Narrative Medicine: Form, Function, and Ethics

Sickness and healing are, in part, narrative acts. Patients write about their illnesses with increasing frequency, which suggests that finding the words to contain the chaos of illness enables the sufferer to endure it better (1–3). We physicians, too, write more and more frequently about ourselves and our practices (4, 5). In many forms of narrative writing, doctors are endorsing the hypothesis that writing about oneself and one's patients confers on medical practice a kind of understanding that is otherwise unobtainable (6).

What Is Narrative Medicine?

The growth in publication of patients' and physicians' stories is joined by other signs of the increasing importance accorded to narrative dimensions of sickness and medicine. Residing in what is called narrative knowledge, the human capacity to understand the meaning and significance of stories is being recognized as critical for effective medical practice (7, 8). Physicians are reaching to practice what I have come to call *narrative medicine*—that is, medicine practiced with the narrative competence to recognize, interpret, and be moved to action by the predicaments of others (9, 10).

Narrative conceptual frameworks have been advanced—and accepted with gratitude—for examining and understanding medical reasoning, clinical relationships, empathy, and medical ethics (11–13). The growing acceptance of and demand for qualitative clinical research to complement quantitative clinical research demonstrate physicians' realization that both the singular and the statistically significant must be comprehended in the study of disease or its treatment (14, 15). The rise of narrative medicine may signify fundamental changes in the experience of disease or of doctoring. It also suggests that medicine, as part of its culture, is responding to the forces propelling similar narrative turns in such fields as literary studies, history, qualitative social sciences, and ethics (16). Examining narrative medicine's practice of writing may help us to understand its significance, its consequences, and the means to participate in it responsibly. This essay undertakes such an examination by combining analytic and reflective methods.

Classification of Genres of Narrative Medicine

There are at least five distinct genres of narrative writing in medicine: medical fiction, the lay exposition, medical autobiography, stories from practice, and writing exercises of medical training. Each genre has its own traditions, intentions, methods, and consequences, and each calls for specific ethical guidelines.

Medical Fiction

Stories about physicians and patients can be invented. When William Carlos Williams wrote "The Use of Force," he was not writing a chart note after making a house call, even though the "real" Dr. Williams might have visited a young girl with diphtheria in his Rutherford, New Jersey, general practice (17). When Richard Selzer wrote "Brute," he did not photocopy the emergency department chart detailing the suturing of a facial laceration in a man caught in a street fight, even though the "surgeon" Richard Selzer indeed cared for such a man during his training (18). Instead, these writers created fictional worlds that corresponded roughly, perhaps, to authorial experiences but transcended them to express aesthetic vision and artistic coherence.

The Lay Exposition

The New Yorker occasionally publishes essays in a section called "Annals of Medicine." Jerome Groopman has written about a few patients with prostate cancer, interspersing their personal stories with medical facts about the disease told in lay language (19). Atul Gawande has written about medical errors, detailing experiences of troubled physicians and their patients and suggesting means to safeguard the public against medical mistakes (20). Such lay journals as *Harper's* and *The New York Times Sunday Magazine* have published physicians' essays as well. These essays are written to instruct members of the lay public about medical science, to inspire them to keep themselves healthy, or to encourage them to make social changes in how medicine is practiced.

Medical Autobiography

The decision to publish an autobiography embroils the author in the public examination of the private self,

rehearsing past events in order to justify or cohere or accept choices made and deeds done (21–23). When a physician writes an autobiography, it must pertain, in part, to "doctorly" acts.

When becoming physicians, young medical students undergo dramatic personal transformations, often in a relatively short time, that render them unrecognizable to themselves. To become a person who can dissect a cadaver or peer inside a living human body or inflict pain on another person requires one to turn from one's past, during which one did not perform these acts. This inserts an obligatory discontinuity into any medical autobiography. The publication of many memoirs about medical school suggests the urgency to tell of these transformations—and to tell of them in sadness, rage, and contrition (24–28). The width of the alienating discontinuity opened by medical training suits physicians particularly well for writing autobiographies and even suggests that they, more than other professionals, need to write them.

