Narrative Medicine: Honoring the Stories of Illness

RITA CHARON

OXFORD UNIVERSITY PRESS

NARRATIVE MEDICINE
Honoring the Stories of Illness

This page intentionally left blank

NARRATIVE MEDICINE

Honoring the Stories of Illness

RITA CHARON

OXFORD
UNIVERSITY PRESS
2006

OXFORD
UNIVERSITY PRESS

Oxford University Press, Inc., publishes works that further
Oxford University's objective of excellence
in research, scholarship, and education.

Oxford New York
Auckland Cape Town Dar es Salaam Hong Kong Karachi
Kuala Lumpur Madrid Melbourne Mexico City Nairobi
New Delhi Shanghai Taipei Toronto

With offices in
Argentina Austria Brazil Chile Czech Republic France Greece
Guatemala Hungary Italy Japan Poland Portugal Singapore
South Korea Switzerland Thailand Turkey Ukraine Vietnam

Published by Oxford University Press, Inc.
198 Madison Avenue, New York, New York 10016

www.oup.com

Library of Congress Cataloging-in-Publication Data
Charon, Rita.
Narrative medicine : honoring the stories of illness / Rita Charon
p. ; cm.
Includes bibliographical references and index.
ISBN-13 978-0-19-516675-0
ISBN 0-19-516675-2
1. Narrative medicine. 2. Narration (Rhetoric) I. Title.
[DNLM: 1. Narration. 2. Professional-Patient Relations. 3. Communication.
4. Medicine. W 62 C483n 2006]
RC48.C42 2006
616.07′51—dc22 2005051810

Permission to reproduce Mary Cassatt's *The Conversation (Two Women)*, sale # 6594, has been obtained from Christie's Images, London, UK.

Permission to reprint portions of Rita Charon, "The Ethicality of Narrative Medicine," from *Narrative Research in Health and Illness*, edited by Brian Hurwitz, Trisha Greenhalgh, and Vieda Skultans, 23–36 (London: BMJ books, 2004), has been obtained from Blackwell Publishing, Ltd., Oxford, UK.

1 3 5 7 9 8 6 4 2

Printed in the United States of America
on acid-free paper

For George in memory
and
Bernard in the present and future

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.

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 unfairness 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.

ACKNOWLEDGMENTS

I thank the many teachers, friends, colleagues, students, and patients who have nurtured my thinking and writing throughout this project. I was inspired and directed in my studies of literature and of medicine by Harvey Chertok, Elliot Mishler, Joanne Trautmann Banks, and Steven Marcus, whose wisdom and example illuminated my way from the start. I have been fortunate to spend my academic and medical career at Columbia University, whose Departments of Medicine and English shared my time and cross-fertilized one another's imprint on narrative medicine. The dedication to patient care and willingness to come with me into literary exploration exemplified by Gwen Nichols, Steven Shea, Ronald Drusin, Edith Langner, Aaron Manson, and Steve Albert has been of lasting importance in this work. The freedom that has been accorded me at Columbia to try new things in my teaching, research, scholarship, and patient care has been deeply appreciated.

I profess my enduring indebtedness to my colleagues in the National Endowment for the Humanities Exemplary Education Project that has convened regularly from 2003 to 2005 to study the consequences of narrative training in medicine: Sayantani DasGupta, Rebecca Garden, Craig Irvine, Eric Marcus, Tara McGann, David Plante, Maura Spiegel, and Patricia Stanley. Their thinking and insight permeate this text. As an early teacher of English and current coeditor in chief of *Literature and Medicine,* Maura Spiegel deserves particular and happy gratitude. Special thanks go to Tara McGann for keeping many projects and programs afloat during the completion of this book. I am most grateful to Benjamin Everett and Cara Rabin for their careful attention to my bibliographic references.

Far-flung colleagues in literature-and-medicine, including members of the editorial board of *Literature and Medicine,* have over the years shaped and inspired my thinking and helped me to know what to do with my house officer's intuition that there was something for doctors to learn from stories. Humble thanks go to Kathryn Montgomery, Suzanne Poirier, Anne Hudson Jones, Anne Hunsaker Hawkins, Martha Montello, Julie Connelly, Charles Anderson, and David Morris and, in wider circles engaged in this work, to Arthur Frank, Eric Cassell, Jerome Bruner, Shlomith Rimmon-Kenan, Michael Ondaatje, and the late Susan Sontag. My medical colleagues, especially through the good work of the Associa-

tion of American Medical Colleges, have kept me honest through my literary growth, enabling the transformation of erstwhile marginal interests in humanities and medicine into mainstream commitments in medical education. Many of these colleagues from literary studies and medicine read early versions of these chapters and helped me understand what I was trying to say. Many audiences at Grand Rounds and seminars throughout the country were perhaps the unwitting trial listeners to much of this book in its early stages, listeners whose honest and challenging responses helped me to fashion this work along the way, and I thank them for their attention.

I acknowledge pivotal support from the Fan Fox and Leslie R. Samuels Foundation, which funded the outcomes research on the Parallel Chart. I thank the Rockefeller Foundation for a residence at the Bellagio Study Center in spring of 2001 when the very beginning frame for this work emerged. A Guggenheim Fellowship during 2002 and 2003 enabled me to devote a full year to writing, and the book could not have been completed without this support. The National Endowment for the Humanities has underwritten my and my colleagues' time in our most generative study project during the past two years. I thank Oxford University Press for its steadfast commitment to this project and acknowledge with deep gratitude the insight and pivotal direction given me by editors Jeffrey House and Peter Ohlin.

I thank the patients and students and colleagues who have powered this work by their writing and telling and who have given me generous permission to reproduce their stories and texts in these pages. I recognize my debt to Henry James, who is ever-present in my life as a companion and model, and whose thinking and language have transformed my own.

An early version of chapter 10 appeared as "The Ethicality of Narrative Medicine" in *Narrative Research in Health and Illness* edited by Brian Hurwitz, Trish Greenhalgh, and Vieda Skultans (23–36) and published by BMJ Books of London in 2005. I acknowledge the editors' and publishers' permission to reprint parts of that work.

Finally, I thank Mary Marshall Clark, Nancy Dubler, Richard Frankel, Mary Gordon, Angela Klopstech, Donald Moss, and David Plante for their enduring presence and contact through this period. My husband, Bernard, as always, is behind everything I do.

CONTENTS

Part I WHAT IS NARRATIVE MEDICINE?

Part II NARRATIVES OF ILLNESS

Part III DEVELOPING NARRATIVE COMPETENCE

Part IV DIVIDENDS OF NARRATIVE MEDICINE

PART I

What Is Narrative Medicine?

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, interpretation, 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