



Narrative Awareness in Ethics Consultations: *The Ethics Consultant as Story-Maker*

BY LARRY CHURCHILL

Much has been written about the importance of narrative in teaching ethics and humanities to medical students and residents, as well as the value of narratives in clinical care.¹ Relatively little has been said about the essential role of narrative in bioethics consultations.² For most consults, the interpretation of narratives is the central moral feature, and the ethics consultant is inevitably one of the narrators.

Consider the following situation: A resident physician in the surgical intensive care unit called at 8:00 a.m. requesting an ethics consult. According to his brief history, the patient, Henry Bush (this and all case names are aliases), seventy-eight years old with a ten-year history of Alzheimer's dementia, was admitted a week earlier following an unimpeded fall on his face from a standing position. He was at home at the time, cared for by his daughter, Sara Bush. The patient was taking Plavix (an anticlotting prescription medication) at the time of his fall, exacerbating the bleeding, which worsened the consequences of his injuries. Surgical intervention following hospital admission had been unsuccessful, and Mr. Bush remained intubated and unresponsive following the surgery. In the judgment of the attending surgical clinicians and the consulting neurologists, further intervention would not repair his brain injuries or restore him

to consciousness. The medical team thought that an aggressive course of care might soon require a percutaneous endoscopic gastrostomy (PEG), or feeding tube, but they were reluctant to place it given the very poor prognosis. However, discussions with the spouse and the daughter were going nowhere. The spouse also suffered from dementia, of less severity than the patient's but enough that she was clearly unable to act as Mr. Bush's surrogate. Sara, the only child, in her mid-fifties, was the appropriate surrogate for Mr. Bush, but she refused to discuss palliative care and comfort-only measures as an option. The difficulty of communicating effectively with the daughter and disagreement about the goals of care were the primary reasons the resident gave for the ethics consult request.

Having read the information in the electronic medical record, I arrived in the surgery ICU about an hour after the initial consult request. I had brief conversations with the resident and the bedside nurse that confirmed my general understanding of the situation. As I approached Mr. Bush's room, it was clear that the patient's daughter, Sara, was in an intense conversation with the attending physician, who was describing the patient's situation, the very poor prognosis, and why comfort-only measures were—in her view—important to consider now. The daughter was having none of it, saying it was “too early to think about that” and insisting that her father needed a chance to recover. The physician saw me approach but did not signal for me to enter the conversation. I remained outside the room but within earshot. One feature of their conversation struck me—that the

Larry Churchill, “Narrative Awareness in Ethics Consultations: The Consultant as Story-Maker,” *Narrative Ethics: The Role of Stories in Bioethics*, special report, *Hastings Center Report* 44, no. 1 (2014): S36-S39. DOI: 10.1002/hast.268

Narrative is a profound mode for understanding ethics consultation, not because it resolves problems, but because it forces us to attend to the human voices, including our own, behind what is being said.

physician interrupted the daughter as she was speaking, correcting her impressions about her father's condition and citing the evidence of CT scans and other technical metrics of prognosis. The interruptions were not unkind, but they were repetitive. Ten minutes later, as the attending left the patient's room, I walked with her down the hallway. She thanked me for coming and said that the daughter didn't seem to realize how dire the situation was, indicating that what I had overheard was one of several (unsuccessful) attempts to reconsider the goals of care. Given this patient's compromised baseline and the extent of his injuries, there was nothing—either in the collective memory of the ICU team or in the literature—to suggest that a recovery was a realistic possibility. “I never say ‘Never,’” she said, “but this case is about as clear as it gets. Maybe you can help here.”

Many Narratives, Many Narrators

Notice that even at this very early stage in the consult, at least three narratives were in play. The medical record itself was a narrative, or really, a variety of narratives in the form of daily progress notes from physicians, nurses, respiratory therapists, and others; consult notes from neurology; several fragments of social history; and other slivers of information with varying degrees of relevance, most requiring discernment and some hermeneutical skills to build a coherent picture.³ A second distinct narrative was the story of why this case had come to be categorized as an ethical concern for the medical team, as expressed in terms of the daughter's inability or perhaps unwillingness to hear a discouraging prognosis, resulting in the frustration of the professional caregivers.

A third narrative was the tentative sketch running through my mind as a consultant—partly factual, partly anticipatory and conjectural, inevitably personal—about what was going on here. So far I had received a call, read the medical record, talked with three of the professional caregivers, and overheard a conversation with the patient's daughter. These were fragments at best. Yet the story forming in my mind was inevitably influenced by a wide range of people and experiences that I had brought with me to this consult. Among these are other physicians, patients, and families I have worked with in the past and the hospital and death experiences of previous consultations but also my memories of the care trajectory and deaths of both of my parents and some of my friends, my work forty years

ago as a minister, and a range of experiences about such human phenomena as hope, denial, grief, what people do in a crisis, and the beneficial and toxic uses of moral and spiritual resources. In short, my internal story elements are complex and idiosyncratic, and at least some of these elements lie at a tacit level of awareness most of the time. As an ethics consultant, I am inevitably a story-maker. In this role, skepticism about my own interpretations is just as important as skepticism about the reliability of any of the other storytellers on the scene.

