Chapter 10
The Ethics of Self-Care

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Abstract The medical academy’s primary ethical imperative may be to care for others, but this imperative is meaningless if divorced from the imperative to care for oneself. How can we hope to care for others if we, ourselves, are crippled by ill health, burnout, or resentment? The self-care imperative, however, is almost entirely ignored by medical academicians and professional ethicists. Indeed, biomedical ethics focuses almost exclusively on the application of universal ethical principles to the treatment of patients and the protection of research subjects, discounting, even hindering, the introspection essential to the practice of ethical self-care. If we are to heed the self-care imperative, medical academicians must turn to an ethics that not only encourages, but even demands care of the self. We must turn to narrative ethics. Since narrative is central to the understanding, creation, and recreation of ourselves, we can truly care for ourselves only by attending to our self-creating stories. Narrative ethics brings these stories to our attention; so doing, it allows us to honor the self-care imperative.

Keywords Ethics clinical, ethics medical, ethics research, principle-based ethics, narrative medicine, narrative ethics

We are ethically obligated to care for ourselves. This, I believe, is incontrovertible. Our primary ethical imperative may be to care for others, but this imperative is meaningless, empty, if divorced from the imperative to care for oneself. Indeed, we may grant, with Emmanuel Levinas, that the imperative to care for others is the “primordial, irreducible, and ethical, anthropological category” [1, p. 158]. We may even grant that this imperative is so powerful, so fundamental, that one’s response, as Levinas scholar Richard Cohen writes, “goes all the way to giving the very self of the self” [2, p. 294]. Yet I cannot give myself if I have no self to give. I must care

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for my hands, if I am to lift the fallen; my heart, if I am to love the stranger; my mind, if I am to cure the ill; my eyes, if I am to find the lost, and my soul, if I am to guide them home. No matter how it is conceived—philosophically, theologically, psychologically—the imperative to care for others is always already an imperative to care for myself.

Unfortunately, biomedical ethics focuses almost exclusively on the application of universal ethical principles to the treatment of patients and the protection of research subjects, thus discounting, even hindering, the introspection essential to the practice of ethical self-care. As I will show below, if we are to heed the self-care imperative, medical academicians must turn to an ethics that not only encourages, but even demands care of the self. We must turn to narrative ethics. Since narrative is central to the understanding, creation, and recreation of ourselves, we can truly care for ourselves only by attending to our self-creating stories. Narrative ethics brings these stories to our attention; so doing, it allows us to honor the self-care imperative.

Spaceship Ethics

For clinicians and researchers in academic medicine, professionally dedicated to addressing “the inevitable and preemptory ethical problem” of suffering (the other’s demand for aid) [1, p. 158], the self-care imperative should be particularly compelling. Too often, however, this imperative remains entirely unheeded. As the demands on medical academicians grow greater and greater, evidence of burnout, ill health, and resentment also increases [3]. Much is written about the professional ethics of clinical care and medical research, but virtually none of this writing concerns the ethics of self-care. Rather, ethical discourse focuses on the treatment of patients and the protection of research subjects. Certainly, too much can never be written about the ethics of clinical care and the ethics of research, but unless attention is also paid to the ethics of self-care, ethical discourse for medical academicians is missing its essential third leg, without which it must remain perpetually off-balance and thus prone to collapse.

This lack of balance is perhaps most evident in the way the medical academy trains its initiates. Physicians- and researchers-in-training are generally offered little if any instruction in the care of the self, let alone its ethical implications. In fact, what they are taught, both implicitly, by observing their instructors’ behavior, and explicitly, in courses on clinical conduct, is that they are to take themselves entirely out of the equation. Their personal thoughts, feelings, embodiment simply do not matter, do not figure at all in the clinical or research equation. Yet without honest self-reflection—without turning one’s attention explicitly to one’s body, emotions, thought—ethical self-care is impossible. Rather than learning to care for themselves, in ethically sound ways, students learn, in effect, that self-care is immoral.

This suppression of self-care was brought home to me in a particularly poignant way by a story written by a fourth-year medical student, Ashley, for an elective
ethics course she took with me. Ashley’s story was about an experience she had had almost two years earlier, as a third-year medical student, on the first morning of her first inpatient rotation. Early that morning, a patient named Mary was admitted to Ashley’s hospital floor. Mary, who was not much older than Ashley, had been hospitalized with sepsis, caused by immune suppression from chemotherapy. Shortly after arriving on the floor, Mary developed Acute Respiratory Distress Syndrome. The entire team ran to her room, and the Chief Resident told Ashley to sit by the bed and encourage Mary to relax. For more than 5 hours, while residents and attendings ran in and out of the room doing everything in their power to arrest Mary’s respiratory decline, Ashley held Mary’s hand, repeating, over and over again, “Just breath. Relax, it’s going to be okay. Breath. Please try to relax. We’re all here for you. Just breath.” When Mary stopped breathing, the Chief Resident pushed Ashley away from the bed, and he and the rest of the team began the code. Death was declared several minutes later. The team abruptly left the room, leaving Ashley alone with Mary’s battered body. No one ever spoke to her about Mary’s death.

When Ashley finished reading her story to me, she looked up and said, through her tears and without irony, “I just wish I’d been able to do something for Mary, like everyone else. I felt so helpless. Just useless and in the way.” In the two years since Mary’s death, Ashley had never shared this story with anyone at her school.

Ashley was well-schooled in the four “principles” of biomedical ethics: she understood her obligation to respect Mary’s freedom of choice (autonomy), her obligation not to harm Mary in any avoidable way (nonmaleficence), her obligation to help Mary in every possible way (beneficence), and her obligation to provide all the care to which Mary was entitled (justice). Yet understanding all these principles did not help Ashley, in practice. Her ethics education was too abstract to help her work through this particular case—the specific, lived experience of her sense of responsibility to her patient and to herself. She understood how the principles of biomedical ethics apply to patients in general, but Mary was not a patient in general. Ashley’s training offered no guidance or solace in working through her deep sense of moral failure, let alone her grief, following Mary’s death.

