

Listen Up!

Women Are Talking About....

Women's Health Research Project
Phase 1 Report



The social determinants
of women's risk for HIV
infection and illness
progression in Lower
Mainland British Columbia

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and the Listen Up! Project Advisory Group

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Table of Contents

Acknowledgements	2
Summary	5
Background and History of the Project	8
<i>Phase 1 - Methodology</i>	9
<i>Phase 2 -Methodology</i>	11
<i>Limitations of Method - Phase 1</i>	11
<i>Focus Groups verses one-on-one interviews</i>	12
Who Participated in the Research.....	13
Findings	14
Income	14
<i>Classism and Discrimination</i>	14
<i>Food</i>	15
<i>Housing</i>	16
.....	16
<i>The Environment of the Downtown Eastside: cleanliness, safety, and police harassment</i> 16	
<i>The Role of Governments and Cutbacks to Social Services</i>	19
Power In Intimate Relationships	22
.....	22
<i>The Positive Power of Relationships</i>	22
<i>Violence in Intimate Relationships</i>	22
<i>Emotional Abuse and Manipulation</i>	23
<i>Care-givers, Not Cared For</i>	24
<i>Disclosure and the Balance of Power in Intimate/Romantic Relationships</i>	25
<i>Safer sex</i>	26
Relationships To Health Care Providers And Institutions	29
<i>Positive Relationships</i>	29
<i>Experiences of Discrimination from Health Care Providers</i>	30
<i>Addictophobia</i>	30
<i>Homophobia</i>	31
<i>Being Discriminated Against for Being HIV+</i>	32
<i>Discrimination due to Having a Severe Mental Illness</i>	33
<i>Sexism</i>	34
<i>Classism and Discrimination due to Being Poor</i>	34
<i>The Experience of Being a Refugee or Immigrant</i>	35
<i>Culturally Appropriate Health Care</i>	35
<i>Getting Access to Complementary or Alternative Therapies</i>	36
<i>Being Given Inadequate Treatment Information</i>	36
<i>Health Education and Research</i>	37
Discrimination From Other Social Institutions	38
<i>Homophobia</i>	38
<i>Racism</i>	39
<i>Sexism</i>	40
<i>Addictophobia</i>	41

<i>Discrimination due to having a Severe Mental Illness</i>	42
<i>Discrimination due to being HIV+</i>	43
Problems With AIDS Services And AIDS Service Organizations	44
What We Have Learned	47
Recommendations	50
Directions For Future Action	52
References	53
Appendix A: Demographic Information	55
Appendix B: Consent Forms	60
Appendix C: Discussion Guide Questions	64
Appendix D: Evaluation Form	71
Appendix E: Demographic Information Form	72

Summary

All too often, when women get sick we are blamed for it as though we did something wrong (or failed to do something right) by becoming ill. One of the hopes of the Listen Up! project is to stop the blaming of individual women and focus on the social determinants of health — and in particular, women's HIV infection and illness progression. When a literature search done for the project (Kong, 1998) found no published Canadian research on this topic, the need for this project became even clearer. The three social factors we were especially interested in were: income; power in intimate relationships and relationships with health care providers.

The literature search also found that women's voices were not being heard in the research on HIV/AIDS frequently enough. Because this kind of research is usually focused on the thoughts and ideas of care-givers and/or theorists, we set out to create a project that would focus on the words of women in communities.

With these two aims in mind, the first phase of the project involved six focus group discussions with women from diverse communities. Women taking part identified with the following communities or contexts:

- are living with HIV
- sleep with women or are bisexual
- have a mental illness
- are First Nations
- are current or former substance users
- are Spanish-speaking refugees or immigrants.

These discussions brought women together to talk about what they feel are the social factors that influence their health. We hoped to be able to discover with women their risk for HIV infection and produce a document that could be used both to guide program development for AIDS service organizations (ASOs) and as an advocacy tool for the communities involved.

The discussions provided a lot of very rich information. Women pointed to many different social factors they felt had affected their ability to keep healthy. These included:

- 1) **Income** Women who were living in poverty experienced discrimination and marginalization because they were poor which affected their ability to keep healthy. Being poor also made it difficult for women to get enough nutritious food, stable housing, and transportation. It often meant that they were forced to live and/or work in dangerous conditions. Inadequate services and the constant threat and/or reality of cutbacks to government programs only made the situation more stressful.

2) Power in Intimate Relationships Physical and sexual abuse, as well as emotional abuse or manipulation, of women by their intimate partners all got in the way of women's best health. Also, women's socially ascribed responsibilities as care-givers in heterosexual and familial relationships made it hard for them to assert their own needs and have them met. Negotiating safer sex, in both heterosexual and lesbian/bisexual relationships, where power was unevenly distributed had often been difficult for the women in the study.

3) Relationships with Health Care Providers and Institutions Women shared they were discriminated against or received substandard or inadequate health care because a they were:

- living with HIV
- women who sleep with women or are bisexual
- diagnosed with a mental illness or dual diagnosis
- Aboriginal
- a current or former substance user
- a refugee or immigrant
- poor
- a woman

These were the most common problems women reported having with the health care system. The expense of and lack of respect for complementary and alternative health therapies in the main-stream medical system was the next most commonly cited concern.

4) Discrimination from Other Social Institutions Women talked about being discriminated against because of their:

- race
- HIV status
- mental health status
- immigration status
- language ability
- sexual orientation
- class
- sex

in many parts of their lives. They said that the stress and difficulty of dealing with these situations, regardless of where or with whom they happened, could adversely affect their health.

5) Problems with AIDS services or service organizations

Specifically in relation to HIV/AIDS some of the women saw gaps in the services that are currently available in the region. They pointed to these gaps particularly in relation to the lack of medical and support services to women living with HIV living outside of the City of Vancouver itself and to care-givers and

family members of HIV+ people. Women also repeatedly underlined the need for ASOs, and other community agencies, to start giving out free female condoms as they currently do with male ones.

In Phase 2 of the project we will be recruiting women from the same six communities. They will be trained and do research in their home contexts. These peer researchers will work with women to identify possible solutions and priorities for action to address some of these problems. By working to empower communities with the tools to make the kinds of changes they want to see happen, we hope to lay the groundwork for creating and sustaining meaningful change.

Background and History of the Project

The need for the project was first identified when a literature review, done for the project (Kong, 1998), found no published Canadian research that looked at the impact of women's social, economic and political realities on HIV infection and illness progression. However, the effects of social factors — such as women's economic inequality, poverty (including access to quality food, housing, etc.), and experiences of violence — on women's health generally have all been well documented in the literature (e.g. Doyal, 1995; Duvall and Booth, 1978; Gabe and Williams, 1987; Nechas and Foley, 1994; Payne, 1991). Additionally, the effects of power in intimate relationships, violence, sexism, poverty/classism, racism, homophobia, and ableism on women's ability to protect themselves from HIV infection and illness progression have all been discussed internationally (e.g. Christensen, 1990; Morrill and Ickovics, 1996; Sobo, 1998; Weiss and Gupta, 1998). However, the way in which these kinds of social factors effect health is different in every place and time for every woman. Which social factors, how they effect each woman and how these effect relationships between people is different.

It was decided that a local research project that examined the ways in which social factors effect women's vulnerability to HIV infection and illness progression in Canada (and particularly in BC) was necessary. This project would help AIDS service organizations, and other women's equality and health advocacy groups, to better understand and respond to the unique health issues women face.

The guiding principles of the project were as follows:

1. Health is defined in a holistic fashion that takes into account social factors, such as gender, race, and class, and the effects they have.
2. The experiences and ideas of the women who participate in the project would inform and determine both its shape and the use of its results.
3. To be community-driven through the use of a community-based, action-oriented research method.

The main goal of the project was:

To develop local knowledge, of health agencies and interested women, about how specific health determinants affect women's risk of HIV infection and illness progression. The specific health determinants to be looked at were:

- 1) *income*
- 2) *power in intimate relationships* and
- 3) *relationships with health care providers and institutions.*

To make this happen, we set out to discover, with the women who participated in the project, what they saw as the main barriers to their best health. We recorded their suggestions and guidance about how AIDS programming and services available to women in the Lower Mainland, especially those offered by the project's two sponsoring agencies - AIDS Vancouver and Positive Women's Network, could be improved. In the end we aimed to develop a document that, in detailing the above, could be used as an advocacy tool to help promote the kinds of social changes women themselves saw as necessary to diminishing their risk.

Positive Women's Network (PWN) and AIDS Vancouver (AV) received funding from Status of Women Canada to do the first phase of the research project. First we gathered together an Advisory Group for the project. The Group consisted of:

- two women who were living with HIV
- three staff people from PWN and AV who had initiated the project
- two people who were service providers to women who live with HIV or are at risk for HIV/AIDS
- one woman who had expertise in feminist academic research on women's health.

The principal role of the Advisory Group was to make the project as responsive as possible to the daily concerns of women both living with and affected by HIV/AIDS in the Lower Mainland. The group also provided us with expert advice on how to best integrate these concerns into the project. The Advisory Group increased the project's accountability to women in diverse communities by bringing the concerns of these communities to the research process.

Phase 1 - Methodology

For this first phase, focus groups were chosen as the best means to collect information from the widest number and variety of women. The six groups were composed of women who:

- are HIV+
- are women who sleep with women or are bisexual
- have been diagnosed with a severe mental illness
- are Aboriginal
- are current or former substance users
- are immigrants or refugees.

These communities were chosen because they had been adversely affected by the HIV/AIDS pandemic or were under-represented in the research literature on HIV/AIDS.

Six focus groups of 4-18 women, one in each community, were

held over nine weeks during the summer of 1999. At each group food and non-alcoholic drinks were available to women before and during it. Women were also paid \$15, and given two bus tickets and child care subsidies if they wanted them. In all cases the groups were held in partnership with either organizations or individuals actively involved in working with women in those communities and these included:

- Positive Women's Network
- Sadie Kuehn, lesbian/bisexual women's health advocate
- Strathcona Mental Health Team
- Healing Our Spirit
- Drug Alcohol Meeting Support for Women (DAMS)
- Streetfront Orientation Services (SOS).

Women's discussions in the focus groups were taped and then transcribed by the project coordinator. After the transcripts for each group were finished, participants had an opportunity to come back to a follow-up meeting where they could read the transcripts and make changes by:

- adding extra background information
- clarifying words that had not been caught on tape
- taking out information or
- asking us to delete information they weren't comfortable with.

The idea for this follow-up meeting came from the Advisory Group who felt it would increase women's ownership of their words as well as ensure both the project's accountability to participants and the transparency of the research process.

In one group, where it was clear there were no literacy concerns, women were simply given the transcripts to read over and comment on. In all other groups, due to literacy issues, the transcripts were handed out and women were asked to volunteer to take turns to read if they wanted to. The second method proved to be the best way to encourage feedback as it gave women an opportunity to discuss topics they wanted to elaborate on or disagree with in the group. Many women who had been very quiet in the first groups spoke frequently and with passion in the follow-up group. At another site where there had been some problems with the first group, the follow-up allowed the project a "second chance" to establish both its good intentions and ability to get the work done, with the women of that community.

Once participants had read over the transcripts and made any changes they wanted, the revised transcripts were coded and analyzed by the project coordinator. A report and a community pamphlet were written in consultation with the Advisory Group. The community pamphlet was a way of getting the results of the

research back to the communities that had participated in a way that was accessible and inclusive. It was important to the project not to simply “take the data and run away” but to work towards the empowerment of women in the communities that participated by sharing information and analysis with them.

An outcome evaluation of the project was set in motion approximately two thirds of the way through the focus group process. The findings and conclusions of the evaluator’s work are detailed in the evaluation report.

Phase 2 -Methodology

The next phase of the research, funded by Vancouver Foundation, to begin in November of 1999, will focus on recruiting peer researchers from the six communities. These researchers will be trained to do focus group and individual interviews/surveys in their home communities. They will also be provided with skills and have input into:

- the design of the research instruments
- data collection
- data coding, tabulation and analysis; and
- the writing of the final report of Phase 2.

Limitations of Method - Phase 1

Limitations on both time and money meant that the project was not always able to follow participatory methods of doing research as closely as we would have liked.

There was not representation from all of the communities involved in the project on the Advisory Group, thus these communities did not have input into the development of the project.

Due to limitations on the number of times those who were on the Group could be asked to meet, group members did not have input into choosing the research methodology, and coding and tabulating data and had limited input in its analysis.

Also, the study was able to reach only a small, voluntary sample of women who were mostly recruited because they were already involved with at least one service-providing organization.

For these reasons the women who participated in this study should not be seen as “representative” of a larger group of women. They speak only for themselves and their issues may or may not be the same as those of other women and in particular other women who are less well connected to service providing agencies. Similarly, only a small number of the many “communities” of women living in the GVRD were reached by the project

and there are many issues and experiences particular to other groups of women that have been missed and not given voice to.

Focus Groups verses one-on-one interviews

The decision to use focus groups itself also created certain limitations as not all women feel comfortable discussing the kinds of issues that were raised by the project in a group setting. This meant that only those who already had a certain level of comfort with the topics would even attend the groups.

Including women who might not feel comfortable in groups was part of the reason why Phase 2 will include a one-on-one survey/ interview instrument that can either be filled out by a woman on her own or with a peer researcher in interview style.

Phase 1 was seen as a time for the project to establish contacts, build trust and become familiar to women in the communities it had chosen to work with. It was also a time to explore the project's assumptions and hypotheses, and test their appropriateness to the diversity of women we hoped to work with. Having completed this phase, we look forward to the next and increasing both the participatory and community-based nature of the research.

Who Participated in the Research

A total of 57 women came to the focus groups. At the end of five of the six focus groups a demographic questionnaire was given out and women were asked to share whatever personal information they felt comfortable sharing. Demographic questionnaires were not distributed at the group for Aboriginal women because both meetings of this group broke up before their scheduled end time as women were either ill, had other commitments or chose to leave early.

Voluntary demographic questionnaire

Previous researchers on women and HIV/AIDS were been reluctant to ask for demographic information from participants because of a fear that women would hesitate to share or record stigmatized or illegal parts of their activities or identities. This reluctance has meant that there is a lack of information about the demographic trends of women infected and affected by HIV/AIDS in Canada (Gillis, 1999). In response to this situation we decided to include a voluntary demographic questionnaire.

Our questionnaire that made it clear to women that they could chose to answer as many or as few of the questions as they wanted to, and also explained why we were asking for this information and how it would be talked about in this report. Forty women (70% of the participants) chose to answer at least one of the demographic questions. Tables illustrating the demographic characteristics of the women who participated in the project are found in Appendix A.

