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Commentary on Bergman: "Yes . . . But"

Nancy Neveloff Dubler

ABSTRACT

In "Surmounting Elusive Barriers: The Case for Bioethics Mediation,"¹ Bergman argues that professionals trained in bioethics, reluctant to acquire the skills of mediation, would better be replaced by a cadre of mediators with some bioethics knowledge, to which I respond, "yes . . . but."

Bergman's article is an important contribution to a vital current conversation. Any discussion highlighting the importance of mediation in clinical ethics consultation (CEC) is heartening. However, among the useful historical and conceptual information imparted, the author has a "pitch," that maximum use of mediation to address conflict in the healthcare setting is being hampered by the notion that mediation should be employed as part of CEC. He sees CEC as the assumption of superior moral skills and the paternal use of those skills to resolve what he notes to be aporetic conflict where "*Moral aporia* indicates a state of perplexity, impasse, deadlock or stalemate 'from which there is

seemingly no way out, thus forcing the conflicting parties involved to come to a mutual understanding of their ignorance and helplessness about how to proceed.'"²

Bergman argues that professionals trained in bioethics, reluctant to acquire the skills of mediation, would better be replaced by a cadre of mediators with some bioethics knowledge, as freestanding intervention teams growing out of and supported by the sufficiently robust tradition of mediation itself. This is more than interesting. It is *the* issue that must be addressed before mediation can be seen either as a legitimate intervention itself, or as one of, if not *the* key ingredient in CEC when the issue presented is the resolution or management of conflict.

Bergman states:

The premise that a clinical ethics mediator should be, first and foremost, a professionally trained bioethicist is dubious, in that the primary skills demanded are in the realms of empathy, communication, insight, creativity, trustworthiness, and process management. This is not to suggest that basic knowledge of bioethics principles should be omitted as a component of clinical ethics mediation training, but that the dominant skill set lies elsewhere. Indeed, bioeth-

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ics principles may be useful to the practitioner in the creation of chart notes expressed, for the benefit of peers, in a common language.³

To that analysis, I would answer, “yes . . . but.” First of all, arcane and unfamiliar words such as *aporetic* muddy rather than clarify any argument and tend to shut down discussion as if the philosophical term were dispositive. Most of the instances in which CEC is requested are not self-consciously, or in any way, thought of or described as instances of *moral aporia*. They are conflicts, disagreements over which decision, by whom, based on what facts and what understanding of those facts, will lead to an outcome that is in the best interests of the patient. Yes, the following vignettes could be shoe-horned into a box labeled “*moral aporia*,” but why do that? The discomfort is real however we label its philosophical underpinnings. The distress generally involves careproviders wondering whether this is really the best course for the patient, and the patient and family pondering whether their values, beliefs, and wishes will determine the decision.

Bioethics mediation does not address only moral discomfort, it addresses the *despair* of providers facing family members, and occasionally patients, who seem not to care about the medical diagnosis and prognosis, the looming risks and absent benefits that have been explained repeatedly, that seem to have no effect on reasoned decision making. Bioethics mediation addresses patients and families who feel they have been run over by the juggernaut of care, provided by the best intentioned physicians and nurses, who sense a hopelessness that they, the family, will be heard and heeded. Families fear that nothing will amplify their voices, belief systems, and values sufficiently so that these are honored and respected.

The following vignettes attempt to present the realities of bioethics mediation in the context of patients, family members, and dedicated providers. They will, moreover, make a point that is addressed in various writings but never, in my mind, made sufficiently clear. CEC is a critical nesting site for mediation skills, as it is

an accepted part of healthcare institutions and conversations. Some commentators query whether CE consultants may, therefore, not be sufficiently independent. However, consider, in these stories, how their connectedness led to options that might not have been as easily available. Consider also how the mediation skills and bioethical intuitions functioned as hand maidens in the process.

Bioethics mediation addresses the disbelief of a director of an ICU (intensive care unit), facing a patient with end-stage AIDS, who is obtunded and ventilator-dependent with failing kidneys, whose family says, “Do everything,” and wants to make arrangements to take the patient home.

