"A lot of times you don't care when you're using, or even if you're not using and you're working at the cross street, and your self esteem is pretty low, then it becomes less important to look out for yourself, who cares if you're engaging in risky behavior?"

Women's Accounts of the Social Construction of HIV Risk

Lynne Leonard

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Community Health Research Unit
Department of Epidemiology and Community Medicine
University of Ottawa
451, Smyth Road
Ottawa, Ontario
K1H 8M5

Tele : 613 - 562 - 5800 x 8286 Email:leonard@zeus.med.uottwa.ca

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1.0 INTRODUCTION

1.1 Biologically and Socially Constructed Risks for Women

For all women, their biological sex alone places them at differential risk of HIV infection.

It is now well documented that women are at greater risk of contracting HIV from one unprotected act of sexual intercourse than men. The dynamics of the heavier concentration of the virus in semen than in vaginal secretions, the greater surface area of the vagina compared with the penis and the greater permeability of its mucous membranes combine together to construct a higher risk of infection for women than men (Padian et al, 1995). When this biologically constructed risk, which Doyal refers to as the "biological sexism" of the virus (Doyal, 1995 : 77), is overlaid by gender constructed and structurally determined risk situations, women's choices to protect themselves from infection are limited.

This paper reports on the individually and socially constructed determinants of HIV-related risk behaviour from the perspectives of women themselves. Central to the discussion in the paper are selected discourses from women self identifying as being at higher risk of HIV infection. Through an iterative series of guided conversations, these women shared narratives of the experience of the risk of HIV in their lives. In making sense to themselves of their engagement in behaviours that exposed them to risk of infection with HIV, the women in our study shared narratives around several main themes. Several women spoke of the complex issue of equating trust with no risk and of the experience of gendered risks[1], others of the mediating effect of drugs or

[1]Gendered risks exist for a woman when her ability to control her exposure to HIV is mediated by her economic dependency on a male partner who insists on unprotected sex. In addition to an imbalance of financial power in a relationship, an imbalance of physical power and an imbalance of perceived or real negotiating power in establishing protective sexual practices result in too many women living at high risk of contracting HIV and in too many women living with the infection.

alcohol on their behaviour either directly or through their involvement in the sex trade to support their habit. Other women told us stories of developmental correlates of unsafe sexual and injection behaviour such as early emotional deprivation or lack of self esteem. The women's narratives, although unique in many aspects, typically converged on the unifying theme of the pervasive determining effect of the legacy of childhood sexual abuse in determining their engagement in sexual and injection practices placing them at higher risk of HIV.

1.2 The Consequences of Those Risks : The Epidemiology of HIV and AIDS in Canadian Women

I guess I think I can't get it, it can't happen to me.

Of course, it can happen to all women and is happening at an alarming rate. The total number of AIDS cases among adult Canadian women (delay adjusted) has increased from an average of less than 10 cases per year in the early 1980s to an average of 143 cases per year in 1995 - 1997.

In addition, the proportion of AIDS cases in adult Canadian women has increased over time, particularly recently from 5.2% of all AIDS cases before 1990, to 6.7% during 1990-1995, and 13.6% in 1996-1997 (Health Canada (1), 1998). In 1997, female cases reached a level not previously seen since the monitoring of the epidemic began, accounting for 14.1% of annual AIDS diagnoses. Women now account for 7.2% of the cumulative total of reported AIDS diagnoses in Canada (Health Canada (2), 1998).

HIV data also suggest increasing infection among women. The estimated proportion of women among new HIV infections has also increased steadily over time, from 9.8% of all positive HIV test reports in 1985-1994, to 21.8% of all positive HIV test results in 1997 (Health Canada (2), 1998)

In Ottawa-Carleton, where the women working with us in this study live, the HIV epidemic continues to be a major public health issue. Figures just released from the Region of Ottawa-Carleton Health Department HIV Prevention Program, document a 37% increase in HIV infections in 1997 compared with the previous year. The annual

incidence rates in women in Ottawa-Carleton have been fairly consistent over the last three years at 9 per 100,000. The main mode of transmission in 1997 was heterosexual contact with a person at risk at 47%. For the first time in Ottawa-Carlton, two women younger than 19 were diagnosed with HIV through heterosexual contact.

2.0 OBJECTIVES

On a general level, this exploratory study aimed to expand current knowledge of the social experience of HIV risk in the lives of women self-identifying as being at risk of HIV infection.

