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# Risks and Realities: Rochester Area Lesbians' Perceived Risk of Acquiring Sexually Transmitted Infections

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**Abstract:** There was limited information available in the clinical and public health communities about Sexually Transmitted Infections (STIs) among lesbians and bisexual women. This study intends to investigate perceived risks of acquiring STIs among lesbians in Rochester, New York. This research concludes that Rochester area lesbians do not perceive themselves at significant risk of acquiring STIs. A gap exists in the sexual health dialogue between health providers and their lesbian patients. And while there was a broad range of safer sex practices documented in the literature, there seems to be little consensus and few guidelines available as far as motivations to practice safer sex.

**Key words**: Queer, lesbian, bisexual, out, closet(ed), PCP, dyke, dental dam, STI/STD, HIV

## INTRODUCTION

Lesbians are a group of individuals notably left out of popular discourse in both biomedical and public health contexts. Since the emergence of HIV/AIDS in the U.S. in the early 1980s considerable attention has focused on sexual risks in the gay male community – both in research and resources. Gay men's health has indeed received significant recognition, as exemplified by enormous federal funding towards HIV/AIDS research as well as the notable presence of such health institutions as the Gay Men's Health Crisis (GMHC) in New York City and the Whitman Walker clinic in Washington, D.C. Neither the federal government nor private sector offers significant interest or investment in the field of lesbian health research.

Given the lack of information available to health care providers, lesbians are left to their own devices to learn about what, if any, health conditions are specific to them. Like gay men, lesbians face enormous cultural challenges and taboos in bringing sexual behavior issues to the attention of their healthcare providers. The growing field of sexual and reproductive health fails to capture the issues and risks surrounding lesbians and other groups of women who have sex with women.

In 1997 the Institute of Medicine (IOM), an official entity of the National Academy of Sciences, that advises Congress on health policy issues, gathered a Committee on Lesbian Health Research Priorities and convened a series of three meetings between July and November on the issue of lesbian health. The results of these meetings were published in 1999[1] by the National Academy Press entitled Lesbian Health: Current Assessment and Directions for the Future. Funding for this tremendous endeavor was through the National Institutes of Health (NIH) Office of Research on Women's Health with supplemental funding by the Centers for Disease Control and Prevention (CDC).

The committee established the following public health objectives deserving of further study[1]

1. Gain knowledge to improve the health status and health care of lesbians.
2. Confirm beliefs and counter misconceptions about the health risks of lesbians.
3. Identify health conditions for which lesbians are at risk or tend to be at greater risk than heterosexual women or women in general.

Of the above, the second point is perhaps the most relevant to this research endeavor. Misconceptions can and do occur both among lesbians as well as healthcare providers. For example, there is an assumption that lesbians are not at risk of Sexually Transmitted Infections (STIs) and therefore do not need comprehensive sexual healthcare screening that includes Pap smears. Pap smears check for cellular atypia or dysplasia and may detect the presence of the Human Papillomavirus (HPV). Detection of certain HPV serotypes can indicate malignant or pre-malignant conditions. The assumption that lesbians are not at risk for STIs is supported, of course, by the greater medical field:

According to guidelines from the US Preventive Services Task Force[2], a regular Pap smear is recommended for all women who are currently, or have been previously, sexually active with men and who have a cervix, beginning at age 18 or when the woman first engages in sexual intercourse. Although there are generally well-defined categories among heterosexuals, and even among homosexual men of behaviors and

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activities that predispose towards sexually transmitted infections, there are few if any guidelines for lesbians. Using national or local guidelines to track sexual behaviors between women in order to assess risk and routes of infection are therefore futile since risk-classification screens generally exclude same-gender sex among women.

Evidence exists to support the notion that lesbians are, indeed, at risk for STIs. The prevalence of bacterial vaginosis (BV), a clinical syndrome characterized by an imbalance of normal vaginal flora, marked by an elevated pH, gray-white vaginal discharge and odor can be argued to be an STI. BV may or may not be a symptomatic condition and is commonly a syndrome of concern among pregnant women because of high rates of pre-term labor among pregnant women who are positive for BV. There is evidence, however, to indicate that there are higher rates of BV within the lesbian community, suggesting sexual transmission[3]. Rates of BV, for example, among lesbians is reportedly 18-36%[4-5] versus 16% prevalence among pregnant women evaluated in a different study[6].

