

6. Experiences of stigma and discrimination in healthcare

6.1 Introduction

This chapter analyses experiences of stigma and discrimination in healthcare of four groups of persons understood as either *key populations* or persons who are *vulnerable* to HIV and/or discrimination.³⁴² The outcomes of fourteen structured focus-group discussions held in Botswana, Malawi, and Zambia are reflected below in an effort to understand these experiences and to give context to the need for accountability and redress for discriminatory conduct. Discussions were held separately with persons who self-identified as sex workers, women living with HIV, LGBT persons, and persons with disabilities.

Focus-group discussions were conducted through facilitators asking open-ended questions. Participants were asked to describe experiences of stigma or discrimination in healthcare and their experiences, if any, of laying complaints or seeking redress. Certain examples of discriminatory conduct in healthcare were raised by facilitators to engage participants to discuss whether they had experiences of these types of conduct.

The analysis below is largely reflective of the participants' own words and experiences, as translated where necessary. Where possible, effort has been made to categorise the various types of discriminatory behaviour raised by the participants.

The experiences of sex workers, women living with HIV, LGBT persons, and persons living with disabilities, are described in turn including their experiences, if any, of accessing complaints processes. In addition, poverty and location in rural areas, as grounds of discrimination, are briefly discussed to highlight strong perceptions of systemic discrimination in healthcare against persons who are economically disempowered and living outside urban centres. Lastly, the chapter describes the perceptions of respondents from complaints mechanisms, CBOs and NGOs of behaviours perceived as discriminatory.

³⁴² See the definitions of “key populations” and “vulnerable populations”, notes 2 and 3 above.

6.2 Sex workers

“We are intimidated especially by the police when they are in uniform. [It is the] same as the nurses. Often because of the long queue they do not usually pay attention to you and will quickly attend to you without understanding your concerns. This is why people opt to get over the counter medicine and now they are even buying [ART] without going to the clinic. Also nurses are very rude.” (Sex worker respondent – Lusaka)

Introduction

Sex workers in southern Africa are marginalised, face human rights violations, discrimination, harassment, and numerous other barriers to accessing healthcare.³⁴³ The perpetuation of indirect criminalisation³⁴⁴ of sex work not only exposes sex workers to abuse but adds to barriers in accessing healthcare in its own right.

Focus groups

Focus groups were held in Botswana, Malawi and Zambia with persons who self-identified as sex workers.

In Botswana, HIV prevalence amongst sex workers is high at an estimated average of 61.9%.³⁴⁵ While government has initiated programmes to enhance sexual and reproductive health services and access to HIV treatment and testing for sex workers, there remains a significant treatment gap, particularly among migrant/non-citizen sex workers.³⁴⁶ In Botswana, a focus group with sixteen participants who self-identified as sex workers was held in Selebi Phikwe, a mining town located in Botswana’s Central District. Although official estimates are inaccessible, Selebi Phikwe has reportedly high numbers of commercial sex workers,³⁴⁷ particularly non-citizen sex workers, for whom access to healthcare services is additionally constrained.³⁴⁸ Selebi Phikwe has the highest HIV prevalence in Botswana at 27.5%.³⁴⁹

³⁴³ F Scorgie et al. “‘I Expect to Be Abused and I Have Dear’: Sex Workers’ Experiences of Human Rights Violations and Barriers to Accessing Healthcare in Four African Countries” (2011) *African Sex Worker Alliance*, available at: http://www.plri.org/sites/plri.org/files/ASWA_Report_HR_Violations_and_Healthcare_Barriers_14_April_2011.pdf.

³⁴⁴ In Zambia, sections 144-149 of the Penal Code indirectly deal with offences relating to sex work, including crimes of living off the earnings of prostitution, soliciting for immoral purposes, and operating facilities for immoral purposes. Sex workers are frequently targeted through the use of loitering laws (M Mwendela et al. “Legal, Policy, and Socio-Cultural Barriers to HIV-Related Prevention, Treatment, Care and Support for Key Populations in Zambia” *National Alliance of State and Territorial AIDS Directors* (2015), available at: https://www.nastad.org/sites/default/files/Zambia_Law_Review.pdf).

³⁴⁵ Republic of Botswana *Botswana 2013 Global AIDS Response Report: Progress Report on the National Response to the 2011 Declaration of Commitments on HIV and AIDS* (2013), available at: <http://www.unaids.org/sites/default/files/country/documents/file94425.es..pdf>, 19.

