

Hemophilic Patient's Knowledge and Educational Needs Concerning Acquired Immunodeficiency Syndrome

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The Patient Knowledge Assessment Study (PKAS) was conducted among 107 male hemophilic patients, aged 15 to 67 years, at 19 hemophilia treatment centers (HTC). Participants were given a 30-item questionnaire concerning the cause of acquired immunodeficiency syndrome (AIDS), the groups at risk, and modes of transmission. The questionnaire included questions on the participant's status in regard to antibody to human T-lymphotropic retrovirus, type III/lymphadenopathy-associated virus (HTLV-III/LAV), and the meaning of this test result. HTC health-care providers were asked to complete a separate questionnaire containing 17 questions about information given patients concerning their HTLV-III/LAV antibody status and its meaning. Overall, patients had a good base of knowledge about AIDS; however, there were gaps in this knowledge. Twenty-nine percent of patients did not know that spouses of AIDS patients were at risk for AIDS; 47% did not know that sexual partners of persons with hemophilia were at risk; and 32% did not know that hemophilic children were at risk. Further, only 69% understood that antibody-positive individuals had had contact with the AIDS virus. Identifying these and other areas of misunderstanding will provide the information needed to design educational strategies and psychosocial support programs appropriate for the hemophilic population, and which may serve as a model for other populations.

Key words: hemophilia, education, prevention, HTLV-III/LAV

INTRODUCTION

Most of the 15,000-20,000 hemophilic patients in the United States have been exposed to human T-lymphotropic retrovirus, type III/lymphadenopathy-associated

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virus (HTLV-III/LAV), the etiologic agent of acquired immunodeficiency syndrome (AIDS), through blood products. While the current terminology for AIDS is human immunodeficiency virus (HIV), the term HTLV-III/LAV was in use at the time of this study. For that reason, the earlier term will be employed in this paper. Antibody to this virus is present in 74% of US hemophiliacs using factor VIII concentrate and 39% of US hemophiliacs using factor IX concentrate.

Hemophilic patients, their families, and their-care providers are concerned about the risk AIDS represents to hemophiliacs. For four reasons these groups are also concerned about the risks to nonhemophilic individuals who interact with hemophilic patients:

1. HTLV-III/LAV has been found in cells cultured from the semen of AIDS patients [2].
2. HTLV-III/LAV has been isolated from the saliva of several patients with AIDS or AIDS-related complex (ARC) and from asymptomatic homosexual men [3].
3. Sexual partners of some hemophilic patients have developed AIDS or ARC, or have seroconverted to HTLV-III/LAV [4–6].
4. At least one case of neonatal AIDS has been reported in a child of a hemophilic patient who subsequently developed AIDS himself [7].

In response to the concerns of this population, we designed a study to determine what hemophilic patients know and do not know about AIDS, both in general and in relation to themselves. Additionally, we wanted to investigate what educational programs are needed for this population (including hemophilic patients, their families, and their health-care providers) concerning risks, and ways to minimize risks, of transmission of HTLV-III/LAV. Specifically, we assessed:

1. The sources of hemophilic patient's information about AIDS;
2. Their knowledge of AIDS and its cause and transmission, and these patient's areas of misinformation;
3. Their knowledge of the meaning of their HTLV-III/LAV antibody status;
4. Discrepancies between the patient's impression of what they had been told about their HTLV-III/LAV antibody status and the information providers thought they had given to the patient.

PARTICIPANTS AND METHODS

Participants were recruited for the Patient Knowledge Assessment Study (PKAS) from participants in a separate ongoing study, conducted by the Centers for Disease Control (CDC) and the National Hemophilia Foundation (NHF) to determine the effects of exposure to factor-concentrate lots containing donations from identified AIDS patients (matched factor recipient study, MFRS) [1]. The first phase of MFRS began 9–12 months before the (PKAS) and included 171 hemophiliac patients seen at 29 hemophilia treatment centers (HTC). As part of the MFRS, all participants were tested for antibody to HTLV-III/LAV. After this testing, HTC physicians were informed of their patients' HTLV-III/LAV antibody status. This notification was given about 6 months before the administration of the PKAS questionnaires.

