

Putting Public in Public Services:
Research, Action and Equity in the Global South

International Conference – Cape Town, South Africa
April 13-16, 2014

Draft conference paper, please do not cite without permission from the author

Public Health Care for South African Lesbian, Gay, Bisexual and Transgender People: Health Rights Violations and Accountability Mechanisms

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ABSTRACT

Background

Lesbian, gay, bisexual and transgender (LGBT) people in Southern Africa are at high HIV risk: studies with men who have sex with men (MSM), women who have sex with women (WSW) and transgender people demonstrate high HIV prevalence among these marginalised groups. Although the South African constitution guarantees LGBT people the right to non-discrimination and the right to accessing health care, homophobia in society abounds. Little is known about LGBT people's health care experiences in South Africa, but anecdotal evidence suggests significant barriers in accessing care. This study aimed to document LGBT people's experiences in SA public sector health care, including access to HIV counselling, testing and treatment, to analyse to what extent LGBT people's right to health is actioned. It also investigates strategies for LGBT people to seek resolution and create accountability when experiencing health rights violations.

Methods

An on-going qualitative study in three SA provinces (Gauteng, Western Cape, KwaZulu Natal), comprised of semi-structured interviews and focus group discussions (FGD) with LGBT health service users and representatives of LGBT organisations. Data were analysed within the framework of the UN International Covenant on Economic, Social and Cultural Rights General Comment 14 (availability, accessibility, acceptability, quality of care) following a grounded theory approach.

Results

To date, 30 interviews and 2 FGDs with LGBT health service users and representatives of non-governmental organisations have been completed. All interviewees reported experiences of discrimination by health care workers based on their sexual orientation and/ or gender identity. Participants recounted violations of all four elements of the UN General Comment 14:

- 1) Availability: Lack of public health facilities and services, both for general and LGBT-specific concerns
- 2) Accessibility: Refusal to provide care to LGBT patients
- 3) Acceptability: Articulation of moral judgment and disapproval of LGBT patients' identity, and forced subjection of patients to religious practices
- 4) Quality: Lack of knowledge about LGBT identities and health needs, leading to poor-quality care

All but one of the respondents had delayed or avoided seeking health care in the past. While most of the respondents recognised that their health rights had been violated, none had sought out accountability or complaint mechanisms within the health system. Reasons for this were either fear of repercussions when seeking care subsequently, or the belief that homophobia was so pervasive in the health care system that any complaint would be met with the same homophobic attitude.

Conclusion

My findings assert that LGBT people's right to health is often severely violated with in South African public health facilities, and this has negative consequences for the uptake of health services. Many HCWs' attitudes towards LGBT patients are obviously unprofessional and violate the ethical codes of various health professions bodies. Current complaint and accountability mechanisms fail LGBT people who experience discrimination and abuse in the health system. There is an urgent need to challenge HCWs attitudes towards LGBT patients and educate them about LGBT health.

INTRODUCTION

Identifying as lesbian, gay, bisexual or transgender (LGBT¹) is not genetically or biologically hazardous, but societal homo- and transphobia confers risk factors for LGBT people's well being. While L, G, B, and T are usually tied together as an acronym that suggests homogeneity, each letter represents a wide range of people of different races, classes, ages, socioeconomic status and identities. What unites them as sexual and gender minorities are common experiences of stigma and discrimination, and, specifically with respect to health care, a long history of discrimination and lack of awareness of health needs by health professionals. As a result, LGBT people face a common set of challenges in accessing culturally competent health services and achieving the highest possible level of health. Homophobia, the irrational fear and hatred of people who are attracted to the same sex, and transphobia, the irrational fear and hatred of people who do not fit binary

gender identities, lead to social exclusion, experiences of discrimination and stigma, and in the worst case violence directed against people whose real or perceived sexual orientation and gender identity do not fit the narrowly defined heterosexual norms (Wilton 2000). Gender identity and sexual orientation, like other social determinants of health, lead to health disparities and, compared with heterosexual and non-transgender socioeconomically matched peers, LGBT individuals are more likely to face barriers accessing appropriate health care (Gay and Lesbian Medical Association 2001). Beyond these societal risk factors, LGBT people have specific health and health care needs in various fields from chronic disease risk (King & Nazareth 2006), adult and adolescent mental health (Bostwick et al. 2010), unhealthy relationships (for example intimate partner violence (Kulkin et al. 2007), sexually transmitted infections (Marrazzo et al. 2010), and human immunodeficiency virus infection (Lane et al. 2011). Of special concern are LGBT people's mental health needs. Experiences of social exclusion, discrimination and prejudice impact on LGBT people's mental health, and studies from Europe and the United States have shown that people who identify as LGBT have significantly higher rates of depression, suicide, and anxiety disorders than their heterosexual matched peers (Mayer et al. 2007).

