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ESSAY

The Quest for Privacy Can Make Us Thieves

By **ROBERT KLITZMAN, M.D.**

"I stole it for my kids' sake," she told me, "so they will be able to get insurance." The woman had secretly removed pages from her medical record, tucked them into her pocket and left the clinic. Those pages contained information showing that she was at risk for Huntington's disease.

If a parent has Huntington's, a fatal genetic disorder, each child has a 50 percent chance of getting it, too. The symptoms include involuntary and uncontrolled movements and psychiatric and memory problems, usually starting when patients are in their 40's or 50's. The folk singer Woody Guthrie died of it.

This woman, treated in New England, had seen her mother die of the disorder and feared for herself and her children. She was concerned that the information, once in the medical record, would be seen by insurance companies and that her children might then be denied insurance in the future.

The clinic where her sons were born wouldn't fax her file to her; it was too big. She didn't want to pay for the chart to be copied and mailed. So she went to look at it herself.

"On every other page," she said, " 'H.D. risk' was written. My heart pounded as I read it. Then, I ripped out every page that said 'H.D.' "

The woman said she believed that her action was justified because she was going to see a new obstetrician-gynecologist rather than return to that clinic. She also contacted her general practitioner, who wouldn't delete the records but put an alert on the chart: "Don't fax this file to anyone without checking with me first."

The woman also discussed her fears at her first meeting with her new gynecologist, who agreed not to mention the disease in the chart.

But the woman's removal of information from the record bothered me. Did she have a right to

take it?

"The information belongs to me," she argued. "It's mine."

Most doctors would not like the fact that she excised pages from her chart. If a patient comes to a hospital with neurological and psychiatric problems, the doctors might find this family history helpful. If she had trouble in childbirth, some information on those pages might be useful.

I wondered how often such pilfering went on — and whether it would increase in the new age of [genetics](#). At some point soon, we will all be able to be tested for genetic conditions. People who are found to harbor genetic mutations may find that insurance companies will raise their premiums or deny them health insurance or long-term care insurance.

Genetic antidiscrimination laws vary by state, and federal laws apply to group insurance but not to individual insurance. Increasingly, savvy patients are wary, and they are talking with physicians about whether genetic data and other highly personal health information should be included in the record and how it should be done.

What if patients steal pages of the record for other reasons, like a history of [depression](#), drug or alcohol use, [abortion](#) or a [sexually transmitted disease](#)? Should patients have the right to remove pages from their charts?

I think not. Medical records are, after all, important clinical and legal documents. Yet no one had told this woman beforehand to be careful what she told her doctors, and she was upset by that. She felt that she had no choice but to take the pages, she said, and she was glad she did. But she also felt that the system turned some patients into liars.

"I'm having a hard time with my decision," she said. "I don't like stealing. And I don't feel I can talk to doctors fully now. I feel less safe."

I empathized with her. But doctors and policy makers need to ensure as much as possible that privacy is protected — and that discrimination is avoided. Perhaps others can learn from her actions, and doctors and patients can talk in advance about how important personal information will be handled.

In her case, one hopes nothing bad will happen. But now is the time for physicians, patients, family members and policy makers to consider these issues and to prepare to respond in the best way possible.

"You only have privacy if you make it yourself," she told me.

I hoped that that would not always be the case.

Robert Klitzman is a psychiatrist at Columbia University and a co-author of "Mortal Secrets: Truth and Lies in the Age of AIDS."

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