Depressive Symptoms in Blood Donors Notified of HIV Infection

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ABSTRACT

Objectives. Understanding more about the psychological state of persons notified of human immunodeficiency virus (HIV) infection is critical for designing notification and counseling programs that will have the most positive effect.

Methods. The subjects were blood donors who had been notified of HIV infection by the New York Blood Center. A nurse elicited a medical history, performed a limited medical examination, and asked the subjects to complete a questionnaire that included questions about drug use, sexual behavior, and psychological characteristics. The subjects completed another questionnaire approximately 2 weeks later.

Results. The average depressive symptom scores for both men and women were substantially higher than scores typically found in representative population samples. More than a quarter of the men and more than a third of the women reported seeking psychological or psychiatric services in the first few weeks following notification.

Conclusions. Anticipating and meeting individuals' psychological needs may be necessary if HIV screening programs are to address effectively the needs of persons infected with HIV. (*Am J Public Health.* 1993;83:534–539)

Introduction

Screening programs for human immunodeficiency virus (HIV) should provide education and support to HIV-positive persons to help them maintain their health and reduce their likelihood of infecting others. Understanding more about the psychological state of persons notified of HIV infection is critical for designing effective notification and counseling programs.

HIV infection can have a devastating psychological impact.[1–10;cf11,12] Although much of the research on the psychological impact of HIV infection has been conducted with persons with acquired immunodeficiency syndrome (AIDS), individuals with AIDS-related complex may have the highest levels of distress.[1,5,9,13,14] Kessler and colleagues found that emotional impairment declined in a cohort of men who were consistently positive at several assessments, whereas it increased among those who seroconverted between assessments.[15] Moulton et al. found no significant increase in levels of distress shortly after notification in seropositive men.[13]

Most of the research done to date has involved persons who volunteered explicitly for testing. Little is known about the reactions of persons identified as seropositive by routine screening. A goal of this study was to learn more about the psychological reactions of a heterogeneous group of blood donors notified of HIV infection.

Methods

Screening

Anyone who donated blood to the New York Blood Center after April 1985 and was confirmed HIV positive was contacted by mail and asked to call for an appointment at the Center to discuss a "finding of importance to your health." If two attempts to contact a donor failed, a certified letter was sent explaining the blood test results and encouraging the donor to come to the Center or to contact a physician for counseling.

A nurse clinician with psychiatric training saw each donor who came to the Center and explained the test finding, the potential impact of infection on the donor's health, and ways to avoid infecting others. Donors also were given written materials about HIV infection and received counseling and emotional support from the nurses.[16,17]

Subjects

The subjects were drawn from the 708 confirmed HIV antibody-positive persons who donated blood between June 1, 1986, and February 29, 1988.[16] Seventy-nine donors (11%) could not be contacted because of an undeliverable or unclaimed

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letter. Another 90 (13%) never contacted the notification team but were notified of their test results by certified mail. Of the 539 donors who contacted us, 5 were informed of their results by telephone; 140 agreed to come to the site regularly only to have blood test results monitored; 1 was enrolled in another research protocol and was excluded from the present study; 2 were donating for autologous transfusions and were excluded. Of the remaining 391 eligible persons, 271 were enrolled in the study, representing 50% of the donors who contacted the study team and 38% of detected seropositive donors. When study participants came to the Center, a nurse clinician took a medical history, conducted a brief physical examination, and gave each subject a questionnaire to complete in private. At the completion of the visit, each subject was asked to return in about 2 weeks for further counseling and support. Two hundred and sixty-one of the participants completed an initial medical interview and 243 completed a baseline questionnaire. Eight participants completed neither a baseline questionnaire nor a medical interview.

Donor Characteristics

For all blood donors, the New York Blood Center records age, gender, and date of donation. The Center asks all blood donors to indicate on a confidential form whether their blood should be used "for studies only"[18,19] if they have a risk factor for HIV infection.

Medical Interview

The medical history covered information about possible risk factors for HIV infection. A tube of blood was drawn for further blood tests. After the first visit, the nurse clinician recorded information about any reported HIV risk factors.