These health needs are as urgent for LGBT people in South and Southern Africa. For example, LGBT people in Southern Africa are at high risk for HIV: studies with men who have sex with men (MSM) demonstrate high HIV prevalence among this marginalised groups (Lane et al. 2011). Similarly, in contradiction to dominant assumptions about their 'immunity', a recent study shows that in Southern Africa, the HIV prevalence among women who have sex with women might be as high as 10% (Sandfort et al. 2013). Almost half of the women in this study reported that they had had heterosexual sex at least once in their life. Even more importantly, one third of these women had experienced sexual violence in the form of non-consensual sex². These findings complicate the dominant image of women who have sex with women as not at risk for HIV, and indicate that sexual violence is a major risk factor for lesbian, bisexual and gender non-conforming women in South Africa and elsewhere. While there are no statistics on sexual violence against LGBT people in South Africa, findings from the United States suggest that non-heterosexual identities place people at higher risk of experiencing sexual assault, often motivated by homo- or transphobia: a recent review revealed a 43% median estimate of lifetime sexual assault for lesbian and bisexual women in the United States (Rothman et al. 2011). Indeed, in the past few years, cases of so-called 'corrective' rape – sexual violence targeted against gender non-conforming women, often located in poor and predominantly black areas – have sparked publicity in South Africa and abroad (Action Aid 2009). As the findings from the US confirm, these cases ought not to be framed as 'unique', 'cultural', or 'African' problems, as such simplification ignores the structural determinants (Patton 2002) and the generally high levels of violence against women in South African society (Jewkes et al. 2002). However, these cases are significant in that they remind us that the risks of 'heterosexual sex', which are deemed insignificant for lesbian, bisexual and queer women, play out in contexts of homophobia, sexism and misogyny where they acutely shape the HIV risk for these women.

Access to health care is notoriously challenging in South Africa, a country where the vast majority of the population depend on health services by the under-resourced and under-staffed public sector. The private sector, catering for less than 28% of the

population (Statistics SA 2011), accounts for 46% of all health expenditure in the country (Coovadia et al. 2008). Only 16% of South Africans are covered by medical aid (Statistics SA 2011), the rest of private sector users pay out of pocket and rely on public care for hospitalization (Coovadia et al. 2008). In this highly unequal system, LGBT people face not only challenges of service and supply unavailability, long waiting times, and a lack of specialized personnel and services, but also encounter homo- and transphobic discrimination and prejudice on top of these other barriers. Although few in numbers, recent South African studies highlight that LGBT patients experience discrimination at the hands of nurses, doctors, counsellors and even administrative and security staff at public health facilities. In a study among men who have sex with men in Soweto, Johannesburg, all respondents recounted experiences of being insulted, ridiculed, or singled out for their sexual orientation (Lane 2008). Transgender people seeking access to HIV services routinely experienced being called names or being blamed for acquiring HIV on the grounds of their gender identity (Stevens 2012). These experiences emphasise that health professionals themselves often act as gatekeepers to services on the ground (Muller and MacGregor 2013).

The accounts of homophobia in the health system are not surprising, given that the majority of South Africans believe that homosexuality should not be accepted in society³. Justified by arguments calling on 'tradition' and 'culture', claims that homosexuality is 'un-African' are widely accepted, even though they have been widely disproven (Epprecht 2008). Against this widespread homophobia in society, the South African constitution guarantees LGBT people the right to non-discrimination, including the right to accessing health care (Section 9 and 27(a) of the constitution). On a policy level, recent years have brought a shift to include LGBT health into South African health care policy recommendations. For example, following extensive lobbying of a number of transgender organisations and individuals, transgender people are identified as one of the most-at-risk populations in the 2012–2016 National Strategic Plan for HIV, STIs and TB (SA Department of Health 2011). Furthermore, civil society groups have begun to call for action as well: the first South African National Health Assembly, held in Cape Town in June 2012, called for 'appropriate non-judgmental care for marginalised vulnerable groups such as [...] LGBT persons' (National Health Assembly 2012). While these initiatives to include non-heterosexual identities into health policy are to be welcomed, it remains unclear how these new policies are to be implemented and monitored. As described above, emerging research as well as anecdotal evidence from LGBT advocacy organisations and individual activists suggests that it is health professionals themselves who discriminate against LGBT patients, and thus pose significant challenges to the implementation of these progressive policies.

Negative experiences with health professionals contribute to the erosion of a sense of safety in the health care system, and as a consequence, LGBT people avoid seeking care (Brotman 2002). A 2006 South African study highlights the alarming consequences for LGBT people's health-seeking behaviour: in the province of the Western Cape, 16% of LGBT people either delayed seeking health care for fear of homophobic treatment, or did not seek medical help at all (Wells & Polder 2006).

Health professionals in South Africa are bound to a number of professional codes of conduct that prohibit any discrimination based on the stipulations in the South African constitution – including, among others, gender and sexual orientation

(Constitution of the Republic of South Africa 1996). The professional code for doctors is defined by the Health Professions Council of South Africa⁴, and nurses and other allied health workers have to follow the Batho Pele principles which are applicable to all public services in South Africa. The Health Professions Act of 1974 stipulates that “A practitioner shall at all times [...] respect patient confidentiality, privacy, choices and dignity.” (Section 27(b), SA Health Professions Act). The patients’ rights charter has been adopted by the Department of Health and clearly outlines the rights of users of public health facilities. The Department of Health further provides complaint hotlines for each province (some of which are toll-free numbers)⁵, but encourages patients to complain to the relevant clinic or hospital managers first. However, there is no institutionalised structure that collects and analyses these complaints.

