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Commentary on “Beyond *Schiavo*”: Beyond Theory

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Art Caplan and Edward Bergman have written an article that I applaud.¹ I present a complementary perspective — not speculation and theory but experience. My colleagues and I have been mediating disputes for over 15 years in complex “bioethics” cases in a major academic medical center.² Mediation works. It is not a panacea — neutrality and confidentiality are concerns (more theoretical than actual) — but the mediation literature provides teachable skills for parsing cases that are medically, ethically, emotionally, and contextually complex.

A call for bioethics consultation is a cry for help. Clinical care always includes options, even if only the timing of providing or withdrawing care. Bioethics consultation is never requested if the patient is doing well, thriving, and awaiting discharge to embark on a ski trip. A request for consultation is a call to address the complex care choices for patients whose medical and social situations are tenuous. Patients with compromised capacity who are demanding to be discharged to home, families who are demanding “do everything” even though death seems imminent, patients who are uninsured and whose medical needs are compelling.

Consider the following case.

Mrs. B, a 52-year-old Latin-American patient who had been a high school teacher, was brought to the medical center by her daughter, who found her at home because she seemed confused and disoriented. At the time of admission, Mrs. B was minimally communicative and not clearly decisionally capable. She was HIV positive and had a T-cell count of 4 and a viral load of over 400,000.

Mrs. B had been known to the HIV clinic in the hospital for years and had repeatedly refused HAART (highly active antiretroviral therapy). During her current admission to the hospital, Mrs. B had accepted all suggested treatments, but consistently refused HAART. Indeed, about six months before her admission, she had heard an alternative medicine provider on the radio and had sought her out for treatment. The provider, who was also a physician, urged Mrs. B to start HAART, and she refused.

AIDS dementia, documented on Mrs. B’s imaging scans, was extensive, and, according to the AIDS specialists, almost certainly long-standing and now irreversible, even with aggressive treatment with HAART. All testing to discover the cause of a persistent fever had been negative, and the neurologist’s consultation note stated that the fever was likely

the result of neurological deterioration. About six weeks into Mrs. B's hospitalization, her daughter insisted that Mrs. B be given HAART. The daughter insisted that her mother had never realized how sick she was when she had refused it in the past. The team was resistant. A clinical ethics consultation (CEC) was requested by the team.

The clinical ethics consultant went to meet Mrs. B, who was not arousable, and, in her room, encountered Mrs. B's daughter — Sylvia. The consultant had previously met with the medical team and the liaison psychiatrist who had seen the patient over the six weeks of her admission. (It is the protocol for this ethics consultation service to meet with the team first.)

The consultant invited Sylvia to meet with the care team in the conference room. In the conference room, the consultant introduced herself to Sylvia as follows: "I am the clinical ethics consultant at the hospital. I am often asked to become involved in a case when there appears to be some disagreement among the patient, the team, and the family about the plan of care. My task is to search for a consensus that is possible for all . . . that is, I try and mediate a solution.

"As part of this process, I am committed to making space for everyone to be heard. If we agree, or if we do not, I will place a note in your mom's chart and record what seems most important to everyone — their positions and their arguments. I do work for the hospital, but I do try and remain neutral and to act as a facilitator in any case. If that seems all right with you, *tell me about your mom.*"²

Sylvia — a powerful, attractive, articulate lawyer — described her mom as a strong, independent, successful, loving and caring woman, who had never revealed her illness. Sylvia found a note while helping her mother move and had kept her own counsel about her mom's illness. Sylvia loved her mom deeply and could barely conceive of a world without her. She said that she knew that Mom did not want HAART, but, she argued, if Mom really knew now that she was dying, perhaps, just not to leave us, she might agree to it. "She loved us so much, and if she knew that we needed to give her HAART in order to bear her death, she would agree."

One of the physicians asked Sylvia, "Do you really want to start your mom on HAART when she has so consistently refused it?"

The mediator saw the anguish on Sylvia's face, and requested a moment to summarize what she had heard: "This is a strong and loving woman who did not share her AIDS diagnosis with her family, and who, as far as we can tell, repeatedly told the hospital staff that she would accept all other interventions, but refused HAART. She never told anyone why, and never gave any coherent reason."

The consultant continued, talking to Sylvia, "We are not asking you whether to start HAART; the team feels that your mom has rejected this option and is not comfortable with going ahead. So, we don't want you to feel that if you say, 'Don't begin HAART,' that you have in some way harmed your mom and facilitated her death. But, maybe if she knew she were dying, as a symbol of her love for you, maybe she might agree. We can't know that. What do you think your mother might say to you, her daughter, who is so loving and caring?"

