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“I thought we are safe”: Southern African lesbians' experiences of living with HIV

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Abstract

HIV prevention and service programmes have long either ignored or overlooked lesbians. The experiences of lesbians with HIV have similarly been unrecognised and unreported. This erasure has contributed to the invisibility of lesbians in relation to HIV and related health risks. This community participatory study, based on in-depth interviews with twenty-four self-identifying African lesbians living with HIV in South Africa, Zimbabwe and Namibia, focuses on their personal experiences and circumstances. Women's experiences shed light and challenge popular notions around lesbian risk. In particular among this group are lesbians who self-report exclusive sexual relationships with women. For these women, experiences of living with HIV are challenging as they struggle to understand the possibility of female-to-female transmission. While battling with their own perceptions of invulnerability and accepting their HIV positive status, they have to deal also with wide-ranging misconceptions about risk. The paper argues that within the context of HIV lesbians cannot be regarded as a `no-risk' group. Health services and health providers are encouraged to respond to the health needs of lesbians living with HIV.

Keywords

lesbians; HIV risk; transmission; Southern Africa

Introduction

The wide and existing misconception that same-sex practising women and lesbians[1] face no significant HIV-related health threats suggests a lack of sensitive research approaches into the investigation of HIV risks tied to sex between women (Johnson 2007; Reddy, Sandfort and Rispel 2009). Women in same-sex relationships and lesbians remain invisible in HIV research, in prevention programmes as well as to health care providers. Myths and misconceptions about lesbian and same-sex practising women's immunity have come to be believed by health care providers as well as by lesbians themselves (Wells and Polders 2005). For example, Richardson (2000) argues that because of exclusion from HIV

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[1] In this paper, we distinguish between the terms `lesbian' and `same-sex practising women'. The former is used as an identity category to refer to women who self-identify as lesbian and are in (non-exclusive) sexual relationships with other women. The latter term refers to sets of behaviours and expressions of desire by women, and may exclude identifying labels such as lesbian.

prevention messages, many lesbians believe they will not get HIV and thus are ignorant or reject safer sex strategies (Reddy, Sandfort and Rispel 2009).

Anecdotal evidence from the Southern African region, coupled with incidental data developed by OUT, a Pretoria-based LGBT (lesbian, gay, bisexual and transgender) organisation, shows that women who engage in same-sex practices and lesbians are infected and affected by HIV and AIDS. They report that 8% of same-sex practising women who were aware of their HIV status had disclosed as HIV positive. The high rates of HIV amongst lesbians and bisexual women were attributed to alarming levels of rape and sexual violence among women and lesbians, particularly in South Africa, as well as unsafe transactional sex with men generally (Polders and Wells 2004).

Until recently, there has been scant research on same-sex sexuality and HIV and AIDS in Southern Africa (Reddy, Sandfort and Rispel 2009). There is now a developing critical corpus on MSM (men who have sex with men) and HIV in several high impact academic journals. However, there has been a significant lack of attention to the experiences of same-sex practising women or lesbians in relation to HIV in the African continent as a whole. Such neglect of women's experiences within research reflects a more widespread gender-bias in the area where women continue to experience barriers to care and support (Jarman, Walsh and De Lancy 2005). More specifically, lesbians are overlooked in HIV research and prevention strategies because of the failure to recognise and appreciate the social and behavioural complexity of lesbians' lives (Dolan and Davis 2003) or that women are not all the same epidemiologically (Mora and Monteiro 2010).

Lesbian sexual behaviour and HIV

The assumption of a close association between sexual behaviour and sexual identity can also be seen as having contributed to lesbian neglect (Formby 2011; Power, McNair and Carr 2009; Richardson 2000). Lesbians are perceived as not to be at risk for HIV because it is assumed that they engage in sexual activity only with other women. This assumption overlooks a person's sexual history and the reality that sexual identity is not indicative of nor does it directly translate to sexual behaviour. It is therefore not self-evident that a lesbian's sexual history excludes sex with men or various other sexual practices (Roberts et al. 2000). |Khaxas (2008) argues that some cultural practices in Southern Africa render women's bodies vulnerable and thus contribute to the spread HIV and AIDS. Lesbians are not immune to these conditions.