Given the high levels of homophobia, heteronormativity, and documented economic and infrastructural challenges for anybody accessing health care in South Africa, this research aims to investigate the specific barriers that sexual and gender identities face when seeking care in public health facilities. The United Nation’s International Covenant on Economic, Social and Cultural Rights (ICESCR) defines that access to health care, in fulfilment of the requirements for the highest attainable standard of health, consists of four main areas: availability, accessibility, acceptability and quality of care (ICESCR 2000). Following this framework, my paper will analyse access to care for LGBT South Africans, and place a special emphasis on the impact and role of heteronormativity and homophobia on all four levels of access. It is worthwhile to note that South Africa is one of the few countries that have not yet ratified the ICESCR, and are therefore not bound to implementing General Comment 14. However, I believe that nevertheless, the framework provides a useful lens through which to analyse LGBT people’s access to care and the existing barriers.

METHODOLOGY

This on-going study explores the health care experiences of LGBT service users using a qualitative methodology with convenience sampling. Since this is the first research in South Africa that aims to explore barriers to access to health care for LGBT people, it was conceptualized as an exploratory study without a specific hypothesis. Rather, it is aimed at eliciting knowledge following a grounded theory approach. Acknowledging that the experiences of marginalised groups are often excluded from knowledge creation (Gaventa & Cornwall 2001), I decided to base my findings first and foremost on interviews with LGBT health service users themselves.

The preliminary findings presented here are based on information obtained from 45 individuals, through interviews and focus group discussions.

The interviews and focus group discussions with LGBT health service users were based on a thematic guideline that elicited information about use and general experiences in public health care facilities, specific incidences of discrimination based on sexual orientation or gender identity, factors that might facilitate or hinder access to health care, and recommendations for the improvement of health services to sexual and gender minorities.

In order to gain a more structural perspective of the barriers faced by LGBT health service users, I also interviewed representatives of LGBT organisations. The thematic guideline was similar to the one for LGBT health service users, and representatives were asked to provide their opinion based on their experiences working in the LGBT sector. Furthermore, they were asked to provide examples of anonymised cases where possible.

LGBT health service users were identified through a snowball convenience sample method, by the use of social media, existing networks of LGBT service organisations and support services, as well as through the website of this study (<http://queerhealth.withtank.com>). The study was approved by the Human Research Ethics Committee of the University of Cape Town (reference 537/2012), and interview participants all signed informed consent forms.

Interviews and focus groups discussions were recorded and transcribed. I used a grounded theory approach to analyse the transcripts, first reading for emerging general themes, and then re-reading multiple times to identify sub-themes within each theme. I used the framework of the UN General Comment 14 (availability, accessibility, acceptability, quality of care) on the right to the highest attainable standard of health to group and analyse the barriers identified by my respondents. The stipulations of each component of framework are specified in each section in the findings.

FINDINGS

Respondents

To date, I have interviewed 30 participants in the provinces of Gauteng and the Western Cape. In addition to the individual interviews, I conducted one focus group discussion in each province in order to give the participating LGBT service users the opportunity to engage with the topics in a more conversational and unstructured way. I conducted one focus group discussion with men who identified as gay (n=7), and one with women who identified as lesbian (n=8).

Of a total of 14 interviews with non-governmental organisations, I interviewed two representatives from Gender DynamiX and Triangle Project, respectively, as well as one representative from the AIDS Legal Network. In Gauteng, I interviewed three representatives from OUT LGBT Pretoria, two representatives from the Forum for the Empowerment of Women, and the Ekurhuleni Pride Committee respectively, as well as one representative from the Gay and Lesbian Archives in Action. Because of the relative absence of the experiences of transgender health service users, I also interviewed a representative from S.H.E (Social, Health And Empowerment Feminist Collective Of Transgender And Intersex Women Of Africa), an organisation operating at national level for the advocacy of rights of transgender women.

Of the 16 LGBT health service users who participated in individual interviews, seven lived in the Western Cape, in the wider Cape Town area. In Gauteng, nine health service users responded. All interviewees lived in urban or peri-urban areas.

Use of health services

All LGBT health service users had some experiences with health care in public sector facilities. Fifteen out of the 16 individual interviewees had also used private health care when they could afford it, usually because they expected better quality treatment and less homophobic discrimination. For this study, only experiences in public health care were deemed relevant. The reasons why participants had sought public health care ranged from getting an HIV test to being hospitalised after attempting suicide.

Non-availability of services

Functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party. The precise nature of the facilities, goods and services will vary depending on numerous factors, including the State party's developmental level. They will include, however, the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs, as defined by the WHO Action Programme on Essential Drugs.

