

Counseling blood donors seropositive for human T-lymphotropic virus types I and II in a developing country

Aconselhando o doador de sangue soropositivo para o Vírus Linfotrópico Humano tipo I/II em um país em desenvolvimento

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Abstract Human T-lymphotropic virus types I and II (HTLV-I/II) are blood-transmitted retroviruses associated with leukemia, myelopathy, and uveitis. From 51,135 eligible blood donors at the Fundação Hemominas tested in 1993, 689 (1.35%) were repeatedly reactive to HTLV-I/II antibodies by enzyme immunoassay and were notified accordingly. Routes of transmission and preventive measures were emphasized in the orientation. Supplementary laboratory tests should be available and free of cost. Health services should recommend the use of latex condoms and make them available. Avoiding shared use of needles or syringes is important for both the seropositive donor and public health in general. In a country with such widespread malnutrition, the benefits of breast-feeding usually outweigh the risks of virus transmission. Based on our experience, we recommend that: 1) identical orientation be given to donors by all health professionals involved in counseling; 2) level of schooling be considered and information provided accordingly; 3) donors be assisted in understanding and assessing available information; 4) psychological assistance be provided to anxious or depressed donors; and 5) joint counseling be offered to donors with stable partners.

Key words Counseling; HTLV I Viruses; HTLV II Viruses; Developing Countries

Resumo Os vírus linfotrópico humano tipos I e II (HTLV-I/II) são retrovírus transmitidos por componentes celulares sanguíneos e associados à ocorrência de leucemia, mielopatia e uveíte. De 51.135 doadores de sangue da Fundação Hemominas testados em 1993, 689 (1,35%) foram repetidamente reativos a anticorpos contra HTLV-I/II no ensaio imunoenzimático e foram devidamente notificados. As vias de transmissão e medidas de controle foram enfatizadas na orientação. Testes laboratoriais suplementares devem ser disponíveis e gratuitos. O uso de preservativos deve ser recomendado e os mesmos serem disponíveis nos serviços de saúde. O doador soropositivo e os serviços de saúde não devem reutilizar agulhas e seringas. Sendo a desnutrição infantil um problema grave no país, o benefício da amamentação sobrepõe-se ao risco de transmissão de víruses. Baseados em nossa experiência, recomenda-se: 1) a mesma orientação deve ser dada por todos os trabalhadores de saúde envolvidos no aconselhamento do doador, 2) o nível educacional deve ser considerado e as informações fornecidas de acordo com as necessidades individuais; 3) deve-se auxiliar o doador a compreender e criticar as informações disponíveis e 4) fornecer assistência psicológica adequada a doadores ansiosos ou deprimidos e 5) se o doador tem um parceiro estável, as informações devem ser dadas ao casal, simultaneamente.

Palavras-chave Aconselhamento; Vírus HTLV I; Vírus HTLV II; Países em Desenvolvimento

Introduction

Human T-cell lymphotropic virus types I and II (HTLV I/II) are retroviruses that can infect humans and be transmitted through contact with blood. HTLV-I is associated with an aggressive lymphoma, adult T-cell leukemia/lymphoma (ATL), a degenerative demyelinating neurological disease known as tropical spastic paraparesis (TSP) or HTLV-I associated myelopathy (HAM), and uveitis (Poiesz et al., 1981; Osame et al., 1986; Sugimoto et al., 1993). Development of ATL may require years to decades after infection, while data from Japanese patients with TSP/HAM and a history of blood transfusion suggest a mean interval of 2 years (range: 6 months to 8 years) between infection and development of neurological symptoms (Osame et al., 1986). HTLV-II was first isolated from a patient with T hairy-cell leukemia, but the virus has not yet been clearly associated with any disease (Blattner, 1989).

HTLV infection is endemic in several parts of the world (Levine & Manns, 1993). In Brazil, a study performed at *Fundação Hemominas* in 1992 on blood donors at low risk for sexually transmitted disease and blood-borne infections found a point prevalence rate of approximately 0.32% (Proietti et al., 1994).

Screening programs in blood centers and hemotherapy services should provide education and support to HTLV-I/II positive donors to help them maintain their physical and emotional health and reduce their likelihood of infecting others.

Implementation of routine HTLV-I/II serological testing at *Fundação Hemominas* in 1993 helped increase our knowledge of the social and psychological reactions of persons notified of their seropositive status. Such information is critical for designing effective notification and counseling programs.

Diagnosis of HTLV-I/II infection

Of 51,135 blood donors from *Fundação Hemominas* tested in 1993, 689 (1.35%) were repeatedly reactive to HTLV-I/II antibodies by enzyme immunoassay (EIA-Ortho). They have been informed that only HTLV-I is associated with diseases to date, and that current serological tests are unable to differentiate between HTLV-I and II. In the USA, after the implementation of blood donor screening, it became apparent that more than half of HTLV seropositive donors were infected with HTLV type II rather than type I (Lee et al., 1991). In our coun-

try, although HTLV-II was thought to be endemic among isolated Brazilian Amerindians in Central Brazil (Maloney et al., 1992) and the Amazon Region (Azevedo et al., 1994), HTLV-I/II seropositive blood donors have been found in all regions of the country in a recent national serological survey (Galvão et al., 1995).

