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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,"[1] 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-

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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 functions 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[2] 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,[3] 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[4] 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-malfeasance, 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; **A**sk—what should be the recommendation on the outcome.[5] 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"[6] 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."[7] 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.[8]

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

Patient name _____ Age _____ MR # _____
Hospital _____ Unit or clinic _____
Clinical ethics consultant _____ Date of consult _____
Reason given for consult _____
Clinical ethics reviewer _____ Date of review _____

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

	Ethics issues identified		Ethics issues identified
	Advance directive interpretation		Benefit/burden analysis
	Best interest of the patient		Confidentiality
	Cultural values and treatment		Capacity (decision specific)
	Disputes among clinicians		Disputes among surrogates
	Disputes clinicians versus surrogates		DNR/DNI
	Double effect		End of life decision making
	False choices		Fair allocation of resources
	Informed consent		Medical futility
	Palliative versus curative treatments		Patient autonomy
	Refusal of treatment		Religious values and treatment
	Responsibility dumping		Setting limits for care
	Substituted judgment		Truth telling
	Withdrawing/withholding of life-sustaining treatment		

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.[9] 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*[10]) and that New York State's similar law did not violate constitutional guarantees of equal protection (*Vacco v. Quill*[11]). 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."[12]

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

1. I discuss the concept of "principled resolution" in N.N. Dubler, " 'A Principled Resolution': The Fulcrum for Bioethics Mediation," *Duke Law School Journal of Law and Contemporary Problems* 74 (Summer 2011): 170-200; N.N. Dubler and C.B. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solutions,* rev. and exp. ed. (Nashville, Tenn.: Vanderbilt University Press, 2011) 14-15, 302.

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.

9. L.O. Gostin, "Physician-Assisted Suicide: A Legitimate Medical Practice?" *Journal of the American Medical Association* 295, no. 16 (2006): 1941-43, doi:10.1001/jama.295.16.1941; P. J. van der Maas et al., "Special Report: Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," New England Journal of Medicine 225 (28 November 1996): 1699-1705; D.E. Meier et al., "Special Article: A National Survey of Physician-Assisted Suicide and Euthanasia in the United States," *New England Journal of Medicine* 338 (23 April 1998): 1193-1201, doi: 10.1056/NEJM199804233381706.

10. *Washington v. Glucksberg,* 521 US 702—Supreme Court 1997.

11. *Vacco v. Quill,* 521 US 793—Supreme Court 1997.

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