(UN ICESCR, General Comment 14, Article 12.1)

General health services

With regards to the availability of services, LGBT health service users experienced the same challenges as all public facility users: long waiting times, or services only offered at a considerable distance:

"I had to stand too long in the queue. Oh! Oh my word! That is the worst [...] I had to wake up at 5 to be helped at 8 or 8:30 or so [...] Yes, the queues are too darn long." (GT focus group)

In addition to the general non-availability, services addressing LGBT-specific health concerns were usually completely lacking in general public facilities. For example, one of the respondents in Cape Town highlighted that

"there is no queer protection like the safety pack [HIV and STI prevention material distributed by a local NGO, consisting of dental dams, gloves, condoms and lubricant]. I would love to see a dispenser at a clinic".

Echoing with the lack of sexual health prevention resources was a general lack of information about any health concerns of LGBT people. Where participants had sought knowledge about LGBT-specific health risks and concerns, they had turned towards non-governmental organisations:

"And information [...], I do go around and get my information from other sources rather than my clinic, because they do not provide any." (GT)

'You would not even find a small poster on the wall that says 'We give such and such treatment to the LGBT community' (GT focus group)

LGBT-specific health services

None of the respondents had ever received LGBT-specific health information. NGO representatives confirmed that LGBT-specific health services were generally not available in public sector facilities. Both in the Western Cape and Gauteng, non-governmental organisations provided certain LGBT-specific health services, usually around HIV prevention and management, in urban and peri-urban areas. Of note here is that while there exist three clinics that provide services for gay men, such a targeted service does not exist for lesbian women or gender non-conforming people.

With regards to transgender-specific services, only three health facilities in the country provide services for gender reassignment, both hormonal and surgical. All three are situated within tertiary academic facilities (Groote Schuur Hospital in Cape Town, Steve Biko Academic Hospital in Pretoria, and Baragwanath Hospital in Johannesburg). Due to very limited resources, the waiting lists for such services are up to 20 years long.

Non-accessibility of services

Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party. Accessibility has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility, information accessibility.

(UN ICESCR, General Comment 14, Article 12.1)

Accessibility to services came up in numerous interviews as one of the main concerns for LGBT health service users. Barriers to accessibility were as direct as the refusal of services to LGBT patients:

“[The nurse said] ‘No, no, go somewhere else, this is not the place for you.’”
(respondent from Gauteng)

However, more often the barriers were subtler than an outright refusal of services, and speak to the various ways in which homophobia impacts the experience of LGBT people. As various respondents recollected,

“Once we get there [to the clinic], we feel judged” (GT)

As one respondent, who identifies as a sexual minority and also lives with a physical and psychosocial disability acknowledged, the discrimination based on one’s sexual orientation and gender identity needs to be seen in intersection with other discriminations. According to their experience, public health facilities do not provide additional support for these various markers of difference that place some facility users at disadvantage, and therefore significantly impact their ability to access health care:

“It is assumed that you don’t have a physical disability and an emotional disability; and then a mental disability and a hearing disability. And if you do it is assumed that you can fend for yourself and find a way around it.” (GT)

Acceptability of services

All health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.

(UN ICESCR, General Comment 14, Article 12.1)

Violation of the confidentiality of LGBT patients' information was a common theme in the interviews. Patients' sexual orientation or gender identity was often shared by health care workers with colleagues or other patients, and at times attached to their health concern as well. For example, one interviewee from Gauteng recounted that:

“Instead of [the nurse] helping you, they are just going to the others and gossiping that ‘Oh look at them they call themselves lesbians; but they actually sleep with men because if they didn’t she wouldn’t be [...] positive.’”

Many respondents shared experiences of disrespectful treatment based on their sexual orientation or gender identity. Health care workers' disrespect was usually articulated in verbal harassment (“*They say it’s no good, they make [gay men] a laughing stock*” (GT)), or disapproving non-verbal cues (“*If we are there they look at us as if we’re sick*” (GT)). Many interviewees emphasized that this behaviour was not only perpetuated by health care workers, but in cases where service users were suspected to be LGBT, also by administrative and security staff as well as other patients.

Interviewees recounted various instances of unprofessional behaviour by health care workers. This took the form of intense curiosity and focus on the patients' sexual orientation or gender identity, as illustrated by the following quote from a GT respondent:

“They look perplexed in a way that they are a little bit shocked. They ask you ‘So how do you do it [sex]?', yeah things like that, ‘You really don’t have a man?’ [...] it’s not in a professional manner that they are doing it”.

Many LGBT service users had experienced religious judgment from health care workers: “*And [the doctor] is like ‘Okay, but you know that God doesn’t want this, right?’”*. In one recollected incident, a nurse resorted to blaming the patient's sexual orientation for his suicide attempt: “*[The nurse] is like ‘The reason why you [attempted suicide] is because you are having relationships with men and that is not right. So it’s the evil spirit that is making you do all the things that you are doing’”* (GT).

Quality of care

As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality. This requires, inter

alia, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.