³⁴⁶ Republic of Botswana: Ministry of Health *2012 Mapping, Size Estimation and Behavioral and Biological Surveillance of HIV/STI Among Select High-Risk Sub-Populations in Botswana* (2013), available at: <http://www.fhi360.org/sites/default/files/media/documents/BSS%202012%20Final.pdf>, 29 at para 3.2.1.1.

³⁴⁷ See, for example, M Duve “Phikwe Suffocating under Volcanic Sex Trade” *Mmegi Online* (20 November 2008), available at: <http://www.mmegi.bw/index.php?sid=1&aid=9&dir=2008/November/Thursday20/>.

³⁴⁸ A Raw “Legal Barriers to Healthcare for Zimbabwean Sex Workers in Botswana” (2015) 6 *BUWA! A Journal on Women’s Experiences* 80. See, also, Botswana 2013 Global AIDS Response Report: Progress Report on the National Response to the 2011 Declaration of Commitments on HIV and AIDS, note 303 above, 29 at para 3.2.1.1.

³⁴⁹ Botswana 2013 Global AIDS Response Report: Progress Report on the National Response to the 2011 Declaration of

In Malawi, most stakeholders (including sex workers) report an intolerant attitude of healthcare workers towards sex workers and difficulties accessing care from service providers.³⁵⁰ Two focus group discussions were held with fifteen women who self-identified as sex workers in Mwanza (a border town near Mozambique in Malawi's Southern District) and with twenty participants in Blantyre (Malawi's commercial capital and second-largest city, located in the Southern District). Instances of abuse against sex workers by healthcare workers and government officials have been reported in Mwanza, including coercive HIV testing of women presumed to be sex workers, which was the subject of a 2015 High Court decision.³⁵¹ In Blantyre, commercial sex workers face significant police abuse without access to redress, including the arbitrary enforcement of vagrancy laws to arrest and detain sex workers.³⁵²

In Zambia, while there has not been any systemic monitoring of HIV prevalence amongst sex workers, estimates indicate a high prevalence at around 65-69%.³⁵³ Sex work in Zambia appears to be concentrated in Lusaka, tourist locations, major highways, and in border and trading towns.³⁵⁴ A focus group was held in Lusaka with 21 participants who self-identified as sex workers.

An example of discrimination against sex workers in Malawi: *S v Mwanza Police, Mwanza District Hospital*

The Facts

In 2009, eleven women suspected of being sex workers were arbitrarily arrested in Mwanza, Malawi, during sweeping exercises conducted by the police. The women were detained overnight at the Mwanza Police Station and taken to Mwanza District Hospital the following day. At the hospital, the women were subjected to blood tests without their informed consent. The medical officers noted the women's names and test results on pieces of paper and handed these over to the police. Thereafter, the women were taken to the Magistrate's Court where some were charged with spreading venereal diseases, in contravention of section 192 of the Penal Code. In the courtroom, the particulars of the offence were read out loud including that the women were HIV-positive. This was the first time some of the women became aware of their HIV status. Notably, all these actions took place without the women having committed any offence and without there being any evidence of wrongdoing apart from a presumption that they were sex workers.

Commitments on HIV and AIDS, notes 303, 15 above.

³⁵⁰ J Anderson note 262 above, 45.

³⁵¹ See, A Meerkotter and I Southey-Swartz "Malawi High Court Rules that Mandatory HIV Testing is Unconstitutional" *Southern Africa Litigation Centre*: Blog (20 May 2015), available at: <http://www.southernafricalitigationcentre.org/2015/05/20/malawi-high-court-rules-that-mandatory-hiv-testing-is-unconstitutional/>.

³⁵² "No Justice for the Poor: A Preliminary Study of the Law and Practice Relating to Arrests for Nuisance-Related Offences in Blantyre, Malawi" *Southern Africa Litigation Centre* (2013), available at: http://www.southernafricalitigationcentre.org/1/wp-content/uploads/2013/07/09_SALC-NoJustice-Report_Use-of-Vagrancy-Laws-Against-Sex-Workers.pdf, 86-100. See, also, indications of the prevalence of sex work in Blantyre, in: R Mthenga Chizimba & G Tikambenzi "Counting the Uncatchables: Report of the Situation Analysis of the Magnitude, Behavioural Patterns, Contributing Factors, Current Interventions and Impact of Sex Work in HIV Prevention" *Family Planning Association of Malawi* (2011), 40.