The problem is not that Ashley’s understanding of the four principles was inadequate; the problem is with the principles themselves. Or rather, with ethics curricula that rely exclusively on principle-based reasoning. The inadequacy of such curricula is increasingly manifest. As Rita Charon writes, “Over the past decade, conventional bioethics has struggled to find its way among its chosen principles and has found itself too thin to address adequately the actual value conflicts that arise in illness” [4, p. 208].1 Barbara Nicholas and Grant Gillett argue that a principle-based ethics, or “principilism,” not only raises “philosophical difficulties with criteria for application of the principles” and “problems with how one resolves conflict between principles,” but also engenders “an unease among practitioners arising from the realization that the realities and practicalities of clinical practice are not paid sufficient attention” [6]. Indeed, as John O’Toole contends, principle-based

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1 See also [5].
ethics "lays siege to our very ability to act out the ethical dramas we will face daily as physicians," and thus "serves only to further disconnect the medical student from the human experience" [7]. This disconnection from human experience is twofold: it alienates medical students (and researchers, and residents, and all other medical academicians) both from the patient’s experience and from their own.²

Biomedical ethics training thus fosters the medical academy’s hostility to introspection, making it all the more difficult to conceptualize, let alone practice, ethical self-care.³ By employing abstract, one-size-fits-all, deductive reasoning, which argues from general principles down to particular cases, principlism teaches medical academicians to master ethics "cases" in the same way they master proofs in logic or "problems" in biochemistry, physics, and statistics. Principlism reinforces a sense of invulnerability, of detachment, of domination, imposing a "unifying general view," as Arthur Frank puts it [9, p. 13], on all experience and thus bringing it under control. In this regard, Frank finds William James’s self-condemnation of his own "unholy" ambition particularly revelatory:

I am convinced that the desire to formulate truths is a virulent disease. It has contracted an alliance lately in me with a feverish personal ambition, which I never had before, and which I recognize as an unholy thing in such a connection. I actually dread to die until I have settled the Universe’s hash in one more book ...! Childish idiot—as if formulas about the Universe could ruffle its majesty. [10, p. 1344]

James’s "disease," Frank contends, is characteristic of the "modernist universalism" of the medical academy: "To settle the Universe’s hash is to place oneself outside the vulnerability and contingency that being in the Universe involves. The intellectual infected with such an ambition ceases to think of himself as a body, thus disclaiming the vulnerability that bodies share" [9, p. 19]. Unfortunately, disclaiming one’s vulnerability does not make one invulnerable. Indeed, ceasing to think of oneself as a body only makes it that much more difficult to address the injuries, illnesses, stresses, weaknesses, and exhaustion that we all, as embodied beings, must inevitably face. The modernist universalism of biomedical ethics thus magnifies the harms we suffer as embodied beings: refusing to acknowledge them, we only make them worse, allowing them to fester and grow, unchecked. Modernist universalism, Frank writes, is itself a diseased drive—the drive to be "the beginning and end of all things": this is the "weight modernity puts on its heroes. Physicians feel this weight" [9, p. 153]. Far from questioning the morality of modernist heroics, and thus helping to lift its burden, ethics, as traditionally practiced in the medical academy, piles on more weight. By adopting the universalist view of modernism, principlist ethics places us above, outside of, beyond the specific, lived reality of our embodied experience. It turns us away from self-care, thus making us all the more unhealthy.

²As Suzanne Poirier writes, “The inability of many ethics discussions to address the personal values or feelings that often undergird ethical dilemmas suggests that the desire to deny or bury the personal voice under a formalized professional one may limit expression that is valuable to the conversation of bioethics” [8, pp. 57–58].

³"Professional culture has little space for personal becoming. Young doctors are not trained to think of the careers ahead of them as trajectories of their own moral development" [9, p. 159].
Asked to assume a burden impossible to bear, physicians and researchers develop coping mechanisms, Frank asserts, that “can warp an otherwise decent mind” [9, p. 147]. He demonstrates this with a quotation reported by Charles Bosk. During his research on physicians who are genetic counselors, Bosk asked one of his subjects how he “came to grips with all the ‘accidents’ or ‘mistakes’ [of medical practice] that he saw.” Following is the physician’s response:

What you have to do is this, Bosk. When you get up in the morning, pretend your car is a spaceship. Tell yourself you are going to visit another planet. You say, “On that planet terrible things happen, but they don’t happen on my planet. They only happen on that planet I take my spaceship to each morning”. [11, p. 171]

The implication, of course, is that the “terrible things” happening on the hospital planet trouble only its natives (the patients), not the physicians, who are, after all, only visitors. Physicians believe that they are protected from all that happens there, shielded by the principles of biomedical ethics, which we might now rename “space-ship ethics.” These principles allow physicians like the one interviewed by Bosk to place themselves outside of their patients lives. Indeed, the spaceship they travel in is the universalist perspective we examined above. The irony is that these universal principles of biomedical ethics, as we saw, only serve to increase the burden of modernist heroics, an increase that drives physicians to take further refuge in the principles, still further increasing the burden. It is a vicious circle—a relentless, ever widening orbit between two hostile planets (self/home vs. other/work). Once they climb into their spaceships, medical academicians are doomed to a life unmoored—lost in space—as they drift further and further away both from themselves and from others. It is no wonder Ashley was left to her own devices: the rest of the crew was already in orbit. Their behavior was alien to Ashley (and Ashley’s needs alien to them) because she had not yet learned to leave her self behind; consequently, she could not yet pretend that she had not been affected by Mary’s death.