Findings

We, and the women who participated in the project, discovered a lot about what constitutes social barriers to women's best health. Many of the women talked about experiences that spoke clearly and directly to the importance of the three main factors we were initially interested in - income, power in intimate relationships, and relationships to health care providers — in determining their health status. They also talked about other factors — such as the experience of various kinds of discrimination and oppression, and problems with AIDS services and individual service organizations in particular - that they felt had acted as barriers to their best health. The ways in which women talked about each of these factors as influencing their health are laid out in this section.

Income

All of the women in the study agreed that being poor in and of itself acted as a barrier to maintaining good health. This is illustrated most succinctly in the words of one of the participants who responded to the question *“What are some of the things that have helped you stay healthy?”* by stating *“Not living in poverty”*. Medical research supports this claim, noting that the poor are generally more vulnerable to illness and disability than are upper and middle-class people (Doyal, 1995; Evans, Barer and Marmor, 1994; Gladwell, 1990; Nechas and Foley, 1994; Payne, 1991). The same is true in regards to HIV infection and illness progression. Discourses which suggest that HIV/AIDS is everyone's disease are, according to Lorelee Gillis (1999) “necessary fictions”. In fact, people who are economically and socially marginalized are much more likely to both become HIV+ and die sooner once HIV+.

What are some of the things that have helped you stay healthy?

Not living in poverty

[Women are more likely to be poor than men in Canada \(Gillis, 1999\) therefore poverty is a “gendered” determinant of HIV disease.](#)

Classism and Discrimination

Related to the issue of money and income for all of the women was discrimination against poor people in Canadian society — the way we, as Canadians, shame people who are poor and act as though they have done something wrong to “deserve” to suffer in this way, that they are “bad” people simply because they are poor. As one woman said *“There are stereotypes and conceptions about what it means to...not have money...the assumptions that go with that, fault-finding and blaming”*. As a result of this fault-finding women talked about feeling ashamed and guilty when they had been forced to ask for help.

One goes hungry sometimes because she doesn't have a penny. I feel embarrassed to ask people for help, very embarrassed. In November and December last year it happened to me. Welfare did not help me, I don't know why. I don't speak English so I don't know why they did that.

Also connected to the way the poor are shamed and stigmatized was the fact that many women talked about experiencing hostility and suspicion when they asked for help if they looked less than completely desperate. This was particularly an issue for some of the women living with HIV in the study who were struggling to maintain lives of dignity and respect while suddenly finding they were unable to fully care for themselves. As one woman said:

You have to make yourself look bad ...for it to be ok to ask for help. If you walk in [wearing] a nice suit looking all healthy and perky they're going to just go "Nice seeing you, get out. You don't need any help, you can take care of yourself." It doesn't matter that you had to drag your ass out of bed and you're totally fatigued for 2 weeks, that has nothing to do with it. When you're on disability you feel like a lesser person and you have to be desperate looking [to get help].

Food

Women most often talked about not having money for food.

One goes hungry sometimes because she doesn't have a penny. I feel embarrassed to ask people for help, very embarrassed. In November and December last year it happened to me. Welfare did not help me, I don't know why. I don't speak English so I don't know why they did that. I asked people for help but I went hungry many times because I didn't want to bother other people.

In this woman's experience barriers resulting from being a refugee claimant, not speaking English, government cutbacks to social programs, as well as poverty and the shaming of the poor all came together to stop her from getting what she needed to keep healthy.

Another problem was not being able to afford the variety of food necessary to have a healthy and balanced diet." It's the fresh produce that I find really hard, the veggies and the milk." A number of women talked about having to depend on food banks and line-ups to feed themselves. They said that relying on food banks for food could interfere with health in a number of ways. Firstly, food banks usually were not able to give women the variety of fresh food and produce they felt was necessary to keep healthy. This was particularly a problem for the women living with HIV in the study, whose nutritional needs are both more precise and more pressing than those of the general population. (McMulloch, Howard and Ivan, 1999) Women also said that the levels of cleanliness around and in food line-ups was often below standard, and talked about having a hard time dealing with the stress and shame of having to use these kinds of services.

Some hotels don't even have a kitchen.

Some of us don't even have running water.

That's where you end up spending a lot of money on restaurant food. [Money for] one meal...that should have bought you enough groceries for the week and you end up eating it in one sitting.

Housing

Having access to clean, adequate and stable housing was another problem for many of the women. A small number of the women in the study were living on the street at the time of the study and a number of others had done so in the past. All of these women agreed that Vancouver needs more emergency shelters specifically for women.

Another small group of participants were living in hotels at the time they participated in the study. Living conditions in the hotels were often unsatisfactory for a number of reasons.

With some hotels you can't cook in your room...Like the place I live right now I have to go down 4 flights, lug everything out of my room down 4 flights! By the time you get [to the kitchen] you're too tired to cook! But then you have to lug everything back up. And you have to stand there and watch your food like a hawk....most rooms downtown don't have a fridge as far as I know.

Some hotels don't even have a kitchen.

Some of us don't even have running water.

That's where you end up spending a lot of money on restaurant food. [Money for] one meal...that should have bought you enough groceries for the week and you end up eating it in one sitting.

When it is added in that all of the women taking part in this discussion are HIV+ and dealing with both limitations on their health and extra nutritional requirements, the problems with the situation become even more clear.

For those women who had been lucky enough to get clean, stable housing after a difficult period the difference could be remarkable.

I've just moved and I found that living conditions made a big change for me. That it's really helped. I'm not quite in [the Downtown Eastside] anymore....It's just a lot cleaner where I live so it makes a big, big difference.

The Environment of the Downtown Eastside: cleanliness, safety, and police harassment

Vancouver's Downtown Eastside (DES) is well known for the harshness of its poverty. Three of the six focus groups for the study were held in this area and it is therefore not surprising that women talked about a number of issues that were directly related to living conditions in this neighbourhood. Although these issues were raised specifically in the context of the DES, what is happening in the DES should be most understood as an extreme

case on a continuum — a case where perhaps the issues are brought into sharpest and most noticeable relief — rather than an unusual or unique phenomenon.

One of the barriers to health women living in the DES talked about, as illustrated in the previous quote, was the cleanliness of the physical environment around them. This raised concerns for a number of women about public health and the spread of contagious illness, such as HIV/AIDS, as well as underlining for them the discrimination made obvious in the lack of municipal services they faced merely because of being poor and living where they did.

Some of the hotels are pretty dirty and the people with HIV are more susceptible to catching stuff like TB.

I sometimes wonder if the city is being kind of absent-minded or something. I mean the alleys are sometimes a resort for some activities and stuff but I think that it still belongs to the city, you know? It belongs to everybody in the city and I don't think there's much maintenance going on. Like everybody who lives in Vancouver is a citizen of Vancouver wherever they take their activities....If somebody has a different lifestyle than another it doesn't mean that the city should take it out on one citizen...I mean if there are epidemics going on we don't need to have our environment [so dirty].

Some of the hotels are pretty dirty and the people with HIV are more susceptible to catching stuff like TB.

Problems with safety were another set of major barriers to health women living in the DES experienced. Violence, and the increased vulnerability to violence of those living on the street, were a major concern as was the general atmosphere of intimidation, threat and harassment that many of the women felt just being physically present in the area.

There are stereotypes and conceptions about what it means to...not have money...the assumptions that go with that, fault-finding and blaming.

"If [the police] know you as an addict or they know you as a working girl or anything like that, down here they will constantly harass you."

I wanted to get home in a hurry one day so I cut through a parking lot and there was a man masturbating in a car. He asked me if I was working. I said no. He kept at me...then he started verbally abusing me saying "I have never hit a woman in my life". I said "you're abusing me right now, I said no"...because you live in this area there's a stigmatism that you're working [as a prostitute].

Yeah, you can't even stand at the corner and go to the grocery store. It's not by people who live here, it's by people who live outside of the area driving in their cars, asking for sex.

If [the police] know you as an addict or they know you as a working girl or anything like that, down here they will constantly harass you.

Here attitudes to prostitutes and prostitution combine with poverty, classism, and violence to create conditions that work against women's safety, security and ultimately, health. In order to reduce feelings of fear and intimidation on the street, women suggested developing peer safety training for street involved people. They also called for more women only safe spaces in the DES.

Some of the women in the study also talked about working in the sex trade as a barrier to health. Some of the issues mentioned by women who had been sex trade workers, or those who had friends who were, included: the pace (the long hours and the large number of men women could be with in the course of a day), potential exposure to HIV/AIDS and other STDs, the possibility of violent dates and

[I]f you're really sick with drugs you're not together. Sometimes you slip up or whatever. You can be careful 99% of the time but there's always the hundredth time.

For these and other reasons women wanted more viable economic options to street prostitution and greater access to skills training for poor women.

Many of the women living in the DES also talked about feeling harassed and threatened by the people who should be protecting them in these kind of circumstances — the police. Some of the women felt particularly targeted and criminalized by the police simply because of who they were and where they lived.

[I]f you're really sick with drugs you're not together. Sometimes you slip up or whatever. You can be careful 99% of the time but there's always the hundredth time.

For myself, I was down here and then I got away. But when I was down here they treated me bad for being here and then even when I got away and I'd come down every so often to...see my friends and hang out they would still look down on [me]. If they can recognize you in any sense of being down here then they treat you like shit no matter what. Even if your life has changed they won't give you the time of day. I mean there's been a few police officers who...have said hi...that cared. The majority of them treated me like shit. For instance today I was walking around the corner "Hey, come here! What are you doing here? Haven't seen you here in awhile". That was today.

If they know you as an addict or they know you as a working girl or anything like that, down here they will constantly harass you.

Police harassment interfered with women's ability to be healthy in a number of ways. Firstly by adding to the threatening and intimidating atmosphere on the street, secondly by pushing poor

people (such as panhandlers) into the DES, and lastly by directly getting in the way of women's attempts to pursue healthier life-style choices — such as substance users attempts to do harm reduction activities like cleaning their needles before injecting.

[I]n back alleys the way the cops have been going through them the thing is you have to get it done before they come...get it in and out.

I was denied home-making services two days before, they just said "nope, no more, no more". Well, gee whiz, you know I need the respite, I really do....Because me being an [HIV+] mother, my [HIV+] son has to take his medication 5 times a day, 7 days a week. There's no week-ends, there's no holidays, it's gotta be done. And it can be stressing to me...[and] yeah, they just cut me off, the Ministry. So many cut-backs, I don't understand that.

Women in the study recommended that police officers be given additional training regarding issues in the DES in an attempt to improve their treatment of local residents.

It was not only "outsiders" and authority figures who created conditions in which women in the DES felt unsafe though. Women from the DES talked about how there were often times when they felt a general lack of trust, support, and sense of community in the area, a feeling which was also a barrier to health. As one woman said:

Scream for help downtown and nobody will come...it's really hard when no one will listen...when I scream for help no one will listen.

The combination of the violence women face on the street and the lack of community cohesiveness that was sometimes present could be particularly frightening and present almost overwhelming barriers. Women cannot be healthy until they are safe from violence in all of its manifestations.

I was stabbed in front of [a hotel in the DES]. I was laying on the ground dying and people took the shoes off my feet, rings off my fingers...dope out of my hand, stepped over me and told me to quit my whining!

The Role of Governments and Cutbacks to Social Services

Problems that women had encountered with the rules and regulations of income assistance programs, as well as lacks in what they could actually get from income assistance, were another ever-present backdrop to their discussions about money. Underlying all of their discussion about the government, and particularly the Ministry of Child and Family Services, was the hurt, pain and confusion engendered by the recent cut-backs to government services and the stripping away of essential services to families already spread too thin.

I was denied homemaking services two days before, they just said "nope, no more, no more". Well, gee whiz, you know I need the respite, I really do....Because me being an [HIV+] mother, my [HIV+] son has to take his medication 5 times a day, 7 days a week. There's no week-ends, there's no holidays, it's gotta be

done. And it can be stressing to me...[and] yeah, they just cut me off, the Ministry. So many cut-backs, I don't understand that.

I get \$756, or something like that, per month and my rent is \$725 for a two bedroom apartment. Imagine, you know, having to provide for your children [on that]!

For all of the women living on income assistance the costs associated with raising children in an era of ever-shrinking government support had also created barriers to the best health of women themselves. Problems that women experienced around child-rearing that were directly due to not having enough money included: not having enough money for transportation for their children; the added expense of rent for a larger apartment; clothes; sports activities and music lessons; and food.

[Y]ou try to keep your kids off what we had to go through as far as drugs and alcohol...Like my baby's a hockey player and it cost my ex-husband six thousand dollars just to put him on a hockey team. And then my other son is a basketball player and rugby, they have to pay so much. And then my daughter wants to play flute in school and if I try to ask the Minister to help her go to these classes rather than staying on the street, they argue with you!...But, you know, you try to ask them and try to explain to them, it seems like it's coming out of their pockets. Meanwhile it isn't, it's coming from taxpayers money. It's hard to talk to those people.

I get \$756, or something like that, per month and my rent is \$725 for a two bedroom apartment. Imagine, you know, having to provide for your children [on that]!

All of these issues were worse in situations where the woman was not the custodial parent, either as the result of a break-up in the marriage or of having had their children seized by the province, but where the children nonetheless came to their mother and asked for money for clothes, food or entertainment.

I couldn't keep my kids. A lot of stuff happened with how they became wards of the government....But even with them, when we tried to get back together there still wasn't ever enough money for food. Because like [she] said there's always clothing or other stuff and you have to give them money. And then now with my kids and I not working...it's better that we're apart because while they're on welfare they get a lot more...[But] food, I can't refuse my kids food...they come down to my place and I'm living on food banks and hot meals yet they come in and they eat...but you can't turn them away. If that's what they want to eat you have to feed them, you know? So we get left out.

The institutional and systemic factors which keep poor families apart are well illustrated in this story as are the sacrifices mothers living on welfare or disability insurance are too often forced to make. These kinds of situations affected the health of the women

For me, being First Nations, and being a woman, and living with HIV I get all this stigma from the Ministry of Social Services for Children....There is no such thing as support from the Ministry of Family Services, not if you're, if they say that you're all stoned out of your tree or something, they'll nab your kid away from you. So, it's like well, you have to be on top of everything. Well, I can't be on top of everything because I'm not superwoman!

involved not only because they actively denied themselves care by, for example, giving the food off their plate to their children, but also in the incredible amounts of stress, guilt, and shame they felt because of having their fitness to parent under constant scrutiny and attack.

