

*Full Length Research Paper*

# Are HIV positive women who have sex with women (WSW) an unrecognized and neglected HIV risk group in South Africa?

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South Africa is home to the largest population of people living with HIV/AIDS (PLWHA). Of this population gender non-conforming women like women who have sex with women (WSW) remain undocumented. This study is an attempt to fill this information gap as it describes the demographic, health and sexual behaviours of 72 HIV positive WSW. The data indicate that WSW are not protected from HIV because of their same sex desires. These findings suggest the need to include WSW as a most at risk group for both HIV prevention and treatment programmes.

**Key words:** Women who have sex with women (WSW), lesbians, HIV positive, corrective rape, female-to-female transmission of HIV, South Africa.

## INTRODUCTION

The belief that women who have sex with women (WSW) are at no or low risk of HIV infection has led to the exclusion of WSW in HIV prevention efforts, access to health care services, education, treatment and research (Gomez, 1995; Stevens, 1993 as cited in Montcalm and Myer, 2000; Hughes and Evans, 2003; Teti et al., 2007; Gay Men's Health Crisis, 2009). Specific groups of women are more affected by this exclusion than others, these are HIV positive WSW (including those who do not identify themselves as lesbian or bisexual) (Young et al., 1992; Marazzo, 2000; Arend, 2003; Shisana and Louw, 2007; Lenke and Piehl, 2009). This social exclusion is in many respects informed by gender inequities inherent in almost every country of the world. For this reason, any HIV prevention, treatment and care programme for WSW must work from the premise that access to knowledge and services on health is disproportionate for women and

men in a context where gender inequities persist (Doyal, 1995; Lorberm, 1997). While much has been written about the vulnerabilities to HIV infection of men who have sex with men (MSM), there continues to be a silence regarding WSW and their particular vulnerabilities to HIV, particularly in the African context (Johnson, 2007; Tallis, 2009). In South Africa, the South African National Strategic Plan (NSP) on HIV and AIDS and STIs, 2007 to 2011, acknowledged that there is very little known about the HIV epidemic among MSM and has brought attention to the need for HIV prevention strategies for MSM (Department of Health, 2007). The NSP however remains silent on the HIV prevention needs of WSW and is not mentioned as an at risk group, in the country's planned response to the HIV epidemic. This silence is in many instances informed by the perception that WSW are at no or low risk of contracting HIV; such a belief ignores many women who are in both same sex and heterosexual relationships and the risks of infection these relationships pose.

Of much more concern though, is that beliefs like these

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become internalized by WSW and they then do not see themselves as being at risk for HIV infection (James, 1995; Matebeni, 2009). What we do know is that WSW are not risk free. WSW constitute a small, but significant group with specific health care needs, a lack of awareness among health care professionals and false perceptions may lead to ill informed advice and missed opportunities for the prevention of illness (Hughes and Evans, 2003). Even though sex between women is thought to be low risk for transmission of HIV and other sexually transmitted infections (STIs), research indicate that WSW may in fact be at greater risk than women with exclusively male partners, through behaviours such as risky sex with male sex partners and activities such as injection drug use (IDU) (Friedman et al., 2003; Grulich et al., 2003; van Griensven et al., 2004 cited in Mercer et al., 2007).

Similarly, Marazzo (2000) found that around one in five women, who have never had heterosexual intercourse in Britain, have the human papillomavirus (HPV). In addition Berger et al. (1995) illustrated that trichomoniasis has been transmitted sexually, supporting the hypothesis that STIs can be transferred between women through vaginal secretions (Fethers et al., 2000; Marazzo, 2000; Remez, 2001; Marazzo et al., 2001; Lindley et al., 2003; Singh et al., 2006; Mora and Monteiro, 2009). Most of these studies however have been conducted in the United States (US) and in Britain, with a complete neglect of WSW in countries located in Africa. As part of a large cross sectional survey among people living with HIV/AIDS (PLWHA) in townships and suburbs in and around Cape Town, South Africa; we explored whether PLWHA have ever or usually engaged in same sex behaviours. Hence, the overall aim of this study is to point to the neglect of WSW as a risk group in South Africa's response to the HIV epidemic.