As previous research has shown, cultural stigma, stereotypes and prejudice contribute to making lesbians living with HIV invisible (Wells and Polders 2005). The concomitant effect is that the experiences of lesbians with HIV fall off the radar of the wider HIV positive community (Arend 2003). We maintain that to pay attention to the experiences of lesbians living with HIV may assist in transforming general understandings of HIV transmission and consequently challenge assumptions about lesbian risk.

Methods

The study followed a community participatory approach. From the onset, the study was invested in the transfer of skills and capacity building of local LGBT organisations in the areas where research was conducted. Such an approach seeks to enable communities to participate in the analysis of their own reality and to promote social transformation for the benefit of the participants. Key to our understanding is people's involvement in decision-making processes, designing, implementation, sharing of benefits, monitoring and evaluation of projects (Kumar 2000). The process also entails elements such as information giving, consultation, participation for material incentives and self-mobilisation. Central to such an approach is the role of community capacity and its relationship to prevention practice and outcomes.

Participants and study setting

Eligibility criteria for study participants were that they were: (1) 18 years and older, (2) living with HIV, (3) had been in a sexual relationship with other women in the past year, (4) that they self-identified as lesbian, and (5) were willing to give informed consent to participate, including the audio-recording of the interview.

Semi-structured in-depth interviews were conducted from October 2010 to February 2011 with twenty-four (24) self-identifying lesbians living with HIV in Namibia, South Africa and Zimbabwe. The majority (16) of the participants lived in South Africa and four in the two other countries. South Africa has a larger number of LGBT organisations more than any country in the continent. The country's progressive laws make this possible. There were four South African organisations represented in the research group covering different provinces of the country compared to only one organisation each in Namibia and Zimbabwe. Due to organisational capacity between four to six participants from each organisation were recruited to the study.

Ethical considerations

Ethical considerations were pivotal to this research. During training sessions, the whole group discussed in detail the importance of informing participants about their involvement in the study and obtaining informed consent. Confidentiality was strongly emphasised, as many women live in contexts were both their sexual orientation and HIV positive status are highly stigmatised. The rights of participants not to answer any question they were uncomfortable with were also discussed and upheld. Each organisation also ensured that there were possibilities for referrals to relevant partner organisations for those participants who experienced distress during and after the interview. These also had to be treated with sensitivity so as not to `out' any participant who was not ready to disclose either their sexual orientation or HIV status to a third party. Written consent was obtained from all participants. The Research Ethics Committee at the Human Sciences Research Council (HSRC) in South Africa approved all study procedures.

Preparatory activities

Interviewers were members of local LGBT organisations in the three countries where the research was carried out. All interviewers attended training workshops facilitated by the research team (which included the authors). The training sessions and discussions included topics on research ethics, recruitment techniques and conducting interviews.

The training sessions produced well-crafted interview schedules that could be used in all settings while also tailored to address context-specific realities. Particular attention was paid to the terminologies used and how these would be locally translatable or not. Most interesting was the rejection of the term WSW (women who have sex with women) because of its alienating features in many of the contexts. Members argued that while they saw its relevance in public health discourse, it was not used among their organisations' constituencies and thus not relevant for this research. Similar concern has been expressed about MSM categories in HIV research in the continent (Reddy, Sandfort and Rispel 2009). Therefore, in relation to the research findings, we do not talk about women who have sex with women. The term lesbian, with all socially ascribed local nuances and contextual differences, was more appreciated and used by most organisations as well as the people they served.

Through rigorous training and instrument-development sessions, members debated ways in which particular questions could be insensitive, contextually irrelevant or alienating. The structured interview schedule and consent forms were piloted among fifteen individuals from Botswana, South Africa, Zimbabwe and Namibia (recognising that in the end we are reporting on data produced by three countries). Each of the partner organisations had a focal contact person who was responsible for the study in their area.

