

PART I



What Is Narrative Medicine?

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I ■ THE SOURCES OF NARRATIVE MEDICINE

Medicine has grown significantly in its ability to diagnose and treat biological disease. Doctors can be proud of their ability to eradicate once fatal infections, prevent heart attacks, cure childhood leukemias, and transplant failing organs. But despite such impressive technical progress, doctors often lack the human capacities to recognize the plights of their patients, to extend empathy toward those who suffer, and to join honestly and courageously with patients in their struggles toward recovery, with chronic illness, or in facing death. Patients lament that their doctors don't listen to them or that they seem indifferent to their suffering. Fidelity and constancy seem to have become casualties of the cost-conscious bureaucratic marketplace. Instead of being accompanied through the uncertainties and indignities of illness by a trusted guide who knows them, patients find that they are referred from one specialist and one procedure to another, perhaps receiving technically adequate care but being abandoned with the consequences and the dread of illness.¹

A scientifically competent medicine alone cannot help a patient grapple with the loss of health and find meaning in illness and dying. Along with their growing scientific expertise, doctors need the expertise to listen to their patients, to understand as best they can the ordeals of illness, to honor the meanings of their patients' narratives of illness, and to be moved by what they behold so that they can act on their patients' behalf. Nurses and social workers have mastered these skills more fully than have physicians, but all can join in strengthening these capacities in health care.

Doctors, nurses, and social workers began turning for help in these areas to people who know about narratives, which can be defined as stories with a teller, a listener, a time course, a plot, and a point. Teachers of literature, novelists, storytellers, and patients who have written about their illnesses have become collaborators at our medical centers in teaching health professionals the skills needed to listen to narratives of illness, to understand what they mean, to attain rich and accurate interpretations of these stories, and to grasp the plights of patients in all their complexity.² These are narrative skills, for they enable one person to receive and understand the stories told by another. Only when the doctor understands to some extent what his or her patient goes through can medical

care proceed with humility, trustworthiness, and respect. I use the term *narrative medicine* to mean medicine practiced with these narrative skills of recognizing, absorbing, interpreting, and being moved by the stories of illness. As a new frame for health care, narrative medicine offers the hope that our health care system, now broken in many ways, can become more effective than it has been in treating disease by recognizing and respecting those afflicted with it and in nourishing those who care for the sick.

Years ago when I was just out of internal medicine residency training, I would sit in a little clinic room in Presbyterian Hospital, getting to know relative strangers who were to become my patients for more than 20 years. Most were poor, sick, elderly women of color—from the Dominican Republic, Puerto Rico, Central America, and the American South—who now lived in Manhattan’s Washington Heights or Harlem. I realized slowly that my task as an internist was to develop the skills required to absorb my patients’ multiple, often contradictory, stories of illness. I came to understand that what my patients paid me to do was to listen expertly and attentively to extraordinarily complicated narratives—told in words, gestures, silences, tracings, images, laboratory test results, and changes in the body—and to cohere all these stories into something that made provisional sense, enough sense, that is, on which to act. These narratives had many tellers—the patient herself or himself, as well as family members, friends, nurses in the emergency room, interns dictating hospital discharge summaries, social workers, therapists, and all the other doctors who wrote in the medical chart. What I was listening for and reading for were diagnostic clues to help identify a biological or emotional source of the patient’s symptoms, autobiographical background to help me understand who it was who bore these symptoms, and grounds for personal connections between the two of us sitting in that little room.

In order to do all these things at once, I had to do what all doctors—ideally—do, whether they realize it or not. I had to follow the patient’s narrative thread, identify the metaphors or images used in the telling, tolerate ambiguity and uncertainty as the story unfolded, identify the unspoken subtexts, and hear one story in light of others told by this teller. Like the reader of a novel or the witness of a drama—who naturally do all these things seamlessly—I also had to be aware of my own response to what I heard, allowing myself to be personally moved to action on behalf of the patient. I was the interpreter of these accounts of events of illness that are, by definition, unruly and elusive. I saw that, while I had very demanding “listening” tasks, the patient’s “telling” tasks were even more demanding, because pain, suffering, worry, anguish, and the sense of something not being right are conditions very difficult, if not impossible, to put into words.

Around that time, the movement called “literature-and-medicine” was just starting to grow, and I was fortunate to be included in a National Endowment in the Humanities Seminar on Literature and Clinical Imagination in 1982. Joanne Trautmann Banks, editor of Virginia Woolf’s letters and the first literary critic to be appointed to a medical school faculty, directed a monthlong intensive training program in literary theory, texts, and methods salient to medicine. Part of

the training was encouragement to write, in ordinary narrative prose, about our clinical practice. I chose to write about a patient I had just seen the week before the seminar started, because I was unhappy about how I had behaved toward her and it nagged at me that I had acted brusquely and dismissively without knowing her situation. So I wrote a story about this incident, filling in with fiction the gaps there were in fact.

I was picking up some papers from my office, in a hurry, and was stopped by a young woman patient who had dropped in to ask me to sign a disability form for her. I had seen her a couple of times in the office for the evaluation of headaches, headaches that I had not considered terribly worrisome and for which I had prescribed acetaminophen. I remember being irritated, not only that she thought she deserved disability on such slim clinical grounds but that she would appear, without an appointment, and expect me to make time to fill out the form. But I was late for a meeting and did not have the time to inquire about the situation, so, without even putting down the stack of papers in my arms, I quickly scrawled a diagnosis and signed the form, no doubt conveying my displeasure at the patient's request.

In my story, the patient—I called her Luz—had a chance at achieving her dream of becoming a fashion model. Her aunt in Manhattan had met a contact at a big agency and urged Luz to move in with her from Yonkers while preparing for auditions. The disability payments, in my story, would give Luz a needed income while she got a portfolio together and tried to make her dream come true. I wrote the story from Luz's point of view, and the story ends with Luz musing about how hurried her doctor was and how scornful she seemed to be.

When I next saw the patient in the office soon after the seminar concluded, I had been thinking about her a great deal and trying to inhabit her point of view. I had tried, in my imagination, to make sense of her unexplained behavior while realizing what my own behavior must have connoted. And so I asked her with great interest and regard about the situation, apologizing for having brushed her off so quickly the last time.

The stakes were much, much higher in fact than in my imagined fiction. Indeed, Luz *did* need the disability payments to tide her over for an emergency move to Manhattan. But it was not in search of a career in fashion. Luz was the oldest of five daughters, all of whom were being tormented by their father and uncle in their crowded apartment in Yonkers. My patient had been sexually abused since she was twelve, and now she refused to stand by and allow the same thing to happen to her younger sisters. She felt, at age twenty-one, that she could set up a safe house in Manhattan to protect herself and her sisters.

Once I learned all this, the social worker in the domestic violence project and I introduced Luz and her sisters to emergency shelters and support groups and gave them needed resources in facing the violence in her family. They did move to Manhattan, taking their mother, too, away from the abusive male relatives. Over the years, I have taken care of three of the five sisters and their mother. When the father became terminally ill, the women in the family asked me to be his internist too.

Luz taught me about the power of the clinical imagination. Although I did

not know what had preceded her visit that day, I had wordlessly registered her urgency and need to leave home. Until my impressions were expressed in language, I did not know what, in fact, I *knew* about the patient. My hypothesis about the modeling career was all wrong—in my story, Luz was running *toward* something, when, in fact, she was running *away*—and yet my acts of guessing at the patient's situation and trying, imaginatively, to make sense of her behavior had some profound dividends. The hypothesis acted like a prosthetic device or a tool with which to get to the truth, like a crowbar or a periscope will enable you to see under a rock or over a wall. Also, this narrative act helped me to get closer to the patient. My writing exercise *invested* me in learning of her true plight instead of blaming her or suspecting her of malingering. The effort, required by my storytelling, to reach for and visualize Luz's point of view helped me take care of the patient by bringing me to her side, seeking to understand her behavior, taking seriously her situation, and gaining access to the unsaid knowledge I had already developed of her strengths and desire.

In the ensuing years, I have come to realize that these narrative skills are deployed not only in the encounter between an individual patient and doctor but throughout the enterprise of medical practice: teaching, doing research, understanding and diagnosing disease, reflecting on one's life in medicine, interacting with professional colleagues, and fulfilling the public responsibilities of medicine.

THE NARRATIVE ROAD TO EFFECTIVE MEDICINE

Health professionals and patients are at a crossroads. Together, we have to discover means of sustaining the tremendous capabilities of our biomedical sciences while trying to ease the suffering and loss occasioned by serious illness. The price for a technologically sophisticated medicine seems to be impersonal, calculating treatment from revolving sets of specialists who, because they are consumed with the scientific elements in health care, seem divided from the ordinary human experiences that surround pain, suffering, and dying. Whether to protect themselves from the sadness of taking care of very sick people or to guarantee the objectivity of their clinical judgment, doctors seem to operate at a remove from the immediacy of sick and dying patients, divided from sick people by deep differences in how they conceptualize illness, what they think causes it, how they choose to treat it, and how they respond emotionally to its presence. Patients long for doctors who comprehend what they go through and who, as a result, stay the course with them through their illnesses. A medicine practiced without a genuine and obligating awareness of what patients go through may fulfill its technical goals, but it is an empty medicine, or, at best, half a medicine.³

Although they may not show it, doctors, too, long for a medicine different from the current fragmented bureaucracy that health care has become. Everywhere—in high-powered academic medical centers, in small-town hospitals, and in rural communities—clinicians seek out means by which to reflect on their practice, to talk to one another seriously and intimately about their lives around

sickness, and to grasp with as much accuracy and emotional clarity as they can what their patients undergo in serious illness.⁴ On my many visits to distant medical centers, doctors, nurses, and social workers attend workshops where they can write about their lives with patients, ruminate together about their feelings and failures, and review with joy their triumphs. What the participants in my workshops understand urgently (although perhaps preverbally) is that the self is the caregiver's most powerful therapeutic instrument and that effective health care professionals have to find means toward self-knowledge, forgiving self-criticism, and inner nourishment.⁵

Doctors with long lives in medicine behind them know what has been disrupted by the recent economically driven changes. They join primary care physicians and proponents of patient-centered health care in their belief that doctors should grow with their patients, getting to know their bodies and their lives through decades.⁶ They know how the knowledge doctors accrue about their patients' families, fears, and hopes and the trust they earn through dutiful attention are critical to their providing their patients with effective health care.⁷ Not only the personal dimensions of disease but its biological dimensions become clear only over time: to understand what disease a patient might have requires schooled longitudinal curiosity about that person's state of health. Sicknesses declare themselves over time, not in one visit to the consultant. The doctor who has accompanied a patient over a prolonged period of time will have the bank of biological knowledge about that individual necessary for timely and accurate diagnostic vision along with the muscular therapeutic alliance necessary to engage the patient in effective care.⁸

If doctors seem divided from their patients and from themselves, they also seem divided from their students, from one another, from other health professionals, and from the society they are meant to serve. The personal mentorship and role modeling that was once the hallmark of medical education have been eroded by time and money pressures. The competitive—and deficit—environment of most teaching hospitals leaves little room for the dutiful raising of young professionals or the nurturing of those in full career.⁹ Instead of committing themselves to the professional development of their members, professional medical organizations more often indulge in legislative lobbying or market positioning. Turf battles threaten to undermine respectful alliances with nurses, physician assistants, social workers, therapists, and psychologists, leaving many health professionals feeling isolated, distrusted, and struggling against one another instead of working together on behalf of the patient. The threat of malpractice litigation leaves doctors feeling they must practice a rigid, suspicious medicine. And, as medicine has had to round up on itself defensively, it is less equipped to initiate honest and consequential dialogue with the public about such grave issues as equity in health care, the limits of medical power, and the ideals of health care envisioned—and invested in—by this country.

Medical schools, residency training programs, and professional societies have, in the past two or three decades, responded to the need to humanize medicine. In addition to equipping students and doctors with sophisticated technical knowledge and skills, medical educators are working hard to enable physicians

to practice with empathy, trustworthiness, and sensitivity toward individual patients. Such developments as biopsychosocial medicine, primary care medicine, bioethics, and professionalism in medicine have arisen since the 1960s to widen doctors' narrow focus on biological disease and to encourage them to take stock of patients' emotional, social, and familial needs.¹⁰ These movements have led to several major advances: training in communication skills in medical schools, research and teaching in the social and emotional dimensions of health and illness, awareness of ethical aspects of health care, and attention to doctors' own well-being and personal awareness.¹¹

Until recently, however, these efforts have not had much impact, because no one knew very well how to describe the traits lacking in medicine nor how to teach them. Most agree that medical schools and training programs cannot train adults to be empathetic, respectful, altruistic, and ethically responsible, for such traits are developed and nurtured from infancy onward. Indeed, it is charged that doctors' innate empathy, respect for the suffering of others, and ethical discernment *diminish* in the course of medical training and that doctors become hardened against the suffering they witness through their education.¹² How, then, are we to advance beyond the uncomfortable state of knowing what the matter is but being unable to fix it?

Even if medical educators cannot require a student to respond to a patient's suffering with compassion, they might be able to equip students with compassion's *prerequisites*: the ability to perceive the suffering, to bring interpretive rigor to what they perceive, to handle the inevitable oscillations between identification and detachment, to see events of illness from multiple points of view, to envision the ramifications of illness, and to be moved by it to action. Those who espouse professionalism have learned already that, however highly medicine might prize altruism and accountability, doctors cannot be forced to practice with these traits unless they are helped to develop the antecedent skills required to reflect on their work, to recognize the duties incurred on them by virtue of being doctors, to feel rewarded by the humble intimacy afforded by trustworthy medicine, and to unite with their colleagues in swearing to uphold medicine's ideals. And, however urgent seems the national need for frank discourse and consensual decisions about our health care system, one cannot expect doctors and other health professionals to take the lead in opening the complex and risky discussions that must take place without providing them with the skills of respecting multiple perspectives, hearing and mediating competing voices, and recognizing and paying heed to a multitude of contradictory sources of authority.

To provide to medicine what it lacks today, we have to conceptualize the problems in terms global enough to envision the whole and practical enough to suggest workable solutions. I think it helps us to see that many of the failures of contemporary medicine are concentrically widening consequences of the same set of fundamental problems. Whether enacted in the situation between an individual doctor and patient, within the doctor himself or herself, among medical and nonmedical colleagues in the health professions, or in dialogue with the larger society, medical practitioners often seem isolated from authentic engagement, unused to recognizing others' perspectives and thereby unable to develop

empathy, and at a loss to understand or to honor the meanings of all that they witness.

To know what patients endure at the hands of illness and therefore to be of clinical help requires that doctors *enter* the worlds of their patients, if only imaginatively, and to see and interpret these worlds from the patients' point of view. To reach accurate diagnoses calls for the kind of lived-in, tacit knowledge of disease and health available only through immersion in the natural history of diseases and scrutiny of the changes in individual patients' bodies over long periods of time. To take stock of the costs and rewards of a life lived around sick and dying people entails reflection and self-examination, while to make oneself available to patients as a therapeutic instrument demands risky self-knowledge and personal awareness. To fulfill one's duties toward colleagues and students, to admit mistakes and to lessen the chance of their occurrence, and to commit oneself to medicine's ideals flows from one's fidelity to an affirming yet disciplined (and potentially disciplinary) professional community. And to bring about meaningful decisions with the public regarding matters of health requires the sophisticated communication powers to open fear-laden discussions without triggering defensive anger and to illuminate, despite multiple clashing perspectives, common goals and shared desires.

To accomplish all these goals—empathic and effective care of individual patients, candid reflection, professional idealism, and responsible societal discourse about health policy—requires a unified set of skills. To do all these things requires what psychologists and literary scholars call narrative knowledge, that is, the kind of knowledge that Luz taught me years ago. If narratives are stories that have a teller, a listener, a time course, a plot, and a point, then narrative knowledge is what we naturally use to make sense of them. Narrative knowledge provides one person with a rich, resonant grasp of another person's situation as it unfolds in time, whether in such texts as novels, newspaper stories, movies, and scripture or in such life settings as courtrooms, battlefields, marriages, and illnesses. As the literary critic R. W. B. Lewis writes, "Narrative deals with experiences, not with propositions."¹³ Unlike scientific knowledge or epidemiological knowledge, which tries to discover things about the natural world that are universally true or at least appear true to any observer, narrative knowledge enables one individual to understand particular events befalling another individual not as an instance of something that is universally true but as a singular and meaningful situation. Nonnarrative knowledge attempts to illuminate the universal by transcending the particular; narrative knowledge, by looking closely at individual human beings grappling with the conditions of life, attempts to illuminate the universals of the human condition by revealing the particular.¹⁴

Medicine can benefit from learning that which literary scholars and psychologists and anthropologists and storytellers have known for some time—that is, what narratives are, how they are built, how they convey their knowledge about the world, what happens when stories are told and listened to, how narratives organize life, and how they let those who live life recognize what it means. Using narrative knowledge enables a person understand the plight of another by participating in his or her story with complex skills of imagination, interpreta-

tion, and recognition. With such knowledge, we enter others' narrative worlds and accept them—at least provisionally—as true. Our genuine curiosity and commitment toward the truth enable us to peer through the twilight of another's story as we try to see the whole picture and as we reflect on what it might mean. We recognize what parts we play in one another's lives and how entailed we are in our shared creation of meaning. We get to know ourselves as a result of the vision of others, and we are able to donate ourselves as instruments of others' learning.¹⁵

This form of knowing about the world that makes sense of the told predicaments of others—risky, demanding, self-defining, horizon-opening—seems to be at least part of what medicine today is lacking. Narrative medicine—or medicine practiced with narrative competence—is at once attuned to the individual patient, replenishing for the individual professional, dutiful in generating and imparting medicine's knowledge, and cognizant of the responsibilities incurred by the public trust in medicine.¹⁶ Narrative medicine can help answer many of the urgent charges against medical practice and training—its impersonality, its fragmentation, its coldness, its self-interestedness, its lack of social conscience.

