The British Columbia Positive Women's Survey: a detailed profile of 110 HIV-infected women

Evidence

Études

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Abstract

Objective: To describe the health, social environment, medical care received and satisfaction with medical care of HIV-infected women in British Columbia.

Design: Self-administered 75-item questionnaire distributed by mail or in person between March 1994 and February 1996 through community AIDS organizations and physicians' offices.

Setting: British Columbia.

Participants: A total of 110 HIV-positive women.

Outcome measures: Sociodemographic data, risk factors for HIV infection, details about HIV testing, health status and medical treatment, use of health care services, degree of satisfaction with medical care and psychosocial stressors.

Results: Most of the women surveyed were aged 25 to 39 years (70.0%), were Canadian born (76.4%) and were white (80.9%). Over one-third did not complete high school, and half had an annual household income of less than $20 000. Of the 110 women 51.8% had children, who were HIV-positive in 12.3% of cases. The most frequently reported risk factor for HIV infection was sex with a man (49.1%); 19.1% reported both sex with a man and injection drug use, and 12.7% reported injection drug use only. Seventy-five women indicated that they had become infected through sex with a man, with or without injection drug use. Of these, 65 indicated whether or not this was the result of sexual assault or rape; 8 (12.3%) answered affirmatively. Of the 81 women who responded to the question regarding prior sexual assault or abuse, 43 (53.1%) reported being sexually assaulted as an adult, 35 (43.2%) reported being sexually abused as a child, and 22 (27.2%) reported being sexually abused or assaulted both as a child and as an adult. Women who were sexually abused as a child were more likely than those who were not abused as a child to have injection drug use as a risk factor (54.3% v. 7.5%). Menstrual cycle changes were reported by 70.1% of the respondents. Most women stated that they had not received adequate pre- or post-test counselling, and 47.0% were not satisfied with their doctor's care. Psychosocial concerns identified to be of greatest importance were financial problems, lack of intimacy or satisfying sexual relationship, and fear of rejection or discrimination.

Conclusion: Several important concerns for HIV-positive women were identified, including dissatisfaction with medical care, fear of discrimination, violence and abuse, and poverty.

Résumé

Objectif : Décrire l'état de santé, l'environnement social, les soins médicaux reçus et la satisfaction à l'égard des soins médicaux chez les femmes infectées par le VIH en Colombie-Britannique.

Conception : Questionnaire de 75 questions, à remplir soi-même, distribué par courrier ou en personne entre mars 1994 et février 1996, par l'entremise d'organisations communautaires de lutte contre le SIDA et de cabinets de médecins.

Contexte : Colombie-Britannique.

Participantes : Au total, 110 femmes infectées par le VIH.

Mesures de résultats : Données sociodémographiques, facteurs de risque d'infection par le VIH, détails sur les tests de dépistage du VIH, état de santé et traitement médical, utilisation des services de soins de santé, degré de satisfaction à l'égard des soins médicaux et facteurs de stress psychosocial.

