Bioethics and Human Experience

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The dominant way in which the medical humanities have contributed to applied ethics has been through the use of narrative, in general, and the notion of the life story, in particular. Rather than simply valorizing the narrative approach to medical ethics, I would like to point to some substantial theoretical problems that I think need to be addressed.

Let me begin with a prosaic example—the recounting of a story of a movie. For someone trying to find details about movies, the Internet Movie Database (IMDB) is an exceptional resource. At this Web site, one can find a film's full cast and crew, trivia, trailers, photo gallery, and writing credits. One can also find plot summaries. Interestingly, some films have more than one plot summary, for IMDB—in a manner typical of the anti-authoritarian leanings of the Internet—permits anyone to add a plot summary to a film's listing.

Look, for example, at two plot summaries for the film *Eternal Sunshine of the Spotless Mind.* One summary says, "A man awakes disheveled. Impulsively, he skips work, heading instead to the shore. On this chilly February day, a woman in orange, hair dyed blue, chats him up. She's Clementine. He's Joel, shy and sad. By day's end, he likes her. The next night, she takes him to the frozen Charles River. As he drops her off, she asks to sleep at his place, and she runs up to get her toothbrush. Strange things occur. Their meeting was not entirely by chance, and they have a history neither remembers. Our seeing how Lacuna came to be and their discovery of the memory loss take the rest of the film."

Here is another plot summary. "This is a story of a guy, Joel, who discovers that his longtime girlfriend, Clementine, has undergone a psychiatrist's experimental procedure in which all of her memory of Joel is removed, after the couple has tried for years to get their relationship working fluidly. Frustrated by the idea of still being in love with a woman who doesn't remember their time together, Joel agrees to undergo the procedure as well, to erase his memories of Clementine. The film, which takes place mostly within Joel's mind, follows his memories of Clementine backwards in time as each recent memory is replaced and the procedure then goes on to the previous one, which is likewise seen and then erased. Once the process starts, however, Joel realizes he doesn't really want to forget Clementine, so he starts smuggling her away into parts of his memory where she doesn't belong, which alters other things about his memory as well."

These two summaries are quite different. Although some overlap exists in characters and the themes of romantic relationship and memory loss, each of the authors relates the story in a distinct way. Such divergences have been accounted for by narrative theorists as having their origin in the differences between the basic story material, or what the Russian formalists referred to as *fabula,* and the particular presentational mode used within a specific narration, or *sjuzet.*

For narrative theorists, this distinction is particularly important when analyzing narratives that rely on their rhetorical effect by playing with the time sequence, as does the film *Eternal Sunshine of the Spotless Mind.* Thus, from a traditional narratological perspective, both tellings share an essential *fabula* and the deviations are simply the result of having different *sjuzets*.

Narrative theorist Wallace Martin notes that while conceptually such a distinction permits one to talk about the narratological rhetoric of a particular telling, it

"is achieved at a certain price: it implies that what the narrator is really telling is a chronological story—one that the reader tries to reconstruct in the right temporal order—and that the elements of narration are deviations from a simple tale that existed beforehand."[1]

This criticism of narrative theory has been most seriously presented by Barbara Herrnstein Smith. In her often cited essay "Narrative Versions, Narrative Theories," she notes that, "a lingering strain of naive Platonism" has been an ongoing feature of contemporary narrative theory.[2]

Such distinctions between *fabula* and *sjuzet* encompass a belief that there is a "basic story" or a "deep structure" that is "independent of any of its versions, independent of any surface manifestation or expression in any material form, mode, or medium—and thus presumably also independent of any teller or occasion of telling and therefore of any human purposes, perception, actions, or interactions."[2] In short, there exists somewhere a versionless version.

In order to naturalize narrative ethics, one must attend not to stories, but to storytelling.

Yet, Smith counters, the attempt by narrative theorists to find the deep structure of fairy tales is itself a fairy tale. She looks, for example, at the supposed unity of the various versions that have been cited for the story of Cinderella, which were at one time catalogued as having 345 variants.

The "basic story" of the narrative theorist is not so much a master narrative as it is a particular telling that is conditioned by the purpose of relating the narrative. Smith is not saying that there is no association between one story and another, but rather that there is little evidence to believe that there is some *fabula*, some basic narrative structure that exists outside of particular tellings.

It is my contention that in order to naturalize narrative medical ethics, one must attend not to stories, but to storytelling. That is, one must understand that stories do not exist to be "found," but are continually engaged in rhetorical work.

In *After Virtue: A Study in Moral Theory*, moral philosopher Alasdair MacIntyre argues that one of the essential qualities of the human animal to function as an agent is the ability to see oneself within a story.[3] Lacking the ability to construct such a narrative leaves one unable to make sense of one's actions as well those around one, so MacIntyre comes to conclude that the human agent is "not only an actor, but an author."[3]

The most important authoring that we can do is to be able to understand our life as functioning within a narrative whole. It is only with a narrative sense of the self—that is, one that maintains some degree of cohesion over time—that the self can be considered accountable for actions in the world.