Narrative medicine not only describes an ideal of health care but also provides practical methods to develop the skills needed to reach that ideal. Narrative medicine recognizes that some of the skills currently missing from medicine are, in fact, narrative skills, that we know what narrative skills are, and that we know how to teach them. Literature departments, creative writing courses, anthropology and ethnography departments, and psychotherapy training programs, among many others, have developed well-tested methods of teaching students how to read, write, and interpret texts; how to systematically adopt others' points of view; how to recognize and honor the particular along with the universal; how to identify the meaning of individuals' words, silences, and behaviors; how, as a reader or a listener, to enter authentic relation with a writer or a teller or a text; and how to bring one's own thoughts and sensations to achieving the status of language. We know how to educate students in these skills. We just have not been doing it in medical schools or nursing schools. By recognizing these skills as fundamentally narrative competencies, medicine is beginning to know how to provide them.

HOW NARRATIVE COMPETENCE ENTERS MEDICINE

An 85-year-old woman with bad asthma comes in to see me. I've know her for almost 20 years. We have managed to decrease her hospitalizations and emergency room visits dramatically over the years, and so she is grateful and I am proud. Today she sits and weeps. I know that her 28-year-old grandson just last week drowned in the ocean off Miami. I know that her son, this dead man's father, was shot to death on the streets of Harlem at the age of 36. She sits next to me and she weeps. Her English and my Spanish enable us to reach one another. Her pain is unbearable. Suffering again the loss of her son by virtue of the loss of her

grandson, she is overwhelmed by her grief. Yes, she prays to a God she still feels near; yes, she is comforted by the presence of her daughter; yes, she allows herself to talk about her two lost men. She knows that time will heal her pain, and she knows to wait. I weep with her, unable to fathom her agony but able to honor her bereft state. I listen as she tells of her anguish, knowing that her telling of it is therapeutic. I will see her next week, and the week after that, not to fix anything but simply to watch with her, to listen to her, to behold, in awe, her faith and power and love.

Medicine is joining other disciplines such as anthropology, history, psychology, social science, law, and even mathematics in recognizing the elemental and irreplaceable nature of narrative knowledge.¹⁷ A narrative shift has taken place across these many fields of human learning, challenging scholars and practitioners from religious studies to psychoanalysis to police work to concentrate on not just the facts but the situations in which these facts are told.¹⁸ Although narrative is defined somewhat differently by literary scholars, psychologists, autobiographers, and historians, each of these narrative-users shares fundamental ideas—that narrative knowledge and practice are what human beings use to communicate to one another about events or states of affairs and are, as such, a major source of both identity and community. The narrativist turn that has overtaken many fields exposes the centrality of storytelling in many human activities from teaching kindergarten to enacting religious faith. Telling stories, listening to them, being moved by them to act are recognized to be at the heart of many of our efforts to find, make, and honor meaning in our lives and the lives of others.

Narrative is a magnet and a bridge, attracting and uniting diverse fields of human learning. The Ozark storyteller knows something that helps the lawyer in the courtroom. The police officer interviewing the crime victim adopts methods developed by the anthropologist in the field. The richness and exhilaration of narrative studies today, whether in the social sciences or in journalism or in a class on Henry James, arise from our recognition of our common concerns and shared goals. In an age of specialization and fragmentation, how satisfying to discover the deep, nourishing bonds that hold us together—storytellers all, bearing witness to one another's ordeals, celebrating our common heritage as listeners around the campfire, creating our identities in the stories we tell.

As an enterprise in which one human being extends help to and shares knowledge with another, medicine has never been without narrative concerns. Like narrative acts, clinical practice requires the engagement of one person with another person and realizes that authentic engagement is transformative for all participants. Narrative competence permits caregivers to fathom what their patients go through, to attain that illuminated grasp of another's experience that provides them with diagnostic accuracy and therapeutic direction. And, as has more recently come into view, this same narrative competence increases the power of all health professionals to come to grips, through reflection, with what being a caregiver means in their own lives and the lives of their families. It makes them all better teachers, better researchers, better colleagues with all other health professionals. It equips them to more effectively enter serious con-

versations with the public about the choices medicine forces upon us and gives us the privilege to consider those choices.

By no means a replacement for scientific competence, narrative competence allows all that a professional knows to be placed at the service—now—of this patient who suffers from asthma and grief. It allows the doctor or nurse or social worker to provide care that strengthens and does not belittle, care that deepens and does not blunt the patient's search for meaning in the face of illness. Most important, medicine practiced with narrative competence can bridge some of the divides between the sick and the well, enabling all to recognize their common journey. Using narrative competence, caregivers can do what anyone who witnesses suffering does—in a family, among friends, in the news, on the stage, in fiction, on the street, in the hospital—one knows, one feels, one responds, and one *joins with* the one who suffers.¹⁹ It is as if the heads of the teller and listener are bowed over the suffering that happened in the attempt to interpret and understand it.

A young man came in to see me, referred by his wife who had been my patient for some time. She said that he had been enduring bothersome symptoms for years but had not wanted to subject himself to a medical evaluation. The patient, a muscular man of serious demeanor and stiff carriage, described severe abdominal pain, terrible difficulty with digestion, and bowel symptoms that interfered dramatically with his work performance and his leisure time. I wondered at his stoic acceptance of these intrusive symptoms for many years, and I noticed the pressure with which he held himself in during our conversation.

It was then time for the physical examination. Instead of changing into the cotton gown as I had asked him to, my patient stood hunched over the stainless steel sink near the examining table, fists clenched, head bowed, his back to me, motionless. I knew not what was happening, but I knew not to move. I sat at my desk, quarter-turned away from him, gaze slanted down, arrested by the force field of his stillness. We were part of a tableau, wordlessly enacting what, it came to me, must be an old truth.

When he spoke, it was to say, "It's because of what happened the last time I was at the hospital." And so I knew to use great caution, slowness, and gentleness in touching him, so that performing the physical examination could be not an assault but an effort to help.

To call this medicine narrative medicine brings to health professionals and patients critical knowledge and practice from many other fields of human learning and actions. What Luz and I did in marshaling the clinical imagination forms a part of what has become an international movement toward incorporating narrative studies into medical education and practice. By now, medicine is beginning to acknowledge the requirement for narrative knowledge and skills in the care of the sick. In the same way that medicine can do more today by virtue of all that it has learned from the scientific disciplines, medicine can do more today by virtue of all that has been learned from the narrative disciplines.

Narrative medicine has come to understand that patients and caregivers enter whole—with their bodies, lives, families, beliefs, values, histories, hopes for the future—into sickness and healing, and their efforts to get better or to help oth-

ers get better cannot be fragmented away from the deepest parts of their lives. In part, this wholeness is reflected in—if not produced by—the simple and complicated stories they tell to one another, whether in medical interviews, late-night emergency telephone calls, or the wordless rituals of the physical exam. Without narrative acts, the patient cannot convey to anyone else what he or she is going through. More radically and perhaps equally true, without narrative acts, the patient cannot himself or herself grasp what the events of illness mean. And without telling about or writing about the care of a patient in a complex narrative form, the caregiver might not *see* the patient's illness in its full, textured, emotionally powerful, consequential narrative form. It remains to be proven—although it appears a most compelling hypothesis—that such narrative vision is required in order to offer compassionate and effective care to the sick.

Not so much a new specialty as a new frame for clinical work, narrative medicine gives doctors, nurses, and social workers the skills, traditions, and texts to provide nuanced, respectful, and singularly fitting clinical care to the sick while also achieving genuine contact with their own and their colleagues' hopes and ideals as health professionals. As a result, the health care they practice is focused on the fully envisioned plight of each patient, of each caregiver, of each institution of health care, and of the whole society that suffers and that tries to heal.

NOTES

1. See Norman Cousins, *Anatomy of an Illness as Perceived by the Patient*; Anatole Brody, *Intoxicated by My Illness*; Anne Fadiman, *The Spirit Catches You and You Fall Down*; and Simone de Beauvoir, *A Very Easy Death* for clear statements, by patients, families, and their allies, of the health care system's failures to care.

2. Joanne Trautmann, *Healing Arts in Dialogue*, and Delese Wear, Martin Kohn, Susan Stocker, eds., *Literature and Medicine: A Claim for a Discipline* document the beginnings of these practices.

3. Many of the pathographies written by patients or their families about their illnesses document these problems. See William Styron, *Darkness Visible*; Reynolds Price, *A Whole New Life*; or Nancy Mairs, *Waist-high in the World: A Life among the Nondisabled*. Health professionals, too, are deeply troubled by the emptiness of contemporary medicine. See Melvin Konner, *Medicine at the Crossroads*; Arthur Kleinman, *The Illness Narratives*; Rachel Remen, *Kitchen Table Wisdom*; and Bernard Lown, *The Lost Art of Healing*.

4. See the regular features entitled "A Piece of My Mind" in the *Journal of the American Medical Association*, "On Doctoring" in the *Annals of Internal Medicine*, or "Narrative Matters" in *Health Affairs* for examples of reflective writing, published in professional medical journals, that testify to doctors' growing desire and need to tell of their lives in medicine and to struggle to understand what their patients go through.

5. The British psychoanalyst Michael Balint made the observation that the self is the most powerful therapeutic instrument in his 1957 book, *The Doctor, His Patient, and the Illness*. Dennis Novack et al., "Calibrating the Physician: Personal Awareness and Effective Patient Care," survey and summarize recent work done in the field of reflection in health care. Diane Meier and Anthony Beck apply these concerns to individual clinical decision-making in "The Inner Life of Physicians and the Care of the Seriously Ill."

6. See Christine Laine and Frank Davidoff, "Patient-Centered Medicine: A Profes-

sional Evolution"; William Branch, *Office Practice of Medicine*; Thomas Delbanco, "Enriching the Doctor-Patient Relationship by Inviting the Patient's Perspective"; Eric Cassell, *Doctoring: The Nature of Primary Care Medicine*; and Laurence Savett, *The Human Side of Medicine*, 163–71.

7. Recent examples include William T. Close, *A Doctor's Life*; Jerome Groopman, *The Measure of Our Days*; and John Stone, *In the Country of Hearts*. See review of evidence-based studies of the consequences of continuity of care in Richelle Koopman et al., "Continuity of Care and Recognition of Diabetes, Hypertension, and Hypercholesterolemia."

8. I thank Peter Watkins for helping me to understand this fundamental point.

9. Kenneth Ludmerer, *Time to Heal*.

10. George Engel, "The Need for a New Medical Model: A Challenge for Biomedicine"; John Stoeckle, ed., *Encounters between Patients and Doctors*; Albert Jonsen, *The Birth of Bioethics*; and P. Reynolds, "Reaffirming Professionalism through the Education Community." The transformations in these areas within medical education and practice are, indeed, most startling and impressive, even as they seem not to have had very much impact on the routine medical care that patients experience. For summary overviews of the developments in humanistic medicine, see Moira Stewart et al., *Patient-Centered Medicine*; Jeremiah Barondess, "Medicine and Professionalism"; Eric Cassell, *The Nature of Suffering and the Goals of Medicine*; and Rachel Remen, *My Grandfather's Blessings*.

11. Mack Lipkin Jr., Samuel Putnam, and Aaron Lazare, eds., *The Medical Interview: Clinical Care, Education, and Research*; David Mechanic, *Medical Sociology*; Tom L. Beauchamp and James F. Childress, *The Principles of Biomedical Ethics*; C. P. Tresolini and the Pew-Fetzer Task Force, *Health Professions Education and Relationship-Centered Care*; and Ronald A. Carson, Chester R. Burns, and Thomas R. Cole, eds., *Practicing the Medical Humanities*.

12. Jodi Halpern, *From Detached Concern to Empathy*; Susan Phillips and Patricia Benner, eds., *The Crisis of Care: Affirming and Restoring Caring Practices in the Helping Professions*; and Fred Hafferty, "Beyond Curriculum Reform: Confronting Medicine's Hidden Curriculum."

13. R. W. B. Lewis, *The American Adam*, 3.

14. For useful and nontechnical descriptions of narrative knowledge, see Jerome Bruner, *Actual Minds, Possible Worlds* and *Making Stories: Law, Literature, Life*. See also such seminal works written by literary scholars and narratologists as Seymour Chatman, *Story and Discourse*; Shlomith Rimmon-Kenan, *Narrative Fiction: Contemporary Poetics*; W. J. T. Mitchell, ed., *On Narrative*; Paul John Eakin, *How Our Lives Become Stories: Making Selves*; and Wallace Martin, *Recent Theories of Narrative*.

15. See the recent works by physicians and nurses that endorse the use of narrative in their practices. Trish Greenhalgh and Brian Hurwitz, eds., *Narrative Based Medicine*; Kathryn Montgomery Hunter, *Doctors' Stories: The Narrative Structure of Medical Knowledge*; Rita Charon, "The Narrative Road to Empathy"; Melinda Swenson and Sharon Sims, "Toward a Narrative-centered Curriculum for Nurse Practitioners"; and C. Skott, "Caring Narratives and the Strategy of Presence: Narrative Communication in Nursing Practice and Research."

16. Rita Charon, "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust."

17. For narrative's influence in psychology, see Theodore Sarbin, ed., *Narrative Psychology*; Jerome Bruner, *Acts of Meaning*; and Karen Seeley, *Cultural Psychotherapy*. John Paulos describes the relationship between statistics and stories in *Once upon a Number: The Hidden Mathematical Logic of Stories*. Hayden White outlines history's reliance on narrative processes in *The Tropics of Discourse*. Alasdair MacIntyre recognizes the narra-

tive nature of ethical thought in *After Virtue*. There are just a few examples of this very widespread intellectual current toward narrative modes of thought and practice.

18. See Martin Kreiswirth detailing what he has called the narrativist turn in the social sciences and the humanities in “Trusting the Tale.”

19. Eric Cassell, “The Nature of Suffering and the Goals of Medicine”; Charles Aring, “Sympathy and Empathy”; Patricia Benner and J. Wrubel, *The Primacy of Caring*; and Louise Rosenblatt, *Literature as Exploration*.

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2 BRIDGING HEALTH CARE'S DIVIDES

Narrative medicine is a very practical undertaking. It arises from the day-in, day-out events of the doctor's or nurses' office—right there off the crowded waiting room, the desk drawers filled with prescription blanks and rubber hammers, the gauze and the scalpels and the needles and the betadine, the telephones ringing and the computer screens filled with lab test results. Or it arises in the anonymous hospital room, strangers overhearing, through the green cloth curtain, a doctor telling a patient bad news, sad news, news of defeat, and sometimes—though it seems rarely—news of success and cure. Here, relative strangers meet—one prepared to deploy clinical knowledge and the other prepared for the worst.

In addition to needing expert diagnosis and treatment, seriously ill people simultaneously need those caring for them to recognize that something of value has abandoned them, that a deep and nameless sadness has settled in at home. It would seem that those entrusted with the care of the sick should by nature extend great reserves of comfort, of hope, of tenderness, and of strength toward those struggling through the pain of disease, the discomfort of treatment, and the toll of all the losses.

In *Devotions upon Emergent Occasions*, John Donne writes, "As Sickness is the greatest misery, so the greatest misery of sickness is *solitude*."¹ A doctor who recognizes the patient in the face of the sickness, who respects the patient's strength despite the fear, who accompanies the patient through the territory of illness that the doctor knows well, and who honors the meaning of the patient's suffering provides not just knowledge of diseases but knowledge of the direction toward either health or the ability to live authentically without health. Such a doctor provides *company* to combat the isolation and with it an animating belief in the patient's ability to endure whatever will come.

The 2000 Pulitzer Prize in drama went to a young author unknown until she published the play *Wit*.² Margaret Edson captured the attention of theater audiences and the culture at large by her depiction of literary scholar Vivian Bearing in her ordeal with ovarian cancer. The play enacts the divides between this patient and all the health professionals who attempt to provide medical care for her—the arrogant senior oncologist who lies to her, the young physician-

scientist so intent on getting data for his research project that he is blind to his patient's suffering, the nurse who cannot mobilize her awareness of Vivian's pain into effective action. Professor Bearing is a scholar of the work of John Donne, an expert on Donne's courageous sonnets about death. *Wit* unfolds with Donne as backdrop, and all that happens to Vivian is underscored by the immense power of Donne's poetic vision about death.³

When the play opened at a Union Square theater in New York, the producers had to hire psychologists to facilitate after-theater discussions of the play: playgoers refused to leave the house! Many came time and time again to view the play, and then they stayed in their seats, some weeping, needing to talk together about what they had witnessed. Clearly, this depiction of routine health care was recognized as true—or at least recognized as feared—by New Yorkers.

