ABSTRACT

Forty HIV-positive women from diverse socioeconomic backgrounds were interviewed. Most (90%) did not perceive themselves to be at risk of HIV infection prior to knowing their HIV-positive status. The majority (61%) were tested because they developed symptoms, or because someone with whom they were intimate, or their child, tested positive for HIV or became ill. The majority (93%) of the women interviewed indicated that they did not receive both pre- and post-test counselling.

The findings from this study suggest that encouraging individuals to be tested if they have engaged in "at risk" activities will not be appropriate for individuals who have no perception of risk, and other strategies to encourage appropriate testing may be needed. This research also suggests that continued emphasis needs to be placed on the counselling process, and that consideration may need to be given to multiple counselling sessions to ensure individuals clearly understand the information provided.

ABRÉGÉ

Quarante femmes séropositives au VIH issues de milieux socioéconomiques divers ont été interviewées. La majorité d'entre elles (90 %) ne se percevaient pas comme courant des risques d'infection par le VIH avant d'apprendre leur sérodiagnostic. La plupart (61 %) ont fait l'objet d'un dépistage soit en raison de l'apparition de symptômes, soit parce que leur enfant ou une personne avec laquelle elles entretenaient des relations intimes était séropositif au VIH ou bien était tombé malade. La majorité des femmes interviewées (93 %) ont indiqué qu'elles n'avaient pas bénéficié des deux types de counselling, à savoir tant avant qu'après le test de dépistage.

Les résultats de cette étude tendent à montrer qu'encourager les individus à se faire dépister s'ils ont pris part à des activités «à risque» ne convient pas aux personnes qui ne perçoivent pas les risques et qu'il peut être nécessaire de mettre au point d'autres stratégies pour favoriser le dépistage. Cette étude indique également qu'il faut continuer d'insister sur le counselling et qu'il peut être nécessaire d'envisager de multiples séances de counselling pour s'assurer que les individus comprennent clairement l'information qui leur est donnée.

HIV-positive Women Living in the Metropolitan Toronto Area: Their Experiences and Perceptions Related to HIV Testing

Lois A. Jackson, PhD,^{1,2} Peggy Millson, MD,^{1,3,4} Liviana Calzavara, PhD,^{1,4}
Anita Rachlis, MD,^{5,6} Cheryl Rowe, MD,⁷ Steffanie Strathdee, PhD,^{8,9}
Cheryl Wagner, MD,¹⁰ Sharon Walmsley, MD,^{5,11}
and The HIV Women's Study Group¹²

It is estimated that worldwide approximately nine million women have been infected with HIV.¹ To date in Canada, over 600 female adult AIDS cases have been reported,² and there may be as many as 4,000 to 5,000 HIV-positive women living in the country. In Ontario, 1,374 confirmed positive female cases have been reported and this is approximately 9% of the total confirmed cases in the province.³ The number of known female HIV infections by year of diagnosis in Ontario increased from 6 or approximately 2% of total cases in 1985, to 236 or 14% of total cases in 1994.³

According to a number of studies, the medical and social needs of HIV-positive

women are frequently improperly addressed by health-care professionals, service agencies, and policy makers.⁴⁻¹⁰ A major reason for the relative lack of attention to women's needs is the perception (especially prevalent in the 1980s and early 1990s) that HIV is a "gay man's" disease.^{4,6} Until quite recently, women in Canada, as well as in many other Western countries, were viewed as caregivers for others who are HIV positive, but they themselves were not considered to be at great risk of becoming infected, particularly if they did not belong to traditionally defined risk groups such as injection drug users.¹¹

As more and more women are becoming infected with HIV, increasing attention is being given to understanding HIV-positive women's experiences related to HIV. Researchers are examining how women's "place" in this epidemic is different from men's because of gender-related biological differences, the different roles women and men play in our society, and gender-related socioeconomic inequities. There is also an attempt to redress the current void in our understanding of the social, economic, emotional, and psychological impacts of HIV on women, and to examine gender differences in physical symptoms and mortality rates.^{5,6,12-16}

We seek here to add to this small, but growing, body of literature on women's needs and experiences related to HIV. Based on interviews with 40 HIV-positive women living in the Metropolitan Toronto area, we present information on women's perceptions of risk of HIV prior to an HIV diagnosis, and we also describe the women's experiences related to HIV test-

1. The Department of Preventive Medicine and Biostatistics, University of Toronto
2. City of Toronto, Teaching Health Unit
3. City of Toronto, Department of Public Health
4. HIV Social, Behavioural and Epidemiologic Studies Unit, University of Toronto
5. Department of Medicine, University of Toronto
6. Sunnybrook Health Sciences Centre
7. Department of Psychiatry, University of Toronto
8. British Columbia Centre for Excellence in HIV/AIDS
9. Department of Health Care and Epidemiology, University of British Columbia
10. HIV Primary Care Group
11. Toronto Hospital
12. Ontario HIV Clinics, Physicians and Community (HIV-related) Service Organizations