## METHODOLOGY

### Study procedure

PLWHA were recruited to participate from organizations that provide care, treatment and support to HIV positive people like anti-retroviral (ARV) sites, service providers for PLWHA and established support groups. Thus, the sampling method used was convenience sampling. Eleven fieldworkers were recruited, 10 of whom were HIV positive and openly living with their HIV status. An almost equal number of men and women were recruited as fieldworkers. At the time of recruitment all of the fieldworkers were unemployed. Fieldworkers attended a two day training workshop that focused on the importance of ethics in research; basic interviewing skills and overall planning of the implementation of the survey.

Before the administration of the survey, participants signed informed consent forms. Participants were asked not to indicate their names anywhere on the questionnaire. Ethical clearance was obtained from the Human Sciences Research Council's Research (HSRC) Ethics Council (REC 3/13/10/04). According to the fieldworkers, none of the study participants approached to participate in the study refused to take part in the study, although refusal forms were available for this purpose. Participants were

given a monetary incentive that is equivalent in value to 3 \$US after completion of the questionnaire, as a token of appreciation but they were not told of this beforehand, to prevent participation bias.

## Measures

The draft survey questionnaire was piloted with a group of seven HIV positive community health workers from diverse sociocultural backgrounds, two of whom were self-identified gay men. The changes suggested by this group were incorporated into the construction of the final version of the questionnaire. Since the questionnaire was designed for self-administration, fieldworkers reported that the respondents found it generally easy to complete, although there were a few cases where the fieldworkers interviewed participants.

Survey questionnaires were available in Afrikaans, English or Xhosa, the three official languages spoken in the Western Cape. Some Xhosa - speaking respondents also completed the questionnaire in English. The questionnaire included demographic and health characteristics, HIV risk history, internalized AIDS stigma, HIV/AIDS discrimination experiences, cognitive affective depression, social support, substance use and sexual behaviour in the last three months.

## Data analysis

Descriptive statistics was used to analyze the demographic, health and behaviour characteristics of the sample. Data analysis was conducted using the Statistical Package for the Social Sciences Version 17.0 (SPSS). For descriptive purposes, the frequencies of responses to the demographic, health, HIV risk history and sexual behaviours in the last three months were examined.

## RESULTS

### Demographic characteristics

Anonymous surveys were completed by 641 HIV positive women<sup>1</sup>: 72 (11%) of those reported that they have ever had sex with a woman, whilst 41 (57%) of the 72 indicated that they usually have sex with a woman. The majority of the sample described themselves as black African (34 of the 72 WSW). Of the 72 WSW, 21 indicated that they were currently married to men at the time of recruitment. The majority of the sample were between the ages of 26 and 35, and 27 (19%) were between 18 and 25. Of the 72 HIV positive WSW, 28 (39%) reported that they are currently employed, 47 (65%) reported having children. With regards to educational status, 52 (72%) of the participants had a secondary (high school) education, whereas 5 (6%) of the 72 HIV positive WSW reported to have had no schooling.

<sup>1</sup>For a more detailed description of the 641 HIV positive women, please see the following published articles, Simbayi, et al. (a) (2007). HIV Status Disclosure to Sex Partners and Sexual Risk Behaviors among HIV Positive Men and Women in Cape Town, South Africa. *Sexually Transmitted Infections*, (83) 29-34. Simbayi, et al (b) (2007). Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS, Cape Town, South Africa. *Social Science and Medicine*. (64) 1823-1831.

## Health characteristics and HIV risk history

Participants were asked to report their current perception of their own health. With regards to perception of current health, 43% indicated that they perceive their health as good, whilst 12% perceived their current health status as poor. Similar proportions of the sample reported that they have been hospitalized two or more times (38.9%). Twenty nine percent reported that they are currently taking ARVs (Table 1).