I hated the play the several times I saw it. I felt attacked by what I considered to be a crude and one-dimensional caricature of doctors and nurses. I felt defensive in the face of the wholesale blaming of medicine as a cruel enterprise. I could not assess the play's literary merits, for I felt deeply hurt by its assault. Many of my colleagues in health care were more humbly accepting of Edson's message, hosting readings or productions of the play in their hospitals and medical schools, and assigning the play as required reading to their medical students.

I have come to realize that Edson has done a great service to medicine by offering, in her creative synthesis, the portrait of a complex woman, crushed by an incurable disease, who learns of her own failings as a teacher and scholar by virtue of the failings of her doctors. Here, she recalls a session with her eminent professor of Donne, E. M. Ashford, discussing Holy Sonnet Ten:

E.M.: The sonnet begins with a valiant struggle with death, calling on all the forces of intellect and drama to vanquish the enemy. But it is ultimately about overcoming the seemingly insuperable barriers separating life, death, and eternal life. . . .

In the edition you chose, this profoundly simple meaning is sacrificed to hysterical punctuation:

And Death—*capital D*—shall be no more—*semicolon!*

Death—*capital D*—*comma*—thou shalt die—*exclamation point!*

Gardner's edition of the Holy Sonnets . . . reads:

And death shall be no more, *comma*, Death thou shalt die.

(*As she recites this line, she makes a little gesture at the comma.*)

Nothing but a breath—a comma—separates life from life everlasting. It is very simple really. With the original punctuation restored, death is no longer something to act out on a stage, with exclamation points. It's a comma, a pause.

This way, the *uncompromising* way, one learns something from this poem, wouldn't you say? Life, death. Soul, God. Past, present. Not insuperable barriers, not semicolons, just a comma.

VIVIAN: Life, death . . . I see. It's a metaphysical conceit. It's wit! . . .

E.M.: It is *not wit*, Miss Bearing. It is truth. (14–15)

The truth of the situation is not a metaphysical conceit. The truth of disease is pain, isolation, and hopelessness, in which even those appointed to care for Vivian—including the oncology fellow Jason—become hazards, their presence only exposing her aloneness:

VIVIAN: (*To audience*) In isolation, I am isolated. For once I can use a term literally. The chemotherapeutic agents eradicating my cancer have also eradicated my immune system. In my present condition, every living thing is a health hazard to me. . . .

(*JASON comes in to check the intake-and-output.*)

JASON: (*Complaining to himself*) I really have not got time for this . . .

VIVIAN: . . . particularly health-care professionals. (46–47)

And later, when she is very close to death, a death accelerated by the aggressive chemotherapy research protocol, her oncologist, Dr. Kelekian, and Jason display how aggressively barricaded they are against her condition:

KELEKIAN: Dr. Bearing, are you in pain? (*KELEKIAN holds out his hand for chart; JASON hands it to him. They read.*)

VIVIAN: (*Sitting up, unnoticed by the staff*) Am I in pain? I don't believe this. Yes, I'm in goddamn pain. (*Furious*) I have a fever of 101 spiking to 104. And I have bone metastases in my pelvis and both femurs. (*Screaming*) There is cancer eating away at my goddamn bones, and I did not know there could be such pain on this earth.

(*She flops back on the bed and cries audibly to them.*) Oh, God. (71)

Patients and their families seeing performances of *Wit* felt recognized or even vindicated by the play's savage portrayal of contemporary health care because, I suspect, such inhumane and therefore ineffective care is enacted every day in hospitals everywhere. Health professionals do not understand what patients go through unless they themselves are ill, and so patients feel unbridgeable chasms between themselves and those who are supposed to take care of them. The isolation of each is arresting—the patient isolated by fear of disease, the professional isolated by knowledge of it. There are dangerous divides also, for example, between nurses and doctors, between surgeons and physical therapists, between social workers and psychiatrists, and between home care nurses and hospital nurses. These divides prevent them all from doing their best.

Health care professionals may be knowledgeable about disease but are often ignorant of the abyss at which patients routinely stand. They have no idea, most of the time, of the depth and the hold of the fear and the rage that illness brings. They have no idea how fundamentally everything changes when one's husband or mother or child is seriously ill. That which once seemed important—mortgage payments, getting the promotion, the Dow Jones, the Middle East—shrivels in comparison to the baby's white blood cell count or the result of Mom's head CT. The wife weeps in the shower, asking herself, "Why didn't I

make him go to the doctor when he first had trouble breathing? Why didn't I make him stop smoking? Why did I keep cooking steaks?" as her husband lies, alone, miles away, without her, in his narrow bed in the coronary care unit. All is as if lost. Her view of life narrows to her husband's pale wrist encircled by a plastic hospital name tag, his pale forearm taped up with intravenous tubing.

Later, the cardiologist makes his rounds in the CCU and tells the wife, "He's got a severe blockage in two of his coronary arteries, and we feel we need to do an emergency bypass operation right away." What does this mean? Will he live? Will he die? They will open her husband's heart like a bruised fruit; he will bleed into the gloved hands of strangers. But will he be well? Will he live? Will he die?

Pale and tired-looking, the wife tightens her grasp on her husband's wrist—she better not dislodge that intravenous line, thinks the cardiologist, the nurses had trouble getting it started. The patient's wife stutters something about her husband's allergy to anesthesia and getting a second opinion at Cornell. Doesn't she realize how sick her husband is? Sending him across town for a second opinion is too risky. He might not survive the ambulance ride. She doesn't trust me to be her husband's doctor, the cardiologist thinks with a sinking heart. How can I do the right thing in the face of her suspicion?

This doctor, this patient, and this family are at a loss. They are unable to deploy the powers of medicine to help them unless they can reach one another. Unless they find ways to grasp one another's perspective, they are doomed. The husband's heart disease will claim him while his cardiologist and his wife argue about proper treatment, separated by differentials of language and knowledge, divided by mistrust and fear.

We are beginning to understand what is *missing* in this imaginary scenario. In a repetition of the scenario enacted in *Wit*, what is missing is the health professional's ability to comprehend the plight of this patient and this wife. This doctor is not equipped with the imagination, the ability to see from another's point of view, the knowledge of human fears and hopes, and the ear for language and silence necessary to grasp fully the predicament of his patient and his patient's wife. If only the doctor would, as a matter of routine, be prepared for the jarring, jolting, inarticulate presence of dread; if only he would be attuned to the inevitable and exorbitant terrors that illness brings. Of *course* the wife thinks she has been slowly killing her husband. Of *course* she is already imagining her life as a widow, her children as part orphans. This is the nature of illness, that it transports ordinary people to imagine extraordinary losses.

THE DIVIDES

As a doctor, I can speak with some experience about what I have observed to occur between doctors and patients. I believe that the relationships patients have with nurses, social workers, and therapists are less troubled than the relationships they have with doctors, due in part to issues of power, gender, class,

clinical training, and patients' expectations of the different professions.⁴ Although the barriers described here no doubt exist in clinical situations with all health care professionals, I cannot speak to their consequences with professionals other than physicians. I suspect that the divides between nurses or social workers and their patients are less formidable than those of doctors; in an ideal world—perhaps in a narrative health care world—doctors will learn from nurses and social workers about how to lessen these gulfs and how to bridge the inevitable divides among us all.

Despite the complexity and consequences of the events that unfold in the doctor's office, the participants are often ill prepared for their meeting. They speak different languages, hold different beliefs about the material world, operate according to different unspoken codes of conduct, and are ready to blame one another should things go badly. Many patients feel abandoned by their doctors, dismissed in their suffering, disbelieved when they describe their symptoms, or objectified by impersonal care.⁵ As personified in part by *Wit's* Dr. Kelekian, the intellectual ambition, scientific competition, professional privilege, and greed of many doctors too often overshadow the primary service goals of medicine. Sadly, patients have come to reconcile themselves to a forced choice between attentiveness and competence, between sympathy and science.⁶ At the same time, many doctors feel aggrieved by the extravagant hopes patients have come to hold for the powers of medicine. They feel unable to measure up to patients' inflated expectations and demands that medical treatment will reverse the results of unhealthy behaviors, poor health choices, or random and unfair bad luck. Realizing how "slow" are their true fixes, doctors prepare to disappoint patients or to be sued for not being as effective as everyone seems to think they are.

What is enacted in these medical offices is the divide between the sick and the well, or, in Susan Sontag's words, the realization that "illness is the night-side of life, a more onerous citizenship."⁷ Unlike other divides—gender, race, class, place, age, time—that separate one human being from another, the divide between the sick and the well is capricious, unpredictable, sometimes reversible but in the end irrevocable. It spares no one. One hurtles with the speed of a fall down a mountain from one side of the divide to the other; one is turned by years-long, silent, cell-by-cell malignant change into a person with cancer. The world is transformed after the diagnosis of a serious disease, not only in the corporeal aspects of everyday life—now with pain, now with pills, now with slippers, now with a wheelchair—but in the deepest wells of meaning—now with limits, regrets, forced separations, final plans.

These divides between the sick and the well are unspeakably wide. Levered open by shame, rage, loss, and fear, these chasms can be unbridgeable. And yet, to get better, the patient needs to feel included among those who are not ill. The sick person needs to continue to be, somehow, the self he or she was before illness struck. For the sick patient to accept the care of well strangers, those strangers have to form a link, a passage between the sick and the healthy who tender care.

We need to see the chasms clearly if we want to bridge them. Here, I describe

four different types of divides that contribute to the divisions between doctor and patient. They seem to me the most urgent among the many divides that separate us. Each reflects a peculiar dimension of the difference between the sick and the well:

The relation to mortality: Doctors and patients differ fundamentally in their natural understanding of mortality. Doctors, who know materially about death, accept an actual, present awareness that we are mortal and we will die, while patients, depending on their own personal experiences with illness and death, usually have not developed such concrete realizations. Doctors may look upon death as a technical defeat, whereas patients may see death as both unthinkable and inevitable.

The contexts of illness: Doctors tend to consider the events of sickness rather narrowly as biological phenomena requiring medical or behavioral intervention while patients tend to see illness within the frame and scope of their entire lives. The doctor's concept of a sickness can be incommensurable with the patient's concept of the same sickness. They deal with two different things.

Beliefs about disease causality: Health care professionals and patients can have deeply conflicting ideas about the causes of symptoms and diseases and fundamentally different ways of thinking about those causes. Because beliefs about causality dictate action and ascribe meaning to the illness, the treatment, and the ill person, these conflicts can rend care.

The emotions of shame, blame, and fear: These emotions, among others, saturate illness and add immeasurably to the suffering it causes. Unless explicitly acknowledged and examined, these emotions and the suffering they cause can irrevocably separate doctor from patient, therefore preventing effective care.

THE RELATION TO MORTALITY

Leo Tolstoy writes, in the magnificent story "The Death of Ivan Ilych," about a St. Petersburg lawyer who becomes seriously ill. Although written in the mid-nineteenth century, there has perhaps not been a more eloquent, accurate, and brave depiction of terminal illness and dying conveyed in literature. When the doctor pays a house call on the now wasted and terminally ill Ivan Ilych, Ivan finds the doctor's health offensive:

And Ivan Ilych began to wash. With pauses for rest, he washed his hands and then his face, cleaned his teeth, brushed his hair, and looked in the glass. He was terrified by what he saw, especially by the limp way in which his hair clung to his pallid forehead. . . .

Always the same. Now a spark of hope flashes up, then a sea of despair rages, and always pain; always pain, always despair, and always the same. . . . "I will

tell him, the doctor, that he must think of something else. It's impossible, impossible, to go on like this." . . .

There is a ring at the door bell. Perhaps it's the doctor? It is. He comes in fresh, hearty, plump, and cheerful with that look on his face that seems to say: "There now, you're in a panic about something, but we'll arrange it all for you directly!" . . .

The doctor rubs his hands vigorously and reassuringly. . . .

"Well now, how are you?" . . .

Ivan Ilych looks at him as much as to say: "Are you really never ashamed of lying?" But the doctor does not wish to understand this question, and Ivan Ilych says: "Just as terrible as ever. The pain never leaves me and never subsides. If only something . . ."

"Yes, you sick people are always like that."⁸

What seems unbearable to Ivan is the contrast between his terrifyingly wasted body and the doctor's hearty, plump, and cheerful one. Whoever occupies the role of the doctor—no matter what his or her actual physical health status—will stand for health to the person diagnosed with sickness. What distinguishes them, fundamentally, is that Ivan is dying and the doctor is not.

Like Ivan, the newly sick person looks across the desk or examining table to see the not-sick, exemplified for the time being by the doctor peering at the chart, summing up the numbers, assessing the patient's chances, oblivious to the patient's horror at his or her change in status, seemingly smug in his or her own freedom from illness. The presence of health in the office can be galling, taunting, jeering. "What gods intervened on your behalf," the patient might silently ask, "that you were spared this AIDS that I got, this lung cancer that I got, this diabetes that I got? What gods failed to intervene on my behalf to spare my sight, my kidney function, my mind?" This awareness of mortality, so different for patient and for doctor, pinpoints one's present position in the trajectory of life, calculating what portion of life has been lived and what portion remains.

An old man was dying. He had had a large stroke, leaving him partially paralyzed and with the ability to say only one word, the name of his wife, "Sarah." Over and over, he called out, "Sarah, Sarah." His rhythmic one-word lament told me, an inexperienced third-year medical student, all that he could not put into words. His lament conveyed to me that he was lost, that he felt alone, that he wanted to be with those who could recognize him, even in his altered state. Over the time that I helped to take care of him, I grew to know his body very well. I examined him and drew his blood as tenderly as I could, slowly coming to know how not to hurt him. I think he came to recognize me, or at least my hands on his body.

Sarah and her daughter were usually in his room, staunch in the face of their suffering, bereft even before his death by the loss of him. They, too, lamented, their full vocabularies no more eloquent than his one word.

The night he died, I remember I was on call and was often in his room. I remember very specifically how he was lying on his side and that he would wave his thin arms in front of his face and then curl them palms outward as if to shield himself from some unwanted visitor. In retrospect, I wondered if he had

seen death coming for him, if he had known before the rest of us did that he was being taken away. I always wonder what he must have suffered, having known.

I remember that the next day our whole team had to go his autopsy. The pathologist displayed my patient's organs in rectangular stainless steel pans—his shrunken kidneys, his baggy heart. I tried to hide my tears from my intern and resident, but how I wept to see him now so finally dead, so finally not alive, this man I had tried to care for, this man I had watched decline.

The day after he died, his wife and daughter came to get his belongings from the hospital. His daughter gave me a gift to thank me for taking care of her father, a little scarf, that I have kept through many moves over the intervening decades. I behold it as a reminder of him and all that he and his family taught me about grief and about death and about love.

Thinking of this man and his family helps me to dwell on the gravity of what we do every day. This moment changed their lives—for his daughter, there is before Daddy died and after Daddy died. For his wife, there is now widowhood. For him, of course, we cannot know. For me as an inexperienced medical student witnessing her first death, there was a grave and sad and frightening realization that I had given myself over to mystery, to irrevocable loss, to irremediable sadness. It was also the beginning of my experiencing these tragic human events within the capsule of pathology, of technical duty, and of the inevitable guilt over medicine's powerlessness.

As a result of these routine elements of medical training, doctors suffer two conflicting delusions about their own mortality. On the one hand, the ordeals of training during which they are awash in other people's sickness and other people's deaths can convey the irrational belief that such intimate contact with disease and death confers immunity. The intern's consolation for the unbearable months of forty-hours-at-a-stretch training is the irrational belief that he or she will never die. But equally powerful are the opposing candid realizations that all must die, that no one escapes death, and that death is never easy. When I wrote a former medical student to get his permission to reproduce in this book a description of a death he had witnessed and written about, he wrote back about his life as a general surgery resident on a busy trauma service: "Strange to remember a single passing at this point in residency when the dead of West Harlem seem to have blown between my feet like so many autumn leaves."

Patients suffer their own delusions about death. Depending on one's own contact with death—in the military, as a hospitalized patient, with family losses, through personal experiences of political violence or natural trauma—a patient might feel death a personal enemy or a distant abstraction. Some patients feel they have forestalled death many times and, catlike, will continue to find more and more lives within themselves. Others—perhaps for religious reasons or psychological ones—sense their own portion running out or their own desserts coming to an end. As Susan Sontag reminds us, the constant media exposure of the violence of war and repression and natural disaster simultaneously shocks the viewer and inures the viewer against repeated, unspeakable destruction of human beings.⁹ If the Vietnam War was fought as if in our living rooms and the Iraq invasion was accomplished as if in a video game, the contemporary layer-

son's relation with death is highly detailed by virtue of the global web of pictures and information that now bombard us, leaving us familiar with dying but certain that it occurs only far away. And yet, in part because today's health care system insulates people from death by moving it from home to hospitals, people have little concrete idea of what really happens as death nears, what is that passage from the living to the dead.¹⁰

Awareness of mortality, although very different for doctor and patient, need not separate them. What would happen if doctors asked, as a matter of course, about each patient's assessment of his or her current health status or how close to the end a patient feels? Doctors may want to know something about each patient's frank appraisal of his or her state of health, including survivorship as well as frailty, hope as well as resignation.¹¹ And perhaps doctors could share some of their realism about death with patients. Instead of seeming to gloat about their own freedom from evident disease, doctors might reach to attain an equilibrium between their two deluded beliefs about death and then help patients achieve a balanced perception of their own relation to their ends.