This research was funded by the Ontario Ministry of Health (Grant #04818F) and Burroughs Wellcome Positive Action Programme

Correspondence and reprint requests: Lois A. Jackson, Assistant Professor, Department of Preventive Medicine and Biostatistics, 4th Floor McMurrich Bldg., 12 Queen's Park Crescent West, University of Toronto, Toronto, ON M5S 1A8, Tel: 416-978-4320

During this work Dr. Millson received support from the City of Toronto Department of Public Health, Dr. Calzavara was supported by a National Health Scholar award, and Dr. Strathdee by a National Health and Welfare Post-doctoral award.

ing with a special focus on the reasons for being tested, and their perceptions of pre- and post-test counselling.

METHODS

From October 1994 to February 1995, 40 interviews were conducted with a convenience sample of HIV-positive women. One of the major goals of the interviews was to pre-test an interview schedule that was to be used in a future study involving HIV-positive women from across the province. However, the interviews were also aimed at obtaining information from the 40 women concerning a number of key social, psychological, and economic issues, and it is some of this information that is presented here. The interview schedule was constructed based on consultations with over 15 community organizations providing services to HIV-positive women, and physicians treating HIV-positive women. Questions about sociodemographic background, HIV testing experiences, and the socioeconomic and emotional impact of HIV were part of the questionnaire.

In order to obtain some understanding of the diversity of women's experiences, women of different ages and from varied socioeconomic backgrounds were approached by Metropolitan Toronto physicians and community groups, and asked to participate in the study. Any woman agreeing to participate was asked to telephone the study co-ordinator, or if she preferred, her first name and telephone number was given to the study co-ordinator by the contact person. A notice was also placed in the newsletter of an HIV/AIDS community organization aimed at HIV-positive women in the province ('Voices of Positive Women') in order to help communicate information about the study to HIV-positive women on their mailing list, and potentially access women who might not otherwise be reached through a physician or community group. Of the 40 women interviewed, 58% (23) were recruited through a physician, 30% (12) through a community-based group, and 13% (5) through the 'Voices of Positive Women' newsletter or another source.

It is unknown how many of the HIV-positive women approached by community

Characteristic	Number	(%)*
Age (Average 38 years, Median 34 years, Range 23-70 years)		
<40 years	23	(58)
≥40 years	17	(43)
Income (Annual Household)(n=38)		
\$5,000 – \$24,999	14	(37)
\$25,000 – \$49,999	16	(42)
\$50,000 – \$99,999	7	(18)
\$100,000 – \$150,000	1	(3)
Highest Educational Level Achieved (n=38)		
Some or all High School	25	(66)
Community college	6	(16)
University (Undergraduate)	3	(8)
University (Graduate/Professional degree)	4	(11)
Children		
Yes	24	(60)
No	16	(40)

* Percentages do not always add up to 100 because of rounding error

Mode of Transmission	Reasons for Lack of Perception of HIV Risk					
	With One Partner	Did Not Think About HIV/Not Relevant	HIV Confined to Gay Community/High Risk Groups	Did Not Know Anything About HIV	Not Sexually Active	Other Reasons
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Sexual transmission	8 (26)	7 (23)	3 (10)	1 (3)	1 (3)	1 (3)
Blood or blood products	2 (6)	1 (3)	1 (3)	—	—	2 (6)
IDU	—	2 (6)	—	1 (3)	—	—
Unknown	—	—	1 (3)	—	—	—
Total	10 (32)	10 (32)	5 (16)	2 (6)	1 (3)	3 (10)

* Percentages are calculated with reference to the overall N of 31. Percentages do not add up to 100 because of rounding error.

groups or physicians decided not to volunteer for this study. However, a previous study concerning the willingness of HIV-positive women (living in Ontario) to participate in an interview-based psychosocial issues research project, reported that 68% of the 177 HIV-positive women surveyed indicated that they would be willing to participate, 10% were uncertain, 20% said they would not be willing to participate, and 3% did not provide an answer.¹⁷ This study also found that 'willingness to participate' was not strongly associated with sociodemographic variables or with HIV

illness or mode of infection although it was associated with need for support.

In our study, a written 'Letter of Information' was provided to each woman prior to the interview, and the purpose of the study was explained verbally before obtaining informed consent. The interviews were conducted at a time and place convenient for each woman, and in a setting that ensured confidentiality. All the women were interviewed in English by the same trained female interviewer, and at the time of the interview all of the women were living in the Metropolitan Toronto

area. Each interview lasted between 1 hour and 2 1/2 hours with the average interview taking approximately 1 1/2 hours to complete.