(UN ICESCR, General Comment 14, Article 12.1)

Health care workers' lack of knowledge of LGBT identities and LGBT-specific health needs was of great concern to all interviewees. As one respondent stated:

"The challenge that people face is [...] having to explain who they are [...] and go through very common myths and preconceptions [...] Which is difficult because you go there and you want to seek care, and instead [...] you are explaining very basic things to them and you are thinking 'But why weren't you taught this in med school?'" (GT)

Such lack of knowledge, or existing misinformation, results in exclusion from services. One example was provided by a lesbian women from Cape Town, who was turned away by a nurse when seeking voluntary counselling and testing for HIV, based on the fact that the nurse believed that lesbian women are not at risk for HIV infections. All lesbian interviewees echoed this misconception:

"To them [nurses] it's only the straight people that can get HIV [...] because straight people they are usually the ones that are sleeping with men"

Health care workers' misconceptions also impacted the services that male survivors of sexual assault received. Dominant misconceptions about gender performances and (in)vulnerability led to secondary victimization of a gay man who wanted to access services after experiencing sexual violence:

"You get a nurse you know who is supposed to be educated who is like 'how can you be raped whereas you are a man' and I'm like well... 'Like how can you but you are a man couldn't you defend yourself; why didn't you fight back?'" (GT)

Of great concern to NGO representatives was the lack of nationally recognized standards of care for transgender-specific health services. Of the three facilities that provide transgender-specific health care such as hormone replacement therapy and gender reassignment surgery, only Groote Schuur Hospital in Cape Town follows the current, internationally accepted guidelines published by the World Professional Association for Transgender Health (WPATH). This lack of national guidance severely compromises the care that transgender people receive with respect to their specific health concerns. Inappropriate standards of care were not restricted to transgender patients, and LGB patients also recounted instances of receiving inappropriate treatment due to their sexual orientation. Unprofessional attitudes, and most notably religious judgment, often provided the basis for health care workers' inappropriate medical decisions and denial of care, such as in the case of a young gay man who sought psychiatric care after attempting suicide:

"[After learning about my sexual orientation] the psychologist read me some scriptures from the bible; and she told me 'you know what just pray'" (Respondent from GT)

Impact on LGBT people's health-seeking behaviour

The experiences that LGBT service users make in public health facilities shape the way they perceive, and access health services. As a result of health rights violations that they have either experienced themselves, or have heard about from friends and peers, many LGBT people expect judgement and discrimination when they access public health facilities:

“We have to go to the clinic now, eish, they are going to judge me – no, I’m not gonna go” (GT)

“People don’t want to go get their ARVs because people are afraid that ‘if I get my ARVs and I’m gay, it’s just gonna be like: you are promiscuous, you deserve it’” (GT)

A recurrent theme among both LGBT service users and NGO representatives was the avoidance of health care services. The fear of experiencing discrimination, homophobia, or secondary victimisation, combined with an acknowledgement that public facilities often could not provide care for LGBT-specific health concerns constituted significant barriers to accessing care. Subsequently, LGBT people either avoided seeking care at public facilities, or consciously concealed their sexual orientation or gender identity in order not to experience homo- and transphobia. People who had the financial means would seek services in the private sector for as long as they could afford it.

Lack of accountability mechanisms

Given the amount of health rights violations that LGBT people experience in accessing the public health system, I also investigated whether LGBT service users knew of, and had used, existing accountability mechanisms within the health system. The majority of respondents did not know about the patients’ rights charter, or were aware of what the procedures for laying a complaint against a health care worker were:

“In public clinics, you get what you get and you get out. That’s how we are used to it, so I haven’t complained about somebody; but I didn’t even know the procedure to doing so. You know, so I haven’t, and if I was given a chance to, I think I would like to put my word across...” (GT)

Of the few that did, none had actually filed a complaint. While these service users did recognise that the treatment they received was in violation of their right to health, two reasons emerged that stopped them from reporting the discriminatory incidents. A recurrent opinion was that the facility manager would not understand laying a complaint about homophobic treatment. In other words, LGBT service users did not trust that the complaint system would provide a satisfactory outcome because the system itself was homophobic. A second reason was the fear of receiving negative treatment at subsequent clinic visits. This is an important consideration, especially in semi-urban and rural spaces with less health infrastructure, where service users cannot choose not to attend a certain facility, or not to see a certain health care worker.

DISCUSSION

All LGBT health service users that were interviewed had experienced some form of discrimination based on their sexual orientation or gender identity. The interviews with representatives of LGBT non-governmental organisations confirmed this view. The findings from this on-going research confirm what has been reported in previous studies. Lane et al. (2008) documented that all gay men in their study who visited clinics in the Soweto area experienced name-calling, ridiculing or other forms of discrimination. Similarly, 60% of transgender respondents in a study by Stevens (2012) had negative experiences in public clinics. The non-governmental organisation OUT reports that 12% of gay men and lesbian women in Gauteng and 13% in KwaZulu-Natal delayed seeking treatment at clinics because of fear of discrimination, while 6% of participants in Gauteng and 5% in KwaZulu-Natal had been refused treatment because of their sexual orientation (Wells & Polders 2006). On the basis of these quantitative findings, the on-going study presented here offers important insights into the actual experiences of LGBT service users in public health facilities.