Women in the study also reported experiencing many different forms of discrimination at the hands of government workers. A number of the Aboriginal women were particularly clear that various aspects of their culture's commitment to and style of child-rearing were not respected by government workers or made room for in their policies. Furthermore, the disproportionately high number of child apprehensions from Aboriginal communities in B.C. constituted an ever-present threat to these women and one that almost all of them had had to deal with in one way or another. This led to fear, distrust, and anger toward government officials as women struggled to repair broken families and keep others in tact. After explaining how her HIV medications can make her appear sleepy or "drugged" a woman said:

For me, being First Nations, and being a woman, and living with HIV I get all this stigma from the Ministry of Social Services for Children....There is no such thing as support from the Ministry of Family Services, not if you're, if they say that you're all stoned out of your tree or something, they'll nab your kid away from you. So, it's like well, you have to be on top of everything. Well, I can't be on top of everything because I'm not superwoman!

The conditions in which women living on income assistance were forced to live could often present barriers to health not only because it meant they were unable to afford essential goods or services, but also simply because of the stress of trying to make ends meet while living in a world where resources were so obviously available to others.

[T]here's no balance in the world. It's obvious that some in this society are very, very loaded with money and when somebody who's coming from a welfare office walks outside and sees millions of people running around with millions of dollars it adds to the depression. It doesn't seem fair.

The government's role in establishing standards and services for women living on income assistance was not only a source of stress and tension to women but actively worked against their efforts to maintain health. Culturally insensitive programs, inadequate services, unrealistic expectations regarding how far money could be stretched, and the unwarranted supervision and surveillance of those on income assistance were all identified as barriers to women's optimal health and happiness.

Power In Intimate Relationships

I know for myself to clean up I needed somebody else to believe in me so I could end up believing in myself. Cause I really thought I was horrible and there was no [hope]...Who cares? Nobody cares, my family don't care, nobody cares. But there's this one person who stayed in my life and was persistent and kept coming around and kept bothering me...until finally I was able to...believe in myself

I have a friend who was sponsored [to immigrate here] by her husband. Now she is here in Canada and her husband drinks a lot and abuses her. She cries a lot and is unable to ask for support money. She was asking me if she were to leave her husband, she is afraid the government will not help her financially just because he has sponsored her.

The Positive Power of Relationships

The one thing women most often talked about as having helped them be healthy was relationships with people they were close to. While a small number of women talked about relationships with their children or with their own mothers as having been particularly close and supportive, most of the close relationships women mentioned positively were with friends or other non-family members, such as peers and community members. Friends supported each other by sharing information about health practices, encouraging each other to try new experiences, helping each other through attempts to get off drugs, and generally being there to hold your hand at the end of the day. These were all seen by numerous women as important health related activities. As one woman said:

I know for myself to clean up I needed somebody else to believe in me so I could end up believing in myself. Cause I really thought I was horrible and there was no [hope]...Who cares? Nobody cares, my family don't care, nobody cares. But there's this one person who stayed in my life and was persistent and kept coming around and kept bothering me...until finally I was able to...believe in myself that I could do things....But I know I probably would have stayed down here [in the DES] if that person wasn't in my life and never gave up on me and always believed in me and helped me when I couldn't help myself.

The support of friends and family could play an important role in helping women to create healthier lives for themselves.

Violence in Intimate Relationships

As intimate relationships of various kinds could provide women with unique sources of strength, they could also prove to be unique barriers to health. It is well documented that women are most likely to face both physical and sexual violence from people they are close to and the women in this study were no different in this regard. Some of the women reported experiencing violence at the hands of their own husbands or male partners and another woman told the following story:

I have a friend who was sponsored [to immigrate here] by her husband. Now she is here in Canada and her husband drinks a lot and abuses her. She cries a lot and is unable to ask for support money. She was asking me if she were to leave her husband, she is afraid the government will not help her financially just because he has sponsored her....She doesn't know what to do. She thinks that Canada Immigration will deport her if she leaves him and she has to suffer for this.

[I had] so much fear and so much anxiety that I had ulcers and that and I've been hospitalized because of it. And now I'm on anti-depressant pills....It's really hard when you're trying to stay clean and you have things going on like that.

Immigration laws, being an immigrant in a new country where she doesn't speak the language, sexism, and the power all three of these factors give the husband in the story over his wife, create a complex web of barriers to her being able to do what she wants to. Not only is she experiencing violence but in the words of one of the other women in this discussion:

Just imagine how difficult it must be for this woman to negotiate safer sex to protect herself.

In fact, women's experiences of violence are a well documented threat to their sexual and reproductive health, including increasing the threat of HIV disease (Kahn, 1998; Weiss and Gupta, 1998)

Experiencing violence directly effected women's health in other ways as well. Another woman described the after-effect of being raped by an acquaintance as follows:

[I had] so much fear and so much anxiety that I had ulcers and that and I've been hospitalized because of it. And now I'm on anti-depressant pills....It's really hard when you're trying to stay clean and you have things going on like that.

Added to the fact that this woman is also HIV+ and actively street involved, the complex web of barriers women face in trying to be healthy is quite clear.

The violence women experienced in relationships was not only directed at them however, they were themselves, on occasion, the source of it as well.

I can never even try to hurt my ex-partner but when I was drunk I sure flung her around Hastings pretty good. Like, I even threatened to kill her. I wouldn't do that when I'm straight. It's just something I let build up and it's something I gotta learn [to find other ways to deal with anger]...cause like I didn't even say "hi" or nothing, I just started flinging her around Hastings. Like I was throwing her into walls everything. And it got to the point where I was threatening her with...a gun..... That's one of the reasons I don't drink [anymore] is cause all the hurt that I've ever had or what people have done to me comes out but I take it out on the wrong people and in the wrong way.

The violence and pain women experience can thus become cyclical as they reproduce it in their own lives.

Emotional Abuse and Manipulation

Abuse in relationships doesn't stop with physical or sexual abuse however, emotional and psychological abuse or manipulation can be just as damaging and dangerous. While by no means unique to women who are HIV+, being HIV+ meant some of the women

in the study were particularly vulnerable to certain distinctive emotional ploys:

I wasn't believed because I was an addict. Like this stuff didn't happen or I just imagined it or whatnot because of the drugs. And that really bothers me.

[A] couple of years ago I was living with one individual and he became [HIV] positive he said...And he was a very violent person and I found that [catching HIV from me] was one of the things that he wanted to use against me in order for me to stay with him.

Another particular vulnerability some women experienced around emotional manipulation had to do with substance use. Women who were or had been substance users reported being told that no one would believe their tales of abuse because of their substance use — an assertion that was unfortunately true for at least some of the women.

I wasn't believed because I was an addict. Like this stuff didn't happen or I just imagined it or whatnot because of the drugs. And that really bothers me.

Care-givers, Not Cared For

Social expectations around gender roles — what it means to be a woman in Canada today — effect women's experiences of intimate relationships in other ways as well. One of these ways is the fact that women are often given the responsibility to do the bulk of the caring and nurturing work in many different kinds of intimate relationships. One of the most common experiences of care-giving for women is that of caring for children. Some of the women talked about the stress of being responsible for raising their children while HIV+ and how the state of their children's health directly effected their own.

*[W]e have to listen to our kids' problems, our spouses problems and we're not, I don't know...
We're supposed to be the care-givers,
Yeah, that's it!
[B]ut what about me? I need care too!*

One of the things that I really wanted to do was have some kind of support network for my child...I find in order for me to stay healthy that will take a lot of stress off me, just having that network for my child.

Having primary responsibility for care-giving creates stress in women's lives as they struggle to make sure the needs of others are being met. It also makes it hard for them to assert their own needs and find both the time and resources for their own health. As the women in one of the groups discussed:

[W]e have to listen to our kids' problems, our spouses problems and we're not, I don't know...

*We're supposed to be the care-givers,
Yeah, that's it!*

[B]ut what about me? I need care too!

Another woman described her own situation:

[D]uring my struggles to try and straighten myself out I found I was still worried about [my partner] and his feelings rather than straightening out myself. I felt guilty for passing on the virus to him even though...he chose himself not to use a condom. But I still carry the guilt. [I wasn't able to] get away and work on myself.

Social expectations and conditioning that make it difficult for women to assert their own needs within relationships, and make them feel guilty when they do, are therefore another barrier to optimal health.

Disclosure and the Balance of Power in Intimate/Romantic Relationships

The balance of power in intimate relationships doesn't only result in different kinds of abuse however. One of the issues that was more or less unique to the women living with HIV in the study was the uncertainty they felt about disclosing their HIV status in intimate relationships because of the vulnerable position being HIV+ put them in in these relationships. While women agreed that full disclosure was necessary both before beginning a new relationship as well as within an already established one, the shame and guilt that they felt about their HIV status, along with fears of rejection, had made it difficult for some women to establish close, intimate relationships. This also meant that women's partners had leverage and huge amounts of power over women themselves because of their HIV status.

The difficulties or hesitancy women had about establishing new relationships had two main consequences for their health. The first of these was that a woman could find herself in a manipulative relationship where her partner wielded incredible power over her by the simple fact of knowing about her HIV status. The other health implication is that women sometimes ended up not pursuing relationships because they feared being rejected and consequently did not have the kind of support and care, which was mentioned positively by so many women.

When I first found out actually I had no sex for 5 years. I thought it was a game show after awhile but its just I didn't want the burden [of worrying about possible transmission]....[Recently] I even backed off [a relationship] so this way I didn't have to tell the person. Because it was a lot easier for me and sure it was an easy road out but the things is, yeah, maybe we could have been together but its just now I'll never know. I'd rather have it like that than when a person walks away from me.

Not having support networks, as well as a vulnerability to getting "caught" in an unhealthy relationship, were two of the possible health risks women could experience because of the social stigma associated with HIV/AIDS.

When I first found out actually I had no sex for 5 years. I thought it was a game show after awhile but its just I didn't want the burden [of worrying about possible transmission]....[Recently] I even backed off [a relationship] so this way I didn't have to tell the person.

In our culture we let ourselves believe that men are machos. Sometimes they bring something to the partner and if we suggest the use of the condom we get the "What do you think? I am doing this only with you, only with you". In cases of marriages some men have affairs and can bring diseases from outside the relationship. Therefore I think it is very risky to accept macho concept [but] we do accept it regardless.

When he infected me he didn't know he was infected [but] he knows now, he has no excuse to be going and dippin' anywhere without a condom. And I freaked right out. I was outraged that he was doing this. He knows he's infected and he doesn't give a shit. And he said "well, you know me, it feels better without a condom.

Safer sex

Negotiating safer sex in the context of a heterosexual relationship is one area of health research that has received a lot of attention recently. Weiss and Gupta (1998) argue that these negotiations are typical of the ways in which power in heterosexual romantic relationships gets played out as men, bolstered by a patriarchal system that grants them power over their female partners in innumerable ways outside of the relationship, use that power to enforce the non-practice of safer sex within it. This certainly was the experience of some of the women in the study. As one of the women in the group for Spanish-speaking immigrants said:

In our culture we let ourselves believe that men are machos. Sometimes they bring something to the partner and if we suggest the use of the condom we get the "What do you think? I am doing this only with you, only with you". In cases of marriages some men have affairs and can bring diseases from outside the relationship. Therefore I think it is very risky to accept macho concept [but] we do accept it regardless.

While Latin and Hispanic cultures are unique in having the concept of machismo to explain this phenomenon, men's refusal to wear condoms was by no means an experience that was unique to women within that culture. Women in the mental health group also talked about problems with both partners and tricks refusing to wear condoms and one of the women in the group for women living with HIV told the following story:

I recently had a experience where the guy who gave me [HIV] called me up and told me he had a baby with another woman. And I'm just sitting there thinking "how the hell did this happen?". When he infected me he didn't know he was infected [but] he knows now, he has no excuse to be going and dippin' anywhere without a condom. And I freaked right out. I was outraged that he was doing this. He knows he's infected and he doesn't give a shit. And he said "well, you know me, it feels better without a condom.

[Women in the study recommended women-initiated, culturally appropriate campaigns to convince men to use condoms even in long-term monogamous relationships.](#)

In response to the problems many of the women reported with getting men to use condoms, the existence of the female condom was universally applauded. Some women talked about their experiences of being able to successfully use it in situations where a male partner had refused to wear a condom and women agreed that useful, realistic methods of female-controlled safer sex were necessary in order to optimize health for all women. Even women from communities, such as those with severe mental illness, whom care-givers have traditionally assumed

It would be nice if other people took care of our health but it's us who have to take care of our health so I think [the female condom] is a very good solution. Because right now the onus is on the man to protect two people's health, this way it would be each [person] for themselves in a way that's safer.

would have difficulty negotiating and/or sourcing the female condom reported having successfully used it in relationships. Finally, women in all of the groups who had not heard of the female condom before coming to the group were excited and enthusiastic about its potential. As one of the women in the group for those with severe mental illness said:

It would be nice if other people took care of our health but it's us who have to take care of our health so I think [the female condom] is a very good solution. Because right now the onus is on the man to protect two people's health, this way it would be each [person] for themselves in a way that's safer.

Women did however, express frustration at the price of the female condom. As one woman said: *They've said that women can take it into their own control [but at 3 for \$19.95]...it's like you have a choice, who pays for dinner and who pays for the condoms!*

[Women called on AIDS service organizations, health clinics and other social service agencies to provide free female condoms, as they currently do male condoms.](#)

Issues around negotiating safer sex don't just happen in the heterosexual community however. HIV/AIDS is present in the lesbian/bisexual community, as are other STDs, yet very few of the lesbian/bisexual women in the study reported engaging in safer sex practices on a regular basis, if ever. Those who did were almost invariably the HIV+ lesbian/bi women, one of whom noted that pressure to go without protection is certainly not unique to heterosexuals:

I am a [HIV+] gay female and I have yet to have sex with one female who has not tried to talk me into having unprotected sex.

Lesbian and bisexual women in the study speculated that some of the reasons for this very low rate of safer sex practice in their community might include:

- the sense that woman-on-woman sex is simply cleaner and safer or that there's something inherently beautiful in it that simply can't be "sullied" by disease
- perceived taboos against safer sex in the lesbian community
- the relative smallness of the community instilling fears that other women might spread rumours about you for breaking this taboo
- you might end up knowing more information than you want to about the sex practices of past or current partners
- the fact that pregnancy is not an issue, creating lessened motivation to use condoms or other barrier methods

They've said that women can take it into their own control [but at 3 for \$19.95]...it's like you have a choice, who pays for dinner and who pays for the condoms!

- the cumbersome nature of methods of safer sex practice currently available to women who have sex with women.

I'd like to say that those of us of a certain age do not talk to anybody about sex. I never asked men when I was with men and I never asked [my current female partner] before we got together. And I'm thinking listening to you that it really has a lot to do with early conditioning. Despite having been on AIDS boards, despite knowing how devastating [AIDS can be] I think you'd have to drag me kicking and screaming to ask ahead of time.