Information from the closed-ended questions was coded and entered into a SAS database, and is presented according to the number/percentage of women reporting a specific practice/experience/belief. A formal statistical analysis was not undertaken because of the small number of women interviewed. Information concerning testing and counselling experiences obtained from open-ended questions was classified manually according to common themes, and rank-ordered from most com-

mon to least common. This information is presented as descriptive qualitative data.

RESULTS

Sociodemographic characteristics (see Table I)

The average age of the women was 38 years. Most of the women (26 or 65%) were not employed outside of the home at the time of the interview. Approximately one third of the women (14 or 32%) reported an annual household income of between \$5,000-\$24,999 indicating that many may be at, or close to, the "unofficial" poverty line developed by Statistics

Canada. (The current Statistics Canada poverty line is \$15,454 for a family of one, and \$20,945 for a family of two.) Just over one half of the women (24 or 60%) have, or have had, a child(ren). Of these 24 women, 2 (8%) had a child who had died of HIV-related complications prior to the interview, and 2 (8%) had a living child who was HIV positive.

Reported mode of infection and health status (see Figures 1 and 2)

The majority of the women (28 or 70%) reported that they were infected through sexual transmission, and one woman reported that her infection was the result of a rape. Smaller numbers of women were infected through contaminated blood or blood products (7 or 18%) or injection drug use (4 or 10%). One half (20 or 50%) of the women indicated that they were asymptomatic at the time of the interview, 12 or 30% symptomatic, and 6 or 15% reported that they had AIDS.

Perceptions of health risks prior to knowing HIV status

The majority of the women (36 or 90%) either had no perception of any great health risk prior to testing positive for HIV, or perceived themselves to be at risk of diseases and disorders other than HIV. Only 9 (23%) women perceived themselves to be at any or some risk of HIV, and this perception was because of unprotected sex (7 women), the sharing of injection drug equipment (1 woman), or a blood transfusion (1 woman). The reported reasons for not having any perception of risk were as follows: had one partner only (10 or 32%); never thought about HIV/ thought it was not relevant to them (10 or 32%); thought it was a "gay disease" or confined to "high risk" groups (5 or 16%); did not know anything about HIV (2 or 6%); and, were not sexually "active" (1 or 3%). (See Table II).

HIV-testing experiences (see Table III)

The most common reported reason for testing was because the woman had some direct knowledge that someone with whom she had been intimate (sexually or through the sharing of injection drug equipment)

TABLE III
HIV Testing

Times Tested (n=40)*	Number	(%)†
1 – 2x	27	(68)
3 – 4x	10	(25)
> 4x	3	(8)
Where Tested‡		
Physician's office	17	(46)
Hospital or clinic (HIV/STD)	14	(38)
Anonymous testing site	7	(19)
Insurance company	5	(14)
Jail or detention centre	2	(5)
Blood donation	2	(5)
Why Tested (n=40)		
Sexual contact, or sharing IDU equipment with HIV+ person	13	(33)
Symptomatic	9	(23)
Insurance screening	5	(13)
Donated blood	3	(8)
Toronto Hospital for Sick Children press release/direct contact reports/called	2	(5)
Child ill	2	(5)
Other (e.g., raped)	6	(15)
Time Between Infection (Believed) and Knowledge that HIV+ (n=34)		
2 years or less	16	(47)
> 2 years – 4 years	6	(18)
> 4 years	12	(35)

* The reason(s) for multiple testing, i.e., more than 2x, is not known. The questionnaire asked about reason(s) for testing and number of times tested but not reason for each test. It is assumed that testing two times is, in many cases, confirmation of the results.

† Percentages do not always add up to 100 because of rounding error.

‡ Numbers add up to over 40 and percentages add up to over 100% because of multiple testing at different types of facilities.

was symptomatic or had died of AIDS (13 or 33%). Nine women (23%) indicated that they were tested because they themselves were symptomatic, and 2 women (5%) because their child was ill. Eight women (21%) indicated that they did not directly initiate testing, but rather, were tested for insurance policy purposes or because of a blood donation, and 2 women (5%) heard about The Toronto Hospital for Sick Children's attempt to trace individuals who had potentially been infected by contaminated blood or blood products.¹⁸ Thirty-four women indicated that they know, or believe they know, the year in which they were infected, and of these 34 women, approximately one half (18 or 53%) were tested and told of their infection more than two years after they believe they were infected. The years during which the women were tested ranged from 1986 to 1994.