Doctors may look at death with the worry that they have caused it—purposefully, passively, through negligence or error—and patients may look at death as something that they fear or defy or desire. Death divides not only doctors from patients but also all the sick from all the well and the living self from the dying self. And yet, if death seems often to divide, it also unites as the universalizing, ultimately humanizing element of life. Gabriel muses in the final scene of James Joyce's magnificent story "The Dead" as he comes to grips with the knowledge of his wife's long-dead lover Michael Furey and the future deaths he can so easily envision:

[S]now was general all over Ireland. It was falling on every part of the dark central plain, on the treeless hills, falling softly upon the Bog of Allen and, farther westward, softly falling into the dark mutinous Shannon waves. It was falling, too, upon every part of the lonely churchyard on the hill where Michael Furey lay buried. It lay thickly drifted on the crooked crosses and headstones, on the spears of the little gate, on the barren thorns. His soul swooned slowly as he heard the snow falling faintly through the universe and faintly falling, like the descent of their last end, upon all the living and the dead.¹²

Charon is a grave name for a doctor, recalling Charon the boatman in Greek mythology who ferries the dead across the River Styx to Hades. My grandfather Dr. Ernest Charon, my father Dr. George Charon, and I are all marked by this mournful name. The first time a patient recognized my name was on the hospital wards when I was a third-year medical student. A 26-year-old man was dying of a hepatocellular carcinoma, widely metastasized. On the first day that I joined the ward team, he read my red student name tag and said, "So this is it?" He died two days later of pulmonary hemorrhage. Aghast at having perhaps added to this unfortunate young man's suffering, I thought I should change my name. I did not, however, slowly coming to realize that Charon's task is ours—to know as best we can how to navigate that journey, how to recognize that shore.

 THE CONTEXTS OF ILLNESS

Any phenomenon has to be contextualized in order to be understood. We locate events in space and historicize them in time, registering their contiguity with related events while divorcing them from distracting ones. The efforts to make sense of anything—the Battle of Gettysburg or *The Wings of the Dove*—require fundamental decisions about the spheres within which to consider them. Differences of interpretation proceed, in large part, from differences in how we contextualize the matter at hand.¹³

The context of events of illness can be drawn narrowly, for example, around the left anterior descending artery in our ICU patient's chest or broadly around the lives of this patient, his wife, and their family's experience of the past and hopes for the future. The psychiatrist George Engel propounded what he called the "biopsychosocial" framework for medicine years ago, suggesting that medicine had to take into account not only biological changes of illness but also the familial, community, and societal consequences of disease.¹⁴ Engel's work was influential in challenging medical practice and medical schools to look beyond pathophysiology toward social and cultural factors that permit disease, that alter patients' behavior in the face of disease, or that influence the effectiveness of medical treatment for it. A robust research enterprise in medical sociology, behavioral medicine, and cultural studies of health and illness continues to widen medicine's knowledge about what, in the end, constitutes health and what signifies an effective response to it.¹⁵

The sociolinguist Elliott Mishler best describes the contexts that clash in the doctor's office. He examined tape-recorded and transcribed routine medical interviews and distinguished between the stretches of talk originating in what he calls the World of Medicine and those originating in the Lifeworld. In his pivotal 1986 study, *The Discourse of Medicine: Dialectics of Medical Interviews*, Mishler traces the course of conversations that veer between one end of meaning and the other. As the doctor interviews a woman patient with abdominal pain, he learns of her considerable alcohol intake:

"How long have you been drinking so heavily?"

"Since my husband died."

"How long ago was that?"¹⁶

A chasm opens up between the doctor placing the patient's symptoms in chronological order and allowing them, perhaps, to make biological sense and the patient offering her symptoms in the unfolding order of her life allowing them, perhaps, to make personal sense.

A horrified patient reported how a doctor insulted her gravely during her very first visit to him. "He asked me whether my two daughters had the same father! What could he possibly think of me?" While the patient felt that she had been taken for a loose woman, the doctor, no doubt, was going through his first-visit routine, starting with the history of present illness, past medical history, and social history. When he got to the so-called family history, he perhaps tried to save time by drawing the family tree at the same time that he collected the information about the new patient's family illnesses. One doesn't know where to draw the symbol for each child without knowing the identity of both parents,

and so the doctor's question about the father of the daughters was simply a formal one from the World of Medicine, while the patient took it as a question of meaning from the Lifeworld.

This clash of contexts pits the doctor's impulse to reduce against the patient's impulse to multiply. Medicine's reductionism narrows its gaze, eliminating that which proliferates around the biological phenomena of sickness in a patient's always generative and teeming life. It is as if medicine were ametaphoric. What is at stake in this conflict is the singularity of the patient's life. What, the doctor should learn to ask, is *different* about this disease as it manifests itself in this particular patient? What, he or she should ask at the same time, is unique about this patient as a host of this disease? Clinical medicine is only beginning to tailor therapeutic approaches to disease to the particular patient. Only recently have clinical researchers distinguished between how men and women experience symptoms of a disease and how they respond to treatments for them.¹⁷ Only recently have we begun to understand, at the genetic and molecular level, why some diseases occur more frequently or act more aggressively in some races than in others.

The recent growth in patient-centered care is a response to the narrowness of medicine's contextualization.¹⁸ Patient-centered care is a conceptual and clinical movement, arising both in the United States and the UK, that emphasizes the patient's perspectives and desires throughout all aspects of health care. Such care respects patients' preferences, attends to patients' needs for information and education, involves family and friends, assures continuity and coordination of care, and addresses the emotional aspects of illness. One of the leaders of the movement, Moira Stewart, notes that "[p]atients want patient centred care which . . . seeks an integrated understanding of the patients' world—that is, their whole person, emotional needs, and life issues; finds common ground on what the problem is and mutually agrees on management; . . . and enhances the continuing relationship between the patient and the doctor."¹⁹ Patient-centered care is, in effect, health care without the divides.²⁰

As medicine matures, perhaps its practitioners will develop the skill to register the singular contexts that donate meaning to each clinical situation and will take upon themselves the responsibility to learn about singular aspects of their patients' lives. Such efforts are bound to enhance clinical effectiveness, not only by guiding choices of treatment interventions but also by alerting doctors to all considerations that might help or hinder patients from following medical recommendations and becoming true partners in achieving and maintaining the best health within their reach. Even more fundamentally, such partnerships can help to equalize the ground on which we all stand as sick and well, contributing to our efforts to see clearly our bodies and lives in time, in relation, and in meaning.

BELIEFS ABOUT DISEASE CAUSALITY

The *causes* of illness can be understood in divergent and even contradictory ways, often leading to baffling and damaging differences between doctors and patients. Doctors may be convinced that autoimmune cellular reactions in the

joints, probably of viral and genetic origin, cause the symptoms of rheumatoid arthritis. What happens when the patient is convinced that the pain in her hands is caused by all the housework she's done over the decades? Western doctors may ascribe seizure disorders to abnormal foci of electrical activity in the neural tissue in the brain, while the Hmong parents of a little girl with epilepsy ascribe the seizures to their family ancestral spirits' inability to settle down.²¹ Prescribing methotrexate for the arthritis or diphenylhydantoin for the seizures is not likely to work, not only because the pills will probably not be swallowed but also because the other causes—biological or not—will continue to exert their power over the patients' behavior and expectations and sensations. Matters of belief as well as fact, ideas about the causes and cures of disease run deep in one's culture, religion, and family, and discrepancies between the causal ideas of doctor and patient are inveterately difficult to mediate.

Beliefs about the cause of disease—or etiology—recapitulate one's very deeply held ideas about how the universe is put together. (I remember once being at a seminar in which the presenter was talking about the etiology of tuberculosis. I followed all he said with great interest, learning only at the close of the seminar that the word he was saying was not "etiology" but "ideology," pronounced with the short "i." The whole discussion made sense either way.) Doctors might be convinced about the cause of a disease only by replicable scientific evidence, while patients may be swayed in their beliefs about etiology by faith, culture, family lore, and mythic/magical notions of human biology. Doctors' beliefs about etiology are revised every time new knowledge or data become available. Their insistence on the truth of a causal fact is matched only by their certainty in the truth of a more compelling competing claim. That is to say, the grounds on which scientifically trained people subscribe to a causal belief are both rigid and revisable, while the grounds for a lay belief in disease causality might be based less on up-to-the-minute findings and more on an enduring and meaningful sense of the workings of the world. And so, when the cardiologist and the patient's wife meet in the coronary care unit, not only the need for open-heart surgery is at issue: their entire way of making sense of the universe is in conflict as they survey the future for this patient and husband.

Clashes over etiology pit the general against the particular.²² Doctors, as a rule, offer explanations for disease that "apply" to more than one person, and a finding or theory or method must be generalizable if it is to be clinically useful. Patients, on the other hand, are usually not troubled if what is true of their disease is true *only* of theirs. More: they realize the value of recognizing what is true only of their disease, hoping that their caregivers too will recognize the importance of these unique phenomena. What is true only of their disease is true only of them, and so the experience of being sick—be it a small consolation—at least reveals something enduring about the self.

One can trace the development of Western medicine's beliefs about disease from its Hippocratic and Galenic roots to the present by attending to the tensions between the general and the particular.²³ The anticontagionists of the 1840s in England, for example, understood cholera to be caused by miasmatic or global or religious forces that exerted themselves in the environment with little

regard for the specific behaviors of the charwoman or the harness-maker, whereas the contagionists believed cholera to be caused by specific occurrences within the bodies and proximities of individual stricken patients.²⁴ Today, the “quantitative researchers” are pitted acrimoniously against the “qualitative researchers” in performing studies of health and illness, one group accepting only findings that are replicable and generalizable and the other group addressing those aspects of illness that are singular and, well, narrative.²⁵

A bracing critique of Western medicine's slant on the nature of disease was published in 1923 by Dr. F. G. Crookshank as a supplement in *The Meaning of Meaning*, written and edited by the eminent literary scholars and aesthetic theorists I. A. Richards and C. K. Ogden. Crookshank exposed the mistaken and dangerous notion that a disease is a thing. He reminded his readers that people make up diseases so as to have conceptual means of attending to symptoms and accountable ways of treating them. And yet, entreats Crookshank, diseases are not countable things in the universe. Instead, they are manners of speech:

It is a vulgar medical error to speak, write, and ultimately to think, as if these *diseases* we name, these *general references* we symbolize, were single things with external existences. . . . Nevertheless, in hospital jargon, “diseases” are “morbid entities,” and medical students fondly believe that these “entities” somehow exist *in rebus Naturae* and were discovered by their teachers much as was America by Columbus.²⁶

Calling the notion of diseases as entities an “inheritance from Galen,” Crookshank concludes this section:

That our grouping of like cases as cases of the same disease is purely a matter of justification and convenience, liable at any moment to supersession or adjustment, is nowhere admitted; and the hope is held out that one day we shall know all the diseases that there “are,” and all about them that is to be known.

Although the search for the diagnosis is *always* part of an effort to cure it or to at least relieve its symptoms, the search for diagnosis can eclipse or even replace the attempt to relieve suffering. In Eric Cassell's words:

[W]hen a patient has a widespread cancer whose primary (place of origin) is unknown, physicians will often go to considerable lengths to find the place of origin even though it may cause the patient great discomfort without offering *any* benefit. They do this because disease theory (the concept that when people are sick a disease can always be discovered whose constant characteristics provide a rational basis for the illness and for the action of doctors) dictates the importance of making a diagnosis—knowing the disease. . . . [T]he need to know the disease conflicts with the more fundamental dictum, “Above all, do no harm.”²⁷

The effort, in the end, to assign causality to symptoms is an effort to *know* and, therefore, to control. Whether a psychiatrist chooses a number to the sec-

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.²⁸ 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.²⁹ 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.³⁰

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.³¹ 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*.³² 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.³³

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.³⁴) 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.³⁵ 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.

All I learned about medicine from trying to take care of my patient was its anguish and isolation and powerlessness in the face of disease and age and time. We had little clinically to offer this man. I did not know, then, that there is no limit to what one can give as a doctor. I did not know that I was allowed, as a doctor, to donate my presence, my attention, my regard. The patient's wife need not have been utterly alone in her ordeal; I could have accompanied her with courage and vision instead of caving in, with her, to the fear of the disease.

What I did not know how to do for my patient and his wife was to get to the heart of their suffering. I knew how to manage the man's fluid status and antibiotics, and I even knew, more or less, when to call a halt to aggressive care, but I did not know how to manage the fact of his dying. I did not know how to manage his wife's fear and loss. Nor did I know what to do with my own suffering in the face of theirs.

What I needed, I now can see in retrospect, was to be able to imagine the plight of my patient's wife and to realize that she required honesty and support and courage from me, her primary doctor. With more sophisticated narrative skills than I had as an intern, I would have been able to articulate my own fear of incompetence and lack of clinical judgment and therefore seek better guidance from my supervisors. I might have been able to identify personally significant memories—of the long, slow death of my own grandmother—stirred up by the patient's ordeal. I might have better imagined the situation of the patient himself, realizing the injustice of continuing to subject him to such painful procedures—if, indeed, he was sensitive to pain—as deep surgical scraping of his sacral wound. And by reflecting critically on my own professional actions and complementing my judgment with that of more experienced doctors, I would have made myself available to this patient and his wife—and his children or siblings or friends, the presence of whom I had not even wondered about—in living through the losses of his terminal illness. By having recognized more accurately the patient's and family's experiences and by having claimed my own fear and horror and sadness, I could have released the natural collective impetus in all of us to extend help toward the frail and injured. As it was, I remained divided from my patient by his nearness to a death that was unacceptable to me, my reduction of the complexity of his full life, the mismatch between his wife's and my calculus of the road we were on, my shame at my own inexperience and uncontrollable emotion, and my paralyzing sadness for us all.

Donne's Holy Sonnet Ten, of course, begins with these lines:

Death, be not proud, though some have called thee
Mighty and dreadful, for thou art not so;
For those whom thou think'st thou dost overthrow
Die not, poor death, nor yet canst thou kill me.
From rest and sleep, which yet thy pictures be,
Much pleasure, then from thee much more, must low
And soonest our best men with thee do go,
Rest of their bones and soul's delivery.

Addressing the poem directly to death—and not to God or to Satan as most of the Holy Sonnets are—Donne personifies and *lowers* that which claims us mortals. In stripping poor death of its haughtiness, Donne achieves an expansiveness of life despite its measured end. If “soonest our best men with thee do go,” then we who go, including my patient, are also of the best.

The divides between doctor and patient erected by different notions of mortality, causality, context, and emotions can be bridged by doctors and patients who are committed to the health of their clinical relationships. In the following chapters, I outline specifically how narrative methods can help to bridge each of these divides. If with narrative’s help, we can grasp our relation with mortality and time, the singular contexts in which illness arises, the central roles of both causality and contingency in health and illness, and the emotional forces that prevent genuine and ethical relation, then patients and doctors can find their way to unite in the shadow of death, to respect that which is unique about each one, to join in authentic regard, and to face the unknown with courage, justice, and hope.

NOTES

1. John Donne, *Devotions upon Emergent Occasions*, 30.
2. Margaret Edson, *Wit*. Page references to this work appear in parentheses in the text.
3. Wayne Booth, “The Ethics of Medicine, as Revealed in Literature,” 10–20.
4. See Barbara Ehrenreich and Deirdre English, *Witches, Midwives, and Nurses: A History of Women Healers* and Susan Reverby, *Ordered to Care: The Dilemma of American Nursing, 1850–1945* for explorations of the gender, class, and power situations within medicine and nursing.
5. Many patients have published such accusations about the heartlessness of medical care. In addition to Edson’s *Wit*, see Louise DeSalvo, *Breathless*; Kathlyn Conway, *Ordinary Life*; Jay Neugeboren, *Open Heart*.
6. The choice between sympathy and science is enacted in the impressive flight from conventional Western medicine to alternative and complementary care. What masseuses and acupuncturists and holistic healers provide that doctors do not is attention and regard, and their lack of scientific rigor is overlooked for the dividends of their caring. In *Sympathy and Science: Women Physicians in American Medicine*, historian of medicine Regina Morantz-Sanchez writes about medicine’s gendered dichotomy between sympathy and science, some early women physicians seeming to choose the first while disdaining the other, or perhaps only lusting after it.
7. Susan Sontag, *Illness as Metaphor*, 3.
8. Leo Tolstoy, “The Death of Ivan Ilych,” 140–41.
9. Susan Sontag, *Regarding the Pain of Others*.
10. When the surgeon Sherwin Nuland wrote his *How We Die*, it was to fill this gap in laypersons’ knowledge of what really happens to people in the course of dying. The combination of pathological, phenomenological, and lyrical prose in the book testifies to the extraordinarily complex dimensions of these moments at the ends of our lives. The hospice movement, of course, tries to build familiarity with the inevitability of death and the

comfort available to all involved by admitting it into our midst. See Michael Kearney and Timothy Quill for recent publications on the care of the terminally ill.