The research process also included a regular monitoring process as well as regular support to interviewers for the duration of the study. As indicated earlier, the benefit of collaborating with community-based organisations is that they know and understand the dynamics of their own contexts and could implement the research in ways that are sensitive and culturally relevant.

For many organisations, the physical safety and privacy of the location where the interview took place, as well as the safety of the participants had to be considered due to various threats, violence and hate crimes experienced by lesbians in African countries (Mkhize et al. 2010; Moshenberg 2009).

For similar reasons, recruitment also had to be carefully considered and snowballing or chain referrals were the most effective strategies in accessing known and unknown members of the population. As living with HIV is still highly stigmatised in the areas where research was carried out, fieldworkers had to use discretion during recruitment. Most research participants were known members of organisations who were already accessing HIV and other health-related services. Others were recruited from partner organisations or via networks of people living with HIV.

In Zimbabwe in particular, because of state-wide homophobia and targeting of lesbian and gay people, recruitment of participants had to be clandestine. It was easier to recruit participants in South Africa, as there are more LGBT organisations than in other countries.

Data collection

The interview schedule included the participant's biographical information, sexual history, experiences with HIV testing, knowledge of own infection or transmission route, experiences with disclosure, personal and social experiences of living with HIV, as well as experiences with treatment (if applicable), care and support.

Trained members of various LGBT organisations in the respective countries conducted face-to-face interviews. The duration of interviews ranged from 45 minutes to three hours. The interview schedule was in English but the interviews themselves were carried out in the participant's chosen language. All interviews were audio recorded, transcribed and, as far as needed, translated back into English. Where vernacular was used, the interviewers as well as another member of the organisation conducted back-checks on language and content for all transcripts that related to them. No names of participants were recorded during interviews. All participants were given codes and all transcripts were coded.

Conducting these interviews turned out to be challenging. For many participants and fieldworkers this research was the first time they had been exposed to talking in depth about HIV, infection and the experiences of living with the disease. A final training session post the data-collection phase included a robust debriefing session for interviewers. A few had experienced difficulties interviewing people they knew about their experiences of living with HIV.

Data analysis

Data were analysed manually. This was important as it allowed for members of organisations to participate in interrogating the data during follow-up training sessions. Organisations raised questions and as a team we explored themes emanating from the data. Themes were developed to draw similarities and contrasts in the experiences of the participants. Thematic analysis also allowed for an in-depth view of how participants experienced their lives. A dominant theme was finding out about one's HIV positive status. Focusing on this theme revealed the many ways in which lesbians experience living with HIV. Anger, fear of disclosure and confusion about how transmission occurred all related to participants' experiences of living with HIV.

Findings

We begin by describing the general characteristics of the research participants. We then proceed to present the data under the main theme `finding out one's HIV status'. The women were aged between 22 and 48 years. Of the twenty-four participants, six had tertiary education qualifications, another six had completed secondary education school-leaving certificates, with two of them studying towards a tertiary qualification. A third of the participants had not finished high school and half of them had a primary school education.

Employment levels were similarly low. Only seven participants were in full-time employment, and only four had private health insurance. Those who had fixed monthly incomes earned not more than R7000 per month (less than US$900). Most of the participants were unemployed.

Six participants were single (with no partners) and five reported that they were not sexually active at the time of the interview. Most women lived with their partners and two were married. Participants self-identified as lesbian and mostly reported engaging in sexual relationships exclusively with women. Two of the participants had a regular male partner and identified as lesbian[2] or sometimes bisexual. The majority (16) of the women had children (from previous relationships with men) who lived with them.

All participants had been living with HIV for periods varying from four months to 17 years. At the time of the interview, eight participants had been living with HIV for more than ten years. The majority of the participants (18) were receiving Anti-Retroviral Treatment (ART), some for more than six years.

