

# NARRATIVE & MEDICINE

## *Illuminating the Real of Health, Expressing the Real of Illness*

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I thought I would be with you here today to deliver a talk called “Illuminating the Real of Health, Expressing the Real of Illness.” But the real of illness interfered, and instead I had a three-hour-long operation on my left shoulder last week. It was just a rotator cuff tear—not a life-threatening situation at all. Yet it interfered with my life and brought with it its share of terror. I want to tell you about two moments during it as a prelude to what I would have said to you today, but that now I understand more deeply than I did before last week.

In the weeks leading up to the surgery, I envisioned all the horrible things that could go wrong. In my internist’s imagination, I gave myself a fatal pulmonary embolus. I had a premonition of an anesthesia emergency that rendered me permanently comatose. I made a copy of my will to give to my executor, just in case I did not survive. I postponed the buying of an apartment in Manhattan, for what would my heirs do with a newly purchased cooperative apartment but be saddled with the mortgage and maintenance payments every month?

Nothing untoward happened, and here I am typing, one-handedly, my now absentee talk for you. Instead of disaster, some rather revelatory things happened that I want to tell you about.

Because I was half-awake during the whole thing (but with lots of propofol and ketamine on board), I was intermittently able to see what was going on in the operating room. I was amazed to see that there were at least 10 people in that room, taking care of me. I had no idea that, in addition to my surgeon, there was his fellow, two residents, the anesthesiologist and his assistant, a nurse assigned to the arthroscope they were using to see inside my shoulder joint, a scrub nurse, a circulating nurse, and a float who could go in and out of the room as needed. It was exhilarating as it was sobering. Both at the same time, it felt like a luxury and it felt like a reminder of the peril of what was going on. I knew that they were relaying news of their progress to my family sitting in the waiting room in the civilian world outside. At one point when I was awake, the surgeon says, “Hey, we have no music in this OR.” He turns to me and asks, “What do you

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want to hear?” I remember answering, to laughter, “Bach . . . and some Grateful Dead.”

The first assistant to the chief surgeon is a senior fellow in orthopaedics. She had been a student of mine many years ago, when she was a first-year medical student at Columbia. I was her teacher for the intensive “doctoring” course at Columbia in which we try to teach students how to listen to patients, what it is like to be ill, what patients look for from their doctors. After the surgery, I wrote to her to thank her for her skill and to say how comforting it felt for me to be in her capable hands. She wrote back immediately, expressing her gratitude at having been able to be part of my OR team.

I hope you see the magnitude of this interchange. As in all events of illness, there is a wordless surrender of the sick to the skilled. There is simultaneously a wordless gratitude from the skilled to the sick for the trust of that surrender. When these forces are, indeed, put into words, they form a muscular reciprocity of kindness and confidence and recognition. In this little 3-hour operation, my former student and I lived out tremendous mutual commitments of the deepest kind. And this happens every time a skilled person helps another person who is ill.

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This conference now in Lisbon and our entire movement in Narrative Medicine is the dedicated effort to put such deep currents into words, to *have* the means with which to express thoughts, feelings, memories, emotions surrounding illness and health. We understand, more than we can say, that illness lifts the veil on that which matters in life and living. Each of you here understands—whether you are a patient, a family member of a patient, a scholar studying some aspect of health care, an artist, a nurse, a physical therapist, a scientist, a

physician, a chaplain, a hospital administrator—that events of illness underline our identity, illuminate our values, force us to articulate our lives’ meanings. Inevitably.

The peril and gift of mortality come clear in John Banville’s novel *Infinites*. Not his best novel, it stages a scene on Mount Olympus when Zeus explains to his fellow gods, as they gaze down in amusement at the hapless mortals they have created, why he envies us our mortality:

This is the mortal world. It is a world where nothing is lost, where all is accounted for while yet the mystery of things is preserved; a world where they may live, however briefly, however tenuously, in the failing evening of the self, solitary and at the same time together somehow here in this place, dying as they may be and yet fixed forever in a luminous, unending instant.<sup>1</sup>

Where but in proximity to failing or threatened health might we mortals achieve sight of the meanings, the mysteries, the failures and the luminous unending instants of this, our ordinary lives?