The findings on availability of health services are in accordance with studies of access to health care among the general population of South Africa (Coovadia et al. 2009). The challenges of a general lack of services, long waiting times, and under-resourced facilities reflect the inequalities in South Africa's health system, which struggles with a quadruple burden of disease and a serious lack of medical personnel (Coovadia et al. 2009). LGBT people, like all South Africans who rely on public health facilities are negatively affected by these developments. However, LGBT people face homo- and transphobic discrimination on top of the general challenges to accessing health care. To my knowledge, this is the first study to investigate LGBT people's experiences in a health system as unequal and under-resourced as the South African one. Research from Europe and the United States confirms that LGBT people face discrimination in the health system based on their sexual orientation and gender identity (Mayer 2008), but all of these have been conducted in contexts with relatively well-resourced and functional health systems. In the case of the United States, which has arguably one of the world's most unequal health systems, the US Institute of Medicine (2011) did not report on factors other than sexual orientation or gender identity that would impact on access to health care, even though these surely exist.

With the exception of three facilities providing care for gay men, and men who have sex with men, there exist no specialised health facilities for LGBT people in South Africa. Current health sciences curriculum do not teach health professions students about LGBT specific health needs (for example, sexual health or mental health needs, see Müller 2013), and the experiences of LGBT health service users in this study affirm that health professionals do not possess the knowledge and skills to provide adequate care for sexual and gender minorities. Using the framework of the UN General Comment 14 requirements for realising the highest attainable standard of health provides concrete areas for action in order to improve LGBT people's right to health and access to health care. In accordance with section 9 of the South African constitution (1996), the Covenant prohibits any discrimination in access to health care on the grounds of, among others, sexual orientation (ICESCR 2000). Interpreting the findings of the study in the covenant's framework can contribute to a more thorough understanding of the realities in which such a non-discrimination clause would need to be interpreted and reinforced. These realities point to two crucial areas where intervention is needed in order to improve access to health care

for sexual and gender minorities, and, in turn, realise the right to health for LGBT people: the inclusion of sexual orientation and gender identity in health professions education, as well as in the design and execution of accountability mechanisms.

In order to reduce homophobia among medical professionals, two important target groups emerge: current health professionals, as well as health professions students. Health professionals need to be reminded of the relevant professional codes of conduct, and it needs to be highlighted that discrimination based on sexual orientation and gender identity is as unprofessional as discrimination based on, for example, race. In addition, sensitisation workshops by non governmental organisations as well as LGBT health-specific professional development courses can help to increase the capacity for well-informed and competent care for LGBT people in the current public health system (Makadon 2006). For students, a pedagogical approach that combines a critical interrogation of students' attitudes towards homosexuality with concrete information about LGBT people's health concerns seems the most promising (Lock 1998). However, current health professions education in South Africa usually does not include teaching about sexual and gender minorities or their specific health needs. A recent review at the health sciences faculty of the University of Cape Town highlights that important educational areas that would empower students to provide competent and non-judgmental care to LGBT people are not covered in the current health sciences curricula (Müller 2013). Creating opportunities for health professions students to engage with their own attitudes towards homosexuality can provide the space to challenge these societal assumptions. Kelley et al. (2008) showed that students who received teaching on sexuality and LGBT health felt better equipped and more comfortable treating patients who identified as LGBT, and increasingly understood the clinical relevance of sexual orientation and gender identity. In light of South African society's generally disapproving view of homosexuality², the education of professional, non-judgmental, and competent health care workers seems to be a crucial step towards eradicating homo- and transphobic discrimination in the health system, and would be a requisite to delivering adequate public health services to sexual and gender minorities.

The accounts of lesbian women accessing HIV services highlight a crucial misinformation of nurses and HIV counsellors: the belief that women who have sex with women (WSW) are not at risk for HIV. A recent study from Southern Africa has shown a HIV prevalence rate of 10% among WSW (Sandfort et al. 2013), and gender non-conforming women have a higher risk of experiencing sexual violence, which, in turn, increases the risk of HIV infection (Rothman et al. 2011). Despite these facts, Southern African lesbian women interviewed by Matebeni et al. (2013) had been discouraged to test for HIV due to their perceived lack of risk. Health professions education needs to include information about the health risks of LGBT people, in order to reduce these barriers that arise out of health care workers' ignorance.

It is important to note that all informants for this study lived in urban or peri-urban areas. While the experiences that interviewees recounted suggest that LGBT people's health rights are significantly impacted by homo- and transphobia in these urban and peri-urban facilities, it is likely that the situation in rural areas is even worse. Access to health care in general is much more challenging in rural areas, as public health facilities are at greater distances, and in more desolate state than in urban areas. Furthermore, LGBT people in urban areas have some sort of support

network in the form of non-governmental organisations or informal communities, both of which are almost non-existent in rural areas. An important area for future research is to investigate the experiences and health barriers of LGBT people who live outside of the better-resourced urban centres.

The results from this study suggest that current complaint and accountability systems fail LGBT health service users. The vast majority of interviewees did not know of current ways to lodge complaints, and even those who did were afraid of encountering further homo- and transphobia in the complaint system. In order to improve accountability mechanisms, two important strategies stand out. First, people who facilitate complaint structures need to be aware of the health needs of LGBT people. The same strategies that can reduce homophobia among health care workers (Lock 1996) can be employed to sensitise administrative health personnel in public facilities. Furthermore, the existing accountability mechanisms need to be strengthened, not only to accommodate complaints from LGBT health service users, but in order to provide better accountability to all health service users. With the introduction of the National Health Insurance policy in South Africa, a number of improvements are foreseen to improve accountability in the public health system. The National Department of Health is to establish a central Office of Standards Compliance, which is meant to act as a central overseeing body to address complaints and grievances by health service users (SA Department of Health 2011b). Furthermore, the Department of Health is currently piloting a cell-phone based, facility-independent system of reporting patient satisfaction across a number of pilot districts. This system should be expanded to account for the specific needs and potential grievances of LGBT health service users.