Sylvia responded, "I think she would say no." She then asked, "Why did you invite me to this meeting if you had already made up your mind?" The consultant replied, "We invited you because you, too, are our responsibility. We want you to be able to go on when your mom dies, and we think that she is dying now. If it were so important to you to start HAART, even though the experts say it is highly unlikely to bring about any change, the team might consider it . . . as a way of helping you. The team feels that your mom is beyond suffering, and that starting her on HAART would not harm her or cause her pain. If your mom were to appear to suffer in any way from the medications, it would be stopped immediately. The medication would do your mom no harm, and may support you. The medical team seems uncomfortable with this, but would consider it if it were crucially important to you and your siblings."

The attending physician said, "It might be possible to start Mrs. B on HAART and move her to hospice so she could be in her own home. Some hospice programs permit interventions for possible palliation — the fever may give us this option; perhaps this might be possible."

Sylvia agreed to meet with the hospice physician and to speak with her siblings before she would give her answer. Their decision was to bring Mom home on hospice without starting HAART.

How different this mediation is from a narrow, principled analysis that would state:

The patient, when presumed to be capable, refused HAART and that disposes of the need for discussion and closes off all options.

Caplan and Bergman agree. Unfortunately, much of what passes for bioethics consultation is still an exercise in brittle, principled analysis. Mediation provides space for a broader discussion that is more fitting to the enormous depth, intricacy, and intimacy of medical and family situations. Was Mrs. B, given the degree of dementia, really decisionally capable over the last years as she refused HAART? Would she have agreed to HAART if she knew that the alternative was death, or that acceptance of the treatment would help her loved ones come to terms with her death? What could be done, now, to ease her family into her death?

What might a mediator point out from this much-edited chart note?

- Explanation of the mediation process, the limitations of confidentiality, and the fact that the mediator is a hospital employee [issues noted by Caplan and Bergman] were all presented at the outset.
- Options were constructed and explored during the discussion.
- The mediator used reality testing — "What do you think your mother might say to you. . . ." — to help relieve the daughter of the burden of giving up her position about starting HAART.
- Ethical principles — prior autonomous statements — were not ignored, but were not immediately dispositive.
- Attempts were made to bring the persona of the patient to the discussion at hand.
- The daughter's feelings and fears were elicited and validated.
- Risks were taken by the staff to support this family;
- The attempt was made to have the team shoulder the terrible burden of this decision without disempowering the family.

In fact, it was a classic bioethics mediation with a family member who initially took the position that she "wanted everything" done for her mother.

Finally, a word about the chart note: a bioethics chart note tells a story. It tells the reader, and reinforces for the participants, what happened, how it happened, who the players are — patient, family, providers — what their interests were, and how the options for care were ethically developed and supported.

The bioethics chart note has a plot, and perhaps a subplot. It has intertwining characters, some of whom have interacted before and have a history together, and some of whom are new to the setting and the issues. How the players perceive the situation and their threatened rights or interests will determine, to some part, how they play out their roles. The note documents who participated, what the dynamic of the interactions were, what issues emerged, how an ethical analysis would look, and what recommendations emerged from the process.

The author of the chart note is also a character in the unfolding narrative; she, too, has a role and interests. Her interest is largely in reaching a consensus that encompasses, to the degree possible, all of the clashing, colliding, and conforming values and interests of the other parties. She is the mediator of all of the past and collected history in the context of the present clashes of perspectives, needs, wants, and desires. It is through her eyes, and in her voice, that the chart notes take form. That voice should reflect the reality, as far as it can be determined, of the meetings and interaction. When it is the voice of the "bioethics consultant," that, too, must be clear.

The bioethics consultant is also an employee of the hospital and must be aware, at all times, that her voice is one among a chorus. So if the outcome of the consultation might cause concern to the administration or to the office of legal counsel, the chart note detailing what happened should be sent to them — after it has been placed in the chart. Institutions need to trust and respect this voice, but, under certain circumstances, might disagree with the outcome and intervene accordingly.

At Montefiore Medical Center we have conducted more than 1,000 consultations since the early 1990s in which mediation has set the tone and provided the skills. Mediation skills can be taught; we have trained medical professionals nationwide to use these skills: to listen for and acknowledge interests and feelings, frame, reframe, summarize, stroke, explore options, and search for consensus.

Finally, not all cases can be mediated. Before or after *Schiavo*, situations involving family members who despise each other must be decided by persons other than themselves. Mediation is collaborative and explorative. It is not for all situations.

MASKING OF THE CASE

The case presented in this commentary has been changed to protect the identity of the patient and the patient's family members.

NOTES

1. A.L. Caplan and E.J. Bergman, "Beyond *Schiavo*," in this issue of *JCE*.
2. N.N. Dubler and C.B. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solutions* (New York: United Hospital Fund, 2004).
3. "Tell me about Mama" is a program at Montefiore Medical Center that instructs residents to sit down and ask about the patient before they ask any permissions for interventions on the patient.