³⁵³ Republic of Zambia and National AIDS Council *Zambia Country Report: Monitoring the Declaration of Commitment on HIV and AIDS and the Universal Access Biennial Report* (2014), available at: http://www.unaids.org/sites/default/files/country/documents/ZMB_narrative_report_2014.pdf, 16.

³⁵⁴ As above, 29.

The women subsequently filed an application in the Blantyre High Court challenging their subjection to mandatory HIV tests, the admission of the HIV test results as evidence in criminal cases against them, and the public disclosure of their HIV status in open court. The Blantyre High Court delivered judgment in favour of the women in May 2015. The Court held that the mandatory HIV tests violated the women's constitutional rights to privacy, dignity, non-discrimination, and freedom from degrading treatment.

The case highlights the systemic discrimination faced by sex workers, where the police and healthcare facility jointly acted in a manner that showed poor regard for the women's rights. The case shows that it is possible for vulnerable populations to hold the government accountable when their rights have been violated but it also illustrates the lengthy process of litigation and the need for less formal and accessible complaints mechanisms.

Experiences of stigma and discrimination in healthcare

In all four focus groups, clear examples of healthcare workers **refusing to treat healthcare users** were described, including examples of outright refusal to treat (sending the healthcare user away) and refusal to provide particular types of treatment, such as contraceptive care:

"I was refused to be given [ART] at Queens when I went there to get more drugs when I had only a few pills left. The nurse there told me that they will not assist me because I sleep with their husbands." (Sex worker respondent - Blantyre, Malawi)

"I had gone to Mzuzu for business, whilst there I ran out of my [ART]. I went to Mzuzu Hospital and met one doctor who also happened to be my client. Since he knew who I was, he refused to give me the drugs." (Sex worker respondent - Blantyre, Malawi)

In Zambia, several examples were described by sex worker respondents of refusing sex worker healthcare users access to PEP.³⁵⁵ The respondents stated that nurses explained this was to discourage reckless behaviour and that the treatment was only offered to "rape patients", behaviour which the respondents described as "unfair":

"I had sex [with a client] and the condom broke. And in the morning I went to the clinic, [because] I knew about PEP because a few years ago I was raped by a taxi driver ... and when I went to the clinic, they put me on meds to protect me from getting sick. So when I went this time around, I had hoped I would be assisted with the same treatment. Yet the nurse said that was only for rape cases: 'we don't give it to people like you because you decided to put yourself in that situation and all.' ... She said they don't encourage people to know about PEP because they can become careless." (Sex worker respondent - Lusaka, Zambia)

Sex worker respondents in Lusaka related difficulties accessing PEP even following rape, largely as a consequence of the perceived criminalisation of their work and police abuse:

³⁵⁵ See note 194 above for an explanation of PEP.

“For me it’s the police. When you are moving, let’s say at night to another club, the police will catch you and tell you, ‘if you don’t want to be arrested give us some sex’ and they threaten you and so you agree, which I think is rape. But when you go to the clinic, the people there ask you to go back to the same police to get the report from them [to prove you have been raped]. So you are scared to go back to the police and so you end up not getting any treatment.” (Sex worker respondent – Lusaka, Zambia)

“I had a client. ... We negotiated everything but the condom broke. I asked him for my money but he even slapped me ... and he said he would finish me. When I went to the clinic to get some sort of protection for being exposed, they asked me what happened. They said they could only attend to me if I came back with a police report. They could not attend to me without it. That’s how I ended up at the police station. The police also were cruel. They asked me to mention the person I was with. When I told them (because the guy is a government official) they were scared and were like, ‘manje wenze kuchita chani na abo bamuna, ndiwe hule ka.’ [Facilitator’s translation: ‘What were you doing with that man? You must be a prostitute.’] That is how they threw me in cells. But I called a lawyer friend the following day who came and spoke to them. They called the man who I gave that service to and he agreed to pay me even more to go to a private clinic. The people at those government clinics are really mean and they don’t care about treating you even when the issue could be an emergency. I don’t have any trust for government clinics or even the police.” (Sex worker respondent – Lusaka, Zambia)³⁵⁶

