

**Teaching Creativity and Doubt in Health Professions Education  
with Narrative Medicine Methods: Honoring the Stories of Illness**

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The care of the sick unfolds in stories. Who tells? Who listens? What happens as a consequence of the telling that seems universal in health care?

I realized quickly, a young internist in practice, that what I was paid to do was to cohere complex and contradictory stories that I heard—from the patient, the family, the nurse in the ER, the intern on the ward. I knew I could not capture the “truth,” but that I could work toward a provisional sense of the events, at least “true” enough to act upon.

I remember exactly the first time someone—it was literary scholar Joanne Trautmann Banks—invited me to write a story about one of my patients. It was very early in my medical career. I had never done anything like that. “If there’s a part of the story that you don’t know and didn’t ask the patient about, go ahead—make it up. The story won’t be true, but it will help you get to the truth.”

I wrote about a 20-year-old patient of mine whom I called Luz. She came in specifically to get disability insurance, which is a kind of long-term insurance that is awarded to persons too ill to work with a sickness deemed incurable. The illness she thought qualified her for disability was an iron-deficiency anemia, very common among young menstruating women patients. Her anemia was not very severe. She had been given iron tablet to take but never even filled the prescription. Luz lived with her 4 sisters and 1 brother in a tenement house in a small poor town in New York. I remember feeling there was a lot more to the story than Luz was telling me, but I didn’t know how to learn it.

As I wrote the story for this assignment, I imagined that Luz had gotten an offer from a scouting agency to become a model for style magazines. She wanted desperately to do this but could not afford the move to New York City that would be required. The disability income would allow her to move to the city to try out this new dream of a new life for herself.

After I wrote the story, and wondered where on earth did this come from, I continued to see Luz in my medical office. Because I had been thinking very much about her and generating questions about her situation, I could ask her much more clearly to tell me why she needed the disability. I told her that I had been thinking about her and wondering why the disability insurance had become so urgent now.

The story was much worse than the one I had imagined. Luz and her sisters were being physically threatened by their father and uncle. She had already been sexually abused. Their mother could not protect them. As the oldest, Luz had to protect them. She wanted to bring the girls with her to live with their aunt in New York so that the little ones would not go through what she had already gone through.

With the social worker in my clinic, I helped Luz and her mother to find safety in a shelter while offering them all treatment for the traumas they had undergone. As years went by, I became the doctor for Luz’s sisters, then her mother, and, years later, I was asked to care for her father.

What a dramatic lesson in the power of the stories of illness. What this experience showed me was that I, as the doctor, “knew” a lot more about my patient than I realized. The imaginative writing unlocked some knowledge that, until writing, stayed out of awareness. My writing had shown me something about the urgency of Luz’s current state and about her seriousness. Only then could I, with conviction and commitment, invite her to tell me about her situation. The writing had put me very forcefully and unconditionally on her side.

I continued to do this kind of writing on my own, but realized a deep desire to know more about how stories worked, why writing them made me see things I couldn’t otherwise see. So I went to the English department at Columbia and asked them, can you teach a doctor something about how stories work?.

And they did, not letting me out until I had finished my PhD in English.

Stories are not simple things. I worry sometimes in health care that some of us regard stories as easy—oh, yes, you have to get the story from the patient, then you find out what medicines they take, and then you find out what they’re allergic to. Stories are complicated things. They do not display themselves easily to the reader or listener. They have to be entered *into*. Brilliant Canadian short-story writer Alice Munro describes how she reads a story:

I don't take up a story and follow it as if it were a road, taking me somewhere, with views and neat diversions along the way. I go into it, and move back and forth and settle here and there, and stay in it for a while. It's more like a house. Everybody knows what a house does, how it encloses space and makes connections between one enclosed space and another and presents what is outside in a new way.

