

The self-telling body

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This essay will examine some of the narrative practices emerging in the health care professions — medicine, nursing, social work, and psychotherapy. We have always, of course, understood that the most fertile and clinically salient information we derive about patients comes from listening to them talking about their illnesses. Nonetheless, medicine's recent past is marked by not so much a suspicion of as a dismissal of word in diagnosing and treating disease. Of late, medicine (and because I am a doctor, I will limit myself to thinking about medicine in the essay) has found sustenance from such fields as trauma studies, oral history, and testimony work. Finally, we are coming around to understanding that our tasks include the duty to bear witness as others tell of trauma and loss. The narrative practice of medicine — or, as I have come to say, the practice of narrative medicine — unites a host of neighboring concerns and approaches. Historically, medicine came *into* the narrative realms through qualitative social science, especially sociolinguistics, as a means to represent and comprehend the conversations that take place between doctors and patients. Such scholars as Elliot Mishler, Richard Frankel, Catherine Riessman, and Candice West really altered medical practice by making medical discourse amenable to inspection and then analysis. Around the same time, we also turned to literary texts and ways of thinking that help us to enter the worlds of patients, see others' experience from their perspectives, greet the metaphorical as well as the factual power of words, and be moved by what we hear. Oddly, then, medical practice became a bridge between the qualitative social sciences and literary theory, letting us, from the inside, see how very similar are the efforts of the sociologist examining discourse and the novelist creating it. We doctors feel great good fortune in having the ultimate objective correlative — what might be captivating but ethereal theorizing becomes as practical and concrete and earthy as can be by virtue of being about somebody's body — particularly somebody's ailing body. What extreme pleasure that my thinking complicated thoughts and being attuned to the complex ways of language can translate into control of my patients' blood sugar or relief of their migraines or diagnosis of their coronary artery disease. Narrative medicine

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becomes, in the end, a heady, brainy, compassionate, corporeal practice that can heal the patient and nourish the doctor at the same time — by virtue of the talk. (*Narrative Medicine, Life-Writing, Medical Interviewing, Doctor–Patient Relationships*)

The effort really to see and really to represent is no idle business in face of the constant force that makes for muddlement.

Henry James, Preface to What Maisie Knew

New narrative practices are emerging in the health care professions — medicine, nursing, social work, the physical therapies, and psychotherapy — that bear consideration by narratologists not only as demonstrable consequences of the narrativist turn of the past decades but also as sources of perhaps widely applicable knowledge about how narratives in the world work. Clinicians have always at least implicitly understood that the most fertile and clinically salient information we derive about patients comes from listening to them talking about their illnesses. We also understand, at some level, that without narrative acts of some kind — talking, writing, or enacting — 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. Nonetheless, medicine's recent past is marked by a dismissal of if not frank suspicion of word in diagnosing and treating disease. "At the risk of sounding anecdotal" is the preface to much of the story-telling that goes on in medicine, and students or clinicians who take the time to hear patients out are thought of as either poorly trained or daft.

Of late, medicine (and because I am a doctor, I will limit myself to thinking about medicine in this essay) has found sustenance from such narrative fields of study and practice as the qualitative social sciences, literary studies, and the aesthetics of creative writing. (I should say found anew, for the medicine of Hippocrates, Galen, Sydenham, Chekhov, Blackwell, Freud, and William Carlos Williams had certainly been nourished by them in the past.) This narrative practice of medicine — or, as I have come to say, the practice of narrative medicine — unites a host of neighboring concerns and approaches that have always inflected the care of the sick but that have recently yet again been allowed to influence directly the way medicine is practiced by doctors and experienced by their patients. These concerns include attention to lived experiences of illness, representation of what patients say and endure so that they can be fully grasped by those listening and witnessing, and the affiliation that results once the divides between the sick and the well are narratively bridged.