As one woman said: *Dental dams, excuse me but they're encouraging group sex because there has to be a third person there to hold the thing!*

Perceived taboos against safer sex in the lesbian/bi community, along with the fact that most prominent safer sex campaigns have targeted heterosexuals or gay men, meant that community norms around safer sex practice were simply not present. The lack of safer sex messages targeted specifically at lesbian/bisexual women has been noted elsewhere in the literature (Leonard, 1990; Morrow, 1995) as a risk factor for HIV disease and the resulting lack of norms around safer sex practice clearly effected the (non)-practice of some of the women in this study as well:

I mean when I was with men it was one thing, you know, kind of socially accepted to say "ok, put a condom on". With a woman everybody, well I shouldn't say everybody but women that I've been with, you don't lie down and go "ok, let's get out the condom" or "let's get out the saran wrap", "oh, ok honey". That would be [laughed at]. For me anyway I would be embarrassed to do that. Or I would want to do that to protect myself but I'm not sure I would be able to.

Issues of trust, intimacy, and power were paramount for all of the women in the study — lesbian/bisexual and heterosexual — with fears that one would be perceived as accusing a partner of "something" being the most commonly cited reason for not engaging in safer sex. The difficulty that older women especially have around asking for safer sex has been researched with primarily heterosexual populations (Leonard, 1998; Maxwell and Boyle, 1995) but in the current study was another factor that cut across sexual orientation.

I'd like to say that those of us of a certain age do not talk to anybody about sex. I never asked men when I was with men and I never asked [my current female partner] before we got together. And I'm thinking listening to you that it really has a lot to do with early conditioning. Despite having been on AIDS boards, despite knowing how devastating [AIDS can be] I think you'd have to drag me kicking and screaming to ask ahead of time. I'm 55 so I think for the moment I'm going to take it as just how I've somehow been taught or been [un]able to unlearn.

Relationships To Health Care Providers And Institutions

Like I said, my doctor, she said "I don't want you to die needlessly". And that was just [wonderful to hear]. Like that's a big ego boost – my doctor likes me and wants me to live! Shit like that I never hear.

After going for 19 months [to doctors who pretended to have the answer when they didn't my husband and I] came back to the doctor [who had helped us before] and he said "I will be your primary care physician. However, I don't know about this disease [HIV/AIDS]" But he was at least honest enough to say "I'm willing to learn with you".

Positive Relationships

Positive relationships with doctors could leave women feeling validated, cared for and worthwhile. Doctors who cared and let it be known that they cared can make a tremendous impact in women's lives.

Like I said, my doctor, she said "I don't want you to die needlessly". And that was just [wonderful to hear]. Like that's a big ego boost — my doctor likes me and wants me to live! Shit like that I never hear.

Women also appreciated it when doctors and other health care professionals used their power to advocate with other people in authority for changes in women's lives that they would not have been able to make happen on their own. Being patient, understanding and supportive of women, even when they made mistakes, were other positive qualities mentioned in health care professionals.

These [two street] nurses...you can tell them anything! You know, absolutely anything and you know that she's going to be in your corner....Not for a moment of my time do I wonder if they're going to be in my corner.

Doctors and other health care professionals didn't have to know everything to earn the respect of their patients and, in fact, one of the things women appreciated most about some doctors was their willingness to admit when they didn't know something and then to go out and learn it.

After going for 19 months [to doctors who pretended to have the answer when they didn't my husband and I] came back to the doctor [who had helped us before] and he said "I will be your primary care physician. However, I don't know about this disease [HIV/AIDS]" But he was at least honest enough to say "I'm willing to learn with you". And I would get all the mail-outs from BCPWA, all the little magazines and all the little pamphlets and I'd give them to him and he'd photocopy them and he'd read them. And I know for a fact that he phoned Treatment Information on a number of occasions to say "I have a patient that's on this medication and I don't know what to do with him"...He's just a doctor who cares about his patients.

The pride, joy and amazement in these three women's voices as they told their stories speaks strongly to the ways in which doctors and other health care professionals can positively effect the health and lives of their patients.

Experiences of Discrimination from Health Care Providers

Unfortunately, women also reported experiencing many negative interactions with health care providers and institutions as well. Many of these negative experiences were related to instances when women had been discriminated against or received substandard or inadequate care because of some aspect of their social identity.

Addictophobia

One of the most virulent and wide-spread oppressions which women encountered in dealing with health care providers was what Nancy Stoller (1998) calls "addictophobia" — fear and intolerance of, and discrimination against those who are addicted to street drugs.

Almost all of the women who were current or former substance users told stories of times when they had been treated poorly by support staff or received inadequate or faulty care from providers because of their status as substance users. These are just a very few of their stories.

I was playing with my son when he jumped on the back of [my leg] so hard that I really, really could not walk. I got up to [the hospital] in the ambulance and everything was fine till they found out I was on methadone. [All of a sudden], no, I [should be able to] walk on my own. And I couldn't even stand on it! I couldn't even stand on crutches, I had to be in a wheelchair. But as soon as they found out I was HIV and on methadone, outta here!

[I]f you got it on your [file] that you're an addict you don't get nothing for pain...[Or if] you just did a heroin overdose, 2 hours later they're shipping you on the street. Go back down there, you know? As far as I'm concerned [you're] just out of the hospital, just out of an overdose, then they put you on the street, you're just like a little old lady...you're looking and you don't know what to do. It's hard. Because you got that word addict written on your file they tend to not pay so much attention to you. They figure you're just there to scam them.

I brought it up about people bringing their pets into [a medical clinic]. Because they're cute cuddlies when they're in your home but if other people [are allergic to them it's hard on their health]. Then one lady [who worked there said] to me, I said something about the pets, and she said "A pet's safer to have around than people that smoke crack"....It's ignorance like that from the

As far as I'm concerned [you're] just out of the hospital, just out of an overdose, then they put you on the street, you're just like a little old lady... you're looking and you don't know what to do. It's hard. Because you got that word addict written on your file they tend to not pay so much attention to you. They figure you're just there to scam them.

"A few years back I went to a general practitioner doctor. He thought I needed counselling for my illness, which was lesbianism, after I told him I was gay."

I went in and got an X-ray and they kept grilling me..."Are you sure you're not pregnant?" They must have asked me about ten times before I got the X-ray and I'm like "I know I'm not pregnant! I know it! I know it!" And then they ask if you're sexually active [and if you say yes] "Oh, ok, you should be on the pill", "well, no, I shouldn't be on the pill".

doctors, from the interns, from health care. Yeah, we are, we'll always be addicts. But the thing is we're trying to make a change. I'm trying to be a clean addict. But I will be categorised because I dare. And sometimes yeah, I do think about it and it hurts. I get moody and it's hard to explain when people get on my case and I'm trying to stop myself from walking out that door and going downtown to score. And they're saying to my face at least we're not an addict? Don't say shit like that!

Having experienced discrimination from particular health care providers in the past also made some women reluctant to use various health services and suspicious of the goals and motivations of some of the people working in the DES. Women avoided places where they felt stigmatized and looked down on regardless of what services were provided there.

"A few years back I went to a general practitioner doctor. He thought I needed counselling for my illness, which was lesbianism, after I told him I was gay."

Homophobia

Lesbian and bisexual women in the study also reported receiving substandard and, commonly, inappropriate care from health professionals due to assumptions of a heterosexual sexual orientation or discrimination once their true identity became known.

A few years back I went to a general practitioner doctor. He thought I needed counseling for my illness, which was lesbianism, after I told him I was gay.

I went in and got an X-ray and they kept grilling me..."Are you sure you're not pregnant?" They must have asked me about ten times before I got the X-ray and I'm like "I know I'm not pregnant! I know it! I know it!" And then they ask if you're sexually active [and if you say yes] "Oh, ok, you should be on the pill", "well, no, I shouldn't be on the pill".

I went to counseling...but the counselor she was really great in lots of ways but she really just did not know how to deal with the lesbian thing. She just acted really odd, like trying too hard and trying to get my acceptance that she was doing all right in counselling me. So I spent my time looking after her needs and it was really odd.

One time I was out at the Lotus dancing...and I had an allergic reaction.... Finally the paramedics came and I guess they didn't like being there cause of the women only...so they kind of took it out on me. They wouldn't bring a stretcher in and they wouldn't help me at all. I could barely make it up the stairs...and I stumbled into the ambulance and I'm running out time and they're not going anywhere! Why? Because I have to give them my vital

This doctor told me, once he learned I was [HIV] positive, he didn't want me in his office. He said that I would infect his staff and that they didn't have the facilities there to be treating me.

We went into the hospital the second day, the nurse comes running out of the back room "Oh, are you the one that has AIDS? Do you have K[arposi's] S[arcoma]?"

[After] I moved to Vancouver it took four years and 15 fired doctors for me to find a doctor that could actually deal with any non-HIV related instances, let alone HIV related.

stats...so they can bill me the 40 bucks for ambulance care. But I couldn't breathe!...I turned grey and when people turn that colour they don't usually come back. But when I went into the hospital they looked after me right away...and I was fine in three hours....I was totally, totally discriminat[ed against]. Not only for being lesbian but [for being] a punk rocker type.

Medical insurance was another area of health care lesbian and bisexual women mentioned as creating barriers to their best health, particularly as companies either refused to provide same sex spousal benefits or made these difficult or awkward to actually collect.

Being Discriminated Against for Being HIV+

Many of the women living with HIV also reported being discriminated against by individual doctors, nurses and support staff. As well, many of the women living with HIV reported difficulties in finding doctors who could provide adequate, integrated care for them.

This doctor told me, once he learned I was [HIV] positive, he didn't want me in his office. He said that I would infect his staff and that they didn't have the facilities there to be treating me.

My [HIV-] ex-girlfriend and I went to Tofino....She ended up getting an infection, went to emergency and they gave her antibiotics. And she said "My partner is [HIV] positive I think you'd better double that prescription". [And they said] "Oh no, she has AIDS. She'll get weird things, she won't get something like this". She had to go back and get the dressing changed each day. We went into the hospital the second day, the nurse comes running out of the back room "Oh, are you the one that has AIDS? Do you have K[arposi's] S[arcoma]?"

[After] I moved to Vancouver it took four years and 15 fired doctors for me to find a doctor that could actually deal with any non-HIV related instances, let alone HIV related....[One] female doctor not only had me up in the stirrups and her 3 year old child in the room at the same time, but told me I was being silly, that of course I had PID and I didn't have to have anything done about it....And yet here I am, after seeing her for a year and a half, and her telling me I couldn't have this and I couldn't have that, finally I went to a non-HIV related doctor and found out that forget PID, I had a disease that had been in there for 25 years, I had endometriosis. I've now had a partial hysterectomy on the way to having a full hysterectomy and these are doctors, it

Finding a good dentist, a good doctor, anybody that will treat you is really difficult in the region. So when you're not being treated well in the region and you consistently have to come down to the city to come and see the specialists here...it's frustrating....You feel isolated even more so. You have to come down and deal with strangers.

[M]y husband and I] came back to the doctor [who had helped us before] and he said "I will be your primary care physician. However, I don't know about this disease [HIV/AIDS]" But he was at least honest enough to say "I'm willing to learn with you".

was the AIDS doctor in town who said "Leave in her ovaries, leave in her ovaries! The shock of menopause will kill her" They left the ovaries and 6 months later I had cancer of the ovaries.

Systemic discrimination related to the structure of the health care system itself had also created barriers to optimal health for a number of the women living with HIV in the study. One of the most notable ways this played out was in the lack of AIDS-specific services and specialists outside of the downtown Vancouver core and the difficulty that women living with HIV in rural, and even suburban, areas had in finding anyone to provide them with any kind of treatment at all. The frustration and anger that women felt as result of this situation can simply not be underlined enough.

There have only become recently a couple of AIDS specialists in Kelowna and there are no AIDS specialists in Kamloops. Trying to find a primary care physician in the region, anywhere, that knows anything about AIDS and that is willing to not only take care of you but learn and grow with you is really impossible. Finding a good dentist, a good doctor, anybody that will treat you is really difficult in the region. So when you're not being treated well in the region and you consistently have to come down to the city to come and see the specialists here...it's frustrating....You feel isolated even more so. You have to come down and deal with strangers....the common response that would happen from agencies was "well, move down here if you don't like it". And we get tired, being people from the country, we get tired of being told that we have to transplant our lives, our lifestyles, to accommodate the city and we don't think it's fair.

I think a lot of women have ended up having to move into the downtown, into Vancouver to get services of any kind....I'm really disgruntled with having moved from a beautiful, serene, peaceful country into an urban area where I feel over-whelmed by the noise and the smells and everything.

The lack of social support and health care services available to women living with HIV in their home communities has been an enormous barrier to maintaining health for many of the women. Not only as they dealt with the stress and strain of either making frequent trips back and forth to Vancouver or moving themselves and their lives into the city, but also as they literally fought for their lives to receive care in the meantime.

Discrimination due to Having a Severe Mental Illness

Women faced discrimination from health care providers and institutions and experienced inadequate or sub-standard care due to a number of other possible identities they might share as

I finally, after four years of complaining about stomach ailments, I got to see a [specialist] and found out that I have severe liver damage from the medication they give me here. But nobody listened to me because I'm a mental patient.

well. One of these was that of suffering from a severe mental illness. Many of the women in the group for women with severe mental illness talked about not having their medical concerns taken seriously by physicians because of their mental health status.

Sometimes I've noticed in the past with doctors I've had, because I have a mental illness it seems like they don't want to listen and they kind of poo-poo anything you say.

I finally, after four years of complaining about stomach ailments, I got to see a [specialist] and found out that I have severe liver damage from the medication they give me here. But nobody listened to me because I'm a mental patient.

Sexism

Women also reported feeling that their health concerns are not listened to or taken seriously simply because they are women.

[W]omen's problem's aren't listened to as well as men's. That's what I find. I don't know why. I guess it's just we don't get listened to enough.

Classism and Discrimination due to Being Poor

Being poor, or living in a poor area of town, acted as another barrier to women's best health because of problems receiving good quality health care or having health concerns taken seriously. As one woman said in response to a question about what she would be able to have, that she didn't have right now, if she had more money: *You have the respect of doctors. You get to see a specialist much sooner, they take you seriously, they don't send you away when they don't find something, they investigate further on and that is so important.*

Another woman shared the following story: *I've had this, you guys have all seen the stab wounds, right? And the doctor who [treated] it, you know, Downtown Eastside, he just slashed, slash and gash, toss me out on the street. And [a street nurse] came in and she said "How can you be out of the hospital"?! And then she sent me back to St. Paul's.*

Other ways in which women found the care they received, as poor people living in a poor area, inadequate included:

- the very small number of specialists that were available to women in the DES
- the lack of palliative care facilities and home support available to terminally ill people in the area
- the small number of women doctors who worked there;
- the lack of mourning and institutionalized support structures to help those who are mourning in the DES.

