

Narrative and Ethics Consultation

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For more than twenty years, there have been many within the bioethics world who were unconvinced that the principles approach to case consultation offered the objective and universal guidance that had been envisioned.¹

Physician and philosopher Howard Brody has written extensively about how principles have turned out to be less transparent and universally helpful than hoped. In fact, the process of applying principles to real cases in bioethics has proven to be challenging because most often there is so much information lacking about the situation and the individuals involved. As Brody puts it, “Principles tell us ... to respect patients’ autonomy; but what might it mean to respect the autonomy of Mr. Smith in Room 1303? Principles cannot instruct us how to act unless we first add quite a long list of facts and assumptions about Mr. Smith, his mental capacity, how he relates to various people around him, his medical condition and so forth.”²

Others offer similar criticism. Margaret Urban Walker points out that a diverse group of moral philosophers and bioethicists has challenged theories based on a system of principles built on impersonal, action-guided formulas, such as utilitarianism or Kantian deontology that are deductive processes that render moral judgments through a top-down application of codelike theories.³ Walker suggests that these criticisms generally fall under three common themes. First, principles lack appreciation for the social situation of morality. Second, principles miss the importance of viewing morality in the context of particular situations. And third, principle-based theories lack the recognition that moral deliberation and decisions often change communities, relationships and sometimes moral ideas themselves.⁴

What most critics argue for is the appreciation that narrative understanding of moral problems and narrative as a means of moral deliberation better capture the particulars of the situation and enrich the case with context and details often cut off when a case is framed by principles. Walker

believes that moral understanding and resolution require an understanding of the person’s history of trust, expectation and responsibility. There must be consideration of the stories of relationship, identity and beliefs to see how decisions will affect the patient as well as those who are close to the patient. She argues that when health care providers or ethics consultants talk in terms of informed consent or confidentiality, they may be speaking a different language than patients and families who are concerned about filial obligations, gratitude, trust and self respect.⁵

In the introduction to *Stories Matter*, physician Rita Charon traces the recognition of narratives’ centrality to looking at cases. She states: “[N]arrative approaches to ethics recognize that the singular case emerges only in the act of narrating it and that duties are incurred in the act of hearing it.”⁶ In her essay “Narrative Contributions to Medical Ethics,” Charon offers a rather loose framework for using narrative knowledge in the practice of ethics consultation. Charon argues that narrative helps to contextualize and particularize the conflicts in which medical ethics consultants find themselves. Using a narrative approach in ethics deliberation allows the ethicist to look for some narrative coherence in the patient’s life. This coherence often is the clue needed to help family and caregivers make decisions for the patient who cannot speak for herself. The ethics consultant often must wade through multiple tellings of the patient’s story, as well as the different interpretations of that story. There may be contradictions in the various tellings and the ethicist must try to sort out truth from fiction. But if the ethicist or ethics consultant develops the skills to do this, her effectiveness and accuracy in ethical deliberations will increase.⁷ The following case illustrates the importance of hearing the patient’s narrative from various viewpoints.

Mrs. Smith is ready for discharge and her physician believes she should go to an extended care facility for rehab. Mrs. Smith’s daughter, Ann, agrees with the doctor that her mother would benefit from rehab. However, Mrs. Smith is adamant about going straight home. Her husband has

Parkinson's and she has been his caregiver for over five years. Ann thinks her mother is just being stubborn, as she often is. In fact, her mother is the reason that Mr. and Mrs. Smith haven't moved to assisted living as Ann has suggested. The doctor thinks Mrs. Smith is unrealistic about her ability to go home and care for John and that it will be unsafe for both Mrs. Smith and her husband. Mrs. Smith stands her ground and refuses to consider an extended care facility, even for a short time.

One could argue that the patient's autonomy should trump and it is Mrs. Smith's decision to make, but much would be missed if the stories of both the patient and the family aren't filled out. For example, is Ann's anger at her mother long standing and does that make it difficult for her to be sympathetic to her mother's concerns? Does the doctor just want to discharge the patient and not worry about the "whys"? Has anyone offered Mrs. Smith other options or asked why she is so steadfast in making what appears to be an unsafe decision? An ethicist skilled in eliciting the patient's story and assessing the narrative for authenticity and trustworthiness would want this information before making a recommendation. Although filling out the narrative takes time up front, it may actually facilitate a timely and appropriate resolution of the impasse.

