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

is less clear whether artificial blood based on hemoglobin extracted from outdated human blood will be acceptable to Jehovah's Witnesses when these products become commonly available in the next several years.

Until recently, it appeared that such artificial blood would be banned for Jehovah's Witnesses. For instance, consider the comments of Richard Bailey and Tomonori Ariga who, writing in an official capacity in 1998, explained Watch Tower Bible and Tract Society policy to the medical community: "Jehovah's Witnesses do not accept whole blood, or major components of blood, namely, red blood cells, white blood cells, platelets and plasma. Also they do not accept hemoglobin which is a major part of red blood cells … According to these principles then, Jehovah's Witnesses do not accept a blood substitute which uses hemoglobin taken from a human or animal source."[1] Recently, however, there has been an important but subtle change in Watch Tower Bible and Tract Society policy.[2] Whereas the Society had previously permitted Jehovah's Witnesses to accept fractions of blood plasma, it appears that they may now accept fractions of all "primary" components. The Society defines primary components as red cells, white cells, platelets and plasma.

This policy seems to open the door to the use of hemoglobin-based blood substitutes for Jehovah's Witnesses. This would be expected to save a sizeable number of lives annually. More information is available at www.ajwrb.org, the Web site of Associated Jehovah's Witnesses for Reform on Blood.

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[The Watch Tower Bible and Tract Society responds:]

In an article published in the June 15, 2000, issue of *The Watchtower*, the official journal of Jehovah's Witnesses, this Christian faith repeated its long-standing religious belief that the Biblical command to "abstain … from blood" (Acts 15:20) rules out accepting blood transfusions.[1] It also repeated the long-standing position that individual members make their own personal decisions with respect to fractions of blood components. Further, it showed that this position extended to the clinical reality of red-cell substitutes, several of which are nearing regulatory approval.

Individual Witness patients might

or might not accept fractions of plasma or cellular components. Respecting the conscientious choices of their patients is an intrinsic professional duty of physicians.[2] Since it is *patients* who will primarily be affected by the treatment they receive, it is rightfully *patients* who should make the value-laden decisions about their care according to their religious beliefs, personal conscience and the medical facts and uncertainties.

John Doyle's comments about saving lives are uncomplimentary to the specialist physicians worldwide who utilize life-saving blood conservation techniques. Moreover, a recent Canadian study demonstrated that a liberal blood transfusion strategy led to increased morbidity and mortality.[3] Most investigators now accept that allogeneic blood impairs immune system defences and leads to higher rates of cancer recurrence and postoperative infection.[4,5] The potential for transmission of disease cannot be eliminated and has been a force driving the development of red-cell substitutes and bloodless surgery programs. The Health Sciences Centre in Winnipeg announced the first such program in Canada.[6]

Doyle evidently relied on information from a source that purports to present the position of Jehovah's Witnesses. Information on the Internet sometimes has an aura of credibility that it does not deserve. Physicians seeking accurate and authoritative information about the position of Jehovah's Witnesses regarding medical care may refer to our Web site at www.watchtower.org or contact Hospital Information Services for Jehovah's Witnesses (Canada) at 800 265-0327.

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Comparing international infant mortality rates

A report in *CMAJ* provided an international comparison of infant mortality rates based on data recently published by the Organization for Economic Cooperation and Develop-

ment (OECD).[1] Although the OECD and other international organizations such as UNICEF publish international comparisons using data they obtain from Statistics Canada and other national bodies, their estimates are sometimes erroneous.[2] For instance, the OECD reported the 1996 infant mortality rate in Canada to be 6.0 per 1000 live births. In fact, in 1996 the infant mortality rate in Canada was 5.6 per 1000 live births,[3] whereas that in the United States was 7.3 per 1000 live births.[4] In 1997, infant mortality rates in Canada and the United States were 5.5 and 7.2 per 1000 live births respectively.[5,6]

International comparisons of infant mortality are compromised by a lack of standardization with regard to birth registration practices. Studies have documented wide variation in the rate at which extremely small babies at the borderline of viability (e.g., < 500 g) are registered in different countries.[7,8] In fact, recent secular trends and interprovincial comparisons of infant mortality within Canada are also affected by such differences in birth registration.[9] As a potential solution, the World Health Organization has recommended that international comparisons of infant mortality be restricted to live births in which the newborn weighs 1000 g or more.[10] Such a restriction would eliminate a substantial proportion of neonatal deaths from the infant mortality counts of most industrialized countries, however. This and other challenges inherent in birth-weight-specific comparisons mean that international infant mortality rankings will continue to be based on crude rates and will favour industrialized countries, which tend not to register extremely small live births.

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Youngest medical graduate

I too was only 22 years old when I graduated from medical school[1] in Scotland in 1966. After a 1-year rotating internship (this was before the start of family medicine training programs), I became a rural family physician in a group practice when I was aged 23 years.

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The last trial of a Nazi doctor

We read with great interest the news item on the last trial of a Nazi doctor.[1] The following question arises in this connection: What is the role of the political and medical community? Health professionals working in situations of widespread human rights abuses can face significant personal risks in carrying out their duties. In the early 1980s in Central America numerous health care workers were targeted because of their professional activities.[2,3] In 1994 in Iraq, doctors were required by law to amputate the ears and brand the foreheads of deserters. They were told that if they refused, they would suffer the same fate. One doctor was executed and many were imprisoned for their refusal to exercise medicine punitively.[4] This example underlines the vulnerability of the individual health care practitioner in the absence of strong collective refusal to compromise ethical and professional standards.

Is Dr. Heinrich Gross really the last physician of his "kind"? What about physicians who have contributed or still contribute to corporal punishment? There should be more precise international standards including but not limited to medical associations taking steps against the participation of medical staff in corporal punishment and in carrying out the death penalty.

Some steps have been taken by the World Medical Association,[5] but a much more active commitment by professional bodies to defend human rights and oppose abuses is required, such as the establishment of human rights representatives in each national medical association who would visit and report on a regular basis to the World Medical Association and the Amnesty International medical office.

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A man for all centuries

The *CMAJ* editorial of 11 July 2000 misplaces Leonardo da Vinci, "the 17th-century artist and visionary"[1] by about a century: Kenneth Clark cites him as living from 1452 to 1519.[2]

Fortunately, Leonardo's statements and your comments on them are relevant without reference to dates.

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[Editor's note:]

Oops. The year 1513 was incorrectly transcribed as 1613 in a draft of this editorial, advancing da Vinci by a century. Thank you for acknowledging that his words are timeless.

Correction

A recently published commentary by Michael J. Rieder contained an error. The fifth sentence in the second paragraph should read as follows: "Adverse effects include tachycardia, muscle spasms and fatal hyperthermia associated with rhabdomyolysis and renal and cardiac toxicity, the risk of which may be increased by the high environmental and core temperature and vigorous activity likely to occur at a rave party."

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