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Guest Editorial: Bridging the Gulf



A friend once asked me to participate in a film she was making about doctors who had spent some time as patients. Ruth Drazen was curious about what happened when the tables were turned (Drazen, 2011). One of her most unexpected findings was how little doctor-patients like myself knew about being ill. Despite our years of studying medicine, our years spent talking to and treating the sick, we were startlingly ignorant about what it was like to live with illness. How was that possible? Even more troubling, if we were indeed ignorant in this regard, then how could we be truly effective in serving our patients.

The problem seemed to hinge on perspective. “They are and suffer,” wrote W.H. Auden of the sick; “we stand elsewhere,” he wrote of the healthy (Auden, 2007). While both health care provider and patient may be grappling with the same entity, they do so from completely different vantage points. One lives with disease, feels it in every bone of his or her body, and experiences it in the 1st person; the other observes it from afar, in the 3rd person, clinically and dispassionately. There is the case study of a patient with paroxysmal nocturnal hemoglobinuria published in a medical journal on the one hand and the memoir of David Biro’s experience on the other (Biro, 2000). They are nothing alike.

Health care providers are trained to focus on what can be perceived, quantified, and articulated, the outward manifestations of disease: signs such as fever, cough, and pain (in terms of the Faces or numeric pain scale) and tests that include bloodwork, EKGs, and MRIs. When you become ill, however, the public, shared world shrinks in importance. What matters much more are events taking place inside the body, their deeply personal and subjective nature, and the effects of those happenings. Life is lived beneath the bandage and all else pales in comparison—“For who when healthy can become a foot?” (Auden again). “To the typical physician,” wrote Anatole Broyard, “my illness is a routine incident on rounds—while for me it is the crisis of my life” (Broyard, 1992).

As I and many other doctor-patients come to learn, the crisis of illness encompasses not merely fever, dyspnea, and malaise but a host of deeply felt emotions that contribute to suffering. There is anger and fear: What is happening to me now and why? What will happen tomorrow? Will there be a tomorrow? Beyond the uncertainty, there is shame and stigma;

even when the disease is not overtly disfiguring, patients feel different and alienated from others. One’s sense of self is often shattered; patients feel diminished and broken. Most distressing of all, however, is the loneliness of illness: “Nothing is quite so isolating as the knowledge that when one hurts,” wrote Robert Murphy, “no one else feels the pain; that when one sickens, the malaise is a private affair; that when one dies, the world continues without barely a ripple” (Murphy, 1990).

In a real sense, the two perspectives are mutually exclusive; the healthy doctor, even the healthy doctor-patient, cannot see illness from the outside and the inside simultaneously. But that does not mean that providers cannot try to shift vantage points from time to time to bridge the gulf. Knowing what it is like on the other side, being familiar with the entire emotional landscape of lived illness would help. That is why education is critical. I once wrote about the need for a companion course to Gross Anatomy in the medical curriculum, an Anatomy of Illness, in which the voices and experiences of patients—culled from movies like Ruth Drazen’s, illness memoirs, chat rooms, and other sources—are studied in as systematic and rigorous a way as the cranial nerves and the pathophysiology of disease (Biro, 2010a).

This kind of study will clearly show that patients’ priorities are not always aligned with those of providers; that patients’ needs often go unmet; and worse still, that on occasion providers can exacerbate patients’ suffering through their blatant lack of understanding. Instead of standing elsewhere, providers can reach out to patients who feel isolated. Providers may not be able “to become a foot,” but they can ease the turn inward by listening to patients when they try so urgently to express themselves. When language runs dry, as it often does in illness and especially in pain, providers can encourage patients to use more figurative language, imagery, and metaphor, that would help make their interior worlds more visible (Biro, 2010b). Providers can also work to restore a level of control to patients’ lives and help buttress their diminished sense of self.

Medicine should offer the sick more than antibiotics and chemotherapy. The compassionate words and actions of practitioners, versed in the lived experience of illness, would enhance medicine’s healing abilities.

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David E. Biro, MD, PhD, FAAD*
Clinical Associate Professor
SUNY Downstate at Brooklyn
Brooklyn, NY

* Corresponding author: David E. Biro, 9921 Fourth Avenue,
Brooklyn, NY 11209. Tel.: +1-718-833-7616.
E-mail address: bayridgederm@aol.com.

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