Finding out about one's HIV status

Participants relayed finding out about their HIV status to how they got infected. The majority of the participants (17) self-reported seeking an HIV test because of an illness or signs thereof. For a few, a partner or a child's illness (or death in a few cases) made them seek an HIV test. One participant tested during pregnancy. A few participants reported testing because a (male) partner had been unfaithful and this had led to suspicions. Nine participants reported that they had been infected through their former male partners.

Eight participants reported that they had been raped. Three of them sought an HIV test directly following the rape incident. The three associated their HIV positive status with the rape incident:

> “I was young and there was not much I knew. I was 12 years old in 1994 and I was raped by my uncle. (I tested) because I was raped and I had to (test). My parents

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[2] This suggests that naming oneself as lesbian does not automatically exclude sexual relations with men.

> took me to hospital and the doctor said he would do all the tests. (When I found out) I thought I was dying. But then I was a kid so I didn't know…I think I was numb to everything…" [Buli, 28 yrs old, Durban]

> "If only I was not raped, I would not be HIV positive…I had a lot of anger…" [Mapule, 29 yrs old, Johannesburg]

> "How I got infected…I have three boys. Since I am a lesbian and very butch, most of my friends were males. When we would be drinking, they would take advantage of me… For me it was rape because that's how I got my children… ". [Glenda, 37 yrs old, Namibia]

Lesbians in South Africa particularly have become specific targets of rape, a form of rape that aims to `heterosexualise' them (Mkhize et al. 2010). While we may not claim that the women in this study were targeted because they were lesbians, it is alarming that even in such a small sample, so many women reported having been raped.

Experience with testing

Participants stated that it was difficult and generally unpleasant to seek an HIV test, as VCT counsellors tend to be ill-informed or curious about same-sex sexual preference. As one participant stated, her counsellor shifted the focus away from offering support about HIV to a pre-occupation about her sexual orientation:

> "All I can say is - it's hard for a lesbian to go for HIV test. I know this personally, first when you go for counselling it depends who is giving you that counselling… You go there and they tell you about condoms and that you have to use them…you tell them "I don't do men". You get someone who is empty (not informed) and the topic for counselling changes. `How do you do it? (have sex with women)' You just get agitated when you are supposed to be dealing with the news that you are HIV positive and the conversation has now changed because you are gay." [Lesego, 29 yrs old, Pretoria]

For another participant, the health provider was so insensitive after learning about her sexual orientation that he threw her HIV test results on the floor:

> "I had this constant headache which…would not stop. I then went to the doctor… Two weeks later, I went back again, and HIV tests were run on me, that's when they told me I was HIV positive. That doctor wasn't so very nice with me because one of the things he asked me was am I sexually active, and I said `yes'. He then asked if with a man or a woman. I said `both' and then he threw my results letter on the floor and said that if I could sleep both with men and women I could read the report on the letter that I am HIV positive. He dropped it on the floor." [Mapule, 29 yrs old, Johannesburg]

The anxieties associated with HIV testing for lesbians suggest that more work needs to be done to sensitise health professionals about people's diverse sexual preferences and orientations. This would go a long way to ensure that clients are not faced with the potential double stigma of disclosure of their sexual orientation. If it is not a negative attitude, as one participant above explained, it is the curious questions about same-sex sexual acts that the participant had to entertain.

"It's very confusing…I thought we lesbians are safe"

Five participants self-reported, with much disbelief, that their female partners could have possibly infected them. All these participants reported they had never been with male partners or had exposure to medical transmissions or injecting drug use (we did not ask if participants were born with HIV or other possible risks of transmission). Although difficult for all of them to understand, the only possible route of transmission and risky behaviour they could report was sex with other females. All participants also stated that they were shocked to find out they had been infected with HIV and could not understand how it had happened. They had all believed that because they had only been with women, they were safe:

> "…I couldn't understand how it happened because I was fine and I thought we (lesbians) are safe, and the only person I was sexually active with was also a female. I couldn't understand… I couldn't understand. I couldn't understand how I could have contracted the virus when I had thought I was safe in a way!" [Zanele, 31 yrs old, Durban]