When poverty compounded other factors, such as addictophobia, mental illness, sexism and racism, the barriers to women attaining optimal health were multiplied and intensified.

It would be nice to have services available to us according to our [preventative] needs. Why go [to the doctor] when we are already dying?

The Experience of Being a Refugee or Immigrant

Women who had recently arrived in Canada as refugees or poor immigrants also experienced barriers to their best health arising from living in poverty, as well as a number of other factors. Most refugees arrive in Canada with very little and for many months are eligible only for Interim Federal Health (IFH) coverage. IFH covers only emergency care, of both medical and dental needs, and does not allow for any kind of preventative care at all. This is particularly a problem for women who need regular gynaecological check-ups. As one woman said:

It would be nice to have services available to us according to our [preventative] needs. Why go [to the doctor] when we are already dying?

Many of the refugee and immigrant women had also experienced numerous frustrations navigating the Canadian health care system, which operated in what were perceived as unusual and confusing ways. Difficulties women talked about included:

- finding a primary care physician they were comfortable with and who could meet their needs
- accessing specialists, particularly gynaecologists and pediatricians
- receiving care outside of doctors' office hours
- not having medical procedures explained to them in a way they could understand.

In short, the women felt that while they were not being given adequate financial resources to secure proper health care for themselves and their families, they also were not being given adequate informational resources to access even the things that were theoretically available to them. Clearer and more complete orientations to the health care system from immigration and health officials were a clearly identified need.

Culturally Appropriate Health Care

The importance of having access to culturally sensitive and appropriate health care services was highlighted by a number of women across a range of cultural and sub-cultural identities. As so many women felt their needs were not being adequately or respectfully met by the mainstream health care system, it is perhaps not surprising that many of them indicated a desire for more responsive and respectful services, able to address their communities particular needs. Three of the communities that strongly identified needs for more culturally/socially appropriate

services were: Spanish-speaking refugees and immigrants, First Nations women and women who are living with HIV.

Getting Access to Complementary or Alternative Therapies

After experiences of discrimination from health care institutions and providers, the next most commonly mentioned barrier to health was the difficulty many women had experienced in accessing alternative or complimentary therapies. The cost and the mere fact of having to pay to access these therapies at all had resulted in many of the women simply not being able to follow through with treatments that they knew would work but were unable to afford. The limited numbers of visits to some kinds of practitioners covered by MSP often left women frustrated and angry as they experienced pain relief, increased mobility, and other positive effects of treatment which they were forced to give up once the approved number of visits ran out. Women identified a lack of institutionalized support for alternative therapies, which resulted in mainstream practitioners - often the only ones women could afford to see - lacking knowledge about alternatives and alternative therapists not receiving the legitimization and respect they deserved for their knowledge from funding bodies or the provincial health insurance system.

[Women called on the health care system to increase the levels of funding accorded to “alternative” healing practices through the provincial health insurance plan and recognize and respect the vital role these practices can play in preventative and palliative care.](#)

This issue was particularly, though by no means exclusively, highlighted by the women living with HIV in the study. Given that current Western medical knowledge about HIV/AIDS is at best incomplete and at worst highly problematic, many women had found that the treatments that worked best for them, or were a necessary complement to Western ones, were those classified as “alternative”.

Given that this usually meant that the treatments were very costly and most of the women living with HIV were living on disability benefits, the situation could be extremely frustrating as the power of the traditional medical establishment intersected with poverty, and illness to prevent women’s best, or desired, health choices.

Being Given Inadequate Treatment Information

Another barrier that women identified to their best health was receiving inadequate information from doctors and other health care professionals about both why the doctors thought specific courses of treatment were necessary and the possible side-effects of medications that were part of those treatments. This lack of information not only left women feeling powerless and

With this virus some of us have had it in our bodies longer than doctors have been studying it. But when we keep going to the doctor and expecting them to know they don't. So what do you think they're going to give us as advice? Who's supporting them to get that specialist title? That's the pharmaceutical companies.

frustrated, but often made them fearful of the procedures and the practitioners themselves. This was particularly an issue for women who were HIV+ — who often reported not understanding why they were on certain medications instead of others, or being told about possible side effects after they had accepted medications — and women from the group for Spanish-speaking immigrants and refugees. As one of these women explained:

I was given a lot of shots when I came here. So many that I got scared. I had had all my vaccines before I came in and once here I was vaccinated again....I had a lot of tests done and always wonder why did they need so much blood from me. But I thought that maybe they had to do it and got worried. When I told my parents they got really worried. They were afraid I could have gotten bacteria or a virus with so many needles.

Women stressed the need for patients to receive thorough and comprehensive explanations of any treatment regime before engaging in it.

Health Education and Research

Finally, women identified problems with the way medical education and research are done which had created barriers to their best health. Women living with HIV in particular were appalled at the lack of education and training which future doctors and other health care providers receive about HIV/AIDS. They also condemned the close ties between large pharmaceutical companies and researchers, which allow the companies to control research and conference agendas regarding HIV/AIDS knowledge and treatment.

With this virus some of us have had it in our bodies longer than doctors have been studying it. But when we keep going to the doctor and expecting them to know they don't. So what do you think they're going to give us as advice? Who's supporting them to get that specialist title? That's the pharmaceutical companies. The pharmaceutical companies send them to a conference and they get all this information about what drugs [the companies] are pushing this week, that pharmaceutical's drugs. So you're not really getting open and honest information about what your choices are.

Women felt that the school curricula for doctors, nurses, medical/lab assistants and associates, support staff and alternative healers of all kinds must include relevant, up-to-date information on HIV/AIDS in women and men. They also believed the allopathic medical establishment should reexamine its ties to the pharmaceutical industry and look for other funding sources.

Women living with HIV were also concerned about the lack of accurate research data regarding women's risk factors and behaviours around HIV/AIDS as well as the lack of movement from researchers generally regarding increasing responsiveness to women's concerns and finding solutions to women's problems. A number of the women were quite clear that they often experienced research and the research process itself as a barrier to health, not only by sapping resources better allocated elsewhere, but also by providing and presenting false or misleading information as universal and cutting-edge truths.

Women were impatient to see the research process move ahead and start providing "better" answers but were suspicious of its motives and possible implications. They felt that research on HIV/AIDS must seek to be more responsive to the real concerns of women living with HIV.

For me, when I've had to be really closeted through feeling not safe at a work place or at school or something, then I start actually having physical symptoms. My jaw will start hurting, cause it's almost like I'm shutting down my voice, I'm silencing myself. And then I just start clenching my jaw all the time and I get a lot of pain in my head. I actually get physically ill when I have to be closeted.

Discrimination From Other Social Institutions

We had originally set out to look at the effects of these three factors — income, power in intimate relationships and relationships to health care providers. However, as women talked about the barriers they had faced to achieving their best health they noted other factors which were equally important. Most important were the various experiences of marginalization or discrimination they had experienced from mainstream Canadian culture. While the experiences of discrimination from health care providers and institutions discussed above presented clear barriers to women's best health, discrimination from other kinds of institutions and individuals also affected women's ability to keep healthy. The various forms of discrimination women in this study identified as having acted as barriers to their best health included: homophobia; racism; sexism; "addictophobia" (Stoller, 1998); discrimination due to being HIV+; and discrimination due to being a mental patient.

Homophobia

Women drew clear cause and effect relationships between their experience of homophobia in Canadian society and their experience of various health problems. One of the most direct ways this happened was having had health problems result from living in a situation where sexual orientation must remain hidden.

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As in this example, homophobia could act as a clear socially determined barrier to women's best health as the stress of living in a marginalized community could be expressed through bodily pain.

Specifically with regard to HIV prevention and care, homophobia has combined with sexism to mean that women who have sex with women were largely excluded from HIV/AIDS research (Leonard, 1990; Morrow, 1995). This has meant that women themselves have been given mixed messages about their risk. Research, including this study and others (e.g. Brabazon, 1994), indicates that the majority of Canadian women who have sex with women do not consider themselves to be at risk for HIV, despite a seroprevalence rate of approximately 5% in this community (Kuehn, personal communication).

Women in the study noted that a lack of knowledge about the sexual practices of women who have sex with women, including a tendency to not see it as "real" sex at all, has meant that for many years researchers refused to conceive of woman on woman sex as a "risk behaviour". Even now, if a woman has engaged in any other kind of risk behaviour woman on woman sex is automatically ruled out as a possible transmission route. This has resulted in much misinformation about the nature of risk in these relationships and researchers, theorists, (e.g. Leonard, 1990) and the women in this study are united in their call to change the way transmission statistics are conceived of and reported to more accurately reflect the possibility of woman-to-woman transmission.

Racism

Statistics coming out of the US show that people of colour are consistently and remarkably over-represented in reported cases of HIV/AIDS (Aral and Wasserheit, 1995; Banzhaf, 1995, Friedman et al, 1998; Rodriguez, 1995). While there have been no national Canadian studies examining HIV prevalence in women by race (Gillis, 1999), smaller local studies suggest that the situation is likely to be the same here. For example, the BC Aboriginal HIV/AIDS Task Force (n.d.) reports that a disproportionate number (16%) of new HIV diagnoses in B.C. occur in the Aboriginal community and further that, in 1997, Aboriginal women made up 40% of all new Aboriginal infections while non-Aboriginal women made up only 17% of the total non-Aboriginal cases. What this means is that not only is the Aboriginal community disproportionately affected by the HIV/AIDS pandemic but that women within the Aboriginal community are being even harder hit.

Women in this study noted a number of ways their experiences of racism had impacted on their ability to stay healthy. These

There is another kind of aggression. [Canadians] are very subtle about it. It is not like in our cultures where we are direct and up front. It doesn't happen that way here. It seems like it is just about hurting and I think that affects [people] more in a psychological way because it is not direct aggression. For any reason we get cut off from our support money or [Social Services] gives us a lot of obstacles or makes us wait. It is another form of preference.

included: increased stress due to living as a woman of colour in a racist society; dealing with the legacy of colonialism and imperialism negatively impacting the dynamics of intimate relationships (for both lesbian and heterosexual women); police harassment due to being a woman of colour or Aboriginal woman effecting women's ability to pursue healthy activities; and discrimination regarding both employment and social service provision. The following discussion, from the group for Spanish-speaking immigrants and refugees, is indicative of the kinds of concerns women raised.

I feel that even though people don't think so there is a bit of discrimination, even when we go to seek employment. I know that in the schools people are taught not to discriminate...[but] we see it, we feel it, and I believe that each and every one of us has been looked at in a different way.

Racism, like racism. There is some rejection.

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[By creating psychological and bureaucratic barriers to services and other resources necessary for health racism in Canadian society had acted as a barrier to women's best health.](#)

Sexism

The devaluing of women in contemporary society leads not only to inequalities in intimate relationships but to inequalities in the larger social world as well. While many examples of the ways in which sexism affects women's lives have already been mentioned, including discrimination from the medical system and government bureaucracies and harassment on the street, women talked about others as well including sexual harassment on the job, and the well known gap between women's and men's average salaries.

The devaluing of women can result in devaluing ourselves as well. One of the ways this manifests itself is in fear and embarrassment of our own bodies. Women talked about how feeling ashamed or embarrassed of their bodies had made them reluctant to seek out medical attention and in this way acted as a very concrete barrier to their best health. This issue was raised in the group for Spanish speaking immigrants where one of the women described it as follows.

Sometimes we women have many problems because of a lack of education we feel very ashamed when it comes to a sexual organs examination. This affects us because we just let time pass by and we don't go [to see a doctor] until it is already serious, or when we are already infected or when we already have a grave sexual problem. Sometimes we cannot overcome shyness when it comes [time] to see a doctor for this reason.

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Another result of sexism in contemporary Canadian culture is that violence directed towards women continues to pervade our society. Women face violence not only in intimate relationships but also on the street - not only on the streets of the DES (as has already been discussed) but also on whatever streets we happen to be on. Women identified the fear of violence, as well as the experience of street violence itself, as disturbing: the all too real threats to their feelings of well-being, security, and health. Women expressed both sadness and anger at its continued presence despite many years of advocacy and activism fighting it.

Addictophobia

There are two primary ways in which addictophobia effected women's lives. One was in the lack of medically and socially appropriate services that were available to women who were current or former substance users. The small number of addiction treatment facilities and recovery houses for substance users and for women in particular has been well documented in the literature (Gillis, 1999; Rockwell, Friedman, Sotheran and Des Jarlais, 1998; Saalfeld, 1995; Weissman and Brown, 1995). This was also noted by some of the women in the study as a barrier to their best health. They talked about the fact that there are currently no recovery houses at all in Vancouver that accept women on methadone as particularly problematic.

Some women also wanted to have more information about their medical situation, especially about the interaction between the use of street drugs and prescription drugs to treat HIV/AIDS. They said that they thought the lack of research done on these issues was a problem and felt strongly that having the information necessary to make more informed choices about their own health would be helpful to them.

Harm reduction services are also an integral part of keeping healthy for women who are substance users (Saalfeld, 1995). Women in the study mentioned the Needle Exchange program in Vancouver as an essential part of their health maintenance activities and the lack of a shooting gallery to provide a safe, monitored space to inject as a major barrier.

Women called for the number of services and level of information available to women who are current or former substance users to be increased.

The other way in which addictophobia effected women's lives was through the stigma and discrimination current or former substance users reported experiencing. One woman who has been recognized for her work and advocacy on behalf of women in the community of substance users told a story which illustrated how this kind of discrimination can interfere with women's attempts to attain their best health.

I've been asked to talk, I went to UBC...[and] I've been to a couple of other things [including] Vancouver General Hospital. I've talked to a lot of people...[and] they're amazed I'm still sitting here. Like I was telling you, I had a habit that was \$500 a day. I lived like that for 5 years, I did not care. My outside world did not go past the 100 block [of East Hastings]. I didn't care what anybody thought when I was at that point. But now I have to, it's forced upon me, I have to care because I wanted to leave the 100 block. But I keep getting it shoved in my face. Like they [say] "you're still an addict", I had somebody tell me that, "you're still an addict". "Well", I said, "I'm only spending 30, 40 bucks, that's better than 500 bucks a day". I said "I think I'm pretty damn good. Before you couldn't even get a hello out of me". It's just when people...knock you down it makes you really totally hard.

Feeling that they could never get away from being looked down on for having been a substance user made women frustrated and angry.