Narrative Permits Persons to Appear

For the case, the next obvious conversation was with the daughter, who had, with brief respites, kept vigil at her father's bedside since his admission. Through my initial conversation with her, several signposts marking the terrain of her story became evident. She was an only child, was single, and felt a deep sense of obligation to her parents. A year ago she moved nearby from another state to take care of them, and she was now experienced in the daily hard work of caregiving. And her tone indicated that she may well have felt some responsibility for her father's predicament. Although she did not say so explicitly, her father fell “on her watch.”

A second marker in the daughter's narrative was that she was until recently engaged professionally with rehabilitating children with injuries. Not only did she move her residence in order to care for her aging parents, but she also gave up a career in her mid-fifties to satisfy these filial duties. Given her knowledge of rehabilitation processes, she felt she had some warrant to speak about her father's prognosis. And yet her experience was entirely with children, none of whom were as severely compromised as Mr. Bush. (A bedside nurse later explained that she had discussed the differences in prognosis between injuries in children and trauma in the elderly with the daughter several times but with no sense of uptake.)

A third and more complex turn in the narrative was that Mr. Bush had completed advance care planning. He had both a living will and a durable power of attorney for health care. On his admission, the daughter had indicated the presence of these documents but kept them in her possession. As her father's condition worsened, she decided not to show them to the health care team or talk about their contents for fear they would be used against her and com-

promise her father's care. "I wish they could be shredded," she said. She refused to give them to me as well. She was willing to let me read them in her presence but not to make copies.

They were the standard advance care planning forms, duly executed, with signatures of witnesses in place and properly notarized. Mr. Bush's initials were scratched into his signature line. The intent of the documents was clear: to forgo life-sustaining treatment in situations just like this. What to make of the authenticity of such a document from a person with progressed Alzheimer's disease became the new puzzle within the old one. The date on the forms was barely a year earlier. Moreover, the durable power of attorney named the spouse as the surrogate, and she had already been informally disqualified from acting in this capacity. "Do you think this is an accurate indication of your father's wishes?" I asked. "No," she replied, "I don't think he knew what he was doing, and I am sorry we ever did this." "We all hope for improvement," I said, "but it may not happen. Do you think your dad would want to be sustained in his current state?" Her reply startled me. "People are waiting on him here. He always liked being waited on. He enjoyed that sort of attention."

Sometimes the rituals of caring persist even when the acts of caring have no conscious recipient, no possibility of being knowingly received as care. That seemed very likely here. Yet in the presence of caring, interrogation of its logic can seem out of place. So I decided, rightly or wrongly, not to probe then with the next obvious question: "What if he is not able to experience being waited on? Would that count?" I couldn't find it in me to pose this further question to her, one I would have immediately launched toward graduate or medical students. There is educational value to ethics consultations, but this woman was not my student, and she had trusted me with information she had denied to others. More important, she had entrusted me with some of her story, a narrative that, whatever else I made of it, I could not ignore or discount. In that fifty-minute conversation, she had ceased to be a "case" or a "problem family member in denial" and become a real person. I had, in the middle of our conversation, begun to call her Sara.

Responsibilities Arising from Attention to Narratives

I then silently considered a worrisome set of questions—a private sidebar narrative. Should I ask the daughter for permission to reveal the contents of the advance care planning documents to the health care team? As an advocate of "best care" for this patient, was it my responsibility to speak with the professional caregivers, with or without her permission? Would the clinicians find in these documents too easy a confirmation of the course of action they

thought most advisable? Most ethics consultants can recount many cases in which family ignored advance care planning documents, sometimes because they disagreed with them, sometimes because they felt it would be like giving up, sometimes because their courage failed in spite of their best intentions. By failing to discuss my findings with the health care team, was I becoming complicit in yet another such family failure to honor what the patient wanted? Would these advance care documents now simply be irrelevant, given the patient's prognosis? And if relevant, did they have a shred of validity? After a pause, I asked the daughter: "You are facing such a tough decision here. Can I discuss the contents of these documents with the medical team? I think it may be helpful to them, and perhaps also to you." "Okay," she said, to my surprise and relief. The relevance of these documents, or lack of it, could now become an explicit part of any future conversations, making communication more transparent.

At this point I took my leave, and following instinct rather than protocol, I said, "God bless you." My own theological convictions are too skeptical to imply any concrete meaning to this departing gesture, but something about crisis and habit seem to push this phrase out of me in consult work. More than anything, perhaps, it's a token of empathy and regard for a fellow human being.

