Giving Pain a Voice: Narrative Medicine and the Doctor-Patient Relationship

Mary T. Shannon, MSW, MS

Portland, OR, USA.

> *"The good physician treats the disease; the great physician treats the patient who has the disease."*
> *~ William Osler, 1849–1919*

We stood huddled in a circle at the nurse's station—medical students, nurses, bioethics interns—listening to a bearded, big-bellied physician as he conducted ICU rounds. I was the newest bioethics intern in the group.

"Let's move on to bed 3," he announced, and we followed him down the hall to stand outside a patient's room, where he drilled the medical students on the basic science and physiology of the patient's disease, questioning lab results, reviewing organ systems, ordering new labs.

"Let's move on to bed 5," he said, repeating the same drill as before. "Let's move on to bed 7, bed 9."

As each case was reviewed, I listened for the patient's name or other identifying information, but all I heard were disease names, bed numbers, and lab results, as if the disease and its treatment were somehow separate from the person they inhabited. I found it difficult to concentrate, for there was no face, no body with which to link this information—only the sound of the physician's voice, and the incessant beeping of high tech machines in the background. No mention was made of the context in which these diseases dwelled—the person's family situation, particular culture, religious beliefs, or unique understanding and experience of disease. I looked up at the clock. It was 8:30 a.m. An hour and a half had passed. In that time, my knowledge of certain disease processes had grown, but the individuals experiencing the ravages of these diseases remained a mystery.

We were nearing the end of rounds when the patient in "bed 9" began moaning—a long, mournful sound without words that sent a chill up my spine. The physician spoke louder as he reviewed the metastatic pattern of the man's cancer. When the man moaned again, the physician spoke louder still. With each moan I clutched my notebook even tighter—its metal coils digging into the palm of my hand as I turned to steal a quick glance at "bed 9."

Lying under crisp, white hospital sheets was a pale, thin elderly man. Fluorescent ceiling lights cast a too-bright glow around the tubes coming from his nose and arm. Strands of thinning hair fell over his forehead in a boyish sort of way, and suddenly I imagined him as a young man in his twenties—the same age as my son, healthy and pulsing with life. I wondered what this man's life had been like—if he had any family or friends to stand by his side as he battled his cancer. He began moaning again, even louder this time. The physician raised his voice once more; almost bellowing over the man's anguished cries.

"Why is he *moaning* like that?" asked a dark-haired nurse in an irritated tone.

The man continued to moan, the physician continued to bellow over him, and all the while not one nurse, doctor or bioethicist ventured into the man's room to touch his hand or stroke his head—offering the kind of 'comfort care' that we were supposedly there to provide. I knew the physician's role was to elucidate the science behind the disease, but wasn't it also his role to acknowledge and care for the person behind that disease?

As I stood frozen in that bleak hospital unit, my mind raced. I wanted to speak up on the patient's behalf, demand that he be recognized and attended to, but I was afraid—afraid that as a non-physician, my voice would be disregarded. Even as the man in "bed 9" continued his struggle to be heard, I continued my struggle to stay silent. By the end of rounds, no voice but that of the physician had been heard.

As the day dragged on I couldn't stop thinking about all the patients who, like the man in "bed 9," were unable to speak up for themselves—about how much we might have learned if the physician had given voice to the *patient's* narrative as well as that of the disease. I also wondered what happened to the patients who, like me, didn't feel their voice would be welcome or taken seriously and chose instead to remain silent. Without the patient's voice, the doctor-patient interchange lacks authenticity and is at best an empty relationship—one of form but not substance.

Unable to sleep that night, I lay thinking about the Narrative Medicine Master's program I'd recently completed at Columbia, where patient's stories of illness were honored and respected as primary conduits to more humane, more ethical, and even more effective medical care. I got up and rifled through my files until I

J Gen Intern Med 26(10):1217–8
DOI: 10.1007/s11606-011-1702-0

found a paper I'd written about the transformative power of telling and listening to the plight of another, how this simple yet profound act can change a life for the better, even in the face of death. It was based on an illness interview I'd done with Pat, a woman suffering from ovarian cancer, and as I sat down to read it, I could still see the rainbow-colored baseball hats hanging from her living room wall, each dotted with sequins that sparkled like jewels in the late afternoon sun. I remembered how she'd perfectly spaced them to form a large floor to ceiling rectangle, reminding me of a totem—a symbol of her hard-won fight to stay alive amidst the ravages of an aggressive cancer, and yet it was only three years before that she seriously contemplated suicide.

"I was suicidal until I got cancer," she'd told me, without shame or embarrassment. In fact, it wasn't until Pat was a year into her disease that she experienced what she termed a transformation, one that occurred in relation to her doctor. "Dr. Fleischman came in and he sat down, and for the first time he was relaxed…I mean, I was a star patient. I was not dying on him. So he said, "Okay, here's the plan. I'm gonna see ya every two months for the first two years, every three months for the third year, every four months for the fourth year, and the fifth year, we'll do every six months that year, and then we'll see where you're going." I almost cried….I mean, I was thrilled. And I realized, somebody cared. Somebody was going to take care of me. Somebody had a plan for me…..it struck me how somebody cares, just because I'm alive. And it was the most astounding moment."

Since that moment, Pat said she'd never been happier, and over the course of her treatment, had become friends with Dr. Fleischman. She spent a great deal of time helping to raise funds for his research into early detection, and was passionate about this effort. When asked if she thought the genuine sense of caring she received from him was the primary reason for her transformation, she replied: "You know, it has to be him. Bottom line—my trust level has been beyond a hundred percent."

It wasn't until after this interview that I fully realized the centrality of the doctor–patient relationship, which connects the experience of illness with narrative meaning powerful enough to impact a patient's course of treatment and quality of care far beyond what one would imagine. Pat's voice was not only welcomed by Dr. Fleischman, it was embraced. He provided a safe haven for her fears and anxieties—a trustworthy container for all the shifting emotions borne from the experience of illness. It is here, at the juncture of self and other in the clinical encounter, where we risk exposing ourselves, hoping the physician standing before us will look past the edge of our wound, listen past the edge of our silence, and hear our pain.

The self is the physician's most important therapeutic tool, for the healing that comes from sitting by a patient, leaning forward and listening fully—without interruption or ready judgment—often goes beyond any cure. While listening for the nuances of a patient's story, to what the body—and person—are saying, a relationship of authenticity and trust begins. It is a relationship which may also require the physician to make himself transparent, to move beyond the white coat to a shared, frail humanity—to be "seen," so that in turn, he may "see" ever more clearly.

Our lives unfold through relationship, and it is within those relationships where we gain meaning, creating an ever-evolving narrative where new truths and perspectives are found. I will never know the name of the man in "bed 9," nor will I know what happened to him, but I do know that in silencing my own voice during rounds that morning, I lost my ability to be a voice and an advocate for him. I now see that while honoring a patient's story, I must also honor my own story, and in so doing, move toward becoming a better provider, a better colleague, and a better human being.

Corresponding Author: *Mary T. Shannon, MSW, MS, Portland, OR 97205, USA (e-mail: marytshannon@comcast.net; URL: www.marytshannon.com).*