On a specific level, the study gave space to women to tell their stories describing how they experience, how they understand and make sense to themselves, and how they would construct protective strategies around, their perception of their risk of HIV infection. In addition, it provided women with the opportunity to reflect upon, and to voice, the contributions of social, economic and interpersonal context in the dynamic construction of HIV risks.

3.0 RESEARCH DESIGN

Semi-structured interviewing was selected as the best means to achieve the active involvement of the women in the construction of data about their lives.

As the unique parameters of each woman's experience could not be known from the outset, the interview was an inductive process with few predetermined questions. General thematic areas only were identified to allow the women's responses to determine the order of subjects, time spent on each and the introduction of additional issues.

Consistent with the exploratory nature of the study, it was also an iterative process in that questions were added, both within and between interviews, as unanticipated patterns emerged. When questions were posed, they were widely framed and understandable on many levels so that the women could respond in their own terms without feeling constrained or directed in their responses.

This approach probably has some similarities to phenomenological interviewing in terms of attempting an interviewee guided investigation of a lived experience that asks very few prepared questions.

4.0 RESEARCH METHODS

4.1 Sampling Strategy

Purposeful sampling (Patton, 1990) was employed to determine final sample size, where events, incidents and experiences, not people per se, are typically the objects of the purposeful sample (Miles & Huberman, 1994; Strauss & Corbin, 1990). Central as the women are to the enquiry approach, as Sandelowski (1995 : 180) states,

"[people] enter qualitative studies primarily by virtue of having direct and personal knowledge of some event (e.g., illness, pregnancy, life transition) that they are able and willing to communicate to others and only secondarily by virtue of demographic characteristics (e.g., age, race, sex).

Women of a particular age, class, race or ethnicity (demographic variation) were not therefore sought out; rather maximum variation sampling in terms of women's situations (phenomenal variation) was adopted as the sampling strategy most suited to the objectives of this research.

The variables, the women's situations, considered to constitute phenomenal variation were those documented in the admittedly sparse literature on women's experience of HIV risk and informed by discussions in the Women and HIV Risk Study Group and included:

- women who were injection drug users
- women whose partners were injection drug users
- women whose profession was the sex trade
- women from resource poor environments

4.2 Recruitment Strategy

Recruitment strategies, consistent with the adopted sampling strategy, were

employed in order to achieve maximum phenomenal variation within the sample.

The least successful method of recruiting women to join in the study was the display of posters in selected community agencies and the distribution of business cards asking women to phone in and schedule an interview at a neutral location. (Poster reproduced as Appendix 9.1).

The most surprising method was women openly and publicly joining with the investigator following presentations of the research at Drop In Centres and breakfast and lunch programmes to complete immediate, on-the-spot interviews.

The most successful method was working with trusted, safe community contacts who confidentially introduced women into the project. Through the active support of a volunteer-driven women's support group for example, it has been possible to work with women who agreed they would not have joined with the project through any other method of introduction or recruitment.

4.3 Interviews with the Women

The in depth exploratory interviews were facilitated by a woman researcher, with the women's consent were audio taped, typically lasted between one and two hours and finished with an extensive debriefing and an opportunity to ask questions. Whenever appropriate and again with the women's consent, the interviewer initiated a referral to a community agency or other source of support if this was mutually considered to be in the women's best interest. The women were compensated $20 for their time spent away from their other tasks and activities and child minding expenses and bus tickets were provided.

4.4 Analysis of the Women's Stories

> "Data analysis is the process of bringing order, structure, and meaning to the mass of collected data. It is a messy, ambiguous, time consuming, creative and fascinating process. It does not proceed in a linear fashion; it is not neat. Qualitative data analysis is search for general statements about relationships among categories of data; it builds grounded theory." (Marshall & Rosman, 1995 : 111).

The analysis of the data collected in these interviews has been exploratory and descriptive, congruent with the objectives of the research study.

The transcript of each taped interview was read three times by two analysts, researchers with extensive experience of analysis of qualitative research. The transcripts were read at the same time as listening to the audio tape of the interview to identify the women's affect (tone of voice, emphasis, hesitation, etc) as well as to initially identify, and latterly to confirm, main themes and variations.

Once the interview transcripts had been annotated as to tone and emphasis they were entered into NUD*IST files. Categories for the preliminary analysis were developed in NUD*IST by the two analysts separately and were discussed with the Co-Principal Investigator, Lynne Leonard, who had conducted most of the interviews.

