

NARRATIVE MEDICINE  
*Honoring the Stories of Illness*



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ond decimal point from the DSM-IV to signify the condition of a mentally ill patient or a patient asserts that her headaches come from thunderstorms, all who suffer or try to relieve suffering strive to banish the unknown from their ills and to replace it with the known. Even if, in retrospect, the hypothesis of causality is wrong—miasma does not cause cholera, the *Vibrio cholera* toxin does—the hypothesis has functioned to limit uncertainty temporarily, giving at least the impression of purposeful action in the face of the disease and some help in tolerating the uncertainty that remains.

After his hearty, cheerful doctor leaves Ivan Ilych, having lied to him, the specialist arrives:

At half-past eleven the celebrated specialist arrived. Again the sounding began and the significant conversations in his presence and in another room, about the kidneys and the appendix, and the questions and answers, with such an air of importance that again, instead of the real question of life and death which now alone confronted him, the question arose of the kidney and appendix which were not behaving as they ought to and would now be attacked by Michael Danilovich and the specialist and forced to amend their ways. (143)

Ivan dies alone, doubly injured by his disease and the deceit of his doctors and family who have not the courage to face with him the unknown, "the real question of life and death." Nothing will ease patients' uncertainty in the face of illness, but perhaps their doctors can help them to articulate the uncertainty and thereby live less painfully with it. Our clashes, in the end, over the causes of disease signify the desperate need for answers, for knowing, for certainty about why disease comes and how to remedy it. The bridge over this chasm may come not from more knowledge or shared epistemologies but from the bravery to face the contingencies of health and illness and death.

### ■ THE EMOTIONS OF SHAME, BLAME, AND FEAR

The emotions of shame, blame, and fear erect the most unbreachable divides between doctors and patients. I start with shame. Much of what goes on inside the body is, to some people, shameful to discuss. Patients often do not feel comfortable talking with physicians—especially of the opposite gender—about their sexual practices, bowel habits, substance abuse, or emotional problems. Questions about these matters are often left unasked because of embarrassment or humiliation.<sup>28</sup> If patients feel ashamed to talk about such symptoms, doctors are embarrassed to hear them or cannot find the equanimity to ask about them. Furthermore, some doctors cannot ask about particular aspects of patients' symptoms because they fear giving in to voyeurism or unprofessional curiosity. And so the doctor and the patient collude in their experiences of shame or their gambits to avoid it, all of it truncating attention to important aspects of health and illness.

If shame is the interior experience that one must hide from others what one

is, its counterpart, guilt, is the remorseful realization that one has done something wrong. Guilt saturates the lives of patients and health care professionals. Some of the guilt experienced by patients is due—the smoker who develops lung cancer or emphysema *knows* his or her part in having brought it about and, hence, suffers a more complex form of despair than would one who had had no hand in what befell him.<sup>29</sup> The movements to medicalize such conditions as alcoholism, obesity, or drug addiction can be understood, in part, as efforts to absolve sufferers of the full guilty responsibility for their situations and to shift the blame to brain chemistry or genetic propensity. On the other hand, illness seems to induce irrational guilt in patients who search for *something* they may have done to cause their lymphoma or breast cancer or multiple sclerosis, almost as if identifying something concrete in their experience as the proximal cause of an illness is preferable to accepting its random unfairness, even at the cost of assuming some of the responsibility for their illness themselves.<sup>30</sup>

Health care professionals' guilt is a powerful engine for their behavior. We are burdened and also supported by a highly developed sense of personal accountability. When we inevitably err in the course of practice, we must deal with the tremendous pain of guilt. David Hilfiker was perhaps boldest in publishing an account of a really terrible error in the *New England Journal of Medicine*—he had aborted a live fetus on the mistaken belief that fetal death had occurred.<sup>31</sup> Since Hilfiker's brave revelation, there have been many, many such accounts, both in the professional and the lay literatures, confessing serious error and metabolizing the induced guilt. Because we hope that guilt leads to caution and increases safety in the future, we endorse such public displays of personal accountability as mortality and morbidity rounds (professional meetings of a clinical department in which bad clinical outcomes are scrutinized so as to identify fixable sources of error) and the more systems-oriented examinations of error-prone practices endorsed by the Institute of Medicine's *To Err Is Human*.<sup>32</sup> In the face of a more forgiving stance toward medical mistakes, many health care professionals and patients hope to bring about openness in speaking of error, for the sake both of patients and of professionals who suffer from the silence and the concealment induced by guilt.<sup>33</sup>