Stories from Practice

More and more medical journals have inaugurated narrative features, including *Annals of Internal Medicine*'s "On Being a Doctor," *Journal of the American Medical Association*'s "A Piece of My Mind," and *Health Affairs*'s "Narrative Matters." Essays in these columns differ from lay exposition and medical autobiography in audience and intent. Because physicians write these essays for other physicians to read, they adopt the narrative stance of the insider, expecting their readers to pick things up between the lines. Physicians write such essays to present unique experiences to colleagues, to brood aloud to others like themselves, and, sometimes, to seek forgiveness for perceived lapses.

Writing Exercises of Medical Training

Many medical schools and residency programs ask trainees to write about their clinical experiences in journals, critical incident reports, or what I have called parallel charts (29–33). Often, students are asked to read what they have written to one another and to faculty members, thereby generating and articulating the personal and emotional agendas of training that can otherwise be neglected. Residency programs in internal medicine and family medicine incorporate such reflective and textual activities as Balint groups, literature and medicine seminars, and narrative presentations of patients (34, 35). These narrative practices encourage trainees to reflect on what their patients experience in illness and what they themselves undergo in the care of sick and dying patients (36).

Consequences of Narrative Writing in Medicine

Having surveyed some specific genres of narrative medicine, let me turn to a more personal reflection on the consequences—for doctor and patient—of such writing. This natural history of one internist's narrative writing about patients may offer a prelude to needed longitudinal studies that assess the outcomes of such practices.

With the guidance of literary scholar Joanne Trautmann Banks (37), I began to write stories about patients who troubled or baffled me. The more I wrote about my patients and myself, the more confident I became that the act of narrative writing granted me access to knowledge—about the patient and about myself—that would otherwise have remained out of reach. I also realized that writing about patients changed my relationships with them. I became more invested in them, more curious, more engaged, more on their side.

I next found myself showing patients what I had written about them. If my writing constituted the hypothesis-generating step of a form of intersubjective research, only the patient could test the hypotheses. After a particularly moving or confusing visit with a patient, I would write as accurate an account as I could summon of what I thought the patient had told me. On the next visit with that patient, I would invite her to read what I had written and would ask whether I had gotten her story right. I would do this several times, so that each visit resulted in a "chapter" about the patient's life.

In two early efforts, the patients read what I had written and then said, in effect, "We left something out." These two patients then told me about episodes of abuse—for one, childhood sexual abuse and for the other, spousal violence in young adulthood—that, in their minds, were related to their current clinical situations. Both women then brought me texts—a childhood journal, poems about a marriage—that they had written about their experiences. In both cases, the patients' responses to my "chapters" about them were clinically sig-

nificant because they brought to my attention aspects of their histories that were salient to their current emotional and physical health. It was as if my writing about and for my patients quickened a process of disclosure that may have come much later, if at all, in the relationship. (It may be that this form of diagnostic narrative writing, if it is replicable, constitutes another genre for my classification.)

I then found myself reviewing the charts of longtime patients to remember and reflect on all that we had seen one another through in almost two decades of care. I found the exercise extraordinarily useful and wanted to share the idea with my fellow internists. However, before publishing a paper that included rather extensive clinical descriptions of two identifiable patients, I felt that the breach in confidentiality required me to obtain their informed consent. I showed the manuscript to the patients (in one of the two cases, to the patient's daughter, because the patient himself had become cognitively impaired), and I asked them for permission to publish it (38).

In both cases, the patient and family member granted permission. More important, the disclosure was therapeutic. The daughter of the elderly patient said, after reading the relevant parts of the manuscript, "You really knew my father." This knowledge—the fact that the patient was personally known and recognized by his doctor—became a source of comfort for the patient's whole family. When the second patient read what I had written about her (and about me), she told me that she recognized herself in what I had written and then said, at our next office visit, "How can one person know so much about another?" In ways that I cannot yet fully explain, writing about this patient and then showing her the text remodeled our clinical relationship quite dramatically. Instead of sharing a sense of discouragement about her health, we now sit in my office as two powerful women, working hard together to solve problems and to help her get better.

Ethics of Narrative Medicine

This reflection on my own writing of stories from practice offers a starting point from which to inspect some of the consequences of narrative writing in medicine and to suggest some guidelines. For whose benefit is such writing done? How can physicians perform such writing responsibly? What obligations are incurred by writing about patients and, perhaps more urgently, by publishing such writings?