A reduced number of categories was developed, with detailed descriptions for coding choices. A sample interview was double coded by the two analysts separately and emerging categories and descriptors refined and made consistent. An index tree of 12 nodes or categories, with sub categories was created in NUD*IST, and the interviews coded. Sections of several interviews were coded by both analysts at different points and coding strategies compared and adjusted to enhance consistency and reliability.

Content in each node was ordered and reordered to develop clear and exhaustive categories relating to women's behaviour, beliefs, needs and past history.

The content of all nodes was analysed, including text searches for key phrases suggested by emerging theories, such as the interrelationship between childhood sexual abuse and engagement in prostitution. Finally, all nodes and sub nodes were re-analysized as themes, strands and patterns emerged.

5.0 RESULTS

5.1 The Women in the Study

Consistent with a non directive interviewing approach, specific demographic questions

were not asked in order to resist categorisation or positioning of the women early on in the interview process which could possibly influence the subsequent direction of the interview. However, from the rich description in their narratives, the women who have joined with us in this project are straight, lesbian and bisexual women aged 15 - 58 years of age whose lives have included or include activities posing higher risk of HIV infection - unprotected sex with multiple partners and with men known to be active injection drug users; engagement in their own injection drug use which frequently involved sharing needles and other injecting equipment; engagement in "prostitution", "hooking", "survival sex" and sex trade work in escort agencies.

The social and interpersonal context of the lives of the women who joined with us also present challenges in negotiating protective behaviours particularly for those women who described themselves as unstably housed or who have lived or are living on the street and for those women who described their sexual partners as injection drug users, drug dealers and pimps.

We spoke with Caucasian and aboriginal women from privileged and resource poor living situations. We spoke with women who disclosed sero-negative and sero-positive status and with women who described themselves as survivors of AIDS as their previous life style "was just what AIDS was looking for." Nearly half of the women made reference to a mental health diagnosis or described themselves as recovering alcoholics or recovering addicts and nearly all of these women made reference to time in therapy or to seeing a counsellor regularly.

5.2 Variability in Perception of HIV Risk

This research has generated "thick description" of the variability in perception of risk to HIV held by these women and of the impact of this perception on their ability to engage in healthy sexual lives. More importantly perhaps, it has generated specific examples of how this risk is mediated by the life circumstances of the women which determine their power - and their will - to engage in lower risk practices.

The majority of the women saw themselves at risk,

> *So, anyway, it's - have I been at risk? I guess I have been.*

Many of the women described specific situations in which this awareness became

more acute or conscious,

> *And I just said, yeah, am I taking it? Am I taking it, all right? Or am I risking it, or am I risking myself, or what.*

For some women, being at risk was an ongoing concern; for others, they were aware that they may have been taking risks, but did not care about it at the time. In the words of one woman,

> *You see, if I had gotten AIDS, I would have.....it would have taken my all, ...but I think I would have really accepted it. Because my lifestyle was exactly what AIDS was looking for.*

A few women were quite fatalistic about the risks they have taken, and will continue to take:

> *I don't really care any more. I either have it, or, as far as I'm concerned, I have it. I live my life as if I have it.*

> **("Were you scared at that time about getting HIV from sharing needles?")** *No. No. ...Well, I didn't, I didn't really care. I really didn't care.*
> **("Had you thought about HIV at all when you were injecting drugs?")**
> *No, no. None whatsoever. I had no fear whatsoever. I just didn't care, basically."*

A small, but significant, number of women stated that they did not think of themselves as being at risk at all,

> *No. I've always used condoms and I've slept with five guys, but we've always used condoms and I don't share needles, I don't do needles. So, I know my life hasn't been at risk at all.*

Some seemed to downplay their level of risk,

> *It isn't that easily communicable.....I don't think that I'm positive.....Yeah, all the time [shared needles] yeah. Because it's, we slept together, we had sex together, we ate together. It's nothing more risky than all those other things.*

But none of my boyfriends have complained that they have got it. So, maybe I'm okay. I have to live with that hope.

For some women, unfortunately, their perception of their suspectability to risk conflicted with their description of engagement in risk-conferring behaviour:

> *("Do you think you might be at risk?") No. (" Are you sexually active at the moment?") Yes. ("But you don't use condoms?") No. I guess I never did.*

> *("Do you think you might be at risk?") I really don't think so. Because any time that I have had intercourse, a condom has always been used, simply because I didn't want to get, you know, pregnant....So, I don't really think so. And I'm not promiscuous, believe me. And, so. If I, you know, were sharing a needle and having sex without, you know, using a condom, then I would be very worried. But I haven't done that.*

Sadly, this woman later described being an alcoholic for over twenty years, to the extent that she has been experiencing blackouts and seizures. She has only been sober for one month. Later in the interview, she talked about the kinds of risks that people take when they are on alcohol.

