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ORIGINAL ARTICLE

Improvement of the understanding of blood donors with human T-cell leukaemia virus type 1 using a new information booklet

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Abstract

Background: Human T-cell leukaemia virus type 1 (HTLV-1) tests have been mandated in Japan since 1986, and notification of HTLV-1-seropositive donors started in 1999. However, donor knowledge and response to notification has not been assessed.

Study design and Methods: A questionnaire survey was conducted among blood donors notified of HTLV-1 seropositivity regarding their knowledge of HTLV-1 and unmet information needs. To reduce anxiety among notified individuals and raise awareness of their infection status, we created a booklet containing information that would be useful for these individuals without causing unnecessary anxiety while also requesting that they refrain from donating blood in the future.

Results: A questionnaire survey conducted before the distribution of a new booklet revealed that 15.0% of respondents donated blood again despite receiving an HTLV-1-seropositive notification at the previous donation. While 62.2% of respondents reacted to the notification favourably, 40.2% expressed anxiety and 32.5% requested information on related diseases and medical institutions for consultation. In the secondary survey after distribution of the new booklet, 87.9% of respondents reported that the information was comprehensible, and an increase in consultations of medical institutions by notification recipients was observed. Furthermore, no re-visiting donors were observed among the HTLV-1-seropositive recipients who were notified using the new information booklet.

Conclusion: The new information booklet provided enlightenment on HTLV-1 infection and facilitated the consultation of medical institutions by seropositive donors, leading to an improvement in the health-related quality of life of seropositive blood donors and the safety of blood products.

KEYWORDS
blood donors, blood safety, education, HTLV-1, information booklet, notification

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1 | INTRODUCTION

Human T-cell leukaemia virus type 1 (HTLV-1) is a causative agent of human T-cell malignancy, adult T-cell leukaemia/lymphoma (ATL) and HTLV-associated myelopathy/tropical spastic paraparesis (HAM/TSP).[1–3] The number of HTLV-1-infected individuals is estimated to be 10–20 million worldwide[4] and over 1 million in Japan,[5] and >95% of infected patients will remain asymptomatic throughout their lifetime. Therefore, asymptomatic HTLV-1 carriers could be at risk of becoming blood donors in Japan. Regarding the transfusion-transmission of HTLV-1, a serological test for all blood donors was mandated by the Japanese Red Cross Blood Centre (JRC) in 1986. At the same time, the JRC has permanently declined blood donation from HTLV-1-seropositive donors, and subsequently, in 1999, a notification programme for HTLV-1-seropositive blood donors was started in order to ensure the safety of blood products for transfusion, according to the recommendation from the government committee on notification of HTLV-1 infection. Although a unified document for HTLV-1-seropositive blood donors was prepared in the JRC headquarters, the format and information content were not put practical use among the regions at this point. The reason why uniform materials were not used nationwide is that the required information varies according to the prevalence in the region.

The Kyushu region, located in the south-western part of Japan, is well-known to have the highest prevalence of HTLV-1 among developed countries. In the Kyushu region, we annually detect >300 HTLV-1-seropositive blood donations, and approximately 2% of seropositive donors visit for repeated blood donation. As the only facility to collect and supply blood products in Japan, the JRC has a responsibility to maintain the safety of blood products by instructing HTLV-1-seropositive blood donors to refrain from blood donation. However, whether or not the notified donors correctly understand the results and what information they need has not been investigated. In order to promote the awareness of HTLV-1-seropositive blood donors, it is important to provide accurate and up-to-date information that addresses the unmet needs of notification recipients.

In this study, we conducted a questionnaire survey to define the unmet needs and knowledge on HTLV-1 infection among donors who were notified of HTLV-1-seropositivity. Based on the responses, we created a new information booklet that contains updated information on HTLV-1 and HTLV-1-specialised medical institutions, with a comment instructing the individual to refrain from blood donation in the future. To assess the impact of the new information booklet on the comprehension of notified donors and their consultation of designated medical institutes, a follow-up survey was conducted. And the number of repeating HTLV-1-seropositive blood donors was compared before and after the distribution of the new information booklet.

2 | MATERIALS AND METHODS

2.1 | Study design

From December 2018 to March 2020, 388 donors (male, $n = 222$; female, n = 166) were notified of their seropositivity on a confirmatory test of HTLV-1. We mailed the notification along with an explanation of the purpose of this study, a consent form, a questionnaire survey form (Appendix S1) and a postage-paid envelope to the notified donors.