11. See, for example, ongoing work characterizing the contribution of patient optimism to clinical outcomes of health and recovery. Michael Scheier et al., "Optimism and Rehospitalization after Coronary Artery Bypass Graft Surgery," and Michael Scheier and Charles S. Carver, "Effects of Optimism on Psychological and Physical Well-Being: Theoretical Overview and Empirical Update."

12. James Joyce, "The Dead," 223–24.

13. See W. J. T. Mitchell, ed. *The Politics of Interpretation* for a series of essays examining these fundamental intellectual operations. See E. D. Hirsch, *Validity in Interpretation* for a study of interpretation as an exercise of mastery and Wolfgang Iser who, in *The Range of Interpretation*, suggests that interpretation is a mode of translation.

14. George Engel, "The Need for a New Medical Model: A Challenge for Biomedicine."

15. See David Morris, *Illness and Culture in the Postmodern Age*; Phil Brown, *Perspectives in Medical Sociology*; David Mechanic, *Medical Sociology*; Arthur Kleinman, Veena Das, and Margaret Lock, eds., *Social Suffering* for examples in these vast fields of social commentary on biological illness.

16. Elliott Mishler, *The Discourse of Medicine*, 85.

17. The NIH only in the 1990s insisted that women and members of minority races be enrolled in clinical trials of experimental drugs because of the inability to generalize therapeutic response from one gender to another or one race to another. The recently inaugurated *Journal of Gender-Specific Medicine* reports on findings local to either male or female patients, giving respect to their ineluctable differences throughout the provision of medical care.

18. See the report of the Committee on Quality of Health Care in America, Institute of Medicine, *Crossing the Quality Chasm*, 48–51, for a summary of patient-centered care developments.

19. Moira Stewart, "Towards a Global Definition of Patient Centred Care."

20. See Moira Stewart et al., *Patient-Centered Medicine*. The U.S. Agency for Healthcare Research and Quality provides resources on the web to help patients and providers to arrive at singularly fitting health care decisions—from choosing surgery or watchful waiting for BPH to choosing a health care plan—for patients based on individual symptoms and preferences. UK researchers are investigating the contributions of shared decision-making on outcomes as well and providing patients with guidance through the Centre for Health Information Quality. See Halsted Holman and Kate Lorig, "Patients as Partners in Managing Chronic Disease: Partnership Is a Prerequisite for Effective and Efficient Health Care" and Michael Barry et al., "Patient Reactions to a Program Designed to Facilitate Patient Participation in Treatment Decisions for Benign Prostatic Hyperplasia" as instances of the voluminous literature on the importance of recognizing and respecting patients' preferences in tailoring their health care.

21. Anne Fadiman's brilliant study of the Hmong culture's understanding of disease, *The Spirit Catches You and You Fall Down*, stands as a cautionary tale for all health professionals working with members of other cultures.

22. Rita Charon, "To Build a Case: Medical Histories as Traditions in Conflict."

23. I am indebted to Eric Cassell for his private tutorial in modern medicine's epistemology. I cite heavily here not only from his writings but from his conversation and inspiration. See particularly chapter 1, "Ideas in Conflict: The Rise and Fall of New Views of Disease" in *The Nature of Suffering and the Goals of Medicine*, 3–15.

24. See Arnold Weinstein, ed., "Contagion and Infection," special issue of *Literature and Medicine* for a collection of essays on the nature of contagion and its theories within

the rise of Western medicine. See also Harris Coulter, *Divided Legacy* and Robert Hudson, *Disease and Its Control* for helpful summaries of these developments.

25. An almost laughable outbreak of this clash was published in the *Journal of General Internal Medicine* in 1998. See the essay by Roy Poses and A. M. Isen crankily refuting the findings of qualitative researchers and the deluge of indignant responses.

26. F. G. Crookshank, "The Importance of a Theory of Signs and a Critique of Language in the Study of Medicine," 342.

27. Eric Cassell, *The Nature of Suffering and the Goals of Medicine*, 5.

28. See the psychiatrist Aaron Lazare's landmark study "Shame and Humiliation in the Medical Encounter." Lazare contends that much of the routine procedures and "manners" of the office visit are manifestations of the attempts to manage both the patient's humiliation and the doctor's potential shame. He argues that a medicine attuned to safeguarding the patient from undue shame or humiliation will provide a major improvement in effectiveness.

29. A survey of recently published pathographies fails to identify illness narratives about lung cancer in a smoker. Alice Trillin's prescient "Of Dragons and Garden Peas," published in the *New England Journal of Medicine* in 1981, takes pains to point out that the author/patient was *not* a smoker. Some pathographies about heart disease, for example Jay Neugeboren's *Open Heart*, assert that the author is *not* a smoker, obese, sedentary, or a consumer of a high-fat diet. See William Styron's *Darkness Visible* for one pathography in which the author admits to having contributed to at least one aspect (alcohol intake) of his illness.

30. See Richard Zaner's "Broader's Hill" in *Conversations on the Edge: Narratives of Ethics and Illness*, 89–110, for a discussion of the difficulty of "living in the face of the awful happening of chance events," 101.

31. David Hilfiker, "Facing Our Mistakes." See also his more recent book-length examination of errors in medical practice, *Healing our Wounds*. See also Atul Gawande, *Complications* and Charles Bosk, *Forgive and Remember* for examinations—the first by a surgeon and the second by a sociologist—of the occurrence of error and the medical profession's response to it. In very large part, what must be handled is not only the result of the error itself on the welfare of the patient but also the sequelae of guilt and fear in the practitioner who committed the error.

32. Committee on Quality of Health Care in America, Institute of Medicine, *To Err Is Human*.

33. See Nancy Berlinger, "Broken Stories: Patients, Families, and Clinicians after Medical Error." See also accounts written by patients or their survivors of serious clinical error, including Sandra Gilbert, *Wrongful Death*.

34. Wendy Levinson et al., "Physician-Patient Communication: The Relationship with Malpractice Claims among Primary Care Physicians and Surgeons."

35. See, for example, *The House of God* by Samuel Shem; *Gentle Vengeance* by Charles LeBaron; *A Not Entirely Benign Procedure* by Perri Klass; and *The Desire to Heal* by Rafael Campo.

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3 ■ NARRATIVE FEATURES OF MEDICINE

The divides in health care need to be bridged in order for effective treatment to proceed. I have proposed that narrative means might help to bridge these chasms, because narrative ways of knowing and experiencing the world and self are held in common by health care professionals and patients. Anterior to our differentiating into doctors, nurses, and patients, that is, we are united *and can be reunited*. Furthermore, the specific divides that separate doctors from patients—beliefs about mortality, the contextualization of illness, understanding of disease etiology, and emotional factors that lead to suffering—have direct correlates in narrative aspects of medicine.

Medicine is itself a more narratively inflected enterprise than it realizes. Its practice is suffused with attention to life's temporal horizons, with the commitment to describe the singular, with the urge to uncover plot (even though much of what occurs in its realm is, sadly, random and plotless), and with an awareness of the intersubjective and ethical nature of healing. I invite you to examine with me five narrative features of medicine—temporality, singularity, causality/contingency, intersubjectivity, and ethicality. All these complex conditions or states are active aspects of routine clinical practice. They are also bedrock aspects of narrative practice. They line up with the divides we have just considered in almost a one-to-one configuration, helping us to examine and perhaps even to bridge each of these complex and deep chasms. *Lancet* editor Richard Horton writes in *Health Wars* that there is "a schism in medical practice that is at the heart of the present challenge to medicine. The solution is to discover a way to reconnect doctor to patient through a bridge of common understanding and shared ways of knowing about disease. We need nothing less than a new philosophy of medical knowledge."¹ I suggest that this new philosophy of medical knowledge is a narrative one, and that learning about and developing competence in these narrative dimensions of medical practice can offer urgently needed help to us all as we try to bridge the divides in health care and improve the effectiveness of our care.

As a living thing, narrative has many dimensions and powers. The novelist values its creative force; the historian relies on its ordering impulses; the autobiographer redeems its link to identity; the anthropologist requires its recognizing specificity. What is clear is that narrative *does* things for us, perhaps things that

cannot be done otherwise. Narrative structures such as novels, newspaper articles, and letters to friends enable us to recount events, to depict characters, to suggest causes for events, to represent the passage of time, to use metaphor to convey meanings otherwise elusive. As an instrument for self-knowledge and communion, narrative is an irreplaceable—and often silent or at least transparent—partner to human beings as they make and mark meaning, coping with the contingencies of moral and mortal life.

Those who study narrative are in some agreement about its basic elements. Such texts as Shlomith Rimmon-Kenan's *Narrative Fiction*, Seymour Chatman's *Story and Discourse*, and Gérard Genette's *Narrative Discourse*, originally published between 1978 and 1983, identified central features of narrative that continue to be endorsed by the narrative theorists who follow them.² These theorists agree, roughly speaking, on the major features of narrative. Some event happens or state of affairs obtains within a temporal sequence and specified setting to and by characters or agents, and the opening state gives way to an altered state. This situation is represented for the reader or listener by a speaker or register who absorbs and reports the event from a particular point of view. The large objects in the room, if you will, in narrative theory can be distilled into time, characters, narrator, plot, and the relationships that obtain between teller and listener, which accord with the narrative features of medicine we are examining. With these simple components, stories are built, told, undergone, and understood. The branch of literary studies called narratology analyzes how stories are built, how they are told, and how they are received, the better to understand what they mean and how they exert their profound effect on us.

Narratology's evolution began with the Russian formalists Vladimir Propp and Boris Tomashevsky, the phenomenologist Roman Ingarden, and the linguists Frederic Saussure and Emil Benveniste in the 1950s and 1960s, who developed very complex taxonomies to describe a text's narrator, the generic properties of the narrative, a rather limited number of characters (or actants or agents), and a catalog of discrete action elements that could be combined to form plot.³ These early formalists aspired to a scientific examination of text, that is to say, a reproducible, generalizable system of understanding and of describing the anatomy of a story. By the 1960s and 1970s, these formalist concerns informed what became known as structuralism, a movement powered by the French anthropologists and linguists Claude Lévi-Strauss, A. J. Greimas, Claude Bremond, Roland Barthes, and Gérard Genette. Blending linguistics and anthropology with traditional literary studies, the structuralists paid attention to the semiotic conventions of the works they studied, the linguistic rules and norms that encode meaning, and the social and cultural work accomplished through discourse. These interests contrasted with the other major development in Anglo-American formalism, New Criticism, which came of age around the same time. The New Critical scholars T. S. Eliot, Ronald Crane, Cleanth Brooks, and William Empson studied such intratextual aspects of poetry as irony and ambiguity with restrained interest in the personal or cultural worlds from which the text emerged.⁴

Although by now, in poststructuralist times, we do not believe that a story can be dissected scientifically to reveal the same meaning to more than one observer,

literary scholars today owe a great debt of clarity to the work of the structuralists for having recognized that the structures of texts are the sources of their meaning. However, in retrospect, the reversals of the effort are striking. The early structuralists thought they could banish singularity from texts and replace it with measurable, generalizable knowledge (with predictive value!) of paradigm texts and others like it, that they could develop metrics with which to analyze stories' plots and times, and that they could dispense with the reader in favor of the laws of language. They failed at these tasks. Yet their failures have led to the realization of the brilliant singularity of each narrative text and the irreplicability of any narrative situation, so complex and individualized have acts of writing and reading been found to be. The field of study that inspects how stories are built and how they work continues to renew itself. Lately, narratology—or the new formalisms, the pluralism with which narratology often designates itself—is concerned with subjectivity, race, body, and culture in written texts as well as in oral, film, and visual texts. “[T]he concept *narrative* has come to encompass a wide range of semiotic, behavioral, and broadly cultural phenomena; we now speak of narratives of sexuality, for instance, as well as narratives of history, narratives of nationhood, and even, more notoriously, narratives of gravity.”⁵ In the face of the democratic uses to which narrative theories and practices have been put, its theory has consequently become more pluralistic, populist, and accessible to writers and thinkers along a wide range of interests.⁶ Students of narrative today are committed to close examination not of dead texts but of living textuality and discourse, wherever they may erupt, for narrative “constitutes a logic in its own right, providing human beings with one of their primary resources for organizing and comprehending experience.”⁷ They find that a commitment to form, in W. J. T. Mitchell’s words, “is also finally a commitment to emancipatory, progressive political practices united with a scrupulous attention to ethical means.”⁸

Like lawyers, teachers, historians, and journalists, health care professionals have come to realize that they must understand these building blocks of stories in order to do their work.⁹ A symptom or disease is indeed an event befalling a character, sometimes caused by something identifiable, within a specified time and setting that has to be told by one to another from a particular point of view. However, health care professionals often lack the means to recognize explicitly the temporality within which lives and diseases unfold, to grasp and value the singularity of each person or character, to face both the search for causality and the acknowledgment of underlying contingency in life in general and in disease in particular, and to comprehend the intersubjective and ethical demands of telling one’s story and receiving the stories of others.

TEMPORALITY

Henry James writes, in the third and last (and unfinished at his death) book of his autobiography, “We are never old, that is we never cease easily to be young, for *all* life at the same time: youth is an army, the whole battalion of our faculties

and our freshesses, our passions and our illusions, on a considerably reluctant march into the enemy's country, the country of the general lost freshness."¹⁰ James's figure of youth invading the enemy territory of the future gives particular sharpness to the stories clinicians hear in their day-in, day-out work. We sit in our offices, hearing patients tell of the defeat—or the fear of such—of their youth and their health, at the hands not necessarily of disease but of time. Degenerative diseases—what most of our patients these days die of—are not so much pathology as they are the consequences of the passage of time.¹¹

Human beings take stock of the passage of time through narrative, the only kind of telling that takes account of chronology, duration, and temporal order. In his comprehensive *Time and Narrative*, philosopher Paul Ricoeur asserts that narrative dwells in temporality and that, conversely, time dwells in narrative. "[B]etween the activity of narrating a story and the temporal character of human experience there exists a correlation that is not merely accidental but that presents a transcultural form of necessity. To put it another way, *time becomes human to the extent that it is articulated through a narrative mode, and narrative attains its full meaning when it becomes a condition of temporal existence.*"¹² From *One Thousand and One Nights'* power to postpone the sequelae of time, to Proust's masterful reimaginings of the intimate moments of his life, to Joyce's re-creation of a day in the life of Leopold Bloom, a day that contains and recapitulates and contests all we might consider to be of human meaning, narratives provide the traces as well as the sources of our consignment to and our celebration of time.

Narratives teach us where we come from and where we are going, allowing us to understand the meanings of our own lives.¹³ Fairy tales, bedtime stories, family myths, and traditional holiday legends contribute to a child's understanding of where he or she is from. Families, towns, nations, and cultures rely on the commonalities donated by shared accounts—Genesis, Columbus's voyage, the Middle Passage, the Holocaust—to identify what it is that binds them as one in the present. The patrimonial practice of continuing names along a blood line can be read as a narrative reminder—or even a metaphor—of the familial progression in time. Novels, memoirs, plays, movies, and what we ourselves write are the forms of knowledge that help us to wonder at where we are going or, more savagely, what it is all *for*. By respecting the beginnings, middles, and ends of human events, narratives require, from each reader and writer, adherence to the human's obligatory existence within the flow of—and the buoyancy of—time.

Narrative might be the most important discovery humans have made in order to deal with the problem of time. The philosopher and literary scholar Georg Lukács writes, "We might almost say that the entire inner action of the novel is nothing but a struggle against the power of time."¹⁴ Such scholars and writers as Henri Bergson, Marcel Proust, Gérard Genette, and Fredric Jameson all try, in their turns, to face the twin submission to and mastery of time as it passes, time as it stamps us, time as we waste it and use it and live through and beyond it, and it is through narrative thought—in fiction, in history, in reverie, in dreams—that humans are able to come to at least provisional accord with the relentless and merciful passage of time.¹⁵

Both writing and reading are activities accomplished within time, and both activities leave tracks of their journey from past to present to future. In the introduction to *The Golden Bowl* written for the 1909 *New York Edition*, James makes explicit his journey as a reader through a text he himself had written some seven years ago. In a breathtaking trope, James figures his act of reading to be like a walk on newly fallen snow, his footsteps marching through a territory he had invented yet creating new tracks through it. “It was, all sensibly, as if the clear matter being still there, even as a shining expanse of snow spread over a plain, my exploring tread, for application to it, had quite unlearned the old pace and found itself naturally falling into another, which might sometimes indeed more or less agree with the original tracks, but might most often, or very nearly, break the surface in other places.”¹⁶ *He read a different book from the one he had written*, because his new reading act took place at a new temporal stance.

Not an undifferentiated element of stories, fictional time is distinguished into order, duration, frequency, story-time, and discourse-time. Readers compare the time it takes to read a passage with the time it might have taken for the action of the passage to occur to arrive at the so-called velocity of the text. The order of some stories is chronological, starting at the beginning and moving sequentially through the actions depicted. Often, though, a story is told in flashbacks (narratologists call these analepses) in which the narrator recalls or reports on events of the past. Sometimes, there will be prolepses, or flash-forwards, in which the reader is given access to events of the future. A pivotal distinction was made by the linguists in structuralist times between diachrony and synchrony; roughly speaking, diachrony is the condition of time passing, of being “within” sequence, while synchrony is an epiphanal eternal state of having arrived. Diachrony contains frequency and repetition, while synchrony has no habit or antecedent. Diachrony is longitudinal; synchrony is cross-sectional.