Questionnaire

The initial (baseline) questionnaire asked about the period prior to notification. It included questions about self-esteem, perceived locus of control, and optimism; sexual and social functioning; coping styles; social support; health concerns; positive health behaviors; and depressive symptoms. At the 2-week follow-up visit, subjects were asked to complete another questionnaire, which included questions about depressive symptoms and use of health and social services in the previous 2 weeks. The questionnaires were developed by a team of social scientists and clinicians who had experience working with HIV-infected individuals. We either used existing scales or selected items on the basis of face validity and relevance for the study population.

We measured self-esteem with 6 of the 10 questions from Rosenberg's self-esteem scale.[20] To assess perceived locus of control, we selected 7 items from the subscales of the Multidimensional Health Locus of Control Scale.[21] We measured optimism on a 4-point scale by asking whether the subject agreed with the statement "It will take at least several years to develop a treatment for AIDS." We used a 5-item social functioning scale from the Functional Status Questionnaire.[22] The questionnaire also included 4 questions about sexual functioning.

To measure strategies that subjects used to cope with concerns they had about their HIV infection, we selected some items from the instruments used in the Coping and Change Study, a component of the Multicenter AIDS Cohort Studies.[23] We developed other items on the basis of results from pilot interviews. The content of the questions was guided by a typology developed by Stone and Neale.[24] The coping categories they have described are distraction, situation redefinition, direct action, catharsis, acceptance, seeking social support, relaxation, and religion. We included eight questions about denial or distraction, one to assess situation redefinition, two about religion, six about behavioral strategies, and one each for social support, catharsis, and resignation. In addition, on the basis of information from pilot interviews, we added questions about substance use.

To assess social networks and activity, we used the Social Network Index from the RAND Health Insurance Experiment.[25] We also selected from the Interpersonal Support Evaluation List[26] four questions that measure appraisal support and five that measure tangible support.

We measured concern about casual transmission by asking donors whether they thought an HIV-infected person should or should not avoid six low-risk behaviors (e.g., using towels or silverware that may be used by others). We measured concern about health by asking respondents three questions about whether they thought an HIV-infected person should take certain health precautions (e.g., avoid getting physically run down). We calculated how many positive health behaviors (e.g., sleeping at least 7 or 8 hours a night) donors reported and whether they engaged in some type of exercise (e.g., riding a bicycle) at least once or twice a week.[27]

Depressive symptoms were evaluated using the Center for Epidemiologic Studies Depression (CES-D) scale,[9,10,28-30] which has an internal consistency (coefficient α) of about 0.85.[31]

At the 2-week follow-up we asked whether the respondent had sought help for an emotional or personal problem in the previous 2 weeks from a psychiatrist, psychologist, psychiatric social worker, other mental health professional, other type of medical doctor, minister, priest, rabbi, or self-help group.

Analyses

We compared subgroups of donors by means of χ^2 statistics for categorical variables and t tests for continuous variables. We estimated the associations between donor characteristics and the outcome variables with Pearson product-moment correlations for continuous variables and point-biserial correlations or fourfold point correlations for dichotomous variables. Because of gender differences in coping styles and response to stressors,[32] we present data from men and women separately. For analyses involving CES-D scores we used both the total score and a dichotomous variable representing whether the person's score was 16 or greater. A cutoff score of 16 has been used frequently to indicate people with a higher probability of being clinically depressed.[28]

To estimate the independent effects of donor characteristics on the outcome variables, we used multivariate regression models. We included gender, age at donation, and baseline CES-D scores as independent variables and then used forward stepwise selection procedures to select other variables that were statistically significant predictors ($P < .05$). For depressive symptoms we estimated a linear regression model and for psychological help-seeking we estimated a logistic regression model.

Results

Participants

Donors who participated in the study were more likely than nonparticipants to be female (22% vs 18%) and to have said that their blood should be used for "studies only" (39% vs 25%), but these differences were not statistically significant.

