### V REDDY, Z MATEBENI, T SANDFORT and I SOUTHEY-SWARTZ

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### Health needs and HIV risk among southern African women who have sex with women: Further policy options for an overlooked population

### **Executive summary**

This policy brief addresses the health needs and HIV risk among southern African women who have sex with women (WSW),<sup>1</sup> and arises out of a research study that reflects insights from qualitative and quantitative data sets (see Matebeni et al. 2013; Sandfort et al. 2013). HIV and sexually transmitted infection (STI) are relevant issues for all WSW and lesbian and bisexual (LB) persons and therefore require research, programmatic and policy attention. The brief draws on data from a multi-country (Botswana, Namibia, South Africa and Zimbabwe) research study that investigated HIV/STI vulnerability in this population, the way in which this population perceives and negotiates HIV/STI transmission risks, the way in which it is affected by HIV and AIDS, and the healthcare experiences and needs in this population.

HIV and AIDS and sexuality operate in gendered and often patriarchal contexts

in which women generally are silenced and made invisible, and usually bear the brunt of social, economic and cultural inequalities that prevail in society. This briefis underpinned by the view that WSW, andLB women in particular, require attention in policy efforts. Attention is required in respect of their position, needs and requirements at the level of community-building, the impact of their lives on policy and the donor community, and the strategies that could emerge from focused research. All of this is directed toward improving health and combating HIV and AIDS.

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### Introduction and background

Anecdotal evidence from the southern African region, coupled with incidental data taken from a study by a Pretoriabased LGBT (lesbian, gay, bisexual and transgender) organisation, shows that WSW and LB women in southern Africa are at risk and are infected with and affected by HIV and AIDS (Polders & Wells 2004; Rich 2006; Wells 2006). This has, however, not translated into recognised attention from policymakers and programming of targeted interventions. While there is a growing focus on men who have sex with men (MSM) in southern Africa and globally, there is scant attention paid to WSW and

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We use the label WSW as a term for expressions of same-sex desire by women. In this context, WSW includes women who self-identify as lesbian, those who may self-identify as bisexual, those who may not self-identify as either lesbian or bisexual while engaging in sex with their own gender, and those who use the acronym as an identity label.

LB women who are living with HIV, even in organisations of HIV-positive women (Reddy et al. 2009). It is thus evident that research with marginalised and vulnerable groups (in this case, WSW) is an important first step in providing evidence for policymakers to act upon.

### The policy context

There have been significant developments globally since the development of the Country Harmonization and Alignment Tool (CHAT) developed by the Joint United Nations Programme on HIV/ AIDS (UNAIDS). This tool provides three interconnected dimensions for addressing health needs of same-sex practising individuals (UNAIDS 2007), namely:

- LGBT participation and engagement in the response to HIV;
- a mapping of the epidemic and relevant information on key risk factors; and
- the creation of an enabling environment for service provision, including financial and human resources (however, not all countries account for this in their guiding policy documents related to HIV and AIDS).

### **Policy in South Africa**

The National Strategic Plan (NSP) on HIV, STIs and TB: 2012–2016 in South Africa (Department of Health, RSA 2011) was the second significant document (since the first NSP in 2007) to mention the need to include same-sex practising individuals in national HIV policies and programmes.

Table 1: Country-specific policies on HIV and AIDS

While MSM and transgender populations are prioritised, no significant policy attention is given to WSW in the latest plan. The situation is similar in various plans in other countries in southern Africa, as illustrated in Table 1.

### **Policy in Botswana**

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The Second Botswana National Strategic Framework for HIV & AIDS: 2010–2016 (NACA 2009) addresses guiding principles, which include sexual orientation, but does not specify anything in relation to samesex practising populations, either for men or women.

### **Policy in Zimbabwe**

The Zimbabwe National HIV and AIDS Strategic Plan (ZNASP 2) 2011–2015 (NAC 2011) recognises male and female partners of MSM as sources of new infections, but does not spell out how these populations will be targeted in the response. WSW are excluded.

### **Policy in Namibia**

The National Strategic Framework for HIV and AIDS Response in Namibia 2010/11–2015/16 (MoHSS 2010), identifies MSM as a most at-risk population but does not specify any reference to WSW as warranting any attention. In essence, there appears to be varied focus and attention to same-sex practising populations and the least attention to women within this population.