A narrative’s reading time, or the literal amount of time it takes to read it, is an oddly powerful determinant of the text’s influence. Living within the narrative world of Hans Castorp and his fellow Berghof residents for the time it takes to read *The Magic Mountain* conveys, as the plot alone could not, what Mann means to tell us about time. Wayne Booth argues that reading a novel enables the reader to dwell within its climate and to inhabit the world of its characters for “long enough” to achieve familiarity with the story-space and intimacy with its people. Short stories cannot give the reader this transforming contact, merely as a function of the time one spends in the work.¹⁷

We see that medicine’s accounts of events, too, are “nothing but a struggle against the power of time.” Humans struggle to come to terms with the bracketing, in time, of their own existence, engaging in many of the local battles against immortality in the presence of doctors and nurses—in the delivery room, in the emergency room, in the waiting room outside the OR, in hospice. While waiting for the birth of the first grandchild, the older adult feels the pinch of senescence and the grandeur of fecundity. As the daughter reaches the age at which her mother died, she resigns herself to duty or she rages against her doom. And when the doctors offer comfort care, the patient submits to counting days, no matter how brazenly time was snubbed in the healthy past. The temporal frag-

mentation and rupture seen especially in postmodern narratives are exactly what occur when disease forecloses narrative coherence over time, leaving the patient able to say only, “Now what?”

When the doctor or nurse enters the room to do something—to palpate, to cut, to medicate, to stitch—he or she remains within vectored time, that is, a state of time in which one event leads to another and can even be conceptualized as having caused it while the patient inhabits a timeless enduring. This is not just the difference between passivity and activity but the more unfathomable distinction between living within and outside of time, between diachrony and synchrony. When the pediatrician John Lantos depicts the difference between being a patient and a doctor, he figures it in literary terms, suggesting that patients dwell in modernism’s focus on the interior while doctors enact the pre-modernist choice for acting, causing, derring-do.¹⁸ Not only does the nature of the actions accomplished by the sick and the well differ but also their temporal states of being differ according to their tempo, durability, evanescence, and stillness. T. S. Eliot’s “still point of the turning world” indeed refers to the timelessness within the shell of time that, perhaps, best explains the sick person’s dwelling in temporality.¹⁹

Time is medicine’s necessary axis—in diagnosis, prevention, palliation, or cure. Time is, as well, the irreplaceable ingredient in the healing relationship: time to listen, time to recognize, time to care. Medicine becomes transformed if it is practiced with a real respect for time and timeliness.²⁰ Doctors equipped with temporal sense might not make patients wait through a weekend for the result of a biopsy, realizing that the fear of an illness is almost as painful as the reality of it. The skirmish about waiting room time might be taken seriously—we doctors are never on time, and our assumption that patients do not mind being kept waiting is a pervasive and powerful message about differential worth. Some doctors have changed their appointment policies dramatically, vowing to see patients on the day they call, and find that such schedules of immediacy are, as it turns out, easy to manage.

Temporality grounds most diagnostic and therapeutic acts. We need time and continuity to understand what disease afflicts a patient, to let a disease declare itself. And yet, however skilled we get, we will never govern time; no matter how far into the country of the general lost freshness we extend life expectancy, death will come. What, finally, might a practice of medicine become if it were fortified with a real, earthy, lived sense of mortality? Our current health care system assumes that everyone lives forever, turning away from the realization that lives begin and end, on their own trajectories, but within the biological limits for the species. It is we health care professionals, as curators of the body, who should model the bravery to face the shadow of the end, the honesty to desist from false promises, and the humility to remind us of our limited portion on earth.

A third-year medical student described in his *Parallel Chart* an early lesson about temporality:²¹

A 57-year-old woman with terminal ALS was admitted refusing food, water, and non-palliative treatment. We were to control her pain until she died. Though

there were other patients on our service, the resident and I revolved around the patient with this horrible disease like shy comets. She was paralyzed, unable to speak, in tremendous pain, and, worst of all, fully lucid. Every couple of hours she would breathe with loud stridor and indicate she was in pain and we would draw up huge boluses of morphine and push it into the line. A minute later she would fall silent and then sleep for a time until she awoke in pain. Then we would go through the routine again.

After a few cycles of this the intern told me that the doses of narcotic we were giving her were enormous and that another bolus that afternoon would probably put her in respiratory failure. I asked what we would do if she were in more pain. He told me we would give her more morphine.

When the pain came again I offered her morphine and her blue eyes accepted it. As the resident prepared the syringe that would end her life, I stood by the bedside, my emotions roiling. Then, at that fateful moment, I sneezed. Her eyes met mine and her lips moved in the last communication they would ever have with another person. They said, "God bless you."

SINGULARITY

What distinguishes narrative knowledge from universal or scientific knowledge is its ability to capture the singular, irreplicable, or incommensurable. Despite the organizing principles donated to literary study by linguistics and semiology—and in the wake of the now dashed hopes of the ancestors of structuralists that the codes of literary works could be "cracked" and their understanding based on replicable processes—the text remains a zone of indeterminacy, of the pleasure of the new, the never seen. As described by Gérard Genette, the French structuralist who christened the field "narratology" in 1969, no story (narratologists call the events or state of affairs to be represented the story, or *l'histoire*) replicates any other story. No representation of that story in words (the narrative, or *le récit*) repeats any other representation. And no act of telling (the narrating, or *le narration*) recurs in any other performance or delivery of that which is being told.²² In *Narrative Discourse*, itself a book-length comment on Proust's *A la recherche du temps perdu*, Genette writes, "The specificity of Proustian narrative, taken as a whole is *irreducible*, and any extrapolation would be a mistake. . . . [T]he *Recherche* illustrates only itself."²³

Form confers singularity. Built into each narrative's structure and genesis is its originality and irreproducibility. The Russian narratologist Tvetzian Todorov emphasizes the emergence into view, through narrativization, of that which does not exist prior to its being told: "Meaning does not exist before being articulated and perceived . . . ; there do not exist two utterances of identical meaning if their articulation has followed a different course."²⁴ The narrating, that is to say, creates that which is seen for the first and only time. The telling does not merely expose or report that which exists prior to the narrating. It produces it.

Writers understand how they watch the paper or the computer screen, in

great suspense, to see what will appear next, even if it is their fingers on the pen or the keyboard. Whether writing fiction or autobiography, authors have surrendered to the realization that, however much they might covet control or power or *authority*, they function merely as hosts to the writing impulse.

This idea of telling as creation, however, may threaten those who regard themselves as dutiful observers of reality and careful scribes of what is found. The dermatologist describes a rash as a “2 cm diameter dry, erythematous eruption with silver-scaling periphery.” It is a case of psoriasis, identical to many others seen. There is no creativity in that act of describing, merely a transparent rendering of fact. Not so: despite the commitment to describe only what one sees, one’s seeing is influenced by prior categories, diagnostic impulses, comparative memory, conventionalized diction, and concurrent clinical facts that suggest this diagnosis instead of that one. As the philosopher Arthur Danto puts it, “observation is (if I may borrow a locution from Derrida) ‘always already’ permeated by theory to the point that observers with different theories will interpret even retinally indiscriminable observations differently.”²⁵ An experiment could easily be done in which an artist and a dermatologist describe the same rash. The artist and the dermatologist would see and describe different phenomena—the artist responding to color, form, and texture and the dermatologist responding to taxonomy, pathology, and probability.

However, the medical impulse toward replicability and universality has muted doctors’ realization of the singularity and creativity of their acts of observation and description. When a dermatologist meets a patient complaining of scaling and itch, he or she is a singular person in that room with the singular patient. That dermatologist *donates* to the situation more than a memorized dermatological atlas. That doctor donates all human powers of thought and emotion, able to categorize the lesion correctly while able to comprehend empathically the patient’s plight. These two events happen at the same time because of the singularity of the human instrument.

How can we create as we tell and, at the same time, recognize what we see? Doesn’t the singularity cancel out the usefulness of the diagnostician? The diagnostic act entails two contradictory impulses at once: the effort to register the unique features of that which is observed and the simultaneous effort to categorize it so as to make it “readable.” The French structuralist Roland Barthes, who initiated and instigated much of what has come to be called both structuralism and poststructuralism, distinguishes between *le lisible* and *le scriptible*, that is, the readerly and the writerly.²⁶ The readerly text is the dead one, the one that, once written, can only be read in one certain way. The reader cannot contribute to its meaning or form, and the only action open to the reader in the face of such a text is to submit to it. The writerly text, on the other hand, comes into the hands of the reader incomplete, still alive, requiring active creation from each reader it visits. The reader of the writerly text is coauthor of it, not by virtue of observing what its author did but by virtue of performing what the text compels. In reading a readerly text, Barthes says that “reading is nothing more than a *referendum*,” while “the writerly text is a perpetual present . . . the writerly text is *ourselves* writing.”²⁷

And so the rash, to the dermatologist, is simultaneously a readerly text and a writerly text. It is readerly in its recognizability. The doctor has seen psoriasis before. He or she is *cognizant once again* of the silvery scales, the characteristic array of patches on extensor surfaces of the joints, the marks of excoriation surrounding the eruption signifying scratch. Is it too much to ask of the ordinary dermatologist that he or she also apprehend the singularity of this event? Perhaps the patient has just come down with psoriasis and is terrified that it is terminal. Perhaps the patient thought that, with all the tar and UV light, he was cured. Perhaps, like John Updike, the patient feels at war with his skin while feeling its certain distinction, “I was always in danger, with my skin, of forgetting that I was its victim and not its author.”²⁸

When patients complain that doctors or hospitals treat them like numbers or like items on an assembly line, they lament that their singularity is not valued and that they have been reduced to that level at which they repeat other human bodies. It is in the sphere of narrative that patients, of late, have attempted to take back their singularity, their subjectivity. In explaining the explosion of illness narratives being published by patients in the last few decades, Thomas Couser writes, “As patients seize, or at least claim, more authority over their treatment, they may also be more inclined to narrate their stories, to take their lives literarily into their own hands in part to reestablish their subjectivity in the face of objectifying treatment.”²⁹ Proving the assertion that singularity resides in narrative, patients’ new authorship of their illnesses may exert a tremendous power on medicine’s capacity to recognize the singularity not only of every case of psoriasis but of every patient, every doctor.

Some developments in medical practice speak to a growing respect for singularity in care. Biologically, health care has become more tailored—think of the many regimens for treating hypertension or diabetes or depression—to take into account comorbidities, genetics, and patient preferences. Concurrently, medicine is making room for patients’ personal singularity—witness advance directives regarding end-of-life care. House calls are coming back into vogue, in part because seeing a patient in his or her home gives a wealth of knowledge about that singular life, knowledge that can inflect care profoundly.

Along with recognizing patients’ singularity, doctors seem more willing to recognize their own. The reflective writing that is growing in medicine for students and for professionals (see chapter 7) testifies to professionals’ willingness and skill to examine their own experiences and to make sense of their own journeys, not for solipsistic reasons but for the sake of improving the care they can deliver. That dermatologist who understands that there are two singular people in the room—one with psoriasis and one who can treat it—will accept his or her singularity, not as a risk to objectivity but as a bonus to effective care. Genette continues, as if speaking to our dermatologist, to observe that though “there are no objects except particular ones and no science except of the general” it is the case that “the general is at the heart of the particular, and therefore (contrary to the common preconception) the knowable is at the heart of the mysterious” (23).

A social worker wrote the following text in narrative oncology, a narrative

training program in which doctors, nurses, and social workers who staff the inpatient oncology unit at Presbyterian Hospital meet regularly to read to one another what they have written about their clinical work.

My gruff, unpleasant friend, always an insult, “For a short person, you make a lot of noise around here,” you say. You interject, correct me when I speak with each of your roommates, so many in these 69 days of captivity. We both know you are my favorite. I savor my end of the day time with you, no chart or pen comes in with me. You take me to the battlefields of W.W. II, to your kitchen table where you and your brothers debate baseball—back in time we fly together, leaving your always darkened room behind. You transform this environment subtly, magically. My access to you, your past, your point of view is a gift to me, Pete. No code on the statistics sheet so honored here captures this.

Here the health professional savors her magical time *outside* the generalized statistic, finding within the highly personalized past of this patient an enlivening, “favorite” mode of being as she listens, in a darkened room, on a flight into the past, to the captivating intersubjective truth of another human being.

☐ CAUSALITY/CONTINGENCY

By definition, a narrative has a plot; that is, it not only announces a series of separate events or states of affairs, but also asserts meaningful causal relations among them. We remember E. M. Forster’s definition of a plot: “‘The king died and then the queen died’ is a story. ‘The king died and then the queen died of grief’ is a plot.”³⁰ The engine of narrative is its urge to make *sense* of why things happen, its longing to find or imagine connections among things, either through motive or cause. This might even be true of fragmented postmodern texts that find “sense” by reconciling to the absence of connections among things. Myths, legends, novels, historical accounts, and admission notes in a hospital chart search for reasons for events, their purposes, their antecedents, their consequences and encode these reasons in their plots.

Plots are functions of the beholding of events and not a function of the narrated events themselves: “[O]ur minds inveterately seek structure, and they will provide it if necessary. . . . The reader ‘understands’ or supplies it; he infers that the king’s death is the cause of the queen’s.”³¹ Causality is always a human invention, as we saw in the discussion of patients’ and doctors’ differing assumptions about disease causality, whether one thinks that Merton Densher’s betrayal in *Wings of the Dove* led to Milly Theale’s death or that the tubercle bacillus leads to pulmonary consolidation. Defining plot as “the very organizing line, the thread of design, that makes narrative possible,” Peter Brooks finds that “plot is the principle of interconnectedness and intention which we cannot do without in moving through the discrete elements—incidents, episodes, actions—of a narrative.”³² Whether the cause of an effect has been proven conclusively or is fancifully hy-

pothesized, one expresses their relation by putting them together into a plot, or, as a narratologist would say, through narrative emplotment.

Emplotment is the action not of the tale but of the teller, not Genette's story but his narrative. Any sequence of events or actions can be "told into" different plots. Perhaps vertiginous, the realization hits most listeners and readers that there is not a replicable and governing *story* at all. Depending on the teller's point of view, intention, and stance, the same set of events can be told so as to make many contradictory plots. As Tod Chambers and Kathryn Montgomery write in describing the emplotment of bioethics, "Plot *is* meaning. Plot shapes a story to represent the significance of its events and to reveal their meaning for the teller and (the teller hopes) the listeners."³³

In fact, we all know that many events are random, unpredictable, unexplainable, and unknowable. Even those who believe that meteor showers or genetic mutations are random, acausal events seek out with great rigor their grounds, the better to feel less victimized by their occurrence. Danger is contained in the unknown, and human astronomy, navigation, exploration, natural science, and medicine evidently emerged as a response to the perilous unknown. The imperative to sail across the unsailed sea, to settle wild frontier lands, or to peer within the human body all emit from the refusal to be frightened in the face of the unknown. The 42-year-old mother of three with Stage 4 breast cancer asks, "Why did this happen to me?" and all know that her question has no answer. Even without a provable answer, she may develop a plot line that posits *some* cause for her ordeal, for "how can we live and make sense of our lives in the face of the awful happenings of chance events?"³⁴

The emplotments of epic, myth, and the novel are, like the emplotments of astronomy or genetics, impulses to address the unknown, to tame danger, to conquer fear, to brave, full in the face, any predicament in which a human being finds himself or herself. (Think, for example, of what Joseph Conrad represents in *Heart of Darkness*.) If the future, the great unknown, waits, then what one does while waiting might, in some form of magical thinking, alter the future to come; it will at very least ease the suspense or the anxiety of anticipation. So Columbus probably told tales of East India on the blank blue mid-Atlantic; Sioux hunters enact buffalo dances around the campfire to prepare for the hunt; and prayers like the Hail Mary or the Kaddish await death with some promise of being accompanied into it.

All efforts to find causes—from science to space travel to literary prose—try to bring order, to unearth Genette's "knowable at the heart of the mysterious." Emplotment, whether in an earthly garden or a fictional text, *claims* land or thought as one's own, as possessed, as ordered, as granted form. However, unlike other impulses with which to face the unknown—the expropriative impulse, the imperialistic impulse, the reductionist impulse—the narrative impulse does not excavate the unknown beyond recognition. It does not sanitize it of danger; it does not consign it to sameness with other such predicaments. Nor does it take away from it what makes it itself, or take it apart beyond putting it back together. It celebrates the uniqueness and respects the unity of the event while representing it. Expansive rather than restrictive, multiplying possibilities

instead of reducing them, narrative practices enable the observer or the participant to live in the face of contingency without trying to eradicate it. Writing and reading are, in the end, expeditions into the mysterious, potentially dangerous, uncharted continent of the contingent.

