and Bergman identify as a common concern for the patient's best interests, may be far less stable and more complex, and thereby less directive, than first imagined. When Caplan and Bergman sketch their expectations for mediation and for mediators, they are right in noting that abstract principles "articulated as dispositive by designated 'experts' fail to capture, and arguably respect, the unique and complex nature of each such individual decision-making process," and that "patients and families are at the extreme end of a power imbalance." It is less clear that their descriptions — or their hope for mediation — capture this enormous challenge.

SITUATING THE PROJECT AND THE PARTICIPANTS

"There is nothing that we can really think of except what happens to us."

— Robert Frost

Might there be two ways to interpret Caplan and Bergman's project? On one reading, the focus is limited to an "especially painful class of disputes," caring for those who are not competent to communicate their

wishes. If these cases are the most difficult, it must be because the patient is unable to participate and because relationships within families and with careproviders are the most divided or fractured. On this reading, the "lack of effective mechanisms" affects a small class of families in disputes where nothing works (and the fear is nothing will work); these families cannot hope, and careproviders and ethics consultants cannot hope with them, for a consensual resolution.

Here, it is less clear how the participants may understand a patient's best interests, perhaps even as different from their own interests, and here appeals to competing bioethical principles are less likely meaningful. Here, I imagine that individual defense mechanisms and habits of thought are least accessible to introspection or self-reflection as participants struggle to keep the external world consistent with their inner world.² Here, those participating in bioethics consultation may find it especially difficult, if not impossible, to think about the problem in an appropriate way, in this intense context.³ There is abundant evidence to suggest that most people are able and willing to alter their attitudes to bring them in line with how they have behaved.⁴ When cases become the most difficult, the most emotionally charged, it seems that a resolution of differences is always just beyond reach — and will likely be imposed after an appeal by one party to a legal authority and through court-enforceable directives. How well are the special needs of these families understood?

Here, it may require an imaginative leap to understand and respond to what it means when each participant "invariably lays claim to the same concern — the best interests of the patient," especially when "there is nothing that we can really think of except what happens to us." In these cases, in this practical context, it seems inevitable that some participants will suffer a loss of dignity, privacy, and hope. After all, this is a very hard conversation: a conversation about hopes and fears, understanding defenses and denial, and one's own inner conflicts. It is a conversation to open new ways of thinking; ultimately, it is about how people change: Have I understood myself and others accurately? These challenges are not limited to the most difficult cases or the most defensive participants; they are at the center of this encounter for all participants. What is it about mediation "mechanisms" that might make them more effective?

On a broader reading, taking as a key Caplan and Bergman's review of the extensive literature on what counts in ethics consultation and their comprehensive review of competing approaches and principles, their identification of a lack of effective mechanisms seems also to include a potentially larger class of cases in which the environment for consultation is less contentious than in the most difficult cases, and in which there may be a possibility for greater openness, a more robust unity among participants, but in which participants are deeply concerned or troubled and are divided and uncertain about what is best. It is in these cases, in which, despite varied interests, we find a uniting thread: all "stakeholders" voice the same concern — the best interests of the patient — although each participant may appeal, sometimes unwittingly, to a different abstract bioethical principle: patient autonomy; beneficence; non-maleficence; or the patient's total life and value system. In these instances the facts of the case seem to resonate in an entirely different way.

If I am right in this two-tier reading, the lack that Caplan and Bergman identify may apply to more than an "especially painful class of disputes"; it may signal a lack at the foundation of ethics consultation itself. Before elaborating on the consequences of this alternative reading, and developing a discussion of what families desire, what they lack, and what difference this makes — for all families — I will comment briefly on defining relationships, stakeholders, and public concern.

STAKEHOLDERS AND PUBLIC CONCERN

The authors' opening reference to the ongoing discussions of rights and wrongs in the dramatic, and painfully public, *Schiavo* case reminds us that there may be no bright line for deciding who the stakeholders are in relationships, once cases become public. As in *Schiavo*, differences and disagreements can easily move beyond intimate and relational differences between patients, surrogates, families, and careproviders, to become inseparable from more public and social concerns, when vigorous discussions of "rights" and "wrongs" are not enough and more radical measures are played out, all in the name of the "patient's best

interest." It seems that any consideration of a more "effective mechanism" to address differences and disagreements in end-of-life decision making must also account for substantial challenges to who counts in "relationships"; how family members are inextricably linked to others; the effect and role of social concern, which can be played out through legal and legislative interventions; and the incorporation of organizational issues in the delivery of healthcare and decision making. Just as the mechanism of the traditional physician-patient relationship has changed, more or less significantly depending upon the setting, so too has the definition of those who may be seen as "stakeholders."

