Look-back notification: How do we assess effectiveness?

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Notifying the recipients of blood and blood components about newly discovered risks of transfusions received in the past continues to be a controversial practice. Busch states, “In light of the data showing the very limited efficacy of previous look-back efforts, we are warranted — indeed, compelled — to transcend these approaches.” Similarly, the Canadian Hospital Association affirms that “targeted notification to communicate directly with individuals who received a blood transfusion in the period 1978–85 to inform them of the risk of transfusion-related HIV infection should be the exception rather than the rule.” However, the Interim Report of the Commission of Inquiry on the Blood System in Canada (Krever inquiry) recommends that “hospitals undertake reviews of their records in order to identify former patients who received blood and blood components between 1978 and the end of 1985; and that, where such records are still in existence, the hospitals directly notify these patients . . . .” In light of these conflicting views, it is not surprising that not all hospitals across Canada have undertaken look-back notification. In a survey of 117 hospitals conducted by the Ontario Hospital Association, only 41% of the respondents reported that they had attempted some type of notification program.

In this issue (page 149) Nancy Heddle and colleagues describe the experience of the Chedoke–McMaster Hospitals (CMH), Hamilton, Ont., with a look-back notification program for patients who may have been exposed to HIV or hepatitis C virus (HCV) through transfusions received before age 17. Although they provide a clear description of the program, discussion of its effectiveness is lacking. I would therefore like to reflect on the information that we may gain from this and other reports and then to address the issue of evaluating the effectiveness of look-back notification.

Heddle and colleagues’ description of the process of notification — and of some of the problems they identified in that process — may be useful for others undertaking similar projects. The cost and resources required for notification very much depend on the ease or difficulty of retrieving patient information. Heddle and colleagues’ experience demonstrates that identification and tracing of former patients often requires integrating information from several sources. Another use-
ful observation is that the extra effort of obtaining input from physicians who knew the transfusion recipients was well spent; in particular, it helped to prevent the hospital from contacting the families of patients who had died or were terminally ill.

One outcome measure used in Heddle and colleagues’ report was the percentage of patients contacted. Results were consistent with those obtained by programs at the Hospital for Sick Children, Toronto, and the Children’s Hospital of Eastern Ontario, Ottawa. All 3 programs found that even with the use of additional data sources such as the Ontario Health Insurance Plan, a significant proportion (between 16% and 34%) of patients could not be reached through direct mailing. It could therefore be argued that a reasonable goal for direct notification would be to contact 66% to 84% of the targeted population, since reaching 100% would require extraordinary measures.

The level of awareness that a transfusion had been received was consistent with that of families who responded to the Hospital for Sick Children survey. That is, about one-third of parents were not aware of their child’s transfusion. Several factors may have contributed to this finding. For example, parents whose children were treated in tertiary care hospitals may not have been present when the transfusion was done; some parents may have been informed of the transfusion but were overwhelmed by more immediate concerns; and receipt of a blood component other than red cells may not have been perceived by some parents as a transfusion. These factors are important to consider in developing systems to document informed consent for transfusions: information should be provided in such a way that, several years later, parents would know or could easily find out whether their child had received a transfusion.

Responses to the questionnaire that accompanied the letter of notification indicated that 96% of patients (or their parents) would consent to HIV and HCV testing knowing that a transfusion had been received. This finding is almost identical to that of the Hospital for Sick Children survey, in which a preference to be informed of the risk of HIV from transfusions was expressed by 96% of respondents and 93% of respondents said that other transfusion recipients should be similarly informed. Only a few families expressed concern about the anxiety provoked by notification. In both studies, only 3% to 4% of respondents said that they would not want testing.

The expected number of transfusion-related HIV cases in Heddle and colleagues’ study can be estimated knowing that a median of 2 units of blood component ranged from 0.01 in 1978 to 0.50 in 1985. Even if the rate of successful notification were 100% in the CMH study and all the patients were tested, the expected number of positive test results would be 0 to 2.

Heddle and colleagues state that “from a practical perspective, the value of the process should be questioned” but go on to say that the notification program was “useful” and will be extended to another group of transfusion recipients with regard to possible exposure to HCV. How then are we to measure the effectiveness of look-back notification programs? Clearly this must be done with reference to the goals of notification, which include the following.

1. Identifying new cases of HIV or HCV infection.
2. Informing patients of their transfusion history.
3. Providing information to patients about their risks of infection.
4. Providing patients with information about testing.
5. Developing and maintaining the trust of patients and their families by sharing information.
6. Sustaining community trust in public institutions by demonstrating a commitment to share information.

The first goal — case finding — is important to the health care system, public health officials and the blood services community and is the goal referred to by Busch. It is clear that a general notification program is not an effective means of achieving this goal. As we have seen, the CMH program could be expected to identify at most 1 new case of HIV infection. Thus, case finding cannot be the main goal of such a project.

Goals 2, 3 and 4 are related to the social goals of health education and health promotion. It appears that the CMH program was effective in increasing the awareness of patients and their families of their transfusion history and risk of infection. Notification motivated patients (or their parents) to pursue testing, and we may assume that many were relieved to receive negative results. The benefit of receiving a negative test result should be included in the assessment of look-back notification. However, because notification projects have to date been directed toward patients who received transfusions in childhood, it is not known whether the responses of adult transfusion recipients would be similar.

Goals 5 and 6 are more difficult to measure but are no less important. As physicians we hope to inspire trust. At the level of physician–patient relationships, trust is built in the context of open, respectful partnerships. At the societal level, public trust in institutions and systems also requires open, respectful partnerships. Many Canadians are skeptical about the safety of the blood supply. The Krever inquiry has demonstrated that Canadians want to be informed of potential health risks and expect health agencies to err on the side of caution and quickly identify po-
Potential risks. It is quite possible that the high level of approval given by patients and their families to the CMH notification program expresses a desire to build trust as much as a need for information. Perhaps we should be developing instruments to measure public trust in medical professionals and their institutions.

References


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