In the first survey, the donors who received the notification were asked about their knowledge of HTLV-1, their feelings on receiving the notification, their unmet information needs, the tools they used to obtain on-demand information, whether or not they wished to visit a medical institution and any problems they encountered when receiving the notification. When introducing medical institutions for HTLV-1 carrier consultation in the booklet, we referred to accredited institutions registered in the Japanese Society of HTLV-1 and Associated Diseases (JSHAD). Consent to include the name and reception hours of each medical institution designated for consultation in the attachment of the new information booklet was obtained from all nine certified HTLV-1-specialised medical institutions in the Kyushu region.

The new information booklet was created through consideration of the responses to the first questionnaire survey, and distribution with notification of HTLV-1-seropositive test results started in June 2019. We assessed the recipients' impressions and comprehension of the information in the new booklet, as a second survey targeting newly notified seropositive individuals. Next, we investigated the change in the number of the newly notified blood donors who visited the medical institutions listed in the attachment. In addition, the number of repeating HTLV-1-seropositive blood donors was compared before and after receipt of

TABLE 1 Characteristics of the respondents to the questionnaire survey

	Total (*n*)	Age (years) 16–19	20–29	30–39	40–49	50–59	60–69	Median (range)
Male								
Notified donors	222	15	18	36	41	88	24	50.0 (17–65)
Respondents	46	0	2	4	3	31	6	56.0 (20–64)
Response rate (%)	20.7	0.0	11.1	11.1	7.3	35.2	25.0	
Female								
Notified donors	166	8	10	16	28	75	29	52.0 (17–67)
Respondents	57	2	2	8	6	31	8	53.0 (18–66)
Response rate (%)	34.3	25.0	20.0	50.0	21.4	41.3	27.6	

the above booklet as an evaluation study of new information booklet with attachment from January 2017 to March 2021.

2.2 | Ethical approval

Ethical approval for this study was obtained through the JRC Ethics board (Infection-112, 2018-037-1).

3 | RESULTS

3.1 | Questionnaire survey for notified HTLV-1-seropositive blood donors and the preparation of the new information booklet

Of the 388 notified HTLV-1-seropositive donors, 103 donors (male, $n = 46$; female, $n = 57$) gave their consent to participate in this