Of the 72 HIV positive WSW, 55 (76%) reported having had an STI. Other markers for HIV risk history included having received money for sex (33%) and having given money for sex with someone else (18%). IDU was reported by 15% of the sample, whilst almost 20% reported a sex partner having used injection drugs. Almost half of the sample (45%) reported having been forced to have sex whilst 47% reported being hit by a sex partner (Table 2).

## Reported sexual behaviours without using condoms

Twenty six (48%) WSW reported having had sex with two or more sex partners whom they knew to be HIV negative in the last three months since data collection. In addition, 31 (45%) reported that they had sex with two or more partners in the last three months who did not know that they were HIV positive when they had sex with them. Twenty nine (44%) reported unprotected vaginal sex more than once in the last three months with a partner of unknown or negative status. Anal sex without condoms with partners of unknown or negative status were reported on by 16 (22%) of the participants. In this study, anal sex was described as penis into anus, whilst vaginal sex was described as penis into vagina. This provides an indication that even though this sample of women reported same sex behaviour ever and usually, they also engage in heterosexual sexual practices.

## DISCUSSION

These data indicate that WSW are not insulated, by virtue of their same sex desires, from the risks of HIV/AIDS. Even though the study sample is small and only descriptive, the data illustrates a need for HIV strategies tailored to the needs of WSW. Data from this study revealed the continuation of unprotected behaviour that can lead to HIV transmission. Yet as a group, WSW have been invisible in the US Centers of Disease Control and Prevention (CDC) classification system, while categories of risk groups for men include MSM, IDU and heterosexual contact, among others (CDC, 1995). There is no category for WSW. If a woman has sex with another woman and has other risk factors, such as drug use, the CDC would traditionally classify the transmission under one of those factors or classify it as undetermined (De

**Table 1.** Health characteristics of HIV positive WSW.

Characteristic	N	%
<b>Current perception of health</b>		
Excellent	8	11
Very good	22	30
Good	31	43
Poor	9	12
<b>HIV-related hospitalizations</b>		
Non-hospitalized	28	38
One hospitalization	15	20
Two or more hospitalizations	28	38
Taking ARVs	21	29

**Table 2.** HIV risk history of HIV positive WSW

Characteristics	N	%
Has had an STI	55	76
Received money, drugs or a place to stay in exchange for sex	24	33
Given someone else money, drugs or a place to stay in exchange for sex with you	13	18
Injection drug use (IDU)	11	15
IDU partner	15	20
Have been forced to have sex	33	45
Have been hit by a sex partner	34	47

Carlo and Gomez, 1997). To date, however, there are no confirmed cases of female-to-female sexual transmission of HIV in the CDC database. However, case reports of female-to-female transmission of HIV and the well-documented risk of female-to-male transmission indicate that, vaginal secretions and menstrual blood are potentially infectious and that mucous membrane (for example, oral, vaginal) exposure to these secretions has the potential to lead to HIV infection (CDC, 2006).

In terms of HIV, sex between men is highly infectious because it can involve anal sex which when unprotected carries a very high risk of HIV transmission (De Gruttola et al., 1989). On the other hand, the vulnerability to HIV infection of WSW is not the result of specific sexual practices, but the result of a myriad of societal factors. In South Africa, for example, women who do not conform to stereotypical ideas of what a woman should look like and whom she should love and have sex with (gender non-conforming women) are sometimes subjected to "corrective/curative rape" by men (where men attempt to

„turn“ women into „real African“ women). This violence presents a high risk for HIV transmission. A lesbian activist from Khayelitsha a black township in the Western Cape Province of South Africa writes that, she was gang raped by four men on account of her sexual preference. The story of Zoliswa Nkonyana, is also reported in the same article, Zoliswa was stoned, beaten and stabbed to death for being a lesbian. Other media reports reiterated that lesbians are subjected everyday to victimization in the townships.