Narrative Ethics

Given the predominance of spaceship ethics, how could Ashley hope to learn to care for herself? How could she face the traumas of her work—face them directly, honestly, ethically—if her work is utterly separate from her life, alienated from the familiar, homely life of her feelings, her embodiment? Is she doomed to climb on

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4 “According to modernist universalism, the greatest responsibility to all patients is achieved when the professional places adherence to the profession before the particular demands of any individual patient. Such professionalism—paradigmatic of modernity—is responsible less to individual people than to truth” [9, pp. 15–16]. Of course, the “individual people” that professionalism holds hostage to the “truth” includes the professionals themselves.

5 As Martha Nussbaum writes, “Our cognitive activity centrally involves emotional response. We discover what we think ... partly by noticing how we feel; our investigation of our emotional geography is a major part of our search for self-knowledge” [12, p. 15].
board—doomed to a voyage utterly alien to self-care—or is there an alternative to this cold, orbital drift into space?

The answer, I believe, lies in Ashley’s story—or rather, in her act of storytelling itself. In this act we discover an ethical alternative that not only encourages, but even demands care of the self. In storytelling, we discover narrative ethics, an ethics that “lightens the load on people,” [9, p. 153] that is “reciprocal and reflective, [demanding] vision and courage, all the while replenishing one’s store of vision and courage” [13, p. xii].

Stories are the primordial means through which we make sense and convey the meaning of our lives. Our very selves, Frank writes, “are perpetually recreated in stories. Stories do not simply describe the self; they are the self’s medium of being” [9, p. 53]. As the universalist notions of modernism are challenged by postmodern thinkers, the power of narrative to create, express, and recreate the *unique* reality of the self—its irreducible, inassimilable particularity—has become increasingly manifest: “Postmodern times are when the capacity for telling one’s own story is reclaimed … when people’s own stories are no longer told as secondary but have their own primary importance” [9, p. 7]. This primacy is acknowledged across diverse disciplines. Indeed, “[h]istorians, cognitive psychologists, social scientists, theologians, psychiatrists, and literary critics,” Charon and Montello note, have all “come to recognize the central role that narrative plays in the way we construct knowledge, interpret experience, and define the right and the good” [13, p. x].

If narrative is central to our construction of knowledge, our interpretation of experience, and our definition of the right and the good, it stands to reason that it is indispensable to moral inquiry [9, 13]. One cannot hope, after all, to recognize, illuminate, and resolve moral dilemmas without considering the narratives—the very medium of our *being*—in which those dilemmas live [14]. A biomedical ethics based in narrative would engage every level of our being, including and perhaps especially our emotional life, immeasurably deepening our moral sensitivity. Narrative bioethics, therefore, “would look beyond a calculus of principle and reason. It would require us to account for the emotion so crucial to ethical action and to the ways in which stories work on us” [15, p. 210].

As we saw above, Ashley could not understand the meaning of her experience at Mary’s bedside until she had written and shared her story. Before this, Ashley’s moral view was circumscribed by the universalist principles of her medical training—principles with which she could not possibly make sense of her role in Mary’s

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6“Narrative is often indispensable in helping us grasp what our deepest values are. … In contrast to principle alone, narrative in its detailed, emotion-rich representation of experience can help us recognize implicit values and negotiate conflicts of moral action” [15, pp. 212–213] See also [16].

7Narratives, Hilde Lindemann Nelson writes, “cultivate our moral emotions and refine our moral perception; … they teach us our responsibilities; they motivate, guide, and justify our actions” [17, p. 47].
death. Writing and reading her story, as I’ll make clear below, allowed Ashley to re-interpret her role, to “define the right and the good,” to value her experience in the context of a much broader ethical horizon—a horizon that embraced her particular, lived, emotional experience as a medical student, a young woman, a caring human being.

Looking beyond principle and reason, we find the wellspring of meaning, in all its glorious complexity, ambiguity, superfluity. This narrative source is beyond the grasp of our technical mastery. We can never get behind or above the act of storytelling, can never obtain a comprehensive view, can never fully account for it, master it, because it is the very condition of all accounting, all meaning. Attending to narrative, we challenge the technical mastery through which we dominate reality, and we engage questions of right and wrong with humility, nurturing our connection both to others and to ourselves—to our shared humanity. Sayantani DasGupta has coined the phrase “narrative humility” to highlight the way narrative moves us out of the mastery so damaging to ourselves, our patients, and our research subjects: “Narrative humility,” she writes, “acknowledges that our patients’ stories are not objects that we can comprehend or master, but rather dynamic entities that we can approach and engage with, while simultaneously remaining open to their ambiguity and contradiction, and engaging in constant self-evaluation and self-critique about issues such as our own role in the story, our expectations of the story, our responsibilities to the story, and our identifications with the story—how the story attracts or repels us because it reminds us of any number of personal stories” [18, p. 981]. Narrative ethics, unlike spaceship ethics, is therefore inseparable from everyday life [13]. This does not mean, as Jerome Bruner notes, that the proponents of narrative ethics hope to “detechnicalize sickness or health care.” Obviously, no one aims to hinder the scientific progress of medicine’s highly technical understanding and treatment of disease. But for health care to progress ethically, attentive to the care of others and the self, “you’ve got to rehumanize it as well—relate it to life. Who on earth,” asks Bruner, “wants to practice like a robot? Or turn their patients into robots?” [19, p. 8].

