

DIALOGUE



Narrative Medicine: Attention, Representation, Affiliation

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Sick persons and those who care for them become obligatory story-tellers and story-listeners. Hippocrates knew this, Chekhov knew this, Freud knew this, and yet knowledge of the centrality of storytelling was obscured in medicine throughout much of the last century. With the rise of interest in the humanities in general and literary studies in particular among medical educators and practitioners, today's medicine is being fortified by a rigorous understanding of narrative theory, appreciation of narrative practice, and deepening respect for what great literary texts can contribute to the professional development of physicians and the care of the individual patient (Hawkins and McEntyre; Anderson and MacCurdy). This rise of the power of storytelling in medicine helps me to conceptualize what has been evolving in my own practice of internal medicine and in the emerging field of narrative medicine.

You'd think that doctors, nurses, and social workers know of the centrality and privilege of storytelling in their practice. What else do we think we are doing when we ask someone in pain about their situation? Even the junior medical student who says, "What brought you to the clinic today?" and is met with the answer, "The M104 bus" knows that he or she is in search of a story. And yet, there has been an odd diminishment of the status of storytelling in medicine ever since we decided we knew enough about the body by virtue of reducing it to its parts that we did not need to hear out its inhabitant.

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As a general internist and literary critic, I have been brooding about the place of narrative in medicine for a long time. Our Program in Narrative Medicine at Columbia University has developed an agenda in research, teaching, and scholarship devoted to examining and studying the relations of narrative thinking and practice to being sick or taking care of sick people. Indeed, the field of literature-and-medicine or medical humanities has for decades been excavating the relationships between literature and medicine, both in terms of literary texts and literary theory (see Hunter; Gilman). Narrative medicine is a more evidently clinical cousin of this intellectual discipline. I define it as medicine practiced with the narrative competencies to recognize, absorb, interpret, and be moved by the stories of illness (Charon). Not unlike nuclear medicine or internal medicine, you can practice narrative medicine and still be a doctor!

It became clearer and clearer to my colleagues and me that doctors, nurses, and social workers *need* rigorous and disciplined training in reading and writing *for the sake of their practice*. I am by no means the only one to have observed that being a close reader equips one to perform some of the most difficult tasks of the health care professionals: attentive listening, simultaneously being transported by a text while analyzing it most meticulously and critically (Keats would call this negative capability and psychiatrists might call it splitting), adopting alien perspectives, following the narrative thread of the story of another, being curious about other people's motives and experiences, and tolerating the uncertainty of stories (Holt).

More recently, many of us within medicine and within literary studies have realized the critical importance that writing—autobiography, memoir, pathography, fiction, personal essay—has developed within health care.¹ Patients and their families are giving voice to their suffering, finding ways to write of illness and to articulate—and therefore comprehend—what they endure in sickness.² The therapeutic potential of narrative medicine expands when we encourage patients to join us in writing their own medical charts, for patients are, or should be, the co-authors and curators of whatever records are kept about them. Health professionals, too, are writing reflective essays about their practice for medical journals or the trade press (Bolton). By *telling* of what we undergo in illness or in the care of the sick, we are coming to recognize the layered consequences of illness and to acknowledge the fear and hope and love exposed in sickness.

In examining the narrating that goes on in health care, my colleagues and I have found it helpful to look separately at the different movements within clinical telling and listening.³ There is at the beginning the movement of clinical telling, in which a patient conveys in one way or another what he or she experiences in illness and the doctor watches and listens, hoping to absorb and interpret and honor what is heard or beheld. Sometimes the “telling” is in action and not words. That is to say, our tellings are performative tellings, not only unfolding in linear prose but in gesture, movement, happenings in time, and changes in the body. I am using these terms of “telling” in rather broad ways. The person listening and beholding must develop

great powers of absorption and attention in order to register that which is conveyed. There is then the movement of representing what is heard or witnessed or undergone, when the health care professional writes it down, be it in a hospital chart or office record or in a piece of reflective writing about the clinical experience. The first movement I have called attention, and the second movement I have called representation. These two movements—attention and representation—spiral inevitably and very powerfully to the third movement, that of affiliation.

