Commentary on Bergman: “Yes . . . But”

Nancy Neveloff Dubler

ABSTRACT

In “Surmounting Elusive Barriers: The Case for Bioethics Mediation,” 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.’”

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-
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 shoehorned 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 handmaids 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-
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 begin-
ning of the inquiry. One must query, Why is
she refusing? This lesion is oozing, painful, mal-
odorous, 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 ethi-
cally and legally binding decisions about her
care? Even if she seems capacitated, is she de-
lusional or delirious? What definition of capac-
ity could she meet? Is there a psychotic denial
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 eco-
nomic core, a fear of costs to her husband? Is
there a misunderstanding of the purpose of the
surgery? Given the advanced state of the can-
cer, 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 “to-
gether” may not mean that she is “playing with
a full deck,” to quote my former colleague John
Arras. The bioethics literature makes the me-
diator 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 com-
promised short-term memory that real capac-
ity (which includes the ability to remember a
decision and incorporate it into ongoing plan-
ing) cannot exist.

A mediator who is not schooled in bioeth-
ics concepts and best practice would not have
his or her explorations with the physician and
patient grounded in this literature. And it is pre-
cisely this literature that alerts one to the is-
ues 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 bio-
ethics 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 recommenda-
tion, as the legal care of the patient is the re-
sponsibility, and under the authority of the at-
tending physician. The mediator, as a CE con-
sultant, 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 con-
trast 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 pa-
tients 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 Thanks-
giving, a call on a private line to a valued psy-
chiatric 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 bio-
ethics mediator needs to resolve the moral un-
certainly and the practical questions that lie at
the vortex of conflict at the bedside? Underscor-
ing, 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 medi-
cine 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 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 care describe a clear pattern of exclusion from medical care that surrounds persons of color. Echoes of Tuskegee 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. 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.”

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.

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.”

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.

ACKNOWLEDGMENT

Many thanks to Carol B. Liebman, who read an earlier draft of this manuscript and tried her best to prevent my public humiliation.

MASKING OF PATIENTS’ IDENTITIES

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

NOTES


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.


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.”


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.)
When difficult decisions must be made about health care, clinical ethics consultation provides an additional resource and a conduit for complex communication among patients, their families (including relatives, significant others, close friends, and appointed surrogates), and the care team. CE consultants address some of the most divisive and contentious issues in American society. While other disciplines, such as chaplaincy and palliative medicine, have developed training standards and become viable, funded disciplines within the medical center, clinical ethics consultation (CEC) has yet to mature. Although there are stipulated competencies for consultants, there is no agreement on (1) standards for practice (outside of the Veterans Administration system), (2) qualifications for practitioners, or (3) valid and reliable measures to rate the quality and effectiveness of the CEC process. There is neither accreditation for training programs nor an accepted curriculum for what such programs should teach. Finally, there has been no agreement that these clinicians must be credentialed and privileged in order to practice, in contrast to what is required for all other health care professionals.

Clinical ethics consultation has become an important resource, but unlike other health care disciplines, it has no accreditation or accepted curriculum for training programs, no standards for practice, and no way to measure effectiveness. The Clinical Ethics Credentialing Project was launched to pilot-test approaches to train, credential, privilege, and evaluate consultants.
The patient safety movement and quality improvement practices in health care have changed how insurers, the federal government, and patients rate and measure excellence in health care delivery, and increasingly they will determine how care is reimbursed. CEC has remained insulated from these evaluations, however—a fact that must change if its full potential is to be realized. It was precisely to bring about this change that the Clinical Ethics Credentialing Project (CECP) was launched. The project was designed to pilot-test possible approaches to training, credentialing, and privileging clinical ethics consultants and evaluating their work. It enrolled twenty-eight professionals, previously trained in the Montefiore-Einstein Certificate Program in Bioethics and Medical Humanities, who worked at the New York City Health and Hospitals Corporation, and forty-two previously trained professionals from a variety of hospitals surrounding New York City. Some applicants to the program who had not graduated from the Montefiore-Einstein certificate program were tested to gauge their fluency with health care ethics topics. The faculty—who were recruited from Bellevue Hospital and from Montefiore Medical Center—designed the program, taught the participants, and reviewed written assignments. For privacy reasons, HHC and non-HHC hospitals were grouped separately for teaching and discussion, although all case materials were redacted.

In November 2008, a working group of nationally recognized experts in bioethics and CEC convened to critique the project and advise the CECP on its products and processes. The goal of the meeting was to examine the project’s experience and see if consensus was possible among these experts on standards for the organization and practice of CEC. Given the group’s depth and diversity, its findings should reflect the current state of CEC in the United States.

The working group identified the following salient characteristics of a CEC service, comparable to other clinical services:

- The CEC service should be staffed by professionals whose education, experience, and present ability receive a high level of scrutiny.
- The CEC service should have a clear and transparent process.
- CE consultants should have the respect and support of clinical and corporate authorities in their institutions.
- CE consultants should be adequately compensated for their expertise and contribution to the clinical care environment and should be supported in ongoing educational activities.
- The processes and products of a CEC service should be subject to regular evaluation and peer review and to a rigorous quality improvement process, comparable to other clinical services.

Even though the issues of CEC may be similar, every health care institution is different. Because of the emotional, professional, and moral content of the dilemmas, misunderstandings, disagreements, and dis-
Clinical ethics consultation is an intervention in which a trained clinical ethics professional:

- responds in a timely fashion to the request for a CEC from any member of the medical care team, patient, or family member;
- reviews the patient’s medical record;
- either interviews relevant medical stakeholders or gathers the clinical care team and other consultants to discuss the case;
- visits the patient and family whenever possible;
- as a preliminary matter, identifies the ethical issues at play and any sources of conflict;
- involves the patient or family with care providers to promote communication, explore options, and seek consensus, when appropriate;
- employs expert discussion of bioethical principles, practices, and norms and uses reason, facilitation, negotiation, or mediation to seek a common judgment regarding a plan of care going forward;
- attends to the social, psychological, and spiritual issues that are often at play in disagreements about the proper course of care;
- triggers a further process with hospital medical leaders or a bioethics committee to resolve the situation, if a resolution is not reached;
- follows up with a patient and family after the initial consultation (although this feature of CEC varies, since in some systems follow-up is a task solely for the medical team);
- records the process and substance of the consultation, including the consultant’s recommendations and their justification, as part of the patient’s medical record;
- reviews the consultation with others on the CEC service as a basic level of evaluation and peer review; and
- utilizes a formal and rigorous quality improvement process.

medical situations; and, whenever appropriate, mediating conflicts between staff members or among staff, patient, and family. The CE consultant must strive to help those who are involved in a case to understand and resolve—in a timely fashion and on terms that are ethically sound—the problem that led to the consultation request. However, mindful of the danger of solutions imposed by powerful institutional professionals, if resolution is precluded by the nature of the facts or by virtue of the participants’ characteristics, the CE consultant must work quickly, clearly, and constructively with the particular process stipulated in that institution for resolving “unsolvable” situations. These may include referral to the institutional ethics committee or presentation to the medical director or corporate leadership.

