

Narrative's Medicine (from *The Chronicle of Higher Education*, March 6, 2011)

A literary competence might better attune doctors to their patients' humanity and struggles.

One of the stranger places I've given a talk was a cluttered, windowless conference room on the obstetrics floor at St. Vincent's Hospital in New York. Along the hall, open doors revealed women in various stages of labor. My audience was dressed in scrubs, beepers in hand. I was there to speak as a parent, not a professor of English, in a lecture series. A genetics counselor at the hospital had invited me and another mother to tell our stories. My child Henry has Down syndrome, and I have plenty to say about how obstetricians could better discuss genetic disability with new or expecting parents. Conversely, many doctors report feeling ill-prepared to face parents who have received a "positive" prenatal diagnosis or have just learned that their newborn has Down syndrome.

I was intrigued but dubious about what would come of this meeting. Since Henry's birth, in 2007, I've spent a lot of time with doctors. Thanks in part to excellent medical care, Henry is thriving. Nonetheless, my background in disability studies makes me skeptical of the way doctors tend to focus exclusively on the effects of individual ailments and ignore the overall physical and developmental well-being of a patient. Doctors are good at treating Henry's blocked tear ducts and ear infections, but they never think to ask what he's up to in his integrated preschool classroom, or how we've assimilated his therapy into our family life.

Lately, however, I've become interested in the field of narrative medicine, which takes a more sympathetic view of doctors. The idea here is that studying narrative--training doctors to read literature, to become more compassionate listeners and interpreters of the stories their patients tell--can make doctors better at what they do. To develop "narrative competence," doctors are encouraged to undertake self-reflective writing exercises to help them process the emotional residue left by confrontations with illness, pain, and death. As the parent of a child who needs medical attention, I'm attracted to the idea that my training as a literary critic might help doctors more capably realize the ideals of their own profession.

I brought these mixed feelings to the talk at St. Vincent's. The other mother spoke first. She described feeling devastated after receiving a prenatal diagnosis of Down syndrome, struggling to break the news to friends and family, and having to repeatedly justify her decision not to terminate the pregnancy. She said it meant so much to her when a doctor congratulated her on the birth of her son.

A youngish resident broke in: "Excuse me, but I need to say something. You're telling us what to say and how to act. But I don't think you understand. We're dealing with the shock of this birth, too." His voice rose. "Before you had this baby, did you ever know someone who was pregnant with a baby with Down syndrome? We don't see this every day. We have feelings, just like other people."

Another resident jumped in to chide her colleague, telling him that his feelings shouldn't influence how he treats his patients, who need his compassion and medical expertise. Others chimed in. Everybody was talking at once. The presentation had been completely derailed. By the time I looked up, the hour was almost over. I had planned to read from the memoir I'm writing about parenting a child with a disability. Instead I had only minutes to summarize the contents of my carefully written pages.

Afterward, the hospital administrator who organizes the lecture series apologized. But it occurred to me that I'd learned something important: The students were not ready to hear my story. The agitated young resident had made it clear that his training--focused as it is on curing and preventing illness--leaves him unprepared to handle his patients' shock, pain, and grief, or to cope with his own emotions. As an obstetrician, he sees more joy than tragedy. But pregnancy involves many unknowns, and the unexpected discovery of disability in a fetus or an infant can be devastating. At those moments, new parents need the sort of empathic care that narrative medicine is designed to teach.

According to Rita Charon, director of the Program in Narrative Medicine at the College of Physicians and Surgeons at Columbia University, health-care professionals are increasingly dissatisfied with the conditions

of medical practice in the United States. The humanities offer doctors a way to connect with patients and the ethical principles of their profession. And doctors aren't alone in believing that literary techniques can enhance their interactions with patients. Narrative medicine has sparked interest among professionals in other fields where storytelling matters, like law.

It's time for literary critics to reconsider narrative's capacity to teach us about humanity, compassion, and responsibility. Those virtues might sound quaint in the halls of a Modern Language Association conference, but I sure as heck want to find them in any doctor who treats my child. Practitioners of narrative medicine can also learn from disability studies' concern with the social dimensions of disease and impairment. "Narrative competence" should pertain not simply to individual stories of suffering, but to the broader social contexts that produce disability. This would mean, for example, not only hearing a patient's complaints about the symptoms of multiple sclerosis, but also considering how she is affected by an environment of broken bus lifts and elevators, and by struggles with her insurance company and an unaccommodating workplace.

In the humanities, we're constantly struggling to defend what we do to administrators, trustees, and taxpayers. Here's an opportunity to directly affect the quality and effectiveness of medical care and perhaps other professions as well. Of course, given the broken state of health care in the United States, it's hard to say how many doctors--no matter how good their intentions--will be able to administer such care. But for the future health of my child--and my profession--I have to believe that it just might be possible.

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