Reading or listening to a story is an active process, committing, intimate, transformative. When we read, we use all parts of ourselves—cognitive, emotional, metaphorical, relational, mythical, mystical. All our ways of knowing about self and other and the world are mobilized as we try to comprehend what the teller is conveying. Sometimes the first clue about the meaning of a story is the mood in which the reader finds herself or himself. Sometimes it is in what other stories come to mind during the course of reading or listening to the first story. Sometimes the reader comes to a room in the house that is locked. She rattles the door, she hunts in her pockets for the key (this is what I was doing with Luz), she has to admit that there is a patch of darkness, impenetrable, at the heart of the story. Then with the imagination and creative curiosity, the reader will keep wondering at the story's mystery, sometimes finding clues along the way, and sometimes tolerating the doubt inherent in any brush with the mysterious.

Now think about the stories of illness. They are an especially complex brand of stories, because they are "about" the very agency who tells the story. I keep calling the teller of stories of illness "the self-telling body." The patient—the teller of the story—is using the telling instrument, the body, to tell the story about that very instrument. In this redundancy or reflexivity is the invitation for the listener to "use" his or her listening body in response, thereby offering all parts of self in the engagement with the patient.

We tellers and listeners meet *in* stories of illness. The stories treat our mortal human conditions, conditions that we tellers and listeners share. The stories of illness, therefore, call into a clearing all of us at risk for illness. This means all of us humans, mortals, with bodies, who share the same illnesses, who die the same deaths, who gather in these clearings of health.

But entering these rooms of illness means that the listener has to accept the commonality between teller and listener. Entering the rooms of these stories requires that you, as listener, bend to the story's logic—that we are human, and we are mortal, and we have bodies, and we will die.

You have to decide to go into the room. A gifted writer and editor loses her mind to dementia and becomes unable to speak. Instead she makes sounds in human speech that sound like words but are not really words. It is a very complicated form of double-speak. When she speaks to me now in the office or on house calls, I enter her double-speak, simply echoing the sounds she makes with human speech inflections. This allows us to near one another. It also reminds me how easy it is to lose one's mind, and gives me a form of terror.

I had to enter the room of the Antioch Baptist Church for the funeral of a 50 year old woman who used to be my patient with Charcot-Marie-Tooth disease, a congenital neuromuscular degenerative disease that paralyzes patients in their 20s. Her mother, many of her aunts and uncles, 4 of her 6 siblings, and her daughter have the disease. I now take care of her husband, her daughter, and one of her sisters. There were more motorized wheelchairs in that church than I have ever seen in one room. In this case, I had to ponder and quake in the face of the random unfairness of a universe that would inflict such horrible suffering on one family while completely sparing the neighbors, like tornadoes on the plain.

I recently became the internist for a 45-year-old woman whose hypertension and migraines had been out of control for over ten years. She had seen many of the residents in clinic and different doctors in the Emergency Room over the years since these symptoms started. When I first saw her, I learned of her father's death in 2001, which was the start, more or less, of her own symptoms. Her father was a dish-washer in a restaurant in lower Manhattan. It was called Windows on the World. It was on the top floor of the World Trade Center. September 11 was her father's day off, but he switched with a friend. He perished in the September 11 attack.

Other doctors had learned of the father's death. One resident even wrote in her note that the father died in the World Trade Center attack. But there was no follow-up treatment for this patient of her traumatic loss. I learned that for years and years after the attack, the city kept finding pieces of my patient's father's body, little scraps of bone. So the family had to keep having funeral after funeral for this dead man.

In addition to treating her hypertension and headaches, I arranged for her to see the psychologist for trauma care. She and her daughter entered treatment and benefited a lot. Her blood pressure came under control. The headaches improved. I got into the habit of seeing her early every September to check in prior to the memorial services on September 11. Last year, she said to me with clarity in her eyes that she did not have to attend the memorial service, that she was alright on her own.

That room of illness contains one person. And her daughter. And the ghost of her father. And all of New York City. And the US. And the mid-East. And the perils and dangers and terrors of our lives today. This is why these rooms, sometimes, can be very very hard to enter.