Published research regarding woman-to-woman transmission of HIV prompts the pressing need to explore sexual behaviors and relatively low perceptions of risk of transmission between women. One recent case report suggests that WSW are not likely to perceive risk and therefore engage in unsafe sexual behaviors, even among couples when one is HIV seropositive[7].

Further evidence that supports the notion that lesbians are at risk of acquiring STIs also includes a groundbreaking study on genital infections among women who have sex with women concluded[8] Genital human papilloma virus (HPV) infection and squamous intraepithelial lesions are common among women who are sexually active with women and occur among those who have not had sex with men.

Given the volumes of information that suggest penile-vaginal contact for transmission of classic STIs, chlamydia, gonorrhea and syphilis may be more rare in women who exclusively have sex with women, however, more research is needed to confirm this assumption. It is unclear whether penile-vaginal contact specifically is required for transmission or whether it is the contact of mucous membranes, despite the sex of the participants. Further examination of the perceptions of risk of acquiring STIs between women and the corresponding safer sex practices will allow for a link between perception and behavior within the lesbian community.

The IOM report explores issues around research methodology and challenges that face scientific studies of STIs among lesbians. Generally speaking, lesbians are often perceived to be at low risk of infection due to three major assumptions: previous reports of low prevalence, assumptions about sexual practices that include presumed modes of transmission among women, and finally, assumptions about the course of lesbian relationships[1].

There is growing evidence that disparities exist among lesbian populations across the country in understanding risk of acquiring and taking appropriate measures to prevent STIs[3]. Despite an overall increase in the number of research articles geared towards gay and lesbian health in the past few decades, there has been a dearth of research covering the sexual health of lesbians. This gap prompted the following qualitative exploration into the experiences of lesbians in the Rochester area.

## OBJECTIVES OF THE RESEARCH

The following research endeavor attempts to assess the interplay of beliefs and behaviors by qualitatively obtaining information about past sexual experiences and sexual choices.

It is worth mentioning that terminology can become extremely complicated in the exploration of sexual orientation and assignment/labeling. For the purposes of this research, lesbians are defined as women who have either exclusively partnered with women or those women who have exclusively partnered with women in the past five years. These women self-identify as "lesbian," "dyke," "homosexual," or often "bisexual." Medical and public health literature often refer to these women as WSW or women who have sex with women.

More specifically, the research will:

- Assess the perceptions of risks of acquiring STIs
- Compare sexual health risk perceptions with sexual behaviors – including exploring safer sex knowledge and practice
- Identify barriers in sexual health dialogues between patients and providers and
- Provide recommendations to the Rochester area lesbian community via the Gay Alliance of Genesee Valley (GAGV) to encourage programs in the area of lesbian sexual health

## MATERIALS AND METHODS

The setting of the research is Rochester, New York, U.S.A. As with any public health research endeavor, it is of utmost importance to select a well-defined and manageable community. Based upon the first author's (Singh's) experience of living in Rochester as a bisexual South Asian woman, Rochester has much to offer towards the lesbian and gay community for a city of its size.

Based on the 2000 census, the city of Rochester has a population of more than 220,000. Rochester is home to eight colleges/universities, 65 visual and performing arts groups. More than 40% of Rochester's workforce is comprised of people in technical, scientific, professional or precision occupations.

It is challenging to quantify what segment of Rochester's population is lesbian. However, there certainly is a visible presence of resources targeting the LGBT community, given the annual Gay Pride and Image Out film festivals as well as the presence of LGBT community and health centers. Most of the outreach for this research occurred in settings specific to the LGBT community, including sponsored events by the local gay resource center. At the time of this study, there was no legislation in place that protected lesbian women from job or housing discrimination in New York State. This may have limited our ability to recruit for this study.

## DATA COLLECTION

We used two different qualitative methods to collect our data: individual, in-depth interviews and focus group discussions. Given the sensitivity of the topic (sexual health), the social stigma attached to same sex partnerships, and how little is currently known about this issue; the dual format for data collection was designed to insure a robust data set. The individual interviews would provide the privacy some people might need to fully disclose their experiences and thoughts on the one hand, while on the other hand, the focus group discussion format may yield additional insights as the result of the group comparing experiences and thoughts. Each format is described below.