The design of the MFRS includes yearly follow-up evaluations of all participants. The PKAS questionnaires were administered during the first yearly MFRS evaluation, between April and July 1985. One hundred thirty-two male hemophilia patients from 19 HTCs participated in the PKAS, representing all individuals returning for their first MFRS follow-up evaluation by July 1985 (77% of the patients and 66% of the HTC participating in the first phase of MFRS). We confined our analysis to the 107 patients who were ≥ 15 years of age and who could complete the questionnaires themselves. We therefore excluded 21 children < 15 years of age and four children 15 years of age who required assistance with the questionnaire (median age, 13.3 years; range, 4.9–15.9 years). According to the "SMOG" readability formula* and conversion table, the questionnaire was written at the 8th grade level [8].

The purpose and nature of the study were explained to all patients, and their informed consent was obtained. The PKAS questionnaire (available on request) included 15 items about the cause of AIDS, AIDS risk groups, transmissibility of AIDS, blood product safety, and medical treatment of AIDS.

Respondents were asked to indicate the degree to which they agreed with the statement or question ("definitely yes," "probably yes," "don't know," "probably no," and "definitely no"). In our analyses, "definitely yes" and "probably yes" were scored as "yes" responses and "definitely no" and "probably no" were scored as "no" responses. "Correct" responses were defined on the basis of five of five AIDS medical researchers at CDC giving concordant responses to a given question. Participants were also asked questions concerning their HTLV-III/LAV antibody status.

HTC health-care providers of the participants were asked to complete a separate questionnaire consisting of 17 questions about what information they had given their patients concerning HTLV-III/LAV antibody status and its meaning (available on request). All personnel at each HTC were asked to collaborate on these responses, and one questionnaire was to be completed by each HTC.

RESULTS

The median age of participants was 28 years; 73% had at least a high school education, and most were single with no children (Table I). The main sources of participants' information about AIDS were media and NHF (Table II).

The majority of participants responded correctly to questions for which there was consensus among CDC experts (Table III). Most knew that the etiologic agent of AIDS is a virus; 55% knew the proper scientific name(s) (at the time of the study) as HTLV-III or LAV (Table III).

A series of questions about additional risk groups and transmissibility of AIDS were asked, the answers to which all five of the five CDC scientists did not concur. Not surprisingly, the experts' lack of consensus was reflected in the responses of the hemophilic patients. Participants were asked if children of hemophilic fathers were at risk for AIDS; 26% responded "yes." Respondents were further asked if AIDS can be spread by the following: changing dirty diapers, 4% responded "yes"; kissing, 44% responded "yes"; assisting in giving concentrate or cryo, 24% responded "yes";

*Source of acronym "SMOG" could not be determined.

TABLE I. Characteristics of Hemophiliac Participants Patient Knowledge Assessment Study, 1985*

	Median range	28.1 15.4-67.6 (%)
Age		
Education		
< 12 years		17.8
HS grad		21.5
College		29.9
College grad		21.5
Unknown		9.3
Total percent		100.0
Marital status		
Single		43.9
Married		29.0
Divorced		7.5
Unknown		10.3
N/A ^a		9.4
Total percent		100.0
No. of children		
0		41.1
1		11.2
2		10.3
3-5		5.6
Unknown		10.3
N/A		21.5
Total percent		100.0

*n = 107.

^aN/A indicates participant was < 18 years old (n = 10).

TABLE II. Hemophiliacs' Main Sources of Information About AIDS

	% using ^a
Media ^b	86.9
National Hemophilia Foundation (NHF) ^c	82.2
Physician	55.2
Nurse	52.4

^aParticipants could indicate as many sources as they wished, but were asked for their "main sources of information regarding AIDS."

^bMedia includes television, radio, newspaper.

^cNHF includes NHF and NHF local chapters.

sharing eating utensils, 30% responded "yes." We asked if AIDS could be spread in saliva, 51% responded "yes".