Country-specific policies on HIV and AIDS	Inclusions	Exclusions
<b>South Africa</b> National Strategic Plan (NSP) on HIV, STIs and TB: 2012–2016	Prioritises MSM and transgender populations	WSW not given attention
<b>Botswana</b> Second Botswana National Strategic Framework for HIV & AIDS: 2010–2016	Has sexual orientation guiding principles	Same-sex practising populations not mentioned
<b>Zimbabwe</b> Zimbabwe National HIV and AIDS Strategic Plan (ZNASP 2) 2011–2015	Male and female partners of MSM	WSW excluded
Namibia National Strategic Framework for HIV and AIDS Response in Namibia 2010/11–2015/16	MSM as a most at-risk population	WSW not given any attention

In order to make a stronger case for policy interventions, it was decided to conduct research to determine a more accurate understanding of the impact of HIV and AIDS on WSW.

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### Language and categories

WSW and LB persons are considered a vulnerable group as they are prone to stigmatisation, lack appropriately targeted health facilities, receive little or no attention within national HIV and AIDS programmes, and, as a group, epidemiological information about their sexual practices is inadequate or unreliable. Prejudice and discrimination not only predispose such women to trauma but also discourage access and disclosure in community and healthcare settings.

This description of WSW and LB persons does not imply that all their expressions are negative, or that such expressions lack pleasure. The framing of this population in the negative highlights the negative location and position of women in the broader context of homophobia.

Despite constitutional protection, many lesbian women in southern Africa have become victims of hate crimes (some are murdered; others raped by men who hope they will become heterosexual), and with rape, many women become HIVpositive. The situation is dire in countries such as Zimbabwe and Botswana where there are no constitutional protections. Namibia has limited protection. Although in the context of HIV and AIDS, women are viewed as vectors of disease in a largely heterosexual epidemic in sub-Saharan Africa, WSW are too often erased from epidemiological investigations and HIV and AIDS prevention efforts.

### The problem

WSW in southern Africa, including women who identify as lesbian or bisexual, or who have same-sex desires for persons of the same gender, are

at the brunt of discrimination and oppression in patriarchal, heterosexist societies. Some of these women face deeper marginalisation because of race, class, ethnicity or HIV status. Multiple marginalisation impacts on different aspects of these women's lives, including their health. Women's health in general and the health needs of WSW and LB persons in particular are not high on the agenda of policymakers, health service providers or researchers. This lack of attention is partly based on the fact that adequate knowledge of the complexities and issues around the provision of appropriate health services for WSW and LB persons is missing. There are huge gaps in knowledge about sexual practices and preferences, including the frequency of same-sex conduct and the number of people who claim same-sex identities, and about violence against the LGBT community. The voices, experiences and issues of the diverse groups of WSW and LB persons are glaringly absent from research, programmatic and policy agendas.

#### **Research study**

In view of the paucity of data, a study was undertaken that used both qualitative and quantitative methods. Local LGBT organisations in four countries were crucial partners and fieldworkers in the study.

### The qualitative study component

For the qualitative study, the eligibility criteria for study participants were that they had to be:

- 18 years and older;
- living with HIV;
- in (or had been in) a sexual relationship with other women in the past year;
- self-identifying as lesbian; and
- willing to give informed consent to participate, including the audio recording of the interview.

Semi-structured in-depth interviews were conducted with 24 self-identifying

lesbians living with HIV in South Africa, Zimbabwe and Namibia. No data were collected in Botswana as researchers could not identify lesbians living with HIV. The majority (16) of the participants lived in South Africa and four in each of the two other countries (Zimbabwe and Namibia). The study paid attention to the experiences of lesbians living with HIV, and may assist in transforming general understandings of HIV transmission and consequently challenge assumptions about lesbian risk.

### The quantitative study component

For the quantitative component (a survey questionnaire), criteria included being biologically female and 18 years or older; having had sex with a woman in the preceding year; and currently living in Botswana, Namibia, South Africa or Zimbabwe (N = 591). Women were recruited into the study by community-based organisations that used social media, referrals, announcements at relevant meetings and spaces, and (gay-friendly) religious services to advertise the study.

In addition to questions about demographic characteristics, we assessed various aspects related to gender and sexuality (including women's perceptions of their masculinity and femininity), sexual behaviour (lifetime number of partners), experiences of transactional sex (including sex with men) as well as forced sexual experiences, testing status and HIV serostatus.