Many assume that CEC is limited to interventions that seek to resolve classical ethics dilemmas, such as the beneficent obligation of the physician to do good versus the desire of a patient to exercise his or her autonomy. However, experience indicates that CEC can be required in a variety of circumstances that fall well beyond the typical “clash of relevant principles.” The underlying situations requiring CEC may include, among other issues, questions about whether the voice of the patient has been adequately sought or attended to in the process of choosing a path for care; conflict between and among care providers or among providers, patient, or family; questions about ethical interpretation or analysis of alternative care plans; and the clarification of institutional ethics policies.

**Standards for Clinical Ethics Consultation**

**Easy access to CEC and a plan for responding to requests for CEC** from staff, patients, and family members (or other patient representatives). The system for responding to requests for CEC must be well publicized, easily accessible, and broadly based to address patient care concerns related to uncertainty about values or relevant ethical and legal principles, or conflicts between and among stakeholders. The ethics consultation service must be able to triage, assign a lead consultant (if a team is involved in the consultation), and coordinate among the patient, family members, and the relevant clinical services, such as palliative care, pastoral care, consultation-liaison psychiatry, and the involved medical services.

The CEC office is not the proper location for complaints, allegations, or investigations (concerning, for example, alleged physician error or malpractice, health care worker misbehavior, or billing and scheduling dysfunctions). CEC staff may analyze institutional systems as part of their role in enhancing organizational ethics, but they should refer investigations of individual behavior to another resource. Events are appropriate for CEC when they reflect a clash of values, present ethical uncertainty, or raise ethical-legal questions at the boundaries of each domain, and when they pose conflicts or the potential for conflict in the clinical decision-making process.

A **clear process for gathering information and making appropriate arrangements to make sure all relevant stakeholders are heard.** Respect for the patient requires that the CE consultant see the patient whenever possible. This visit may only confirm the report that the patient is on a ventilator and unresponsive. Yet the visual imagery of this patient is critical to later professional and family discussion. This visit serves a number of purposes: First, it shows respect for information-gathering and respect for the patient. Second, it permits verification and facilitates insight into how the patient’s appearance factors into the family’s perspective. Third, it helps the consultant resist any tendency to treat the patient as an abstraction.

Many CEC services encourage formal meetings of the multidisciplinary care team at the outset as a way of airing different medical interpretations of patient data. When care providers convey opposing opinions to patient and family, confusion and conflict may result. Although some patients and families may appreciate communication of uncertainty, others may be distressed and upset by such ambiguity. A CEC meeting attended by all of the attending physicians, fellows, house staff, social workers, nurses, and other relevant team members may be the first opportunity for subspecialty providers and the team to meet and share their opinions and perspectives. Such a meeting may help to clarify the patient’s status and prognosis and may circumvent breakdowns in communication based on medical politics and hierarchical power structures within the health care team.

Discussions with the family should attend to the grief and fear of loved ones experiencing anticipatory bereavement, suffering, and loss and requiring comfort and support. It often helps to begin with a question about the family’s personal experiences with the health care system or with the patient—“Tell me about Mama,” for example. The medical team is the expert on illness and disease, but the family is the expert on “Mama.” Plumbing their perceptions and encouraging them to tell their stories helps to bring the patient to the center of the discussion and gives voice to and empowers the family amidst the alien discourse of medicine.

A **formal note in the medical record.** A formal note in the medical record, such as a typed note in the chart, is the standard method care providers use to communicate about all aspects of the patient’s care. An ethics consultation summary note should be entered into the medical record of every patient for whom a CEC has been completed. It is the
legal record of what has occurred, the intellectual repository of discussion and deliberation about the care options, and the rationale for actions taken. When appropriate, the note should contain a recommendation and its ethical justification. The chart language must always be professional and respectful. Professionals must be approved by the appropriate institutional committee in order to write a note in the medical record.

Ideally, the chart note presents the patient’s story and provides insight into it, identifying the characters, sharing the patient’s perspective, presenting the plot (including the CEC service’s breadth of expertise and depth of penetration into the institution and providing an important step in developing a system that responds to all consultations in a thorough, high-quality manner. When possible, all of these materials should be included in the institution’s quality improvement process since, in almost all jurisdictions, this protects requests from disclosure during litigation.

The chart note is always an opportunity both for education and for

In order to be authorized by a health care organization, clinical ethics consultants should successfully complete both a formal bioethics program and an apprenticeship that includes observation, participation in debriefing of cases, and supervised leadership of consultations.

request), and identifying paths taken and abandoned. This linear thread proceeds while specifying, clarifying, and assessing the ethical contours of possible options by discussing and referencing the relevant ethics literature and demonstrating consideration of the possibility of multiple morally acceptable outcomes. When appropriate, the note should make clear recommendations. It should always demonstrate sound reasoning. The chart note is evidence of the transparent, collaborative, inclusive, and empowering nature of the CEC process.

It is the convention at some sites for copies of the chart note to be sent by e-mail to all staff who participated in the consultation. This practice, when confidentiality measures are assured, serves five purposes: (1) it facilitates an initial level of quality improvement—a check for accuracy—by subjecting the chart note to review by others present; (2) it promotes transparency; (3) it permits the participants in the conference to review how the issues discussed were relayed to the naive chart reader—that is, the vice that these notes are somehow more dangerous to the institution as possible evidence for malpractice suits than other sorts of patient care observations are. But an institution that has carefully selected the CE consultant or consultant service leader and is aware of her practice in regard to chart notes should be comfortable that the note will thoughtfully reflect the interests of the relevant parties, sound ethics analysis, and appropriate recommendations.

