NARRATIVE MEDICINE
Honoring the Stories of Illness

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Preface

I invite readers to look with my colleagues and me at this form of clinical practice we have come to call narrative medicine, defined as medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness. When we human beings want to understand or describe singular people in particular situations that unfold over time, we reach naturally for narrative, or storytelling, to do so. When we try to understand why things happen, we put events in temporal order, making decisions about beginnings, middles, and ends or causes and effects by virtue of imposing plots on otherwise chaotic events. We hail our relations with other human beings over time by receiving and alluding to stories told by others—in myths, legends, histories, novels, and sacred texts. We seek connections among things through metaphor and other forms of figural language. By telling stories to ourselves and others—in dreams, in diaries, in friendships, in marriages, in therapy sessions—we grow slowly not only to know who we are but also to become who we are. Such fundamental aspects of living as recognizing self and other, connecting with traditions, finding meaning in events, celebrating relationships, and maintaining contact with others are accomplished with the benefit of narrative. A medicine practiced with narrative competence will more ably recognize patients and diseases, convey knowledge and regard, join humbly with colleagues, and accompany patients and their families through the ordeals of illness. These capacities will lead to more humane, more ethical, and perhaps more effective care.

The field of narrative medicine has emerged gradually from a confluence of sources—humanities and medicine, primary care medicine, contemporary narratology, and the study of effective doctor-patient relationships. A clinical cousin of literature-and-medicine and a literary cousin of relationship-centered care, narrative medicine provides health care professionals with practical wisdom in comprehending what patients endure in illness and what they themselves undergo in the care of the sick. As I was working on a paper tentatively entitled "The Narrative Hemisphere of Medicine" some time ago, I realized suddenly that there is little in the practice of medicine that does not have narrative features, because the clinical practice, the teaching, and the research are all indelibly stamped with the telling or receiving or creating of stories. The phrase

"narrative medicine" came to me as a unifying designation to signify a clinical practice informed by the theory and practice of reading, writing, telling, and receiving of stories. The name appealed to me because, as a nominal phrase, it points to a "thing" and not an idea (fulfilling William Carlos Williams's dictum that there are no ideas but in things) and connotes a kind of practice along with a set of conceptual relations in which it nests. The notion would not have been compelling to me had it been either an atheoretical tinkering with how we do things or an abstract but pointless set of ideas. Neither atheoretical nor pointless, the practice of narrative medicine has already shown its proliferative salience to individual practice, clinical education, health professional standards, national policy, and global health concerns.

What do narrative and medicine have in common? What might this field of narrative medicine know that is news to both fields? The enthusiastic and grateful responses of clinicians, students, literary scholars, writers, and patients to early work in narrative medicine have encouraged me to think that we are developing useful approaches to medicine, to literature, and to suffering. Even more powerfully, what this field brings to both clinical practice and narrative theory seem to be exactly what each field needs. On the one hand, medicine, nursing, social work, and other health care professions need proven means to singularize the care of patients, to recognize professionals' ethical and personal duties toward the sick, and to bring about healing relationships with patients, among practitioners, and with the public. Strengthening our narrative capacities can, I suggest in this book, help in all these efforts. My hypothesis in this work is that what medicine *lacks* today—in singularity, humility, accountability, empathy—can, in part, be provided through intensive narrative training. Literary studies and narrative theory, on the other hand, seek practical ways to transduce their conceptual knowledge into palpable influence in the world, and a connection with health care can do that.