Patients were asked whether, when, and how they were notified of their HTLV-III/LAV antibody status and, for those not notified, whether they wanted to be. Of the 57 (53%) of patients who stated that they had been told their antibody status, 38 (67%) indicated that they were first informed during this clinic visit, just before participating in the PKAS and MFRS follow-up. Antibody-positive participants were much more likely than antibody-negative participants to be informed at this visit (81%

TABLE III. Hemophiliacs' Knowledge of AIDS in Areas of Scientific Consensus*

	Yes (%)	No (%)	Don't know (%)	n
Q: The cause of AIDS is:				
Virus	82.9 ^a	2.9	14.3	105
Q: Risk groups for AIDS (groups most likely to get AIDS):				
Adults with hemophilia	83.0 ^a	12.2	4.7	106
Drug abusers who share needles	88.7 ^a	5.7	5.7	106
Homosexual Men	98.1 ^a	0.0	1.9	107
Q: Others at risk for AIDS:				
Spouses of AIDS patients	71.2 ^a	10.6	18.3	104
Sexual partners of persons with hemophilia	53.3 ^a	24.8	21.9	105
Children with hemophilia	68.3 ^a	17.3	14.4	104
Q: AIDS can be spread by:				
Sexual intercourse	86.0 ^a	8.4	5.6	107
Touching and hugging	7.6	79.1 ^a	13.3	105
Q: AIDS can be spread in:				
Clotting-factor concentrates	95.3 ^a	2.8	1.9	107
Cryoprecipitate (cryo)	73.3 ^a	7.6	19.1	105
Plasma	88.6 ^a	3.8	7.6	105
Semen/sperm	76.4 ^a	8.5	15.1	106

*On the basis of a consensus of 5 persons at the Centers for Disease Control doing AIDS research.
^aIndicates consensus answers.

vs. 37%). A nurse informed most patients (68%, n = 39). Of those who did not know their antibody status, 76% (31/41) stated that they want to know (Table IV).

Participant's responses to questions on the meaning of testing positive for antibody to HTLV-III/LAV and the implications of seropositivity (Table V) were generally less likely to agree with the expert's consensus than were responses relative to risk groups (Table III).

Responses to the HTC health-care provider questionnaire indicated that of 19 participating HTC, 58% [11] had informed all their patients (36 patients), 26% [5] informed only those patients who asked to be told (40 of 78 patients), 5% [1] informed only antibody-positive patients (1 of 4 patients), and one did not inform any patients. One HTC had no record of receiving the results of testing, and one did not complete the questionnaire.[†] Eighteen of 18 HTC gave responses concordant with CDC's interpretation of what having the HTLV-III/LAV antibody means.

Because of small numbers, it was not possible to test for differences in patients, responses by whether or not they had received the counseling and education attendant with information on their antibody test results. However, there was a suggestion in the data that patients who had been told of their test results at the current visit were more likely than those who had not been told of their test results to respond correctly to the questions for which there was expert consensus.

[†]These data from providers include the 25 children whose patient questionnaires were excluded from the above analyses and the 107 adults whose patient questionnaires were included in the analyses.

TABLE IV. Notification of HTLV-III/LAV Antibody Status, by Antibody Status

Notification status	No. positive (%)	No. negative (%)	Total (%)
Not Told ^a	—	—	41 (38.3)
Told on this visit	30 (81.1)	7 (36.8)	38 (35.5)
Told within last week	2 (5.4)	2 (10.5)	4 (3.7)
Told within last month	2 (5.4)	1 (5.3)	3 (2.8)
Told 1-3 months ago	0 (0.0)	6 (31.6)	6 (5.6)
Told > 3 months ago	3 (8.1)	3 (15.8)	6 (5.6)
Don't remember	—	—	7 (6.5)
Don't understand	—	—	1 (0.9)
Unknown	—	—	1 (0.9)
Total	37 (100.0)	19 (100.0)	107 (100.0)
Q: How were you told? (for those told) ^b			
By letter	0 (0.0)	4 (21.0)	4 (7.0)
By telephone	0 (0.0)	2 (10.5)	2
In person, on a one-to-one basis	32 (86.5)	12 (63.1)	45 (78.9)
In a group setting	4 (10.8)	0 (0.0)	4 (7.0)
Do not remember	1 (2.7)	1 (5.3)	2 (3.5)
Total	37 (100.0)	19 (100.0)	57+ (100.0)
Q: If not (told), do you want to be told?			
		n (%)	
Yes		31 (75.6)	
No		2 (4.9)	
Not sure		7 (17.1)	
Unknown		1 (2.4)	
Total		41 (100.0)	

^aBased on participants' responses concerning their antibody status; therefore, data are unknown for some responses.