Sadly, practicing “like a robot” often entails treating stories robotically. Typically, medical professionals “understand stories as something to carry a message away from—as in, ‘What did you learn from that history?’ The professional, as paradigmatic modernist, is always moving on, the sooner to get to the next thing and move on from that” [9, p. 159]. In contrast to this mechanistic approach, which treats stories as objects from which information is extracted by “superior,” nonnarrative, cognitive tools, narrative ethicists recommend that we learn to think with stories:

Not think about stories, which would be the usual phrase, but think with them. To think about a story is to reduce it to content and then analyze that content. Thinking with stories takes the story as already complete; there is no going beyond it. To think with a story is to experience it affecting one’s own life and to find in that effect a certain truth of one’s life. [9, p. 23]

As Frank makes clear, the way that stories create and communicate meaning is primary and complete. There is not a more “fundamental” way of thinking that must be
applied to stories in order to reveal their ethical import. On the contrary, storytelling itself is ethic’s invocation and attentive listening ethic’s response. David Morris puts it thusly: “Thinking with stories is a process in which we as thinkers do not so much work on narrative as take the radical step back, almost a return to childhood experience, of allowing narrative to work on us” [15, p. 196]. It is impossible to categorize or to comprehend all of the ways stories work on us; one cannot reduce their content to analyzable data, subsumed under universal principles. As soon as we apply principles to stories, we lose their primary meaning, a primacy that includes the invocation of emotion as integral to ethical self-understanding [21]. “The first lesson of thinking with stories,” Frank contends, “is not to move on once the story has been heard, but to continue to live in the story, becoming in it, reflecting on who one is becoming, and gradually modifying the story. The problem is truly to listen to one’s own story, just as the problem is truly to listen to others’ stories” [9, p. 159].

This final point of Frank’s—that to practice ethics one must truly listen to one’s own story—is key to understanding narrative’s role in the ethics of self-care. Since narrative is central to the understanding, creation, and recreation of ourselves, we can truly care for ourselves only by attending to our stories. Our needs, desires, and aspirations are given both form and content—integrated and reintegrated into the continual unfolding of ourselves—through the self-creating power of narrative. Narrative, Joanne Trautmann Banks writes, “inevitably expresses and transforms who we are at every level of our being” [22, p. 219]. Through my self-story, I decide, express, and enact who I will be. I therefore take responsibility for myself through active, self-conscious engagement in the narration of my story. What Arthur Frank writes of ill people applies equally to physicians and researchers: “Postmodern illness stories are told so that people can place themselves outside the ‘unifying general view.’ For people to move their stories outside the professional purview involves a profound assumption of personal responsibility” [9, p. 13]. In postmodern times, Frank contends, “becoming a narrator of one’s own life implies an assumption of responsibility for more than the events of that life. Events are contingent, but a story can be told that binds contingent events together into a life that has a moral necessity” [9, p. 176].

8“I am interested,” Howard Brody writes, “in what Hilde Nelson has classified as telling, comparing, and invoking stories; that is, using narrative as part of moral reasoning, rather than merely as illustrative of moral conclusions derived from other methods of reasoning.” [20, p. 149]
9As Hilde Lindemann Nelson puts it, narratives “make intelligible what we do and who we are; ... through them, we redefine ourselves” [17, p. 47].
10“The self-story is not told for the sake of description, though description may be its ostensible content. The self is being formed in what is told” [9, p. 55].
11“What the story teaches is that there is always another story, and other stories have always been possible. One meaning of this lesson is that life is lived in decisions, each setting in place a different way of telling the story. Because these decisions have consequences—the plot cannot be reversed at will at any point—they are moral. Thinking with stories means that narrative ethics cannot offer people clear guidelines or principles for making decisions. Instead, what is offered is permission to allow the story to lead in certain directions” [9, p. 160].
Storytelling’s ability to grant an individual life moral coherence is restorative, healing. This healing, however, is not just personal, but interpersonal as well: “Because stories can heal, the wounded healer and wounded storyteller are not separate, but are different aspects of the same figure” [9, p. xxi]. Narrative ethics recognizes that all of us, at one time or another, will become fractured—whether by illness or by professional setbacks, stress, disappointments, or even success: “Sooner or later,” writes Frank, “everyone is a wounded storyteller” [9, p. xiii]. Narrative ethic’s recognition of this shared vulnerability undermines modernist heroics, with its spaceship ethics that so effectively, and damagingly, alienates healers from ill people, from other healers, and from themselves.

Writing, reading, and discussing the story of one’s alienation, therefore, are often the first steps in overcoming it. This was certainly true for Ashley. During our discussion, we considered the role the “character” of the medical student plays in the story of Mary’s death. In this story, Ashley discovered, the student plays a much more important role than any of the doctors: Mary would have died whether or not Ashley was there, but her death would have been far less peaceful. While the importance of Ashley’s role seemed immediately obvious to me, as it would to most readers of the story, Ashley had not, previously, been encouraged to acknowledge the moral authority of her actions. On the contrary, her professional training had actively discouraged this acknowledgement. Every death, for medicine, is simply a defeat—end of story—at the hands of its worst enemy. Writing and sharing her story offered Ashley a means of memorializing Mary’s death—a means of preserving the memory, and so placing the meaning, of an event radically dislocated by her professional training. This was healing for Ashley. Reflecting on the story of her life, of Mary’s life, of their lives, Ashley heeded the imperative to care for herself.

Obviously, writing and relating the story of Mary’s death could not possibly repair all of the psychic, and ethical, injuries Ashley suffered during her medical training. It was, however, an essential first step in what must be a continuous, ever-evolving narrative process: for Ashley, as for all health professionals, healing requires an ongoing commitment to narrative self-reflection. This commitment goes beyond the reparation of injuries wrought by the modernist heroics of the medical academy. Indeed, narrative ethics requires and promotes a fundamental change in the very culture of the medical academy itself.