Margaret Urban Walker, a philosopher and ethical theorist, points out that, "Narrative understanding of the moral construction (and reconstruction) of lives is central to understanding how responsibilities are kept coherent and sustainable over substantial stretches of life that, in important—but not imperial—ways, remain people's own."[4]

Lacking a life story, one would have what philosopher Charles Taylor refers to as the "punctual self," a person who has the ability of self-consciousness, but nothing else.[5] This Lockean notion of the self lacks a narrative sense of being in time and, thus, oriented to some good. A narrative self for Taylor permits an orientation within moral space that is analogous to our ability to be oriented in physical space. "We determine what we are by what we have become, by the story of how we got there."[5]

Although Walker is drawn to the utility of narrative in moral understanding, she finds the notion of "dominant identities" as simply too all-inclusive to represent accurately our moral lives. "There are . . . reasons not to assume that such story lines are, can be, or should be global or largely unified or strictly continuous. Can one imagine a totally or maximally unified life?"[4] Such a notion Walker finds to be either "desperately simple or intolerably suffocating."[4]

As the use of the personal narrative was translated from moral philosophy to the applied arena of medical ethics, the particular type of personal narrative shifted from a concern with the autobiography to the third-person genre of the biography. For the moral philosopher, the autobiography becomes a genre tool for responding to the questions, "What is the good? What narrative am I a part of? How should I live my life?" For medical ethicists, the question is not inward toward understanding personal authenticity, but rather outward in a more Levinasean manner toward authentically responding to the needs of another. The moral philosopher asks, "What is my story?" The medical ethicist asks, "What is this person's story?"

In 1990, the journal *Second Opinion* began a new series called "Case Stories." The editors of the series, Steven Miles and Kathryn Montgomery, began by noting that because "human understanding is grounded in narrative, ethics has always been in some sense a storytelling enterprise."[6] In a later discussion of these issues, Miles and Montgomery focus on storytelling as "the substance of communication within families and between friends, lovers, doctors, and patients. Telling, hearing, and interpretively retelling stories is how people come to understand themselves and each other and appreciate their duties to one another."[7]

The first case that they selected concerned a woman who died alone in a hospital. Miles begins his description by revealing his source.

"This is not a proper biography. I did not know Margaret Hull. I talked to no one who knew her, except for the brief professional contacts on the day of her death. I found her story by extracting data from the medical record. Her 'chart' took up six thick binders

describing 14 hospitalizations, 73 clinic visits, 21 emergency room visits, and innumerable laboratory reports and administrative procedures."

The lengthy collection of notes does not narrate a story. An astute medical student is the only person to record the notable onset of a potentially life-threatening cardiac arrhythmia seven years after the fact. A nurse notes the patient's fear the night before cancer surgery. These are recorded as data, not as human history. These moments suggest the outline of a coherent story. That Margaret Hull's story was lost at the medicalized end of her life shows how alienated medical conceptions of our duties to others have become.[6]

As Miles himself admits, there are no instances of storytelling from which he gains Hull's narrative. The data for his analysis come from the chart notes, which do not narrate a story. But there remains in Miles' account a belief in the existence of a particular story, a particular biography of Margaret Hull that has been lost by medicine.

Miles envisions that, like the narrative theorist's *fabula*, all these fragments are part of a disembodied story that lies in wait for his discovery. Miles is the teller, but also, from his perspective, the story he tells is simply the story he finds. In the end, we see from Montgomery's final discussion of their narrative ethics project that it is not storytelling that interests them or guides more reflection as much as it is a belief in a patient's life story.

Montgomery argues that our identity is itself the life story. She seems attentive to the way someone's story will be a particular interpretation of the events of his or her life, and this includes the moral problem that brings the person to the attention of an ethicist. Yet there lingers within her view a belief that there is a story to be found.

Returning to MacIntyre, we find that narrative exists outside of human construction. "Narrative is not the work of poets, dramatists, and novelists reflecting upon events which had no narrative order before one was imposed by the singer or the writer; narrative form is neither disguise nor decoration."[3] In her discussion of MacIntyre's approach, Hilde Lindemann Nelson argues that MacIntyre fundamentally misunderstands what a story is. That is, it is constructed "by selecting incidents and themes from the minutiae of our existence and explaining their importance by how we represent them in narrative form. Autobiography, then, isn't life."[8]

And neither is biography. MacIntyre is aware that there can be opposition to his position, and he quotes Louis Mink: "Stories are not lived but told. Lives have no beginnings, middles, or ends; there are meetings but the start of an affair belongs to the story we tell ourselves later, and there are partings, but final partings only in the story."[3]

MacIntyre responds by noting that the fact that there is death demonstrates that life naturally has a narrative ending. It is difficult, however, to see the event of the end of life as being the same thing as the end of a narrative. MacIntyre has an even more difficult time justifying how life has genres outside of a particular telling.

