

Narrative Medicine: How Stories of Illness Affect Caregiving

A physician diagnoses the condition and either treats it or refers the patient to someone else for treatment. End of story. Or is that just the beginning of the story? Narrative medicine challenges the medical model by bringing a new tool to the table: the story of the patient.

By Dana Martin

Theme. Setting. Characters. Point of view. These are some of the central elements of story development, ones you might remember from literature and composition classes. But they are also important to patient care, perhaps as important as gathering information through exams and testing. Narrative medicine is an emerging clinical discipline that focuses on medicine practiced with the narrative skills of recognizing, absorbing, interpreting and being moved by patients' stories of illness.¹² It marries the objectivity physicians have been

trained to bring to their work with the empathy needed to understand and care for each patient as an individual with a unique story. As Bradley Lewis, author of *Narrative Psychiatry: How Stories Can Shape Clinical Practice*, writes, "The doctor's interest and concern ought to be as much about the objective facts about cancer of the colon, for example, as about how the unique individual in front of him or her subjectively experiences their situation and what this means for this particular individual's life."³

Though steeped in such disciplines as medical



humanities and bioethics, narrative medicine as a distinct concept is a relatively new approach to medical care.⁴ In 2000, Rita Charon, MD, PhD, founded the Program in Narrative Medicine at the Columbia University College of Physicians and Surgeons. While pursuing her PhD in English at Columbia, she realized stories have clinical significance⁵ in that sickness unfolds in stories.⁶ As an internist, much of her job consisted of listening to people's stories, deciphering them and taking action. This aspect of medicine, she concluded, was all around her students, but it was never discussed.⁶ "Before I started doing this, I knew my students had those experiences, but there was no way to capture it. There was no way to open it. There was no way to honor it."⁷ The Program in Narrative Medicine not only brings the story element of medical care into the light, it also ensures students have the necessary training to gather, interpret, understand and act on their patients' stories.⁵ This insight allows for better care, she says.⁸ The program's goals include building trust, developing empathy and fostering a sense of shared responsibility in a patient's health.⁵

Developing Narrative Competence

Students in Columbia University's Program in Narrative Medicine primarily approach the art of narrative medicine by working with two types of charts. The first is the scientific charting they are familiar with. The second is a record, in essay form, of their encounters with and their emotional reactions to patients.⁷ At first, it may seem counterintuitive to chart one's own response to patients. The objective is, after all, getting at the patient's story, not the story of how the caregiver responds to the patient. But Charon and others in the area of narrative medicine believe such introspection is necessary in terms of story excavation. One of the things students do as part of their parallel charting is talk about their own responses as part of their medical training. Charon says, "By doing it this way in training, it says, 'This is what it takes to be a doctor.'" Thus, the approach gives caregivers more access to knowledge about themselves as well as their patients. "What we know about going through this, however much it hurts, is that it makes us better. It makes you deeper, and you feel the defeats,"



Charon says. “You agonize over the mistakes, or even what you think could have been one. Your patients visit you in your dreams. And, paradoxically, there is a tremendous, joyous reward.”⁷

Lewis Mehl-Madrona, MD, PhD, MPhil, has been studying indigenous doctoring with traditional North American healers for more than three decades, with an emphasis on narrative approaches. “Narrative medicine is the encompassing of our awareness of health and disease into a storied structure,” he states. “We embed the illness into the life story of the person in such a way that we discover meaning and purpose in both the illness and the experience of recovery. And we come to a new respect for the illness, in the context of the life that it appears in.” For him, a person’s story includes friends, ancestors, interests and spiritual orientation. Ceremony is a central part of his work as it is part of the story of community and healing.⁹

The Need for Narrative Medicine

Charon writes: “Sick people need physicians who can understand their diseases, treat their medical problems, and accompany them through their illnesses.”¹⁰ Mehl-Madrona says the person is “as important to the outcome as the histology of a biopsy in the laboratory, maybe more important.”¹¹ Narrative medicine allows for the understanding Charon speaks of, as well as the

person-centered care for which Mehl-Madrona advocates. Four advantages of narrative medicine are outlined below.

First, narrative medicine can overcome the ways in which specialization and technical jargon can limit the work caregivers do with their patients.⁷ Lewis asserts that the language of bioscience too often divides physicians from patients, themselves, colleagues and society, and that the goal of narrative medicine is to bridge those gaps.⁴ “These gaps make it too hard [for] physicians to communicate and make it too easy for important variables of healthcare to escape,” he explains.⁴ In fact, there is preliminary evidence that narrative medicine creates caregivers with a deeper understanding of their patients’ needs,⁶ perhaps because it overcomes the barriers that language can present.