Sociological and literary approaches to clinical phenomena

Medicine's recent congress with social sciences and literary studies, although more or less simultaneous, occurred independently from one another in response to the same

vexing failures of medicine — its relentless positivism, its damaging reductionism, its appeal to the sciences and not the humanities in the academy, and its wholesale refusal to take into account the human dimensions of illness and healing. Starting with the magisterial work of Talcott Parsons (1951), Robert Merton and Renée Fox (1957), and Eliot Friedson (1970), sociology (or what would become medical sociology) reminded medicine that its practice was a sociocultural enterprise and, as such, was answerable to precepts and tenets that govern human interchange in general. During the 1980s and early 1990s, qualitative social scientists — especially sociolinguists and anthropologists — recognized health care as a source of particularly good problems that might be amenable to sociological ways of seeing and might be open to obtaining actual benefit from such gazing. Such scholars as Elliot Mishler (1984), Richard Frankel (1983), Candace West (1984), and Catherine Riessman (1990) fundamentally altered medical practice by making medical discourse amenable to inspection and then analysis. They showed doctors that there were means to represent and therefore to analyze and comprehend the conversations that take place between doctors and patients and that such representation was the first step in a radical process of recognition, reflection, self-examination, and change.

Timed along with the rise of the women's movement and consumerism when doctors were responding to many progressive challenges to the profession's imperializing gestures and expropriations of power, these sociological and linguistic studies of medical conversations amplified the until-then silenced conversations between doctors and patients, those conversations that often dismissed, derided, and disrespected patients who were trying, simply, to tell what was the matter. Such dismissal, we found, was not only the product of the individual doctors' intentions or goals but also the result of the structural practices that had grown up in American medicine. Embedded in such discursive features as turn-taking, interrupting, asking questions with the "right" answers implied by them, or speaking in technical jargon, doctors were systematically usurping authority, withholding critical information and thereby deceiving patients about their medical conditions, ignoring what patients brought to the conversations, and controlling what would be talked about and how.

Once doctors *saw* how they controlled the medical conversation and how that control prevented patients from telling them what they needed to hear in order to help them, some were able to make significant changes in medical discursive practice. For the first time since at least the post-WWII explosion in biomedical research, doctors were seriously interested in medical interviews, doctor–patient relationships, and what came to be called patient-centered care. So-called communication skills or interviewing skills were introduced into the curricula of American medical schools. Medical students and trainees were explicitly taught not to interrupt patients, not to conversationally bully patients, and to value that which patients spontaneously provided as their worries, concerns, and hypotheses about what had caused their health problems (Kleinman, 1988; Lipkin, 1995; Stewart, 1989; Stoeckle, 1987). Sadly, patients today can rarely see the dividends of such training in attentive listening and respectful partnership, in large part because of the tenacity of the forces opposing these changes — professional dominance, regressive authoritarianism, structures that penalize patients, and greed.

Around the same time but in different circles, medicine also turned to literary texts and ways of thinking that help us to enter the worlds of patients, see others' experience from their perspectives, greet the metaphorical as well as the factual power of words, and be moved by what we hear. The field of literature and medicine arose in the early 1970s, with the appointment of a few PhDs in literary studies to medical school faculties. The rise in the study of literature in medical settings accompanied the rise in the study of humanities in general, even though eclipsed by moral philosophy and its offspring bioethics (Hunter et al., 1995; Trautmann, 1981; Charon et al., 1995). The moral and aesthetic resonances of novels, poems, and plays offer different kinds of evidence from that offered by scientific experiments, and yet it is an evidence that counts very much in understanding humans' predicaments. Literary training, we hoped, would expand both clinical and moral imaginations, letting clinicians behold and value the singularity of individual patients and letting them reflect on their own experiences in the care of the sick. By 1998, 74% of U.S. medical schools either required or offered elective study of literature, and this number has grown since then (AAMC, 1998). The point of such teaching is not to produce literary critics out of doctors and medical students but to equip them with the readerly skills to follow a narrative thread, to adopt multiple and contradictory points of view, to enter into the teller's narrative world and see how that teller makes sense of it, to identify the images and metaphors used, to recognize the temporal flow of events, to follow allusions to other stories, to tolerate stories' ambiguity, and to be imaginatively transported to wherever the story might take the one who surrenders to it. The result might be that patients were heard — both the said and the unsaid — and that doctors could use the self as a potent therapeutic instrument.