> "It's the way you get infected as a lesbian because it's really confusing how it is possible. Other women know that they get it from their partners during penetrative sexual intercourse but then as a woman who is a lesbian who also sleeps with other women - it's very confusing." [Lebo, 22 yrs old, Pretoria]

The participants' confusion and disbelief is clear from the above examples. In the first quote, Zanele repeats how she "couldn't understand" being HIV infected. This sense of confusion and almost not believing that one is HIV positive was a recurring theme for the five participants who reported exclusive sexual contacts with women in their lifetime. It remains unclear for many of them how possible transmission could occur between females.

For these participants, living with HIV demands constant explanations of how one got infected as assumptions override lived realities. Not only are participants unable to understand possible infection for themselves, they simultaneously struggle to answer constant questions from others about how they could be infected:

> "People think that you have slept with a man and that's how you got HIV. It makes my life harder because as a lesbian woman who is HIV positive, I need to explain how I got HIV." [Bongi, 33 yrs old, Johannesburg]

> "In the community they raise many questions about the fact that I am a lesbian and when they see…my partner is a woman. Then, `how did I become HIV positive when I am a person who loves other women?' they ask. Some even go as far as saying it is not surprising that I have HIV - where have I ever heard that a girl and another girl can be involved?" [Gugu, 30 yrs old, Durban]

It is apparent from the above quotes that their HIV positive status creates various difficulties in the lives of these women. The constant demand to explain one's status to others suggests that there are still misconceptions about HIV transmission coupled with ignorance about same-sex relations.

Deciding to disclose

Participants were also asked if they had disclosed their status to anyone other than the interviewer. Responses indicate that almost all participants had disclosed to a partner, some family members and few friends. However, a few participants had only disclosed to one or two other individuals. Some had disclosed to family members, friends and also publicly. Among the participants were a few AIDS activists who were known in their communities to be living openly with HIV. For those participants who had disclosed to family members and friends, disclosure was couched in the language of protection – i.e. protecting oneself and another from possible infection:

> "As I would like to protect the next person, I still have to do the same for myself. I would not like to get re-infected…As long as you keep on having unprotected sex, you can still get re-infected." [Zintle, 22 yrs old, Pretoria]

> "My mother as well knows (about my HIV status) because if I collapse in front of her she must know that she must use gloves to help so she won't be infected" [Gugu, 30 yrs old, Durban]

While participants may shy away from disclosing to the general public, all stated the necessity and importance of disclosing to intimate partners. Central to such disclosure is protecting a partner and ensuring she does not get infected:

> "Most of the partners that I was dating - most of them are actually HIV negative and I just make sure that they will always remain HIV negative. I wouldn't risk their lives and I just make sure that I wouldn't do anything…" [Taati, 26 yrs old, Windhoek]

> "I care about my partner; I care not to infect my partner. So I will be very careful of making sure that we use all kinds of precautions to prevent so that I don't transmit the virus over to the girls" [Glenda, 37 yrs old, Windhoek]

Disclosure to family was articulated as a way of accessing support, particularly treatment adherence for those on treatment, or for people to know what to do when a one becomes ill. Those participants with family members living with HIV reported that having an HIV positive family member made disclosure more possible.

Many participants described living with HIV in the context of support in relationships. These were relationships with a partner or family members. Participants suggested that disclosing one's status to a female partner or a female family member was much easier than to a male partner. For instance, some lesbians living with HIV claimed that received notions of feminine attributes (such as being caring, understanding and compassionate) of the person being disclosed to made it "easier" for them to divulge their status to female partners:

> "Females are very accommodative and very caring compared to males. If you are in a relationship with another female, it becomes easier to tell another female (about your status) than as a female to have to tell a male person, males are very cruel" [Phindi, 43 yrs old, Durban]

> "Generally women are more understanding of these things than men. So, it would be easier for me to tell a female partner about my status than a woman to tell a man." [Lungile, 26 yrs old, Pretoria]