Causality and contingency join in the development of plot as the teller arranges the events or states of affairs in hand in order to lead, provisionally anyway, to one of many endings. In both of conclusion's definitions, plot enables us to find meaning and, quite literally, to stop. Frank Kermode, the obligatory literary critic to cite on theories about endings, ends his meditations in *The Sense of an Ending* with these thoughts, "Our geometries, in James's word, are required to measure change, since it is on change, between remote or imaginary origins and ends, that our interests are fixed."³⁵ It is only when human representers frame events or states of affairs that beginnings, middles, and ends are mapped and measured and that meanings emerge from them. As Verbal Kint's crippled foot straightens out at the end of the movie *The Usual Suspects*, we viewers too ask Slavoj Žižek's question: "Does Keyser Soze . . . exist at all, or is he the fantasmatic invention of the pitiful Kint? . . . Is he the fabricator of his own myth? In a properly dialectical way, the very quilting point (*point de capiton*) that promises to establish the true narrative resolving all inconsistencies, radically undermines our narrative security, throwing us into an abyssal echoing of deceptions."³⁶

Clinical practice is consumed with emplotment. Diagnosis itself is the effort to impose a plot onto seemingly disconnected events or states of affairs. We test one diagnostic algorithm after another—and the more seasoned we get, the more automatically and underconsciously this process occurs—in the effort to categorize this set of events, *in the effort to emplot it*. The clinician endowed with the gift of plot—and aware of the abysmal echoing of deceptions possible with illness—will search out with great inventiveness and open-endedness and courage (for tolerating the unknown requires it) multiple possible causal relationships among the disparate symptoms and situations that the patient presents. Improving the effectiveness and range of diagnostic powers, this gift teaches the listening doctor or nurse how many possible plots there might be hidden within a simple recitation, how many motives and antecedents might be at work, how many different points in time might be considered the "beginning" of the story. The plot-strong clinician will not stop with the obvious or the evident story line but will keep looking—generatively, creatively, hopefully in collaboration with the patient—to construct a wide and deep and varied differential diagnosis. This is narrative medicine in practice.

I close this section with an excerpt from a clinician's writing for narrative oncology. The poem is a meditation offered by an oncologist to a patient, trying to fill in what she does not know about how he got to where she found him:

I know he must be embarrassed, sitting in his ICU bed
 With tears he has no energy to hide
 He knows me so poorly, for only 3 days
 And he feels he has failed in some way.

“How are you holding up emotionally?” I ask
 although it is patently obvious the answer is “poorly.”

He’s in a hospital far from home, with an illness that came on suddenly
 And with such an aggressive force to make him a prisoner
 To ICU beds, dialysis machines, Tenckhoff catheters.
 He has a brother and a sister who appear to be close,
 But I know nothing of why he is 50 and alone
 Who he is as a man, when he’s not incapacitated in a bed
 Or whether he’d normally let a woman he barely knows see him cry.

The plots that we encounter and create in medical practice are very practically and irrevocably about their endings. They point to human ends, using their geometries to understand or to imagine the vectors of life, the plottedness of life, the inevitability of death, and the narrative connections among us all.

INTERSUBJECTIVITY

The subject is the self-who-knows, the self-who-acts, and the self-who-observes or, in the philosopher Paul Smith’s formulation, the “bearer of a consciousness that will interact with whatever the world is taken to consist in.”³⁷ Intersubjectivity, it follows, is the situation that occurs when two subjects, or two authentic selves, meet. It is in meeting with other selves that the self comes alive. As Charles Taylor writes, “One cannot be a self on one’s own. . . . A self exists only within what I call ‘webs of interlocution.’”³⁸ Analytic philosophers consider intersubjectivity in a narrow sense as the triangulation that occurs when two subjects simultaneously observe an object external to both. Starting with Heidegger and Husserl, the phenomenologists deepened philosophy’s ideas about intersubjectivity to not only encompass the cognitive acts of perception and interpretation but to include as well the personal transformations incurred by virtue of human relation. Complexly joining cognitive, perceptual, and ontological considerations, Husserl writes, “I *experience* the world (including others)—and, according to its experiential sense, *not* as (so to speak) my *private* synthetic formation but as other than mine alone, as an *intersubjective* world, actually there for everyone, accessible in respect of its Objects to everyone.”³⁹ Their joint being-in-the-world grants fellowship to its cohabitants, in both their mutual regard of its objects and their becoming objects for one another’s regard and experience. Emmanuel Lévinas culminates this stream of philosophical exploration by promoting ethics, which he defines as the responsibility that one human harbors toward another human, to become the *cause* of philosophy. Replacing Husserl’s problem of knowledge and Heidegger’s problem of being, Lévinas proposes the problem of ethics as primary, transforming philosophy into an enterprise committed to intersubjective human responsibility.

Literary scholars are of late greatly interested in the intersubjective events of authorship, readership, interpretation, and influence. They probe the com-

plexity that results when one human being engages with another in transmitting and receiving texts. Like medicine, narrative situations always join one human being with another, and, indeed, one can argue that the joining of one human being with another always requires narrative acts of one kind or another. The literary scholar Barbara Herrnstein Smith defines narrative discourse as “someone telling someone else that something happened,” emphasizing narrative’s requirement for a teller and a listener, a writer and a reader, a communion of sorts.⁴⁰ Much of narratology’s early work examined the acts of narrating that occur in works of fiction, discriminating between first-person and third-person narrators, narrators within the action and those outside the action, and the like.⁴¹ Although most of such formal narratology is beyond the scope of our discussion, its focus on the obligatory locatedness of any act of telling reminds us, in medicine, to attend to the consequences of *how* and *from whom* we hear the narratives of patients—the demented woman’s unrecognized daughter? the ER face sheet? the note scribbled by the night float at 4 A.M.?

Any act of reading embroils the reader and narrator in an intersubjective situation, because a relation obtains between the person who tells and the person who listens or reads. The narratively skilled reader or listener realizes that the meaning of a narrative—a novel, a textbook, a joke—arises from *and is created by* the meeting between teller and listener. It follows that narrative acts build relationship as they convey information, emotion, and mood. When I read a novel by Henry James, I can be thought of as entering a relationship with him. Even though he has been dead for almost 100 years and I never met him and he does not know who I am, my act of seriously reading him engages the two of us in a powerful and transformative connection.

Serious readers and writers have always known that their literary acts make them who they are by virtue of a baffling communion with one another. The contemporary field of reader-response criticism arose specifically to understand the intersubjective dimensions of reading and writing. Whether described in terms of expressivity, inspiration, or collective cultural wisdom, writing texts and reading them were recognized as powerful, mysterious, interior acts that define the self through contact with the thoughts and productions of others. A confluence of interest from phenomenologists, psychoanalysts, cognitive psychologists, neurobiologists, and literary scholars raised the interpersonal events of reading to visibility. Readers, we realized with great excitement, are fundamentally changed by virtue of their reading acts. Whether by exercising their metaphorical range, intensifying some of their characterological means of coping with uncertainty, or rhetorically remodeling their patterns of thought, reading was identified as transformative.⁴²

Now, reading and writing do not generate the kind of personal relationships one finds in, say, families or neighborhoods. My relationship with Henry James cannot be called a friendship, or a sexual union, or a familial bond, but it is a central and very powerful relationship in my life. Those who disagree with me so far in this section will say, “But, Rita, James does not *know* you,” or, perhaps, “James does not know *you*.” Here is where the mystery starts. James writes for his reader. He may not know exactly who that reader is—in the “now” in which

he writes and during the future life of the work. Nonetheless, as he writes, he has forcefully in mind the image of *and the reality of* the person who holds his book to read him. Despite the centuries and the distance, he knows me, as, might I say, I know you.

The dedicated reader finds herself in a delicate pact with her author. Once armed with the knowledge that unlocks the text, the reader owes something to her author. She has entered the world of meaning of an author, perhaps bidden, perhaps not. She has overheard the secrets, has maneuvered around the subterfuge or surface distractions to “get” what the text is about. And so upon her is conferred a duty to honor, to protect, to respond to, and even to expose the true meaning of the work. Old-fashioned notions of authority vested in the person who writes must contend with opposing notions of the creative freedoms of readers able to find their own meanings within any given text, meanings that perhaps the author cannot see. The tensions inherent in this relationship—writer/reader, teller/listener, analyst/analysand, patient/doctor—are exactly the tensions that *produce* the intersubjective connections and duties of the text and that clarify, through contradiction, that which the reader owes the writer or the teller owes the listener.

Writing, or telling, gives a speaker the authority and the opportunity to reveal the self. Writing, or telling, includes within its act the thrust, the penetration into the meaning-making apparatus of another to deposit that which one has to discharge. Reading, or listening, requires an equally perilous and daring ability to acknowledge another self, to open oneself to being penetrated by another. What a remarkable obligation toward another human being is enclosed in the act of reading or listening. Assuming genuineness in the transaction, the speaker is revealing deep and unknown truths, not only by the words chosen but also by the forms, the diction, the metaphors adopted in the course of telling a tale, while the reader is exposing his or her private organ systems of meaning-making for use by another. Within these acts of intimacy and trust arise notions of the erotics of text, championed by Roland Barthes before anyone knew what he meant.⁴³ Two strangers, the reader and the writer, ultimately surrender themselves into one another’s hands. They both experience great peril, insofar as both selves are exposed beyond the ability to call the exposure back.

The relationships that develop in medicine, as it turns out, bear an uncanny resemblance to the relationships between tellers and listeners in general, perhaps more resemblance than they do to other categories sometimes used to describe them—friends, neighbors, adviser/advisee. What literary studies give medicine is the realization that our intimate medical relationships occur in words. Our intimacy with patients is based predominantly on *listening to what they tell us*, and our trustworthiness toward them is demonstrated in the seriousness and duty with which we listen to what they entrust to us. Yes, doctors touch patients and do rather extraordinary physical things to them, but the textuality and not the physicality defines the relation. These therapeutic relationships are not conventional love relationships, nor carnal relationships, nor familial dependency relationships, nor relationships of the marketplace. In fact, we are misled when we try to conceptualize medical relationships as if they were

based on love, desire, power, or commerce. They are based on the complex texts that are shared between doctor and patient, texts that encompass words, silences, physical findings, pictures, measurements of substances in the body, and appearances.

If this aspect of the parallel between medicine and literature holds, then literary methods are of tremendous practical use to us in medicine. These methods can help us learn how to be astute receivers of our patients' stories and how to join with them to create meaning. Literature is hardly of interest to medicine only because great books have been written about illness and death. More fundamental by far than the content of *Bleak House* or *King Lear* is the modeling, by literary acts, of deeply transformative intersubjective connections among relative strangers fused and nourished by words. Recognizing that my responsibility toward my patient includes my being a dutiful and skillful reader helps me to understand what skills to develop within my doctorly self.⁴⁴

The following text is transcribed from an interview with a third-year medical student completed as part of the research study on the use of the Parallel Chart in medical training. Although the interviews are reported anonymously, the sentiments of attunement heard by this student are widespread among these young protodoctors. Here, the student describes meeting with a young woman patient, dying of AIDS, who was looking back with great regret at her relationships with her children, two of whom had been taken away from her and raised in foster care.

INTERVIEWER: This AIDS patient, who, you know, you began to talk with. How is that going? Is it easy to talk to her? How do you do it?

STUDENT: Well—I guess today—I mean, I'm very moved by her, because, today we mostly just talked about her sons, she has a 2½ year old son, and, I guess I just really appreciated and, you know, gave her room to appreciate her relationship with him, and I was just kind of marveling, you know, what a gift that she gets to know this kind of love, you know, 'cause she actually had two other kids and they're like, twelve and thirteen but, you know, I don't think [she] was ever their primary care giver, and so, she just talked about what it meant to like, you know, breast feed and to really love him, and just, he's her life, and it's very beautiful, and—I don't—she hasn't raised this with me, but I read from one note with the social worker that she had talked about this being the last birthday of his that she'll see—I know I said 2½ but I think he's turning three, and so, that's . . .

INTERVIEWER: That *she'll* see.

STUDENT: Yeah. That she'll be there for. I guess I—I guess I was appreciating, you know, she's recognizing the end of her life, I think, although we haven't talked about it exclusively, um, about how she's just enjoying these things, enjoying her son and the beauty in their relationship. I think that—I think a lot of times when you're talking to patients is mostly giving them room to talk, and I think that a lot of times, patients don't have that safe space . . . so kind of listening for a minute and giving people, you know, just exploring what they're going through or what they're feel-

ing and—it doesn't always have to be, you know, that she has to explore the fact that she's dying, but that she can explore, you know, what's meaningful to her right now.

We can learn from this sensitive student that the intersubjective meetings that occur in hospitals, between relative strangers, are replete with the occasions of great personal discoveries. These meetings are therapeutic to the extent that they enable one person to tell while the other listens, and to tell and therefore to know of "what's meaningful to her right now."

▣ ETHICALITY

Now that the intersubjective relations that develop between teller and listener (or writer and reader) have been examined, the ethical relations that develop in narrative can be recognized. Both bioethicists and literary scholars write about narrative ethics, scaling the disciplinary boundaries between health care and literary studies to contemplate the obligations incurred in narrative acts, the ethical vision afforded by stories, and the ethicality of the very acts of writing and of reading. A branch of literary criticism called ethical criticism has arisen recently to look specifically at these questions. Although muted in today's climate of ironic skepticism toward earnestness of any kind, the voice of the ethical critic gently but gravely reminds us that reading and writing are high-stakes actions with consequences not only in books but in ordinary lives.⁴⁵ Adam Zachary Newton in *Narrative Ethics* suggests that "a narrative is ethics in the sense of the mediating and authorial role each takes up toward another's story. . . . Storytelling lays claims upon all its participants, those circumscribed within the narrative as well as those . . . witnesses and ethical co-creators from without—its readers."⁴⁶

The receiver of another's narrative owes something to the teller by virtue, now, of knowing it. This is the intersubjective bridge to narrative's ethics. The act of reading or hearing an author's work confers upon the receiver an uncanny intimacy, as if learning a new private language. The learner of such a personal language incurs duties toward the originator of it; once one is fluent in the language of another, one harbors toward him or her a great and sacred trust. Serious literary scholars bend toward their authors a delicacy and honor, even when critiquing the work. Unlike those who expose or expropriate damning facts about a writer's life or demeaning aspects of the work, the serious scholar devoted to an author enacts the same kind of professional demeanor toward the author that an analyst might toward an analysand.

Beyond the intersubjective threshold of narrative ethics, we enter the ethical dimension of stories. "There is a peculiar and unexpected relation between the affirmation of universal moral law and storytelling," writes J. Hillis Miller in *The Ethics of Reading*. "Without storytelling there is no theory of ethics. Narrative, examples, stories . . . are indispensable to thinking about ethics."⁴⁷ The

philosopher Martha Nussbaum found that she could not *say* what she meant to say in moral philosophy without recourse to Henry James's *Golden Bowl*. It was only the singularity and penetration of James's densely woven narrative context that could represent and enact the moral texture of human life that she wished to probe: "The adventure of the reader of this novel, like the adventure of the intelligent characters inside it, involves valuable aspects of human moral experience that are not tapped by traditional books of moral philosophy. . . . For this novel calls upon and also develops our ability to confront mystery with the cognitive engagement of both thought and feeling."⁴⁸ By representing particular events, characters, obligations, rights, and wrongs in language, stories display for readers varieties of ways in which to consider what one "ought" to do or how one might judge the actions of others. "The real problem in life is knowing how to *judge* things," suggests the critic Marshall Gregory, "and this is a problem that, over and over, narratives' ethical visions help us answer."⁴⁹

The ethical vision of a story displays what the *story* itself deems to be the right way to live, while also intimating what the teller or writer deems to be the right way to live. An author achieves an enduring ethical vision, developed or repeated in work after work, that can educate his or her serious reader. Geoffrey Hartman writes that "Shakespeare's plays are certainly pervaded by moral concerns, by questions about public and private life, by concerns about justice, goodness, friendship, fidelity, love. He rouses our sympathy for all these positive qualities, even when he shows their defeat. He makes us think, again and again, 'How should one act in such a world?'"⁵⁰ When a reader is claimed by an author as is Hartman by Shakespeare or Nussbaum by James, it is because there is a powerful *channel* between the author's moral vision and the reader's own. "This is how *I* see the world," the amazed recognizing reader says—feeling, of course, recognized in the process. Through such mutual recognition, reading *constitutes* the reader's own moral vision, feeding the reader the proteins and carbohydrates and vitamins that get metabolized into the reader's ethical self.

Narrative ethics exposes the fundamentally moral undertaking of selecting words to represent what before the words were chosen was formless and therefore invisible and unhearable. It is the very act of fitting language to the thoughts and perceptions and sensations within the teller so as to let another "in on it" (that other, the listener or the reader, now bound intersubjectively if, indeed, authentic contact is made) that constitutes the moral act. The telling exposes the moral freight of the story (along with, of course, its aesthetic freight, its psychological freight, its freight of delight) not only to the light of day but also to the lights of others. When James writes in the preface to *The Golden Bowl*, "To put things is very exactly and responsibly and interminably to do them," he nails for us the *fact* that writing is an act, that writing carries the irrevocable moral duty to live up to one's actions of having told.⁵¹ If it is in the "putting" that acts of cognition and art occur, then the ethical response to having known or perceived something requires that the "putting into words" occurs.