Second, narrative medicine can make caregivers more empathetic. One example is that of an experiment in which 891 diabetic patients were followed for three years to determine whether their health outcomes were correlated with their physicians’ empathy levels, measured in part by an understanding of the patient’s experiences, concerns and perspectives — the skills taught in narrative medicine. The results showed that the likelihood of good control was significantly higher in the patients whose doctors had high empathy scores than it was for patients whose doctors had low empathy scores.¹²

In another example, staff members at a mental health center employed a narrative approach to caregiving as part of a course in which they created narrative descriptions of patients presented by medical staff as hopeless.¹³ Mehl-Madrona and Michael Valenti, PsyD, published one caregiver’s narrative of a patient that reveals the power of the narrative process to positively affect how caregivers see patients. “Narratives give physicians the skills, methods and texts to learn how to imbue the facts and objects of health and illness with their consequences and meanings for individual patients and physicians,” Valenti and Mehl-Madrona write. The narrative approach created the picture of a competent human being as opposed to the clinical narrative of incompetence that was usually presented. It also allowed the caregiver to see the patient in a more complex way, which leads to greater empathy on the part of the caregiver.¹³

Third, stories can contain information that’s essential for treating the patient — information that would otherwise go ungathered. “By teaching clinicians how stories work, what happens to their tellers and listeners, and where stories hide their news — in form, in metaphor, in mood, in time and space — we enable them to enter the narrative worlds described by their patients,” Charon says. “So clinicians can receive what their patients reveal about their lives and health, leading to accurate clinical diagnoses and personal recognition. They hear in depth what their colleagues report about their patients. They even come to be more forcefully aware of their own interior voices in self-awareness.”²⁵

Resources

Books

- *Integrating Narrative Medicine and Evidence-Based Medicine: The Everyday Social Practice of Healing*, by James Meza and Daniel Passerman
- *Narrative Medicine: Honoring the Stories of Illness*, by Rita Charon
- *Narrative Medicine: The Use of History and Story in the Healing Process*, by Lewis Mehl-Madrona
- *Narrative Psychiatry: How Stories Can Shape Clinical Practice*, by Bradley Lewis

Programs

- Master of Science in Narrative Medicine at Columbia University: sps.columbia.edu/narrative-medicine
- Narrative Medicine Workshops at Columbia University: www.narrativemedicine.org/workshops.html

Videos

- Program in Narrative Medicine at Columbia University YouTube channel: www.youtube.com/channel/UCvPbfEqk0gbJ0s0Lx9jUuUQ
- “Bodies, Stories, and Selves: How Narrative Saves Lives” by Rita Charon: www.youtube.com/watch?v=OhSNzp4cGCE

Lastly, beliefs about illness can make a difference in patients' outcomes.¹¹ The flip side of objective data collection and monitoring is the subjective experience about illness, which is a story in and of itself — one that has tremendous power in terms of healing. Mehl-Madrona expands on this connection between one's personal narrative and health outcome. "Whatever you do to get well, it has to fit into the story you have about how people get sick and get well," he observes. These stories vary from one patient to the next, and none of them can be factored in or even influenced if they aren't identified and acknowledged. "Through metaphor, [patients'] stories help create a context of hope and a path to wellness — features that often are lacking from the 'story' patients get from mainstream medicine based on statistics and life-expectancy tables," Mehl-Madrona adds.¹¹

The Limitations of Narrative in Medicine

Narrative medicine isn't beyond scrutiny. One criticism is that, in its current form, the approach largely ignores the limits of narrative. Nurse practitioner Josephine Ensign teaches narrative medicine but also asks questions about its limitations. She says there are human experiences beyond narrative, particularly those that fall within the contexts of trauma, suffering and oppression. Ensign argues that caregivers need more than listening skills. They need to learn to listen in socially just ways, which includes developing the skills necessary to listen to stories that challenge them, not just those that are comfortable.¹⁴

Other challenges of medicine based in narrative include the steep learning curve involved, which includes significant technical and attitudinal changes, and the fact that some patients don't want to share their stories.¹⁵

Learning the Art of Narrative Medicine

According to Charon, narrative medicine, simply put, is medicine practiced by someone who knows what to do with stories.¹⁶ For those who can do so, training at the Program in Narrative Medicine is the ideal way to learn this skill. In 2009, Columbia University inaugurated a Master of Science in Narrative Medicine to fulfill the demand for training.⁵ Columbia also offers basic and advanced workshops on the subject that each last three to four days. Other schools, such as the University of Virginia, are also incorporating narrative medicine into their programs.

For those who can't formally train in narrative medicine, there are things they can do to pay better attention to the stories their patients are telling. These include keeping a journal of their interactions with patients, paying better attention to their own reactions to patients, paying attention to nonverbal communication such as body language and facial expressions, and using ordinary language when speaking with those in their care.

Joan Didion writes: "We tell ourselves stories in order to live."¹⁷ We also carry those stories into our roles as patient and caregiver alike. Listening to patients and understanding their stories, then allowing those stories to help guide care, is a skill

Narrative medicine can make caregivers more empathetic.

just like any other acquired in medicine. It needs to be learned and practiced — honed over time, as opposed to picked up overnight. But the rewards of this work can be tremendous for everyone involved. ❖

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