Résultats : La plupart des femmes sondées étaient âgées de 25 à 39 ans (70,0 %) d'origine canadienne (76,4 %) et Blanches (80,9 %). Plus du tiers n'avaient pas terminé leurs études secondaires et dans la moitié des cas, le ménage avait un revenu annuel de moins de 20 000 $. Sur les 110 femmes, 51,8 % avaient des enfants, dont 12,3 % étaient infectés par le VIH. Le facteur de risque d'infection par le VIH signalé le plus souvent était des relations sexuelles avec un homme (49,1 %); 19,1 % ont signalé à la fois les relations sexuelles avec un homme et la consommation de drogues injectées, et 12,7 % ont mentionné les drogues injectées seulement. Soixante-quinze femmes ont indiqué qu'elles avaient été infectées à la suite de relations sexuelles avec un homme, avec ou sans consommation de drogue injectée. De ce nombre, 65 ont précisé si les relations sexuelles s'étaient produites dans un contexte d'aggression ou de viol; 8 (12,3 %) ont répondu affirmativement à cette question. Sur les 81 femmes qui ont répondu à la question sur les agressions ou les abus sexuels antérieurs, 43 (53,1 %) ont signalé avoir été victimes d'une agression sexuelle à l'âge adulte, 35 (43,2 %) ont signalé avoir été victime d'abus sexuels au cours de l'enfance, et 22 (27,2 %) ont déclaré avoir été victimes d'agression ou d'abus sexuels à la fois au cours de l'enfance et à l'âge adulte. Les femmes qui avaient été victimes d'aggressions sexuelles au cours de l'enfance étaient plus susceptibles que les autres d'avoir la consommation de drogues injectées comme facteur de risque (54,3 % c. 7,5 %). Parmi les répondantes, 70,1 % ont signalé des changements de leur cycle menstruel. La plupart des femmes ont déclaré qu'elles n'avaient pas reçu de conseils suffisants avant ou après le test et 47,0 % n'étaient pas satisfaites des soins reçus de leur médecin. Les préoccupations psychosociales jugées les plus importantes étaient les problèmes financiers, le manque d'intimité ou de relations sexuelles satisfaisantes et la crainte du rejet ou de la discrimination.

Conclusion : On a dégagé plusieurs préoccupations importantes chez les femmes infectées par le VIH, y compris l'insatisfaction à l'égard des soins médicaux, la crainte de la discrimination, la violence et les abus, et la pauvreté.

The number of women infected with HIV in Canada is rising. As of Dec. 31, 1995, there were 3762 reported positive results of HIV tests in girls and women in Canada (some of which may have been duplicates).[1] Between Nov. 1, 1985, and Dec. 31, 1994, females accounted for 9.5% of all HIV-positive test results in this country.[1] The proportion increased to 18.9% in 1995.[1] In British Columbia a statistical back-calculation done in 1994 estimated that at least 600 women were infected with HIV.[2] Data derived from the Enhanced HIV Surveillance System, which minimizes duplicate reporting, show that another 323 females tested positive for HIV in the province between Jan. 1, 1995, and Dec. 31, 1996.[3,4]

Despite these increases, the complex medical and psychosocial concerns affecting women with HIV infection remain poorly understood. There have been few studies examining the demographic characteristics and health of this population in Canada. Preliminary results from the Canadian Women's HIV Study, which includes participants from 12 sites across Canada, provide information on the prevalence of abnormal Pap smears and human papilloma virus infection among women infected with HIV.[5] Hankins and associates have studied a number of issues facing HIV-infected women in Montreal, including risk factors for HIV infection among incarcerated women, HIV testing experiences, and the effect of HIV status on sexuality and the intention to have children.[6–9] In Toronto Jackson and colleagues[10] interviewed 40 HIV-positive women to obtain sociodemographic data and their perceptions and experiences related to HIV testing. In British Columbia a survey of physicians and street nurses working with HIV-positive women provided some information on the health status and demo-

graphic characteristics of women with HIV infection.[11]

We surveyed 110 women with HIV infection or AIDS to obtain a detailed profile, including information about sociodemographic characteristics, risk factors for HIV infection, HIV testing experiences, health status and degree of satisfaction with medical care.

Methods

Patients and sampling procedure

The survey was distributed by mail or in person between March 1994 and February 1996 to HIV-positive women through community AIDS organizations (BC Positive Women's Network, AIDS Vancouver Island and AIDS Vancouver) and by physicians or nurses at Vancouver HIV and AIDS specialty clinics (Oak Tree Clinic and Street Nurse Clinic) and family doctors' and dentists' offices. A previous study in the province identified physicians caring for HIV-positive women.[11] Each respondent was given a copy of the questionnaire, a cover letter and a prepaid, pre-addressed return envelope. Anonymity was maintained by not collecting identifying information. Duplication was avoided by a statement in the cover letter asking women who had already completed the questionnaire elsewhere to mark a box and return the blank questionnaire in the envelope provided.

The study was approved by the Ethics Committee for Human Experimentation at St. Paul's Hospital, Vancouver.