Blame can block patient and doctor from understanding one another's perspective and achieving good medical treatment. Patients' readiness to blame—and sue—their doctors for bad outcomes leads many doctors to practice defensively and to treat patients with suspicion. (Malpractice litigation is, of course, a most complex phenomenon. Some who study the phenomenon have found that patients sue their doctors when they feel they have not been listened to.<sup>34</sup>) Doctors blame their patients, too, for having caused their own diseases—"What does she expect, she smokes a pack a day for twenty years? What does he want after bacon and eggs every day for breakfast?" Patients are routinely blamed by doctors for the oddest things. "Patient a poor historian," doctors typically say when they cannot follow a complex story of an illness. "Patient noncompliant" says the doctor whose advice to take certain medicines is declined. Such descriptors as "morbidly obese" and "sexually promiscuous" transform a physical or behavioral description into not only a moral judgment of the patient but also an accusation that the patient caused whatever ails her. Interns at a New York City

municipal hospital used to refer to it as the "Hospital for Self-Inflicted Diseases." As soon as the patient is identified as having caused the illness, the doctor's responsibility is accordingly shifted from cure to censor. "We cannot be expected to reverse the effects of decades of physical abuse," reassure the doctors to one another and to themselves. Blaming the patient gives the doctor an excuse in failing to cure disease—if only the patient had behaved!

Of all emotional factors that separate the doctor from the patient, the most powerful and important to face is the fear. Patients come into the doctor's office, even for a routine checkup, with fear in their hearts. "What will she tell me now?" wonders the 48-year-old sedentary man whose father died suddenly of a heart attack at age 49. "Is he going to make me get a mammogram?" broods the middle-aged woman who cared for her aunt through a long, slow death from breast cancer. "Can they tell if my baby got it?" thinks the young pregnant woman afflicted with sickle cell disease, hospitalized already 52 times in her short life, looking ahead to strokes, infections, and always in pain, tormented that she may have bequeathed this curse to her yet-to-be-born child.

Unless the doctor has recently been ill or has illness in the family, he or she will not as a matter of routine be attuned to the patient's fear. Doctors know cognitively that patients fear for their health, and they understand abstractly that patients will be apprehensive as they wait to hear a biopsy report or a diagnostic test result. Yet the depth of the anguish cannot be appreciated by the person in health. In the same way that pain is difficult to remember once it is over, fear is difficult to imagine when one is not afraid. The doctor setting about his or her routine, medical chart open, computer screen showing that the 48-year-old man's LDL cholesterol is 167 and that the middle-aged woman's mammogram is overdue cannot enter the patient's state of fear. It is usually a soundless fear. The body tells—in tremor, in nausea, in paleness, in sweat—what the words cannot: I will die and my kids will lose their dad at 14 like I did; I will develop the horrible disease that killed Aunt Bernadette; my baby will suffer as do I.

The doctor, too, undergoes deep and painful emotions in his or her care of the sick. Although the patient's suffering must remain at the heart of medicine, it is undeniable that doctors, too, suffer through the illnesses of their patients. The most moving evidence of such emotional suffering is to be found in the hundreds of memoirs of training written by medical students and physicians.<sup>35</sup> Although the specifics of the suffering may change—paralleling the technological realities of practice—the heart of the suffering remains the same: shame at being powerless, guilt and rage in the face of the blame, and fear of all the dying.

Sadly, though, these dual sufferings are not joined. A metaphor can be taken from child psychology. Before infants develop the intersubjective capacity to respond to one another, they engage in what psychologists call parallel play, in which they play happily alongside one another without true interaction. It is only when infants mature into the capacity for relation that they are able to enjoy collaborative play, that is, playing *with* instead of simply playing *next to*. At this stage, the unique contributions of each "player" are allowed to inflect and give meaning to the activity of the other, heralding the beginning of genuine relation. In like manner, patients and doctors seem to engage in parallel suf-

fering, in which both parties suffer, but they suffer in isolation from one another. Only with the capacity to be open to genuine intersubjectivity can these two participants approach an authentic relation in which the suffering does not separate them but is shared. Once shared, the suffering is lessened.