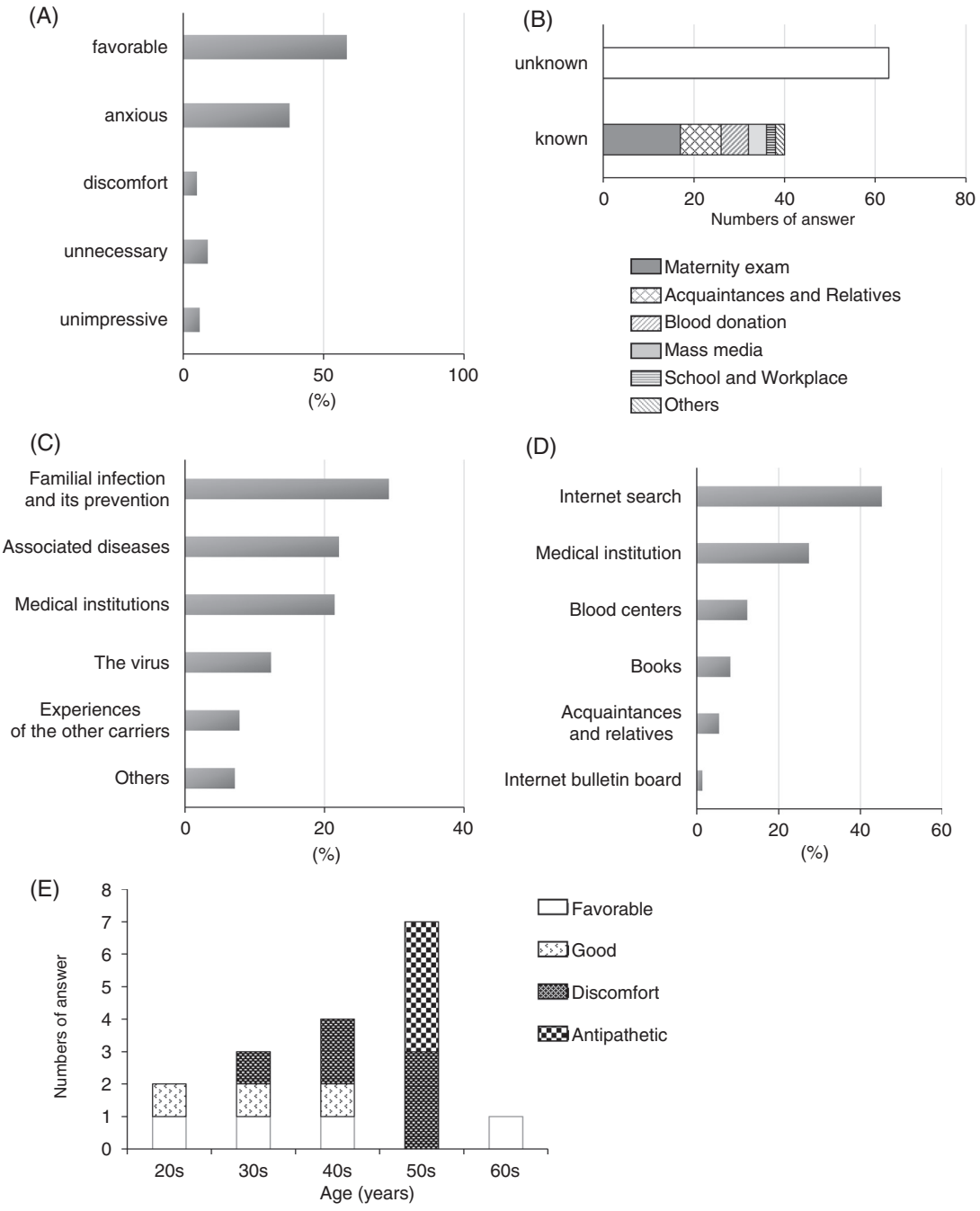

FIGURE 1 Answers to the first questionnaire survey. The questionnaire was sent along with a notification concerning seropositive test results for HTLV-1, and answers were obtained from respondents who consented to participate. (A) Donors' feelings at the time of receipt of the HTLV-1-seropositive notification (numbers of answers: 119), (B) Awareness of HTLV-1 when receiving the notification (numbers of answers: 103; white, did not know about HTLV-1 prior to the receipt of seropositive notification; shaded, knew about HTLV-1 prior to the receipt of seropositive notification). The horizontal axis shows the numbers of respondents. (C) Type of information requested (numbers of answers: 154), (D) Tools for obtaining on-demand information (numbers of answers: 73), (E) Impression about the MHLW Manga material

study and completed the questionnaire. The median age of the male and female respondents was 56.0 years (range 20–64 years) and 53.0 years (18–66 years), respectively (Table 1). Sixty (58.3%) of the 103 respondents accepted the notification of HTLV-1 infection calmly and viewed the contents of the booklet favourably. Thirty-nine (37.9%) experienced anxiety and 5 (4.9%) experienced discomfort after being notified of their HTLV-1 infection status (Figure 1A). Forty donors answered that they had been aware of HTLV-1 before receiving the notification, and 17 (42.5%) of them had learned of HTLV-1 through maternity examinations and prenatal (pre-mom) classes. Six (15.0%) had received the same notification at their previous blood donations. Two of the four responders who answered 'Other' revealed how they had learned about HTLV-1 (at school, $n = 1$; at their workplace, $n = 1$). Nine (22.5%) had received information on HTLV-1 from acquaintances and relatives, possibly reflecting the fact that this study was conducted in a highly endemic area (Figure 1B).

We obtained 154 answers from 80 donors about the information they needed. Forty-five (29.2%) requested knowledge about the transmission of the virus among family members and its prevention. Following that, 34 (22.1%) sought information about HTLV-1-associated diseases, 33 (21.4%) sought information about available medical institutions and 19 (12.3%) and 12 (7.8%) sought information about the virus itself and experiences of other HTLV-1 carriers, respectively (Figure 1C). The most commonly used tools to obtain on-demand information were an Internet search engine ($n = 33$, 45.2%), followed by consulting an HTLV-1-specialised doctor at a medical institution (n = 20, 27.4%; Figure 1D).

In addition, we received 35 telephone inquiries, saying that the word 'HTLV-1' was unfamiliar and difficult to remember and pronounce for ordinary people or even the notification recipients. Therefore, when creating a booklet, we chose 'HAD', as the easy-to-remember and easy-to-pronounce word; this was taken from JSHAD. Namely, 'HAD' is the abbreviation of 'HTLV-1 and associated diseases'.