Skill in *narrating* and in representing what we observe or undergo in moments of illness give us access to knowledge that, without the narrative representation, would remain outside of awareness. We all know this. This is why we have found our way into this clearing of narrative medicine.

But narrating is hard. I find lately that I shy away from using the word “story” in my writing or teaching. Persons often think that telling and listening to stories are easy, things they’ve done all their lives. I disagree. Of course, human beings are story-using organisms, and none of us would have survived without the capacity to tell and receive stories. But to know, seriously

and skillfully, what to *do* with stories is another matter. I believe what joins us in narrative medicine or health humanities or related fields is the awareness of the sophistication and rigor necessary for fully absorbing the meanings of the accounts given of self. When I teach close reading in my Master of Science in Narrative Medicine graduate program at Columbia (several of my colleagues or graduates of that program are, I believe, here in Lisbon today), I spend a semester teaching one novel, Virginia Woolf's *To the Lighthouse*. I insist that my students read and come to understand some of the seminal works of narratology—Henry James, I.A. Richards, Bakhtin, Genette, Forster, Barth, Booth, Ricoeur, Butler, Bachelard, de Certeau, Bourdieu, Aristotle. My mid-term paper asks students to choose an inch of text in the novel and write a 5-10 page paper on that one inch. My students learn enough about textuality and representation to be faithful to what ill persons in their care might tell them or to teach clinicians to achieve such fidelity.

In my teaching at the medical center, I have become committed to developing or at least encouraging creativity among the clinicians and proto-clinicians. We do not teach reflective writing, as do many health professions schools. We teach creative writing. We want our students and colleagues to experience the range of their own imaginations as well as the transit possible when they behold a creative work—be that a poem, a painting, or the situation of a patient in their care. I want for them to experience that sense of being carried away, of being summoned out of one's ordinary self, by the presence of another, whether in person or in view of the representation (novel, painting, partita) that that person has created. This summoning can happen by virtue of the natural world too, of course, and Shelley's "Mont Blanc" is perhaps the best description

we have of this experience of being carried away by the sublime.

So our teaching sessions usually begin with a close inspection of a work of art—a poem, paragraph from a novel, painting, photograph, piece of music or dance—followed by some conversation about the work. Then, a writing prompt is offered, something that can expand the mind of the students. They write then-and-there in class, usually for just a few minutes, freely letting themselves go wherever the work and the prompt might invite them. When they read to one another what they have written, they discover things they did not know they knew, both about themselves and about one another. Invariably, they discover that they have the creative power to write.<sup>2</sup>

Our Program in Narrative Medicine has been invited to do this kind of teaching for many clinical groups. So far, we work with general internists, general pediatricians, emergency room clinicians, psychoanalysts, child psychiatry fellows, palliative care and pain medicine fellows, interns and residents in pediatrics, medicine, and, of all things, radiology. We teach faculty and students from the schools of nursing, dentistry, public health, physical therapy, occupational therapy, and nutrition. We work with patients and staff on the wards in pediatric oncology and adult oncology. I just submitted a grant application to the National Science Foundation to fund me to bring such teaching to basic scientists in their laboratories, for the creative acts of science are not unlike the creative acts of artists, and I hypothesize that increasing scientists' creative powers will increase their potential for discovery in science.

Such contemporary scholars as Rita Felski in *Uses of Literature*, Ann Jurecic in *Illness as Narrative*, Adriana Cavarero in *Relating Narratives*, and Philip Davis in *Reading and the Reader* help us to understand the nature of the

contact formed between reader and writer, teller and listener. Such contemporary novels as John Banville's *The Sea*, Colm Toibin's *Nora Webster*, and my colleague and friend Nellie Hermann's absolutely stunning *The Season of Migration* bring from the imaginative realm the power of this transport. And of course one cannot do without all 26 volumes of *The Novels and Tales of Henry James* (including the Prefaces) to orient oneself on this life-long and high-stakes journey of coming to know the self and other.