What power would devolve on our medical care if these two could take stock of one another's emotions and engage fully in their joint suffering. The intersubjective recognition of doctor by patient and patient by doctor would deepen knowledge, steady presence, and prove commitment. Such mutual recognition, transcending parallel suffering, would enable them both to reflect on their common journey and, by virtue of being "together" on it, would lessen one another's suffering. The practical effects of such a change on the delivery of health care would be impressive, leading to more accurate knowledge of the patients' experience of illness and a realistic understanding of the powers of medicine to counter the disease. More of the patient's difficulties would be acknowledged and faced, while care would proceed in full view of the uncertainty and limitations of our science. By recognizing the mutuality of their work together, patient and doctor would call forth the authentic in one another. Together, they would stay the course.

### ▣ BRIDGES WITHIN OUR REACH

This encounter between health professional and patient lies at the heart of medicine. So many pitfalls are possible—the professional might not be smart enough, patient enough, imaginative enough; the patient might not be trusting enough, brave enough, receptive enough. Yet from this inauspicious meeting between two unlike people proceeds whatever healing medicine might provide. Perhaps caring for routine or trivial or reversible symptoms can be accomplished despite such divides. But when faced with serious, life-threatening illnesses that come randomly, unfairly, and without warning, how can these two people reach toward health?

I remember taking care of a gravely ill elderly man in the hospital. I was an intern—sleep-deprived, unused to my authority, unsure of what to do for this patient. He was irretrievably sick, bed-bound for months, with a large infected craterlike skin wound on his lower back. He had a serious infection in the blood, and his kidneys were failing. Multiple strokes had left him comatose for many months in the nursing home. And yet his wife sat at his bed all day, every day. I remember her tasteful blouses and her pearls. She would ask me every day, "Is he going to be all right?" And I would page the plastic surgeon to come attend to my patient's wound. Eventually I learned to debride the wound myself, for plastics would not come. The surgeons could do nothing to save my patient's life. I did not know he was beyond saving. I was alone with his wife in her pearls, her life that was coming apart, and I couldn't get plastics to come. We were in it, together, we three—this gravely ill man trying so hard to die, his wife bereft by his loss and unable to fathom her life without him, and me, the intern, who wanted like crazy to save him.

toward the patient until writing. Looking up definitions of the words "empathy" and "pity," he expected of himself the same clarity in anatomizing his feelings that he did in presenting the clinical events. As a result of representing both the patient's actions and his own responses, he uncovered the dualities of this care—two immigrants, one unaware and the other aware, one ill and the other committed to caring for him. What impressed the listeners of Tolu's story was the exacting demand the writer placed upon himself to visualize, comprehend, and claim his own slow movement toward this patient, reflecting in the gravity of his prose the weight of his own professional duty. We all agreed that Tolu had, after all, achieved empathy for his patient, for his pity enabled him to see the events from the patient's perspective, not only recognizing the stated aspects of the situation but also even imagining the patient's fears for his future.

### BIJAN

Bijan next read from his text. He was helping to take care of a 65-year-old man with idiopathic pulmonary fibrosis, a debilitating lung disease whose only definitive treatment is lung transplantation. This patient had been on the list to receive a lung transplant for the past nine years, but he had not had the good fortune to receive one of the rare donated organs. The student has just learned that the patient has been taken off the list because of his age.

My mind began to wander as I put down the phone and started writing in the chart. . . . I had just finished talking to Mr. Encarnacion's pulmonologist, Dr. M, about why Mr. Encarnacion recently had been taken off "the list" for a lung transplant and a new life. Dr. M had rather matter-of-factly informed me that the age "cut-off" for lung transplants was around 60, and that Mr. Encarnacion, being 65, *became* ineligible because his age boded poorly with respect to prognosis. . . .