Bioethics mediation combats the incomprehension of a surgical resident whose patient, with a fulminating breast cancer lesion, refuses surgery and will not give a reason for her decision.

Bioethics mediation searches for why a patient who has multiple heart blockages and can no longer walk across the room is refusing CABG (coronary artery bypass surgery), for which he is an excellent candidate and which will likely restore him to a prior level of health.

Or, finally, consider Isaiah, a 15-year-old dying of perinatally acquired HIV infection from his heroin-using Mom. He had lived for many years with the disease and had finally been sent by a judge to get treatment because he looked so ill. But the clinic to which he was sent prescribed pills, and no one had ever taught him to swallow a pill. By the time he arrived at the hospital with end-stage AIDS and kidney failure, he had passed the markers that could be reversed to restore his health, and palliative care was his only option.

Let us take each of these vignettes in turn and ask, in each case, if the knowledge, skills, and approach of a person trained in bioethics and mediation might differ from a professional who is trained primarily in mediation. Also note how familiarity with a healthcare institution plays a role in identifying viable options for that particular institution. This last is different from bioethical knowledge. Let us call it “institutional savvy” or “particularized bioethics sav-

vy.” In some cases it may be the most important information.

Vignette 1, a woman dying of AIDS in the ICU. The bioethics mediator first met with the legally appointed healthcare proxy of the patient, a 21-year-old daughter who was working full time while attending college full time. The mediator and the daughter then met with the director of the ICU. The daughter stated that she understood the issues, but that her eight siblings, her grandmother, step-grandfather, and other involved family members would need to be involved in the decision. Their collective goal was to bring the patient home to die. She understood that she had the legal authority to make a decision for her mom. She was clear, however, that the moral authority and responsibility was in a space shared by many others. The bioethics literature states that healthcare agents should try to do what a patient would want—if known—and what is in the best interest of the patient, if they are unaware of the patient’s particular preferences. However, equally important is to fashion a solution that permits the family and loved ones to go on comfortably with each other when the patient dies.⁴

The next evening, all of the siblings and other relatives—17 persons, many of whom only spoke Spanish—all met in a large room near the ICU. It emerged that the patient, although unable to stop using heroin, was the moral center of her family. Grandma had raised the children, but Mom, whenever she was able, had been deeply involved in their lives and care. Using STADA (Sit, “Tell me about Mama,” Admire, Discuss, Ask),⁵ the mediator first let everyone talk about MOM. Then she admired the family for their love and devotion. Finally, the ICU director, who was fluent in Spanish, began discussing the patient’s status and then moved, slowly, to the statement that she was dying. There were many tears, a growing acceptance of the impending death, but also insistence that Mom be moved home to die. What emerged was that the family wanted to be with her every second, so that there was no possibility that she would die alone. Their “do everything and bring her home” translated into a burning interest to prevent the patient’s aloneness.

The bioethics mediator who knew the rules for entrance into hospice and home hospice, as well as the rules for ventilator support in a home, realized how difficult, or impossible, this would be to accomplish. She had asked one of the members of the palliative care team to be at the mediation so that this person might be able to construct some kind of in-hospital solution that might substitute—not really, but in the reality of U.S. healthcare Medicaid financing—for home. This was useful, as the palliative nurse practitioner could promise a private room with 24-hour access, which was, in fact, the most important issue for the family.

This vignette demonstrates the utility of knowledge about the funding for and limitations of home care, and savvy about the palliative care structure of an institution. Would a mediator not familiar with these have been able to help the parties formulate a solution? Probably not as quickly, as she or he would need to do some fact-finding. But the strictures and structures the family faced would have been evident quickly with the help of a good social worker, who should have been involved before this, and, if logistically possible for an evening meeting, should have been a part of the mediation.

But the bioethics mediator was not only a person resolving conflict between the family who was saying “do everything” and the physician’s perception that the patient was in the process of dying. Here the CE consultant knew the members of the relevant teams and the limitations on funding imposed by Medicaid. Both were necessary components of a solution. The mediator also knew the literature, which argues that persons who have been appointed as healthcare agents must try to do what the patient wanted, or what is best for the patient in the context of what the living can accommodate in their future relationships.