### Key findings: Qualitative component

- The women were aged between 22 and 48 years.
- Of the 24 participants, six had tertiary education qualifications. A third of the participants had not finished high school and half of them had a primary school education.
- Only seven participants were in full-time employment and only four had private health insurance. Those

who had fixed monthly incomes earned less than R7 000 per month (approximately US\$900).

- 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 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 10 years.
- The majority of the participants (18) were receiving anti-retroviral treatment (ART) – some for more than six years.

### Finding about status

The majority of the participants (17) self-reported seeking an HIV test because of an illness or signs thereof. For a few, a partner's 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.

Five participants reported that their female partners could have possibly infected them. They all claimed they had never been with male partners or had exposure to medical transmission or injecting drug use (we did not ask

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 years old, Namibia)

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 how I could have contracted the virus when I had thought I was safe in a way! (Zanele, 31 years old, Durban)

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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'l 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 years old, Pretoria)

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...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 years old, Durban)

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 years old, Zimbabwe)

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 years old, Windhoek) if participants were born with HIV or exposed to other possible risks of transmission). It was difficult to understand how these participants could be HIV-positive when they thought they were not at risk because of their sexual orientation.

### **Experience with testing**

Participants stated that it was difficult and generally unpleasant to seek an HIV test, as voluntary counselling and testing (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 with her sexual orientation.

### Accessing health services

Many participants reported positive experiences accessing healthcare services. In particular, participants who were accessing treatment stated that service delivery in relation to HIV care was satisfactory. However, there were some participants who indicated that negative attitudes of healthcare providers and lack of knowledge hindered them from accessing public health services. Healthcare providers were referred to as having very little, if any, information about lesbian sexual health.

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.

### **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 a few friends. For those participants who had disclosed to family members, partners and friends, disclosure was couched in the language of protection – protecting oneself and another from possible infection.

### Key findings: Quantitative component

Even though WSW are usually understood to be at no or very low risk for HIV infection, we explored whether LB women in a geographical area with high HIV prevalence (southern Africa) get tested for HIV and whether, among those women who get tested, there are women who live with HIV and AIDS. Most participating women identified as lesbian and black. Almost half of the women (47.2%) reported ever having had consensual heterosexual sex.

- A large proportion of the women reported to ever having been tested for HIV (78.3%).
- Whether women ever had been tested was not associated with the number of lifetime female and male sexual partners.
- 9.6% of the women who had ever been tested for HIV, and knew their status, reported to be HIV-positive.
- In trying to identify the most likely transmission route for the 41 women who were HIV-positive, we found that two of them reported to having used needles for intravenous drug use.
- Twenty-six women reported to have had consensual sex with and/or forced sex by men.
- Based on the available data, we could not identify a transmission route for 13 of the infected women.
- Women who had engaged in transactional sex with women only or with women and men were less likely to have been tested.
- Engagement in transactional sex (lifetime) was reported by 18.6% of all women. Transactional sex with men was reported by 10.5% of the women, and transactional sex with women was reported by 15.2% of the women.

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- Money was the most frequently reported reason for transactional sex with men as well as with women.
- Compared to women who never engaged in transactional sex, women who during their lifetime had had transactional sex with both men and women were more likely to be HIVpositive.
- Compared to women who did not report any forced sexual experiences, women who had forced sex only by men, only by women, or by both men and women were more likely to be HIV-positive. Forced sex by men or women was reported by 31.1% of all women.
- Besides age, the sole independent predictor of a positive serostatus was having experienced forced sex by men, by women, or by both men and women.

### **Summary of findings**

Findings indicate that despite the image of invulnerability, HIV and AIDS is a reality for lesbian and bisexual women in southern Africa. Surprisingly, it is not sex with men per se, but rather forced sex that is the important risk factor for self-reported HIV infection among the participating women. HIV and AIDS policy should also address the needs of lesbian, bisexual and other women who have sex with women.

### Recommendations

Based on findings across four southern African countries addressing the health needs and HIV prevalence among southern African women who have sex with women, future policies should take the following factors into account:

- 1. There exists a rich diversity among WSW as a group across demographics, sexual practices, age and class.
- 2. Lesbian women can be infected with HIV. This is mainly attributed to sex with men, but there are some questions regarding women-towomen transmission.