We collected the latest information for the contents of the new information booklet to address the unmet needs of notification recipients as follows: the virological and epidemiological aspects of HTLV-1 virus, the routes of infection, associated diseases, transmission and prevention of transmission in normal life among the family and in the workplace, and medical institutions to consult, along with comments from and experiences of other HTLV-1 carriers. A question-and-answer format that used easy-to-understand expressions was adopted, with technical terms eliminated when possible. The illustrations, which were drawn by an illustrator, an HTLV-1 carrier who had also learned about the infection after donating blood, were appropriately placed in order to promote understanding.

The new information booklet was reviewed by virologists, haematologists, neurologists, an ophthalmologist and a transfusionist, who were all authorities and experts in the field of HTLV-1. Considering the high rate of respondents who retrieved information using Internet search engines, we introduced the Ministry of Health, Labour and Welfare (MHLW) website, as well as a search map for medical institutions and attached a guide to consulting the HTLV-1-specialising medical institutions available in each prefecture in the Kyushu region.

As the most important issue for the improvement of the safety of blood products, we explicitly stated in the new information booklet that future blood donations from the notified recipients would be declined.

3.2 | Follow-up survey to assess comprehension after distribution of the new information booklet

The reviewed and revised information booklet (available at: https://www.bs.jrc.or.jp/bc9/bbc/special/m6_05_04_index.html) has been distributed to the HTLV-1-seropositive donors since June 2019. A follow-up survey was conducted to assess the comprehension of the notification recipients and their status of HTLV-1 infection.

For the follow-up survey, we distributed a questionnaire about the notification to 233 HTLV-1-seropositive blood donors, and 58 donors (male, $n = 30$; female, $n = 28$; 24.9%) replied. The median age of the male and female respondents was 56.0 years (range, 20–64 years) and 52.5 years (range, 24–64 years), respectively; and 19 (63.3%) of the male respondents and 16 (57.1%) of the female respondents were in their 50s (Table 2). Fifty-eight respondents reported 66 impressions of the new information booklet; 33 (50.0%) found it 'easy to understand', 11 (16.7%) found it

TABLE 2 Characteristics of the respondents to the follow-up questionnaire survey

	Total (*n*)	Age (years) 16–19	20–29	30–39	40–49	50–59	60–69	Median (range)
Male								
Notified donors	147	12	10	20	29	58	18	50.0 (17–65)
Respondents	30	0	2	2	2	19	5	56.0 (20–64)
Response rate (%)	20.4	0.0	20.0	10.0	6.9	32.8	27.8	
Female								
Notified donors	86	0	5	5	16	44	16	53.0 (20–66)
Respondents	28	0	2	2	4	16	4	52.5 (24–64)
Response rate (%)	32.6	0.0	40.0	40.0	25.0	36.4	25.0	

'useful' and 14 (21.2%) found it 'difficult to understand but still comprehensive', meaning that 87.9% of the respondents were able to gather the necessary information from the contents of the new information booklet (Figure 2). By attachment of the consultation guide for available medical institutions specialising in HTLV-1 consultation, seven of the nine introduced hospitals confirmed that they had outpatient visits from blood donors with an HTLV-1-seropositive notification.

3.3 | Deterrent effect of the new information booklet on repeated donation by HTLV-1-seropositive notification recipients

The first questionnaire survey revealed that 38.8% of respondents had been notified of their HTLV-1-seropositive status before their latest blood donation. After the distribution of the new information booklet, we investigated the change in the rate of repeating donors who had already received the notification of their HTLV-1-seropositive status at their previous donation.

To evaluate the utility of the new information booklet, we assessed the re-visiting rate of notified HTLV-1-seropositive donors from January 2017 to March 2021. Among 1383 HTLV-1-seropositive donors, 853 were identified before the distribution of the new information booklet. Among these 853 donors, 19 donations were made by 17 donors (1.99%) who had been notified of their HTLV-1-seropositive status at their previous donation. Five recipients (0.59%) had re-visited for blood donation within 1 year after HTLV-1-seropositive notification. A total of 530 of 1383 received our new information booklet after the initiation of delivery in July 2019. Among these recipients, 310 were observed for more than 1 year, and none had re-visited for blood donation (Table 3).