In addition to written notes in the patient’s chart reflecting full consultations (augmented by an early progress note of response to the consultation request), some record should also be kept of all advice and analysis given over the telephone, by e-mail, and in informal settings. However, informal discussions, such as “curb-side” consultations, should be avoided if they go beyond providing general information. Patient-specific recommendations must not be offered; they risk missing important information or steps in the consultation process that could negatively affect subsequent patient care decisions.

These records will give a full picture of the CEC service’s breadth of expertise and depth of penetration into the institution and provide an important step in developing a system that responds to all consultations in a thorough, high-quality manner. When possible, all of these materials should be included in the institution’s quality improvement process since, in almost all jurisdictions, this protects requests from disclosure during litigation.

The chart note is always an opportunity both for education and for

A standard format for writing in the chart. A clear format should govern a first intake note, the body of the chart note, and a final summary note, if required. If the chart note format tracks the elements of an established quality improvement tool, it will provide readily available material for later organizational evaluation.
ADVANCE DIRECTIVES

Advance Directives provide documentation of an individual’s wishes in relation to health care and end-of-life care in the event that he/she is no longer able to make such decisions for himself/herself. The Living Will and the Health Care Proxy are the two most commonly used advance directives. A Living Will is a written document that expresses the patient’s specific instructions about care. These instructions often include the patient’s stated choices for or against certain interventions such as artificial hydration and nutrition, ventilatory support, cardiopulmonary resuscitation, and control of pain at the end of life. As a legal document, a Living Will can be recognized as an indication of a patient’s wishes regarding care at the end of life. The Health Care Proxy is a legal document that allows a patient to designate an individual (“Health Care Agent”) to make medical decisions on his/her behalf in the event that he/she lacks the capacity to do so for himself/herself. A Health Care Agent has legal authority to make medical decisions on the patient’s behalf regarding end-of-life care. Appointment of a Health Care Agent generally allows for a more flexible and more responsive approach to the nuances of medical conditions than the written directions expressed in a Living Will.

SUBSTITUTED JUDGMENT

Proxy decision-making for incapacitated patients must place particular emphasis on respecting the wishes and values of the patient when he or she had capacity. The prior wishes of the patient, however, may not be known, or were never expressed. Under these circumstances, proxies should consider whether a substituted judgment standard can be applied to the case at hand. A substituted judgment is a decision by others based on the patient’s inferred wishes. The question to ask here is, “Knowing what you know about this individual’s values, behavior, and decision history, what do you think he/she would decide in this grave situation?” It may also be helpful to pose the question this way: “Suppose that the patient were lying here now, capable of making decisions, listening to this conversation and knowing his/her grave medical condition and end-of-life prognosis. What do you think he/she would tell us to do for him/her?” Persons who know the patient well and are familiar with his/her values and beliefs, such as close friends or family members, are in the best position to make substituted judgments. It is particularly important to stress that decisions should be based on what it is believed the patient would want, not what they would want for the patient.

A clear format for a CEC chart note will be recognizable and will encourage the reader to expect a detailed ethical analysis that is applicable both to this case and to similar cases in the future. Treating like cases alike is one of the important bases of justice and fairness that a carefully crafted chart note can promote.

Recognition of CEC as one of many collaborating services that must be integrated and transparent in its functioning. In the increasingly complex world of health care institutions, many voices are present in conversations about troubling situations where ethics questions or concerns arise. These perspectives may include those of the patient, family, care team, and CE consultant, as well as those of the medical director, risk manager, and the office of legal affairs. If organizational ethics issues emerge, or if the patient situation is particularly distressing, the chief executive officer, members of the financial management group, or other top administrators may also be involved. All of these professionals have different, important, and valid perspectives. None should dominate at all times, yet some have the power, in some cases, to dictate the outcome.

American case law (and scholarly comment on it) and American bioethics adhere to similar modes of analysis. But the tasks of legal counsel and of risk management are to protect against possible future liability and legal challenge in an extraordinarily adversarial system. The task of the CE consultant is to identify, clarify, and analyze the ethical issues in the case and the interests and rights of patients, family members, providers, and administrators, and—where they clash—to facilitate or mediate a “principled resolution: a plan that falls clearly within accepted ethical principles, legal stipulations, and moral rules defined by ethical discourse, legislatures, and courts and that facilitates a clear plan for future intervention.”23 These are generally similar goals and usually converge. However, given the state of the law, the litigious nature of American society, the lack of justice in access to care, and the scarcity of health care re-

FIGURE 2.
Sample Concept Paragraphs

Every participant in the Clinical Ethics Credentialing Project received a file with possibly relevant concept paragraphs to be used as reminders for analysis and as drafts for inclusion into chart notes (for a complete list of topics covered, see Figure 3, section D2). Individuals and institutions were encouraged to revise as desired.

Two examples of the draft paragraphs (written by Jeffrey Blustein) are as follows:
sources, ethics and law may occasionally diverge. This can be healthy and instructive for a robust discussion of professional and institutional values. Understanding the unique role of CEC in the landscape of institutional responsibilities and understanding the roles of the offices of legal counsel and risk management is a critical bridging component of the CE consultant. It will frequently require recognizing their differences, and sometimes, agreeing to disagree and to proceed by understanding whose view prevails and why. However, it is also the case that many attorneys in offices of legal counsel judge it to be helpful, in a difficult case, to have a well-crafted and carefully argued ethics note.

The only productive route for approaching the multiplicity of tasks and perspectives in any organization is to consciously recognize and acknowledge difference and create a respectful and transparent process for identifying and resolving conflicting perspectives. For example, a chart note and analysis that may raise issues for the institution’s office of legal counsel or risk management could be brought to the attention of these professionals as part of the ongoing process of respectful dialogue, both to alert them to generic issues and to warn them about cases that might require their attention. In a case that may be the subject of legal action, the chart note must be crafted with special sensitivity and precision. Conversely, we hope that a perceptive office of legal counsel would refer to the CEC cases that would be better served by a less rules-based process than the one legal counsel is likely to follow. It is often useful for CE consultants, members of the offices of legal counsel and risk management, and relevant clinicians from the consultation psychiatry liaison service to meet together to discuss difficult cases and sharpen commonly agreed-upon concepts and processes. These complex, interdisciplinary discussions will be more likely in large academic medical centers or teaching hospitals, where authority and responsibility must be carefully parsed and disciplinary boundaries tested in pursuit of optimal care.