One hundred ninety-six (72%) of the participants returned for the 2-week follow-up visit. The median follow-up time was 16 days and the mean was 23 days. Those who did not return for the 2-week

TABLE 1—Sociodemographic Characteristics and Confidential Unit Exclusion Status of Seropositive Study Participants

	%
Confidential unit exclusion status: donated for transfusion (n=271)	69.0
Sex (n = 271)	
Male	77.9
Female	22.1
Age (n = 271)	
18–24 y	21.0
25–29 y	31.7
30–34 y	17.3
35–44 y	19.9
45–54 y	7.4
55+ y	2.6
Education (n = 260)	
Did not complete high school	10.4
High school graduate	21.9
Some college and/or post–high school training	46.5
College graduate	12.7
More than college	8.5
Marital status (n = 260)	
Never married	63.1
Married	20.8
Separated or divorced	14.6
Widowed	1.5
Race/ethnicity (n = 259)	
White, non-Hispanic	44.8
White, Hispanic	19.7
Black, non-Hispanic	30.5
Black, Hispanic	3.5
Other	1.5

TABLE 2—Mean Scores on Measures of Psychological Characteristics, Social Support, and Coping Strategies of Participants at Initial Interview

	Potential Range	Men (n = 191)	Women (n = 52)
Self-esteem	1–4	3.3	3.3
Perceived physician control over illness	0–3	1.7	1.7
Perceived personal control over illness	0–3	1.1	0.9**
Optimism about AIDS treatment	1–4	1.8	1.7
Sexual problems	5–16	8.4	9.7*
Social functioning	13–30	24.7	23.9
Coping strategies	1–4		
Denial/distraction		2.5	2.5
Reappraisal		3.2	3.1
Active behavioral		3.4	3.3
Substance use		1.8	1.7
Religion		2.6	2.7
Emotion-focused		2.4	2.4
Use social support		2.5	2.5
Catharsis		2.4	2.4
Resignation		2.1	2.3
Social support			
Confident support	4–8	7.3	7.3
Instrumental support	5–10	9.4	9.5
Social network	1–5	2.7	2.8
Not concerned about casual transmission	1–5	2.6	2.7
Not concerned about general health	1–5	1.5	1.5
Perceived risk of AIDS	1–9	3.9	4.2
Positive health behaviors		4.7	4.9

*$P < .01$; **$P < .001$.

follow-up visit were not significantly different ($P > .05$) from those who did with respect to CD4 count, age, gender, ethnicity, education, marital status, risk factor, confidential unit exclusion status, period of donation, any of the psychological characteristics, or most coping strategies measured. Those who did not return were more likely to be cautious about casual routes of transmission ($t = 2.2$, $df = 240$, $P < .05$), less likely to talk with friends to cope with their fears and worries ($t = 2.9$, $df = 195$, $P < .01$), and less likely to make themselves feel better by letting out anger (catharsis) ($t = 2.2$, $df = 194$, $P < .05$).

Donor Characteristics

The study population was predominately male, young, highly educated, single, and White, reflecting the characteristics of blood donors in general (Table 1). The risk factors for study participants were similar to those for the general population of HIV-infected persons, except that the study participants included more women and fewer intravenous drug users.[19]

Psychological Characteristics, Social Support, and Coping Styles

Both men and women reported that the coping strategies they were most likely to use were active behavioral strategies (e.g., talking to a health professional). They were least likely to cope by using substances (e.g., alcohol or tranquilizers) or by resignation (Table 2). Women were significantly more likely than men to report less perceived control over illness ($t = 4.8$, $df = 239$, $P < .0001$) and more problems with sexual functioning ($t = 3.0$, $df = 233$, $P < .01$). Women had significantly higher CES-D scores than did men (Table 3) at both the initial visit ($t = 2.6$, $df = 238$, $P < .05$) and the follow-up visit ($t = 2.0$, $df = 193$, $P < .05$). The average scores for both men and women were slightly lower at the follow-up visit, but not significantly so.