This study is subject to a number of important limitations. For one, the presented findings are part of an on-going examination of LGBT health service users' experiences. In the course of this project, the emphasis was on eliciting narrative experiences from a range of service users who identify as lesbian, gay, bisexual or transgender. As such, it does not seek to portray a universal truth about LGBT experiences, but rather highlight specific cases that illustrate shortcomings in the current public health system. A second phase of the project will hopefully allow quantifying the identified health rights violations, and providing possibilities of intervening at problematic health facilities. The interviews for this study were conducted in the Western Cape and Gauteng, the two wealthiest provinces that have the best health infrastructure in South Africa. I decided to interview in these two provinces because they provide at least some support network for LGBT people. I was very aware of the fact that the interviews, by their nature, might resurface traumatic events, and therefore chose to conduct them in areas where my interviewees had access to LGBT-friendly support services. What is missing in this study is an examination of the experiences of LGBT people in less resourced provinces and rural areas, where the challenges to access health care might be multiplied and consist of different foci.

In summary, this on-going study highlights that LGBT people face numerous challenges when accessing public health care in South Africa. While some of these challenges can be attributed to the general lack of resources in the South African public health system, persisting homo- and transphobia among health care workers and administrative staff lead to systematic discrimination against people of non-normative sexual orientations and/ or gender identities. As a result, LGBT people

who already face health disparities based on their sexual orientation and gender identity lack access to culturally competent health services. While some emergent policies recognise the specific health needs of LGBT people, the public health system in general needs to improve vastly in order to provide adequate services to this particularly vulnerable group.

REFERENCES

Action Aid. 2009. *Hate Crimes: The Rise of 'Corrective Rape' in South Africa*. London: Action Aid.

Bostwick WB, Boyd CJ, Hughes TL, McCabe SE. 2010. Dimensions of sexual orientation and the prevalence of mood and anxiety disorders in the United States. *Am J Public Health*, 100(3): 468-475.

Brotman S, Ryan B, Jalbert Y, Rowe B. 2002. The impact of coming out on health and health care access: The experiences of gay, lesbian, bisexual and two-spirited people. *Journal of Health & Social Policy*, 15(1): 1-29.

Constitution of the Republic of South Africa (1996). Johannesburg: Constitutional Court. Available online at

Coovadia H, Jewkes R, Barron P, Sanders D, McIntyre D. 2009. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet*, 374(9692): 817-834, doi:10.1016/S0140-6736(09)60951-X

Eprecht M. 2008. *Heterosexual Africa? The History of an Idea from the Age of Exploration to the Age of AIDS*. Athens: Ohio University Press.

Gaventa J & Cornwall A. 2001. Power and Knowledge. In: Reason P & Bradbury H (eds.) *Handbook of Action Research: Participative Inquiry and Practice* (pp. 70-80). London: Sage Publications.

Gay and Lesbian Medical Association and LGBT Health Experts. 2001. *Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health*. San Francisco, CA: Gay and Lesbian Medical Association. Available at: [http://www.glma.org/_data/n_0001/resources/live/Healthy CompanionDoc3.pdf](http://www.glma.org/_data/n_0001/resources/live/Healthy%20CompanionDoc3.pdf). (Accessed June 29, 2011).

International Covenant on Economic, Social and Cultural Rights (ICESCR). 2000. *The right to the highest attainable standard of health: General Comment No 14*. Geneva: United Nations.

IOM (Institute of Medicine). 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Washington, DC: The National Academies Press.

Jewkes R, Levin J, Penn-Kekana L. 2002. Risk factors for domestic violence: findings from a South African cross-sectional study. *Social Science and Medicine*, 55(9): 1603-1617

Kelley L, Chou CL, Dibble SL, Robertson PA. 2008. A critical intervention in lesbian, gay, bisexual, and transgender health: knowledge and attitude outcomes among second-year medical students. *Teach Learn Med*, 20(3): 248-53

King M, Nazareth I. 2006. The health of people classified as lesbian, gay and bisexual attending family practitioners in London: a controlled study. *BMC Public Health*, 6:127.

Kulkin HS, Williams J, Borne HF, de la Bretonne D, Laurendine J. 2007. A review of research on violence in same-gender couples: a resource for clinicians. *J Homosex*, 53(4):71-87.

