Right Brain: Reading, writing, and reflecting

Making a case for narrative medicine in neurology

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A narrative, at its simplest, is a story. Doctors listen to and tell stories every day. At morning report, on rounds, at case conferences, while taking a patient's history in clinic and when signing out in the evenings, stories are told, revised, and retold. These narratives are the foundations of clinical practice and the currency of patient–physician and physician–physician relationships.

Neurologists are the custodians of speech and language within the medical community. We study, examine, and characterize speech and language and can diagnose pathology based on their aberrations. Not only do details and subtle nuances frequently make the diagnosis, but how the patient tells a story, including word choice, sentence structure, and prosody, takes on clinical significance. Neurology is one of the few specialties in which the patient's history has retained its value despite increasingly sophisticated diagnostic technology.

More can be gained from a patient's story than dry facts placed in a sequential pattern. Absorbing, interpreting, and responding to a patient's narrative require a special skill set. These skills, called "narrative competence" by narrative scholars, include those that are practical, such as recognizing a story's structure and appreciating metaphors and illusions, those that are creative, such as envisioning multiple endings, and those that are emotional, such as feeling empathy and recognizing a story's mood.[1] By developing narrative competence, physicians can better understand a patient's experience and thereby be better equipped to help him or her.

WHAT IS NARRATIVE MEDICINE? Narrative medicine, rather than a specialty, is a framework for clinical practice based on developing and utilizing this skill set. It is a way of approaching the clinical encounter that focuses on appreciating and reflecting on the patient's experience and the patient–physician relationship in order to improve both by building trust, developing empathy, and fostering a sense of shared responsibility in a patient's health.

Narrative competence rarely is taught as part of traditional medical school courses or on hospital wards. Specific programs in narrative medicine, however, have been implemented in many medical schools and residency programs throughout the world. Curricula in narrative medicine typically include two parts: reading of literary texts related to health and illness to gain practice in hearing and interpreting the stories of others and reflective writing about the patient's and the professional's individual and shared experience.

LITERATURE IN MEDICINE

> . . . [Y]ou can't understand. You're using the language of reason, not of the heart; you live in a world of abstractions.
>
> —Albert Camus, *The Plague*

Literature and medicine have amicably coexisted since Apollo was recognized as the Greek god of both medicine and poetry. The novel, the case report, and the autopsy were even developed at roughly the same time. Many of the great literary texts, such as *Middlemarch* by George Eliot, *The Plague* by Albert Camus, and *The Magic Mountain* by Thomas Mann, are centered on illness and its victims. Neurologic illnesses are well-represented in literature with works including those as diverse as *The Idiot* by Fydor Dostoevsky, *Awakenings* by Oliver Sacks, and *The Diving Bell and the Butterfly* by Jean-Dominique Bauby. The large number of physician–writers, including Sir Arthur Conan Doyle, Anton Chekhov, and William Carlos Williams, underscores the shared interests and methods of the two disciplines.

The study of literature has been part of medical school curricula since the early 1970s, introduced at a time when medicine was especially focused on nurturing patient-centered practice.[2] An informal survey conducted by the Society for

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Health and Human Values in 1994 found that approximately 30% of US medical schools taught literature as part of its curriculum.[3] By 1998, the most recent statistics available, 74% of those medical schools taught courses in literature and medicine and in 39% of them, it was a required course.[4] Literature and medicine as a subdiscipline currently has its own scholarly journals, professional societies, graduate programs, and sources of research funding.

The study of literary texts offers many advantages to students and develops skills that may not be obtainable in any other way. Through literature, a reader enters into another person's experience, often historically, culturally, and physically different than his or her own. The situations, reactions, emotions, and effects on the character are laid bare in a way that would be impossible in reality. Expert writers present readers with whole, complex characters, meaningful scenarios, and a purposeful plot structure allowing them to make sense of the story and come to their own conclusions. The partially or wholly fictitious nature of most of these works is an advantage as it strips the situation of the uninteresting and confusing elements that complicate real life.

