

Personalizing Medicine: The Need for a Companion to Gray's

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So many unexpected events can alter the course of a life. For me it was an illness. A few months after finishing my dermatology residency, I was diagnosed with a life-threatening blood disorder and would need a bone marrow transplant. Overnight I went from being a doctor to being a patient. And though I would metamorphose back again, I would never be the same, surely not the same doctor.

Now 15 years later, much healthier, happily married with two beautiful boys, and enjoying my chosen profession, I am still consumed by the discoveries – also very much unexpected – made during my journey to the land of the ill.

Becoming sick, I found out, isn't just a matter of the body breaking down. It involves the breaking down of one's entire being. Beyond fever, headaches and pain, there is also anger (why me?), fear (what will happen to me?), shame (what has become of me?), and vulnerability (why do I feel so helpless and alone?). These extra-physical symptoms of illness changed the way I saw myself, affecting everything important to me, my career, marriage, friendships.

I also discovered that when a sick person becomes a patient, when he enters the medical system, the breakdown of self often accelerates. Much of the time during my illness, I felt less than human, almost invisible. The well-being of my bone marrow took precedence over the well-being of me. Many doctors could barely hide their excitement at encountering a "great case"; they mumbled in jargon and rifled off statistics while I could barely think straight; they poked and prodded and talked about me as if I weren't there; and one practically abandoned me when I chose a treatment he didn't agree with. In the end, medicine might have cured my body but in the process, further diminished my damaged psyche, which would take years to recover.

Returning to the considerably more sustaining role of doctor, I became aware that my discoveries weren't unique. All patients feel the same as I once did, at least to some degree. And more and more, they're speaking up about it, in the exam room, on the Internet, and in essays and books. They want to clarify what illness means to them and they want doctors and the rest of the world to listen for a change. John Updike, for example, was bothered by the tenderness and smell of his scabby, alligator skin, but the humiliation of living with psoriasis as a

child and later as an adult hurt even more.¹ Lucy Grealy suffered from cancer and its treatment, but the worst pain of all, the pain that drove her to suicide, was the isolation and loneliness.²

Yet what is forefront in the minds of the ill is completely opaque to the people who care for them. In their myopic focus on the physical (disease), doctors are oblivious to the far reaching effects disease has on the person (illness). And because of this ignorance, they not only routinely fail to alleviate the suffering of patients but often exacerbate it.³

Medicine's rationalization, of course, is that as long as it could repair the primary problem to the body, the collateral suffering will resolve in due course. This is true if the repair is swift and definitive. The problem for many patients, however, is that such outcomes are often unattainable. Most medical conditions, especially as our population ages, are chronic and incurable: psoriasis, rheumatoid arthritis, coronary heart disease, even cancer. For patients with chronic diseases, focusing on the body will always be incomplete. They need so much more: strategies for coping with the uncertainties of illness, for finding hope in desperate situations, for repairing broken egos, and for alleviating loneliness. Doctors will not likely be able to provide *all* these measures to *all* patients, but at least they can do their share and not make things worse.

Initially, I thought that the recent outpouring of stories by patients chronicling their harrowing experiences would serve as a wake-up call – stories by famous patients like John Updike and Oliver Sacks as well as stories by not so famous ones, like mine and many others.⁴ But doctors don't listen very well and besides their medical journals, don't read much either. I thought too that the introduction of humanities courses into the medical school curriculum would help. At SUNY Downstate Medical Center in Brooklyn, we offer electives in literature, ethics, and history of medicine. But while well-attended and appreciated, these courses aren't nearly enough.

If we truly want doctors to expand their perspectives, then more systemic changes will be necessary. Medical school admissions committees must reevaluate their criteria; emphasis should be given not only to candidates' scientific skills but to their awareness of the suffering of others and commitment to alleviating it (as evidenced, for example, by their interest in the humanities, their

volunteer work, or their own experiences with illness.) And curriculum committees must find ways to teach students, from the very outset, about what living with illness is really like.

I envision a major first-year course standing side by side with anatomy. This different kind of anatomy would require a textbook like the fabled *Gray's*, but instead of mapping out the human body, it would map out the emotional landscape of illness, showing in meticulous detail how disease plays out on multiple levels of human existence simultaneously: disrupting the body, then the person, then the person's place in the world. And instead of cadavers, it would require live patients with whom young doctors could interact, allowing them to marvel at (and memorize) the interconnectedness of these disruptions – and the courage with which patients struggle to preserve their identity in the face of them⁵ – just as they marvel at the exquisite intricacy of the cranial nerves and their insertions in the other anatomy course.

In forgetting its roots and purpose, medicine has lost its way, has become in fact ill itself, steadily eroding its effectiveness in managing the illness of others. No longer present at the bedside, meeting the sick on their own terms, taking their hands, medicine now stands outside

the door, coldly looking in from the distance, and seeing only a fraction of a much larger picture. Only by reacquainting doctors with the rest of that picture, with the living, breathing, suffering person beyond the sick body, could they recover their lost and ailing skills and become better healers again.

¹Updike J. “At War with my Skin” in *Self-Consciousness*. (New York: Fawcett Crest, 1989), 42–80.

²Grealy L. *Autobiography of a Face*. (New York: Harper, 1994), 37, 177.

³See Cassell E. *The Nature of Suffering and the Goals of Medicine*. (New York: Oxford, 1991), 28–65.

⁴Biro D. *One Hundred Days: My Unexpected Journey from Doctor to Patient*. (New York: Pantheon, 2000).

⁵In *The Man Who Mistook His Wife for a Hat* (New York: Touchstone, 1998), Oliver Sacks rightly protests medicine's emphasis on disease, especially neurologic, as deficit or loss. Instead, following Ivy McKenzie, he urges physicians to also focus on the inevitable and positive reactions to those losses: “There is always a reaction, on the part of the individual, to restore, to replace, to compensate for and to preserve its identity. (p.6).”



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