This cultural change, I believe, can be effected in every academic setting in which medicine is researched and practiced. I am confident that this is true, because I have witnessed narrative’s efficacy in what is perhaps the environment most hostile to any such transformation: the inpatient wards. It is on the wards that medical professionals are the most rushed, the most anxious, the most focused, and so the most in thrall to medicine’s modernist heroics. Yet in this setting I have held Narrative Medicine Rounds every other Friday morning for the past seven years. The Family Medicine inpatient team of the New York-Presbyterian hospital consists

12“According to Kleinman, narrative brings order and cohesions to suffering” [16, p. 131].
of two attendings, one first-year resident and one second-year resident, two interns, and one or two medical students. We begin rounds by together reading a short essay, story, or poem by a professional author. We then discuss the ways the author constructs and conveys meaning in her or his text. Following this discussion, I ask the team to write about their inpatient experiences, keeping in mind the narrative lessons we have learned in our discussion. When they have finished writing, the team reads their stories aloud, and we discuss them in much the same way as we discussed the opening texts.

Over time, the culture on the Family Medicine wards has shifted from one that, at best, tolerated thinking about stories to one that now fully welcomes thinking with stories. The benefits of this change are striking. On a recent Friday morning, for example, one of the attending physicians, Marion, asked if she could read a story to the team that she had written the previous evening. Marion has been with our program for many years, having completed her residency training at Columbia before joining our faculty. As an intern, Marion had been utterly focused on learning the medicine, the whole medicine, and nothing but the medicine. Like most interns, she was understandably resistant to anything that she felt might distract from this focus; all such distractions seemed to threaten her ability to keep her patients alive. Now, as a young attending, she is one of the faculty members most gifted at thinking with stories. I was therefore happy to set aside Hemingway’s “Hills Like White Elephants,” which I’d planned to read with the team that morning, so that Marion could read the following story:

“My mother is dying,” the voice says. I must go see her. My family calls her “the fruit lady.” She always brings a heavy bag of fruit, pineapples peeled ever since I told her I was too lazy to peel them. I can see her red lipstick and thick, straight, salt and pepper hair. Before she chemo, that is. There was something young and alive about her; even sexy, despite her 60 years.

“They put in a chest tube to drain the fluid and her lung collapsed. The other was full of cancer,” her daughter explained. I had hoped this procedure would let her walk around without oxygen during the final few months.

I had forgotten that she had smoked many years ago, when she first complained that her throat felt tight, her heart was racing. It took a few visits to realize this was not a virus or a sour stomach. I told her right away, feeling encequid in plexiglass during that conversation, trying to convey facts.

She rallied with her usual grace and we had two more years of warm, intimate visits, stories of her family and friends, bags of fruit. And now she was dying.

On the train there were lots of people shoved into the car, going home after a long day of work. What will I say to a room full of her family, even to her? What explanation can I offer them about why medicine cannot stop this process, this pain? How will I say goodbye, in Spanish, no less?

Prestigious Hospital subway stop—so familiar, but somehow different tonight. On the way into the hospital, lots of important looking people—surely they have saved lives today. I am going to watch one end.

How does one say “goodbye” in Spanish? I racked my brain. Hasta luego, nos veimos, sí “dias quiere”... what else? I seriously wonder if this is a language that does not have a word for a final goodbye.

The room is full of people. She is blue and in pain, struggling with each breath, her oxygen sat is in the 50s. I hold her hand and swallow my heart as she says, “Gracias por todo, doctora, te quiero mucho.” I whisper in her ear that I will think of her whenever I eat pineapple, that I love her too. I think she smiles.
Marion’s story, I believe, highlights beautifully the benefits of a sustained and sustaining culture of ethical self-care. To nurture this culture, one must offer forums for clinicians and researchers to write, share, and reflect on their own self-telling narratives, like the inpatient narrative medicine rounds described above. While the benefits of this cultural change are numerous, I would like to focus on the four that are most clearly in evidence in Marion’s story and in the team’s response the morning it was shared: (1) attention to singularity, (2) heightened awareness of narrative temporality, (3) strengthening of community, and (4) greater acceptance of death.

Singularity

Marion’s story is not universal. Unlike the principles of biomedical ethics, this story about the relationship between Marion and the “fruit lady” does not apply to all relationships between all doctors and all patients. If any other doctor wrote a story about this patient, it would be a different story with an entirely different meaning. If Marion wrote a story about any other patient, it would be a different story with an entirely different meaning. She is not just any doctor, filling a role with any patient. As her story reveals, Marion is this doctor, caring for this patient.13

It is precisely narrative’s focus on singularity that makes possible and structures all true moral deliberation,14 including deliberation about care of the self. Once again, what Frank writes about ill people applies equally to physicians and researchers: “My concern is with ill people’s self-stories as moral acts, and with care as the moral action of responding to those self-stories” [9, p. 157]. Moral activity has two sides: care given to the other in response to the other’s self-story and care

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13“Narrative knowledge addresses the particulars of the case, attends to multiple perspectives, and depends on descriptions of a specific or situated context and personal details that define meaning. It allows many possibilities to be present at once and recognizes the emotional aspects of living one’s life” [24, p. 143].

14“Narrative 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” [13, p. ix].