What I called Narrative Medicine arose from a confluence of primary care, patient-centered medicine, literature & medicine, and medical humanities. I gathered a team of faculty members at Columbia from the departments of English, creative writing, philosophy, psychoanalysis, oral history, medicine, pediatrics, and family medicine to bring narrative skills and habits into practical use in the clinic. We wanted to answer the lacks in medicine—what is missing in our doctors and nurses that patients find that we don't listen to them and seem indifferent to their suffering. What might we provide to clinicians that might help them to recognize the stories, to recognize their tellers, to enter those rooms.

Narrative Medicine became the name we call health care practiced with narrative routines. The person who practices narrative medicine listens for form as well as plot—not just the facts told but how they are told, what is given as the beginning of the story, what images arise in the telling, what the mood of the story is, what the story reminds you of. Just like what Alice Munro does in entering the room of a story, that person allows himself or herself to be interpretive, imaginative, curious, hypothesis-generating. Virginia Woolf wrote about reading stories by Anton Chekhov. She says in reading Chekhov, you peer around in the twilight, gradually being able to see the order in which he ranges the large objects of life. This is what we do in our listening to patients—we take in the narrative world being described, notice its climate, accept it as provisionally true, follow its rules. Calling this Narrative Medicine is a way of suggesting that the “medicine” offered to a sick person includes the narrative acts of receiving the accounts that others give of self. The listening itself is medicine. The listening itself is necessary for the care.

In Narrative Medicine, both patient and clinician are **self-telling bodies**. Events of the body are understood to be events of life. Sickness or fear of sickness or even the effort to remain healthy are part of the ongoingness of life and not fragmented, isolating, strangenesses of illness. An illness does not alienate a person from himself or herself but becomes part of who they are and the life they lead. This way of thinking erases the magical thought that once you “get over” this illness you return to life as you knew it before the illness. This, we know, is simply not true. Instead, the illness is part of the ongoingness, to be cohered and comprehended and accepted as part of self, part of the story of self, part of the never-ending development of one's identity. To help patients achieve this view of their bodies as parts of their selves, those who care for them cannot treat the disease as something that can be separated, dissected, reduced—the gall bladder, the bi-polar, the amputee. (I remember once while working a busy emergency room shift, I referred to a patient I had just seen to my colleague as “the guy with the neck.” I was horrified.) We can perhaps be more useful to patients by seeing the unity *under* the disease in one of the organs, recognizing and summoning the integrated self of the patient instead of making them feel that they are being treated like just one part—the thyroid, the colon, the left great toe—of that unity.

We write a lot in my practice. I write about patients to understand their situations. I show them what I've written, asking, “did I get it right?” Many times, simply reading what I've written about them will elicit new stories—patients say things like, “We left something out,” and then talk about aspects of their health that it might have otherwise taken me months or years to learn. I share my notes from practice with patients, simply printing an extra copy of the electronic medical record entry that I type into the computer so that the patient has his or her own copy and keeps his or her own chart. Patients write back. Patients have sent me stories they wrote, poems they wrote in prison, other stories or poems that have helped them through a situation. I often have a witness in the office who, with patient's permission, takes field notes like an anthropologist would, of the complex events of our 20 minute clinical encounter. A witness can behold aspects of the medical visit that neither the patient nor I can see, because we are in it. And so the witness notes, that I sometimes share with the patient, become an additional source of evidence of what happened between us in our care.

My position in these encounters is not the typical interviewer/ diagnostician/manager in health care but rather one who enters narrative worlds, those rooms, to behold their mysteries and grave beauty.

What do I learn about my patients that non-narrative medical practitioner might not learn? Is it just “small talk”? Does it matter for their health? My diabetic patients do not always have better control of their blood glucose than do the patients of my colleagues. Nor is blood pressure control universally better. So it does not

automatically translate into improved measurable clinical health. How might we describe the contributions to health care that these methods make? What kind of health is it? Is it a kind of health?