By reading an author's rendition of sickness, suffering, and death, the physician can better understand his or her own patient's experience with illness. For example, Bauby, in his *The Diving Bell and the Butterfly*, describes the helplessness and frustration he feels by being trapped inside his locked-in body while his mind remains active:

> Reflected in the glass I saw the head of a man who seemed to have emerged from a vat of formaldehyde. His mouth was twisted, his nose damaged, his hair tousled, his gaze full of fear. One eye was sewn shut, the other goggled like the doomed eye of Cain. For a moment I stared at that dilated pupil, before I realized it was only mine. . . Whereupon a strange euphoria came over me. Not only was I exiled, paralyzed, mute, half deaf, deprived of all pleasures, and reduced to the existence of a jellyfish, but I was also horrible to behold.[5]

The book itself, each individual letter of which the author communicated via eye movements, is a monument to the irrepressibility of the creative spirit, even in the face of catastrophic obstacles. Through great texts, such as this one, physicians become more familiar with the experience of pain and illness in a way that is more personal than could be safely ascertained with a real patient.

The act of reading itself is also beneficial. Reading literature builds interpretive, communicative, and empathic skills.[6,7] Physicians can put the skills developed in reading literary texts to use while reading other complicated narratives such as medical charts, case studies, and even medical texts.[8]

PERSONAL REFLECTION

> But whatever else poems do, or do not do, at the very least they profoundly alter the man or woman who wrote them.
>
> —Daniel Abse[9]

Reflective writing is another method for developing narrative competence. Reflections take the form of clinical journal writing or critical incident reports where the writer is free to choose a patient or case significant to them or else to write centered around a predetermined theme (e.g., death or breaking bad news) or event (e.g., the illness of a relative). Participants experiment with different perspectives, voices, styles, and literary formats (e.g., plays, poems, prose). The only fixed rules are that reflections be stories or impressions of experiences rather than case reports, that medical language be avoided, and that the reflections be written. Writers frequently share their reflections in a small group environment.

Reflective writing often centers on a patient's experience, frequently from the patient's perspective. The physician is allowed time and space to ruminate on how it feels to be the patient, and how the patient is reacting to what he or she is experiencing. Writing about a patient in this way reduces the emotional distance between doctor and patient that traditional clinical practice imposes and increases a physician's ability to empathize.[10] Unrecognized attitudes and feelings emerge which can then be dealt with rather than left to linger, making a doctor more available and useful to his or her patient. In addition, reflecting on one's own actions in a clinical encounter allows the doctor's voice, typically absent, to be brought back into the patient's story.

Learning is a cycle of action, reflection, interpretation, and reaction. Reflective writers study their own decision-making, feelings, behaviors, interactions, and gaps in knowledge and skill. Reflecting on one's own practice coincides with the development of insight into one's own educational needs and the ability to better practice well autonomously.[11] Reflections draw out professional and ethical issues that the writer can then think about seriously on his or her own and subsequently gather the viewpoints and judgments of his or her colleagues.

RESEARCH INTO NARRATIVE MEDICINE The desired outcomes of narrative medicine, such as empathy, personal satisfaction, and relationship-building, are inherently difficult to study, not

lending themselves easily to quantification and measurement. The research that has been done into narrative medicine courses, however, has shown them to be effective in developing the specialized skills associated with narrative competence and in improving the overall well-being of physicians and students. Outcome studies of literature and medicine courses, relying on post-course student evaluations, questionnaires, and faculty member assessments, reveal that such programs improve students' understanding of patients' experiences, their relationships with patients, and their functioning in clinical situations.[12-14] Within the more general scientific literature, writing about challenging or traumatic experiences has been shown to have health and psychological benefits in multiple studies including those in new mothers, victims of crime, and college freshmen.[15] Writing about prior trauma boosted immune response to hepatitis B vaccinations in a subgroup of medical students.[16] Another study found improved PEV_1 measurements in people with asthma and a decrease in disease severity scores in people with rheumatoid arthritis in those who wrote about stressful experiences compared to a control group who wrote on neutral topics.[17]

The effects of narrative medicine on patients themselves, however, are still unclear, as little research has been done on the subject. Recent studies in the psychiatric literature are using new validated tools to measure patient-perceived physician empathy via skin conductance.[18] Researchers into narrative medicine could follow suit by measuring patient-perceived physician empathy before and after the physician undergoes narrative medicine training and then correlating those results with patient satisfaction. Other possible lines of research include investigating practical measurements of the patient–physician relationship such as time to diagnosis, number of follow-up phone calls, likelihood of being lost to follow-up, and long-term survival.