What narrative competence brings to practice

Narrative skills and practices have come to saturate medical education and practice, including the methods of the social scientist/linguist and the methods of the literary scholar. We routinely videotape medical encounters of physicians and physicians-in-training, thereby exposing to close inspection those micro-processes of gaze, touch, and talk that make up therapeutic contact. So-called performance assessment has been added to virtually all medical evaluative milestones — graduation from medical school, certification by specialty boards, state medical licenses, and the like — in which doctors are videotaped either in actual clinical encounters or in standardized clinical encounters and their clinical skills evaluated by experts *and by the patient*. What they actually say and do or fail to say and do are now the grounds upon which to decide their competence (Barrows, 1993).

Teaching of close reading and coaching of narrative writing in the clinical setting have increased dramatically. Many hospitals and medical schools offer literature seminars or reading groups for doctors, nurses, social workers, and students of all these disciplines, some of them funded by the National Endowment for the Humanities or by individual state Councils for the Humanities (Bonebakker, 2003). Nurses, doctors,

social workers, and chaplains are among the groups who are encouraged to write about their experiences of caring for the sick. Benefits of such writing are being documented (Anderson & MacCurdy, 2000; Bolton, 2001). We see writing groups prosper in AIDS clinics, in-patient oncology units, hospital chaplaincy training programs, neonatal intensive care units, medical social work divisions, and training programs at all academic levels in medicine, nursing, physical therapy, and psychoanalysis (Charon, 2006).

We are beginning to understand, even, the mechanisms and intermediates of these benefits. Close reading builds the capacity of the reader to achieve the state of attention required for effective clinical work. If, indeed, close reading equips one to adopt alien perspectives and cohere complex narratives toward multiple meanings, these same capacities might improve a clinician's ability to attend to what sick people say and then, one hopes, to act on that teller's behalf. Strengthening the skills of representation may deepen the capacity to perceive to begin with, and certainly to attend to what is seen. The skilled writer can represent formless or chaotic experience by conferring form on it — genre, diction, imagery, temporality, narrative voice — so that the erstwhile formless can be *seen*, both by the writer and by those who hear or read what is written. The formless experience thereby becomes as if an edifice — a pavilion, a pagoda, gazebo — around which the writer can walk, seeing it from all directions, understanding aspects that, until form was conferred, were invisible (Charon, 2005). Without writing about the care of a patient in a complex narrative form, the care-giver 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.

I have been recognizing the therapeutic potentials of narrative methods in my general internal medicine practice. When I meet a new patient in the office, I say two sentences: "I will be your doctor, and so I need to know a great deal about your body and your health and your life. Please tell me what you think I should know about your situation." I have trained myself to then be silent, not to write or to type, but to attend to and to absorb what is then said. Although some patients have been perplexed (one woman said, "You mean, you want me to talk?"), all have accepted my invitation and have delivered eloquent rich accounts of their health concerns. Because I don't specify what it is I want to hear, I am privileged to be the recipient of complex accounts that weave together physical health concerns with accounts of family, home, work, school, desires, fears, and hopes for the future. While the patient is changing into a gown in preparation for my physical examination, I write down as accurate a representation as I can of what the patient says — in the order in which it was said, using the words and images of the patient — without sanitizing it into the genre of a medical note, and then I give a copy of that note to the patient at the end of our visit. I am on the brink of writing an IRB protocol to be able to tape-record and transcribe these utterances, so powerful are they and *useful* in the care of the teller that I don't feel right squandering them to poor memory.

Sometimes, I write what I remember patients to have told me during a visit later on. Especially if I find myself confused or baffled about what is happening with a

patient, I will write a description of an office visit and then show the patient what I wrote. Often, the patient will say, upon reading what I have written, “We left something out.” And then he or she will proceed to tell of complex underlying losses or fears that *explain* current symptoms in ways too intricate to have simply been said. As access to the unsaid, in this case, these simple narrative methods enable us to learn that which, without them, would have remained hidden.