In Botswana and Malawi, sex workers described instances where they had been denied access to healthcare in the absence of being accompanied by a male sexual partner:

“One respondent in Mwanza narrated her ordeal that took place in 2009 when she contracted [a sexually transmitted infection]. She was told to bring a man whom she had slept with when she sought help at Mwanza District Hospital. Knowing that there was no way she could get hold of the man, she revealed that she was a [sex worker]. In spite of her explanation, she was still asked to bring the man, failing which she could not access the healthcare services. After all attempts had failed, she finally decided to pay for healthcare services at a private clinic.” (Facilitator – Mwanza, Malawi)

In both Botswana and Malawi (in Mwanza), sex worker respondents gave examples of their children being denied treatment, either due to the mother’s status as a sex worker or as a result of the mobile lifestyles inherent to their mother’s work. In Selebi Phikwe, for example, respondents noted that if their children had been registered elsewhere, they could not access healthcare when travelling in a different district.

³⁵⁶ As explained in Chapter 5, PEP is recommended under Zambia’s 2013 Consolidated Guidelines for Treatment Prevention of HIV Infection, following a determination of the need for PEP based on the risk of transmission and the risks and benefits of taking or not undertaking the intervention. There is no explicit limitation of its application in the case of rape or that healthcare users are required to prove rape in order to access the treatment.

In some cases, refusal of treatment is described as being coupled with **sexual coercion**:

“Yes, I went to the hospital because I had stomach pains and I was told by a doctor that he will not assist me because I had the previous day refused to sleep with him.” (Sex worker respondent – Blantyre)

Multiple, disturbing examples of **sexual abuse** were described by sex worker respondents in Blantyre, Malawi and Lusaka, Zambia. No examples were offered by sex workers in Botswana, however, no explicit questions were asked relating to sexual abuse by healthcare workers.

“At one point I had gone to a clinic to terminate a pregnancy. The doctor asked me to sleep with him before he did the procedure. He paid me money and had unprotected sex with me in the examination room and proceeded to do the procedure after.” (Sex worker respondent – Blantyre, Malawi)

“I was also sexually abused by a doctor. He told me that the hospital had run out of [ART] but that he knew where he would get them for me only if I could sleep with him. I had unprotected sex with him in the examination room and he only gave me three pills.” (Sex worker respondent – Blantyre, Malawi)

“At one point I went to the hospital with a friend who had a similar problem to mine. When she went into the examination room, she was told to pull her dress half up for examination. But when I went in for examination, I was told to take off all my clothes and be naked. There were three doctors in the examination room and all three were just touching me. I did not understand why they treated me differently from my friend who had gone in earlier with a similar problem. They were just taking advantage of me.” (Sex worker respondent – Blantyre, Malawi)

In all three countries, sex worker respondents related being **ignored by healthcare workers**, which they understood to be on the basis of their status as sex workers. In Botswana, sex worker respondents stated they were ignored for long periods of time – especially if they were HIV-positive and particularly when presenting repeatedly for treatment of sexually transmitted infections.

“A friend of mine, who is also a sex worker, was involved in a car accident, the doctors did not attend to her in time because they were notified that she is a sex worker. They kept ignoring her the whole night until she died.” (Sex worker respondent – Blantyre, Malawi)

Sex worker respondents described instances in all three countries of healthcare workers **not examining them before prescribing or administering medication**:

“Sometimes when the doctors know that you are sex worker, they will just write down a prescription without taking time to examine you. When you go back to the hospital after some days of taking the medication and noticing that there are no changes, the doctors will still not examine us. Sometimes when we ask to be examined when it’s a sexually transmitted disease, they will say sarcastically that we love taking off our clothes.” (Sex worker respondent – Blantyre, Malawi)

The **refusal of healthcare workers to communicate** with healthcare users or to undertake proper informed consent procedures was described in all three countries and met with strong concurrence amongst participants. In Botswana, sex worker respondents bemoaned in particular the commencement of invasive examinations without explanation or forewarning. This included, for example, the insertion of a speculum or the use of a spatula for internal examinations without forewarning or explanation when testing for sexually transmitted infections.