Discrimination due to having a Severe Mental Illness

People with severe mental illness were turning up very early in the AIDS epidemic as HIV+ (Cournos, 1996) yet, as of January 1999, there had been NO published Canadian research on preventing HIV/AIDS in women with mental illness (Gillis, 1999). Stereotypes of people with severe mental illness as asexual, and ignorance by medical and social researchers of the issues in this community (Carmen and Brady, 1990) are partly to blame for this lack of research. This has also resulted in very little public education being done with women in this community (Brouwer, personal communication). What this meant for the mentally ill women in this study was that many of them, despite living mostly in the DES (an area that has one of the highest seroprevalence rates in all of Canada), did not feel that HIV/AIDS was an issue that concerned them or one they particularly needed to worry about.

Women who suffer from severe mental illnesses are at risk for HIV/AIDS however, due to high levels of poverty, homelessness,

Why are you so concerned about AIDS? Why is it so important and why isn't it important about what's happening [to mental patients]? We're dying from the side effects of the medication we're taking. Why is AIDS more important than what's happening to my liver right now?

We already judge ourselves so horribly in our quiet moments. We don't forgive ourselves easily for having this virus and when everybody around us who's not infect[ed] and who seems or feels to be in control, who's in positions of power asks us questions like [how we got HIV], for me, it feels like one more way of taking my power away. One more way of discrediting me. One more way of not ever being able to feel like I can be on equal footing again.

dual diagnoses (involving drug addiction), control by care givers and the mandatory use of powerful medications to control the symptoms of their illnesses (Mental Patients Association. n.d.). It was some of these same issues that women in the study felt were higher priorities for them to deal with than was the threat of HIV/AIDS. Other priorities involved dealing with the realities of their illness and the effects that it had in their lives. Dealing with symptoms such as over-whelming fears and anxieties, as well as voices and other hallucinations was an obvious psychological priority for women. Dealing with side effects of the medications they were taking was their top medical priority.

Women's perception that their concerns and priorities, as mental patients, were not taken seriously is reflected in the words of one woman who said:

Why are you so concerned about AIDS? Why is it so important and why isn't it important about what's happening [to mental patients]? We're dying from the side effects of the medication we're taking. Why is AIDS more important than what's happening to my liver right now?

Sometimes the best route to take to reduce the risk of HIV infection or illness progression is to help women deal with the other health concerns in their lives which are draining their resources and creating conditions in which they simply do not have the energy to pursue HIV/AIDS prevention.

Discrimination due to being HIV+

One of the biggest barriers to health identified by the women living with HIV in the study was the discrimination and stigma they faced as a result of being positive. While the ways in which this happened with regard to the medical system have already been examined, women also mentioned experiencing discrimination — such as inappropriate curiosity, belittling questions and attitudes, blaming women for being positive or seeing them as bad people as a result of being positive, and either being denied service or given inadequate or inferior service — from the legal system, from government offices, from businesses they frequented, from neighbours and other community members and even from staff at various AIDS Service Organizations (ASOs). One woman summarized the effect this treatment had had on her when she explained:

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And there are a lot of us with good educations, who had jobs and were wonderful mothers and worked full time at taking care of their children and their husbands and don't have the energy to do it anymore. We don't need to be demeaned by the kind of question that automatically pops out of the health care and bureaucracies like this building — "Do you know how you got it?". It doesn't matter how I got it. I have it, now let's move on. How can we work together on this?

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Women found this kind of inappropriate curiosity regarding the cause of their HIV status, and assumptions that tended to accompany it that they were either IV drug users or prostitutes extremely frustrating and difficult to deal with.

Problems With AIDS Services And AIDS Service Organizations

As the people who use the services of AIDS Service Organizations (ASOs) women living with HIV in the study were well positioned to comment on how the services and programs provided by ASOs might be improved. The most common recommendation women had was to increase the number of street-based outreach workers. They expressed frustration and anger at the low level of services that were currently available from outreach workers.

[T]here's very minimal outreach workers in all AIDS organizations and that really friggin' pisses me off....'cause like they'll always say to me, just give me a call and when you need me I'll be there, well, I call and they're never there!...I mean I'm grateful to be able to come here [to an Aboriginal ASO] every day but there's other women out there who don't have what I have today. There's lots of women down there that I know today are really into their IV drug use and they're dying of AIDS. These women need that support, right? And they keep hearing the same thing too, give us a call and we'll come helping you. Well, they don't! [Outreach workers] don't because they're too over-booked, there's too many people in the community so that they need more outreach workers.

Women also called on ASOs to increase inter-agency networking to better share knowledge as well as to pay increased attention to facilitating networking opportunities for their clients. One of the changes women desperately wanted to see, both within the AIDS movement and elsewhere, was that various communities of women would take an increased role in organizing and lobbying for necessary changes.

As one woman said "It's time for us to ask for what we need, loudly and together". In order to facilitate this organization women

It's time for us to ask for what we need, loudly and together.

suggested that ASOs should sponsor networking or discussion groups facilitated by clients/members for them to identify their needs and strategize around solutions. They also felt that ASOs should place an increased emphasis on allowing their clients/members to speak for themselves, both when agencies are invited to give presentations to other community groups/members and in the media. Women were generally unsupportive of the recent professionalization of many of the city's ASOs which they felt took the emphasis off of the needs and ideas of positive people themselves. Women also called for more 24 hour services noting:

...our addiction or our disease does not stop at five o'clock and my mental health or my emotional state does not end at five o'clock. It's like "oh god, I can only get nervous for another 2 minutes".

Another frequent suggestion that women had about how to improve services for positive people in Vancouver was to increase the number of programs and services directed at family members and care-givers of HIV+ people both while the positive person is alive and after they have died. While women were careful to acknowledge that it should not necessarily be existing ASOs who should add this to their already stretched resources, they felt that the lack of services available to care-givers and family members was one of the most obvious and pressing gaps in the programs currently available in Vancouver. One woman described her situation as follows:

[I]f you can access [respite care for care-givers] you are made to feel,...if you are healthy,...you shouldn't need it. [You're] made to feel guilty.

[M]y sibling is positive and I know that there isn't anything out there for family members to do anything with them. And that bothers me. That bothers me because...I think my family has come a long way so we can sit down with him and talk about it with nephews and nieces however young they are but we've had to do that in our own home, we haven't had any help or counseling or anything for the other siblings that have a hard time dealing with him. And that bothers me. It bothers me that we don't have anywhere else to go to support...our family.

The following conversation describes the situation another woman faced trying to arrange for respite care for herself as a care giver to her HIV+ husband and her two children.

[I]f you can access [respite care for care-givers] you are made to feel,...if you are healthy,...you shouldn't need it. [You're] made to feel guilty. If you phone and say "Look, I have 2 children, I have a sick husband or a sick wife or a sick partner, I need some time for me" it's like "well, you should be able to deal with this"...But if I went down because I can't get that respite care, if I break down,

Nobody seems to look at the preventative stuff. We always wait until there's nothing left and then they have a much bigger situation and can't handle it.

my whole structure, my children's lives, my husband's life, my life, everything [breaks down]....The chain is only as strong as its weakest link.

Nobody seems to look at the preventative stuff. We always wait until there's nothing left and then they have a much bigger situation and can't handle it.

Easier access to respite care and home making services for both HIV+ and HIV- care-givers of HIV+ people is essential to the health not only care-givers but of HIV+ people themselves.

Other suggestions that women had about how to improve the programs and services currently offered by ASOs in Vancouver included:

- opening up the Core Training program available through AIDS Vancouver to friends, family members and co-workers of HIV+ people
- printing "expiry dates" on pamphlets or coming up with some way of indicating when information might reasonably be expected to be out-dated
- increasing the level of language-specific services available to immigrants and refugees by, for example, holding workshops in open-air locations such as parks and other recreational spaces, increasing advertising and promotion in the ethnic press, and being more involved in outreach work to multicultural youth.

What We Have Learned

[W]omen are not just effected by one social factor at a time — being poor, being a woman of colour, being a lesbian — but by all of the factors in the social world that intersect to create the conditions in which we live.

It has been known in the research literature for a long time that women's social, economic, and political realities impact enormously on our health status generally (e.g. Doyal, 1995, Nechas and Foley, 1994; Payne, 1991). The contribution of this research project has been to assess and document how five particular aspects of these realities — income, power in intimate relationships, relationships with health care providers and institutions, discrimination, and how AIDS service organizations work — affect women's risk for HIV infection and illness progression, in the particular locale of the Greater Vancouver Regional District.

None of these three factors operates in isolation from the others, of course, and documenting the particular interactions of each with the others is vital to understanding the true role that each one plays. Women do not live parts of our lives separate from the others — as women only, or as Aboriginal only, or as lovers only — but are always and at the same time living all of the aspects of our lives at once. Similarly, women are not just effected by one social factor at a time — being poor, being a woman of colour, being a lesbian — but by all of the factors in the social world that intersect to create the conditions in which we live. Our experience of one identity can change, or make more or less likely, the experience of another (in the way that, for example, being Aboriginal makes it more likely that a woman will become HIV+). For these reasons it is important to look at the bigger picture of social contexts and not limit our vision of the questions or the answers to the problems when doing research on women's health.

Being able to have this broader vision by looking at how different social factors affect women's lives and health was a clear strength of the project. Being able to talk to women and learning from and with them about their concerns and ideas made it possible for us to present a more grounded and real document based on women's own words.

Practically, using focus groups made it possible for us to listen and learn from a large number of women in a relatively short period of time. It also gave women an opportunity to listen and learn from each other and to brainstorm and share possible solutions to commonly experienced problems.

Doing the focus groups in partnership with organizations or individuals that had established contacts and rapport with women in communities was vital to the success of the project and another clear strength. Not only did it make the recruitment of participants much easier, it allowed for a much freer and more open flow of information in the focus groups. This was because the women from these organizations who chose to participate in

the project had already established relationships of trust and safety with the organizations and/or the facilitators of the groups. It gave the agencies we worked with a valuable chance to reach out and connect with members/clients and to “check-in” with them about their satisfaction with current programming and ideas for new services.

Finally, taking the time to build this first exploratory stage into the research design gave us an opportunity to establish contacts as well as to test out the appropriateness of the research model. It allowed us to use a community-based planning technique - rooted in women’s own words and experiences - to develop and lay the ground work for the next phases. Future phases will move more towards strategizing and action for problem solving. In this way this study works as an example of using action-oriented research as part of a community based planning process.

Some of the obstacles we met included the reluctance of workers from some agencies whose clients had already been over-researched (such as those teaching English to new immigrants and refugees) to be part of the study. By being flexible and being able to move to a discussion done in Spanish we were able to find a community partner for this group. The importance of having services and research protocols available in a variety of languages was a clear lesson to be learned from this experience.

The importance of being knowledgeable about and respecting cultural and racial boundaries around levels of comfort discussing different topics was another invaluable lesson. Some of the material that was discussed in many of the groups was very painful and difficult to talk about. This became a problem most dramatically in the group for Aboriginal women when the initial meeting broke down after the first hour in part because of the emotional rawness of the topics being discussed for the women who were present. One of the real weaknesses of the project was in not having ensured that there would be someone present at all meetings should women need to process emotional material apart from the group while the group continued. This proved to be a real problem in this situation.

While there were other problems with the group process as a whole as well, some Aboriginal women have suggested that the particular rawness and sensitivity of these issues in this group may be indicative of a lack of accessible and appropriate services for Aboriginal women in Vancouver. It also demonstrates the importance of cultivating inter-cultural communication skills and respecting cultural boundaries when presenting potentially distressing material. This issue will be at least partially addressed in the next Phase by having peer researchers organize groups and survey interviews only in their own communities.

Finally, attempting to identify barriers around the broad range of women's social, political, and economic realities plus strategize around solutions to them, proved too much to do in a two hour focus group. The search for solutions invariably got squeezed in at the very end, if it was discussed at all, and this is reflected in a lack of specificity in some of the recommendations. Focus groups in the next phase will focus much more on identifying solutions as the centerpiece of their discussions and move the project further in the direction of establishing an action plan.

The purpose of this phase of the project was to develop a local picture of the social determinants of women's risk for HIV infection and illness progression. Reaching out and talking to women within the communities in which they live, work, love and plan, produced a grounded, community-focused understanding of the complex web of barriers women face in seeking to pursue their own best health options. The next step is to work more concretely toward positive changes both within and across communities to address the barriers identified in this stage of the research.

Recommendations

The following recommendations are based only on the discussions women had in the focus groups. Some of the suggestions are clearly about HIV/AIDS per se but others are not. This is partly because some women identified other health priorities in their lives, and partly because women saw their risk for HIV infection and illness progression as closely tied to other health conditions as well as to a wide variety of social factors. Some of the recommendations are very broad while others are quite specific. This reflects the complexity of the issues involved and the multi-pronged approach that is needed to deal with them. Both concrete short-term strategies to ameliorate immediate suffering and long-term structural and systemic change to address the sources of suffering at their origins are necessary.

There are many more things than are listed here that will need to change before all women can live lives free from the risk of HIV infection and illness progression. The next phase of the project will continue to work with women to identify both possible solutions to barriers and priorities for action.

Poverty

- Advocate for the creation of more emergency shelters specifically for women in Vancouver.
- Reduce women's feelings of fear and intimidation on the street by developing peer safety training for street involved people.
- Increase the number of women only spaces in the DES.
- Increase the variety of viable, economic options to street prostitution.
- Facilitate access to skills training for poor women.
- Provide additional training to police officers working in the DES regarding issues in the community in an attempt to improve their treatment of local residents.
- Increase and make more accessible funding for children's transportation and educational costs.

Power in Intimate Relationships

- Reduce cultural acceptance and normalization of violence against women.
- Implement women-initiated, culturally appropriate campaigns to convince men to use condoms, even in long-term monogamous relationships.
- ASOs, health clinics and other social service agencies should provide free female condoms, as they currently do male condoms.

Relationships to health care providers and institutions

- The provincial government and health care system should work in partnership to find ways to increase the level of medical care available to women living with HIV living in suburban and rural communities.
- Ensure that women living with HIV are not turned away from emergency facilities.
- ASOs should continue to increase their responsiveness to and responsibility to represent the concerns of their clients/members who live in suburban and rural areas.
- Immigration and health officials should implement clearer and more complete orientations to the health care system for refugees and immigrants.
- The health care system should recognize and respect the vital role that complementary and alternative healing practices can play in preventative and palliative care by increasing

the levels of funding accorded to “alternative” healing practices through the provincial health care plan.