**Institutional and peer oversight.**

The CEC service should reflect the diversity of the medical institution. It will address the most vulnerable patients and families, in times of emotional stress, and perhaps help to avoid a developing crisis. At a minimum, it should report to the institutional ethics committee, which should review consultations and chart notes and report to the medical board or governing body. It may also be part of the governing body. In either role, the CEC should not only report on individual cases but also identify troubling policy and process issues that have broad applicability to the medical institution and deserve attention, discussion, and perhaps revision. The CEC service should, in all of these forums, promote institutional self-reflection and systems-level quality improvement to address reforms that might prevent similar ethics concerns in the future.

Institutional reporting structures vary widely. An informal survey of the working group members reveals that some directors of a CEC service, as chairpersons of the hospital’s ethics committee, are also members of the hospital’s executive committee. Some CEC directors report to hospital medical directors or to a committee of the medical staff. One study reported that most CEC services were primarily accountable either to the hospital administration (36 percent) or the medical staff (29 percent).

The CEC service should create a regular process for consultants’ peer review of cases. This ongoing review is central to accountability and professional development. In the absence of a formal network (such as the CECP established) or an institutional ethics committee, lone clinical ethics consultants should develop a peer review supervision structure similar to that created by therapists and various other counseling professionals. A group of hospitals might create a consortium to structure peer review and quality improvement for CEC. Whatever structure is created, the responsible hospital authority should review the process to be certain that it receives maximal legal protection.

**Consultants** must be subjected to the same level of transparency, accountability, scrutiny, and oversight as other staff members who see patients, and like other members, they must write notes in the chart.
Credentialing and privileging might not be the only institutional option for ensuring the qualifications and competency of CE consultants. For example, an institution might provide oversight of CE consultants through scope of practice agreements. Understanding the laws and regulatory requirements that apply in a given jurisdiction is an important component of developing an institutional system.

An institution seeking to establish a policy for ensuring the qualifications and competency of CE consultants should address specific questions in its jurisdiction, including at least the following:

- As the Joint Commission requires reprivileging every two years, how often will qualifications and competency be assessed, how will that process proceed, and where can professionals turn to acquire the necessary continuing education (or alternative) credits?
- Under the laws of the jurisdiction, are those who are credentialed and privileged more difficult to dismiss for cause? Might they face any unintended adverse effects from the credentialing and privileging process?

---

**Figure 3. Initial Clinical Ethics Consultation Chart Review**

The Clinical Ethics Credentialing Project found that a structured tool was useful in assessing the quality of the consultation and in evaluating change in quality over time. It also provided a checklist for those carrying out and documenting a CEC. The members of the CECP developed the following set of questions for assessing quality. The questions were listed on the left-hand side of a table, and each question could be answered by indicating “yes/most,” “some/part,” “no,” or “not applicable.” The table also provided space to comment on each answer.

**A. Participants**

1. Was it clear who requested the consultation? (specify in comment field)
2. If it was not the attending physician, was s/he informed in person or by telephone?
3. Were important care providers involved?
4. Was the patient cognitively able to participate?
5. Was there a face-to-face patient visit?
6. Were important family stakeholders involved?

**B. Relevant history**

1. Ethically relevant medical history?
2. Ethically relevant social history?

**C. Consult implementation**

1. Was the consult largely mediation—that is, dispute resolution among care providers, family, or patient?
2. Was the consult largely consultation—that is, clarification and analysis of relevant ethical principles and practices?
3. Were there meetings/discussions with care providers only?
4. Were there meetings/discussions with family only?
5. Was there a joint meeting/discussion with care providers and family?

**D. Ethical problem**

1. Was the ethical/mediation issue(s) well identified?
2. Which of the following issues most apply (indicate “yes” to all that apply, or rank them 1–3 according to importance)
   - allocation of scarce resources
   - benefit/burden analysis in care options
   - best interest of the patient
   - confidentiality
   - cultural values and treatment
   - decision-specific capacity
   - doctrine of double effect
   - end-of-life balance of acute and palliative care interventions
• Are there alternative means for securing the right of CE consultants to write in the chart and to have their practice insured that would not require credentialing and privileging, but could proceed through human resources, the medical staff office, or another department?

• Would designation of authority to practice from within human resources or other departments be sufficiently rigorous for identification, training, and supervision without involving the institution’s medical staff office, as is required by the Joint Commission for credentialing and privileging?

• Would the institution’s bylaws need to be changed to permit this new process?

• Should the CEC program be designated a separate clinical department—affiliated with, but independent of, the hospital ethics committee?

• How would the credentialing and privileging or other process for ensuring the qualifications and competency of the CE consultants relate to the status of the ethics committee chairpersons and members?

• How will informal experience (“grandparenting”), formal training, and ongoing learning all be valued, supported, and monitored as qualification processes change?

Measures for credentialing CE consultants. For credentialing, the institution should require the following or a similar plan, while keeping in

* failure of the medical team to assume “responsibility” for difficult medical choices
* informed consent
* withdrawing and withholding treatment
* justice in the context of American medicine
* medical futility
* patient autonomy
* prior directives and delegation of authority
* proposing ‘false choices’ to patient and family
* treatment refusal
* religious values and treatment
* setting boundaries for care
* special pediatric issues: best interest for neonates, children, and adolescents
* substituted judgment
* truth-telling
* other (describe)

E. Ethical analysis
1. Was relevant bioethics knowledge integrated into the note?
2. Was the chart note sufficient for educational purposes?

F. Process
1. Does the note give a clear description of the dynamic of the discussion?
2. Was the voice of the patient clear?
3. Were the voices of the family stakeholders clear?
4. Were the positions of the care providers clear?
5. If there was disagreement among health care team members, was consensus achieved?
6. If there was disagreement among family members, was consensus achieved?
7. If there was disagreement among health team and family members, was consensus achieved?

G. Recommendations
1. If consensus was achieved, were the recommendations clear?
2. If consensus was not achieved, was it clear what should happen next?

