

Who's Afraid of the Empowered Patient?

HERE, FEEL THIS," MY FRIEND SAID, LIFTING HER SHIRT. Under my fingers, in her 41-year-old breast, was a rock-hard mass.

After a hellish 6 months of crippling nausea, fatigue, and the amputation of one of her breasts, Shelly (not her real name) felt battered, poisoned even, by her wild ride through the medical machine. She wanted a new breast, a good one, and she hoped her research would help her get one. She learned about the TRAM flap, implants, and a newer procedure called the DIEP. The TRAM flap, which uses abdominal skin and fat to create a breast, would require the sacrifice of all or part of her rectus abdominis muscle. The DIEP, on the other hand, would preserve her abdominal muscles and allow for a quicker recovery. She had consulted her support group, her sister the nurse, her friend the physician, and, of course, the Internet. She knew what she wanted—the DIEP procedure—and she had dutifully followed the steps to get it—a referral to an in-network plastic surgeon, weeks of waiting, then baring her misshapen chest to the studying eyes of a stranger.

"We'll do a TRAM flap," the surgeon said brusquely, not leaving room for dissent. "What about a DIEP?" Shelly asked, more meekly than she intended. "No. You should have a TRAM flap," the surgeon said. Case closed.

She called me, her doctor friend, crying. "Why won't he do a DIEP?" she asked with a quivering voice. Then she sobbed more than she had after learning she had cancer. This was about more than a procedure. She had given up so much—her flesh, her hair, her dignity. Her battered psyche was fighting to regain a crumb of control. Her hours of research, discussion, and ultimate decision about her reconstruction procedure were symbolic of a woman taking back control of her body and her life. With a dismissive "No," her surgeon had pulled the rug out from under her shaky feet and left her in a withered heap on the ground.

"I'll bet he doesn't even do the DIEP," I said. "What?" she asked incredulously. "Wouldn't he have just said that?" I was feeling cynical. "Maybe. Maybe he would have told you, or maybe he just wanted you to have the procedure that he knows how to do. Why don't you ask him?"

That conversation didn't go well. The surgeon didn't feel like being challenged by this "empowered patient" and didn't bother to hide his irritation. "I don't do that procedure and neither does anyone else in the network, so you can't have it," he said with annoyance. What he didn't say was "I don't do the DIEP, but I know a great doctor who does. He's out of network, but since there isn't anyone in network who does it, your HMO will still pay." Why, in honor of physicians everywhere, didn't he say that?

The most cynical among us might guess that it was all about money. After all, if he referred her to another surgeon he couldn't bill for his services. I disagree. I think that to understand this disordered interaction we need to look deeper into the shadows, to see the threatened ego and the battle for control. My friend was trying to steer the health care encounter to meet her needs, but her surgeon wrestled the steering wheel from her hands in order to meet his own need for control.

It would be easy to judge him. We would be more accommodating, more caring, right? Perhaps. It is woven into our self-concept that we put our patients' needs above our own, but is that really what we do? We do give up sleep, meals, and family time, but how readily do we give up control? For people facing serious illnesses, the profound loss of control of their bodies, their lives, and their future is a significant source of suffering. We have the power to give back some of that control and ease their suffering. But we can be stingy.

Yet patients can be stingy too—stingy with their respect and their gratitude. For all our hard-earned knowledge and personal sacrifice, don't we deserve a little reverence? Of course we do. However, whether we deserve it or not is irrelevant because times have changed. Patients are no longer passive and adoring, and our relationship is no longer hierarchical and paternalistic. It is when we see this change as a demotion, rather than as an evolution, that our hackles get raised.

Rather than being impressed by their patients' empowerment or inspired by their quest for wellness, some physicians are suspicious and occasionally blatantly hostile toward patients who demand an active role in their health care. We physicians enjoy our kingdoms and we don't take kindly to challengers. Yet the occasional physician who embraces her patient's empowerment often discovers a gem—a patient who is engaged, adherent, and motivated to get well.

A truly empowered patient is the ideal patient. Empowered patients will challenge us, yes, but they will also take their medicine and go for their tests. They will ask when they don't understand our instructions rather than simply ignoring them. And, most important, they will be more likely to get well, which will make us feel successful.

Are some of them bossy and overbearing? Absolutely. Some patients attack our suggestions, question our wisdom, and doubt our compassion. In their misguided at-

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tempts at empowerment they manage to alienate the very people they are paying to make them well.

Often their attitudes clash with our egos and communication breaks down. They insist and we resist. Their frustration feeds our annoyance. The irony is that we, patients and physicians, have the same compelling goals. We both wholeheartedly want a healthy and satisfied patient. Yet we often find ourselves firmly planted on opposite sides of the health care fence. We tout evidence-based medicine, but our patient wants Reiki. We suggest a local oncologist, but our patient wants a national expert. We wish for patients who respect our knowledge and skills, yet we get ones who demand inappropriate antibiotics and plunk piles of Internet printouts on our desks.

Is there a solution? Can physicians and patients get back on the same team? I think we can.

Just as in any relationship, it is not as much what you say as how you say it. "My last doctor always gave me antibiotics for this" is irritating and hostile. But "I'm going on va-

cation next week. Could I have an antibiotic that I'll only fill if I'm not better by Monday?" isn't as bad.

Behind the brash tough-guy patient is a frightened person who has been robbed of his health and safety. What may seem commonplace to us, like cancer, diabetes, and heart disease, are life-altering experiences for our patients. Offering humanity and quiet presence along with our knowledge brings comfort. A patient grasping for a shred of control as his health spirals downward isn't trying to annoy us. He is simply doing the best he can.

Empathy is contagious. Perhaps as we acknowledge our patients' need for control they will understand our need for respect and trust. As collaborative partners we will be stronger. We will strive for medical excellence, rekindle the patient-physician relationship, and, most important, bring the heart and soul back into medicine.

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Literature is a form of permanent insurrection. Its mission is to arouse, to disturb, to alarm, to keep men in a constant state of dissatisfaction with themselves.

—Mario Vargas Llosa (1936-)