At other times, my representing what I hear the patient say, using not technical jargon but ordinary language, has prompted patients themselves to write of illness and all that surrounds it (Charon, 2002). Patients have brought me things they have written — sometimes from a long time ago — in letters to children, childhood diaries, once a book of poetry written while the patient was in prison. I find that, once a patient begins to write on his or her own about a health problem or worry, I can leave off writing myself. Indeed, I have established a new medical chart for my patients engaged in this narrative work with me. I give patients copies of what I write about them — either duplicates of what are filed in the medical record or originals of what is for their reading only — to form a private medical chart. Convinced that the patient ought to be the curator of what is written about him or her, especially what is written as a result of our intersubjective work, I give patients folders that look much like the “official” hospital chart in which to keep what I write about them and what they might be encouraged to write about themselves.

I have started a witnessing project in my practice. I invite non-clinically trained colleagues to join me in my office to help me attend to what happens. These are pre-medical students, health advocates, various trainees and fellows who are not doctors or nurses but persons interested in narrative medicine. As such, they are not hampered by my professional blinders. If the patient permits, the witness sits in with me during the whole visit. I ask the witness to keep field notes, more like an anthropologist than anything else. I want the witness to register the mysterious rituals of this complex sub-culture of illness. I want to defamiliarize my office routines so that I can see them fresh, and the best way to do that is to have it seen by someone unfamiliar with it.

I realized the power of this practice early on. A man from far away, accompanied by his wife and daughter, was assigned to my care. At age 37, he had been found to have lung cancer and had received surgery, chemotherapy, and radiation in his home country. Now, seven years later, he developed back pain that was caused by spread of the cancer to his bones. He reentered treatment with his oncologist, and yet in the very midst of chemotherapy, he opted to move to New York where his daughter lived to find a new oncologist. And here he was in my clinic office, a non-citizen with no insurance and no money, putting in my lap this dire and most difficult request. I couldn’t fathom why anyone would have done such a rash thing — with no oncology referral, merely a handwritten note, not in English, detailing a strange chemotherapy regimen. But in a hospital system where it can take weeks or months to get sub-specialty clinic appointments even for our patients, what was I going to do for this stranger?

At least I had the sense to leave the room when I experienced this grumbling frustration. I asked my witness, an English major and literary journal editor now completing pre-medical requirements, to continue the conversation while I saw the next

waiting patients. It was only in my absence that the patient and family were able to tell about their horribly degrading experiences at the hands of the doctors back home. They were insulted, ignored, treated as if they were stupid. Finally, they could not bear the assault and took control, coming to New York where they knew there were great hospitals. Now, they could not tell me this — it was too risky to tell the doctor all this. But through my witness, they were able to convey to me what I needed to know. As soon as I heard all this, I moved heaven and hell to get the patient an appointment the next week in oncology clinic so that his treatment could proceed.¹

Many of my colleagues are providing writing opportunities for patients as adjuncts to or alternatives to more traditional supportive psychotherapy. Evidence of the health benefits of writing for patients is accruing (Smyth, 2002; Pennebaker, 2003). The Narrative Therapy movement spearheaded by the work of family therapists Michael White and David Epston is the most fully developed clinical specialty that relies on narrative interventions in the care of the sick (Beels, 2001; White & Epston, 1990). Through their work in Auckland and Adelaide, they have spawned a network of clinicians throughout the world developing and evaluating narrative treatment of such health problems as anorexia, bed-wetting, and post-traumatic stress disorder.