H. Style
1. Is appropriate medical language used throughout?
2. Is neutral language used throughout?
mind the need to allow existing competent clinicians who have operated effectively under prior arrangements to continue to practice.

- Participation in a formal training program and verification of qualifications. CE consultants should successfully complete a substantial, formal program in bioethics, including material specifically addressing clinical ethics. Any such program should emphasize the development of core competencies in the following areas:

  - Knowledge: CE consultants must know the vocabulary and nomenclature of clinical medicine. In addition they should know (a) the central concepts, principles, and theories of bioethics; (b) common clinical ethical issues; (c) relevant health law; (d) codes of professional ethics; and (e) institutional policies and practices.

  - Interpersonal skills: Consultants should have training and proficiency in recognizing and managing the social, psychological, and spiritual aspects of CEC, and in the techniques of facilitation, negotiation, or mediation in order to gather and communicate information, address issues of uncertainty, and help resolve disagreements.

  - Educational background: Consultants should have participated in a formal training program to assure that they have the knowledge described above. The candidate’s teachers or mentors must provide written evaluations of his or her performance and fitness to do CEC.

- Completion of an apprenticeship. CE consultants should also complete an apprenticeship—a supervised period of practice similar to a clinical fellowship for medical specialties, although flexible in regard to time. The supervisor should have the leeway to state, after a specified period, that the person is qualified to perform CEC. The apprenticeship should consist of the following elements:

  - participation as an observer in CEC performed by experienced consultants (for example, at least ten case consultations, although viable standards will need to await empirical data);

  - attendance at a monthly multidisciplinary chart review, ethics committee meeting, or quality improvement meeting to debrief past and ongoing cases that raise ethical issues; and

  - successful completion and documentation of three consultations as lead consultant, under the supervision of experienced mentors.

These requirements will be difficult for many health care institutions to meet at present. Many excellent consultants will have had sufficient education and “on the job” training to be “grandparented” into an officially sanctioned status. For many institutions, the requirements outlined here will define future goals rather than reflect a present reality and will help to fashion a plan of phased-in training. Until programs that address these requirements in a comprehensive manner become readily accessible and adopt universal criteria, institutions must identify alternative methods of training and apprenticeship that CE consultants seeking to become credentialed or sanctioned must complete. This is an area ripe for systematic study.

A robust quality improvement process. Quality improvement is mandatory in all subspecialties of health care. As CEC moves into the mainstream, it must be judged by mainstream standards. CEC and CE consultants must be subjected to the same level of transparency, accountability, scrutiny, and oversight as other members of the staff who see patients, and, like other members of the staff, they must write notes in the chart. This next step would be easier if there were clear standards for accrediting these professionals, but even without this platform, the obligation of hospitals to ensure quality mandates that they take responsibility for quality improvement efforts in CEC services.

The CECP has found that a structured quality improvement tool, based in reviews of the CEC summary notes, is not only useful for retrospective quality analyses, but also serves as an educational tool, a checklist for the key interventions needed in a CEC, and a template for the chart note. (See Figure 3 for a sample quality improvement tool.) An ethics case consultation that documents all of the data required by the quality improvement tool is likely to meet a high quality standard.

Any quality improvement program for CEC will likely need to be incrementally employed. For many institutions, observation of consultations, regular case review by the ethics committee, and peer review processes will be the first efforts in quality improvement. Reviews of quality by colleagues—now required to maintain the privilege to practice at many hospitals—may be useful. (The “360-degree” review is an example of this kind of quality review.) Reviews of process and outcome are basic to a quality improvement plan. A gradually maturing process of quality improvement will embed CEC in the quality culture of the institution. As a formal CEC service evolves along with a quality improvement program, work may include research that identifies outcomes that inform the practice of CEC and yield significant learning opportunities for the profession. 27

**CEC in Context**

Ultimately, securing excellence in clinical ethics consultation hinges on four overarching principles identified by the CECP working group: providing institutional support for the CEC service, overseeing the qualifications and expertise of...
consultants, compensating the critical CEC services, and evaluating the quality of CEC service. Institutions that support a CEC service will have the potential for enhanced quality of patient care in the context of more robust intellectual analysis of clinical decision-making and institutional policy. Creating a quality improvement model that improves over time in order to evaluate whether CEC interventions meet established and evolving standards will ensure that this service merits its place in the institution.

The CEC standards articulated in this consensus document are one way to enable a CEC service to function effectively and accountable in health care settings and to negotiate ethically justifiable solutions when values uncertainties or conflicts arise regarding a patient’s plan of care. These CEC standards recognize that the best possible decision arises from a process that includes the perspectives of all interested parties, provides robust ethical reasoning, recognizes the range of values that influence beliefs and behaviors in a morally pluralistic society, and supports a resolution that integrates all the parties’ perspectives. A quality CEC service must be nested in an institutional environment that values the voice of CEC as a champion for transparent, quality patient care, and serves as a conduit for building trust in clinical medicine through deliberate, inclusive action.

Acknowledgments

The Clinical Ethics Credentialing Project (CECP) was funded by FJC, A Foundation of Philanthropic Funds; the HHC Foundation; the United Hospital Fund of New York; and the New York Community Trust. We would also like to thank four individuals who as leaders of Montefiore Medical Center supported the development of this model: Elaine Brennan, Spencer Foreman, Gary Kalkut, and Steven M. Safyer.

References


7. American Society for Bioethics and Humanities, Core Competencies, 3.

8. Ibid., 6.


17. Blustein, Farber-Post, and Dubler, Ethics for Health Care Organizations, at 47.


23. Dubler and Liebman, Bioethics Mediation, 11.

24. Fox, Myers, and Pearlman, “Ethics Consultation in United States Hospitals.”


The Art of the Chart Note in Clinical Ethics Consultation and Bioethics Mediation: Conveying Information that Can Be Understood and Evaluated

Nancy Neveloff Dubler

ABSTRACT

Unlike bioethics mediators who are employed by healthcare organizations as outside consultants, mediators who are embedded in an institution must be authorized to chronicle a clinical ethics consultation (CEC) or a mediation in a patient’s medical chart. This is an important privilege, as the chart is a legal document. In this article I discuss this important part of a bioethics mediator’s tool kit in my presentation of a case illustrating how bioethics mediation may proceed, and what this approach using both bioethics and mediation may add.