I believe that I have come to perceive things that happen as a result of my growing skill as writer and reader. These things I can now perceive about my patients are important in their care. Narrative Medicine believes that giving and receiving of accounts of self are the central events in health care. Not just in words, of course but in gesture, expression, posture, mood, silence. We understand that illness is a heightened time for *telling*—like any trauma, it has to be *told* in order to happen, in order to know that it has happened. PTSD, rape, torture. Each illness is a non-catastrophic trauma.

Typically in clinical settings, the giver of this account holds back out of fear or doubt or powerlessness while the receiver of this account is not trained in how to receive complex stories from the self-telling body. Our goal in Narrative Medicine is to help the clinician to develop **attention** so that the accounts of illness are fully received. In this way, the patient's situation can be beheld in all its complexity, including its impenetrable patches of darkness, its intolerable doubt. If this state of attention can be cultivated and practiced, it will, we believe, lead to **affiliation** with the patient, that state of unconditional "being on the patient's side" that is the requirement for effective care.

Seeing a patient in clinical practice does not automatically result in attention. As a general internist, I have to do many things at once every time I welcome a patient into the room, as do you all wherever you practice. I am embroiled in the necessity to act. I am confronted with the need to analyze, to judge, to decide. I am beset by states of uncertainty, doubt, the feeling of stupidity, disappointment, admiration, triumph, or love.

How can I achieve attention in the middle of a busy practice? I've gathered from and learned from studies of attention from other fields, and I think this helps us in doing our clinical work. Artist and aesthetic theorist Roger Fry writes, "It is only when an object exists in our lives for no other purpose than to be seen that we really look at it."<sup>1</sup> And Paul Cezanne writes, in a letter to his fellow artist Emile Bernard, "[o]ne should penetrate what one has in front of one."<sup>2</sup>

So in the midst of my clinic session, I've taught myself to attend—to behold and to separate the beholding from the acting. I literally sit back in my chair. When I first meet a new patient, I say two sentences: "I will be your doctor, so I have to learn a great deal about your body, your health, and your life. Please tell me what you think I should know about your situation." And then I listen. I do not write. I do not type. I do not open the computer to the patient's chart. Instead, I place my hands in my lap and listen, trying to absorb all that the patient conveys.

The first time I did this, the 55-year-old man with joint pain told me that his father died 20 years ago of kidney failure. Then his brother died 10 years ago of kidney disease. Then he told me about the trouble he was having with his 21-year-old son who was rebellious, getting into trouble, lost his job. And then he started to cry. I break my silence to say, "Why do you weep?" He said, "No one ever let me do this before."

I wrote a description of that visit, because I thought it was just amazing. I showed the patient what I had written about us, helping him see how much he had taught me that day. He was excited about this and enthusiastically gave me permission to publish the description in an article I was writing for the *New England Journal of Medicine*. That was in 2004.

These experience in my own practice helped me to understand that the writing was important, even if I didn't exactly know why. I knew my goal was not to become a novelist or make my medical students into novelists. In order to learn about these narrative methods, we studied the consequences of writing in clinical settings. One study was on the pediatric oncology in-patient unit. We offered a six-week Narrative Medicine Writing Seminar for doctors, nurses, social workers, and child life workers. Once a week, we met with them in small groups to read together and then to write in the shadow of what we had read. We invited participants to write about particular aspects of their work with these very ill children. And then everyone read aloud what they had written.

We had them do surveys of mood and burnout before and after the seminar. We held focus groups with the participants at the end to learn what they had derived from the seminar. We found that the writing seminar led to improvements in capacity to live with the stress of illness and improved their team work. The seminar let clinicians share what each knew about patients, and helped the different clinicians to near one another. They said in the focus group that the effects of the seminar "spilled over onto the wards," meaning that what they

experienced together in the writing helped them in the care of the individual patients they shared. They have continued to do similar work together since.