Simply being an auditor to Sara's story and participating in this modest interaction with her placed me in a changed relationship with her. Knowing even a few parts of her larger story, I couldn't ignore them. The poverty of principled ethics, when taken alone, is that they flatten out this fragile sense of belonging to, protecting, and honoring another person's story. When they flatten narratives of care, the loss is all the more damaging. Even if I might choose differently for my own parents (in fact, I did), I now knew something about who this daughter was in relation to her father, how her sense of helping him now at a margin of his life was ultimately rooted in her love for him, and how her sense of self was grounded in that affection. This rootedness did not, of course, make her choices "right," but beneficent motivation should always, at least, give us pause in thinking we know better. To approach the medical team about the advance care documents without her permission would have been in some sense to betray her and to betray whatever sense of his own well-being her father might have held, influenced as he likely was by her care for him over the last year and, indeed, by her concern for him over many years of her adult life. Narrative is a profound mode for understanding ethics consultation, not because it resolves problems, but because it forces us to attend to the human voices, including our own, behind what is being said.

Hermeneutical Humility

This was not a particularly difficult consult, as consults go. Many others have included more complex problems, more angst and frustration. The most vexing are drawn out over weeks and, on rare occasions, even months. I chose this consult experience because it is more or less typical and has various narrative threads that can be displayed in a few pages.

I am acutely aware that this is my story, told from the point of view of an ethics consultant with certain framing assumptions and agendas and also colored and shaped by my history, both professional and personal. I am therefore reticent to declare the outcome good or bad, successful or unsuccessful, with regard to the problems that occasioned my being called. I think and hope that communication was improved because of my presence, and perhaps that is an inherent good as well as an instrumental one. But whether and how decision-making was improved is an open question. I am also agnostic about whether the “best care” for Mr. Bush was realized. “Best” always presupposes some goal, and goals are a function of which narrative is accredited or becomes dominant.

In this case, the daughter’s narrative was dominant, and so within a few days, Mr. Bush received a PEG and a tracheostomy and was discharged to a long-term, acute care facility. Some, including members of the ICU team, might count this as a failure, but I think this judgment presumes too much. My hope was that with a little more time, Sara was able to let her father go. Ethics consultants typically do not know how cases resolve; they work for institutions, not patients or their families. But whatever the outcome, an attitude of robust pluralism in ethics seems best. Practicing ethics is not like finding universally correct answers in the back of the math book. It is more like muddling through, doing what is possible, and often trying to find the least harmful alternative in tragic situations. Indeed, the point of being narratively aware as a consultant is to resist the temptation to adopt a privileged position that assumes I know what is best, or even that I know the

right ethical methods or processes for each situation. Often ethics consultation is an effort to help patients, families, or professionals to locate, interrogate, and finally to trust their own moral resources while also seeking some measure of convergence with the other stakeholders. One measure of success in an ethics consultation might be that the key actors find the courage to be decisive without the pretense of being definitive.

Since as a consultant I am never free of a narrating role or an interpretive task (including this narration and its interpretation), and since I never move beyond these to a clear and determinative moral assurance, humility is always needed, always a virtue. In *Core Competencies for Health Care Ethics Consultation*, the American Society for Bioethics and Humanities notes humility in passing; I would make it a foundational moral trait for consulting work.⁴

1. Among many other works, see R. Charon, *Narrative Medicine: Honoring the Stories of Illness* (New York: Oxford, 2006); R. Charon and M. Montello, *Stories Matter: The Role of Narrative in Medical Ethics* (New York: Routledge, 2002); H. Brody, *Stories of Sickness* (New Haven, CT: Yale, 1987); and the journal *Literature and Medicine*, especially volumes 7 (1988) and 10 (1991).

2. Some exceptions are M. Walker, “Keeping Moral Spaces Open: New Images of Ethics Consulting,” *Hastings Center Report* 23, no. 2 (1993): 33-40; R. Charon “Narrative Contributions to Medical Ethics: Recognition, Formulation, Interpretation and Validation in the Practice of the Ethicist,” in *A Matter of Principles? Ferment in U.S. Bioethics*, ed. E. DuBose, R. Hamel, and L. O’Connell (Valley Forge, PA: Trinity Press International, 1994), 260-83; and E. DeRenzo and M. Strauss, “A Feminist Model for Clinical Ethics Consultation: Increasing Attention to Context and Narrative,” *HEC Forum* 9, no. 3 (1997): 212-27.

3. See also S. Poirier, “Voice in the Medical Narrative,” in *Stories Matter: The Role of Narrative in Medical Ethics*, ed. R. Charon and M. Montello (New York: Routledge, 2002), 48-58.

4. American Society for Bioethics and Humanities, *Core Competencies for Health Care Ethics Consultation*, 2nd ed. (Glenview, IL: American Society for Bioethics and Humanities, 2011), 32. See also L. Churchill, “Are We Professionals? A Critical Look at the Social Role of Bioethicists,” *Daedalus* 128, no. 4 (1999): 253-74, and J. Coulehan, “On Humility,” *Annals of Internal Medicine* 153 (2010): 200-201.