

San Francisco Chronicle, June 6, 2007

Open Forum

HIV testing should require consent and promise privacy

The lure of federal dollars may be prompting California lawmakers to consider an ill-advised law to make HIV testing routine. But there's nothing routine about testing for HIV, and legislative efforts to make it more common show little concern for the frankness of the doctor-patient relationship, or the insidious threats to patient privacy.

Assembly member Patty Berg, D-Eureka, introduced a bill in February to encourage routine testing for HIV by eliminating state requirements that patients provide written consent to the procedure. The bill was voted out of the Assembly Appropriations Committee on May 31 and is expected to come to a vote before the full Assembly later this week and possibly as early as today.

No lawmaker admits as much, but the effort may, at least in part, be driven by the new federal Ryan White Grant Program requirements that states provide the names of HIV patients -- not just anonymous numbers -- to the federal government in order to receive funding for state HIV programs. To maximize numbers, the bill absolves physicians of any need to obtain written consent or do pre-test counseling, and creates a presumption that the test will be done unless the patient specifically objects.

The U.S. Department of Health and Human Services announced late last month that three California counties (San Francisco, Marin and San Mateo) will lose \$8.6 million in federal funds under the Ryan White program this year, as funds are redistributed from urban to rural areas.

San Francisco was hit especially hard, so Sacramento lawmakers no doubt hope to identify as many patients with HIV as possible, because greater numbers mean more funds. If the law passes, the net result will be that patients are tested with no legal requirement that they've received an adequate explanation of the associated risks. In essence, the law would sweep the "informed" part of "informed consent" under the rug.

No medical care should be so routine that physicians are dissuaded from discussing with patients their individual needs and concerns. A patient should only be tested for HIV if and when a physician determines that it's appropriate in view of the patient's particular circumstances. Unnecessary tests are against the patient's best interests, are likely to create mistrust and could discourage people who might need to be tested from seeking crucial medical care.

Furthermore, when doctors decide testing is appropriate, their patients need to know about the various testing options, the chance of false positives and the parties to whom the results will be disclosed. These are the sorts of things doctors discuss with their patients during the informed consent process. The only logical reason to eliminate counseling and written consent is a fear that the knowledge learned might dissuade patients from consenting in the first place.

The California bill states that documentation and disclosure will be made in accordance with existing state law, but how is that confidentiality to be assured if the Ryan White program requires states to identify HIV/AIDS patients by name? The answer is that it won't. In April, Gov. Arnold Schwarzenegger signed into law a bill sponsored by Sen. Nell Soto, D-Pomona, that eliminated the state's confidentiality protections. No more anonymous privacy codes, just each patients name clearly printed on the HIV test results.

Loss of confidentiality is a real risk, and a real concern. Florida implemented the Ryan White requirements early, and in 2005 a Palm Beach health department employee inadvertently sent 800 employees an internal e-mail containing a list of about 6,500 HIV and AIDS patients. Once the cat was out of the bag, it is hard to know how many of those 800 employees shared what they had learned with spouses and friends or even others.

Reports of HIV patients suing their doctors for inadvertent disclosure to insurance companies and employers are far from uncommon. The fact that the disclosures are illegal is beside the point. The sheer volume of data that doctors need to report to state and federal agencies all but assures such blunders will occur.

The easiest way for states to get as many names as possible to meet the new Ryan White requirements is to make HIV test results a routine entry in patients' charts, whether or not patients understand the consequences of being tested or not, whether physicians believe the tests are necessary or not and whether such testing is even in a patient's best interest or not.

HIV testing is not like cholesterol testing. People don't worry about their cholesterol levels becoming public or about being stigmatized for their cholesterol status. Federal and state governments introduced confidentiality rules and anonymous testing policies to reassure patients that their privacy would be respected, in hopes of encouraging them to choose freely to risk the loss of privacy and get tested. Eliminating privacy protections and testing routinely could cause those who most need to be tested to avoid medical treatment altogether.

It's bad enough for a state government to decide that it wants to protect people from themselves by making medical choices for them. It's all the worse when that supposedly well-intentioned paternalism is really a ploy to dip into federal coffers.

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