Pre- and post-test counselling

The majority of the women interviewed (37 or 93%) indicated that they did not receive both pre- and post-test counselling: 20 women (50%) received post-test coun-

selling only, and 17 women (43%) indicated that they did not receive any counselling. Only 3 (8%) women reported that they received both pre- and post-test counselling.

Of the 17 women who stated that they did not receive any counselling, 8 were tested between 1986-89, 5 between 1990-92, and 4 between 1993-94, suggesting that the year of testing may not play a significant role in the type of counselling received. Likewise, of the 20 women who reported that they received only post-test counselling, 5 were tested between 1986-89, 9 between 1990-92, and 6 between 1993-94. The 3 women who reported that they received both pre- and post-test counselling, indicated that they were tested in 1986, 1992, and 1994 respectively.

The women interviewed were not specifically asked how they were told about their HIV status, but 2 women (tested in 1988 and 1991 respectively) did indicate that they were told over the telephone, and 1 woman (tested in 1990) reported that the message was given to her husband.

CONCLUSIONS

Limitations of the study

The information presented here is based on a convenience sample of women, and therefore, the numbers/percentages of women reporting a specific perception of an issue or a particular experience should not be generalized and interpreted as reflecting the ranking of perceptions and experiences for all HIV-positive women. Moreover, this study is not intended as a complete summary of all the testing-related issues that may be of importance to HIV-positive women. However, the information does add to our current understanding of some of the issues and concerns related to HIV-testing for women.

'Risk' of HIV infection

Our research indicates that some women do not perceive themselves to be at risk of HIV, or if HIV is considered to be a risk, it is perceived as a low risk. This suggests that focussing on "risks" may not be an effective prevention strategy for at least some groups or segments of the population. For some women, traditional gender roles that emphasize women's role in caring for, and trusting, others (rather than concern about personal health risks) may translate into a lack of concern about their own health.^{9,19} Alternatively, some women may assess their health risks but HIV does not rank high enough to be acted upon. In particular, in cases where the woman's life is associated with poverty and other sub-optimal material conditions, HIV (as well as other infectious diseases) may not be a high priority.^{20, 21}

As studies of prostitutes have reported, individuals may experience everyday risks (such as violence on the streets for prostitutes) as much more important to their health than HIV.²¹ This suggests that we need to be cognizant of the multiple and inter-related health risks in individuals' lives if we are to develop appropriate prevention programs aimed at reducing rates of HIV infection.

HIV testing

It has been found that gay men are often tested for HIV because they perceive themselves to have engaged in high risk activi-

ties.²² This stands in contrast to our study which suggests that for some women, perception of having engaged in a "risky behaviour" is not a motivating factor behind HIV testing. Indeed, many women reported that they were tested only because someone with whom they had been intimate was found to be HIV-positive or became ill, or the woman herself became ill. This is consistent with a study of HIV-positive women living in England which found that the majority of the women were tested not because they felt at risk of HIV, but because they developed HIV-related symptoms.²³

Under-diagnosis of HIV due to physicians' inability to recognize symptoms in women has been suggested as a possible reason for delayed treatment and the inability to access treatments that can potentially delay the development of symptoms.¹⁶ Based on this study, we can also suggest that delayed treatment may occur because testing is not initiated until well after infection, given a lack of perception of risk of HIV.

The Ontario Provincial Laboratory indicates that for the past two years, more than 50% of the samples that have been received for HIV testing are from women.²⁴ This raises questions about who is seeking testing and why. It is possible, for example, that messages about testing are causing fear of HIV for some women who are then motivated to be tested, while for other women, HIV testing is not sought even though it might be appropriate to do so. One Australian study found that some women and men are tested for HIV not because of a real personal assessment of risk but as a symbolic closure to a relationship or a commitment to a new sexual partner.²⁵ Regardless of the reason(s), however, it does appear that the motivations for testing may be different for different groups of women and this may require a re-thinking of public health strategies to encourage appropriate testing.

HIV counselling

Many of the women interviewed for this study reported that they were not provided with full pre- and post-test counselling. This raises serious concerns about the counselling process, and suggests that there

may be a need for multiple counselling sessions to ensure that women are receiving and understanding HIV-related information. In addition, more education for physicians and other health professionals about the recommended counselling and notification process may be required to ensure that appropriate HIV counselling is provided.^{26,27} Appropriate and thorough counselling is clearly needed if women are to be adequately prepared to respond to the health and psychosocial issues resulting from HIV infection.

ACKNOWLEDGEMENTS

We thank the community groups and physicians who assisted in the development of the questionnaire and recruitment of volunteers, and we also thank Vivian Rabinovich for her important contribution to the study. Special thanks are extended to the 40 HIV-positive women who volunteered their time, and shared their perceptions and often painful experiences related to HIV.

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Received: June 28, 1996

Accepted: December 10, 1996