



Tying Patients to the Battlements

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TYING PATIENTS TO THE BATTLEMENTS



At a recent meeting, an attorney for a national cancer group suggested that those of us involved with cancer issues need to "avoid tying cancer patients to the battlements." He was suggesting that the involvement of patients in lobbying was a cynical tactic that should be avoided. I'm not so sure.

Peter Barton Hutt, the sometimes laconic, frequently explicit, former FDA attorney, questioned me closely at one of the Lasagna Committee hearings, asking, "Why can't those of you involved with millions of cancer patients mobilize them as effectively as the AIDS lobby has mobilized far smaller numbers of patients?"

Peter's question was rhetorical; he knows the differences between the two groups of patients and the consequent difference in their level of involvement in lobbying efforts. Yet, as I've been thinking about this, it seems to me we need to be a little less presumptuous and automatic in our responses. Sure, it's outrageous to further victimize cancer patients. Using them to get higher profits for the pharmaceutical firms is very cynical, if that's what we're doing. Is that what we're doing?

If, instead, we are trying to get new innovations to patients more rapidly, to make certain that new technology is not suppressed by reimbursement constraints, and to ensure that corporate America has continuing incentives to fund new research, then we are lobbying for the same things AIDS coalitions are seeking: ways to knock down the artificial barriers that impede the use of technologies that have the potential to save lives. The issue that has us checking our consciences regularly is the fact that when patients don't get covered for their treatments, their health care providers (physicians, hospitals, etc.), as well as pharmaceutical and technology manufacturers, all suffer economically. Thus, we all worry about appearing too self-serving, but we all worry more about not having any hope for the future.

Still we are presumptuous about involving patients. This is not a decision we should make on their behalf; it is one they should make for themselves. Given their past track record of noninvolvement, we might conclude that they have made their choice, but I believe caution may be required. AIDS patients start out cautious about establishment values and business as usual. The media has alerted them to the fact that their disease is tantamount to a death sentence. The clock is ticking, and there is a sense of urgency. Cancer patients, by and large, are part of the establishment and tend to support the system. The media and the medical profession (that's us), have spent a good deal of time and money disabusing them of the idea that their disease is a death sentence. The way we react to many of the controversies facing us today is to deny a sense of urgency.

Old firebrands like Jay (Emil) Freireich don't put up with this crap. I bumped into Jay a few years ago at a conference announcing how the new Treatment IND process would work. Jay was delighted. With a twinkle in his eye, he told me he hoped this would be a new way around the barricades that had been erected over the past two decades to slow down innovation.

We are treating the fact that most patients with advanced disease are going to die like a terrible secret that must be kept from those patients. Of course, oncologists have become jaded, waiting for the discovery of the magic bullet(s). Why give patients false hope? Why depress them? Presumptuous.

What we need to do is tell America that too many cancer patients still die. We need to point out that the next decade holds significant promise, if we don't screw it up. And then we need to invite patients and families to join us on the ramparts. This is not just our fight on their behalf; this is their fight. It is not just our ability to hope for the future that is at stake, but the knowledge that today's patients may help those who come after.

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