Those who reported seeking psychological or psychiatric help at the follow-up visit had higher CES-D scores and lower self-esteem at the initial interview than did donors who did not seek help (Table 4). They also reported less perceived personal control over health, were less likely to be males who reported homosexual activity, perceived a higher chance of developing AIDS or did not have an estimate of

their risk, were more likely to have reported at the initial visit that they tended to seek social support or to use substances to deal with their worries about AIDS, and were more concerned about their general health.

The strongest predictor of high CES-D scores at the follow-up visit was a high baseline CES-D score. Other significant predictors were low self-esteem, less social support, sexual problems and poor social functioning, lower optimism about the possibility of AIDS treatment discoveries, use of substances or resignation as a coping strategy, and fewer health-promoting activities. The associations with low self-esteem and low optimism are probably due to the fact that these characteristics comprise aspects of depressive symptomatology.

The regression model results were similar (Table 5). The independent predictors of professional help-seeking were CES-D score at baseline, gender, not being homosexual or bisexual, low self-esteem, high perceived risk of getting AIDS, low perceived personal locus of control, and use of social support as a coping strategy. The variables that predicted increases in depressive symptoms in the multivariate model were age, sexual problems, low self-esteem, using resignation as a coping strategy, and fewer positive health behaviors.

Discussion

To our knowledge, this is the first study to evaluate coping styles and depressive symptoms for persons informed of HIV infection who had not volunteered explicitly for HIV screening. The average depressive symptom scores for both men and women in this study were substantially higher than those of persons in general population studies,[29,30] but not as high as those of depressed persons (Table 6). The gender difference in CES-D scores at notification is consistent with other research on depressive symptoms.[32] The scores for men are slightly higher than those reported in one other study of HIV-seropositive men[10] but substantially lower than those reported in another study.[9] We did not have the necessary data to adjust for differences among studies in other sociodemographic characteristics, such as socioeconomic status, that are known to be related to CES-D scores.

The scores were lower at the 2-week follow-up visit than at baseline. Moulton and colleagues[13] also failed to find any significant increase in distress around the

TABLE 3—Reported Depressive Symptoms and Psychological Help-Seeking of Participants at Initial Interview and at 2-Week Follow-Up

	Initial Interview (n = 271)	2-Week Follow-Up (n = 196)
Men		
Mean CES-D score	13.1	12.9
% with CES-D score ≥ 16	31.4	31.1
Sought psychological help, %	. . .	26.0
Women		
Mean CES-D score	17.3	16.6
% with CES-D score ≥ 16	44.2	44.4
Sought psychological help, %	. . .	35.6

Note. CES-D = Center for Epidemiologic Studies Depression scale.[31] Psychological help-seeking was measured only at the follow-up visit. CES-D scores were not significantly different between the two visits for either men or women. The mean CES-D scores of men and women were significantly different at both interviews.

TABLE 4—Correlates of Depressive Symptoms and Help-Seeking at 2-Week Follow-Up (n = 196)

	Help-Seeking	Depressive Symptoms
Sociodemographic and behavioral characteristics		
Education	.06	−.04
Age	.02	−.13
Sex	.09	.14
Donated for studies only	−.01	.06
Homosexual/bisexual man	−.19*	.13
Psychological characteristics		
Self-esteem	−.22**	−.60***
Perceived physician locus of control	.05	.02
Perceived personal locus of control	−.14*	−.05
Optimism about AIDS treatment discoveries	.01	−.18*
Sexual problems	.12	.27***
Social functioning	−.11	−.43***
CES-D score at initial interview	.25***	.67***
Coping strategies		
Denial/distraction	.05	.06
Reappraisal	.00	−.08
Active behavioral	−.01	−.09
Substance use	.16*	.23***
Religion	.08	.04
Use social support	.17*	−.05
Catharsis	.05	.03
Resignation	.12	.26**
Social support		
Confidant support	−.05	−.21***
Instrumental support	−.08	−.27***
Social network	.10	−.24***
Not concerned about casual transmission	−.07	−.05
No estimate of AIDS risk	.16*	−.05
Perceived risk of AIDS	.18*	.01
Not concerned about general health	−.20**	.09
Positive health behaviors	.09	−.18*

Note. CES-D = Center for Epidemiologic Studies Depression scale.[31]
*$P < .05$; **$P < .01$; ***$P < .001$.

