Letters

Correspondance

A step toward putting a genie back in its bottle

The new rapid HIV test[1] may play a part in putting the genie of a lethal infectious disease back in the bottle. In the United States, at least, people who feel they are at risk can go to a local pharmacy, obtain a home HIV test kit and send a capillary blood sample away to a private laboratory. While a positive test result requires further confirmation and a trip to their local physician, a negative result preserves their autonomy and privacy. As suggested in a *CMAJ* editorial,[2] this would lead to earlier detection and treatment of HIV infections. If this prevents transmission of the virus to others it is certainly a step in the right direction.

While Richard Elliott of the Canadian HIV-AIDS Legal Network and others stress the value of pretest counselling,[1] it has been obvious for years that elaborate pretest counselling as advocated in the Canadian Medical Association guidelines[3] has been an effective roadblock to HIV screening. The harms of counselling (both to patient and physician) were not considered in the rush to be politically correct. How many people with early cases of HIV infection have been talked out of appropriate screening over the years, with tragic consequences for others?

The concerns of Richard Elliott and the Canadian HIV-AIDS Legal Network regarding rapid HIV tests are those of a special interest group. The wisdom of the general public in its search for privacy, personal autonomy and control will be the final arbiter of this debate.

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Research ethics and a patient in her 70s

Our 70-something patient had an envelope in her hand and a worried look on her face. She had just returned from a visit to a far-away urban specialist. "He wants me to be in this study," she explained. "I'd have to go back to the city 8 times in the next 6 months." Her package contained details of an industry-funded trial comparing new drugs, an ambitious project involving many patients and multiple sites. The specialist did not examine her or speak to her about the test she had just had. "He spent 45 minutes explaining it to me and trying to get me to sign up," she said. "He's never spent that long with me before.

"He told me he wasn't getting any money to do it, but what does this mean?" she said, pointing to a section of the patient information package. It said that the doctor "will be compensated by the sponsor" for the time and effort required to conduct the study.

"I can't do it," she said. "It's too dangerous to drive that far in the winter and my husband isn't very good with long trips anymore. I feel bad, though; I should help. Do you think the doctor will still see me every year and if I need him? Will he be angry at me?"

Two related problems are illustrated by this case. First, in an ethical trial design, no group of patients should be penalized for failing to participate. Groups that have been disadvantaged in the context of research include women, people of colour or of different ethnicity, the elderly, children and restricted or dependent people.[1] Rural populations should be added to this list.

In the case of this rural inhabitant, participation would have meant trips of 220 km each way to see a trial nurse for assessment of vital signs and completion of a brief questionnaire and perhaps some lab work. We calculated her basic travel expenses (at 30¢/km) and determined that this elderly woman was being asked to contribute more than $1000 to this trial, along with at least 96 hours of travel time for herself and a companion. Researchers should travel to assess rural subjects closer to their homes.

As was recently reported, "A problem arises when doctors do not recognize the seductive interference of secondary gain. A second problem is the perception of interference with primary duties even when no such interference occurs."[2] Although we reassured the patient that ethical physicians would not allow their relationship with a patient to be altered by refusal to enter a trial, she was obviously concerned by the use of her appointment to seek her participation in the study and by the compensation being received by the physician.

A recent editorial highlighted concerns over the increasing prominence of product-oriented research.[3] We all need to be vigilant that our relationships with patients are not compromised by our involvement with industry-sponsored trials.

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Jehovah's Witnesses and artificial blood

Although it is well known that orthodox Jehovah's Witnesses may not accept blood transfusions, even when medically necessary to save life, it