Questionnaire

The questionnaire consisted of 75 multiple-choice and short-answer questions divided into 5 sections: sociodemographic characteristics; risk factors for HIV infection and details about HIV testing; health status and medical treatment; use of health care services and degree of satisfaction with medical care; and psychosocial stressors. Many of the multiple-choice questions contained the response option "other," with space for written comments.

Sociodemographic characteristics included age, ethnic or racial origin, education, employment status, annual household income, place of residence (derived from the first 3 letters of the postal code), sexual orientation, relationship and family situation. The respondents were asked whether they had ever been sexually assaulted or raped as an adult or sexually abused as a child. The terms "sexually assaulted/raped" and "sexually abused" were not specifically defined. Items regarding testing included reasons for having an HIV test, where and when the first positive result occurred, and opinions about pre- and post-test counselling. The responses to questions about attitudes toward family doctors, level of satisfaction with medical care and psychosocial stressors were graded on a 5-point Likert scale, a positive response being defined as a rating of 4 or 5.

The questionnaire was developed in consultation with local medical experts, an epidemiologist, a statistician, community AIDS educators and HIV-positive women at the BC Positive Women's Network (the province's largest support and advocacy group for women with HIV infection or AIDS). The questionnaire was pretested among a group of HIV-positive women attending a weekend retreat. Two new questions were added based on the feedback from the pretest group. The results from the pretest group were included in the final analysis. A copy of the questionnaire is available from us on request.

Analysis

We carried out analyses using SPSS software (version 3, SPSS Inc., Chicago). Frequency tables were constructed for categoric variables, and means and standard deviations were computed for scale variables. We assessed relations between categoric variables using cross-tabulations and χ^2 tests of independence. The effects of categoric variables on the psychosocial stressor items were examined with *t*-tests and one-way analysis of variance.

After data collection was completed, a focus group was conducted in March 1996 to discuss and review the interpretation of the results. The focus group consisted of 9 HIV-positive women, 1 family member and 1 community HIV and AIDS educator. The focus group session was 2 hours long and was recorded on audiotape, and field notes were taken. The audiotape was transcribed verbatim and reviewed for recurring dominant themes. These themes are highlighted in the Discussion.

Results

Sociodemographic characteristics

The sociodemographic characteristics of the 110 women who completed the questionnaire are shown in Table 1. Most were white (80.9%) and had been born in Canada (76.4%). The majority lived in the Vancouver lower mainland. Forty-four women (40.0%) had had a decrease in income since their diagnosis with HIV infection, and 32 (29.1%) had had an increase in income. A total of 47 women (42.7%) were receiving welfare. Of the 57 women who reported having children, 7 (12.3%) had at least one HIV-positive child. Sixty-five women (59.1%) had had a family member or friend die of AIDS; in 5 cases it was the woman's child. A total of 63 women (57.3%) had at least one current regular sex partner, and in 13 cases (20.6%) the woman was aware that her partner was HIV-positive.

Risk factors and HIV testing

Sex with a man was the risk factor most commonly reported (Table 2). None of the lesbian or bisexual women reported sex with a woman as a risk factor.

Of the 81 women who were asked about prior sexual assault or abuse, 43 (53.1%) reported being sexually assaulted as an adult, 35 (43.2%) reported being sexually abused as a child, and 22 (27.2%) reported being sexually abused or assaulted both as a child and as an adult. Seventy-five women indicated that they had become infected with HIV through sex with a man, with or without injection drug use. Of these, 65 indicated whether or not this was the result of sexual assault or rape; 8 (12.3%) answered affirmatively. The women who reported a history of childhood sexual abuse had a different distribution of risk factors for HIV infection than those who were not abused as children (Table 2). Women who identified injection drug use as a risk factor were more likely than those without this risk factor to have a history of childhood sexual abuse (86.4% v. 30.2%) ($p < 0.001$) and were twice as likely to have been sexually assaulted as an adult (80.0% v. 41.0%) ($p = 0.001$).