“By the ethical dimension,” Kenneth Burke writes, “I have in mind the ways in which, through language, we express our characters, whether or not we intend to do so. ... [W]e could say that language reflects the ‘personal equations’ by which each person is different from any one else, a unique combination of experiences and judgments. Thus there is a sense in which ... each poet speaks his own dialect” [25, p. 28].
given to myself in response to my own self-story. By telling and attending to her unique story, Marion is called to respond to the self-care imperative.\textsuperscript{15} She is called to examine who she is becoming \textit{as a person, as a unique individual}—not as a substitutable role. This examination necessarily entails asking whether her actions are good or bad for herself. As Barry Hoffmaster contends, the “crucial test of a story might be the sort of person it shapes” [26, p. 1161]. This test helps Marion to understand how she might care for herself and thus become the person she wants to be. Michael White writes that a person often finds herself “situated in stories that ... she finds unhelpful, unsatisfying, and dead-ended, and ... these stories do not sufficiently encapsulate the person’s lived experience or are very significantly contradicted by important aspects of the person’s lived experience” [27, p. 14]. To care for oneself, therefore, one must take responsibility for one’s narrative situation: “[P]ersons give meaning to their lives and relationships,” White argues, “by storytelling their experience. ... [I]n interacting with others in performance of these stories, they are active in the shaping of their lives and relationships” [27, p. 13].\textsuperscript{16} Marion thus cares for herself by bringing her story into alignment with her own, unique experience.\textsuperscript{17} As Marion’s story demonstrates, it is possible to achieve this alignment even in the most “modernized” of medical environments.

\textbf{Temporality}

Marion’s story, like all narratives, is a temporal configuration of events. This configuration is not strictly chronological. On the contrary, Marion begins in the story’s “present” (“My mother is dying” \textit{the voice says} “); flashes back to the past (“Before the chemo, that is “); returns to the present (“They put in a chest tube to drain the fluid and her lung collapsed “); moves back to a moment even further in the past (“I had forgotten that she had smoked many years ago “); narrates forward from this past to a point in the present just after the phone call (“On the train there were lots of people shoved into the car “); then narrates from this point forward through the hospital visit (“The room is full of people “), ending with the scene at home (“I open the door to my apartment and see simple signs of life “). This temporal configuration is crucial to Marion’s ability to

\textsuperscript{15}“The moral imperative of narrative ethics is perpetual self-reflection on the sort of person that one’s story is shaping one into, entailing the requirement to change that self-story if the wrong self is being shaped” [9, p. 158].

\textsuperscript{16}“Self-stories are told to make sense of a life that has reached some moral juncture” [9, p. 161].

\textsuperscript{17}“Narrative ethics is compete, within its sphere. This sphere is not clinical adjudication but personal becoming. Narrative ethics is an ethics of commitment to shaping oneself as a human being. Specific stories are the media of this shaping, and the shaping itself is the story of a life” [9, p. 158].
make sense both of her care for her patient and her care for herself. By bringing together events that are not contiguous in time, Marion’s story sparks a flash of illumination that brings to light the meaning of her experience. As Rita Charon puts it, “We learn who we are backwards and forwards, early memories taking on sense only in the light of far later occurrences and contemporary situations interpretable only in the web of time” [30, p. 67]. This temporal interpretation, Hilde Lindemann Nelson argues, is much more conducive to ethical reflection than the atemporal standpoint of principism: “[U]nderstanding how we got ‘here’ is crucial to the determination of where we might be able to go from here, and this is where narrative is indispensable. . . . Because narrative approaches . . . move backward and forward, they are better suited to ethical reflection” [17, pp. 39–40]. Ethical self-reflection demands that we understand events in time. Principist ethics seems to consider events as if they existed outside time—as if moral dilemmas could be understood without considering the past out of which they arise, the present in which they appear, and the future toward which they move. As Marion’s story demonstrates, it is impossible to honor the imperative to self-care unless one attends to the narrative temporality of one’s own self-telling stories. “Constructing time-bound, causal patterns,” Charles M. Anderson and Martha Montiello write, “enables us to make sense of primary experience. The narratives we build shape the ways we come to know ourselves and each other and create the symbolic space within which we make all our moral choices” [31, p. 85].

At the end of her story, Marion returns to her home. There, she feels “peaceful,” she observes all the “signs of life,” and she “breathes a sigh of relief.” Surrounded by her loving and beloved family, she literally learns how to say goodbye to her patient. Like all good endings, this return to her home brings closure to Marion’s story—a closure that gives to her experience, and so to her very self, a healing wholeness. The ending of her story shapes the meaning of the many years of Marion’s experience caring for her patient. It brings that experience to a close in a way that allows her to integrate it into her ever-unfolding life story—to make it a part of the whole of her life, rather than something separate, outside of her life. Paradoxically, telling a story (her configuration of time) about her search for coherence (her experience in time) enacts the coherence

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18 “Life moves on, stories change with that movement, and experience changes. Stories are true to the flux of experience, and the story affects the direction of that flux” [9, p. 22]. “Plot links the complicated and uncertain conditions that may—or may not—be essential ingredients in the events being represented, and then plot traces those conditions over time” [28, p. 77].

19 “Memory is not only restored in the illness story; more significantly, memory is created” [9 p. 61]. David Carr argues that “at no level, and certainly not at the scale of the life-story itself, is the narrative coherence of events and actions simply a ‘given’ for us. Rather it is a constant task, sometimes a struggle, and when it succeeds it is an achievement” [29, p. 96].

20 As Tod Chambers and Kathryn Montgomery write, “If plots are driven by their endings, then what is considered a proper ending will have a profound impact on the story that is told. The sense of an ending that can bring closure to moral problems is arbitrary, perhaps temporary, and always a human construction. These limitations are not negative features but rather, when fully recognized, the very business of bioethics” [27, p. 84].
for which she is searching. This temporal paradox is productive, for it is the paradox through which a narrative becomes the story of why we tell ourselves stories. In Marion’s case, the fruit of her story, if you will, is the story of her fruit.