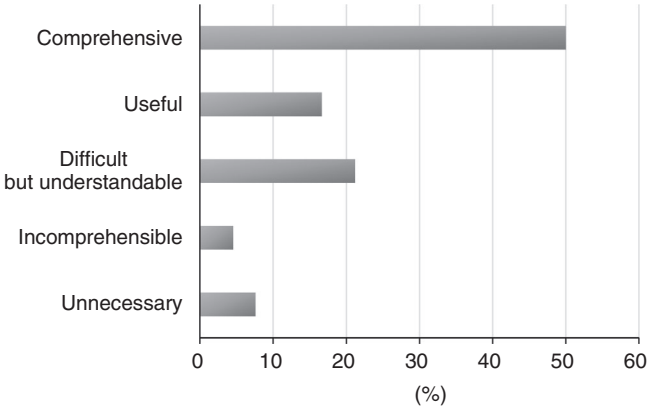

FIGURE 2 Impressions of the new information booklet. After the distribution of the new information booklet with the seropositive notification, a follow-up survey was conducted. Fifty-eight respondents gave 66 answers about their impressions of the new information booklet

4 | DISCUSSION

Japan is the only developed country where HTLV-1 is endemic.[4] In the Kyushu region, in particular, it was estimated that there were approximately 450 000 HTLV-1 carriers.[5]

The WHO reported that 37 countries conduct mandatory testing of all blood donors for HTLV-1 and HTLV-2 and that seven countries conduct selective testing of new donors or donors who have not been previously tested.[6] It is a worldwide consensus in blood programmes that the notification and counselling of blood donors who show seropositive test results are important to blood safety; however, there are no fixed standards for either the regulatory requirements (legally prescribed criteria for notification) or the guidelines for notifying blood donors.[7,8] Notification of HTLV-positive blood donors was reported in Canada,[9] Australia[10] and the United States[11] in the 1990s. For example, in the UK,[12] notification recipients are asked to contact the blood service to arrange a discussion about their test results and onward clinical care. In Japan, this notification program started in 1999. The notification of healthy blood donors about seropositive test results can cause confusion, anxiety, and lack of understanding. In the recent report on health-related quality of life among blood donors who were notified viral infection, cases shown anxiety and depression had been 2.67-fold in HTLV carriers comparing to the control uninfected donors.[13] However, we have not adequately followed up the outcomes of notification.

In the present study, we defined the knowledge of HTLV-1 among notified blood donors and the unmet information needs according to the findings of a questionnaire. Taking the respondents' voice into consideration, we then created a new information booklet to provide the most necessary and up-to-date information in an easy-to-understand format. In the new information booklet, with the aim of improving health-related quality of life of the notification recipients, we included phrases to mitigate their anxiety, recommended early consultation to those with any symptoms, and listed the HTLV-1-specialised medical

TABLE 3 A comparison of the numbers of re-visiting recipients before and after the distribution of the new information booklet

	All notified donors in this study		Recipients tracked over 1 year	
	n	Re-visiting recipients (%)	*n*	Re-visiting recipients within 1 year (%)
Before distribution	853	17 (1.99)	853	5 (0.59)
After distribution	530	0 (0.00)	310	0 (0.00)

institutions for the consultation. In addition, we conducted a questionnaire survey to investigate the comprehension of recipients. In this survey, 90% of the respondents answered that the new information booklet was understandable, indicating that their knowledge had dramatically improved thanks to the contents, which coincided with the unmet needs of the notification recipients.

No HTLV-2-seropositive individuals have been confirmed among Japanese blood donors since the start of the notification program for HTLV-1-seropositive blood donors; thus, we did not mention HTLV-2 in the latest new information booklet. However, we might need to prepare an additional description about HTLV-2 in the future, as the first case of an HTLV-2-infected Japanese pregnant woman was recently reported.[14]

HTLV-1 antibody testing became mandatory in antenatal pregnancy screening throughout the nation in 2010. Simultaneously, the recommendation for mothers with positive results to refrain from breastfeeding was implemented for the prevention of mother-to-child transmission via breast milk. Following that, the MHLW of Japan collaborated in the production of the Japanese animation series, *Cells at Work!*, to conduct a public awareness campaign about HTLV-1 in 2018.[15] Enlightenment posters using popular comic book character have been distributed to health centres throughout Japan.

In our study, regarding the knowledge of HTLV-1, 17 recipients answered that they had learned about HTLV-1 in maternity examinations and prenatal (pre-mom) classes, suggesting that the education system for pregnant women had helped to spread knowledge about HTLV-1 in Japan; however, the efforts to disseminate knowledge regarding the ways to prevent horizontal transmission via transfusion remain insufficient.