Vignette 2, the woman who has a fulminating breast cancer lesion. The patient had refused surgery and would not give a reason for her decision. The surgical fellow called for a CEC. Here knowledge of the literature on refusals of care needed to be central to the approach taken by the mediator. I teach that refusal of care by a presumptively decisionally capable patient is

not the end of the discussion: it is the beginning of the inquiry. One must query, Why is she refusing? This lesion is oozing, painful, malodorous, and disgusting to the residents who must change the dressing twice daily. There is a litany of questions to consider, based on the literature: Is this patient capable of making ethically and legally binding decisions about her care? Even if she seems capacitated, is she delusional or delirious? What definition of capacity could she meet? Is there a psychotic denial⁶ at play? Does the fact that she is being seen by residents and fellows mean there is no senior physician who has established a relationship of trust with her? The literature demonstrates that lack of a trusting relationship is often a primary reason for refused care. Is there an economic core, a fear of costs to her husband? Is there a misunderstanding of the purpose of the surgery? Given the advanced state of the cancer, might she be right: that if the disease is metastatic and she is dying, can the surgery be curative? If it is clearly palliative, is it morally superior to morphine? None of these concerns is articulated by the patient, but would need to be in the mind of the consultant.

The fact that a patient looks and sounds “together” may not mean that she is “playing with a full deck,” to quote my former colleague John Arras. The bioethics literature makes the mediator super-alert to these issues in patients of any age who might be delirious (a condition extremely difficult to diagnose and address) or in elderly demented patients, who might remain socially appropriate but who have such compromised short-term memory that real capacity (which includes the ability to remember a decision and incorporate it into ongoing planning) cannot exist.

A mediator who is not schooled in bioethics concepts and best practice would not have his or her explorations with the physician and patient grounded in this literature. And it is precisely this literature that alerts one to the issues that need to be explored. It is this fact, and the notion that everything that goes on in the hospital is under the legal and moral umbrella of the attending physician, that makes the bioethics mediator a self-conscious player in the

mix of other careproviders: independent, but not alone. It is this fact of focused responsibility that requires a bioethics mediator to write a note in the chart describing the intervention, setting forth the recommendation and explaining her or his role. And it can only be a recommendation, as the legal care of the patient is the responsibility, and under the authority of the attending physician. The mediator, as a CE consultant, must understand the dynamics of the intervention and the “principled solution”⁷ that sets the boundaries for the consensus reached. Thus the options and the possibilities for a decisionally capable patient are in stark contrast to a patient who is delirious or in psychotic denial. The mediator does not need to make a call on the differential diagnosis, but needs to be alert to the possibilities, so that she or he can call for the psychiatric consultants who have the skills, in complex cases, to determine the patient’s cognitive status and consequently level of moral agency—although for most patients decisional capacity is a straightforward component of the clinical picture and is clearly within the skills of the clinical team. And, as these vignettes illustrate, the CE consultant must know the staff at the institution who might be helpful. In this case, on the day after Thanksgiving, a call on a private line to a valued psychiatric colleague drew on the bioethics mediator’s “favor bank” and produced a liaison psychiatry consultation from a senior skilled person.

This leads to the focused question: What is the knowledge base and skill base that a bioethics mediator needs to resolve the moral uncertainty and the practical questions that lie at the vortex of conflict at the bedside? Underscoring, at this point, that if a mediator does not help to resolve these questions, identifying and incorporating the values, beliefs, wants, desires, and preferences of the patient and the family, then other forces within the hierarchy of medicine or the administration of the institution will make the decision. These are not decisions that can be put aside for later. They will be decided at the moment to acquit the legal responsibility of the physician and the institution or to reflect the values of the patient and the family. Medi-

cal decisions have a built-in time trajectory, often along a spectrum leading to the label of “emergency.” In emergencies, the usual rules for decision making for individual informed consent are set aside and replaced by abstract notions of medical need and effectiveness. Someone will surely argue that this woman is in danger of sepsis if the breast is not removed. That argument, absent her and her husband’s views, will then determine the care.