But what do we seek from this rich diet of scholarly and creative works? We seek the muscle and fortitude necessary to look life full in the face. "Live all you can; it's a mistake not to," is the advice given by Strether in James's *The Ambassadors* to the young Bilham, advice that Strether fears he failed to follow himself. We seek the nuance to comprehend the fact that others' experiences are nothing like our own, and that all we have as guides to understanding theirs is the imagination and the courage to use it. We seek the bank of stories accumulated through a lifetime of reading, of theatre-going, of attending to Scripture, to myth, to song. We absorb the beauty, inexpressible, available through museum-lurking, jazz-club-crawling, philharmonic subscribing, horizon-gazing. We even call upon our own creative skills. One week after I read a review of a musicology book on Bach in which pianist Jeremy Denk writes, "Well, if you want to know how Bach's music works, you have to play it," I signed up for piano lessons and can now play, passably, so far 3 of the movements of Bach's Partita # 4. I look at my own now gnarled hands on my piano's keyboard as I quietly add the B and D under the held F# in the Allemande movement, and I can barely believe that I am able to create such beauty.

I am coming to believe—and I am not sure how this part works—that being in the presence of such beauty and making room within the self for it somehow prepares one to contain the terror and the loss of violence and suffering and grief. I don't know yet how this works, but maybe some of you here can help me think about it. The capacity to bear witness to other's pain or to countenance one's own depends, somehow, on having enlarged one's capacity for the experience of beauty. I think there is nothing else that can enlarge that capacity for perception, although I don't know exactly why I think this. I have the image in my mind of the beautiful Greek or Roman amphoras, the large graceful clay vessels, tall and slender, with narrow neck and two well-balanced handles, often painted with scenes of triumph. The larger the amphora, the deeper and more resonant the sound made when one blows gently across its mouth. Amphoric sounds, usually musical in quality, are heard in the presence of spaces filled with air. So we human beings are created to contain the beauty and pain of self and other, and the more capacious that space, the more beauty and pain can be held. That is what I think the practice of medicine requires, and that is what I think the creative process prepares one to do.

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I close with a word or two about the real of my title. A somewhat embarrassing word to use in public, the real is that aspect of life experience on which we mindlessly depend while "knowing" that it does not exist. I never tire of telling the apocryphal story of the early atomic physicists who, upon realizing how vast were the spaces between the central dense atomic nucleus and the electrons whirring around it, took to wearing snowshoes so as not to fall

through the cracks of matter. From aesthetic theory, we know that until a thing is represented, it does not exactly exist. Until the story is told or written, the event did not exactly take place. Abstract expressionist Mark Rothko writes in his manifesto, *The Artist's Reality: A Philosophy of Art*, that the poet's or the philosopher's "chief preoccupation, like the artist, is the expression in concrete form of their notions of reality. Like him, they deal with the verities of time and space, life and death, and the heights of exaltation as well as the depths of despair."<sup>3</sup> Like him, we who live our lives around sickness and death deal with these verities. Like him, we rely on our capacity to see

clearly and courageously so that we can represent that which we perceive. Whether the real be my left infra-spinatus muscle, now expertly reattached to my humerus, or the predicament of a patient in my care, a situation told in fragments whose unity she and I together try to imagine, we use our full capacity to perceive with attention, to represent with skill, to thereby not only recognize but bring into being the real, and, as a result, to affiliate with one another toward a life of health or a life of presence or a life—above all—of meaning.

Thank you.  
Rita Charon

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<sup>1</sup> Banville J. *The infinities*. New York: Alfred A. Knopf, 2010:272.

<sup>2</sup> Charon R, Hermann N, Devlin M. "Close reading and creative writing in clinical education: A reading guide toward attention, representation, and affiliation". *Academic Medicine*. 2015; in press.

<sup>3</sup> Rothko M. *The Artist's Reality: Philosophies of Art*. Edited by Christopher Rothko. New Haven: Yale University Press; 2004:21.