Finally, narrative training helps health care professionals to fulfill their duty to bear witness to the suffering of others. Despite doctors' instrumental tropism for fixing things, they are gradually becoming attuned to the need, in health care, to behold the other, to hear the other out without necessarily jumping in to do something besides listen (Verghese, 1993; Selwyn, 1998; Remen, 1997). Lessons from trauma studies, Holocaust testimonies, and oral history are slowly being learned by ordinary nurses and doctors and social workers, who are training themselves to bear witness to their patients' suffering while they do their best to ameliorate it. Especially when illnesses are beyond the reach of curative treatment or are caused by something other than organic disease, health care professionals are beginning to know how to stay the course, accompanying patients with presence instead of abandoning them to fear, and reading, through the body, the self:

Once, a young woman came to see me with severe and relentless abdominal pain. She was fidgety, spoke in fragmented speech, seemed clearly to be suffering. She had already seen a gastroenterologist, a gynecologist, and an expert in colitis, all of whom had found no abnormality to account for her symptoms. Since this was my first meeting with her, I asked as a matter of routine about the health of her family members. Her father, I learned, had died of liver failure. As she spoke of his horrible suffering — his abdomen swollen with fluid, his muscles spent, his mind clouded — she put both her hands, fingertips interlocked, almost protectively, over her own upper abdomen. I told her that she used the same gesture to discuss her own symptoms as she had to describe her father's illness. For the first time in the interview, she became still. She looked down at her hands, now in her lap.

1. I have changed clinical and personal details to render the patient unrecognizable so as to protect the patient's privacy.

We were both silent. And then she said, "I didn't know this was about my father" (Charon, 2006, p. 66).

Metanarrative bridges through medicine

Medical practice has become a bridge between the qualitative social sciences and literary theory, letting us, from the inside, see how very similar are the efforts of the sociologist examining discourse and the novelist creating it. We clinicians, at least the ones of us involved in these movements, can approximate the efforts of the sociolinguist and the Henry James scholar. We understand through practice that discourse analysis of transcribed clinical conversations and close readings of literary texts are "after" the same kinds of clarity. They both help one get the news from stories. A medical student and I review a videotape of that medical student interviewing a patient. I teach that same student how to navigate his way through Henry James's story "The Beast in the Jungle." In both settings, I am *doing* the same kinds of things with language — seeking its underlying patterns, discontinuities, surprises, and registers and paying fruitful attention to those transactions that go on whenever "someone tell[s] someone else that something happened" (Smith, 1981, p. 228). That one activity measures time in tenths-of-a-second and the other measures time syntactically and metaphorically doesn't obscure their underlying shared fidelity to honoring the power of language to expose the self.

It may be, in the end, the ultimate failure of representation that unites our many narrative-using disciplines. The peculiar syntactical structure of Henry James's *Wings of the Dove*, for example, may be understood to reveal the author's ultimate betrayal of his subject — betrayal not as treachery but as desertion. Works of literature, and perhaps the fiction of James in particular, can be seen as tributes to the unsayable, as they approach their subject and then withdraw, in defeat, aware of the always-futile effort to capture, in words, that which is but dimly perceived in the writer's eye (Holand, 1964; Miller, 2005). All these spheres of human learning — literary studies, social sciences, and medicine — may experience this failure. We all try but fail to express an unreachable meaning, intermittently seen or sensed but not capturable for representation or display. We betray that ultimate meaning — using, now, betrayal in its meaning as unintentional exposure — through our very wordless foundering. Our condition, in the end, is perhaps simply this falling short of saying, this silencing by the ineffable, this running out of language. After *Wings of the Dove* protagonist Milly Theale visits her doctor, "her distinguished friend," and receives news of her illness, she walks the London streets alone:

She literally felt, in this first flush, that her only company must be the human race at large, present all round her, but inspiringly impersonal, and that her only field must be, then and there, the grey immensity of London. Grey immensity had somehow of a sudden become her element; grey immensity was what her distinguished friend had, for the moment, furnished her world with and what the

question of 'living,' as he put it to her, living by option, by volition, inevitably took on for its immediate face (James, 1909, p. 247).

Acts of reading and writing, telling and listening — whether in fiction, conversation transcripts, medical visits, or the embodied wordless gesture of my young patient grieving for her father — put us in the presence of these efforts, futile though they may be, to give voice, to tell, ultimately, what it means for us to be within the grey immensity of human lives — in time, in language, in freedom, in bodies, and in one another's care.