“Another thing is that doctors and nurses don’t tell you anything. ... So you go in there and they scribble on your file, ask you to go to the lab and come back, they scribble more things and then tell you to go collect your medicines. They never interact with you or keep you in the loop for you to know what is going on. Even when, as me, I am a very inquisitive person and I will ask these questions. But the reaction you get, it’s like they are shocked that you are interested to know what is going on with your health. ... I think this is wrong. The patient ... deserves to know what is wrong with them.”
(Sex worker respondent – Lusaka, Zambia)

Sex worker respondents in all three countries most frequently related dissatisfaction with healthcare workers’ use of **harsh or abusive language** as discriminatory conduct. In Botswana, respondents strongly shared the perception that female healthcare workers were less courteous and helpful than their male counterparts. Some respondents acknowledged that when receiving care from doctors who were foreign nationals and who did not speak Setswana, they may wrongly assume the doctors are speaking poorly of them.

Sex worker respondents in all four focus groups referred to healthcare workers **blaming the healthcare users** for their health conditions due to their status as sex workers:

“[Nurses say], ‘Selo ke wena...hane o itshireletsa, o kabo o sa tsenwe ke malwetse a dikobo!’ – meaning, ‘You thing, had you protected yourself through condom use, you would not have contracted a sexually transmitted infection (STI) again!’” (Sex worker respondent – Selebi Phikwe, Botswana)

“I have experienced discrimination by a nurse. I was assaulted at a drinking place and I went to Queen Elizabeth Hospital for treatment. The nurse there told me that since my case occurred at a drinking place and I looked to be a sex worker, I had brought that upon myself and that the hospital only assists serious cases, not mine. I was told to go to a private hospital.” (Sex worker respondent – Blantyre, Malawi)

Respondents in Botswana related examples of healthcare workers’ sense of disgust towards them as healthcare users. Sex worker respondents stated that doctors seldom make eye contact with them and nurses turn on the fans in examination rooms during the winter, inferring the healthcare users smell bad.

Experiences of **confidentiality breaches** were common amongst sex worker respondents:

“For us to access [ART] we usually go to a hospital which is out of Blantyre, because we know that if we go to Queens in Blantyre or any clinic in Blantyre,

the medical personnel, who in most cases are our clients, will spread the news to our other potential clients that we are on [ART] and then we lose out on business. In order to avoid that, we go to the clinics outside Blantyre. The problem comes when we have run out of the drugs and we need the drugs urgently and we have no money to travel to the district where we get our [ART]. When we go to the hospital, like Queens, they will refuse to give us the drugs; they will insist we get a transfer from the district. This leaves us without medication for days.” (Sex worker respondent – Blantyre, Malawi)

“[T]he health workers will call out in the public waiting area, that all those that have this and that STI, stand in a particular line. This becomes so embarrassing for everyone to know that you have come with an STI problem.” (Sex worker respondent – Blantyre, Malawi)

“Sometimes when you go into the examination room with an STI, the health workers will start calling each other in the examination room while you are on the examination table, for them just to see how the disease has affected your private parts. A number of health workers will just be walking in and out which can be very embarrassing.” (Sex worker respondent – Blantyre, Malawi)

Sex worker respondents did not offer many examples of **segregation of healthcare users** or the use of **identifying practices** as instances of discrimination. When direct questions were imposed, some examples were described in all three countries. In Botswana, sex workers noted the requirement that persons with tuberculosis receive their medication outdoors, which was perceived as discriminatory. Further examples related to the use of different-coloured hospital cards for healthcare users on ART and patterns of patient-processing that respondents were concerned disclosed their HIV-status inadvertently:

“As HIV-positive members of society on [ART], our hospital cards are a different colour from ‘normal’ cards that are pink for females and blue for males. Our cards stand out and tell the world that we are on [ART].” (Sex worker respondent – Selebi Phikwe, Botswana)

“I went to Matero clinic, when you go from the VCT centre, so you are all sitting in one room and you go into the counselling room. If you are negative you were asked to go just after getting your result, but if you are positive they asked you to stay back to attend a second counselling. And it was so easy for all of us to tell who was positive or who was not and I thought the treatment wasn’t fair.” (Sex worker respondent – Lusaka, Zambia)

“Again in the ART clinics, like at Kalingalinga Clinic, when you sit at the bench for people awaiting to receive their [ART], everyone will know that you are sick. And it is in such a space that anyone who is going into the clinic sees you seated on that bench waiting to collect your meds.” (Sex worker respondent – Lusaka, Zambia)