A total of 53 women (48.2%) received their first positive test result in 1991 or earlier. Ten women (9.1%) were not aware that they were being tested for HIV at the time of their first positive result. The proportion varied according to the location of the test: 37.5% (3/8) at the Canadian Red Cross Society, 17.4% (4/23) at a hospital, 10.5% (2/19) at the street nurse or STD clinic and 2.4% (1/41) at a family doctor's office. Most of the women (87 [79.1%]) were given their test result in person, 19 (17.3%) received their result by telephone, and 4 (3.6%) obtained the result by mail or by reading their medical chart. Seventeen women (15.4%) had been refused HIV testing in the past.

Overall, 75 women (68.2%) stated that they had received inadequate pretest counselling, and 67 (60.9%) reported receiving inadequate post-test counselling. These proportions were similar when examined by place of residence, location of first positive test result and time of testing (1991 or earlier v. after 1991).

Health status and medical treatment

A total of 92 women (83.6%) knew their most recent CD4 count. The CD4 count ranged from 0.002 to 1.4×10^9/L (mean 0.385 [standard deviation 0.271] $\times 10^9$/L, median 0.35×10^9/L). Of the 92 women 60 (65.2%) reported a count of less than 0.5×10^9/L, and 26 (28.3%) reported a count of less than 0.2×10^9/L.

A total of 27.5% (25/91) of the women had decided that they did not want to try antiretroviral therapy, and 31.1% (33/106) had decided to stop antiretroviral therapy after starting it. Of the 60 women with a CD4 count of less than 0.5×10^9/L, 54 (90.0%) stated that their doctor recommended antiretroviral therapy, and 27 (45.0%) were actually receiving it. The most frequent concerns about antiretroviral drugs were perceived lack of effectiveness

Table 1: Characteristics of 110 HIV-infected women in British Columbia

Characteristic	No. (and %) of women
Age, yr	
< 25	11 (10.0)
25–39	77 (70.0)
> 39	20 (18.2)
No answer	2 (1.8)
Marital status	
Married/common-law	36 (32.7)
Single	33 (30.0)
In a relationship	18 (16.4)
Separated/divorced/widowed	23 (20.9)
Ethnic origin	
White	89 (80.9)
First Nations	12 (10.9)
Other	6 (5.4)
No answer	3 (2.7)
Country of birth	
Canada	84 (76.4)
Europe or Australia	11 (10.0)
United States	5 (4.5)
Developing country	4 (3.6)
No answer	6 (5.4)
Education	
Less than high school	43 (39.1)
Completed high school	15 (13.6)
Some university/college courses	21 (19.1)
University/college degree	21 (19.1)
Other	8 (7.3)
No answer	2 (1.8)
Employment status	
Employed	28 (25.4)
Permanently disabled	32 (29.1)
Unemployed	23 (20.9)
Homemaker/student/other	25 (22.7)
No answer	2 (1.8)
Annual household income, $	
< 10 000	33 (30.0)
10 000–19 999	23 (20.9)
≥ 20 000	38 (34.5)
No answer	16 (14.5)
Sexual orientation	
Heterosexual	96 (87.3)
Bisexual	9 (8.2)
Lesbian	5 (4.5)
No. of children in household	
0	48 (43.6)
1	28 (25.4)
≥ 2	29 (26.4)
No answer	5 (4.5)

and fear of side effects. Of the 26 women with a CD4 count of less than 0.2×10^9/L, 24 (92.3%) had had a doctor recommend prophylaxis for *Pneumocystis carinii* pneumonia, and 20 (76.9%) were actually taking it. The frequency with which the women reported receiving certain vaccinations is shown in Table 3.

Of the 97 women who responded to the question regarding menstrual cycle changes, 68 (70.1%) had experienced some change, 23 (23.7%) reported no change, and 6 (6.2%) stated that the question was not applicable. The most frequently reported changes were irregular periods (30/68 [44.1%]) and heavier periods (25/68 [36.8%]). Of the 20 women with a CD4 count of less than 0.2×10^9/L who responded to the question about their menstrual cycle, 19 (95%) reported a change. The frequency of menstrual cycle changes was higher among women who reported injection drug use as a risk factor than among those without this risk factor (92.0% v. 66.7%). Antiretroviral use did not appear to affect the frequency of menstrual cycle changes.