References

- AAMC (1998). *Curriculum Directory*, 27th edition. Washington, DC: Association of American Medical Colleges.
- Barrows, H. (1993). An overview of the uses of standardized patients for teaching and evaluating clinical skills. *Academic Medicine*, 68, 443–453.
- Beels, C. (2001). "A different story ...": *The rise of narrative in psychotherapy*. Phoenix, AZ: Zeig, Tucker and Theisen.
- Bolton, G. (2001). *Reflective practice: Writing and professional development*. London: Paul Chapman.
- Bonebakker, V. (2003). Literature and medicine: Humanities at the heart of health care: A hospital-based reading and discussion program developed by the Maine Humanities Council. *Academic Medicine*, 78, 963–967.
- Charon, R., Trautmann Banks J., Connelly, J., et al. (1995). Literature and medicine: Contributions to clinical practice. *Annals of Internal Medicine*, 122, 599–606.
- Charon, R. (2002). Time and ethics. In R. Charon & M. Montello (Eds.), *Stories matter: The role of narrative in medical ethics* (pp. 59–68). New York: Routledge.
- Charon, R. (2005). Narrative medicine: Attention, representation, affiliation. *Narrative*, 13, 261–270.
- Charon R (2006). *Narrative medicine: Honoring the stories of illness*. New York: Oxford University Press.
- Frankel, R.M. (1983). The laying on of hands: Aspects of the organization of gaze, touch, and talk in a medical encounter. In S. Fisher & A.D. Todd (Eds.), *The social organization of doctor–patient communication* (pp. 19–54). Washington, DC: Center for Applied Linguistics.
- Friedson, E. (1970). *Profession of medicine: A study of the sociology of applied knowledge*. New York: Harper & Row.
- Holland, L. (1964). *The expense of vision: Essays on the craft of Henry James*. Princeton: Princeton University Press.
- Hunter, K.M., Charon, R., & Coulehan, J.L. (1995). The study of literature in medical education. *Academic Medicine*, 70, 787–794.
- James, H. (1909). *The wings of the dove*. Vol. 19 of *The novels and tales of Henry James: The New York edition*. New York: Charles Scribner's Sons.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.
- Lipkin, M., Putnam, S., & Lazare, A. (Eds.) (1995). *The medical interview: Clinical care, education, and research*. New York: Springer-Verlag.

- Merton, R.K. et al. (1957). *The student physician: Introductory studies in the sociology of medical education*. Cambridge: Harvard University Press.
- Miller, J.H. (2005). *Literature as conduct: Speech acts in Henry James*. New York: Fordham University Press.
- Mishler, E. (1984). *Discourses of medicine: The dialectics of medical interviews*. Norwood, NJ: Ablex Publications.
- Parsons, T. (1951). *The social system*. New York: The Free Press of Glencoe.
- Pennebaker, J.W. (2000). Telling stories: The health benefits of narrative. *Literature and Medicine*, 19, 3–18.
- Riessman, C.K. (1990). Strategic uses of narrative in the presentation of self and illness. *Social Science and Medicine* 30, 172–207.
- Selwyn, P. (1998). *Surviving the fall: The personal journey of an AIDS doctor*. New Haven: Yale University Press.
- Remen, R. (1997). *Kitchen table wisdom: Stories that heal*. New York: Berkley.
- Smith, B.H. (1981). Narrative versions, narrative theories. In W.J.T. Mitchell (Ed.), *On narrative* (pp. 209–232). Chicago: University of Chicago Press.
- Stewart, M., & Roter, D. (Eds.). (1989). *Communicating with medical patients*. Newbury Park, CA: Sage.
- Stoeckle, J. (Ed.). (1987). *Encounters between patients and doctors — An anthology*. Cambridge, MA: MIT Press.
- Trautmann, J. (1981). *Healing arts in dialogue: Medicine and literature*. Carbondale, IL: Southern Illinois University Press.
- Verghese, A. (1993). *My own country: A doctor's story*. New York: Vintage/Random House.
- West, C. (1984). *Routine complications: Troubles with talk between doctors and patients*. Bloomington, IN: Indiana University Press.
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York: Norton.