When Caplan and Bergman write near the end of their article, "the politicization of the Schiavo family's painful and acrimonious struggle over the fate of their wife and child clearly manifests society's failure to invest in processes that facilitate constructive dialogue for the reconciliation of divergent, emotionally charged perspectives on life-and-death issues," it seems reasonable that the assumption is that more effective mechanisms may help to resolve or mitigate differences between participants, so that fewer participants will "go public." But as previously private boundaries become porous or nonexistent, when the private is now displayed or posted publicly, when the intention is attention, the personal becomes public. Here differences become politicized. It remains to be seen if mediation will provide participants "an outlet for catharsis and an arena in which to express dissent," and if this will be enough, especially when power and knowledge can easily overwhelm those who live this for the first time. Is this what it means to have a voice? Having a voice is different than being heard and feeling understood, and still different yet from believing that what you say can and may influence an outcome: that's power.

THE CASE FOR MEDIATION

Having walked us through a critique of current methodologies and practices in decision making and dispute resolution at the end of life, Caplan and Bergman propose, "the time has come for bioethicists and individuals associated with hospital ethics committees to invest in the development of bioethics mediation." They challenge us to examine how mediation mirrors and facilitates the goals of ethics consultation, and whether it can fulfill the "promise of a significant contribution to a pressing issue in American healthcare. . . ."6 Caplan and Bergman's project reinforces the importance of asking of any mechanism or process, *How is this working now?*

A quick review of the literature reveals that mediators are conducting ongoing empirical assessments and evaluations of best practices. Looking to family mediation practices as an example, there is a vigorous discussion about the choice and significance of mediation styles and how they affect outcomes; on understanding and defining the role, participation, and influence of the mediator; and what counts as a good outcome. The mediator is part of a process and has a role to play: what it means to be a mediator. Most strikingly, a prominent concern in these discussions is whether mediators "can set aside all personal biases — developed through attitudes and values — in their decision making and be truly impartial."⁵ Here it is reasonable to wonder how these various attitudes and values affect the hope of consensual resolution. When it comes to engaging participants and mediating disputes in "this most personal and definitive act of decision making," following the concerns of those who have studied this engagement, it "seems exceedingly unlikely that a mediator will be able to monitor internal and automatic cognitive processing of information without their personal attitudes affecting their judgment and behavior."⁶

An assessment of the prospects for mediation will also require a thorough analysis of how knowledge and power function to create and define an environment, the practices and rules in which mediation can and does occur. In bioethics mediation (as currently in ethics consultation), it appears that neither patients nor family members have the prerogative to choose a structure or mechanism of mediation; participants are "asked" to manage within the structure of the mediation process, most often within the healthcare organization. Although the process of mediation may be transparent, it cannot be assumed that it is open, and, because the knowledge base of the stakeholders and their social capital are probably imbalanced, the process continues to be potentially coercive, even though mediators would eschew "philosophical" grandstanding.

As Foucault notes, "Power is relations; power is not a thing, it is a relationship between two individuals, a relationship which is such that one can direct the behavior of another."⁸

The interpersonal structure that may frame and define relationships between patients and their families, within families, and even with a surrogate, is likely very different than the structure of the temporary relationships in consultation or mediation that include careproviders and mediators: between consultation and mediation the boundaries change in what is concealed and what is revealed, but how do they change? In both consultation and mediation, careproviders and members of ethics committees who participate in the decision-making process arrive with their own needs, desires, defenses, and expectations. Despite the prospect of superior tools in mediation (or the clarity of the structure of the process), it seems that some of the key questions that challenge mediation theory and practice have a family resemblance to the very questions and processes that led Caplan and Bergman to suggest "a lack of effective mechanisms" for addressing differences and disagreements in ethics consultation.

More importantly, in discussing mechanisms and processes, we have bracketed a discussion of time: are the participants in mediation open to taking the time necessary "to capture, and arguably to respect, the unique and complex nature of each individual decision-making process"? Does the process allow for it? Practically: what are the limits of reimbursement? What structure, what environment enables each of these diverse individuals to feel safe to disclose or expose their fears, hopes, and hesitations, where there is sufficient trust among otherwise unknown others to risk misunderstanding without feeling alienated or shamed? What standpoint will create a space where participants might work safely to understand what they really want or need, so that they are freer to act for the patient's best interests? Is there time for this?