Use of health care services and satisfaction with medical care

Most of the women (92 [83.6%]) were seeing a family doctor for their general medical care, and 65 (59.1%) were seeing a family doctor for care of their HIV infection or AIDS. A total of 74 women (67.3%) reported that they were visiting their doctor at least once a month. Fifty women (45.4%) said that they did not receive medical care for HIV in their own community; 22.5% (9/40) reported that they had to travel more than 50 km.

Of the 83 women who had a family doctor around the time they received a positive test result, only 23 (27.7%) felt that their doctor was up-to-date with regard to medical knowledge about HIV and AIDS, 55 (66.3%) felt that their doctor was compassionate and respectful, 52 (62.6%) felt that their doctor was willing to treat HIV-positive patients, and 39 (47.0%) were satisfied with their doctor's care. Of the 84 women who answered the question about whether they had switched family doctors since the diagnosis of HIV infection, 53 (63.1%) had done so, primarily because of dissatisfaction with their doctor's care. Of the 110 women 40 (36.4%) reported that their doctor had discussed issues related to pregnancy with them; in almost all cases the doctor recommended against pregnancy. Since their diagnosis with HIV infection, 19 women (17.3%) had had a doctor refuse to see them. A doctor's refusal to see the woman was more common among women with a positive test result in 1991 or earlier than among those with a positive result after 1991 (32.0% v. 5.5%, $p < 0.001$).

Psychosocial stressors

Of the 14 potential psychosocial concerns 3 received considerably higher mean ratings than the others: not having enough money, lack of intimacy or satisfying sexual relationship, and fear of rejection or discrimination (Table 4). There was no significant difference in the order of ranking according to year of first positive test result (1991 or earlier v. after 1991) or CD4 count. Twenty-two women (20.0%) did not know other HIV-positive women, and 19 (17.3%) did not know any HIV-positive men.

Table 3: Frequency of vaccinations

Vaccination	No. (and %) of women
Influenza*	70 (63.6)
Tetanus†	66 (60.0)
Pneumococci	51 (46.4)
Hepatitis B	46 (41.8)
Polio†	31 (28.2)
Haemophilus influenzae type B	22 (20.0)

*Given within previous year.
†Given within previous 10 years.

Table 2: Risk factors for HIV infection by history of childhood sexual abuse

Risk factor	Group; no. (and %) of women			
	Sexually abused as child *n = 35*	Not sexually abused as child *n = 40*	No answer/ not asked* *n = 35*	Total
Sex with a man	10 (28.6)	25 (62.5)	19 (54.3)	54 (49.1)
Sex with a man and injection drug use	9 (25.7)	3 (7.5)	9 (25.7)	21 (19.1)
Injection drug use	10 (28.6)	0 (0.0)	4 (11.4)	14 (12.7)
Blood transfusion	0 (0.0)	6 (15.0)	0 (0.0)	6 (5.4)
Artificial insemination	2 (5.7)	0 (0.0)	0 (0.0)	2 (1.8)
Needle-stick injury	1 (2.8)	0 (0.0)	0 (0.0)	1 (0.9)
Unsure	3 (8.6)	6 (15.0)	2 (5.7)	11 (10.0)
No answer	0 (0.0)	0 (0.0)	1 (2.8)	1 (0.9)

*Includes women who participated in the pilot study, who were not asked about childhood sexual abuse, and women who preferred not to answer.

Discussion

Most of our respondents were white, were Canadian born and had a household income of less than $20 000 per year, and over half had children. An improved understanding of the sociodemographic characteristics of HIV-infected women and the risk factors for HIV infection may enable physicians to better identify women at risk and increase their willingness to test women for HIV infection.