Let me start with attention. The teller of an illness needs a listener. How can one develop the state of attention required to fulfill the duties incurred by virtue of having heard accounts of illness? I have become very interested in the state of attention these days—it seems the most pivotal skill with which to endow a health professional who wants to be a healer. How does one empty the self or at least suspend the self so as to become a receptive vessel for the language and experience of another? This imaginative, active, receptive, aesthetic experience of donating the self toward the meaning-making of the other is a dramatic, daring, transformative move. The best description of it I know comes from Henry James. Here is Milly Theale in *The Wings of the Dove* after her first visit to Sir Luke Strett, the physician in the novel who listens to Milly:

So crystal clean the great empty cup of attention that he set between them on the table. . . . His large, settled face, though firm, was not, as she had thought at first, hard; he looked, in the oddest manner, to her fancy, half like a general and half like a bishop. . . . She had established . . . a relation with it; and the relation was the special trophy that, for the hour, she bore off. It was like an absolute possession, a new resource altogether, something done up in the softest silk and tucked away under the arm of memory (James 19: 230–1).

James called it “the great empty cup of attention.” How did he know about that emptiness? How did he know that, in order for one to heal the other, one has to empty oneself of thought, distraction, goals? One has to donate oneself as the amphora, the clay vessel that resonates with the sound of the breath, the sound of the self. James even knew to embody the relational process—the doctor’s face, the patient’s arm of memory. In his remarkable essay on generative empathy, psychoanalyst Roy Schafer writes, “Generative empathy may be defined as the inner experience of sharing in and comprehending the momentary psychological state of another person . . . experiencing in some fashion the feelings of another person” (Schafer 345). He cites Christine Olden who writes that “the subject temporarily gives up his own ego for that of the object” (Schafer 344). Do we not feel exhilarated when we can achieve this empty attention, when we can place ourselves at the disposal of the other, letting the other talk *through* us, ventriloquize, find the words in which to say that which cannot be said? Attention may be the most urgent goal in our work—to attend gravely, silently, absorbing oceanically that which the other says, connotes, displays, performs, and means.

My group and I are now learning about attention from psychoanalysis, Zen Buddhism, other contemplative states, mindfulness, as well as the works of philosophers Emmanuel Levinas, Gabriel Marcel, Martin Buber, Iris Murdoch, and Simone Weil, and literary scholars Walter Benjamin, Sharon Cameron, Geoffrey Hartman,

and more Henry James. We are also turning toward the work of oral historians and those who work in trauma studies and testimony to learn how they equip themselves as witnesses to others' suffering (Felman and Laub, LaCapra, Caruth). The oral historian or the interviewer in testimony archives is positioned to encourage the telling, to enable the teller to hear himself or herself speak. If the telling cannot go on without a listener, those listeners know that they become themselves implicated, traumatized in their acts of listening. This is all highly salient to the practice of medicine, so impoverished is it by its recent positivism and reductionism that it can't even hear itself think.

How do these manners of thought influence routine clinical practice? Ordinarily, when a doctor sees a patient for the first time, he or she asks a battery of questions about the current illness and all its symptoms and manifestations as well as about the patient's medical history, prior ailments, surgeries, allergies, medications, family health history, and occupational history. This is followed by an exhaustive list of questions called the "Review of Systems," in which one starts at the head and works his or her way down—headaches, trouble with vision, trouble swallowing, wheezing, vomiting—covering the function of each organ system in turn to identify disorders.

I find that I have changed my routines on meeting with new patients. I simply say, "I'm going to be your doctor. I need to know a lot about your body and your health and your life. Please tell me what you think I should know about your situation." And patients do exactly that—in extensive monologues, during which I sit on my hands so as not to write or reflexively call up their medical record on the computer. I sit and pay attention to what they say and how they say it: the forms, the metaphors, the gaps and silences. Where will be the beginning? How will symptoms intercalate with life events? I listen, not with Freudian or Lacanian or gestalt frameworks of meaning-making, but with narratological ones. The first time I did this, the patient started to cry after a few minutes. "Why are you weeping?" I asked him. He answered, "No one ever let me do this before."