The mediator needs to know *enough about*⁸ the ethical framework of decisions, about the medicine of the intervention, about the empirical and theoretical literature of clinical ethics, about theories of conflict resolution, about skills of mediation, to use these skills in pursuit of a consensus that, while perfect for none, is acceptable to all. Moreover, the mediator must ferret out and amplify the values and voices of the patient and family, as the values and voices of medicine infuse all decisions. Without these interlocking pieces of the skill set, the complexities of the situation will be missed.

Vignette 3, the patient with multiple heart blockages. We assume the patient is a capable adult living in the community who is refusing CABG surgery. This is a complicated intervention that may be successful and return the patient to a prior status of robust health or may leave lasting negative cognitive consequences. Patients do refuse CABG surgery. But this patient was a very debilitated, educated African-American man, who seemed to understand that he was a good candidate and was likely to have an excellent outcome. As a mediator or a CE consultant, you might first look to the framing fallacy, that is, had the risks of the surgery been framed as a chance of dying rather than of living? All mediators would try and understand the prior conversations and how and whether the ideas of the surgeon and the patient were similar. Here is a capable patient and it should be possible to penetrate to the issues, in pursuit of agreement. Two concerns emerge: one regarding finances and one regarding the patient’s grandson. The patient is the boy’s guardian, and the patient is reluctant to leave the boy for the period of hospitalization. Once brought to the surface, these issues can be addressed,

especially if part of the team who is meeting with the patient is a skilled social worker.

In this case, a trained mediator would be very helpful in separating out issues and interests and in generating options that may meet the concerns of the patient. There seem to be no focused bioethics interests. But attention must be paid to the documented disparities in healthcare for persons of color, the epidemic of grandparents who raise children as a result of the crack and AIDS epidemic, the regular exclusion of patients of color from regular medical care, all of which lead to distrust and anger. Is all of this a concern for the mediator? It might be. The literature on disparities of care⁹ describe a clear pattern of exclusion from medical care that surrounds persons of color. Echoes of Tuskegee¹⁰ still circulate in the African-American community and regularly are at play in patients who refuse care, thinking that it is some sort of research. This was a critical barrier for persons needing care in the midyears of the AIDS epidemic. These sorts of issues are important for all mediators working in diverse populations, but have particular relevance in medicine, given the need for trust

Vignette 4, young Isaiah. This was not the real name of this African-American young man, who had supported himself and his drug-using mom by running as a drug carrier.¹¹ Once, when he and his mom were subject to a petition for eviction, he came to the judge with his mom and explained that nothing would be gained by evicting them, as they would then burden the homeless system. By the time he came to the hospital, he was dying. He gave a class to the medical students on dying as an adolescent. He was beloved of the staff. (My job was to bring him red gummy bears, which he loved.) One day, as his health status declined one more notch, the director of pediatric nephrology explained a do-not resuscitate (DNR) order to Isaiah, who indicated it would be his very strong desire. But while Isaiah knew he was dying, Mom refused to face this fact. When she came in, Isaiah’s decision was explained to her, and she objected. She said he was just a boy, and she could not see that he would not get better, and she would not agree to a DNR. The adoles-

cent medicine staff had a firm rule of never treating an adolescent patient over his or her objection, and Isaiah was a capable decider. After Mom left, one of the nurse managers, the CE consultant on this case who had managed the discussion between the patient and his mom, wrote a note in the chart and sent a copy round to the CEC team. She sent it to the institutional medical director, who stated that the institution would back the patient. When queried if legal affairs needed to sign off, he stated "No." Two nights later Isaiah coded, and Mom demanded that he be resuscitated. He was not.

