Identifying unidentified recipients of HIV-infected blood

Editorial

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In 1994 the Laboratory Centre for Disease Control (LCDC), Health Canada, commissioned one of us (R.S.R.) and a co-investigator to characterize the epidemiology of transfusion-associated HIV infection in Canada before serologic testing was implemented.[1] In this study, presented in part to the Commission of Inquiry on the Blood System in Canada (the Krever Commission), we estimated through statistical modelling that 1150 persons were infected with HIV through blood transfusion from 1978 to 1985. According to the model, 610 HIV-infected recipients, or slightly more than half, were alive 3 years after transfusion, and 300 were alive as of July 1994. Of these 300, 100 were still not aware that they had received HIV-infected blood. Although the Canadian Red Cross Society (CRC) is responsible for identifying and notifying recipients of HIV-infected blood, the authors also found, somewhat surprisingly, that the CRC had not been notified of as many as 150 or more HIV-infected recipients who had either applied to the Extraordinary Assistance Plan (EAP, the federal program to compensate persons who acquired HIV infection through blood transfusion) or been reported to the AIDS Case Reporting Surveillance System (ACRSS).

In light of these results, it appears that the methods used in Canada to date to identify and notify persons who received infected blood have not been completely effective. On several occasions, including in testimony by one of us (R.S.R.) before the inquiry in October 1995, recommendations were made to initiate procedures to help identify these persons. If the CRC were to have access to data concerning HIV-infected recipients still unknown to it, the CRC could then notify persons who received a transfusion from the same unit of blood or from other units donated by the same HIV-infected donor. This process has been used successfully in one regional CRC centre[2] and could lead to a substantial number of HIV-infected recipients being notified. Specifically, lists would be prepared from the ACRSS and the EAP of persons with HIV or AIDS who meet predetermined criteria for evidence of HIV infection through blood transfusion and would be compared with a list of infected recipients who are known to the CRC. For recipients previously unknown to it, the CRC would perform the necessary trace-back investigations — to identify the source donor — and then the appropriate look-back investigations — to identify other persons who received blood from this donor when the donor was likely to have been infected.

A second approach that should also be considered is matching lists of AIDS cases to blood-donor registries to identify HIV-infected donors who gave blood in the pretesting period but did not donate after HIV testing of donations began. This approach was found to be both feasible and successful at one blood centre in the United States.[3]

To the best of our knowledge, no such initiatives have yet been undertaken in Canada, although their implementation would be relatively simple, rapid and inexpensive. Both approaches would, of course, require legally, ethically and politically acceptable procedures for sharing information among agencies; in particular, the rights and interests of HIV-infected donors must be carefully protected. Given the benefits of notifying potentially infected people relative to the risks of sharing information, these procedures should be acceptable. The actual work could likely be completed within several months at minimal cost. We believe that the Health Protection Branch of Health Canada would be ideal to lead this initia-

tive. First, the Branch has legal responsibility for regulating the collection and distribution of blood in Canada. Second, LCDC, a centre within the Branch, is in a unique position to provide expertise and lend credibility to such an initiative.

Other strategies have been used to find persons infected with HIV through transfusion. Media campaigns can be used to advise persons who received a transfusion during the high-risk period to undergo HIV testing. This approach has had limited success, in part because some people may not know they received a transfusion.[4] Searches of hospital records have been conducted in many jurisdictions to identify and notify all those who received a transfusion.[5,6] This strategy also has limits: hospital records may be destroyed after a statutory holding period, the structure of records may make it difficult to identify persons who received transfusions, and the long delay between transfusion and notification means that some patients may be difficult to locate. The method we propose is likely to be more effective and efficient than these since it uses specific information to identify and characterize "chains of transmission." In any case, the other methods have already been carried out to a variable extent in Canada and cannot be expected to identify many more people.

There are probably fewer HIV-infected transfusion recipients still unidentified in 1998 than the 100 estimated in July 1994. The precise number is somewhat difficult to estimate. The 1994 estimate was itself subject to uncertainty, and other factors, some difficult to quantify, have been at play since. Nevertheless, several indirect methods, including a simplified back-calculation approach, suggest that the number of still-unidentified HIV-infected transfusion recipients may be as high as 50. Indeed, recent data from the province of Quebec appear to confirm the hypothesis that a substantial number of persons infected with HIV through transfusion are still not aware of their HIV serostatus (Dr. Bruno Turmel and Louise Meunier, Quebec AIDS Surveillance Program: personal communication, 1997). Of 9 persons infected through blood transfusion in Canada and in whom AIDS was diagnosed in 1996 and 1997, 3 were apparently unaware of being HIV infected until they had symptoms of AIDS.

It is more necessary than ever to undertake this work immediately, for the following reasons: HIV-infected persons could directly benefit from new and effective combination antiretroviral therapies,[7] transmission from HIV-infected women to their newborn infants could be substantially reduced,[8] and measures could be taken to interrupt HIV transmission to sexual partners (given that some of the longest-surviving recipients were infected as children and are only now becoming sexually active).[9] Thus, it is imperative that the LCDC, in collaboration with the EAP, the CRC and the provincial public health authorities, implement a program to identify and notify persons who received HIV-infected blood.

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