Surprisingly, despite the receipt of a HTLV-1-seropositive notification following prior donations, 15% of respondents donated blood again. Five recipients had re-visited for blood donation within 1 year after seropositive notification, suggesting that we had not provided sufficiently useful information before the distribution of the new information booklet. Continuous blood donation by notified HTLV-1-seropositive donors poses a risk to both the donor and patients, namely; a risk of an adverse effect of unnecessary blood collection for the donor and a risk of transfusion-transmission of the virus for patients. To reduce these risks, we clearly stated in the new information booklet that blood donation by those individuals would be refused. As a result, no repeated blood donations by recipients of the new information booklet were observed, indicating that appropriate presentation of information that addressed with the unmet needs of notified donors corrected their understanding of their HTLV-1 infection status and that blood donation would be declined.

In a study conducted among blood donors in India, donors were notified of their seropositive status in order to prevent transfusion-transmission of blood-borne infectious agents (TTIs).[16] A study in Thailand[17] showed that the behaviour of blood donors could be affected by providing a deeper knowledge about their HIV status, indicating that proper notification is necessary in order to prevent repeated blood donation. These investigations demonstrated that donor notification is an efficient method of curtailing TTIs, which is consistent with the results of our study.

Several limitations associated with the present study should be mentioned. First, the comprehension of recipients was evaluated by self-stated answers for the questionnaire, suggesting that the understanding might not have been sufficient. Second, recipients of the new information booklet could not be tracked for a long enough period to obtain an accurate evaluation of the re-visiting rate compared with before distribution. Third, there may have been some bias, as only 26.5% of recipients participated in this survey. Thus, recipients who did not send their answer sheet might have understood less than the participants. However, since no re-visiting donors were observed after the distribution of the new information booklet, the new information booklet might have improved their understanding of HTLV-1 infection.

We recently received an e-mail from a foreign student living in Kyushu, writing that his Japanese girlfriend had recently been notified that she was HTLV-1-seropositive and that he was strongly concerned about transmission through sexual intercourse. He was anxious to learn about infection routes and the frequency of HTLV-1 transmission, and he would like to visit a medical institution for consultation to HTLV-1-specialised doctors. A basic strategy for preventing TTIs is to notify and counsel infected blood donors. Although counselling of individuals infected with HTLV-1/2 has been recommended,[18] a nationwide consultation system has not yet been fully developed in Japan. The aforementioned international student wrote in his e-mail, 'Unfortunately I live in an HTLV-1 endemic area'. There is thus an urgent need to formulate nationally acceptable guidelines for the notification and follow-up of HTLV-1-seropositive individuals in health checks and to prevent the spread of HTLV-1, both domestically and abroad.

In this study, HTLV-1-seropositive blood donors expressed a strong wish for information about medical institutions capable of counselling HTLV-1 carriers. In response to our request, all nine certified medical institutions in the Kyushu region accepted that the notification of HTLV-1 test results from the JRC would be regarded as a patient referral document and that recipients who visited the designated medical institutions would be exempted from the additional fee for a first-time patient who presented no referral. Owing to the reduction in the additional fee for consultation, the number of consultations for recipients of the new information booklet increased, and visits from those recipients were observed in seven of the nine designated medical institutions. In fact, visits from HTLV-1-seropositive donors increased 1.44-fold at the introduced medical institutions following the distribution of the new information booklets. The result indicated that the disclosure of available medical institutions and the reduction of medical expenses are effective measures for notified donors who are anxious about their status and who desire to visit appropriate medical institutions for consultation. The new information booklet was fruitful in two aspects: one was the facilitation of consultations of HTLV-1-seropositive notification recipients; the other was the deterrent effect in relation to repeated donation by the recipients, leading

to improvement of both the health-related quality of life of seropositive blood donors and the safety of blood products.

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CONFLICT OF INTEREST

The authors have no competing interests.

AUTHOR CONTRIBUTIONS

Hitomi Nakamura and Yasuko Sagara designed this study, analysed data, edited the information booklet and wrote this manuscript. Midori Yamamoto collected data. Atae Utsunomiya and Toshiki Watanabe reviewed the information booklet and supervised this manuscript. Masahiro Satake also reviewed the information booklet, supervised this study and supervised this manuscript. Kazuo Irita supervised this study.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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