- The school curricula for doctors, nurses, medical/lab assistants and associates, support staff and alternative healers of all kinds should include relevant, up-to-date information on HIV/AIDS in women and men.
- The allopathic medical establishment should reexamine its ties to the pharmaceutical industry and seek to establish other funding partnerships.
- Research on HIV/AIDS should be more responsive to the real concerns of women living with HIV.

Experiences of discrimination from other social institutions

- Change the way transmission statistics are conceived of and reported to more accurately reflect the possibility of woman-to-woman transmission.
- Increase the number of services and amount of health-related information available to women who are current or former substance users.
- Services for current and former substance users should be in accessible locations and should be staffed by other women who have “been there” and have experience of the lifestyle and issues for women in the community.

AIDS Service Organizations should:

- increase the number of street-based outreach workers they employ.
- increase inter-agency networking.
- pay increased attention to facilitating networking opportunities for their clients.
- sponsor networking or discussion groups facilitated by clients/members.
- place an increased emphasis on allowing their clients/members to speak for themselves.
- offer more 24 hour support services (and ensure that those that are offered are staffed, especially during the over-night period).
- open up the Core Training program currently available through AIDS Vancouver to include friends, family members and co-workers of HIV+ people.

The AIDS Service Community generally should:

- increase the number of programs and services that are directed at family members and care-givers of HIV+ people both while the positive person is alive and after they have died. This may require the creation of new agencies with these services as their central focus.
- advocate for easier access to respite care and homemaking services for both HIV+ and HIV- care-givers of HIV+ people.
- print “expiry dates” on pamphlets or otherwise indicate when information might reasonably be expected to be out-dated.
- increase the level of language-specific services available to immigrants and refugees by, for example, holding workshops in open-air locations such as parks and other recreational spaces, and increasing advertising and promotion in the ethnic press
- become more involved in outreach work to multicultural youth.
- increase the number and level of culturally-specific services available to Aboriginal women.

Directions For Future Action

Phase 1 of the project laid the groundwork for the project by creating the first steps toward the development of a local analysis of the social determinants of women's health, particularly the social factors that make it easier or harder for women to stay healthy in the face of HIV/AIDS. Our long-term objective, to establish a community-based action plan and mobilize communities around this plan, follow from this first phase and from the peer-based research in Phase 2.

As discussed, Phase 2 will involve training women from the six communities we are working with to provide them with the skills necessary to run focus groups and do interview/surveys with other women in their communities. Training peers to do research is a way to provide skills development and work towards capacity-building in the focus communities. We hope it will help move women towards a place of empowerment and encourage self-advocacy in these communities in the later stages of the project. These focus groups and interviews that women will carry out in their own communities will focus in a more in-depth way on developing strategies and identifying solutions to the barriers identified in this first stage.

Phase 3 will focus on disseminating the results of both previous stages to the wider community and developing a plan for action both within communities and through coalition work across communities. Dissemination will occur through community forums, the development of a web site, street outreach, pamphlet distribution, report distribution, the release of results to media, and professional presentations. Through the bulk of the work at this stage communities will be encouraged to develop their own priorities for action, advocacy, and lobbying and the work of the project for program and policy change will proceed according to their wishes.

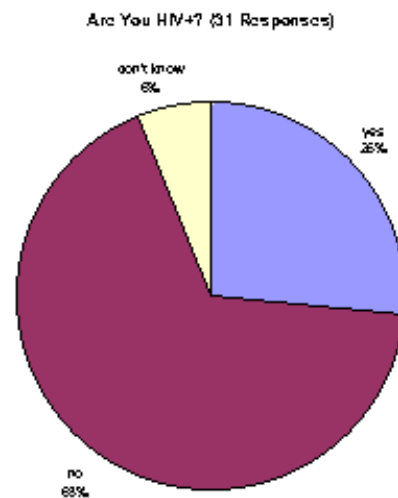
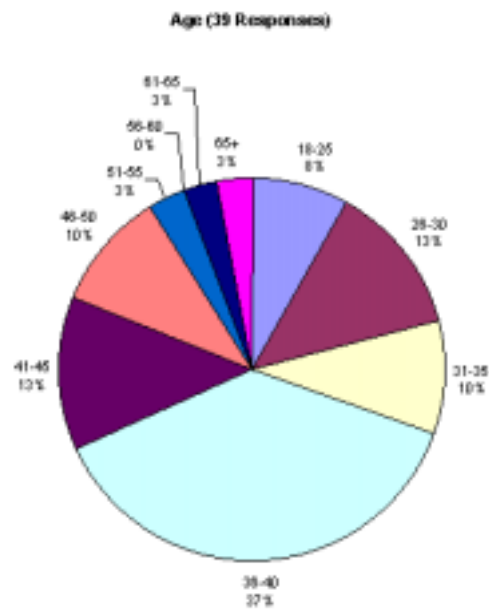
Truly representative community consultation and mobilization is a long and complex process. Nonetheless, by taking the time to develop community capacity and empowerment through skills building and self-advocacy the goal of the project is to set a process in place that can continue long after the research process itself is finished. By valuing and respecting the knowledge that women in communities already have regarding the barriers and difficulties they experience and what would be necessary to alleviate those barriers, the project seeks not to impose the solutions of "experts" or outsiders but to encourage the development and implementation of local knowledges and local solutions. Only by acknowledging the wisdom to be found in local women's communities will the groundwork for a true social change world be laid.

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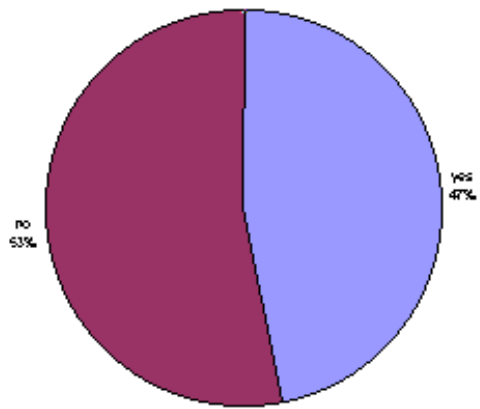
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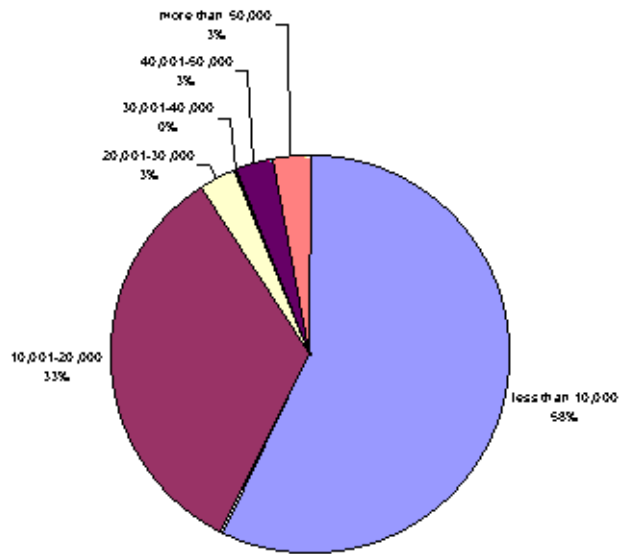
Appendix A: Demographic Information



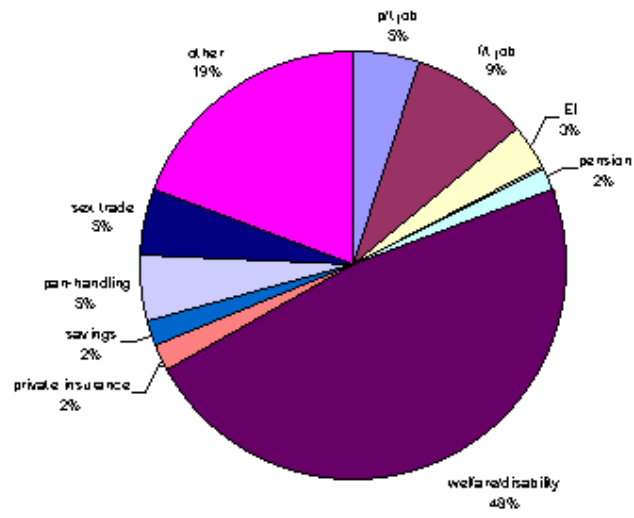
Do You Have Children? (34 Responses)



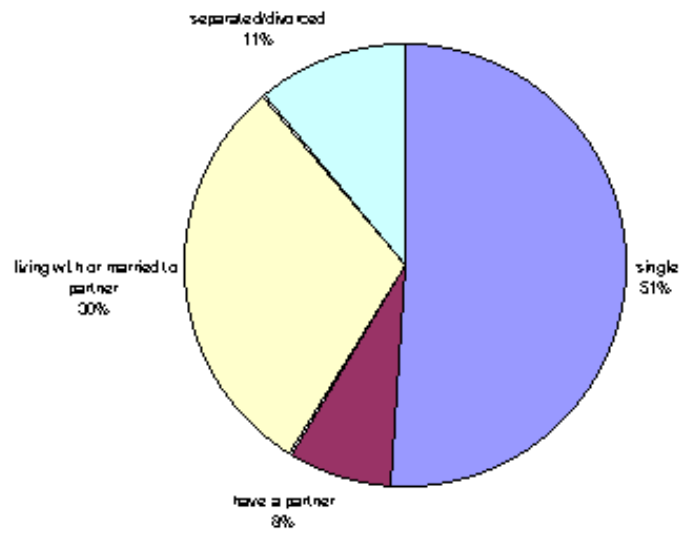
How Much Money Did You Make Last Year? (30 Responses)



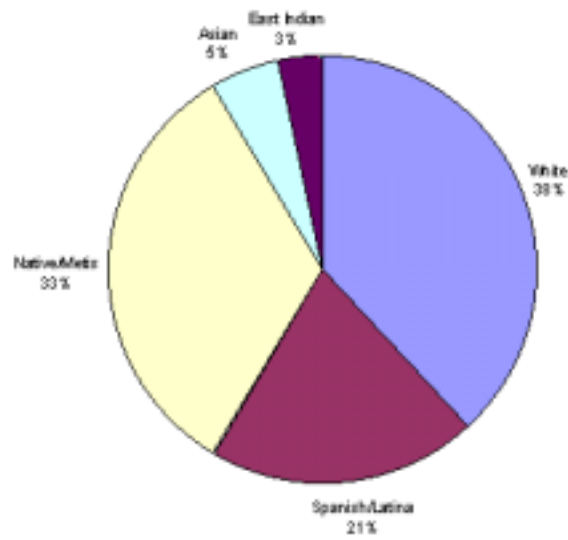
How Do You Get Money To Live On? (36 Responses)



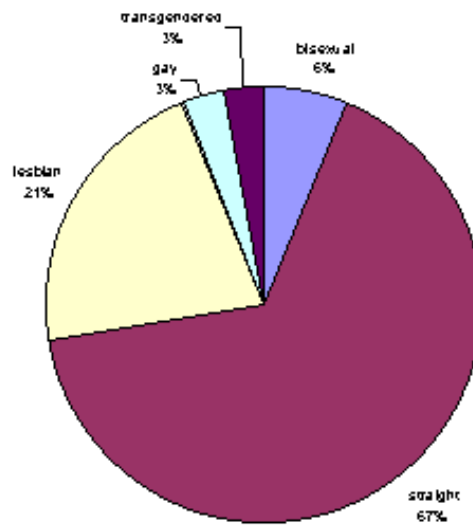
Partner Status (37 Responses)



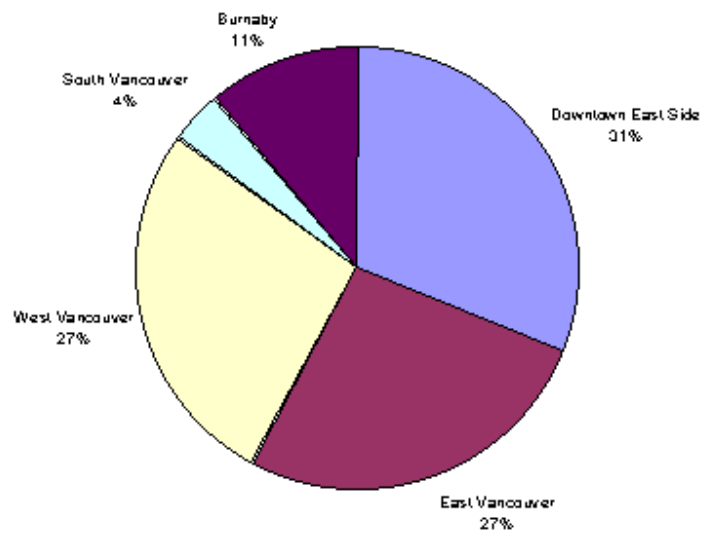
Race/Ethnicity (37 Responses)



Sexual Orientation (34 Responses)



What Area Of The City Do You Live In? (26 Responses)



Appendix B: Consent Forms

Main Consent

Informed Consent Form

_____ WOMEN'S HEALTH RESEARCH PROJECT _____

Sponsored by: Positive Women's Network (PWN) and AIDS Vancouver

Project coordinator: Stephanie Kellington

Why we are doing the study: We are doing the study to learn about how women who are both infected and affected by HIV/AIDS keep healthy. What helps women to be healthy and what makes keeping healthy hard? We are also interested in how social issues (like poverty, housing, sexism, racism, homophobia) effect the health of women infected and affected by HIV/AIDS.

What will happen here today: You will be asked to talk about a number of health and HIV/AIDS-related topics with a small group of other women. The group's discussion will be tape recorded. You will also be asked to share with us some personal information about you (like how old you are and what area of the city you live in) and do an evaluation of the group after it is over. You do not have to do either of these. They are completely voluntary which means you can choose to do them or not depending on what you feel comfortable with.

What happens if you don't want to talk about something in the group discussion: You do not have to talk about any topic you don't want to. Feel free to keep silent about anything you want to. You can also leave the room at any time you want to or need to. If you do leave, you can come back later on or you can leave for good. If you leave for good you will still be paid the full amount.

What happens to your words after today: We will be writing a formal report and a community pamphlet based on what we find out in the project. Both of these will be based on what you, and the other women participating in the project, tell us about your experiences. We may want to directly quote something you said because you said it better than we ever could! However, you maintain ownership of your own words and can tell us not to quote something in particular or to quote nothing at all from you at any point in the research process. All quotes put in either the report or the pamphlet will be anonymous. Your name will not appear anywhere in either the report or the pamphlet.

Where to get the pamphlet or the report when the project is done: The pamphlet will be available at community agencies and clinics around the Lower Mainland. The report will be sent to community-based agencies across BC and Canada. You can also request to be sent a copy of the report at the end of today's group or by calling us, at the number at the bottom of this page, later on.