Given the exceptionally sensitive and private nature of sexual health research, there were enormous challenges in eliciting explicit dialogue specific to sexual practices and safer sex measures. The questionnaire, therefore, was also used to explore both demographic information as well as specific information about sexual behaviors and practices. The findings from the questionnaires were included within the appendices. However, only the dialogue that occurred between researcher and participant are included in the research findings.

### Interviews

Prominent to many qualitative research endeavors are in-depth interviews, hereafter referred to as interviews. The interview is an ideal forum to collect a broad range of experiences – both in terms of cadence and content of shared information. Interviews are ideal for an area of research that is understudied. This is due primarily to the interviewer's ability to probe and explore a full range of experiences[9-10]. The interviewer is working more from a range of topics than a specific set of questions[11].

The interviews were both structured and spontaneous in their format. As with most qualitative research questions, closed-ended questions were avoided in favor of questions that opened up the participant and allowed her to engender trust and the ability to share sensitive personal information. The first five or six interviews were the basis for modifications to the original interview guide that occurred with subsequent interviews.

Interviews occurred with 12 research participants and typically lasted for 45 minutes to an hour and a half in duration. Interviews took place at a time and location convenient to the research participant. Extensive note taking occurred during the interviews. Additionally, when the participant granted permission, interviews were tape-recorded. The first author conducted all the interviews. All interviews were later transcribed from either notes or tape.

### Focus Groups

By definition, focus groups are more than a homogenous group of individuals considering their own views in the context of others. Instead, focus groups can be a forum for an individual to share, express and exchange ideas and perspectives with others whose life experiences may be quite distinct from their own. Moreover, focus groups can be a forum that evokes data based upon group interaction[12]. The focus group format can work quite effectively in provoking statements and reactions that are difficult and often impossible to solicit in an interview[12]. The synergism that occurs in a collective offers both challenge and validation to individuals sharing ideas and experiences. Moreover, the focus groups allow for an opportunity to confirm or clarify some of the results of the interviews. Ideally, at least two focus groups are conducted, allowing for the results of the first group to be compared to that of the second.

The researcher worked from a guide of questions, and like the interviews, allowed for expression of a full range of experiences and perspectives that went beyond the guide. Unique to the focus group experience, the moderator maintained a distance and did not participate as an active participant as in the in-depth interview. In contrast to interviews, where a research participant with the researcher construct a reality, the moderator in a focus group maintains a distance and allows the collective to construct a reality[13].

The first author conducted two focus groups at the GAGV, a trusted environment, as well as a central and convenient setting for participants. The focus

groups conducted for this study consisted of gatherings of 6-12 individuals per group moderated by the researcher. The aim for the number of participants was ten, permitting the probability that a few would not keep their appointment. Participants received food and beverage during the sessions. Both sessions were tape recorded and later transcribed.

## RESULTS AND DISCUSSION

### In-depth Interviews (12 Participants)

Four themes emerged from the data that pertain to perceptions of risk of acquiring STIs: 1) lack of sexual health conversations with PCPs; 2) a broad range of sexual behaviors and safer sex definitions/practices; 3) male partner history as a predictor for perceived increased risk of acquiring STIs; and 4) the LGBT community as a source of safer sex awareness. As predicted in the study design planning, more nuanced interpretations emerged from the focus group discussions, while the interviews captured more personal experiences.

### Lack of sexual health conversations with Primary Care Providers (PCP)

All those interviewed were out to family, friends and most colleagues at either their place of employment or academic institution. Additionally, all women were out to the person they identified as their PCP. In some instances, women came out to one physician but not another, but all were either out to their internist/family practitioner or to their obstetrician/gynecologist.

Half of the women interviewed felt that there were no primary health concerns specific to lesbians they were worried about. Several women expressed that they shared health risks associated with heterosexual women. A few mentioned feeling at risk of conditions that tend to be associated with nulliparous women, including breast cancer. And half of the women interviewed mentioned a lack of knowledge about STIs, including HIV/AIDS.