^bOne individual did not remember his antibody status.

DISCUSSION

AIDS is a fatal disease for which there is to date no cure nor a therapeutic regimen that can produce disease remission. Presently, reducing the transmission of AIDS is the only practical way to control the disease. One way to accomplish this goal is through an effectively designed and targeted educational strategy. This study was designed to assess the knowledge base of one group of hemophiliac patients, the vast majority of whom had been exposed to HTLV-III/LAV and therefore were at risk for AIDS and at risk for transmitting infection. Thus, in this discussion we will focus on findings that suggest the educational needs of this particular population.

We found that, in general, participants demonstrated a good base of knowledge about AIDS, its cause, risk groups, and modes of transmission. However, on the basis of incorrect responses to questions in areas of scientific consensus, we found that a significant number of participants knew less about the risks for themselves and their sex partners, and hemophilic children than they did about the risks not associated with hemophilia. For example, fewer participants listed adult hemophilic patients as at risk for AIDS than listed homosexual men as at risk. Further, fewer listed children

TABLE V. Hemophiliacs' Knowledge of What Being Antibody-Positive for HTLV-III/LAV Means

	Yes	No	Don't know	n
Q: A person with antibodies to the AIDS agent (someone who is antibody-positive):				
Has AIDS	13.3	43.8 ^a	42.9	105
Is protected from AIDS	31.7	32.7 ^a	35.6	104
Has come in contact with the AIDS agent	69.1 ^a	3.7	27.1	107
Can give AIDS to someone else	33.3	23.8	42.9 ^a	105
Can still have the AIDS agent in his/her blood	63.8 ^a	3.8	32.4	105
Q: A person without antibodies to the AIDS agent (someone who is antibody-negative) can still have the agent in his blood:	43.9 ^a	15.9	40.2	107
Q: Some household members of hemophiliac persons with AIDS have caught AIDS:	31.8 ^a	23.4	44.9	107
Q: Some household members of otherwise healthy hemophiliac persons have caught AIDS:	21.5	29.9 ^a	48.6	107

^aIndicates response recommended by CDC.

with hemophilia as at risk than listed adults with hemophilia as at risk. Almost 75% knew that spouses of AIDS patients were at risk for AIDS, but only half knew that sex partners of persons with hemophilia were also at risk, despite the high and increasing seroprevalence of HTLV-III/LAV antibody in the U.S. hemophiliac population.

One goal of this study was to determine participants' sources of information on AIDS. Most patients received information about AIDS from the news media (television, radio, and newspapers), a potential problem because the media frequently do not identify that information which is pertinent only to certain groups [13]. We found that NHF and its local chapters were also sources of information for our study group. These groups provide a variety of educational materials specifically targeted to hemophilic patients and their health-care providers; these materials include informational publications, medical bulletins, and teaching modules. This information might therefore counteract any misinformation obtained by hemophiliacs from the news media.

A second goal of this study was to determine hemophiliac patients' knowledge and understanding of the meaning of their own HTLV-III/LAV antibody status. This study indicates that participants wanted to be informed of their antibody status. This finding needs to be taken into account by health professionals who are responsible for testing people with hemophilia. Of those patients who were informed, 79% had been informed in a sensitive and recommended manner, i.e., in person, on a one-to-one basis.^{††} However, the patients' responses concerning the meanings of antibody status suggest that the health care providers and educators of this population need to realize

^{††}This process should ideally include education and counseling.

that patients may not understand or retain what they are told about this topic. Repeated evaluations of patients' understanding and interpretation of what they have been told need to be incorporated into any educational curriculum. Furthermore, changes in scientific information and interpretation need to be rapidly disseminated to health professionals and patients.