Lane T, Mogale T, Struthers H, McIntyre J, Kegeles SM. 2008. "They see you as a different thing": the experiences of men who have sex with men with healthcare workers in South African township communities. *Sex Transm Infect*, 84:430–433. doi:10.1136/sti.2008.031567

Lane T, Raymond HF, Dladla S, Rasethu J, Struthers H, McFarland W, McIntyre J. 2011. High HIV prevalence among men who have sex with men in Soweto, South Africa: Results from the Soweto Men's Study. *AIDS Behav*, 15: 626-634

Lock J. 1998. Strategies for Reducing Homophobia During Medical Training. *Journal of the Gay and Lesbian Medical Association*, 2(4): 167-174

Makadon H. 2006. Improving health care for the lesbian and gay communities. *NEJM* 354(9): 895-897.

Marrazzo JM, Thomas KK, Fiedler TL, Ringwood K, Fredricks DN. 2010. Risks for acquisition of bacterial vaginosis among women who report sex with women: a cohort study. *PLoS One*, 5(6):e11139.

Matebeni Z, Reddy V, Sandfort T, Southey-Swartz I. 2013. "I thought we were safe": Southern African lesbians' experiences of living with HIV. *Culture, Health & Sexuality: An International Journal for Research, Intervention and Care*, DOI:10.1080/13691058.2013.764016

Mayer KH, Bradford JB, Makadon HJ, Stall R, Goldhammer H, Landers S. 2008. Sexual and Gender Minority Health: What We Know and What Needs to Be Done. *Am J Public Health*, 98: 989–995. doi:10.2105/AJPH.2007.127811

Müller A. 2013. Teaching Lesbian, Gay, Bisexual and Transgender Health at a South African health sciences faculty: Addressing the gap. *BMC Medical Education* 13: 174.

Müller A & MacGregor H. 2013. Sexual and Reproductive Health Rights of women living with HIV in South Africa. Evidence Report 3, Brighton: Institute for Development Studies. Available online at: <http://www.ids.ac.uk/publication/sexual-and-reproductive-health-rights-of-women-living-with-hiv-in-south-africa> (accessed 27 Feb 2014)

National Health Assembly. 2021. *Statement and Call to Action of the First National Health Assembly (NHA) of South Africa. Cape Town 5 - 6 July 2012*. Available online at <http://www.phmsouthafrica.org> (accessed 26 July 2012)

Patton C. 2002. *Globalizing AIDS*. Minneapolis: University of Minnesota Press.

Rothman E F, Exner D and Baughman AL. 2011. The Prevalence of Sexual Assault Against People Who Identify as Gay, Lesbian or Bisexual in the United States: A Systematic Review. *Trauma, Violence & Abuse* 12 (2): 55–66.

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): e53552. doi:10.1371/journal.pone.0053552

SA Health Professions Act. 1974. Ethical Rules of Conduct for Practitioners Registered under the Health Professions Act, 1974. Pretoria: Department of Health. Available online at

SA National Department of Health. 2011a. *National Strategic Plan on HIV, STIs and TB, 2012 - 2016*. Pretoria: Department of Health; 2011. Available at <http://www.doh.gov.za/docs/stratdocs/2012/NSPfull.pdf> (accessed 04 November 2012)

SA National Department of Health. 2011b. *The Green Paper on National Health Insurance*. Pretoria: Department of Health.

SA National, Department of Health. 2012. *Human Resources for Health, South Africa: HRH Strategy for the Health Sector: 2012/13 – 2016/17*. Pretoria: Department of Health. Available online: www.gov.za/documents/download.php?f=152486 (accessed 20 Nov 2013)

Statistics South Africa. 2011. *Use of health facilities and levels of selected health conditions in South Africa: Findings from the General Household Survey 2011*. Pretoria: Statistics South Africa.

Stevens M. 2012) *Transgender people's access to sexual health services in South Africa: findings from a key informant survey*. Cape Town: Gender Dynamix.

Wells H & Polders L. 2006. *Gay and Lesbian People's Experience of the Health Care Sector in Gauteng*. Research Initiative of the Joint Working Group conducted by OUT LGBT Well-Being in collaboration with the UNISA Centre for Applied Psychology. Pretoria: UNISA.

Wilton T: *Sexualities in health and social care: a textbook*. University of California: Open University Press; 2000

¹ I acknowledge that sexual orientation and gender identity are fluid, and encompass more than the LGBT acronym. For example, a growing group of people have reappropriated the word 'queer' to identify their sexual orientation and/or gender identity. However, the majority of the current research evidence that I cite only focuses on LGBT identities, and I have therefore chosen to adhere to this terminology.

² While the term 'rape' is usually used, I have deliberately chosen to use the term 'non-consensual sex' to highlight that it encompasses much more than the dominant conception of rape as heterosexual non-consensual sex (what is commonly understood by the term). Non-consensual sex includes sexual assault of men by men or any, of transgender people by people of any other gender, and of women by women.

³ According to a global study on societal acceptance of homosexuality, published by the Pew Research Center in June 2013. Available online at <http://www.pewglobal.org/files/2013/06/Pew-Global-Attitudes-Homosexuality-Report-FINAL-JUNE-4-2013.pdf> (accessed 19 Nov 2013).

⁴ See http://www.hpcsa.co.za/conduct_generic_ethical_rules.php (accessed 07 Feb 2014).

⁵ These numbers are available on the website of the National Department of Health (www.doh.gov.za/show.php?id=1635).

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