Another new patient came in in a wheelchair, evidently having suffered a stroke. The referral note he handed to me simply said, "Severely ill 52 yo man s/p aortic dissection, s/p CVA, insulin-requiring diabetes." Initially, my heart sank—he looked so very grim and despondent, slouched in the wheelchair, unable to use his left arm or leg. His chart bulged with bad news. And yet, when I asked him to tell me what I should know about his situation, he began a most mournful and powerful account of his prior health, his joy in life, his hard work and hard play, his ruling of his household. Since his surgery and stroke, his wife is in charge, his sons do not know how to act around him, he cannot go out alone, he cannot visit his friends, he lost his job. What he has lost! And he told it all to me within 10 or 15 minutes as I gazed at him, no doubt sadly and attentively.

I wrote down what he told me in as accurate a representation as I could, using his words, his images, his sequence of thoughts and utterances. The note, in part, read:

Man of tremendous courage. Last year, was in good health, worked full-time in the post office, played soccer, met his friends to play dominoes, enjoyed life. He lived at home with his wife and two sons—K and N. He was clearly the head of the household.

He developed chest pain suddenly and was brought to Metropolitan Hospital Emergency Room, had emergency repair of a dissecting aortic aneurysm. He had a stroke in the days following the surgery with paralysis of his left arm and weakness of his left leg. Now he is unable to use his left arm. He can walk with a cane and a left leg brace.

He is home now all day in a wheelchair. His family had to move to a new apartment because the doors in the old apartment were not wide enough for his wheelchair. He has a home attendant. His wife and sons are still at home, but it is very difficult for them all. This has been a horrible ordeal for the whole family. The patient feels all his losses. He sometimes feels pitied by his wife. He knows there is still deep love between them, and with his sons and granddaughter of 10 months, Ela. Yet, he feels no longer in charge.⁴

I read this note to him and gave him a copy so that we both know where we are starting our partnership. It was not just a matter of my having to know which section of his brain infarcted in his stroke but also what his stroke made of him, what it did to him, how he fought back from it, how much he thinks he'll recover, whether he will be the person he once was. It *mattered* to him and to our future clinical relationship that I know these things, that I have heard his fears and rage and grieving. In that first visit, we created for ourselves a medical transference that will enable him to follow my recommendations and will deepen my investment in his future, a great and lasting curiosity about his life.

This is an example of the ways in which representation follows from attention in direct patient care. Sometimes, the acts of representation are accomplished privately by the clinician, producing texts not for the patient to read but in order for the clinician-writer to discover thoughts, feelings, perceptions. In our narrative medicine practice, we are finding that the clinician must *represent* what he or she has witnessed. In many different settings—Narrative Oncology writing seminars for nurses and doctors and social workers who staff the in-patient oncology unit, Parallel Chart sessions with medical students who are invited to write “off the hospital chart” about their care of patients, and primary care residency sessions in which doctors-in-training write naturalistic descriptions of house calls they have paid to patients—we give clinicians permission to write in ordinary language about what they observe and undergo in the care of patients. Without extensive training or practice, clinicians are able to produce complex and moving descriptions of their patients and their work with them.

The texts in the following section were written in a project called Narrative Oncology. This project started as an effort to support oncology professionals through their profound defeats and losses. Doctors, nurses, and social workers who staff the in-patient unit in Presbyterian Hospital for cancer patients meet twice a month to read to one another what they have written about clinical experiences. We are careful to observe all guidelines for protecting patients' privacy and confidentiality in our work. Over time, our writers have found great comfort and joy in these sessions. They learn about one another and about themselves. They learn, by virtue of having

“put” things in a certain way, what they think about or feel about clinical situations. Busy health care professionals make time for these sessions because of the intimacy, the honesty, and the bonding that ensues. The group makes management decisions in these sessions, for example, deciding which nurse should be assigned to a particular patient or which social work support group the patient’s mother might find helpful, because these sessions uncover important aspects of difficult cases.

What are we doing by virtue of such writing? In the Preface to *The Ambassadors*, James writes, “Art deals with what we see, it must first contribute full-handed that ingredient; it plucks its material, otherwise expressed, in the garden of life. . . . But it has no sooner done this than it has to take account of a *process* . . . that of expression, the literal squeezing-out, of value” (James 21: ix–x). That which is represented *comes from* something seen, experienced, perceived, James argues, rather than from “pure” invention. Like the dreamer, the creative artist—or the health professional writing about clinical work—does not sit in his or her garret, with eyes closed, making things up. Too impressionable to *not* reflect impressions, the imagination metabolizes its associated memories and sensations and perceptions, giving them new form but *originating* somewhere, at some level, from that which has been undergone. James then goes on immediately to describe the expressive process as a muscular one, in the sense of expressing the breast milk from a nipple or a secretion from a gland, by which the artist actively *generates* from the perceptions their rare value.