“Also there is a tendency to put the medicines, that is the [ART] in a big

brown folder and if you walk out with that folder then everyone who sees you will know you are from collecting your [ART] and it's in this way that gossip and rumours begin in the community. Also you find even the registry is the same in these clinics, but for HIV it's different." (Sex worker respondent - Lusaka, Zambia)

An issue that came out strongly in Selebi Phikwe, Botswana and in Malawi as discriminatory, was the **failure to accommodate sex workers' needs** for ART in particular when their mobility or financial circumstances do not permit consistent consultations at the same points of care. In Selebi Phikwe, sex worker respondents stated that they were denied refills of their ART prescription if they were late for collection. They stated that if they were turned away, they were unlikely to return for care.

"The health workers do not understand our needs at all. We are always mobile, looking for clients in different districts. So when you are in a particular district and you explain to the health worker that you have run out of [ART], they still refuse to give you more drugs without a transfer letter. This makes us sometimes stay for days without taking medicine." (Sex worker respondent - Blantyre, Malawi)

Only in Blantyre did a respondent describe an example of being sent for **HIV testing or treatment without counselling**. In Botswana, sex worker respondents universally related positive experiences of receiving adequate counselling before HIV testing and treatment.

"Ba e tshwere gotlhe HIV counselling ba botsogo mo Botswana!" [Facilitator's translation: "When it comes to counselling, health human resources in Botswana hospitals have it all!"] (Sex worker respondent - Selebi Phikwe, Botswana)

Why are we discriminated against?

"Normally, we are discriminated against in health facilities because of our status. For instance, I myself was once denied treatment because of my status as a [female sex worker]. At the STI department, the situation is even worse. I remember one healthcare provider who used to play with our genitals and calling us prostitutes in the process." (Sex worker respondent - Mwanza, Malawi)

Sex worker respondents related a variety of reasons why they thought they experienced stigma and discrimination in healthcare settings. Some respondents sympathised with the stress experienced by healthcare workers stating that "they are also human", and acknowledged that nurses experience work and home-related stresses, work long hours and get overwhelmed.

Most frequently, respondents understood that they were perceived as carriers of disease, undeserving of care and reckless because of their status as sex workers:

"The health workers think that we deliberately look for diseases and as such we should not be treated like any other patient." (Sex worker respondent - Blantyre, Malawi)

Sex worker respondents in Botswana felt that the religious beliefs of some healthcare providers cause them to discriminate against sex workers and others like LGBT persons.

The role of perceived criminalisation of sex work was also seen as contributing to stigmatising attitudes:

“Illegality of sex work leads to discrimination, as healthcare providers cannot accept us as we are and treat us as a special group that demands specific interventions.” (Sex worker respondent – Selebi Phikwe, Botswana)

Other accounts included that healthcare workers were not held accountable and did not respect healthcare users generally, perceiving themselves as superior.

Access to accountability and redress

In Selebi Phikwe, Botswana and Blantyre, Malawi, none of the respondents related ever making a complaint following mistreatment or discrimination by healthcare workers or institutions. In Botswana, some respondents noted having seen suggestion boxes but none had ever used them.

On being asked why redress or accountability was not pursued, sex worker respondents variously related a lack of knowledge of where or how to complain, and a sense that their complaints would not be taken seriously, strengthened by related experiences of secondary victimisation and indifference when seeking to report violence or abuse to police:

“We do not know where to go to lay our complaints. Even if we report to the police, the police also abuse us a lot. A friend of mine was raped by four police officers who also took away money from her.” (Sex worker respondent – Blantyre, Malawi)

Examples of proactive complaint efforts given by sex worker respondents in Mwanza described experiences of secondary victimisation from the process. One respondent described discrimination she encountered when she sought antenatal services when she was pregnant. She was called names by healthcare workers because she was a sex worker. She was asked to get a letter from the chief, seemingly in order to access services. The chief similarly also used derogatory language towards her. The result was that the respondent was significantly delayed in terms of accessing antenatal services. When asked why she did not report the discriminatory behaviour, the respondent said she did not know to whom she could turn, as she was discriminated against by the chief himself.