A disturbingly high proportion of women (69.1%) reported childhood sexual abuse or sexual assault as an adult, or both. The reported prevalence of childhood sexual abuse in the general population of women varies widely (6% to 59%).[12,13] This wide range has been attributed in part to the variety of definitions of "child" and "sexual abuse" as well as variation in study populations and quality of study design.[13] Since our survey did not provide a specific definition of "childhood sexual abuse," direct comparison with other studies is limited. Other investigators have explored the possible association of childhood sexual abuse with increased risk for HIV infection in both women and men.[14–19] Some characteristics associated with childhood sexual abuse that may lead to increased risk of HIV infection include increased drug and alcohol use, increased prevalence of depression or passive suicidal behaviour and increased frequency of prostitution.[15,16,19] Further evaluation and increased understanding of the possible link between childhood sexual abuse and risk for HIV infection may be of value in developing strategies for preventing HIV transmission.

The alarming rate of heterosexual transmission of HIV through nonconsensual intercourse observed in our study has not previously been reported in British Columbia. This finding highlights the importance of collaboration and communication between those working to stop violence against women and those working in prevention of HIV infection.

Table 4: Psychosocial problems experienced quite often or most of the time

Problem	No. (and %) of women
Not having enough money	67 (60.9)
Lack of intimacy or satisfying sexual relationship	59 (53.6)
Fear of rejection or discrimination	57 (51.8)
Own health/medical problems	45 (40.9)
Insufficient money for medications and therapies	44 (40.0)
Lack of affordable housing	42 (38.2)
Lack of transportation	38 (34.5)
Dealing with illness in a family member	33 (30.0)
Not having enough emotional support	32 (29.1)
Fear of loss of job	26 (23.6)
Insufficient medical information about HIV infection issues	24 (21.8)
Lack of good counsellors or therapists	21 (19.1)
Insensitivity on the part of health care workers	19 (17.3)
Inadequate child care	14 (12.7)

Over half the women in our survey reported an annual household income of less than $20 000, and 42.7% were receiving welfare. Similar findings have been reported for HIV-infected women in Ontario and Quebec.[10,20] It is unclear from our study whether poverty predisposed women to HIV infection or whether HIV infection led to poverty. Another study in British Columbia showed that poverty is associated with decreased survival among HIV-infected homosexual men.[21]

More than half the women surveyed expressed dissatisfaction with their family doctor's care, most felt that they had not received adequate pre- and post-test counselling, and almost 1 in 5 had had a physician refuse to see them because they were HIV-positive. It is clear that there is room for improvement in the medical care of HIV-positive women. However, it is beyond the scope of this study to determine the most effective approach to this problem. A physician education project was undertaken in conjunction with the BC Positive Women's Network and Health Canada in 1995–96 in the form of medical grand rounds about the care of women living with HIV infection or AIDS. This project was designed to inform Vancouver-area physicians about the concerns expressed by women in the survey.[22] Whether it will lead to a change in physician behaviour remains to be seen.

A limitation of our study is that the sample population may not be representative of all women with HIV infection or AIDS in British Columbia. This is in part because of the difficulty in identifying the study population owing to anonymous testing and patient confidentiality issues, the lack of a provincial registry of HIV-infected people and difficulty reaching the street-involved, indigent population with HIV infection. It is not known how many HIV-positive women who were approached by their physician or a community group chose not to participate in the survey. A statistical back-calculation estimated that at least 600 women were infected with HIV in the province around the time this survey started and that a large proportion — as many as 50% — were not aware that they were infected.[2] Taking into account the continued rise in the number of women testing positive for HIV during the course of the study, we estimate that 15% to 25% of HIV-positive women in the province were surveyed.

Conclusion

Our study identifies several important concerns among the HIV-positive women surveyed. Some of the recurring themes are dissatisfaction with medical care, fear of dis-

crimination, violence and abuse, and poverty. An understanding of these central issues may provide initial direction for those working in prevention of HIV infection, community service groups, funding agencies, health care providers and researchers.

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