Howard Brody believes that narrative ethics has a democratizing influence on the process of resolving challenging ethics cases.⁸ He claims that narratives of the kind told by people are inherently democratic, a point that Brody makes about the moral choice imbedded in honoring a patient's story. Brody says that ordinary people strive for clarity when they tell their story or the story of a loved one. The democratic underpinning is that everyone has a story and that each of us is in the best position to tell it. However, Brody also cautions that in some sense every narration is also an exercise in political power. Communities are generally organized in a way that not just anyone can tell a story and be sure of an audience's attention or acceptance of the story. Brody claims that some stories and storytellers are marginalized even before the telling begins. Others are privileged by power and authority and gain ready assent of the audience, even when the story appears to fly in the face of known facts. Obviously, in the health care setting it has been the physician's telling of the story that has always had more influence, more "truth", and is more worth listening

to. Although the doctor's version invariably carries more weight than the nurse's or the social worker's, the patient's version frequently carries the least weight of all. So Brody cautions that without serious consideration of all versions of the narrative, using narrative in ethics consultation risks being as elitist as he believes the principlist process to be.⁹ For all of us involved in ethics consultation, Brody's words ring with some truth. When a consultation request is made, we read through the chart and speak with the physician before we attempt to see the patient or family members. How often are we unwittingly prejudiced in some way by what we have heard or read before we have even spoken with the patient whose story we are to consider? Brody suggests that without serious consideration of all versions of the narrative, the narrative process will be driven by those with power to determine whose version of the story gets told and accepted.

In spite of Brody's concerns, he and others believe that using narrative as the basis for moral deliberation is not only respectful, but is more reflective of how we come to know about one another and understand our similarities and differences, as well as how we look at moral problems. From the time we were children, when we went to our parents or teachers with a problem, the first question we were asked is, "Tell me what happened?" In our everyday interactions we are often asking for the story or narrative in order to have greater understanding of a problem, a hurtful event, or an ethical dilemma.

Walker claims that story is the basic form of how we represent moral problems. She argues that it is important to know who is involved, how they understand themselves and each other, what in the relationship brought them to a situation that is morally problematic, and what social or institutional boundaries shape their options. She also suggests that narrative is better at capturing the process of moral resolution in a way that is mindful that moral problems are snapshots in the ongoing histories of the people involved.¹⁰

This recognition of the importance of narrative in uncovering moral problems should resonate with those of us doing ethics consultation within a Catholic hospital or system. Our faith tradition, so deeply committed to human dignity and the importance of community, inevitably leads to the appreciation that narrative is the most respectful

means we have of discovering who a patient is and how his story should impact ethical decision-making. Sr. Patricia Talone, CHA vice president, mission services, reminds us that as Christians, we know that Jesus revealed truths through the telling of parables. Jesus' appreciation of the power of story should guide us in our efforts to reveal the truths present in every consultation.¹¹

It's important to keep in mind that none of these writers totally rejects a role for principles. In fact, Rita Charon believes that principles are and should be the underpinning of any resolution of an ethical dilemma. She claims that narrative's role is to particularize the decisions and increase involvement of patients and providers.¹² Brody doesn't take a strong stand on this. He believes that regardless of whether one uses a process grounded in principles and gives narrative a more peripheral role, or one that rejects the use of principles as an essential to ethical decision-making, ethical discernment that employs narrative in some way is always superior to doing ethical analysis without narrative at all.¹³

Of the three, Walker takes the strongest stand that narrative should ground the ethics consultation process, but she does not dismiss the role of principles either. She claims that their role should be to mark broad areas of value or to define generic priorities.¹⁴ Her argument is that only the content of individual and family histories can define what in this situation is owed to whom and why and what different moral resolutions of particular cases will mean to those individuals involved. For example, sending one's mother to an extended care facility may be clinically the best choice, but to do so may cause a breach of trust between a mother and her adult child who has promised that he will never do that. The stress on that relationship might last much longer than the actual stay in a facility and such an effect needs to be considered.