THE HOPE OF CONSENSUAL RESOLUTION

"The fact remains that getting people right is not what living is all about anyway. It's getting them wrong that is living, getting them wrong and wrong and wrong and then, on careful reconsideration, getting it wrong again. That's how we know we're alive: we're wrong. Maybe the best thing would be to forget being right or wrong about people and just go along for the ride. But if you can do that — well, lucky you."

— Philip Roth

"The very foundation of interhuman discourse is misunderstanding."

— Jacques Lacan

"Just because people ask for something doesn't mean that's what they want you to give them."

— Jacques Lacan

For Caplan and Bergman, the primary goal of dispute resolution at the end of life is "the hope of consensual resolution." And although it is unlikely that they sought to emphasize the magnitude and openness of hope in achieving consensual resolution, instead approaching the mediated outcome pragmatically, recognizing both the complexity of life and death and meaning, might there also be a sense in which true consensual resolution, in which each participant understands what is lacking for him- herself, is always in the distance, always uncertain, and sometimes out of reach?

If we may fairly infer, in this tableau, that the participants are each situated believing that their expectations for end-of-life decision making and outcomes — their concern for the patient's best interests — are somehow privileged, what can we imagine, and what do they imagine, might count as "consensual resolution"? Since consensual agreement here is an agreement between multiple stakeholders that pertains to a course of action or commitment to an outcome, how might we account for the differences that remain personal, or when consensus is achieved through quiet resignation? After all, most of us have been in decision-making positions in which we reprioritize our first expressions of interests and expectations for reasons other than a change of understanding; in which our first hope is to get what we want, or what we think that we want, but, on finding resistance to getting what we want or think we want, we alter our expectations. We may

"agree" to accept or to take something different, sometimes something less — and these decisions sometimes haunt us.

Death is the profound human conflict. Death is urgent and intense: it imposes a time limit on discussion. Choices that family members or surrogates make for or on behalf of another are powerful, in ways that may not immediately be understood; they may be life-altering choices for those who must make them. Many of these choices will be woven into the fabric or narrative of individual lives: they will be revisited and rebalanced, to celebrate, reflect, suffer, or deny. Here life philosophies and meaning-making matter. Can it come as a surprise that families (and careproviders) experience a range of conflicting emotions?

Again, power and knowledge, and all our defense mechanisms, may be at work here. How often, and for whom, is "consensual resolution" pragmatic agreement and not resolution? How stable are consensual resolutions? What should participants expect? Do lingering differences, as contentious as they may be, signal a failure of process or a fact of life?

For two very different reasons, following Roth and Lacan, we cannot avoid getting people wrong or misunderstanding them — and they get themselves wrong, what they want and lack; it is the nature of human discourse or the bent of living — we all get it wrong. For Roth, it is getting people wrong that is living: "getting them wrong and wrong and wrong and then, on careful reconsideration, getting it wrong again. . . . That's how we know we're alive: we're wrong." In the hope of achieving consensual resolution, because we can't "just go along for the ride", there must be a space for "getting it wrong."

NOTES

The quotes in the text are from R. Frost, *The Notebooks of Robert Frost* (Cambridge, Mass.: Belknap Press, 2007); P. Roth, *American Pastoral* (New York: Random House, 1997); B. Fink, *A Clinical Introduction to Lacanian Psychoanalysis* (Cambridge, Mass.: Harvard University Press, 1997), quoting J. Lacan, *Seminar II* and J. Lacan, *Seminar XIII*.

1. A.L. Caplan and E.J. Bergman, "Beyond *Schiavo*," in this issue of *JCE*.
2. B. Wexler, *Brain and Culture* (Cambridge, Mass.: MIT Press, 2006), 28.
3. *Ibid.*, 167.
4. G. Chin, "Cognitive Homeostasis," *Science* 318, no. 5851 (2 November 2007): 717.
5. Society for Health and Human Values – Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998).
6. C. Beck and B. Sales, *Family Mediation* (Washington, D.C.: American Psychological Association, 2001), 42.
7. S. Cobb and J. Rifkin, "Practice and Paradox: Deconstructing Neutrality in Mediation," *Law and Social Inquiry* 16, (1991): 35-62.
8. M. Foucault, *The Politics of Truth* (Los Angeles: Semiotext[e], 2007), 134, 148.