THE CASE AND THE SETTING: WHY MEDIATE?

There is, generally, little mention of bioethics principles in bioethics mediation. Mediation exists in stark contrast to the structured intellectual work of a bioethics committee. The mediation is designed to manage or resolve conflict. It seeks to level the playing field and empower all of the participants to search for acceptable solutions that they can all agree on.

The principles and practices of bioethics matter to mediators as they struggle to keep in mind the ethical, legal, and medical literature that sets the boundaries for the agreement they seek. Because bioethics mediation is focused on solving a problem within the confines of a “principled resolution,” and not just applying abstract bioethics principles, it self-consciously eschews abstract discussions that may alienate and silence patients, family, friends, and even staff. But staff, who both participate in the mediation and become involved while working subsequent shifts, must be brought along through notes in the patient’s chart.

Some bioethics mediators act as outside consultants to healthcare institutions. They see this role as a benefit to the patient and family, who may feel that a mediator who is embedded in an institution has a stake in the outcome. I have argued previously that insider status allows bioethics mediators knowledge, status, and power within an institution that outsiders cannot har-
ness. As members of the clinical staff, yet neutral to any particular case, bioethics mediators must have the authority to include a report of the mediation in a patient’s chart. This function as part of the chart—a legal document—and is an important privilege not granted to outside consultants. Equally important, the chart note facilitates peer review and quality improvement initiatives. In this article I discuss this important part of a bioethics mediator’s tool kit in my presentation of a case illustrating how bioethics mediation may proceed and what this approach using both bioethics and mediation may add.

I had come to the Canadian workshop with a prepared presentation on bioethics mediation. However, in attending the faculty meeting on the morning of the conference, and understanding the proposed structure of the day, I made the suggestion to amend my part of the program. The day had been designed to begin with a clinical ethics (CE) consultant directing a hospital ethics committee discussion on a difficult and troubling case. I suggested that I mediate the very same case, with the same role-players, that evening.

The case involved a patient, Joseph, with end-stage multiple sclerosis (MS). He had cared for his mom, who also had MS, until he was unable to manage; she had died insensate in a nursing home. That was the particular end that he feared above all. Joseph had been living at home with shifts of attendants, was deteriorating rapidly, and had managed to save barbiturates, planning to take his life. His attempt was interrupted by an unanticipated visit by the postman who summoned emergency medical services (EMS). Joseph was taken to the local intensive care unit (ICU) and intubated. It was unclear how long he had been without respiration and oxygen.

Two close friends and three former physicians, the primary care physician, a neurologist, and a neuropsychiatrist arrived at the ICU almost immediately and urged removing the patient from the ventilator. All stated that he was not depressed, had assessed his options carefully, and had left explicit advance directives about his care that stated unambiguously that he never wanted ventilation. The ICU attending was reluctant to remove the ventilator as long as the opiates Joseph had ingested continued to diminish his ability to breathe on his own. One day after admission, the ICU attending contacted the ethics committee for help in resolving the growing dispute between herself and the friends and prior physicians of the patient. This case was discussed at the faculty meeting and would be presented to a mock ethics committee that morning.

The ethics committee discussion was directed skillfully and addressed the ethical issues comprehensively. The CE consultant had invited the patient’s closest friends, the primary care physician, a neurologist, and a neuropsychiatrist to the meeting. The CE consultant began by sketching out the case and asking the two physicians, who had known the patient over time, and one who had recently completed a depression evaluation, to explain to the committee their assessment of the patient’s history, diagnosis, prognosis, and emotional and neurological status before the suicide attempt. All reported that he was not depressed, was, other than his underlying disability, quite healthy, and was realistic about his future inevitable deterioration.

The CE consultant then asked the friends to speak about the patient’s values and preferences. They reported a dear and determined man who was a great friend, but who did not want to face his slow deterioration into death. He had been clear and unambiguous with his friends and his physicians about his fear of his future and his desire to end his life.

Finally, the ICU attending was asked to explain her position. She admitted that the reports of both friends and physicians were extremely powerful, but felt that she would be assisting in a suicide if she removed the ventilator while opiates were still present in the patient’s system. The approximately 20 members of the ethics committee then discussed the case.

The committee discussion was impressively scholarly and analytical. It addressed the case in the context of relevant ethical principles including autonomy, beneficence, non-malefeasance, and justice. The ethics committee mem-
bers sympathized with Joseph’s friends and physicians, but agreed that the ICU physician was correct in interpreting contemporary philosophical and legal norms as prohibiting the removal of the ventilator while opiates were operative in the patient’s system. They offered the opinion, and recommended to the ICU attending, that removing the ventilator would be assisting the suicide.

In the evening, the three physicians and the two friends met with me as the bioethics mediator. I shaped the mediation using the acronym STADA: S—Sit down; T—Tell me about Mama (let the family speak from their knowledge and experience); A—Admire the family for coming to help with the difficult decision; D—Discuss the medical facts, diagnosis, and prognosis; Ask—what should be the recommendation on the outcome. We sat together in a small group. I began, as I always do, with the nonmedical narrators: “Tell me about Joseph.” I begin this way because physicians are the experts on medicine, but the family, or in this case the friends, are the experts on the patient. One of the basic tasks of bioethics mediation is to “level the playing field” between medical staff and family/friends. By providing the opening remarks, they become privileged commentators bringing important matters to the discussion.

They spoke movingly about his steady and accelerating medical decline. One of the friends related that Joseph had been sexually abused as a child, and that every time his diapers were changed he re-experienced that terrible trauma. They explained that he loved life and was not depressed, but judged that his quality of life was simply no longer, in his eyes, sufficiently robust to counterbalance his indignity, pain, suffering, and ongoing fear and anxiety about the future. The friends feared, reflecting the patient’s deepest concerns, that if this case were to proceed without immediate removal of the ventilator, the patient might emerge in a permanent vegetative state, but able to breathe, which would send him to a nursing home for months or years as a “lump” of a person—his very worst fear.