Most women were comfortable with the idea of discussing sexual health issues, including sexual orientation with their PCP, but most women admitted that neither they nor their PCP have raised the subject of sexual health in any of their clinical encounters. Most women shared a sense of "it just doesn't come up" or "it's just not an issue that pertains to me personally." One woman's PCP raised the issue of safer sex in reference to men by suggesting that the only risk women have of acquiring STIs is through sexual encounters either with men or with women who have had sexual encounters with men.

### Broad range of sexual behaviors and safer sex definitions/practices

Depending on a woman's definition of safer sex, there was a broad range of beliefs and practices, ranging from having the appropriate conversations with a sexual partner to using barrier methods. Interview participants' definitions of safer sex included:

- "safe sex is not being promiscuous"
- "I'm not into toys or lube or anything so I don't feel at risk"
- "talking to your partner is safe sex"
- "using protective barriers and not having sex with anyone else…and I guess dental dams count as safe sex"
- "safe sex is using a latex cloth maybe while having an infection or something"

As far as safer sex screening, a few women offered the necessity of self and partner HIV/AIDS testing. Additionally there was mention of avoiding sexual encounters that introduce either blood or open wounds, including times when a partner is menstruating or when a partner has a cut on hands or mouth.

When pressed to discuss specific methods of safer sex that they had either experimented with or were aware of, three women mentioned the dental dam. Moreover, they perceived the dental dam fairly unfavorably. One woman who has never used a dental dam expressed, "I've heard that they're laughable!"

Eleven out of 12 interview participants were in long-term partnerships. Ten out of 12 women reported feeling no risk of acquiring STIs. Only one woman, who was in a long-distance partnership, acknowledged "extreme" risk, with a specific fear of acquiring HPV infection. And finally one woman felt at risk "somewhat," because of her past sexual involvements with men.

Based upon written questionnaires, women experienced a broad range of sexual practices, ranging from rubbing to oral and anal sex. In general, interview participants felt at particular risk of very few STIs, with two references to herpes and one to gonorrhea. None of these women acknowledged having an STI either currently or in the past. And while most admitted to practicing safer sex, the most common definition of safer sex was monogamy or careful selection of partners. There were three mentions of safer sex practice that included some form of barrier method.

### Male partner history as a predictor for perceived increased risk of acquiring STIs

Eight women were sexually involved with men at some point in their lives. Six out of eight women used a contraceptive and/or safer sex method, generally,

the condom. Of the two women that did not practice safer sex measures with men, one had endured a violent unsafe sexual assault and the other was attempting to become pregnant.

Women who practiced safer sex with men asserted that fear of pregnancy often outweighed the fear of acquiring STIs. Still, they all shared the opinion that until and unless one was in a monogamous partnership, condoms were the best option of protection.

**LGBT community as a source of safer sex awareness**

Taking into account the varying definitions of safer sex, most women mentioned a number of factors that encouraged the practice of safer sex. These factors included personal sets of values and word of mouth. One woman acknowledged practicing safer sex with her current partner due to her own past experience of a violent unprotected sexual assault.

Women learned about safer sex from a number of different sources, especially the LGBT community. Only one woman expressed learning about safer sex from her physician. And this was upon soliciting the information herself. Interview participants' safer sex resources included:

- Friends in the queer community
- Women's music festivals
- Partner
- Gay newspaper/magazine/poster
- Gay bars
- Gay resource centers

In general, while several women expressed lack of sexual health awareness when pressed to name a major health concern, most did not feel at personal risk of acquiring STIs. Only one woman acknowledged feeling at "extreme" risk, particularly of acquiring HPV infection. And one woman felt at risk only because she was sexually involved with a man more than five years ago. This same woman feels at no risk of being with women who have exclusively partnered with other women.

**Focus Groups (17 Participants)**

Two focus groups were held at the GAGV in an effort to assess risk perceptions among women. There are several common themes, but there were some notable nuances in the themes. The following themes emerged in group settings: lack of sexual health discussions with PCPs, a broad range of sexual behaviors and safer sex definitions/practices, male partner history as a predictor for perceived risk of acquiring STIs, varied perceptions of risk of acquiring STIs between single and partnered women, and the LGBT community as a source for safer sex awareness.