Bergman states, "there is no universal clinical ethics canon and, perforce, no uniform system of decision making with appropriate safeguards. Resort, in traditional ethics consultations, to 'authority', in the form of opinion voiced in the bioethics literature, and claims that said literature constitutes a consensus, are subject to widely differing interpretation and selectivity of sources."¹²

So, I will end with the "yes . . . but" with which I began. In my discussions of the "Principled Resolution" I state,

A principled resolution is a "consensus that identifies a plan that falls within clearly accepted ethical principles, legal stipulations, and moral rules defined by ethical discourse, legislatures, and courts, and that facilitates a clear plan for future intervention." In 2005 Carol Leibman and I were first struggling with the tensions among three competing factors: (1) the stringent limits imposed by law on medical providers and institutions, (2) the powerful decision-making authority permitted to individual patients and families in medical decision making, and (3) the power imbalances that infuse the operations of the modern hospital and medical center. The notion of a principled resolution combines the strengths of a mediative process that levels the playing field with legal norms and ethical conventions, and uses both as support for forging a consensus. A principled resolution reflects the deep and thorough support in the law and in society for decisions of patients and families, especially when these decisions

contest the juggernaut of modern, institutionalized medical care.¹³

And, finally: "Bioethics mediation is the progeny of bioethics as a field of scholarship combined with the skills and perspectives of mediation. It uses those skills, however, within the framework of case law and regulation, much as child-custody mediation uses the notion of the child's best interest against which to measure the appropriateness of adult agreements."¹⁴

I stand by these precepts and argue that this richer and broader sense of bioethics mediation is what is required for the benefit of patients, providers, families, and institutions.

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MASKING OF PATIENTS' IDENTITIES

Details in the vignettes have been changed to protect the identities of the patients and their family members.

NOTES

1. E.J. Bergman, "Surmounting Elusive Barriers: The Case for Bioethics Mediation," in this issue of *JCE*.
2. Ibid., quoting J. Solbakk, "Catharsis and Moral Theory I: A Platonic Account," *Medicine, Health Care and Philosophy* 9 (2006): 63. (A note reference number was deleted.)
3. Bergman, see note 1 above.
4. T. Powell, "Extubating Mrs. K: Psychological Aspects of Surrogate Decision-Making," *Journal of Law, Medicine and Ethics* 27 (1999): 81-6. N.N. Dubler, ed., "In Symposium: The Doctor-Proxy Relationship," *Journal of Law, Medicine and Ethics* 27 (1999): 5-86.
5. N.N. Dubler and C.B. Liebman, *Bioethics Mediation, A Guide to Shaping Shared Solutions*, 2nd ed. (Knoxville, Tenn.: Vanderbilt University Press, 2011), 4, 74, 75.
6. R. Goldbecka, "Denial in physical illness," *Journal of Psychosomatic Research* 43, no. 6 (December 1997): 575-93.
7. The definition of *principled resolution* is from

bioethics mediation, see note 5 above, pp. 14-15, 302; the definition of “legal principles,” *ibid.*, pp. 24, 70, 271. See also, *Core Competencies for Healthcare Ethics Consultation*, 2nd ed. (Glenview, Ill.: American Society for Bioethics and Humanities, 2011), 6, fn 13, regarding “principled resolution.”

8. *Core Competencies for Healthcare Ethics Consultation*, 2nd ed., see note 7 above, pp. 19-32.

9. Institute of Medicine (IOM), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, D.C.: National Academy Press, 2002); IOM, *How Far Have We Come in Reducing Health Disparities? Progress Since 2000—Workshop Summary* (Washington, D.C.: National Academy Press, 2012).

10. U.S. Public Health Service, “Syphilis Study at Tuskegee,” 2011, www.cdc.gov/tuskegee/index.html, accessed 17 February 2013.

11. When draconian drug laws were passed in New York State, drug lords began using teens who were not subject to the same penalties.

12. Bergman, see note 1 above.

13. N.N. Dubler, “‘A Principled Resolution’: The Fulcrum for Bioethics Mediation,” *Law and Contemporary Problems* 74, no. 3 (Summer 2011): 177-200, p. 179. (Note reference numbers were removed.)

14. *Ibid.*, p. 188. (A note reference number was deleted.)