When I was young, most doctors refused to tell terminal patients that nothing more could be done. They would lose hope, the rationalization went. Anxiety or depression would make them suffer more than ignorance. No one, of course, wants to be the messenger of death or face the slippery slope that candor can evoke—painful discussions of what might have gone wrong, witness to tears and fears, troubling questions about the meaning of life. In my family, such silence resulted in intense misery. A father saying nothing about the tumor that inexorably enervated him; a young mother spinning webs of deceit; a son raging against his enforced ignorance when the truth came out... as it usually does.

Although individual variations persist, things have changed. Today, medicine has discarded the norm of evasion and deceit. As we enter the age of electronic medical records, with access to patient information almost a civil right, it is good to remember that communication patterns change in ways that reflect different community expectations and values.

I remember this history when I hear doctors object to making lab reports or visit notes available to patients because they may cause pain and anxiety. No doubt they will in some cases, but then pain and anxiety are part of the human condition and are as likely to be produced by a sense of ignorance and powerlessness as by knowledge. The difference turns on who decides. People have myriad ways of protecting themselves from things they don’t want to know. Making information freely available doesn’t necessarily mean that patients will be forced to learn what they’d rather ignore. The Internet is a model here: Some people devour the plethora of medical information; others avoid it like the plague. If any generalization suffices, to treat patients like adults requires that we, not a well-meaning social reformer to realize that any system failing to take technological capacity into account will disproportionately exclude the poor and the aged, as well as have a potentially disparate impact on minorities. For notes and records to be truly open, ways must be found to include patients who are not computer-based. A related problem, real but manageable, is how to deal with the mentally ill or other persons who are unable to take advantage of the available information. A final concern may present the greatest difficulty. Greater knowledge about one’s medical situation has a potential, physicians will have to make sure they don’t overstep the bounds of their power, whereas patients will have to take more responsibility for what they know and do and, have an informed patient, one who can correct errors, clarify confusion, understand the effects of medications, and be able to discuss specific treatments with family and friends? If a greater flow of information is a valuable adjunct to improved care, including patient adherence to instructions, then using terms laymen can grasp is worth the effort. Obviously, it’s an effort that must engage medical educators who will have to help free future doctors from jargon and technobabble.

Doctors may fear that openness will lead to lawsuits, but there is no credible evidence that patients will rush to the courthouse. Secrecy, and a sense that the doctor is distant or indifferent, stimulates litigation as much as a free flow of information. If that flow improves trust, the likelihood is fewer lawsuits. Make no mistake: Previously dormant errors will be uncovered—that’s the way with more information. But to the extent that those errors are substantial, a profession that prides itself on correcting mistakes can hardly oppose broadening the opportunity to expose them.

Another aspect of greater access to medical records is a distributive issue that will trouble administrators and planners as much as doctors. Data available through interactive hospital-based sites or e-mail are presently accessible only to patients who have access to computers. It doesn’t take a social reformer to realize that any system failing to take technological capacity into account will disproportionately exclude the poor and the aged, as well as have a potentially disparate impact on minorities. For notes and records to be truly open, ways must be found to include patients who are not computer-based. A related problem, real but manageable, is how to deal with the mentally ill or other persons who are unable to take advantage of the available information. A final concern may present the greatest difficulty. Greater knowledge about one’s medical situation has a strong tendency to level the playing field. My mother went along with the recommendation of my father’s doctor in part because in those years you did not question what a doctor told you to do. No doubt there is a secondary benefit to patients in such a world because it’s only a short step from acquiescence to belief that the problem has been turned over to the professional. But we now know that such beliefs are deceptive and unhelpful. To be sure, most decisions have to be made by doctors, and wise patients are happy to let them. However, passivity robs patients of a wide range of steps that they, and only they, can take toward improved well-being. Not incidentally, patient involvement frees doctors from being thought miracle workers or failed miracle workers.

For an open system of information to realize its potential, physicians will have to make sure they don’t overstep the bounds of their power, whereas patients will have to take more responsibility for what they know and do and,
ultimately, for how their lives affect their health. Opening complicated systems to greater client participation always includes dislocation. Here, the benefits that come from a greater flow of information hold considerable promise for creating a healthier society, a result that is plainly worth the costs. Every few years in this country there’s a national crisis over accountability: the legal profession in Watergate; in recent years, banks and bankers. Open notes can stimulate a flow of information that leads to greater accountability on behalf of health care personnel, a development that in the end can only improve the quality of patient care.

When I started thinking about patient access to medical records, it was as a scholar with a history of work on health care issues. In the middle of the journey, I suddenly acquired a serious medical condition and, ironically, a strong personal interest in finding out what my doctors thought was the source and nature of my illness, the available options, my precise response to treatment, and what I could do to increase my chances of survival. Having experienced openness from the doctors I frankly did not fully expect, I am both confirmed in my views about the value of transparency and grateful that we have moved beyond the many grim days my family suffered from its absence.

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