Much has changed fundamentally of late within the health care system for patients and for health care professionals, making the habits and ideas included in this book particularly timely. We all lament the incursion of corporate and bureaucratic concerns into clinical practice. Office hours have been sped up. "Hospitalists" who are strangers to patients are replacing doctors who know patients well in caring for the most acutely ill. The passivity of health care professionals in the face of the commodification of health care that began with the marketplace intrusion into health care in the 1980s continues to stun and trouble us. We still do not have a national health insurance plan in this country, and the numbers of uninsured mount. The gap between rich and poor widens and with it widens the gap of health. Corruption and fraud and corporate greed are present in health-related industries as they are throughout the U.S. business landscape. We see more and more clearly how health care decisions are made not by or even for patients but by and for shareholders and corporate executives. Questions of health care policy, in this country anyway, are cynically politicized and prey to ideological power thrusts. Global health is marred by unconscionable and unjust inequities. Aware of our losses, we often feel empty-handed of prospects for more effective systems of care.

designation to signify a clinical

In the face of these discouraging developments, there is impressive vitality and creativity in health care. The movements for quality improvement in health care are beginning to be felt in palpable and measurable ways. We are making meaningful progress in understanding and teaching communication skills, professionalism, cultural competence, team-building, and patient-centered care. Patients have found new allies in their search for health, notably among one another in advocacy groups and support groups, in the readership of published and electronic "telling" of illness stories, and in increasingly influential legislative and governmental roles. Health care may be in the process of becoming safer and more effective, and issues of equity and dignity are at least beginning to be recognized.

Optimistic developments are surfacing in how we care for the ill. Doctors, nurses, and social workers practice in new ways today as compared to their routines of even a few years ago. Taking a narrative life history is slowly entering clinical practice, for example, and the notion that nurses and doctors and therapists bear witness to patients' suffering is beginning to be heard and considered. We health care professionals are seeking more and more urgently for means to establish our trustworthiness and to be faithful to our own professional oaths. We and our patients know that time must be devoted to developing knowledge of one another in practice, that eight-minute visits do not suffice to expose all that must be said, and that longitudinal fidelity is critical in safeguarding health or responding to illness. More and more insistently, we are refusing to practice according to someone else's bottom line, knowing that short-term saving of a few minutes here and there cannot make up for the chronic damage done to clinical relationships starved of time, dignity, and regard. Such movements as relationship-centered care, spirituality and medicine, and the ethics of virtue and care signal deep commitment to bettering the tattered state of doctor-patient relationships and to improving the outcomes of our medicine.

I have been humbled and impressed of late to meet with large and diverse groups of health care professionals and patients in this country and abroad who are fired up with yearnings for a medicine that makes sense, that takes care of people—both patients and caregivers—and that replenishes and respects all who are marked by it. To offer narrative medicine as a corrective to some of these failings, a support to these emerging strengths, and response to these widespread yearnings serves to unify and cohere divergent aspects of sickness and health care. If, that is, we can provide what patients long for, we will at the same time provide what health care professionals seek—a form of health care that recognizes suffering, provides comfort, and honors the stories of illness.

Achieving narrative competence, however, is not a trivial goal. Although everyone grows up listening to and telling stories, sophisticated knowledge of how stories work is not attained without considerable effort and commitment. Narrative theory is not easy to master—perhaps no easier to master than the science that we absorb on our way to health care professional competence. Close reading takes practice, skill, and long experience with many texts. The designation of practitioner of narrative medicine must be earned by rigorous and disciplined study over time, mastering new concepts, language, and practices in a

longitudinal and demanding schooling. Happily, narrative schooling carries the replenishing dividends of creativity, self-knowledge, understanding of others, and deep aesthetic pleasures.

As we design narrative training programs for health care professionals and as we develop narrative interventions in our clinical practices, we have to be cognizant of what we are asking of our learners. "Hearing the patient's story" has become, sometimes, a catchphrase, as if to do so is a quick corrective to be applied to an existing system of care. As we spell out the implications of narrative medicine for practice and education, we see the radical challenges thrown up by the decision to infuse medicine with narrative competence. Becoming competent in narrative skills *opens up* practice. It does not simply shift some habits or routines. It changes what we do with patients, with colleagues, with students, and with the self. Its implications reach to the health care professional-patient relationship, health professions training, programs for professionalism and humanism in health care, and the practice of narrative bioethics, as well as the structural aspects of routine medical practice, the economics of care, the means to support health care equitably, and the imperative to improve the safety and effectiveness of the American health care system. The circles of influence widen all the way out to global issues of justice and equity in health care. Slowly, we realize that we are no longer doing what we used to do in the office or on the ward or in the professions. We find that we have annexed powers to our work as nurses, doctors, social workers, and therapists that transform our practice.