The challenge for the ethicist of shifting to a model of consultation based on narrative is that it is not as clear a framework as the principle-based model. However, regardless of how the ethicist employs narrative, it is essential to its successful use to hear as many versions of "the story" as possible and then try to sort out the different perspectives in a way that facilitates reasonable and respectful ethical discernment. This ensures that there is active participation by patient and family, along with other caregivers involved in the case.

A few months ago, I received a request from a physician to meet with a family in order to facilitate decision-making for an incapacitated patient. The physician warned me that the family was struggling and would require a great deal of time. The decision-makers were two children of the patient, both of whom were in their early twenties. The patient had been divorced from their mother for many years. The 61-year-old patient had suffered a massive stroke and was unresponsive and on a ventilator. The physician was ready to try weaning the patient, but wanted to know what she should do if the patient failed the trial. She had talked to the patient's children, but felt they weren't really able to make this decision.

I scheduled a meeting with the children and asked if anyone else should come. They wanted their aunt and uncle, the patient's sister and brother-in-law to attend. From the brief conversation with the daughter, it was clear that they were completely overwhelmed by the gravity of the decision they were being asked to make. When I met with them and the other family members, I asked the son and daughter to explain to me what they understood about their father's condition. It was apparent that they had a good appreciation of his condition and his prognosis. I then asked them, as well as the patient's sister and brother-in-law, to tell me about the patient. What was he like, what was important to him, what his goals were, and so on? For over an hour they talked about the man they knew, describing him as adventurous, very active and physical, that he was an avid hunter and was consumed by major renovations to his home that he was doing himself. He had been a loving and engaged father and that he loved his dog. At the end of the conversation, I asked the children if he were able to tell them what he would want, what would he say. Almost without hesitation they agreed he would not want aggressive measures if he were not able to return to an active life. Their aunt and uncle agreed. They decided that if he failed the vent weaning that he should be allowed to go peacefully, and either way he should be a DNR.

This is a case in which the family was able to make decisions for the patient after talking about who he was. There was no discussion of principles, but just recognition of the patient's narrative as they had experienced it. This was likely the final chapter of that narrative and the children and other family members were able to allow it to unfold as they believed he would want.

There are many ways narrative can be an essential part of ethics consultation. It can be a very formal process or a more informal conversation as the one I've described. The challenge of narrative is make sure that the patient's story is heard in as many forms as may be necessary, so that decisions made reflect and honor who the patient is. As Margaret Urban Walker suggests, using narrative encourages the recognition of each other as moral agents, capable of making reasoned and responsible choices that have been made in consideration of responsibilities and values, and that allows individuals to be responsible to self and to others "... for the moral sense and impact of what they do."¹⁵

NOTES

1. The principles approach was popularized by bioethicists Tom Beauchamp and James Childress (1977, 1994, 2001). Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th edition, Oxford: Oxford University Press, 2001.
2. Howard Brody, "Narrative Ethics and Institutional Impact" *HEC Forum* 11 (January 1999): 47.
3. Margaret Urban Walker, "Keeping Moral Spaces Open," *Hastings Center Report*. 23 (March-April 1993): 34.
4. Ibid.
5. Ibid., p. 36.
6. Rita Charon and Martha Montello, *Stories Matter*, New York: Routledge, 2002.
7. Ibid., 260-61.
8. Howard Brody, *Stories of Sickness* 2nd ed., (New York: Oxford, 2003): 26
9. Ibid., 35
10. Walker, op. cit., pp. 35, 37.
11. Talone, Patricia, RSM, Ph.D., "Catholic Health Care Ethics Consultation: A Community of Care," *HEC Forum* 15, no. 4 (December 2003): 323-337.
12. Charon, Rita, "Narrative Contributions to Medical Ethics: Recognition, Formulation, Interpretation, and Validation in the Practice of the Ethicist," *A Matter of Principles? Ferment in U.S. Bioethics*, eds. Edwin DuBose, Ron Hamel, and Laurence J. O'Connell, Valley Forge: Trinity Press International, 1994, pp. 260-283.
13. Howard Brody, *Stories of Sickness*, 2nd ed., New York: Oxford University Press, 2003.
14. Walker, op. cit., pp. 38-40.
15. Ibid., p. 37.

(Editor's Note: Please see the Resource section for a select listing of theological sources on narrative ethics).