I thanked (admired) the friends for being willing to come and help us with this difficult decision about Joseph, whom they knew so well and cherished. The physicians then discussed the diagnosis, prognosis, history, and most recent depression assessment; all agreed that he was not clinically depressed. Finally, when asked to explain her position, the ICU physician addressed her fears about violating the law by removing the ventilator. But after an hour and a half of discussion, when the ICU physician was again asked for a decision, she explained that she was so moved by the discussion and the picture of the patient that it presented that she was willing to remove the respirator. The mediator then urged caution until the ICU physician, with the assistance of the mediator, if she desired, could discuss her decision with the hospital authorities and be certain that they supported her reasoning and decision.

The mediator then briefly explained the “principled resolution” that she had kept in mind for this case: 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.” She discussed the central position of autonomy in the taxonomy of relevant ethical principles and cited this commitment as the basis for endorsing the conscious choice of a decisionally capable patient over opposing notions of beneficence and a commitment to extending life. She also discussed the possibly relevant U.S. Supreme Court cases (admitting that she did not know the Canadian law), especially noting the existence of the doctrine of “double intent” lurking in the case regarding physician-assisted suicide.

**THE CHART NOTE: PROVIDING THE ETHICS FOR BIOETHICS MEDIATION**

When the mediation ended, the audience appeared genuinely agitated in their opening responses, critiques, questions, and attacks. Primary among the responses was: Where is the bioethics in this process? Where are the principles? Where is “do no harm,” beneficence, and non-maleficence? What does this process have
to do with bioethics? Why did the ICU physician present such a diametrically opposite position from the one articulated in the morning? Why didn’t the friends tell the same stories in the morning, especially about the history of abuse?

The panel members first responded, addressing the difference in feeling between the intimate evening meeting and the open, and very public, ethics committee meeting. The discussion of the ethics committee seemed exposed, even though it opened with a promise of confidentiality, but the numbers of the ethics committee already constituted the sort of wide sharing that real confidentiality precludes. The physicians and friends stated that they felt extraneous to the gathered experts. The ethics committee members all greeted each other as friends, as insiders; the physicians and friends felt as though they were outsiders. The morning was, by its nature, public. In contrast, the mediation was quiet and shielded.

Clearly the evening meeting did not have the crisp, organized structure of the bioethics committee. It meandered, especially at the beginning, as the friends shared stories and associations. It sharpened its focus when the physicians discussed the medical facts of the case and strongly shared perceptions that the patient was, without question, decisionally capable and not depressed. The physicians concluded that Joseph was not depressed when he attempted to end his life and saw his action as advancing his self-identified interests. Finally, the ICU physician said that her objections to following the patient’s advance directives were overwhelmed by the tone and content of the discussion, offering the portrait of this strong and determined patient.

The clamor of the audience was correct. There is, generally, little mention of bioethics principles in bioethics mediation. Mediation exists in stark contrast to the structured intellectual work of a bioethics committee. The mediator did comment, in the course of the mediation, on the notion of autonomy and on the principle of “do no harm.” She queried whether only a vitalist notion of life would demand continuing ventilatory support? Is the length of a patient’s life the only relevant measure? Or could the patient’s own self-described notion of value be relevant?

The mediation is designed to manage or resolve conflict. It seeks to empower the nonmedical persons as the experts on the patient and to search for solutions within the medical facts and the patient’s described commitments. The principles and practices matter to mediators as they struggle to keep in mind the “principled resolution.” Mediators need to keep in mind the ethical, legal, and medical literature that sets the boundaries for the agreement they seek.

**CREATING THE CHART NOTE: WRITING TO THE TEST**

Because bioethics mediation is focused on solving a problem, within the confines of the principled resolution, and not on just applying abstract bioethics principles, it self-consciously eschews abstract discussions that may alienate and silence patients, family, friends, and even staff. But staff, both participants in the mediation and in subsequent shifts, who we can assume are familiar with the bioethical language, must be brought along in the chart note. Chart notes are critically important as they:

- Reflect the support of the administration, which approves the particular consultant’s interventions and facilitates a bioethics note in the chart—the legal record of the patient’s care;
- Provide the only reliable basis for engaging in peer review and quality improvement of the CE consultation process;
- Communicate the consensus reached and explain the ethical bases for that agreement, couched in a recommendation that reflects the nature of the principled resolution;
- Explain the resolution/consensus in terms of commonly agreed upon ethical concepts;
- Elucidate the process and the product of the bioethics mediation so that staff members who were not present will be able to understand and implement the agreement;
- Offer the basis for a completely transparent process as the note, once entered into the chart, can be sent to administrative authori-
ties as a record of the actions that were recommended.

The use of a chart note evaluation document, such as shown in figure 1, permits the CE consultant to “write to the test” and include all of the elements that count in the evaluation. If any of these major elements is missing, it may constitute a “deal breaker” and call into question not only the validity of the note, but of the consultation itself. Consider the following as the body of the chart note for this case.

The Chart Note

Relevant social and medical history. Joseph was brought to the hospital by EMS, called by the postman who discovered him unresponsive in his home. He was intubated in the ICU. Thereafter, his close friends, his primary care physician, a neurologist, and a neuropsychiatrist who had recently examined him, came to the hospital to try and convince the ICU attending to disconnect ventilator. They argued that Joseph, in the last stages of MS, had decided to end his life rather than suffer slow and inevitable decline. All of the physicians stated that he was decisionally capable at the time of his decision and it was not caused by a clinical depression. All argued that his autonomous decision was to control his dying while he could before total physical incapacity intervened. To that end, he saved barbiturates and took, what he thought to be, and what would have been—but for the accident of his being found—a lethal dose.

The ICU attending was uncomfortable disconnecting the ventilator while barbiturates were still in the patient’s system and likely suppressing respiration. Once these medications had been excreted, then the residual respiration would be evident. The friends argued that it might be that he would be able to breathe on his own, but given the likely anoxic brain damage (he was not breathing when discovered), he might end up in long-term care in a persistent vegetative state, which was his greatest fear. He had cared for his mom as she had died of MS in a nursing home, and he clearly, in all of his directives, did not want to repeat that voyage for himself. [This discussion could be augmented by the facts described above in this article.]

The process of the CE consultation. This CE consultation consisted of a mediation among the patient’s primary care physician, a neurologist, a neuropsychiatrist who had recently seen the patient to assess his disease and to evaluate his possible depression, the ICU attending, and two close friends of the patient’s. First, all of the participants visited the patient. Then they moved to another room for discussion.