The reader is also summoned by the text to act. Miller asserts that "there is a response to the text that is both necessitated, in the sense that it is a response to an

irresistible demand, and free, in the sense that I must take responsibility for my response and for the further effects . . . of my act of reading” (43). The compact of reading or listening is that the receiver will try to live up to the reception. “I can take it,” claims the reader or listener in the face of the full force of another’s telling. In discussing Conrad’s *Heart of Darkness* and Wordsworth’s “The Ruined Cottage,” Geoffrey Hartman focuses on the teller’s duties and the reader’s response to the telling. He suggests that the narratings in both these works “get through . . . because the incidents are embedded in a responsive human milieu by a structured ethics of narrative. Both authors know that the reception and transmission of traumatic knowledge is like handling fire.”⁵² Not unlike the kind of telling and listening that go on in Holocaust survivors’ testimonies or accounts of September 11 by those who were there, these literary tellings as well as our clinical tellings are like handling fire, for both participants in the narrating acts. If the psychiatrist Dori Laub finds that the interviewer who receives the testimony of the Holocaust survivor is himself or herself traumatized by the listening, then so too might be the nurse or the doctor listening gravely to the patient’s complaint (see chapter 9, “Bearing Witness”).⁵³ These different forms of telling—romantic poetry, modernist fiction, trauma testimony, and clinical interviewing—combine the need to know with the duties incurred by virtue of knowing. The trauma studies scholar Cathy Caruth observes that “the shock of traumatic sight reveals at the heart of human subjectivity not so much an epistemological, but rather what can be defined as an *ethical* relation.”⁵⁴

There is no need, in the clinical context, to detour through textuality when we have a flesh-and-blood patient in the waiting room who indeed exacts ethical duties from her internist unless the transposition from patient to text has dividends. The dividend is that acts of reading, accomplished with adequate skill, will *develop* the means by which that internist can fulfill his or her ethical duties. These means are in the living through. “Literature,” writes Louise Rosenblatt, “provides a *living through*, not simply *knowledge about*,” suggesting that the reader does not remain untouched through the act of reading but rather becomes open to fundamental transformation by virtue of having read.⁵⁵ What a reader undergoes in the kind of reading described by Nussbaum or Miller deepens his or her capacity for perception, discrimination, “ability to confront mystery,” and freedom.

Such exposure risks exploitation. Readers can get ravished by what they read. It has been an anxiety about literature for millennia that writers could force themselves onto unsuspecting victims, damaging their innocence through artful mastery and influence.⁵⁶ Some stories’ ethical visions might be dangerous ones, shaping readers into instruments of sadism or destruction (the dark Gothic novels read by some militant fundamentalist groups come to mind.) Subjects can get exploited by those who write about them, especially subjects vulnerable by reason of age or infirmity and exposed in relationships of professional or personal intimacy.⁵⁷ On the other hand, readers can wield great power against those they read by *knowing* them so intently. If reading or writing is done without authenticity and good faith, the reader’s or writer’s power becomes a source of violence. Lévinas says that “if one could possess, grasp, and know the other, it

would not be the other. Possessing, knowing, and grasping are synonyms of power.”⁵⁸ The anxiety about mastery in psychoanalysis rehearses this same issue.⁵⁹ Such cautions about the powers of narrative must be raised, not as excuses to turn away from understanding stories but as reminders of the risks as well as the benefits of this potent force.

One key to the risk/benefit analysis of narrative is altruism. The altruistic listener listens to advance the project of the authentic speaker so that, after a while, the speaker says, “Thank you, now I understand what I meant to say.” Such clarity would not have come to the speaker or writer without an airing of thoughts, and the airing of thoughts could not have occurred with just any listener or reader. The listener, or reader, is not a passive receptacle. Instead, he or she is shaping, questing, asking, probing, forming hypotheses, trying hypotheses, delving into possible interpretations, looking for clues everywhere, listening for the authentic voice. This is what the good listener does: she listens for the authentic voice. To do this, there must be no preconceptions of the right answer or the good outcome. The listener listens as an instrument of the speaker. The writer writes as an instrument of the reader.

A social worker on the oncology service wrote this description in narrative oncology of a meeting with a patient’s daughter and the interior conversation it occasioned:

I arrive on the floor, rushing to get to support group. A patient’s daughter is standing outside the lounge waiting for me. “How is she?” I ask. “She said she’s scared,” the daughter replies. I look at her and see the cold fear in her eyes. Her mother is dying. The patient knows it, the daughter knows it, and I know it too.

What can I do? What help is the daughter asking for? . . .

Sometimes a dying patient just needs and wants someone there. Company. Human contact. I turn and tell the daughter, “Can you go back inside, sit with her, hold her hand?” “That’s easy,” she replies and turns on her heels, back to the room.

I think about the patient, a Holocaust survivor, a lung cancer survivor, succumbing now to a different, primary cancer. How can a woman who’s been through the greatest atrocities known to humankind still have the capability to feel fear?

I think about myself. Caught like a deer in the headlights. A patient or family member in crisis comes to me for help. At that moment I am gripped by fear. Will I help? Can I help? How long till they see through my flimsy façade of knowledge, experience, school-book learning. I take a deep breath and practice what I preach and put one foot in front of the other and take a wild (hopefully informed) stab in the dark. I enter her room.

This health care professional put into practice her own knowledge about the needs of suffering people, fully realizing that she herself would undergo suffering in the process of receiving the fear and aloneness of her patient. That it was her duty to do so had also been learned.



An architect made an appointment to see me to discuss medical decisions she had to make. I had been her internist for some years and knew about treatment she had received for a cerebral hemangioma. There had been regrowth of the mass despite embolization, and the patient had to decide between two surgical approaches, one of which might threaten her vision and another of which might threaten her cognition. In her recitation in my office, she reported in great detail the opinions of her neurologist and neurosurgeon. She described the results of magnetic resonance angiography (MRA) scans and the like, but I didn't want to see the studies or read the reports. I did not feel the need to perform a physical examination, not even to check her blood pressure. Instead, we sat together, close to one another, as she told in detail what she was going through and I listened—not taking notes, not filling the hospital chart, but doing my best to absorb her transmission. I wanted to hear her out as she described what she had been through in this ordeal. I wanted to let her *hear* herself tell of what the judgments were, what they meant, which of the several scary things she feared the most. I wondered myself how angry she felt that this thing she thought she had bested had come back.

As we sat in my office, I understood that she wanted both my internist's brain and my narratologist's brain. I understood the pact we had made that, by my hearing her out, she would hear herself out. What this "hearing out" took was a complex combination of all five narrative features of medicine. We appreciated the time-bomb nature of this recurrence, the singular details of her own work situation, and how the possible operative complications would interfere with her work, and attempted to look full in the face at the uncertainties incumbent on any course of action, including doing nothing. We relied on our own intersubjective history as patient and doctor, realizing that our previous truth-telling and mutual confirmation were now, when she needed it, paying off. Because she felt free to say *fully* what was in her to say, I could take the measure of her fear, her courage, her resilience, her lack of blame, and her tremendously brave awareness of the possibility for grave losses. I, meanwhile, fulfilled my ethical duties toward my new knowledge of her situation by offering to contact a renowned hematologist at another institution whose research might contribute to the patient's decision-making. As we left my office, we both bowed our heads to signify that we had done important, serious, and moving work together, all of it narrative, all of it medical, all of it mutually constitutive of ourselves.

These five features of narrative are not isolated one from the other. Instead, they arise in congress, intertwining, emboldening one another as the reader and the writer try, in unison, to find meaning in the words. You have noticed, I trust, how singularity blends into intersubjectivity, how temporality is required for causality, and how ethicality devolves from the intersubjective acts of writing or reading. Like any organic whole, the narrative is made up of its conceptually separable "organ systems," but in its living whole, the narrative combines these elements, and life is breathed into static words and forms. The story lives, as the

reader and writer live through it and through one another. When the tellers and listeners are patients and their caregivers, the stories give them the means to bridge the divides that might otherwise separate them.

In either telling or hearing a story, our participants are gravely and joyously giving and receiving at the same time. Both teller and listener achieve both the bountiful and the compliant stance, as it were, together at once. A dance of confirmation, these narrative acts declare the self, celebrate the other, mark their meeting as a mutual creation of identity.

NOTES

1. Richard Horton, *Health Wars*, 58.

2. Shlomith Rimmon-Kenan, *Narrative Fiction: Contemporary Poetics*; Seymour Chantman, *Story and Discourse: Narrative Structure in Fiction and Film*; Gérard Genette, *Narrative Discourse: An Essay in Method* are the classic narratological texts. See also such recently published narratological texts as H. Porter Abbot, *The Cambridge Introduction to Narrative*; Brian Richardson, *Narrative Dynamics*; and Gerald Prince, *A Dictionary of Narratology*.

3. See the first chapter of David Herman's *Narratologies* for a summary of the developments of Russian formalism, French structuralism, and the study of semiotics and linguistics that developed narratology as we know it today. Jonathan Culler's *Structuralist Poetics* is also a fine examination of the development of these ideas.

4. For more background on New Criticism, see Cleanth Brooks, *The Well-Wrought Urn* and William Empson, *Seven Types of Ambiguity*.

5. David Herman, introduction to *Narratologies*, 20. See also Michael Kearns, *Rhetorical Narratology*; Mieke Bal, *Narratology*; and James Phelan, *Narrative as Rhetoric* for recent formulations of contemporary narrative theory.

6. See Monika Fludernik, "The Diachronization of Narratology" and Bruno Latour, "Why Has Critique Run out of Steam? From Matters of Fact to Matters of Concern."

7. David Herman, "Story Logic in Conversational and Literary Narratives," 130. See also David Herman, *Story Logic: Problems and Possibilities of Narrative*.

8. W. J. T. Mitchell, "The Commitment to Form; or, Still Crazy after All These Years," 324.

9. See Martin Kreiswirth, "Trusting the Tale: The Narrativist Turn in the Human Sciences." A recent, well-attended yearlong symposium on storytelling at New York University has displayed and furthered the interest in stories by such groups as law school faculty, psychoanalysts, American historians, performance artists, and medievalists.

10. Henry James, *The Middle Years*, in *Autobiography*, 547.

11. See Rita Charon, "Medicine, the Novel, and the Passage of Time," for a description of medicine's reliance on a nuanced awareness of temporality.

12. Paul Ricoeur, *Time and Narrative*, 1:52. Emphasis in original.

13. See the many general introductions to narrative theory's illumination of human development as it unfolds in time. Jerome Bruner, *Actual Minds, Possible Worlds* and *Making Stories: Law, Literature, Life*; Theodore Sarbin and Karl Scheibe, eds., *Studies in Social Identity*; Paul John Eakin, *How Our Lives Become Stories*.

14. Georg Lukács, *The Theory of the Novel*, 122.

15. Henri Bergson, *Time and Free Will*; Fredric Jameson, "The End of Temporality"; Marcel Proust, *A la recherche du temps perdu*.

16. Henry James, *The Art of the Novel*, 336.
17. Wayne Booth, *The Company We Keep: The Ethics of Fiction*.
18. John Lantos, "Reconsidering Action: Day-to-Day Ethics in the Work of Medicine."
19. T. S. Eliot, "Burnt Norton" in *Four Quartets*, 15.

20. See Kenneth Ludmerer, *Time to Heal: American Medical Education from the Turn of the Century to the Era of Managed Care* for a rigorous examination of contemporary medicine's difficulty making time for the important ingredients of healing. As befits a chapter on the narrativity of these features of clinical practice, I can point to fictions and literary memoirs of physicians as the richest and most accurate representations of the nature of and problems of temporality in practice. See, first, Thomas Mann's *Magic Mountain*. Also, the realist biography *A Fortunate Man* by John Berger and Jean Mohr; Martin Winckler's fictionalized memoir *The Case of Dr. Sachs*; and Franz Kafka's surreal short story "A Country Doctor."

21. The Parallel Chart is a method, developed at Columbia, of encouraging health care professionals and students to write, in nontechnical language, about what they witness about their patients experiences and what they themselves undergo in caring for the sick. They are asked to write that which does not belong in the hospital chart but must be written somewhere. See chapter 8 for a detailed discussion of the method.

22. These terms are borrowed from Gérard Genette's formulations of "*historire, récit, et narration*" (usually translated from the French as story, narrative, and narrating) on which subsequent narratologists rely. See Gérard Genette, *Narrative Discourse*; Shlomith Rimmon-Kenan, *Narrative Fiction: Contemporary Poetics*; and Mieke Bal, *Narratology: Introduction to the Theory of Narrative*.

23. Gérard Genette, *Narrative Discourse*, 22.

24. Tvetzan Todorov, *Littérature et Signification*, 20, cited by Shlomith Rimmon-Kenan, *Narrative Fiction: Contemporary Poetics*, 8.

25. Arthur Danto, *Narration and Knowledge*, xi.

26. Roland Barthes, *S/Z*, 3–6.

27. Roland Barthes, *S/Z*, 4, 5.

28. John Updike, "At War with My Skin," in *Self-Consciousness: Memoirs*, 66. See Mary Ann O'Farrell's discussion of psoriasis as an emblem and curse of identity in "Self-Consciousness and the Psoriatic Personality."

29. G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life Writing*, 11.

30. E. M. Forster, *Aspects of the Novel*, 86.

31. Seymour Chatman, *Story and Discourse*, 45–47.

32. Peter Brooks, *Reading for the Plot*, 4–5.

33. Tod Chambers and Kathryn Montgomery, "Plot: Framing Contingency and Choice in Bioethics," 81.

34. Richard Zaner, *Conversations on the Edge*, 101.

35. Frank Kermode, *The Sense of an Ending*, 179.

36. Slavoj Žižek, "The Ongoing 'Soft Revolution,'" 18.

37. Paul Smith, *Discerning the Subject*, xxvii.

38. Charles Taylor, *Sources of the Self*, 36.

39. Edward Husserl, *Cartesian Meditations: An Introduction to Phenomenology*, 91.

40. Barbara Herrnstein Smith, "Narrative Versions, Narrative Theories," 228.

41. Groundbreaking work by the early Russian formalists and French structuralists, the predecessors to today's narratologists, formed taxonomies of different sorts of narrators, narratees, and narrative situations. The difference between a first-person narrator and a third-person narrator has profound influence on the meaning and the consequences of a text. So-called homodiegetic narrators who take part in the action differ in trustwor-

thiness and impact from heterodiegetic narrators, who speak to the reader from “off the page” and outside the scene. By conceptualizing the narrative levels that can occur when someone tells someone else that something happened—first-hand, second-hand, and the like—narratologists have mapped out quite specifically the consequences of the actual sites of telling and listening. See Dorrit Cohn, *The Distinction of Fiction*; Jonathan Culler, “Omniscience”; and Nicholas Royle, *The Uncanny* for recent studies of narratorial knowledge.

42. Georges Poulet, “Phenomenology of Reading”; Wolfgang Iser, *The Implied Reader*; Norman Holland, *5 Readers Reading*; Richard Gerrig, *Experiencing Narrative Worlds*.

43. See Roland Barthes’s *Pleasures of the Text* for a remarkable examination of the state of bliss engendered through textual acts.

44. See an early essay of mine called “Medical Interpretation: Implications of Literary Theory of Narrative for Clinical Work” that develops this notion of the patient as author and the doctor as reader.

45. See Wayne Booth, *The Company We Keep*; J. Hillis Miller, *The Ethics of Reading*; and Tobin Siebers, *The Ethics of Criticism* for three quite divergent approaches to the questions of reading’s ethical consequences for reader, writer, and text.

46. Adam Zachary Newton, *Narrative Ethics*, 48, 24.

47. J. Hillis Miller, *The Ethics of Reading*, 2, 3. Subsequent page references to this work appear in parentheses in the text.

48. Martha Nussbaum, *Love’s Knowledge*, 143.

49. Marshall Gregory, “Ethical Engagements over Time,” 284–85.

50. Geoffrey Hartman, “Shakespeare and the Ethical Question,” in *A Critic’s Journey*, 89.

51. Henry James, *Art of the Novel*, 347. See Hillis Miller’s wonderful discussion of James’s prefaces in *Ethics of Reading*, chapter 6, “Re-Reading Re-Vision: James and Benjamin.”

52. Geoffrey Hartman, *Scars of the Spirit*, 12.

53. Dori Laub, “Bearing Witness, or the Vicissitudes of Listening.”

54. Cathy Caruth, *Unclaimed Experience: Trauma, Narrative, and History* (italics in original), 92.

55. Louise Rosenblatt, *Literature as Exploration*, 38.

56. See Pamela Gilbert, *Disease, Desire, and the Body in Victorian Women’s Popular Novels* for an examination of one time’s concerns that reading can be dangerous for the reader. More generally, such reader-response critics as Jane Tompkins and Wolfgang Iser have struggled with the inherent power and potential exploitations of the reading transaction. Harold Bloom’s *Anxiety of Influence* typifies the complementary caution that the writer exercises demonic possession over his or her reader.

57. See G. Thomas Couser’s *Vulnerable Subjects* for a wide-ranging examination of the ethics of representing others in personal and professional writing.

58. Emmanuel Lévinas, *Time and the Other*, 90.

59. Gilles Deleuze sees psychoanalysis as “a fantastic project to lead desire up blind alleys and stop people saying what they wanted to say. A project directed against life, a song of death, law, and castration, a thirsting after transcendence, a priesthood,” *Negotiations*, 144.