Irrespective of the reason for taking Mr. Encarnacion off the list, what I was faced with was that he *had* been taken off of it, and was now left without the only known cure for his inexorably progressive disease. And as I had started writing my note, the word "cut-off" had stared up at me from the crisp white page below. A funny word, I thought; did Dr. M even realize the twisted pun within his own phrasing? To him—in fairness, to the rationalist—the cut-off was an austere, unprejudiced number that signified that the risks for transplant outweighed the benefits. But to me, the "cut-off" was a concept that conjured up the image of a vivid dream of falling off a rocky cliff. . . . This "cut-off," little black letters with the trace of an ink smudge, signified to me the cutting off of a life. Due to the simplicity of one designated number, all Mr. Encarnacion's hopes for the last nine years were effectively now extinguished, and he was being left to die.

I couldn't help but think how Mr. Encarnacion had dealt with the news when he had first found out, and how I would deal with such news if I ever were

on the receiving end. How in the world had he gotten to the point where he could tell me with a wry smile that barely crept out from behind his green oxygen mask, "I used to be strong like a bull. That will never again be possible." Had he cried when he found out? Had he been strangely relieved that his wait in uncertainty was over? Or had he simply taken things in stride, knowing all along that hope was futile? At the time, I didn't have even the ability to guess. I figure now that I could have asked him—I could easily have mustered up the courage to get up and walk down the hall, past my own fears that made the hallway so uninviting, and over the threshold of his room. . . . He would have answered me calmly and I would have been crushed by visions of my own mortality and fleeting, fragile existence; I would have left the room an enlightened and broken student.

But I never went into his room; I finished my note and went to lunch because I just didn't have the strength to confront the inevitability of my own death—possibly, hopefully, many years ahead of me. At that moment, it was way too close; so close that I couldn't face Mr. Encarnacion's acceptance of his fate; it was just too eerie, much too unnatural, and very very frightening.

There are many "I's" here: the I who writes in the Parallel Chart, the I at the nurses' station trying to write a note in the chart, the I of a few days ago talking with Mr. Encarnacion, and, of course, the I of Bijan sitting with us in the room, reading what he had written. Noting the verb tenses that mark the story's temporal scaffolding lets the reader appreciate the complex unfolding of the many separate sets of events: the past perfect participial "I had just finished talking" is distinguished from the simple past of "My mind began to wander." Within the first two sentences, the reader or listener realizes that these time periods are laid like transparencies over one another. It is not until the end of the text that we realize how far forward in the life of the author this transparency reaches.

What impresses me about this piece of writing is the way in which the author has gained access to the *connections* among these different I's, in effect harnessing the power of the autobiographical process. From the remove of his current position, he inspects his thoughts, feelings, and actions of the immediate past and of the slightly more remote past. By representing himself as he sits writing his note, he recaptures—or probably captures for the first time—the complex emotions and realizations that emerge in the scene. He *finds* that it is his fear of his mortality that prevents him from entering the patient's room. This discovery is based not just on the plot of the event but also on how it is told. For example, the use of the word "cut-off" is complex and instructive. It becomes a fetish in the story—an object, smudged on the page—as well as a metaphor connecting the nightmare of "falling off a rocky cliff" to the concept of the age limit for medical treatment.

As the reader juggles the many time periods simultaneously in mind—the putting down of the phone and the wandering of the mind—more remote events in both past and future intrude. The patient says in an unspecified past, "I used to be strong like bull," and the narrator imagines the conditional future of "I would have been crushed." Finally, in what the writer hopes is the remote future

but is now visible by virtue of his narrative creation is the time of his own death.

One week after the student wrote this essay and read it to his classmates, he visited Mr. Encarnacion with me. During our visit to the bedside (I was there to observe him conducting a clinical interview and contributed nothing to the actual conversation), the student asked the patient and his wife how they had felt when Dr. M told them that Mr. Encarnacion was no longer a candidate for lung transplantation. Both the patient and his wife wept on hearing the student's question. They spoke at length about their children and grandchildren, and they expressed with great eloquence their trust in God and acceptance of their earthly fate. From then on, Bijan was the most trusted member of the medical team for the Encarnacions, who relied on his advice and guidance in making all future medical decisions.