Narrative training encompasses a constellation of learning. We teach our students fundamental skills of close reading and disciplined and considered reflective writing. We equip them with the skills to receive and critique respectfully and honestly what colleagues write. We introduce them to great literary texts and give them the tools to make authentic contact with works of fiction, poetry, and drama. We present complex theory from literary studies and the narrative disciplines. In settings as diverse as ward medicine attending rounds, staff meetings on the adult oncology in-patient service, the AIDS clinic, and home visit programs, we meet with health care professionals to read and to write, to attend to and to represent all that occurs in these lives led among the sick. As a result, we deepen our students' capacity to hear what their patients tell them.

I have tried to accomplish a number of discrete tasks in this book. I have tried to write a primer for this new field of narrative medicine, detailing the theoretical bases for its practice from literary studies, narrative theory, general internal medicine, and bioethics without getting either arcane or unduly simplified. I have tried to write a manual for teachers of reading and writing in the medical context. My colleagues and I have been learning slow and cumulative lessons about how to teach such narrative skills as close reading, reflective writing, and bearing witness in courses for health care professionals and students, lessons that have been refined in many settings and over many uses. Although I have presented these ideas and procedures at countless workshops and conferences over the years, it made sense to me to collect the guidelines that inform my teaching practices in one more or less coherent statement. I understand that

readers with many kinds of proficiency may be joining me in this text, and I beg indulgence of all readers who will find some sections naively condensed and others impenetrably obscure.

I offer several taxonomies in the course of this book—the four types of divides between patients and health care professionals, the five narrative features of medicine, and the five elements in my close reading drill. I hope it will be clear that these taxonomies speak to one another and support one another—the narrative features of medicine "answer," broadly speaking, the divides we find within health care, and the reading drill helps to mobilize attention to all five narrative features of medicine. These taxonomies culminate in the triad of attention, representation, and affiliation that I came to call the three movements of narrative medicine.

Throughout these chapters, I return to several ideas and themes. Were I a poet, I could present these recurring concepts or images with the simultaneity with which they come to me. I want for them to appear to my readers all at once, not serially or sequentially but there, together, always mutually informing the thinking and actions represented in this work. The awareness of the divides between the sick and the well needs to be present as we contemplate patients' and families' experiences with illness. The narrative features of medicine like temporality and ethicality do not take their turns in influencing illness or care but, in practice, must be apprehended all at once. To grow in our understanding of how patients tell of themselves and their bodies seems a pivotal and enduring effort in our willingness and ability to care for the sick. The skills of close reading are applied in all areas and all at once in our professional lives—reading charts, listening to patients, mentoring students, and writing and comprehending our own reflections on care. Our duties toward the sick and toward their bodies are illuminated and fulfilled by developing the capacity for attention and representation. When we turn the corner toward affiliation and contact, we know that our narrative competence has yielded its most valuable dividends in enabling us to bear witness to suffering and, by that act, to ease it.

As I asked myself by what warrant I was writing this book, I realized that it came from all the stories in my file cabinets—written by medical students, doctors, patients, nurses, and social workers over the years. I would sit at my cherry writing table and function as the medium, the amanuensis for all these voices telling of illness and the efforts to care for the sick. Linguistic research projects in ageism in the clinical encounter, early efforts to develop the Parallel Chart, stories from practice that friends and strangers sent to me, final exams for my medical students in the medical interviewing curriculum, my father's medical charts from his solo practice—all these texts spoke to me, sometimes rather eerily, from my records kept faithfully over time. These are the primary texts for this book. These are the texts that have inspired me and goaded me to think and think again about why this matters, what this says, how this changes being sick and caring for the sick.