**Lack of sexual health discussions with PCPs**

The vast majority of women reported having a regular physician. For the most part, the physicians were either internists or family practitioners. Two mentioned visiting the local Planned Parenthood for regular gynecological care.

Heterosexism was a common theme among several participants, indicated by discussions introduced by PCPs regarding contraceptive methods. In many instances, this interaction spurred women to disclose their sexual orientation to their PCP. For the most part, women felt as though PCPs presented a lack of knowledge of lesbian sexual health issues. In a few cases, particularly good PCPs acknowledged the partner of their patients and asked specific questions regarding the relationship. In another case, one woman revealed "my doctor reminds me that I need a Pap smear even if I'm lesbian…doesn't treat me any differently"

The issue of discussing sexuality and sexual health concerns with PCPs elicited mixed responses. In a few cases, women felt very comfortable engaging in an open and frank discussion regarding sexuality. Only one woman acknowledged having discussed safer sex issues specific to acquiring an STI with her PCP.

One woman acknowledged frustration in an interaction with her PCP that was specific to her STI:
'I was diagnosed with herpes. She Asked me if my boyfriend Knew even though my girlfriend Was sitting right there…I said "well my girlfriend knows"…Once I told her I was a lesbian she Didn't know how to help me…She asked several times whether I Slept with a guy'

**Broad range of sexual behaviors and safer sex definitions/practices**

Eight individuals acknowledged current safer sex practices with a few more indicating having tried safer sex at some point in their lives. Among those who once attempted safer sex practices but ultimately gave them up, several shared the following sentiment "we tried the protected sex thing and that was just ridiculous." Part of the ensuing discussion indicated that women did not feel the necessity to practice safer sex given an overall uncertainty about what specifically they were protecting themselves from. On the other hand, among couples where one partner had genital herpes, they either abstained from oral sex or refrained from sex altogether during times of outbreak. Dialogue from the focus groups led to the following definitions of safer sex:

- "Masturbation"
- "Thinking about safe sex"
- "Fluid-binding – not exchanging bodily fluids"
- "Abstinence"
- "Just touching"

- "Monogamy"
- "Rubber gloves"
- "Dental dams"
- "Hand sex instead of oral or anal sex"
- "Condom tips on tongues"

Based upon written questionnaires, women engaged in a broad range of sexual practices, ranging from rubbing to oral and anal sex. Most women acknowledged some low level of risk ranging from no risk to moderate risk. Specifically, women mentioned feeling most at risk for genital herpes. Four women had either a current or past STI, with those same women practicing safer sex behavior that either constituted monogamy (three out of four women with either a current or past STI) or some form of barrier method (one woman).

**Varied perceptions of risk of acquiring STIs between single and partnered women**

When asked whether women felt at risk of acquiring STIs, most single women mentioned feeling at risk whereas most women who were partnered felt little risk. And when women were challenged to mention specific STIs they felt at risk for, generally "all of them" applied, though a lower risk associated with HIV/AIDS. One woman recalled the emergence of the pandemic in the early 1980s: "I remember hearing that lesbians were the 'chosen ones' by not getting affected. I was careful but not overly careful. I feel less safe than a few years ago."

**Male partner history as a predictor for perceived increased risk of acquiring STIs**

Sexual history with men was another pronounced theme among women in the two focus groups. However, none of the women openly acknowledged having personally been sexually involved with men. They only stated concern about sexually partnering with women who had sexual histories with men. When asked whether women felt at risk for STIs, one participant responded with "yes, because the women I've been with could have been with men." Others assumed greater risks among women who had been sexually involved with men compared with women who had only been sexually involved with women.

A few women mentioned other high-risk behaviors that may pose risks of acquiring HIV/AIDS among lesbians including being sexually involved with intra-venous drug users or women who have been sexually involved with men who have sex with men.

**LGBT community as a source for safer sex awareness**

Most women reported learning about safer sex from sources outside of the clinical setting, with the exception of one woman, who acknowledged the local Planned Parenthood as a good source of information. Informal safe sex information appeared to be a prominent means of passing information along among either a group of friends or some form of a queer social network.