TABLE 5—Multivariate Models of Help-Seeking and Depressive Symptoms at 2-Week Follow-Up (n = 196)

	Help-Seeking	Depressive Symptoms
Age	−.13	−.11*
Sex (male = 1; female = 2)	−.42*	.00
Homosexual/bisexual man	−.60**	
Sexual problems		.13**
CES-D score at initial interview	.35*	.47***
Self-esteem	−.42**	−.31***
Perceived risk of AIDS	.33*	
Perceived personal locus of control	−.29*	
Coping strategies		
Resignation		.10*
Use social support	.46**	
Positive health behaviors		−.13*
% variance explained	. . .	60

Note. The model for help-seeking is a logistic regression model and the coefficients are standardized logistic regression coefficients. The model for depressive symptoms is a linear regression model and the coefficients are standardized linear regression coefficients. CES-D = Center for Epidemiologic Studies Depression scale.[31]
*$P < .05$; **$P < .01$; ***$P < .001$.

TABLE 6—Comparison of CES-D Scores: Community Residents, HIV-Positive Persons, Men with AIDS

Study	Population	Mean CES-D Score	% with CES-D Score ≥ 16
Eaton & Kessler[29]			
Sayetta & Johnson[30]	National sample	8.7	16.4
	Men	7.1	10.8
	Women	10.0	20.8
Present study	HIV-positive, 2 weeks post notification		
	Men	12.9	31.1
	Women	16.6	44.4
Ostrow et al.[10]	HIV-negative men	9.5	
	HIV-positive men	10.1	
Chuang et al.[9]	HIV-positive men	21.6	
	Men with ARC	23.9	
	Men with AIDS	13.4	
Boyd et al.[28]	Community residents without depression		6.1
	Community residents with major depression		63.6

Note. CES-D = Center for Epidemiologic Studies Depression scale.[31] HIV = human immunodeficiency virus; AIDS = acquired immunodeficiency syndrome; ARC = AIDS-related complex.

time of notification among seropositive men. Although there are several methodological problems with interpreting these data, the results do not indicate any elevation in symptoms associated with notification. The donors who had the most persistent symptoms were younger, had lower self-esteem, and were less likely to engage in positive health behaviors.

More than a quarter of the men and more than a third of the women in our study reported seeking psychological or psychiatric services in the first weeks following notification. The nurse clinicians did not expect that donors with low self-esteem would be more likely to seek such help; they predicted that persons with low self-esteem would deal less aggressively with problems. It is possible that the clinicians were successful in their special efforts to encourage such persons to seek help.

The results suggest that self-identification as a gay man is associated with less help-seeking from professionals for psychological problems. Men who identify themselves as gay may think that their needs would not be met by such sources of support or that they have less need for support because of the informal and formal networks within the gay community. Because we did not measure help-seeking prior to study enrollment, we do not know whether this association reflects a preexisting pattern of behavior or a differential response to notification.

The baseline CES-D questions referred to the period prior to notification, but subjects' responses were probably influenced by the notification experience. Furthermore, many donors may have been distressed because they anticipated that the notification was about HIV infection. Because we did not have prospective data, data from an unnotified seropositive cohort, or data from a comparable group of seronegative blood donors, it is impossible to estimate the impact of notification. Changes in CES-D scores could also be due to the counseling provided at the notification visit or even to testing effects. Another major limitation of the study is that only a minority of eligible donors enrolled in the study and an even smaller proportion completed the follow-up questionnaire. Finally, the absence of strong predictive associations may be due to measurement error in the instruments selected.

Nevertheless, these results suggest the types of reactions that other screened populations may experience. Our results suggest that persons with high CES-D scores, low self-esteem, less positive coping strategies, and more social isolation may have more persistent symptoms of depression and a greater need for professional services. Anticipating such problems and helping persons to cope with notification may increase the positive impact of HIV screening programs. □

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