We require first-year medical students at Columbia to enroll in Narrative Medicine seminars, giving them a choice of seminars on the writing of fiction, poetry, or autobiography. There are also seminars on visual arts that students take at our magnificent museums in New York in which they represent what they come to learn in visual media. When we ask medical students who took the seminars, “What do you think this is *for*?” they say what they derive from our seminars is affiliation with peers, faculty, and patients; pleasure; a sense of beauty in their work; self-awareness and personal growth; attention to form; and skill in letting stories be told and knowing how to listen to them.

So we are beginning to understand how Narrative Medicine works. By strengthening the skills of representation—writing, drawing, painting—we strengthen the skills of attention. Without the representation, there can *be* no attention. It is when we confer form on our formless or chaotic experiences that we can see them at all. If we do not represent them, and not only by telling about them orally, we cannot capture our experience. One can go so far as to say—and writers like John Dewey and Martin Heidegger have said this—that without representation, one does not undergo the experience to begin with. Philosopher Nelson Goodman reminds us that what we look at when we look at an object is a version or construal of the object. “In representing an object, we do not copy such a construal or interpretation—we *achieve* it.”<sup>3</sup>

These scholars and writers and artists agree that the artist is doing something with and to actual life. These artists are not copying actual life. Instead, they are accepting the value of their own experience of actual life. They are, in a true manner of speaking, living it. The imaginative life is not a cul-de-sac to the actual life or an elective pleasure in which some indulge. Philosopher Susanne Langer wrote that “the arts . . . give form to inward experiences and thus make them conceivable.”<sup>4</sup> (Langer, 87). This is why we do what we do. It is the means by which human beings know what they are doing in life. It is the means by which we live.

Let me close with a story I wrote about a woman whose doctor I had been for decades. I wanted to let her family know how deeply I felt her loss. I sent this description to her son, who sent it to the other members of my patient’s family. It felt to them as a testament to this woman’s life:

I attended a funeral last week of a patient who had been in my care for thirty years. At her death 94 years old, she had suffered serious lung disease, gastrointestinal cancer, broken bones and chronic pain, and had put up with the indignity of repeated hospitalizations and, toward the end of her life, profound frailty. Over the years, I have written about her, getting her permission to publish in a recent book a description of her own anguish upon losing a young beloved son in a drowning accident. In the hospital the day before she died, her family members and I witnessed the Catholic priest anointing her with the holy oil of the sacrament of Extreme Unction. As he intoned the Latin forgiveness of her sins, I realized that hers was a soul unsullied by sin, that this was an unnecessary sacrament. When I saw her in her white coffin, hands bruised from the final hospitalization’s efforts to instill intravenous fluids, and yet beautiful, I understood for myself the living arc of which I had been a part for all those years. The patient’s home health aide, a woman who had been her daily care-giver for twenty years, and I consoled one another—we who were outside the family but able to partake, by virtue of our care for the patient, in the family’s extraordinary embrace of love. At the wake, a handsome man comes up to me, introduces himself as the patient’s grandson, and tells me he is 37 years old with a grown family of his own. I realize he is the son of the man who drowned. “Dr. Charon,” he says, “I remember taking my grandmother to your office years ago. I was only 12 years old.”

What a privilege we are given as nurses and doctors and social workers and therapists, to enter these rooms of illness, to extend the bounds of care, to heal ourselves of the terror of mortality, to contribute to the care of others. Let us in joy accept it.

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<sup>1</sup> R. Fry, *Vision and Design*, ed. J.B. Bullen (Mineola, NY: Dover Publications, 1981), 19, 18.

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<sup>2</sup> P. Cézanne, "Cézanne's Letters to Emile Bernard," in *The Courtauld Cézannes*, ed. Stephanie Buck, John House, Ernst Vegelin van Claerbergen, and Barnaby Wright (London: The Courtauld Gallery in Association with Paul Holberton Publishing, 153), 146-65, at 153.

<sup>3</sup> N. Goodman, *Languages of Art: An Approach to a Theory of Symbols* (Indianapolis, IN: Hackett Publishing Company, 1976), 9.

<sup>4</sup> S. Langer, *Philosophical Sketches* (New York: Barnes and Noble, 2009), 87.