Particular ethical duties might be incurred by each genre of narrative medical writing. Clearly, the writer of fiction should not be held to the same standards of disclosure and requirements for informed consent as writers who detail clinical situations of individual "real" patients. Texts that are primarily autobiographical might require different approaches to disclosure than texts that are primarily descriptions of patients. Finally, different guidelines might apply to the writings of professionals and those of students.

Ethical considerations and common sense suggest that the health professional who writes about an individual patient and intends to publish the writings—either in medical journals or in the lay press—should first, because privacy and confidentiality are breached, obtain permission from the patient. Even though names, dates, and similar information might be changed, the affiliation of the author points to a given institution, and the highly singular clinical details of illness make patients recognizable, even if only to themselves, their families, and those who work in the author's institution. Because irreparably bad sequelae may result if a patient comes upon an essay about himself or herself—whether favorable or unfavorable—without having granted previous consent, it is prudent to consider a policy of informed consent for published narratives. The trustworthiness of all physicians would be compromised if patients had to worry that their doctors would broadcast information about them in print without their permission. Such guidelines might apply to the case report as well as to narrative writing (and, indeed, a growing number of medical journals in the United States and United Kingdom require the patient's informed consent before publication), although the personal nature of the latter calls more urgently for disclosure (39).

More fundamental ethical reasons support a policy of disclosure, especially when publication of the written material is foreseen. In my personal career of writing about patients and asking them to read what I have written, I have learned that the therapeutic dividends of disclosure are considerable. What the field of narrative medicine is developing is not merely a tool for physicians' reflection but a treatment intervention that may hold substantial power. In view of the therapeutic po-

tential of showing patients what their physicians write about them, altruism recommends disclosure.

Not all that a physician writes about a patient needs to be shown to the patient. Many times, what we write in privacy about our practice enables us to think clearly and critically about private experiences, and such personal ruminations need not and should not be revealed to patients. Certainly, students' and trainees' writings about patients should not be disclosed to patients because these assignments are training exercises meant to develop professional competence. However, if a written description of an identifiable patient is destined for print, perhaps we might agree that the patient's consent for publication should be sought. If, after having read the description of himself or herself, the patient declines consent for publication, then publication should not be pursued.

In a rather profound manner, a disclosure obligation shifts the physician-writer's goal from self-expression to clinical hypothesis-testing, thereby solving some of the vexing problems of potential exploitation of patients for their stories and the temptation toward self-promotion that is inherent in any form of publication. Disclosure guidelines locate these professional writing activities squarely among such professional activities as diagnosing and managing illness, activities for which the physician receives rewards (financial, professional, and personal) but that are not undertaken primarily for his or her own benefit.

CONCLUSION

That narrative medicine is flourishing now is no coincidence. Many forces restrict physicians' abilities to reflect, in language, on their clinical experiences and relationships. The marketplace speeds up medical work, interrupts continuity with patients, and erodes the privacy and autonomy of doctor–patient partnerships. The informatics revolution replaces handwritten chart notes with computerized notations that are limited by format and entry technology to a corner of the physician's concerns. The relentless specialization and "technologization" of medicine undermine the therapeutic importance of recognizing patients in the context of their lives and of bearing witness to their suffering. It may be that out of our current, rather chaotic practices of narrative writing will emerge new forms in which to examine, reflect on, and enact our ongoing commitments to patients.

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"All I maintain is that on this earth there are pestilences and there are victims, and it's up to us, so far as possible, not to join forces with the pestilences . . .

"I grant that we should add a third category, that of the true healers. But it's a fact one doesn't come across many of them, and anyhow it must be a hard vocation. That's why I decided to take, in every predicament, the victim's side, so as to reduce the damage done. Among them I can at least try to discover how one attains to the third category; in other words, to peace."

Tarrou was swinging his leg, tapping the terrace lightly with his heel, as he concluded. After a short silence the doctor raised himself a little in his chair and asked if Tarrou had an idea of the path to follow for attaining peace.

"Yes," he replied. "The path of sympathy."

Albert Camus
The Plague
New York: Vintage Books; 1991:253-4.

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