This study has a number of limitations. First, the participant HTC were self-selected into the recall study and further self-selected into this study. Thus, the centers represent a small and nonrandomly selected group of US hemophilic patients. Moreover, the patients themselves are likely to have an above-average knowledge of AIDS, for at least three reasons.

1. Because they agreed to participate in both the MFRS and the PKAS, these participants are probably individuals who are highly aware of and motivated to address the problem of AIDS.

2. Participation in the MFRS and PKAS suggests that the participants are in contact with their HTC and/or NHF, both relatively accurate sources of information about AIDS.

3. As part of the MFRS and PKAS, providers and participants were supplied with AIDS information. **

A second limitation is that while part of the PKAS was designed for individuals who had been informed of their antibody status, many patients were in fact told their status only when the PKAS questionnaire was given and received counseling regarding antibody status and AIDS only at this time. This subset of patients probably differed in undetermined ways from those that had been informed previously.

Another limitation is that it was not possible to determine exactly the content of the educational intervention provided. Content was probably not uniform across all centers nor for all patients. Apparently most of the education was carried out in the context of informing the patients about their antibody status. Hence we could not determine definitively what level of knowledge the patients should have demonstrated, based on the information provided at the HTC.

Finally, the questionnaire itself is somewhat time-limited, as the information on AIDS is continually increasing. For example, the question regarding whether children of hemophilic fathers are at risk would be more refined today, to take into account transmission in utero from infected mothers, as well as the age of the child when exposed to the father.

Based on our experience with this study, as well as subsequent discussions with providers of care for hemophilic patients, we have devised recommendations to be considered in the development of educational interventions for the hemophilic community. Several of these probably apply to all groups at risk of AIDS. First, hemophiliacs need educational and psychosocial programs that specifically define and effectively transmit information concerning the risks of HTLV-III/LAV transmission. For example, risk of transmission through intercourse is real and can be lessened through sexual abstinence or the use of condoms and spermicides. Conversely, some

**A pamphlet containing questions and answers about AIDS was developed by the National Hemophilia Foundation and CDC for local chapter members and given to PKAS participants after they completed the questionnaire.

forms of intimacy (e.g., hugging and touching) are safe and should not evoke anxiety. Only when such information is clearly understood by these individuals will they be able to make the very practical choices needed to reduce the risk of HTLV-III/LAV infection for themselves and their household members. We could not determine through this study whether gaps in knowledge were due to being uninformed, to misunderstanding information given, or to denying or not accepting information given. However, the participants' psychological responses to personally relevant information may be a factor in their greater knowledge of risks to others than to themselves and their families [9,10]. Thus, education must not only be directed toward informing these persons about the very real risks of AIDS for themselves and their sex partners, but also must deal with the psychological mechanisms of avoidance and denial that may prevent these individuals from assimilating and/or acting upon information [11].

Second, providers and educators should be very straightforward concerning areas of scientific uncertainty. Third, providers need assistance in determining the most effective means of educating this patient population and evaluating the patient's understanding of what he has been taught and whether he has applied this knowledge to his daily activities. For example, active efforts should be made to include sex partners in the education process to ensure maximum understanding about how HTLV-III/LAV is transmitted by all of those at risk [12]. Education in this area should be coupled with materials for periodic evaluations of the patient's understanding.

These materials should be used with the patient both immediately after he is given the educational information and also several months later. Further educational need should then be determined on the basis of these evaluations as well as upon periodic evaluations of how and if this information has been applied to practices [13].

Fourth, many health-care providers were apparently awaiting CDCs follow-up evaluation before they informed those patients who were antibody-positive for HTLV-III/LAV. This fact suggests that providers themselves need support and reassurance in regard to informing their patients about unpleasant facts and admitting that some questions about AIDS cannot be answered yet. Many of these recommendations are now being addressed by NHF to improve further patient/family and health professionals' awareness about AIDS.

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