



What Health Reform Forgot:

Patients often get scant consideration, as one doctor learned from his own illness.

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By David Biro

In his characteristically inclusive way, President Obama invited all the interested parties to help him find a solution to the health-care crisis: insurance companies, pharmaceutical companies, hospitals, doctors, lawyers.

But there was one notable absence: the patients, the group supposedly at the center of all these efforts. Wouldn't it make sense to solicit their input on improving the health-care system?

Then again, I'm not surprised by the slight. Whether it's in the Oval Office, a hospital, or a clinic, the patient is present only in the most marginal ways - a sick body, a case, a number. Patients are rarely addressed as people with real feelings, and rarely heard as people with something to contribute.

I know this not from my experience as a physician, but from my experience as a patient - as well as from teaching medical students about the human side of medicine.

Years ago, I developed a rare, life-threatening blood disorder that necessitated a bone-marrow transplant, a procedure that had come of age only a decade or so before my diagnosis. Although I was grateful for the high quality of care I received, I was profoundly disturbed by the way it was delivered.

The well-being of my bone marrow took precedence over the well-being of me. Many doctors could barely hide their excitement at being in the midst of a "great

case." They mumbled jargon and rattled off statistics while I could barely think straight. They poked and prodded and talked about me as if I weren't there. One of them practically abandoned me when I chose a treatment he didn't agree with.

In the end, after a hellish year, medicine had cured me of my disease and saved my life. But it would take many more years before I recovered from the toll the experience had taken on my psyche.

When my students and I consider the stories of patients like me, we find that illness has a tremendous reach. While it begins in the body, it quickly spreads to involve the entire person and his or her standing in the world. 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 lonely?).

These extra-physical symptoms alter the way patients see themselves, affecting their careers, marriages, and friendships. Somehow, some way, they need to be addressed - and surely not aggravated - if we hope to alleviate suffering.

I don't believe the problem lies with individuals; many of my fellow doctors are well-intentioned and compassionate. Rather, it's the system's exaggerated focus on the abstract at the expense of the personal.

Medical school trains doctors to diagnose, treat, and cure the sick body. Medical practice is increasingly informed by evidence-based algorithms. Insurance companies and, to a lesser degree, the government promote efficiency and cost-cutting measures.

These are all clearly important considerations, but the balance is totally out of whack. The abstractions threaten to stamp out every trace of the sick person. I'm not just an inventory of physical symptoms, or a stage 2A breast cancer, or a \$10 co-pay, I and my fellow patients would tell the president if we were at the health-care reform table. The system is cold, dehumanizing, and humiliating. How can it begin to help us if it doesn't really understand what ails us?

I still have high hopes for Obama's plans for reforming health care. There are also some positive developments taking place on this issue inside medicine (the growing number of courses like the one I teach and other, more systemic improvements in medical education) and outside (the growing number of patients and advocacy groups clamoring for change).

Perhaps, in the second and third waves of reform, more attention will be paid to the concerns and needs of patients. In addition to insuring the 40 million

Americans without insurance and reducing the costs of health care, the interested parties should also strive to make the system truly better at healing not just sick bodies, but sick people.

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