Since January of 2003, 33 black lesbians have come forward with stories of rape and assaults. In 2003, behind the mask<sup>2</sup> has documented 12 rapes, four attempted rapes, six verbal abuse cases, three assaults with a deadly weapon, and two abductions (Mufweba, 2003). It is reported by The Global HIV Prevention Working Group (2007) that since 1998, there has been 31 recorded murders of lesbian women in South Africa and of these murders only one resulted in a conviction (The Global HIV Prevention Working Group, 2007 cited in Mises, 2009). Even though anecdotal reports of violence against black lesbians, has reached the print media, hard data indicating a pattern of such violence generally goes underreported and unnoticed, and therefore remains outside of the public consciousness (Reddy et al., 2007).

In addition, heteronormativity – the way in which it is considered normal for women and men to love each other/have sex with each other, and abnormal for women to love and have sex with each other, also contributes to the vulnerabilities to HIV infection for WSW. As a result of this normative social structure, many WSW are pressured into arranged heterosexual marriages.

Whilst same sex oriented men are also forced into heterosexual marriages, gender inequalities ensure that women have far less ability to negotiate sex. Indeed WSW may be the most “at risk” group of all, not due to biological susceptibility, but to sheer neglect in HIV prevention treatment, counselling and care services (Johnson, 2007). Results of this study should be interpreted in the light of its potential methodological limitations.

In the first instance, the method of sampling led to the selective inclusion of WSW who belonged to established service providers for PLWHA, so findings are not representative of all HIV positive WSW living in Cape Town. Also the study did not explore issues of sexual identity. In fact, the very use of the term WSW is problematic, since it is an identity-free term and it obscures the social dimensions of identity (Young and Meyer, 2005). Therefore, interpretation of the data is limited. Women who self-identify as gay and those who do not self-identify as gay but who engage in same sex practices might have very different experiences in terms

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<sup>2</sup> *Behind the Mask* is a communication initiative around LGBTI rights and affairs in Africa. By way of publishing a website magazine the organization gives voice to African LGBTI communities and provides a platform for exchange and debate for LGBTI groups, activists, individuals and allies. (<http://www.mask.org.za/index.php?page=whoweare>)

of the social factors that increase exposure to HIV infection.

The study also relied on self-reported data and the sample size was small. We also did not ask participants how they think they were infected with HIV. In addition, we also did not ask if they had sex exclusively with men or with women in the last three months since data collection. Finally, there was no procedure in place to ensure that only PLWHA completed the survey. However, it is unlikely that many HIV negative participants would have done so, given the considerable stigma still attached to HIV positive status.

## Conclusion

Non-governmental organizations (NGOs) in South Africa which focus on the rights, well-being, health and psychological needs of living as a lesbian, gay, bisexual, transgendered and intersexed (LGBTI) person in South Africa are scarce. LGBTI organizations and/or NGOs working directly with gender non-conforming communities, including WSW, provide the community-based methodological approaches to gender and sexuality, which is necessary in building knowledge about PLWHA in South Africa. On the other hand, large research institutions, which have a mandate to conduct public purpose research on relevant social issues such as PLWHA and gender in South Africa and other countries in Africa, are strategically placed to engage in the kind of large scale research that is more likely to shift public policies and programmes.

Hence, a relationship between LGBTI NGOs and research institutions can allow for the development of a research agenda focused on WSW and HIV risk. As a partnership, the idea is to develop well thought-out and appropriate methodologies that seek to explore and understand the vulnerability to HIV among WSW. Such a partnership can create a platform for a dynamic research agenda, supported by government and academic institutions, that seeks to provide new and necessary information about sexual minorities and risk for STIs, HIV and AIDS.

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<sup>3</sup>The Triangle Project offers a wide range of services to the LGBT community of Cape Town and the Western Cape. These include a variety of different health services, such as sexual health clinics, counselling and the helpline, public education and training services, an Educator’s Awareness Project, community outreach and safe spaces, and facilities such as the Drop-In Centre and the Gay and Lesbian library. (Available at [www.triangle.co.za](http://www.triangle.co.za))

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