NARRATIVE MEDICINE IN NEUROLOGY

> We have five senses in which we glory and which we recognize and celebrate, senses that constitute the sensible world for us. But there are other senses—secret senses, sixth senses, if you will—equally vital, but unrecognized, and unlauded.
>
> —Oliver Sacks

Neurologic illnesses are unique in how they affect a patient's personhood and ability to function. They dehumanize in a way that heart disease and renal failure do not. A stroke may rob someone of the ability to speak, walk, or feel in a second whereas multiple sclerosis may gradually erode a patient's functioning, leaving him or her struggling to adapt to unexpected obstacles every day. The uniqueness of these illnesses and their impact on people is part of what makes neurology both fascinating and challenging.

This uniqueness can also make it difficult for a neurologist to relate to his or her patients. Few can imagine what it is like to be hemiparetic or aphasic because it is so far removed from healthy life. These patients, however, stand most in need of being listened to and understood. While most neurologists will never know how it feels to have amyotrophic lateral sclerosis or to be locked-in, they can better understand alienation, frustration, and hopelessness through literature and reflective writing and therefore be better equipped to help patients through their own journeys.

The nature of neurologic illness often makes for long and rewarding relationships with patients and their families. The cognitive decline and debilitation of a long-term patient, as well as the effect of the illness on caregivers and families, however, can be hard for a neurologist to process. Self-reflection and discussion with peers can make coping with these issues easier, improving the physician's quality of life and ability to care for patients.

In addition to asking what narrative medicine can do for neurology, however, the inverse should also be asked. The field of neurology, with its historic interest in speech, language, emotion, and cognition and its new fMRI technology that can look at brain function and adaptation in real-time, is poised to take narrative medicine research in a new direction. Does reading literature or writing actually change what parts of the brain are activated during encounters with patients? What areas in the patient's brain are activated in response to perceived empathy? If one of the criticisms of narrative medicine is that its effects are too difficult to measure, the field of neurology has the opportunity and resources to change that perception.

HOW TO TEACH NARRATIVE MEDICINE

> It is far more important to know what person the disease has than what disease the person has.
>
> —Hippocrates

Narrative medicine programs are both cost-effective and minimally time-consuming. Although many medical schools across the country have incorporated narrative medicine programs into their curriculum, few residency programs have followed suit. Given most residents' highly structured and overly scheduled personal and

professional lives, any attempt at integrating narrative medicine into their day must be made to fit within the existing confines, without adding too much extra time for the resident or jeopardizing patient care. Possibilities include substituting narrative medicine content for morning reports or noon conferences once or twice a month or asking senior residents to carry junior resident pagers for the occasional 2 hours in the afternoon and vice versa. Sessions held at night or on weekends may be practical in some programs or among more senior residents with less call responsibility.

Sessions can take many forms. Residents can be asked to read a selected text in advance of a seminar and come ready for a discussion on a predetermined theme, illness, or clinical situation. Another example would be that rather than a typical clinical case presentation, residents could give a narrative presentation of a patient's case including a discussion of the social, psychological, and personal issues involved in the case, the patient–physician interaction, and any ethical or professional issues that come to light.

Reflective exercises may also be incorporated into available time. Residents may be asked to write freely for as few as 3 or 4 minutes on a theme or event, which they afterward share within a small group. Another exercise is to ask residents to interview each other about a time when they were ill or felt vulnerable. Afterwards both write about the experience, the interviewer about how it felt to listen to the other's story and the interviewee about how it felt to share the experience. A facilitator helps to focus the discussion on the content and structure of the writing and the themes and conflicts that emerge. One particular residency program has had success by incorporating these reflective exercises into their program as little as once or twice a year.[19]

CONCLUSION Neurology training is miraculous in the amount of knowledge and skill it instills in a short period of time. The trade-off to the intensity of the residency, however, is the physician's gradual distancing from patients and colleagues. In addition, due to increasing sub-specialization, technologization, and managed care restrictions, neurology as a field has taken a giant step back from patients in recent years. Connecting with patients and one another, finding fulfillment in caring for people, rather than curing, managing, or triaging, is no longer discussed. It simply is deemed unimportant.

Narrative medicine is not a substitute for current clinical practice, but a way to complement it by re-establishing the centrality of the patient's story in the clinical encounter. Within a neurology residency program, narrative medicine could be a valuable tool in developing empathy, professionalism, and communication skills. Finally, narrative medicine is a way to reconnect with patients, each other, and ourselves. Doctors listen to and tell stories every day. Now is the time to hear them.

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