Yet, for another participant it was better not to disclose one's status to people, as this might lead to questions that a participant is unable to answer. For those women who reported they had never been in sexual relations with men, they had to deal with stigma and misconceptions about lesbians and HIV. Participants' disclosure may expose them to prejudice, stigma and endless questions about the possibility of transmission. In particular, the questions always related to the ways in which lesbians could possibly transmit HIV to each other, as mentioned earlier:

> "I don't want them to know. I don't know how they will feel about me (be)cause I said I'm a lesbian and now I'm positive and they'll have their minds twisted…" [Puleng, 30 yrs old, Cape Town]

HIV is still largely considered a heterosexually transmitted disease in Africa (Johnson 2007). This excludes the more recent attention given to men who have sex with men in parts of the African continent (Reddy, Sandfort and Rispel 2009). In our study, participants were unable to understand for themselves how HIV could possibly be transmitted between women. Firstly, it was difficult for them to explain to other people how they got infected as lesbians when they are known not to be in sexual relations with men. Secondly, the general assumption and misconception that lesbians are safe and that they cannot get HIV makes it difficult for lesbians living with HIV to reconcile their realities with widely perceived notions of no risk.

Accessing health services

Many participants reported positive experiences accessing health care services. Participants who were accessing treatment particularly stated that service delivery in relation to HIV care was satisfactory. However, there were some participants who indicated that negative attitudes of health care providers and lack of knowledge hindered participants from accessing public health services. Health care providers were referred to as having very little, if any, information about lesbian sexual health. These attitudes and questions did, however, not deter people from seeking care, even if it meant going to another service provider after a negative experience:

> “The other day I had a problem and went there [to the clinic] with my partner, and then the nurse said I must come back with the “man of the house”. Then, I showed her my partner beside me. Yho! (a popular South African exclamation denoting anger, surprise or shock) She, the nurse, went outside and told another one and it was like they had seen a ghost. The way they behaved, like we are disgusting somehow. And that perplexed me and we decided at that time to go to a private doctor where we knew for sure that we would not be judged.” [Gugu, 30 yrs old, Durban]

> “…We can't even walk into a clinic and ask for a glove. If you ask for a glove, they (nurses) are going to ask you if you are `a home-based care worker, what are you going do with it'? If you tell them about your sexual orientation, especially in hospitals, it makes it a bit more difficult.” [Alletta, 35yrs old, Durban]

The two participants above refer to the ways in which reactions from some health providers can make people feel exposed or even `deviant'. Such behaviours or attitudes can drive lesbians away and hinder access to services, thus putting women at further risk.

In general most health care practitioners were perceived as very supportive in relation to care for people living with HIV. This excluded talking about one's sexual orientation and sexual history. Conversations about personal sexual history were limited to gay and lesbian organisations where most participants received information, care and support. In these spaces, participants could also freely talk about their sexual behaviour and sexual identity. Outside such organisations, participants were uncomfortable to disclose their sexual orientation because of fear of prejudice and stigma:

> “I have never mentioned that (I'm a lesbian) because of the stigma associated with disclosing your sexuality. Some of the (HIV) organisations I am involved with for example --- is a Christian organisation. Talking about my sexuality to them would be so hard.” [Tambu, 40 yrs old, Zimbabwe]

Participants' inability to communicate about their sexuality (because of fear of stigma and prejudice) also hindered their access to safer sex information and protective means. In most cases, protective measures were unavailable, and in places where they existed, they are not freely available.

> “When it comes to sex, well for us (lesbians) - we don't have protection available for free, which means that you can't engage in sex if you do not have money (to buy protection).” [Zanele, 31 yrs old, Durban]

> "Even if we (lesbians) want to use protection we don't have access to it. There are plenty of condoms, which are free. When it comes to my life, my side of protection, I have to see for myself - pop out money from my own pocket and go to a pharmacy to look for something that smells nice - like gloves - not that we can afford things like that. It makes our lives more vulnerable." [Lesego, 29 years old, Pretoria]

Participants stated that even though they might want to protect their partners from being HIV infected, this was difficult as safer sex means were not easily accessible. For those who have access to LGBT organisations, dental dams, finger condoms and other forms of protection were freely available. However, a number of HIV positive lesbians lived away from areas where such organisations existed. Their main health facilities were public clinics and hospitals, which provided male and sometimes female condoms. Participants argued that although male condoms may exist, these do not cater for all lesbian sexual practices.