Community

“Only connect,” E. M. Forster writes in the epigraph to his 1910 novel Howards End [32]. This admonition, I believe, is a vital expression of the self-care imperative. As Bruner puts it, “Everywhere you look, you run into the recognition of the fact that a human plight is never an island unto itself. So, what should you do? You connect” [19, p. 9]. Indeed, Samuel Shem writes, “the primary motivation of human beings is the desire for connection. . . . [T]he seeds of human misery are planted in disconnections, violations, isolation, and domination, and the core of healthy growth is the movement from isolation toward connection” [33, pp. 43-44]. Since the work of establishing interpersonal connections is fundamental to addressing “human misery,” ethics is nothing if not this interpersonal work: “Perhaps the greatest life-value of ethics,” writes György Lukács, “is precisely that it is a sphere where a certain kind of communion can exist, a sphere where the eternal loneliness stops. The ethical man is no longer the beginning and the end of all things, his moods are no longer the measure of the significance of everything that happens in the world. Ethics forces a sense of community upon all men” [34, p. 57].

Narrative honors this centrality of community to ethics—particularly to the ethics of self-care. In this regard, it is the antithesis of spaceship ethics, which actually makes a virtue of remaining un-connected, of fostering isolation. Marion’s story beautifully illustrates the power of narrative to transcend this isolation. Her story expresses and enacts a marriage between her work and home lives. Like all marriages, it is defined—as only narrative can reveal—by the web of relationships that comprise and support it. Marion’s story reveals her active, self-reflective engagement

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21As Frank writes, “The truth of stories is not only what was experienced, but equally what becomes experience in the telling and its reception. The stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experience of those lives” [9, p. 22].

22For Frank, “The Good story ends in wonder, and the capacity for wonder is reclaimed from the bureaucratic rationalizations of institutions, medicine. Being available to yourself ultimately means having the ability to wonder at all the self can be” [9, p. 68].

23“[T]he moral life cannot be conceived apart from one’s relationships with others—a claim that contrasts to modern notions of the self as an isolated unit and that challenges the notion of the moral life as guided by abstract ideas, rules, and principles” [35, p. 73].

In contrast to principist ethics, “the narrative approach . . . sees morality as a continual interpersonal task of becoming and remaining mutually intelligible. In this view, morality is something we all do together, in actual moral communities whose members express themselves and influence others by appealing to mutually recognized values and use those same values to refine understanding, extend consensus, and eliminate conflict” [17, p. 46].
in making interpersonal connections and fostering narrative coherence. She shows how this coherence undergirds her familial and professional lives—how she returns to her family to find the words to say goodbye to her patient. Yet the story itself fosters the very connections, the very coherence, which is its principal theme. Marion's is therefore both a story about self-care and an act of self-care. Yet again, Frank's reflections on illness apply to the self-care of both patients and medical academicians: "Serious illness is a loss of the 'destination and map' that had previously guided the ill person's life; ill people have to learn 'to think differently.' They learn by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared" [9, p. 1].

Reading her story to this audience, Marion fosters both the interpersonal connections narrated in her story (her family, her patient, and her patient's family) and the interpersonal connections created by her story (the inpatient team). As Julia E. Connelly writes, "Narrative knowledge allows and encourages human connections. One shared story triggers the telling of other stories by involved listeners, facilitates memories and personal reflections on past experiences, if only silently revealed, and creates an expanded awareness of the moment, including a recognition of the power of personal presence and connectedness" [24, p. 145]. This "expanded awareness" was certainly in evidence the morning that Marion read her story. When Marion finished reading, we discussed the story's meaning and impact. Every member of the team—from third-year medical student through well-seasoned attending —was inspired to share a story from her or his own experience. In each of these stories the team discovered and created connections to all of the others, thus building upon and reinforcing the shared narrative coherence that characterizes a true community of storytellers. As Frank writes, "Listening is hard, but it is also a fundamental moral act; to realize the best potential in postmodern time requires an ethics of listening. ... [I]n listening for the other, we listen for ourselves. The moment of witness in the story crystallizes a mutuality of need, when each is for the other" [9, p. 25]. The recognition of this mutuality of need shatters the illusion of modernist heroics—the "illusion of oneself as the beginning and end of all things." Once this illusion of self-sufficiency is shattered, "openness to communion is all that is left" [9, p. 154]. In this openness, we heal the wounds of our heroic isolation.

21 "If we assume the truth of the relational self, ethicists receive a personal dividend as they attend to another's interpretations of the patient's story—their work contributes fundamentally to their own self-development" [22, p. 224].

22 "It is one contribution of narrative theory to bioethics to recognize that moral discernment is a form of narrative activity and that arguments and principles are made within the specificity of particular narratives told by particular tellers to particular listeners" [35, p. 26].

23 "People tell stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others—each must create his own—but rather to witness the experience of reconstructing one's own map. Witnessing is one duty to the commonsensical and to others" [9, p. 17].

24 "In the reciprocity that is storytelling, the teller offers herself as guide to the other's self-formation. The other's receipt of that guidance not only recognizes but values the teller. ... Telling stories in postmodern times, and perhaps in all times, attempts to change one's own life by affecting the lives of others" [9, pp. 17–18].
Death

There is no greater challenge to modernist heroics than death. In death we face the absolute limit of our power, that over which, ultimately, we have no control. At best, we may be able to forestall death, but we can never prevent the inevitable: death will have its day. Yet medicine frames death as its enemy then refuses to acknowledge what this framing implies: according to its own terms, medicine’s rate of failure is 100%. As Zoloth and Charon write, “Clinical and research medicine long ago erected death as the enemy, death as defeat. Through terror, perhaps, or through hubris, medicine endorsed the haunting illusion that it could conquer death. Despite the efforts of palliative care and hospice, attempts to understand and sometimes welcome death are marginalized and exert little influence on medicine’s mainstream work—the big business of intensive care, clinical trials, and pharmaceutical and surgical intervention—all of which are predicated on finding the right triumphal ending for the narrative of illness” [36, p. 29]. Maintaining this illusion of its ultimate triumph, medicine denies itself the possibility of finding meaning in death. It therefore also denies itself the possibility of finding meaning in life: how can one find meaning in life, after all, if one refuses to face the single most important fact of our temporal—temporary—existence. As we saw in Ashley’s story, the effects of this denial are devastating: to deny death is to deny our very selves, thus making self-care impossible.