Others sought information through women's health pamphlets and books, but admitted challenges in finding information that was specific to lesbians. For the most part safe sex educational opportunities included similar sources as those revealed among in-depth interview participants:

- "word of mouth"
- Gay Alliance of Genesee Valley (GAGV)
- Gay events such as Pride

Phenomenally, in the focus group setting, women appeared to undergo a revelation over the course of discussing safer sex and their risk of acquiring STIs. The session began with most women indicating little if any fear of acquiring STIs, but by the end, many of the women began challenging their initial assumptions. Many women appeared to initially share very little discomfort in the limited discussions regarding sexual health with their PCPs. However, as the discussion continued, several posed "I wonder why doctors don't ask about safer sex" and "I would hope doctors asked about these questions." Another woman during the course of an in-depth interview shared her personal experience with the healthcare system:

"People think that lesbians are low on the totem pole of STDs, but there are things you can get and they should be talking about them. When I was diagnosed with an STD they gave me the option for other tests that prior to that they had never offered me…they should have mentioned that before"

## CONCLUSION

Common themes to both groups included:

- Low/no perceived risk of acquiring STIs
- Male partner history as a predictor for perceived increased risk of acquiring STIs
- Lack of sexual health conversations with Primary Care Providers (PCP)
- Broad range of sexual behaviors and safer sex definitions/practices
- LGBT community as a source of safer sex awareness

Findings that were divergent between the in-depth interview participants and the focus group participants include:

- More behavioral safer sex measures among focus group participants (gloves, dental dams, etc.)
- In-depth interview participants openly acknowledged past sexual involvements with men whereas focus group participants mentioned men only in terms of high risk sexual encounters (for example, partnering with women who have been with men)

Lesbians in Rochester, NY, in general, do not perceive themselves at significant risk of acquiring STIs. Two factors emerged as significant in impacting risk perception: relationship status and history of male partners. Partner status appears to play a role with single women perceiving more risk than partnered women of acquiring STIs. And women commonly identify either a personal or partner history of sexual involvement with men as significant towards introducing the risk of STIs.

Consistent with lesbian health data that most women who self-identify as lesbian have been sexually involved with men at some point in their lives[2], the majority of in-depth interview participants mentioned men as former sexual partners. And unsurprisingly, six out of eight women had practiced safer sex measures, generally condoms, with men. Focus group participants, however, mentioned men only in terms of factors that raised perception of risk of STIs. That is, lesbians who are partnered with women who have been sexually involved with men have greater perceived risk than those partnered with women who have never been with men.

Women were comfortable disclosing their sexual orientation to their PCPs. There appears, however, to be a gap in the dialogue between PCPs and their lesbian patients on issues pertinent to sexual health. Neither the PCPs nor the lesbians feel comfortable in raising issues specific to either risk of STI or safer sex practices. Lesbians, however, do overall wish that PCPs ought to be eliciting questions specific to sexual health from them. There is clearly either a dearth of knowledge or sensitivity in the area of lesbian sexual health within medicine and public health.

By and large, the majority of those who participated in the research were middle to upper class, well educated and white. This, of course, may be part of the profile of those women who are likely to be out to the community and colleagues and who are likely to be involved in the gay community activities, such as those of the GAGV.

Arguably, discussions around lesbian safer sex practices and perceived risks elicited responses of greatest interest. Given the enormous variation in definitions, there were no agreed upon standards of behaviors and methods that constitute safer sex. Moreover, inconsistencies in practicing safer sex versus knowledge of safer sex methods beg the issue of a more deliberate and careful dialogue between PCPs and their lesbian patients regarding true risks and efficacious protection from STIs.

Further research exploring level of awareness and knowledge of lesbian sexual health issues among physicians and community health advocates is an area worth pursuing. Clearly, part of the lack of awareness may be due to an overall lack of research done in the area of lesbian sexual health. Therefore, it is worth investigating both the quality and quantity of information available to physicians and medical students in the area of lesbian sexual health.

Programs, articles, and some forum of educational sessions for lesbian women and for PCPs would prove enormously beneficial to the lesbian community of Rochester. Several focus group participants and interviewees voiced an interest in gaining more information in the field of lesbian health – both broad-based health as well as sexual health concerns.

Building a dialogue that is explicitly geared towards embracing lesbian sexuality that includes sexual health is the next necessary step that must occur.

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