Discussion

Based on the presented qualitative data, our study suggests that lesbians are not a `no risk' group. Different factors, some similar to other risk factors all women face, can put lesbians at risk of HIV infection. Some women in this study reported sexual relationships with men. Many reported finding out about their HIV positive status during these relationships. Rape and other forms of sexual violence were also reported as putting lesbians at risk of HIV infection. This is a major issue that affects many lesbians' lives in Southern Africa and cannot be overlooked in relation to HIV risk (Polders and Wells 2004; Reddy, Sandfort and Rispel 2009).

The Women's Institute (2009) has noted that the US Centers for Disease Control and Prevention in 2006 identified that "the HIV virus can be transmitted through blood and menstrual blood, breast milk and vaginal secretions". Based on these known methods of transmission, it can no longer be assumed that lesbians and women who have sex with women and whose sexual play involves these methods of transmission are at little or no risk. Furthermore, sexual orientation should not be the basis upon which risk for STDs is presumed (Workowski and Berman 2010).

Evidence of sexually transmitted infection between women through vaginal secretions, although uncommon, exists. For example, Hughes and Evans (2003, 939) show that "more than 10% of women with exclusively female partners have a history of sexually transmitted infections". In our study, one fifth of the participants reported exclusive female partners and possible female-to-female HIV transmissions. The self-reports of participants in this study suggest towards developing further research that can support Montcalm and Myer's (2000, 132) argument that "women with no risk factors other than engaging in sexual activities with infected female partners are testing positive for HIV".

While there is evidence confirming that lesbians are being infected with HIV, many still believe that they are not at risk and are therefore "safe". Women who report a positive HIV status and exclusive sexual relations with female partners believed that they are "safe". Similarly in two studies conducted by the Kaiser Network and by Young et al. (1992) it was found that lesbians believe that they are at no risk for contracting HIV due to their sexual identity (see Women's Institute 2009; Formby 2011). In another study, participants were reported to express that lesbians do not need to use condoms (while using sex toys) "because they are not at risk for either pregnancy or STDs" (Marrazzo, Coffey and Bingham 2005, 8).

Dolan and Davis for their part argue that "lesbian women's construction of risk and vulnerability occur against a backdrop of identity and behaviour." Lesbians "perceive their identity as protective against HIV infection" (2003, 28). Richardson (2000, 44) adds that lesbians "rely on notions of the safety of `lesbian sex' or they may emphasise identity over behaviour". This is a "false sense of security" argues Formby (2011, 1172) and demonstrates a lack of knowledge on the part of lesbians themselves as well as health providers and the general public. Self-reports of participants in our study suggest that respondents believe that because they are in relationships with women, it is almost unthinkable that they can be at risk. This explains their sense of disbelief when finding out about their HIV positive status.

Research has demonstrated that once lesbians know that they are living with HIV, they want to protect their partners or feel a sense of responsibility towards their partner. In one way this can be seen as viewing intimate partner relationships as an important source of support and protection for lesbians living with HIV (Jarman, Walsh and De Lancy 2005). In their study, Marrazzo, Coffey and Bingham (2005, 10) noted how the need to protect a partner from infection was articulated as "courtesy to my partner". Participants in our study attest to similar notions. They demonstrated sensitivity for not infecting sex partners, others or to re-infect themselves. There appears to be a sense of wanting to protect others by not "burdening" them while at the same time protecting the self from the sense of "otherness" that is experienced with living with HIV (Jarman, Walsh and De Lancy 2005). While there may be a desire to protect the self and a partner, this becomes practically challenging when physical means of protection are unavailable.