Acts of representation, then, *develop* that which is seen into something created anew. Writing teacher and psychoanalytic scholar Guy Allen reminds us of the playfulness of narrative writing for his students, suggesting that the writing functions as a Winnicottian transitional phenomenon, opening up for writers a potential space between themselves and others wherein discoveries can be made. By no means a xerox reproduction or neutrally given “reality,” acts of representation proceed from the subject who sees, the object seen, the perspectives of view, the aesthetic endometrium into which this fertilized view nests, and the audience for whom the representation is being prepared.

When health professionals write, in whatever genre and diction they choose, about clinical experiences, they as a matter of course discover aspects of the experience that, until the writing, were not evident to them. It is a commonplace by now for us to hear writers say, “Yes, now that I have written that description, I understand what I thought or felt about this patient.” We see that the representational act is a critical positional step. By giving the formless experience a *form*, the creator can perceive and display all dimensions or facets of the situation. By form, I mean all the aspects of a narrative text that a writer puts in it, whether or not he or she is aware of that putting—diction, genre, figural language, narrative situation, focalization, allusion, temporal scaffolding. Once the experience has had a form conferred on it—once it becomes a poem or an obituary or a letter to someone else told with a certain chronology, metaphors, and voice from a chosen perspective and narrative distance—the writer can, in effect, walk around the representation, seeing aspects around its back or over to its side that were, until bestowing form, unavailable to the subject.

Better than just talking about these things in a support group or venting session, the actual writing endows the reflections with form so that others can join the writer in beholding it. My writers are very proud of what they write. We realize that they are getting better and better *as* writers, able with greater and greater power to capture what they undergo in language. In turn, their language is able to convey their experiences to others. If they can capture it with greater force and accuracy, it means that they are perceiving it better as it occurs. One nurse said recently, “I *knew* when I admitted her that I would write about her,” suggesting to me that even the promise of future representation alters the attentive present. This is very radical. I feel bold enough to say that representing these events enables us to experience them.

Here is a text written and read in Narrative Oncology by a social worker about a woman dying of Stage IV breast cancer:⁵

You seem to rise from this cold, stark environment like a crocus in early spring. Deceptively fragile looking, but oh, so strong. Your delicate beauty is apparent, even in a hospital gown and with IVs running. You crumple when I delve—Yes, this has been so very trying, this cancer. You sway, take a very deep breath, re-rooting yourself. You wipe your tears and smile. “I don’t cry a lot,” you say, but certainly this grief is unavoidable. Your presence suggests an inner core that is, in essence, unshakeable. But how can this be? This disease is so ugly and powerful—or maybe not. Maybe your particular spirit can never be overcome. I say goodbye, and you wink—as if you know my thoughts.

We talked about the metaphor this writer chose—the crocus, the declaration of spring, the hardy miracle after the snow and frozen earth, a beginning of fruitfulness. By having recognized that image (that visited her quite without her will), this writer could express the meaning from her encounter, in both of James’s meanings for “express” simultaneously.

We also looked together at the narrative situation here—who is reporting whose thoughts, who speaks, who is the *I*? “You crumple when I delve” might also signify that I crumple too. Who is swaying and taking the deep breath? Allegedly the patient, of course, but there is liminal travel here between the teller of the words and the teller of the tale. The entire paragraph is a record of the narrator crumpling. To whom is grief unavoidable? The final line—“as if you know my thoughts” is a dazzling ventriloquism, for the writer knows the thoughts of the patient who knows *her* thoughts! Paying attention to this border-crossing confusion helps the author by underlining the evident identification that has occurred with this patient, helping her to see that she suffers her own grief while in the patient’s presence.

A pregnant nurse wrote of a woman dying of ovarian cancer:

Her abdominal girth would put her at 40 weeks—GI is going to tap her today. An unhealthy 7 liters would be born later that evening.

I am self-conscious of my 26-week swell, no longer hidden, when I go in to plan her discharge. She smiles and states that it looks like I have some good

news—it's out there, we can go on with business. I silently thank her for putting me at ease.