- 3. Lesbian women want and need access to general health and specific HIV and AIDS counselling and treatment.
- 4. There are complexities of perceived and actual risk.
- 5. It is clear that, as a group, lesbian, bisexual and other women who have sex with women do not have access to adequate and specific information and services related to HIV. They also have perceived and actual barriers to accessing health services and are at risk of contracting HIV.
- 6. Attention should be given to whether to view LB woman and other WSW as women first, and whether to consider 'mainstreaming' issues of sexual orientation to provide specialised and specific services that address LB women and HIV.
- 7. Further research is required to better understand the modalities of womento-women transmission, specifically around sexual practices, vulnerability, risk and modes of transmission.
- 8. There should be increased access to funding for research on HIV that focuses specifically on LB women and WSW. WSW and LB women should be included in research projects on women as well as on those focused on HIV and AIDS.
- 9. There should be targeted and appropriate development of information that caters for a diverse group of LB women – addressing issues of identity, practice, and so forth.
- 10. Provision should be made for specific services that address mental health issues, self-attitudes, identity and orientation, drug and alcohol use, and other barriers to preventative behaviours.
- 11. Regional and national policies should legislate against violence and hate crimes towards WSW and LB persons. This can be achieved by increasing political engagement by multinational agencies (such as the United Nations, with agencies such as UNDP, UNAIDS, UN Women and UNICEF leading)

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and intergovernmental regional organisations (such as SADC, specifically the Gender Unit).

#### References

- Department of Health, RSA (2011) National strategic plan on HIV, STIs and TB: 2012–2016. Pretoria: Department of Health
- Matebeni Z, Reddy V, Sandfort T & Southey-Swartz I (2013) 'I thought we are safe': Southern African lesbians' experiences of living with HIV. *Culture, Health & Sexuality* 15(1): 34–47
- MoHSS (Ministry of Health and Social Services, Republic of Namibia) (2010) National strategic framework for HIV and AIDS response in Namibia 2010/11–2015/16. Windhoek, Namibia: Government Publications
- NAC (National AIDS Council of Zimbabwe) (2011) Zimbabwe national HIV and AIDS strategic plan (ZNASP 2) 2011–2015. Harare, Zimbabwe: NAC
- NACA (National AIDS Coordinating Agency, Republic of Botswana) (2009) The second Botswana national strategic framework for HIV & AIDS: 2010–2016. Gaborone, Botswana: NACA
- Polders L & Wells H (2004) Levels of empowerment among lesbian, gay, bisexual and transgender (LGBT) people in Gauteng, South Africa. Pretoria: OUT LGBT Well-being
- Reddy V, Sandfort T & Rispel L (Eds) (2009) From social silence to social science: Same-sex sexuality, HIV & AIDS and gender in South Africa: Conference proceedings. Cape Town: HSRC Press
- Rich E (2006) Overall research findings on levels of empowerment among LGBT people in Western Cape, South Africa. Cape Town: Triangle Project
- Sandfort TGM, Baumann LRM, Matebeni Z, Reddy V & Southey-Swartz I (2013) Forced sexual experiences as risk factor for self-reported HIV infection among southern African lesbian and bisexual women. *PLOS One* 8(1): 1–9

UNAIDS (Joint United Nations Programme

policy brief

- on HIV/AIDS) (2007) Country Harmonisation and Alignment Tool (CHAT): A tool to address harmonisation and alignment challenges by assessing strengths and effectiveness of partnerships in the national AIDS response. Geneva: UNAIDS
- Wells H (2006) Levels of empowerment among lesbian, gay, bisexual and transgender (LGBT) people in KwaZulu-Natal, South Africa. Pretoria: OUT LGBT Well-being

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### **STUDY AUTHORS**

Dr Vasu Reddy, Acting Executive Director of the Human and Social Development Programme at the HSRC, and Honorary Professor and Research Fellow, University of KwaZulu-Natal, Durban, South Africa Dr Zethu Matebeni, Research Fellow at the

Institute for Humanities in Africa, University of Cape Town, Cape Town, South Africa

**Dr Theo Sandfort**, Research Scientist and Professor at the HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute, and Columbia University, New York, USA

**Ian Southey-Swartz**, Programme Manager at the Open Society Initiative for Southern Africa, Johannesburg, South Africa

Enquiries to Dr Vasu Reddy: vasureddy@hsrc.ac.za