Several women report having gone through a stage of denial in relation to their possible risk in the past:

> *I didn't think about it. I didn't think I was going to get AIDS. Crazy, I didn't even think I would get pregnant. I did. Three times. It hits you after a while. 'It can't happen to me' is the problem. Everyone thinks it can't happen to me. It can happen to anybody, anytime, anywhere. I don't care what class you are, I don't care what race you are, what colour, what size. Don't matter. It can happen to you.*

> *Basically, like everybody [I think] I can't get it. But I understand there are too many people who have things like that. So, now, I think everybody can get it. But, just hopefully... I never thought about getting it*

> *I didn't realise [I was at risk] until a couple of years ago, actually. I guess it's almost like, I was sort of naive, or ignorant or something. Like, I just figured that, [I wouldn't get AIDS] because, how can I put it, I guess it's just that I'm more aware.*

There were also women who thought that they may have been at risk at some previous point in their life, but that risk situation was now over:

> *I don't think I will be at risk any more, because I put myself there. I'm at the point where, I know what I want now, and I'm not going to let anybody hurt me. I'm not going to hurt myself any more.*

> *I guess on one hand, like, I really feel like, well, I'm really OK, like, because I'm completely abstaining, right now. I'm really low risk. On the other hand, I probably, without actually, like, I'm not promiscuous, but just being with D right there, in that one situation, put me in an extremely high risk group.*

For some women, their perception of HIV risk in their lives has negatively impacted on their current desire and their need to be sexually active, resulting in a "vulnerable", "temporary", "unsatisfactory" state of abstinence, described as "not satisfying", "not a good alternative" and something they "don't want forever". This is a brief selection of the comments made by the women in describing how their lives had been changed by increased understanding and knowledge about their risk of HIV infection:

> *You might think I'm paranoid, but I'm going to live, so having sex right now is out of the question.*

> *It's made my sexual activities a lot less - simply out of fear. I haven't had sex for two years now.*

> *I've stopped having sex, I avoid it like the plague.....See how much the thought of getting AIDS affects me. I have a lonely life.*

For other women, awareness and knowledge of HIV-related risk behaviours had not resulted in any changes in their unprotected sexual activity or high risk injection practices. The comment from this woman is typical of many that reflect either a healthy, if misplaced, sense of optimism or an unhealthy denial of risk,

> *I think I'm not afraid enough. I don't know. Hopefully I am not going to get it.*

One of the older women described how she had achieved some level of comfort with her acknowledged level of risk:

I just keep putting it out of my head. I never think about it. Pretty stupid eh? Like some dumb teenager.

Indeed one of the teens we spoke with had thought about it and had constructed her level of comfort by asserting her invincibility to the virus,

I was never worried about it. I would never use protection or anything. Yeah, it [was my choice]. It was out of my own will. I don't want to. I don't feel like it. I guess I think I can't get it, it can't happen to me.

5.3 Variability in Experience of Risk

Just as the women's stories illustrated the variability in their perception of their level of suspectability to HIV infection, their stories illustrate variability in the types of behaviour that they identified as placing them at risk of infection with HIV.

5.3.1 Describing risk in terms of partner behaviour

Many women explained they were at risk because of their partner's behaviour. They attributed their high risk to their partner being an injection drug user, to their partner having sexual relations with others, or were simply concerned that they did not really know or trust their partners sufficiently to be certain that there was no risk when having sex or sharing needles with him or her:

He did that one night, and went up the street, he was trying to do a hit. He had washed the needle and cleaned it somehow, but I don't think he had a bleach kit for it. So it was all about getting that next hit, you know? He should have not used it - the needle- but he did. But that was the only thing I wasn't aware of, and everything else, we did it all together. So I would be aware if there was something else he did that would put me at risk.

I've slept with this guy that I lived with for two and a half years. This guy was shooting heroin behind his ear and up the back of his knee. I didn't know because I looked for the signs on his arms because I didn't know how you shoot and all, because I don't do that stuff.

My partner, he does intravenous drugs. And behind my back. I don't know if he shares the needles or if he sleeps with people.....But then again, I'm not aware of what my partner is doing.