Before we talked about the affective or medical content of this text, we talked about its form. The word pregnancy is never used. Like any *aporia*, this absence signifies something of heightened importance and freight. It was too perilous to even use the word. It appears only as the “it” in the story.

Use of the future conditional verb tenses (“her abdominal girth would put her at 40 weeks” and “an unhealthy 7 liters would be born later that night”) unite the future conditional state of pregnancy with that of death. The patient was very literally pregnant with her own death. This was an ordeal for this highly competent nurse, pregnant for the first time, alone in her confusion about whether her fecund state would be seen as an assault and a source of additional suffering by her dying young patient. By reading this text aloud to the group, the writer enlisted the help of senior nurses, including her supervisor, to teach her about this momentous intersection of her life with the life and death of her patient.

A young pediatric oncologist who is doing research on a new chemotherapy agent wrote the following text:

Four years ago today I lost my father to cancer. How ironic that my research took a turn to the one drug that might have prolonged his life. Last night a patient lay dying despite my wonder drug. A boy I have known since he miraculously recovered from his first presentation with cancer, with the help of this drug. Trached, unable to speak, he had been transformed into a future basketball star with a winning smile. He had beaten the odds in too many ways to count, and now he needed another miracle.

Last night, I lit a candle and said Kaddish. I asked my father to take care of my patient. This morning, I woke early to discover my patient had passed away, likely right about the time of my prayers. My drug was of little use to him either, but maybe, my prayers will serve him and me well.

After the oncologist read this text aloud to a group of her colleagues, amid tears, a nurse said to the oncologist that her pain is no longer useless, that her grief at losing her father is transformed into something useful—for the parents of her young patient today. We all realized how the passage of time—in her account and on the hospital floor—flowed with remorse, flowed forward while looking back, flowed with potential redemption. We understood that the oncologist's loss four years ago was in her *self*, deepening her capacity to face the loss of her patient and to accompany his parents through their ordeal. Through her ability to represent her many losses, she was able to attend all the better to her own grief, thereby making room within herself for the grief of her patient's family, building affiliation throughout with those in her care and those with whom she cares for them.

Out of this work emerges the productive hypothesis that the development of attention increases the skills of representation and that the skills of representing

increase the attention. Together, they spiral toward affiliation—with individual patients, colleagues, and the institution that houses them all. It is our task to harness the tremendous power of these artistic, creative acts of telling and listening and representing stories for the sake of our patients and our colleagues. It is our duty to bring our full selves into our practice—not just our cognitive apparatus but all our resonant imaginative, meaning-making capacities so that patients' journeys toward health and meaning can be illuminated. Finally, attention and representation, we believe, can enable us to know in earthy, rich detail that we are affiliated as humans, all of us humble in the face of time, ready to suffer our portion, and brave enough to help one another on our shared journeys.

ENDNOTES

1. There has begun to be rigorous study of patients' illness narratives and health care professionals' reflective writing of practice, both in terms of poetics and consequences in the real world of the clinic. Scholars from linguistics, sociology, and literary studies have examined these emerging forms in a productive multi-disciplinarity. See works of Arthur Frank, Anne Hunsaker Hawkins, Shlomith Rimmon-Kenan, and Richard Zaner.
2. Such writing does not only occur in private. Of late, writing groups have developed among patients with HIV/AIDS, among survivors of trauma, in cancer support groups, and among patients with dementia. See the work of Guy Allen and Charles Anderson. The explosion of personal writing on the web in blogs and the like cannot even be estimated, either in volume or consequence.
3. The thoughts in this paper owe much to the deliberations of a two-year project, funded by the National Endowment for the Humanities, to conceptualize the reasons that narrative training benefits health care professionals. My colleagues in the seminar are: Sayantani DasGupta (pediatrics), Rebecca Garden (English), Craig Irvine (family medicine and philosophy), Eric Marcus (psychoanalytic institute and psychiatry), David Plante (creative writing), Patricia Stanley (patient advocacy), and Maura Spiegel (English).
4. I have changed some of the clinical and personal details of this story to render the patient unrecognizable so as to preserve his privacy.
5. All writers whose texts are quoted here have given me permission to cite their work.

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