Months later, the student was asked to comment on his writing in the Parallel Chart:

In one or two cases, I wrote about something I had seen that did not "feel right"; as I wrote, I realized that this was something that was actually bothering me without my realizing it. . . .

After writing down my thoughts for each chart entry, I developed them—trying to find themes and organizing my thoughts to make each chart entry able to "have a meaning" and to be able to stand on its own as a writing sample (and not just as a piece of paper with thoughts written down on it). As this happened, I realized that my thoughts became more structured, and that what had previously simply been an expression of "not feeling right" was now able to be translated into something more meaningful. *In other words, I attempted to transform feelings into organized themes.* As a result of this I was able to find that what really made me feel uncomfortable about Mr. Encarnacion and his ordeal was the fact that I found it difficult to confront my own weaknesses and mortality. I do not think that I would have been able to discover this had I simply written down my thoughts and left them there without editing directed at finding a meaning within what I had written. Likewise, I certainly would not have been able to discover this had I simply spoken about the topic. . . .

I think that this self-discovery enabled me to improve upon how I dealt with individual patients; becoming more comfortable with my own feelings enabled me to focus on the problems of the patient. For example, when we broached the subject of death with Mr. Encarnacion, I was certain of how I felt about it and was able to concentrate my efforts on attempting to make Mr. Encarnacion feel better. [Italics in original.]

Able to report on the activities of his past self's wandering mind, this writer used the practice of autobiographical writing to overhear the language of his prior experiencing self. By writing and editing the resultant text, the student becomes his own reader and interpreter, using the autobiographical gap as an invitation to reflect on the self. That the student credits his writing and rewriting with the insight and wherewithal to do what needs to be done clinically—to

talk with the patient and his family about this serious development in his health—gives us great heart that narrative training has practical consequences for the student or health care professional.

### ▣ NELL

Nell was the last student to read from her Parallel Chart.

One day last week, during hour two and a half of rounding, I saw a young man walking down the hospital hallway towards me. The seven of us on my team were standing in a circle, the two interns, the two attendings, the resident and my fellow student; I was the only one facing his direction. He was unassuming, of average height and build, with wavy brown hair, green eyes and glasses. He had no shoes on, only gleaming white socks. He kept trying to catch my eye, like he knew me, as he walked towards us down the hall. He had a mischievous smile on his face. When he was only two feet from the group, he winked at me. Quickly. Joyously. As if we were in on some great joke together. I don't know if it was my sleep deprivation or the blood rushing from my brain after standing so long, but I thought to myself what if this young man, who seems to want to let me in on his prank, was God? The idea filled me with joy. It was revitalizing. What a strange thought to have! Why would I think that, I asked myself? First, this is exactly where God would want to hang out, in a hospital amongst the sick and the dying and amongst those always around the sick and the dying. And this is exactly how God would want to appear, as a patient, though one inexplicably cheerful in the face of suffering. And why not? He's in on the joke that the rest of us aren't. Finally, God would definitely not want to wear shoes. I can't picture God in shoes.

I was hoping that God would visit some of my patients. Let them in on what was so funny. I hoped he would stop by the room of my 35-year-old patient with CF, now three years older than she ever should have been. God could put on His contact isolation precautions and go in for a chat, put His socked feet up on the windowsill. He could explain why a 35-year-old woman is in the hospital, drowning. Why she is the youngest person on the floor by forty years. Why she is counting the rest of her life in months.

After God told that patient His joke, maybe he could move down the hall and look in on another patient of mine. His ALS has left him trapped in a coffin that once was his body, no longer able to eat, to urinate, to move and almost to breathe. Any day and that will be gone too. He can understand though, his mind is still there. He would want to know God's joke, I think he would appreciate it. If it's a good day, my patient might be able to wink back at Him.

And last of all, I hope God comes back my way and lets me in on the secret. Maybe then I can know how to handle pain and sickness on a daily basis, how to welcome death in the second case and accept it in the first. How to sit with suffering, anger and regret without wanting to avoid it and save myself. The secret