In view of the high degree of cross-reactivity of current HTLV-I assays for HTLV-II, the extremely low disease association, and the uncertainty about the availability of HTLV-II tests, it is not surprising that the Food and Drug Administration Committee did not recommend specific testing for HTLV-II (Bianco & Tegmeier, 1993). It is expected that manufacturers will soon submit tests that are sensitive and specific enough to distinguish between HTLV-I and HTLV-II at no extra cost.

The EIA tests are highly sensitive, thereby minimizing the number of false-negative results. A more significant problem with EIA is the lack of specificity that increases the likelihood of false-positive results. To differentiate false positive results from the true positives, a more specific test, the Western blot, is used. In *Fundação Hemominas*, of 229 HTLV-I/II reactive samples tested by Western blot, 37 (16.2%) were positive, 88 (38.4%) were negative, and 104 (45.4%) were indeterminate (Passos et al., 1995).

Because uncertainty produces great stress in patients with indeterminate results, physicians should inform donors that the majority of individuals tested with one set of commercially available reagents are not infected with HTLV (Kwok et al., 1990).

Counseling about transmission

Our current information indicates that HTLV-I/II seropositive donors should be informed of the diseases associated with the virus, and that it is unlikely that they will suffer any consequences from the infection. They should also be informed about the forms of transmission of the virus (CDC, 1993).

An important point is informing donors that HTLV-I and II differ from the human immunodeficiency virus (HIV), which causes the acquired immunodeficiency syndrome (AIDS).

Seropositive donor candidates should be notified that the virus is transmissible through sexual contact, breast-feeding, needle-sharing, or blood transfusion. As suggested by the CDCP and USPHS Working Group, persons infected with HTLV-I/II should be advised to: 1) share the information with their physician;

2) not donate blood, semen, body organs, or other tissues; 3) not share needles or syringes with anyone; 4) not breast-feed infants; and 5) consider use of latex condoms to prevent sexual transmission.

In a developing country like Brazil, each of the above requires special attention. First, we are reminded once again that the life-sustaining benefits of blood transfusion are not achieved without risk. The decision to transfuse must be critically evaluated and the indications unequivocal.

Supplementary laboratory tests should be available and free in all hemotherapy services. Public health authorities must provide specialized services for assisting HTLV seropositive donor candidates. Such centers must be capable of performing confirmatory tests and convenient clinical follow-up.

Eliminating the shared use of needles or syringes is an important measure for both seropositive donor candidates and health services which reuse such materials. In Nigeria, this practice has been found to be a novel form of risk behavior for HIV transmission (Macaulay et al., 1993). Surveillance measures should be improved to prevent this practice, which is also common in Brazil.

Particular attention should be directed to counseling women of childbearing age, due to the knowledge that ATL is largely a consequence of childhood infection (Murphy et al., 1989). In a country with serious social problems, including undernourished infants and children, the benefits of breast-feeding usually outweigh the risks of virus transmission. To prevent starvation and decrease HTLV transmission, counseling mothers to breast-feed for 6 months could be advisable, since transmission of the virus increases from 7 months of age onwards (Hino et al., 1985). Another suggestion would be to pasteurize or simply boil the breast milk in order to inactivate the virus.

Use of latex condoms is recommended for donors with multiple sexual partners. For donors with a monogamic stable relationship, it is advisable to test the partner for HTLV and use preventive measures if the partner is seronegative. For couples wishing to have children, condom use is still recommended, except during the woman's fertile period.

Emotional reactions and counseling HTLV-I/II seropositive blood donors

Most of the research on the psychological impact of retrovirus infection in persons identified as seropositive through routine screening pertains to HIV infection (Cleary et al., 1993), which entails greater risk of development of disease than HTLV-I/II. In our service, several emotional reactions were noticed during follow-up of more than 300 HTLV-I/II seropositive donors. The ways we have managed these reactions are very important. The following recommendations are based on our experience:

- 1) Homogeneous orientation and information should be given to donors by all health workers involved in counseling.
- 2) Counseling should be continuously discussed and revised based on new experience. Changes should be recorded in writing, based on group consensus.
- 3) Level of schooling should be considered and information provided accordingly. It is not advisable to give more information than demanded by the donor in order to prevent additional stress and misunderstanding. Information should be provided on the basis of individual requirements and reading material provided if requested, based on level of schooling.
- 4) Donors should be assisted in their understanding in order to allow for a critical assessment of media information, including contradictory and sensationalist data.
- 5) Psychological and/or psychiatric care should be provided for extremely anxious or depressed donors, who have frequently experienced previous emotional disorders (Markowitz et al., 1994).
- 6) Donors with stable partners should receive joint counseling if so desired. We have observed that this helps reduce both the level of stress and number of subsequent sessions.

Finally, we believe that a well-trained professional health team following established guidelines helps seropositive donors handle the newly acquired knowledge of their HTLV serostatus.

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