It appears, as participants have stated, being in a relationship with a woman makes it `easier' to disclose one's status. Simoni et al. (2000) have noted similar patterns of disclosure among women. They demonstrated how women's patterns of disclosure favoured intimate partners and female family members first compared to `casual' sex partners and male family members.

Adding to the experiences of lesbians presenting with HIV are the attitudes they encounteredwhen seeking testing and other health services. Importantly, assumptions of heterosexuality can alienate lesbian women's access to health services. Experiences of lesbians living with HIV indicate that attitudes towards same-sex sexual orientation can be seen as a factor adding to prejudice and discrimination (Women's Institute 2009). These, in our view, can also get in the way of adequately addressing the health needs of lesbians.

Not having access to services can also be a barrier to alternative considerations of protection as well as to adequate health care. Studies show that health care worker attitudes and inaccessible protective means can deter lesbians from seeking and utilising protection (Wells and Polders 2005; Women's Institute 2009). In particular, the fear of being discriminated against, or fear of a health care practitioner's insensitivity after disclosing one's sexual orientation, can delay people from seeking treatment. It has been argued and it is also reported by participants in this study, that some disclosures of sexual behaviour "likely elicit negative reactions" (Marrazzo, Coffey and Bingham 2005, 11).

Experiences of lesbians living with HIV illustrate the many complex ways in which HIV and same-sex sexuality remains stigmatised. Additionally, these experiences expose the ways in which lesbians living with HIV still live under great stigma and prejudice. Even disclosure of their HIV status is not a simple issue. It may help or hinder social support (Klitzman et al. 2004). For some, it puts them at risk of alienation, estrangement and marginalisation (Simoni et al. 2000). For lesbian women who are known not to have had sexual relations with men, disclosing an HIV positive status is met with much curiosity and leaves women unable to explain the possibility of transmission.

It would not be appropriate to end without some comment on the limitations of this study. Our findings were based on a small qualitative community participatory investigation which carries both strengths and weaknesses. The findings are not generalisable to all lesbians living with HIV in Southern Africa. Recruitment was also limited to a purposive sample and data based on self-reported experiences. It was also not possible to compare experiences of lesbians with heterosexual women so as to highlight the added risk factors that lesbians experience.

Conclusion

This study confirms that there are existing gaps in HIV research particularly focused on lesbians and women in same-sex relationships. Contrary to popular beliefs that lesbians are `not at risk', self-report data indicates otherwise, confirming that lesbians are not immune from acquiring HIV. As indicated earlier, there is very little known about the experiences of this group of women living with HIV. The implication of this omission skews knowledge about HIV transmission.

The possible occurrence of female-to-female transmission necessitates more research, health information, awareness and culturally sensitive programmes and interventions to address the issues and risk factors involved. Moreover health practitioners require adequate training in lesbians' needs so as not to refuse them services, as this may exacerbate women's perceptions of being at low risk (Formby 2011). As Power, McNair and Carr (2009) argue, health service workers should also be sensitised not to exclude lesbians from “dominant sexual scripts that inform the negotiations of safer sex practices” (67). It is imperative that safer sex messaging and education should include lesbians and focus not only on penetrative sex and condom use (Richardson 2000). Provision should be made for the distribution of appropriate prevention technologies for lesbians and women in same-sex relationships. In addition, attitudes to same-sex sexuality should be sensitive in order to accommodate and engage with lesbians and other women in same-sex relationships.

Lack of knowledge about sexual diversity puts women at risk in many ways. Only when such barriers are challenged can women access adequate health care services (Power, McNair and Carr 2009). Strengthening the links between health practitioners and organisations working on lesbian health (Arend 2003) could go a long way in addressing the needs of lesbian women. What remains important, however, in improving the lives of lesbians living with HIV in Southern Africa is to alleviate the pervasive cultural stigma against homosexuality and HIV, as well as raising awareness and sensitivity to women's diverse sexual practices and behaviours.

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