But within conventional storytelling activities, are the genres of biographies and autobiographies natural forms of storytelling? I'm using "natural" here not in opposition to unnatural storytelling, but rather as the social linguist William Labov and the narratologist Monika Fludernik use it—that is, in opposition to storytelling that is nonspontaneous, highly framed, and stylized. Fludernik observes that, "It is from this angle that some cognitive parameters can be regarded as 'natural' in the sense of 'naturally occurring' or constitutive of prototypical human experience."[9]

Although it may seem that natural narratives encompass all forms of oral storytelling, Fludernik confines the notion to spontaneous, conversational storytelling, which is distinct from formal oral telling genres such as folk tales and oral poetry. These oral genres "constitute a more literary (i.e., institutionalized) form of storytelling," and thus, they depend on "different kinds of competence and performance levels from those sufficient for everyday spontaneous conversation."[9]

Fludernik identifies three genres of natural narratives: experiential conversational storytelling, narrative report, and anecdotes, as well as three nonspontaneous types: folkloristic oral storytelling, epic poetry, and life story. The fact that she categorized life story as an institutionalized form of narrative and, thus, one that is not a natural form should be of particular interest to those who wish to use narrative in the analysis of moral issues.

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Fludernik begins her discussion of the life story by noting that it can occur during "spontaneous conversation."[9] But her Norman Rockwell–like parenthetical example, which is, "Granny, I've always wanted to ask what happened to you during the war," is something I never said to my grandmother. It is clearly not an example of autobiography, but instead a type of memoir. Even in instances in which the life story is told in a very distinct institutionalized form as, for instance, the common activity in Alcoholics Anonymous of telling one's story, it is the experience of recovery that becomes the fulcrum that gives structure to the storytelling event.

Fludernik notes that the most common form of life story genre occurs in the very nonspontaneous genre of the ethnographic field worker trying to collect oral histories. Fludernik admits that, "The life story obviously is no complete autobiography. Very rarely, indeed, is there a situation in which people will be led to narrate their entire life from their birth to the present moment."[9] Instead, it is

the academic who creates a genre that in some manner pretends to be an example of a spontaneous storytelling genre.

Although many people may keep journals or diaries, I doubt many people write autobiographies without an intended audience outside of the self. In other words, life stories should be viewed as performative events that always involve an act of communication between people.

Naturalized narrative ethics must not simply attend to the story, but most also ask questions concerning the relationship between the narrative event and the narrated event.

In *The Wounded Storyteller: Body, Illness and Ethics,* Arthur Frank comes closest to analyzing a natural narrative of medical ethics.[10] Frank has been critical of how bioethicists, including those interested in attending to narrative, continually attend primarily to the stories of health care professionals rather than to patients. We have an ethical obligation, according to Frank, to listen to these illness stories. Frank sees illness itself as a call for stories. He means this in two ways. First, becoming ill demands that one recreate one's self-story, which can be profoundly damaged by the onset of the illness. Second, an ill person is literally asked to engage in storytelling to people around him or her. "Stories of the illness have to be told to medical workers, health bureaucrats, employers and work associates, family and friends. Whether ill people want to tell stories or not, illness calls for stories."[10] Frank recalls how, when he had an abnormal chest X-ray, he had to on one day tell a version of his illness story eight times.[10]

Frank's analysis focuses primarily on institutionalized storytelling of the memoir and the autobiography, which tend to be sites for narrative self-repair, rather than for natural storytelling events. Yet Frank is keenly attuned to the performative dimensions of storytelling. This can be seen in his notion of a narrative ethic that focuses on "thinking with stories," which entails, "allowing one's own thoughts to adopt the story's imminent logic of causality, its temporality, and its narrative tensions."[10] For Frank, this process "requires attending to how a story is used on several different occasions of its telling."[10] Stories are not merely told, but retold. And, in a Heraclitus-like manner, one never tells the same story twice.

A natural narrative ethic attends to the use of stories as a rhetorical tool, rather than simply as part of a general life story. In order to reveal the rhetorical features of storytelling within medical ethics, one must attend to such questions as, "What is the point of telling the story?" One must guard against the desire to create a single unitary narrative out of the storytelling performances, and, instead, keep the storytelling grounded in its rhetorical situation.

Medical ethicists who are interested in using a narrative approach tend to try to combine all the small natural narratives into a single master narrative. They tend to see the true narrative as simply lying "out there" waiting to be found and collected, rather than as entangled within social events. Naturalized narrative ethics must not simply attend to the story, but must also ask questions concerning the relationship between the narrative event and the narrated event—that is, reveal the rhetoric of the telling. Who told the story? When was the story told? Where was it told? What was the conversational frame in which the story was evoked? To whom was it told? What was the teller trying to do with the story? Has the story been told before? Does the story relate to other storytelling events?

By answering these questions, we begin to thwart any attempt at the construction of a single narrative. Instead, we keep the stories embedded in the ongoing social life of the people involved in the medical decision. It forces us to attend to the way stories are naturally evoked in medical ethics decisions.

These questions demand that we attend to the power struggles within the decision-making. When medical ethicists construct the patient story, they are themselves simply another part of this ongoing exchange of stories, for they are also engaging in a rhetorical move that attempts through a storytelling performance to alter the shape of the decision. It is only by moving from a concern with stories to an integration of storytelling that we can naturalize narrative medical ethics and thus bring it closer to human experience.

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