I have obtained permission from all writers who are identifiable—students, health care professionals, and colleagues from afar—to reproduce their texts. I have decided to publish them, on the whole, anonymously, in part because they

"stand for" so many others I might have chosen to print. I have noted throughout the text when descriptions of patients have been changed for the sake of confidentiality. When I was unable to show patients what was written about them so as to obtain their consent for publication, I altered the details of the text to render the patients unrecognizable, even to themselves. There are several times (noted in the endnotes) when I have combined aspects of several patients into one description. This was always done in order to preserve confidentiality.

Writing this book has electrified my own practice of general internal medicine by giving me things to try, ways to improve my routines, new curiosities about patients' experiences of their bodies and their health. I surrender to patients in a different way these days. I think I lend myself to them in new and clinically useful ways. I write a great deal more about my patients than even I ever did before, confirming over and over the truth that writing reveals things to us that we know but didn't know we knew. I show patients what I have written about them as a matter of routine, and I now explicitly encourage writing from patients in the course of routine care. I could go on, but the traces of all these lessons are in the chapters themselves and need no detailed preview.

As I think of what we do with patients and colleagues, I see how complex and fraught and yet *hopeful* are these encounters. So much needs to be said, yet suffering sometimes cannot be asserted but can only be fitfully intimated by another. Sometimes, it is as if doctor and patient were alien planets, aware of one another's trajectories only by traces of stray light and strange matter. "We catch a glimpse of something, from time to time," writes William Carlos Williams, "which shows us that a presence has just brushed past us, some rare thing—just when the smiling little Italian woman has left us. For a moment we are dazzled. What was that?"[1] We can feel like valuable but inscrutable objects of admiration for one another, each trying to penetrate the other's secrets. With what pregnant wonder we meet, trying to take in all that is being emitted by the other, sometimes without the emitter's knowledge. Does the trilobite *know* what truths are transposed on its stony ridges? Do the Pleiades realize what they transmit to earth? Does the dancer whose body is represented on the funerary vase buried with the Egyptian king understand the yield of her gestures? We sit in one another's presence, silenced by the other's mystery, its plenitude, its alterity, in suspense, waiting.

We stay in the presence of this freight of meaning, not only filled with gratitude that we can, now, see it but also filled with satisfaction that we have helped its meaning to be apprehended. Knowing something about the body grants us the license to near another. It grants us admission to a proximity to the self of the other and, by reflection, of ourselves. The images that course through the pages of this book—my amphora, James's great empty cup of attention, Joyce's snow general all over Ireland, the edifices built by form, the spirals of attention and representation that culminate in affiliation—all these images are illustrations of our presence with one another, whether patient or colleague or student.

Perhaps an oncology nurse reads what she has written about the fragility of everyday life. Perhaps a 38-year-old new patient tells with shy pride that she runs 20 miles a week. Perhaps a medical student reveals his rage at the unfair-

ness of disease or its treatment. Perhaps family members gather at the bedside of their mother, who is dying of widespread ovarian cancer. We are at the same time *alone* and *with*, strange and similar. The presence of the other is both mystery and identity. We are simultaneously outside the obscurity and within the familiarity of another's being. Like planets in a solar system, we revolve around and are warmed by a common sun while hosting lives of absolute distinction. In the end, we live with one another as best we can, trying, as health care professionals, to receive what our patients emit and trying, as patients, to convey these all but unutterable thoughts and feelings and fears. Indeed, we are revolving bodies, attracted to one another and held aloft in orbit by the gravity of our common tasks.

I invite you to share this experience with me and to join in developing these ideas and practices. I hope that this frame of narrative medicine can gather new combinations of us—from the humanities, from all the health professions, from the lay world, the business world, the political world—and make new relations among us, so as to look with refreshed eyes at what it means to be sick and to help others get well. Henry James says somewhere that the combinations are, in the end, inexhaustible and, in the preface to *Roderick Hudson*, that "[r]eally, universally, relations stop nowhere."[2] Let us revel in the inexhaustibility of our combinations and the universality of our relations, our affiliations, our common burdens and gifts as we do our best to heal.

Notes

1. William Carlos Willliams, *The Autobiography of William Carlos Williams*, 360.
2. Henry James, *New York Edition*, 1:vii.