It is the task of ethics to move medicine out of this denial. Indeed, ethics “is the profession committed to facing death directly,” Zoloth and Charon argue, “calling out its name, and finally, unlike medicine, finding meaning in the lost places in the clinical world where death has established its dominion” [36, p. 29]. As we saw above, principlist ethics often reinforces medicine’s modernist heroics, colluding in its denial of death. For narrative ethics, on the other hand, “death is the issue, the topic, the thing itself” [9, p. 29]. Narrative ethics is concerned with the whole story. It does not approach the meaning of a story from a perspective outside or above it. Rather, it finds meaning inside the story as a whole. The death of a patient, research subject, loved one, therefore, does not lie outside the story. In Marion’s case, for example, death is integral to, even revelatory of, the meaning of her narrative. Creating a memorial in honor of death—integrating death into the whole of

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24 “Modernity, Bauman argues, exercises the fear of mortality by breaking down threats, among which illness is paradigmatic, into smaller and smaller units. To use May’s distinction, the big mystery becomes a series of little puzzles. Medicine, with its division into specialties and subspecialties, is designed to effect this deconstruction” [9, pp. 83–84].

25 “Modernity disallows any language other than survival; the modernist hero cannot imagine any other way to be, which is why physicians are often genuinely baffled by criticisms. People in postmodern times need different languages of meta-survival with various messages that death is all right. Clinical ethics needs these messages” [9, p. 166].

26 “Modernist medicine has regarded suffering as a puzzle to be ‘controlled’ if not eradicated. Postmodern illness culture, lay and medical, recognizes a need to accept suffering as an intractable part of the human condition” [9, p. 146].
her experience—is a natural extension of Marion’s loving care of her patient, her family, and her self. Her story shines a very bright light on that which medicine would keep hidden. Like all things locked away in dark corners of the mind, death is perverted by ignorance and denial, growing fearsome and strange. Once illuminated, as by Marion’s story, death loses its fearsomeness, its power to appall. As we saw in Ashley’s story, the denial of death is unhealthy; she had keenly suffered, in silence, for two years. Ashley could not respond to the imperative to care for herself in part because she had been trained to hide death away. To care for ourselves, we must face death honestly, without evasion: this is the only way to find meaning in our brief, mortal existence. As we see in Marion’s story, caring for the dying can bring us to a fuller understanding of our own mortality and thus grant us access to the precious wealth of meaning in our life stories—if only we give ourselves the time and space to reflect. The stories the other members of the team shared, after hearing Marion read, were one and all stories of their own encounters with death. Taken together, it is as if these stories cry out with one voice, clear and strong, “Oh Death, where is thy sting?”

Conclusion

This, then, is the conclusion of my ethics work with physicians and researchers over the past ten years: to honor the self-care imperative, one must attend to one’s self-telling narratives. I therefore agree with David Morris that the “goal of narrative bioethics is to get the stories into the open, where we can examine their values, sift their conflicts, and explore their power to work on us” [15, p. 213]. Opening medical academicians to their own stories is crucial to faculty health. To effect this opening, the ethicist must contend with cultural and professional biases that work to keep these stories hidden. As Bruner writes, “The fact of the matter is that if you look at how people actually live their lives, they do a lot of things that prevent their seeing the narrative structures that characterize their lives. Mostly, they don’t look, don’t pause to look” [19, p. 8]. Fortunately, the native ability to see “the narrative structures” of our lives, while underused, is not rare. This ability, in fact, is almost certainly universal.

I believe that the work of the biomedical ethicist must be devoted, in large part, to giving medical academicians opportunities to “pause to look,” so that they might actualize their innate potential for narrative self-reflection. As Anne Hudson Jones argues,

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31 “The intersubjective certainty of death does not lose its terror, nor its countenance, but becomes familiar. Hence, the query of the other is always, on some level, about also this: and I, too, will die?” [35, p. 29].
32 1 Corinthians 15:55
33 “Narrative capacity seems to be an innate human ability” [21, p. 160].
However, natural a part of the human equipment, narrative skill can be developed by exposure to environments rich in stories. ... One consequence of the increasing interest in narrative ethics is the need to think about the kind of training that can enhance the natural narrative capacities of those ... whose professional training has not been focused on the study of literature or narrative. ... Interpretation is a skill that can be learned and practiced by reading complex texts with the guidance of highly skilled readers and interpreters. [21, pp. 160–161]

Over the past ten years, a great deal of effort has been devoted worldwide to developing narrative training in the medical academy and to testing its effectiveness [21, pp. 163–164 and 15, p. 202]. At Columbia University Medical Center alone, the narrative medicine faculty has developed narrative training that includes literature and medicine reading groups, inpatient rounds, graduate seminars, writing groups, parallel charting curricula, intensive weekend workshops, and much more. Starting in fall of 2009, the Program in Narrative Medicine is offering a Master of Science in Narrative Medicine. This full-year Columbia University Master’s program will provide intensive training at the university and the medical center for the theoretical, textual, clinical, pedagogic, and personal facets of a practice of and scholarly career in narrative medicine. Classes will gather a mix of health professionals and scholars from a variety of humanities and social science disciplines.

These narrative medicine initiatives are not focused primarily on care of the self. Indeed, they are, first and foremost, responses to the call of the suffering other, to the demand to offer her care [37]. Yet any such response is ultimately doomed unless it also answers that other call—the call to care for myself, to bring myself to light, and to tell and hear my own story. Like Ashley, I must hold Mary through her terror at death’s approach. If I am not to lose myself to that terror, however, I must join my story—unique and whole—to the story we tell separately together: the always-unfolding story of why we tell ourselves stories.

References