My boyfriend sort of slipped up more than I did. That's where I'm concerned something might have happened....So I think that he might have put us at risk by using someone else's needle, being somewhere else, and then through sexual contact with him.

And he would have been the highest risk, too, in lifestyle. Which adds another element...Well, whether he's an IV injector I don't know, but, I do know that he smokes crack. So, in my opinion, if you smoke crack you might inject, at this day and age, you know, I mean.

[I'm at risk] only from the fact that my boyfriend was cheating on me.

I myself went out with a man for a year and a half, and slept with him, who was bisexual, but who kept that from me. And that was around eighty six, I guess, and certainly AIDS was becoming a really big problem. And I felt that he had put my life in jeopardy.

Because the other one had multiple partners. He told me. But he also told me that he was safe. But he had multiple partners... Because I though he might give me AIDS. It was possible he could give me AIDS because of his multiple partners.

I found out after the relationship that he was very very very very promiscuous, up until the time we were together.

A kind of 'trade-off' of culpability in relation to which member of a couple places the other at greater risk is painfully described by one woman, who starts by relating that she slept with someone other than her regular boyfriend when drunk one night, and did not use any protection,

I haven't told my fiancee about this, and it would kill him. He wouldn't be able to cope with it. He doesn't need to know that, and I'm not going to destroy this relationship for that. But he also has put me at risk, too, with needles, - using somebody else's dirty needles, my fiancee. If he hadn't done anything like that and we'd never used them or slept with somebody else, I would feel more compelled to say that I might have put him at risk. But since he already did something to put himself at risk, then it's like, well, it may not have been me, then. I don't want to introduce that whole thing.

5.3.2 Describing risk in terms of unsafe sexual practices

Many women described their risk situation primarily in terms of having unprotected sex:

> *So, we were having unprotected sex every day. At least five times a week, let's say.*

> *Because I been having sex with the man who, with no safe [condom], you know and no. And you don't know if this guy got this or that from their partner or something.*

Several women talk about specific risk in relation to a particular sexual encounter:

> *I had one other sexual partner, that he didn't use a condom for, very early in my relationship.*

> *I remember being really scared and I remember thinking, I can't say no, and I need to say no because I could get AIDS. And I did it anyway. I felt really sorry for that. I would never do that now. But I remember at that time just feeling really bad and not being able to say no. I think I have had sex with a lot of people to make them feel good more than anything to do with my needs. So that was one time when I did put myself at risk when I really shouldn't have.*

Other women felt that they were at risk because they have or have had multiple sexual partners, or casual sexual encounters:

> *Because I've had a lot of sexual partners. Over nine years, most of them have been monogamous, but in between, yes, I've been out fooling around, drinking, partying and having a good time. It's dangerous, when you're walking on your lifeline.*

> *I hung around with people for many years who did drugs. And many of them are IV users. So, although I didn't share the needle, I was making love to the men who did.*

> *I don' t think I was too promiscuous. But when I think about some of the partners I was with, it's a pretty scary thought, you know.*

But he's been gone for three months, now, and I had, about three months already, three months, different three guys....And God knows, myself, that I could end up getting AIDS too, you know. From anything, you know. from having sex with a guy that I don't know.

Some of the women specifically mentioned the risk involved with being in the sex trade:

You know, over the last 15 years, I'd relapse at different points. I have gone back to prostitution occasionally.

So, I was just, hundreds of men, and prostitution, for a while.

Then he [the john] doesn't want to use a condom. What the fuck am I gonna say. It's really really hard. I did a blow job a couple of times without a condom because of that.

That risk increases when monetary incentives are offered to forgo using condoms:

A lot of them [johns] will try to talk you into it, offering you extra money for doing it without a condom and whatnot, you know.

(Do you get paid more for not using them [condoms] ?)
Yeah, I've noticed that. I've heard that quite a bit from the girls. A lot of guys will pay extra if they won't use it. It's a chance that a lot of girls are willing to take, which is a big problem.

I use condoms all the time. But there have been occasions where I won't use condoms so I could get more money. I say yes to that, as it's a large amount of money - I think it's large.

Many women described engagement in HIV-related sexual behaviour with a regular or 'steady' partner:

I don't use condoms with my boyfriend. ("Do you think he might be at risk?")
I don't know. About the same as I am.

Well, he's the only sex partner I've really had. I've never had anybody else. But I mean, other people I've used condoms with. But we haven't used condoms at all.