Confidentiality: All of the information we get from the project will be kept strictly confidential. This means that we will not link any identifying information about you as an individual to anything you said. Also, the only place your name will appear is on this form which will be kept separately from all the other information from the study. You can sign this form using your real

name, another name you like to be called, a name you want to be called by just here or by making a personally meaningful mark.

Payment: You will be paid \$15 for taking part in the group discussion. There will also be food and non-alcoholic drinks available before and during the discussion. You can also get 2 bus tickets if you want them as well as money to help cover some of your childcare costs. The rates at which we are reimbursing childcare costs are as follows: \$5 per hour for the first child up to 12 years old, PLUS \$5 per hour for each additional child 3 years old or younger OR \$3.50 an hour for each additional child older than 3.

How to contact us: (Editor: All contact information given here is out-of-date and has been deleted.)

Consent: If you have read and understood everything on this form and agree to participate in the project, please sign below.

Signature

Print name (optional)

Date

Lesbian/Bisexual Group Consent

Informed Consent Form

_____WOMEN'S HEALTH RESEARCH PROJECT_____

Sponsored by: Positive Women's Network (PWN) and AIDS Vancouver

Project coordinator: Stephanie Kellington

Discussion facilitator: Sadie Kuehn

Why we are doing the study: We are doing the study to learn about how women who are both infected and affected by HIV/AIDS keep healthy. What helps women to be healthy and what makes keeping healthy hard? We are also interested in how social issues (like poverty, housing, sexism, racism, homophobia) effect women's health.

What will happen here today and later on:

Today -group discussion of HIV/AIDS and health related topics

-optional personal information form

-optional group evaluation form

Later -project coordinator will produce report and pamphlet based on findings of project

-all quotes will be anonymous and confidential

-sign-up to be mailed copy of report

-pamphlet and report available across Vancouver, Nov. 99

What happens if you don't want to talk about something in the group discussion: You do not have to talk about any topic you don't want to. Feel free to keep silent about anything you want to. You can also leave the room at any time you want to or need to. If you do leave, you can come back later on or you can leave for good. If you leave for good you will still be paid the full amount.

Confidentiality: All of the information we get from the project will be kept strictly confidential. This means that we will not link any identifying information about you as an individual to anything you said. Also, the only place your name will appear is on this form which will be kept separately from all the other information from the study. You can sign this form using your real name, another name you like to be called, a name you want to be called by just here or by making a personally meaningful mark.

Payment: -\$15 for taking part in the group discussion.

- food and non-alcoholic drinks available before and during the discussion.

- 2 bus tickets, if you want them

- money to help cover some of your childcare costs. (rates are: \$5 per hour for the first child up to 12 years old, PLUS \$5 per hour for each additional child 3 years old or younger OR \$3.50 an hour for each additional child older than 3.)

How to contact us: (Editor: All out-of-date contact information and has been deleted)

Consent: If you have read or have had read to you everything on this form and agree to participate in the project, please sign below.

Signature

Print name (optional)

Date

AIDS Vancouver Helpline 893-2222 (English), 893-2264 (Chinese), 893-2281 (Spanish)
Positive Women's Network 893-2200 (now 1-866-692-3001)

Spanish-Speaking Group Consent

(Please see Spanish version of this report)

Appendix C: Discussion Guide Questions

What do you see as being some of the most important health issues for women in your community?

(Probes)

- What are some of the major issues around reproductive and sexual health?
- What about HIV/AIDS?
- What are some of the things that you (or your friends) do to stay healthy?
- To prevent/deal with HIV/AIDS?

What are some of the things that have helped you (or your friends) get what you/they need to stay healthy?

(optional examples if needed)

- people, either new people you have met who helped hook you up with the right places, gave you money at a critical point or people you have known before who acquired new meaning\role in your life
- organizations (such as PWN/AV or any of partner orgs in study) — what is it you have gotten from these places that has been especially helpful?
- changes in your living conditions, such as getting a permanent place to stay
- changes in how you feel about yourself (some women have said that it was only after they started feeling better about themselves as people that they were able to start looking after themselves better healthwise)
- new skills acquired (negotiation/inter-gender communication re: condoms, assertiveness etc)
- new information (such as how HIV is transmitted and what to do to prevent it)

***For groups where this is applicable, insert grid exercise here: OK so now we'd like to talk about some of the things that have made it harder for you to stay healthy We'd like to do this by...

For groups where grid exercise is not feasible, the following two questions could be used instead:

What are some of the things that have made it difficult for you to get what you need to stay healthy? (optional examples if needed)

- people (something someone has done or refused to do)
- organizations (for ex. requiring you to make an appointment and come back on another day, being full/ no more openings, they didn't take kids etc.)
- changes in your living conditions
- changes in how you feel about yourself
- being on welfare
- being scared to leave a partner or ask for things because you depend on them for money or social support

Do you know about any government policies or laws that make it hard for you to get what you need to stay healthy? (pick optional examples appropriate to group)

General

for example, welfare isn't enough money to pay for "extras" like vitamins or alternative health care practitioners OR

BC Medical only pays part of the cost for very few visits per year to alternative health care practitioners (if at all) OR

Addiction

laws which make it illegal to own works (which mean you are more likely to have to share) OR

government refusal to support "safe spaces" to fix OR

Aboriginal

confusion around responsibility for health services to off-reserve Aboriginal people OR

laws which mean you don't have official "Indian status" OR

Immigrant

unavailability of culturally sensitive services/ghettoizing of culturally sensitive services OR

fear of losing partners sponsorship for immigration if you cross him in any way OR

Queer

government refusal to force employers to recognize same-sex relationships means you are not eligible for extended insurance coverage OR

SMI

lack of support for sheltered housing/workplaces

Groups with the grid exercise rejoin here, others carry on.

BREAK10 minutes then continue:

What are some things you have wanted to get to keep healthy that you weren't able to get (like food, medicine, condoms etc)? Why couldn't you get them?

- Has not having enough money ever stopped you from getting something you wanted to

stay healthy?

- not having housing?
- some other reason? (doctor wouldn't give prescription, service didn't exist, couldn't get to the doctor's office physically because didn't have bus fare etc)
- Would it be easier to be healthy if you had more money? Why?

What are some of the things people who are close to you have done to make it easier for you to stay healthy? (How have people who are close to you helped you be healthy?)

How have they made it hard for you to be healthy? What have they done or not done?

(optional probes, if needed)

- Have people you are close to ever stopped or prevented you from doing something you wanted to do to stay healthy? (exs. like refused to wear a condom/dental dam/glove?)
- pressured you to share needles? or not let you go to a doctors appointment or appointment with another health care provider? (like a chiropractor, counselor etc)
- Has your partner or someone you are close to ever been violent towards you because of your HIV status or because you had asked him/her to do something to help you keep healthy (like use a condom/dam, clean a needle, get tested for HIV)?
- Have you ever not done something you wanted to do to keep healthy (like ask your partner to wear a condom) because you were afraid of how he/she might react?

What are some of the things you have gotten from the health-care system that have been most helpful to you as you try to keep healthy?

- from doctors, counsellors, alternative healers.....

What are some things about the health care system that have made it difficult for you to get what you need to keep healthy? (optional probes if needed)

Have you ever been denied access to or discouraged from using health services because you are a woman/ queer/Aboriginal/an Immigrant/addict/have a mental illness/ were in prison?

Have you ever been denied access to services because they were full?

How would you describe your relationships with your health care providers?

(optional probes if needed)

- Are they respectful?
- How long do they spend with you?
- Do you feel listened to?
- Do they know about your life generally?

If a doctor/health care provider (your own or one you're seeing in a clinic or a van) gives you some advice that you think isn't right for you or that you know you won't be able to follow through on because it is too expensive or difficult to arrange, what do you do?

Have you ever used the services of an AIDS service organization (like Positive Women's Network or AIDS Vancouver)?

If yes: What can ASOs do to make it easier for you to stay healthy?

What do they do already that has been helpful to you?

What else should they start doing that they don't do now?

If nothing: Why not?

Is there a service you can imagine you might want to get from them or would make you want to go there if they did have it?

What do you think is the best way for AIDS organizations to get educational messages (about transmission, prevention etc) to women in your community or to you personally?

Possibilities include: flyers in doctors offices or other community organizations, small educational workshops, mass media campaigns, through existing community networks and services such as hairstylists, bars, specialty grocery stores, cafes, public lectures.

Grid Exercise Guide

What we're going to ask you to do now is, break up into pairs/smaller groups (need 3 groups in total). In these smaller groups we'd like you to talk about what's written on these three sheets here.

Each group is going to get one of these sheets and as you can see, at the top of each sheet are one of three factors (three things). These are factors that might make it easier or harder for you to stay healthy. Staying healthy might mean dealing with the impact of HIV/AIDS in your life or it might mean dealing with whatever other health issues you are thinking about these days.

The first factor is about money and how having it or not having it makes it easier or harder for you to keep healthy.

The second one is about power in intimate relationships which might mean relationships with your husband, boyfriend, girlfriend or lover OR with people in your family OR with really good friends (write these things down on sheet as saying them). POWER in intimate relationships could get played out in a lot of different ways but generally what we mean is the way that because people are close to you and they care about you or you care about them (or both!) they can sometimes make you do things that other people could never make you do — and sometimes this can be good and sometimes it can be bad. Sometimes we might also let people who are close to us do things to us that we would never let other people do. So what we'd like to know about from you here are what are some of the ways people you are close to have used their power over you to effect your health and how you are able to take care of yourself.

The third factor is about relationships with health care providers who could be doctors, counselors, street nurses or other so-called alternative health care providers like chiropractors, naturopaths or herbalists, as well as with the medical system itself.

Down the side of each sheet are two places or areas of your life in which these factors might have an effect.

The bottom one (political) is asking about government policies and laws or the actions and policies of other people in authority (like for example, researchers) that effect how well you can stay healthy.

The top one (personal) just asks about the effects that the law or policy that you talked about down below has in your life. As it says on the sheet, you might want to think about effects that it has in how you are at home, on things that happen at work (if you have job), or on things that happen in community agencies (like host agency). You don't have to come up with an example for all of these different places, or you might, but just wherever you think it has an effect in your life is what we want to know.

What we'd like to hear about from you are ways in which these factors (the things across the top) have effected your lives in these areas (the things down the side) as you try to stay healthy. Staying healthy might mean dealing with the impact of HIV/AIDS in your life or it might mean just doing whatever it is that you do to deal with the health issues that are important to you right now. We have for you here just a few examples of how we imagine this might work (because this kind of thing is always easier to explain using examples than by describing it). Explain examples.

These are just some of our ideas, you might have completely different ideas about what parts of the political world have most effected your life which is great — please tell us what they are! Or you might have experienced different personal effects of the same policies or laws that we have mentioned here — that's great too, just whatever you can tell us about your experience is what we want to hear.

We're going to ask you to work in pairs/small groups, just so you can talk to each other about some of your ideas, bounce stuff off each other. Each pair/small group will be asked to report back to the bigger group about what they talked about. Does anyone have any questions?

	Income/money/ poverty	Power in intimate relationships	Relationships with health care providers
Personal (at home, at work, at agencies)	Lack of money for food and medicine	on-going abuse by partner	getting turned away from treatment because all spaces were full
Political (government research, lawyers, police)	welfare too low	police reluctance to to charge and prosecute “domestic assault”	lack of funding for addiction treatment facilities

[Suggestions of other examples that could be provided to each group are listed below:

General

- BC Medical only pays part of the cost for very few visits per year to alternative health care practitioners (if at all) OR
- Addiction: laws which make it illegal to own works (which mean you are more likely to have to share) OR
- government refusal to support “safe spaces” to fix OR

Aboriginal

- confusion around responsibility for health services to off-reserve Aboriginal people OR
- laws which mean you don’t have official “Indian status” OR

Immigrant

- unavailability of culturally sensitive services/ghettoizing of culturally sensitive services OR
- fear of losing partners sponsorship for immigration if you cross him in any way OR

Queer

- government refusal to force employers to recognize same-sex relationships means you are not eligible for extended insurance coverage OR

Mental Illness

- lack of support for sheltered housing/workplaces]

Once group has reconvened, ask for a volunteer group to present what they talked about first. After each group has done presenting what they found, ask the larger group if there were other examples from their own lives that they had thought of that would fit in that category that they would want to share with other people now.

When done: thank the groups for their work in making the lists and for sharing personal information with us (if applicable) Say would now like to move further on in this direction and talk in a little but more detail about some of the things that have come up here (as well as some that haven't, if applicable). Start with income and how either having money or not having it can affect ability to stay healthy. And ask you to think about if there been times when.....(return to discussion guide).

Appendix D: Evaluation Form

Evaluation Form

_____ WOMEN'S HEALTH RESEARCH PROJECT _____

The most important thing
I heard today was.....

I really wanted to say but didn't
get to that.....

I liked.....

Changes for next time.....

Appendix E: Demographic Information Form

Personal Information Form

_____ WOMEN'S HEALTH RESEARCH PROJECT _____

We'd like to ask you to share some information about yourself with us. We will use this information to look at who the women are who took part in this project - to help us understand who we have reached and who we haven't reached. We MIGHT also use it to say things about the women who part in the study as a group or about particular sub-groups of women (for example, "All of the women who had blue eyes thought that pigs are great animals".) We will NOT be using it to identify you in anything we write about the project or giving it out to any other agencies or groups.

Any information you choose to share with us on this form is completely voluntary - this means that you don't have to tell us any of this stuff or you can tell us all of it. How much you tell us is completely up to you. If you choose to answer only some or even none of these questions, you will still be paid the full amount for being part of the group today. If you don't want to answer any of the questions please just leave them blank.

How old are you?

18-2536-4051-5565+

26-3041-4556-60

31-3546-5061-65

What is your racial/ethnic background?

How do you identify your sexual orientation (bisexual, straight, lesbian, queer, etc.)?

Do you have a disability of any kind?

How do you get money to live on? (circle all that apply)

Part-time job

Full-time job

Employment insurance (EI or UIC)

Canada Pension Plan (CPP)

Provincial income assistance (welfare, disability, etc.)

Private insurance

Savings

Pan-handling

Other (specify) _____

How much money did you make last year?

Under \$10,000

\$30,001 - \$40,000

\$10,000 - \$20,000

\$40,001 - \$50,000

\$20,001 - \$30,000

over \$50,000

What area of the city do you live in?

Are you:

Single

Partnered, but not living together

Living with your husband/partner/boyfriend/girlfriend/lover

Separated

Widowed?

Do you have children?

If yes: how many? how old are they?

Do you practice a religion or follow a set of spiritual teachings?

If yes: which one?

Are you HIV positive?

Is there anything else that you want us to know about who you are? (please use back of page if necessary)