Ethical issues and analysis. Advance directives contain two sorts of documents: living wills and the appointment of a proxy or healthcare agent. This patient had executed both. A living will is a document that explains what the patient would want in the future if she or he could no longer discuss the decision and provide contemporaneous informed consent. Living wills are value neutral, and could be used to prospectively request or refuse care. Most living wills, however, are structured to refuse interventions like surgery, ventilators, and antibiotics. Healthcare proxy appointments give the person appointed general ability to make decisions for the patient based on the standards of what the patient has said she or he would want (explicit directive), what one could surmise she or he would want from her or his behavior and pattern of life (substituted judgment), and, absent both of these, what is in her or his best interest. Healthcare proxy appointments are generally more flexible and more responsive to the nuances of medical conditions than are living wills. Proxy appointments permit the team, with the proxy, to begin an intervention, to assess its success, and then to continue or withdraw it as the condition of the patient requires. Living wills tend to make absolute rather than nuanced statements, and as such are less appropriate to the art of medicine.

However, in this case, the patient’s advance directives consisted of a living will and the appointment of his two best friends as alternate proxies: Ms. A was first and Mr. B was to act if Ms. A were unavailable. Both advance directives were unambiguous. Joseph had expressed his wishes never to be on a ventilator and never
**Figure 1. Clinical ethics consultation quality improvement review**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>+/-</th>
<th>No</th>
<th>N/A</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it clear who requested the consult?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did the consultant meet with the clinicians?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are the positions of the clinicians clear?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did the consultant visit the patient?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the patient's voice heard?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did the consultant meet with one or more surrogates?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are surrogates' voices heard?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is it clear who is making decisions on the patient's behalf?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did mediation, facilitation, explanation or other intervention achieve consensus?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is ethically relevant medical history included in the chart note?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is ethically relevant social history included in the chart note?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are the ethics issues identified (indicate in the list below)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is relevant bioethical knowledge and analysis included in the chart note?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the chart note sufficient for educational purposes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Ethics issues identified**

- Advance directive interpretation
- Best interest of the patient
- Cultural values and treatment
- Disputes among clinicians
- Disputes clinicians versus surrogates
- Double effect
- False choices
- Informed consent
- Palliative versus curative treatments
- Refusal of treatment
- Responsibility dumping
- Substituted judgment
- Withdrawing/withholding of life-sustaining treatment

**Ethics issues identified**

- Benefit/burden analysis
- Confidentiality
- Capacity (decision specific)
- Disputes among surrogates
- DNR/DNI
- End of life decision making
- Fair allocation of resources
- Medical futility
- Patient autonomy
- Religious values and treatment
- Setting limits for care
- Truth telling

This particular iteration of the chart note review form was composed by James Zisfein, Chief of Neurology, Lincoln Hospital, New York City Health and Hospitals Corporation, for use as an evaluation form for the Ethics Council, which he chairs.

MR = medical record; DNR = do not resuscitate; DNI = do not intubate.
to be in a nursing home. He had written documents and engaged in conversations to these ends with all of his physicians and friends.

The ethical problems in this case lie both in the law and in long-standing physician objections to assisted suicide. In 1997, the U.S. Supreme Court upheld two state laws that absolutely prohibit assisted suicide. The Court found that Washington State’s law did not violate constitutional guarantees of liberty (Washington v. Glucksberg) and that New York State’s similar law did not violate constitutional guarantees of equal protection (Vacco v. Quill). However, in 2006, this same Court upheld the Oregon Physician Assisted Suicide Act over the attempts of the Bush administration’s Attorney General to trump the state’s power with the federal government’s ability to regulate physicians’ use of opiates. Thus, it is possible that the legal norm is evolving and favoring a more nuanced interpretation of patient rights.

It is, in this legal context, especially important to note Justice O’Connor’s concurrence in Washington v. Glucksberg. Implicitly incorporating the doctrine of double effect, she wrote: “In sum, there is no need to address the question whether suffering patients have a constitutionally cognizable interest in obtaining relief from the suffering that they may experience in the last days of their lives. There is no dispute that dying patients in Washington and New York can obtain palliative care, even when doing so would hasten their deaths.”

In the same vein, in the shadow of the doctrine of double effect, the ICU attending was choosing to respect the prior direct wishes of a decisionally capable and nondepressed patient, so well documented by his physicians and friends, even when doing so might hasten his death. The goal of her actions was to support the patient’s autonomy in the face of a likely horrible outcome. This consensus reflected the clear dictates of the patient that he “never wanted to be on a ventilator.”

Recommendation. The consensus of the group was to recommend respecting the wishes of the patient by removing the ventilator in response to his clear and unambiguous prior wishes. Both his friends and his physicians stated that he was unambivalent about his wish to end his life in light of his inevitable deterioration and death.

CONCLUSION

Bioethics mediation is a useful tool for resolving conflicts in medicine. It does not focus directly on the bioethical and legal issues, although knowledge about these is critical in setting the boundaries for possible agreements that could be reached. The analysis of the relevant issues is explored directly in the chart note, which must review the social and medical facts, analyze the dynamic of the intervention, review the bioethics arguments and literature, and state the recommendation reached as part of the consensus.

Not only does the chart note record an event that is a critically important part of the planning for the care of this patient, but it permits the intervention to be reviewed for the purposes of peer review and quality improvement. If CEC (and bioethics mediation as a powerful tool) is to take its place as a part of medicine, it must be subject to review, assessment, and quality improvement initiatives, for which the chart note is the basis.

NOTES

2. Ethics Consultation Boot Camp, Provincial Health Ethics Network of Alberta, Banff, Canada, 3 November 2011.
3. Details of this case have been changed to mask the identity of the patient and family.
4. By Susan B. Ruben, PhD.
5. Dubler and Liebman, Bioethics Mediation, see note 1 above, 74-5.
6. Ibid.
7. Ibid.
8. There is some debate regarding this sort of
generic paragraph. For those who see chart notes as educating the staff, it is useful to explain the concepts. This paragraph and other useful discussions were written by Jeffrey Blustein, Professor or Philosophy and Zitrin Professor of Bioethics, City College, City University of New York. Dubler and Liebman, Bioethics Mediation, see note 1 above pp. 11-130.


12. This is the last paragraph of O’Connor’s concurrence, see note 10 above.