In Lusaka, Zambia, sex worker respondents gave both successful and unsuccessful examples of direct confrontation with healthcare providers who discriminated against them. One respondent gave an example of escalating a complaint to more senior staff:

“[A sex worker friend] noticed that she was having problems with her anal area and had a serious infection in that area. She was admitted just there in Livingstone. The nurses refused to clean her up. It took me when I got there to clean her mess up and wash and change her linen. The nurses called her names and said she had brought it on herself because she is a ‘Hule’ [Facilitator’s translation: derogatory term for sex worker]. The nurses

were going there to change her drip and give her medicine, but for days they did not change or clean her and the dirt just accumulated. I confronted the nurses but they just shut me up saying if I thought I could do a better job. When it was better I took her away and took care of her on my own. I shouted at her. These nurses need to be taught what their job is.” (Sex worker respondent – Lusaka, Zambia)

“I have [complained] in a way. My first born, I had her when I was about 18. I was still young, and being the first pregnancy I didn’t know what to do. And I was going to Chainama for antenatal [care]. My labour started in the morning and I went to Chainama, but they sent me home. When I got home the pains became unbearable and I told my sister I am not going back to that place and so I went straight to [the University Teaching Hospital]. When I got there the nurses refused to attend to me saying I didn’t have a referral. I was in so much pain that I just started to scream and asked for a higher person to talk to. That’s how this doctor came and he directed the nurses to attend to me. Even though they were bitter, they made sure not to do any of those stupid things they do because they were afraid that I would report them.” (Sex worker respondent – Lusaka, Zambia)

A sex worker respondent in Mwanza, Malawi, related an example of complaining through the District Health Officer but was dissatisfied with the outcome of the complaint. In that case, a sex worker had been knocked over by a motorcycle at night. She fell unconscious and was rushed to Mwanza District Hospital by onlookers and a police officer. At the Hospital, a nurse on duty recognised her as sex worker. The nurse treated her with just two pain-killer tablets and discharged her. The sex worker was taken home where she bled until the morning when she was brought back to the Hospital where she died. Thereafter, sex workers took up the issue by informing the District Health Officer. The District Health Officer took up the issue with the nurse who was on duty. The nurse refused to write a statement on what happened and sought protection from the Nurses and Midwives Council. It appears that the complaint against the nurse was not pursued further. The motorcyclist who caused the accident was, however, arrested and taken to court where he was sentenced to a fine of MWK10,000.³⁵⁷ The sex worker respondent said her fellow sex workers were not satisfied with the sentence but felt they did not have capacity to appeal the case further.

In Selebi Phikwe, Botswana, sex worker respondents stated that ideally they would want an effective complaints process to deliver a range of possibilities for redress. This included change in policy and laws where appropriate, changes in behaviour and attitudes of healthcare workers, punishment and discipline of responsible healthcare workers, and an apology to victims of mistreatment. Respondents noted that compensation could also be important when a healthcare user loses opportunities following discrimination or neglect by healthcare workers.

357 Estimated to be equivalent to US\$14 on 19 May 2016.

What is needed for change?

When asked how change could be achieved, sex worker respondents strongly drew links to the punitive legal regime governing sex work and their capacities to be active citizens capable of demanding fair services. In Botswana, for example, it was expressed that without full legal recognition of sex work, engaging effectively in complaints processes would be difficult. When discrimination occurs, respondents felt they could not engage procedures as a group (as sex workers) but had to engage procedures set for all citizens. Although the act of selling sex is not illegal in Botswana, Malawi or Zambia, presumptions about the unlawfulness of sex work result in many sex workers feeling that their complaints would not be taken seriously, whether by police, traditional courts or senior hospital staff.

In Malawi and Zambia, sex worker respondents strongly expressed a need for having NGO partners or sex worker-led advocates supporting the process of reporting complaints and pursuing accountability. The importance of legal recognition for sex worker advocacy groups was noted:

“I think as we are doing this work, we need backup. Because with the current law, we are not safe. We will be arrested and we need some protection and we can do this but it should be calculated.” (Sex worker respondent - Lusaka, Zambia)

Conclusion

- Experiences of sex workers of discrimination in healthcare settings are closely linked to abuse by police and other persons in positions of authority, both in the cause of the abuse and in the inhibitions to accessing justice. The examples cited illustrate how police abuse and anticipated abuse bars sex workers from seeking PEP and sexual and reproductive health services when needed. Experiences of police abuse similarly create distrust for authority among sex workers, while fear of arrest and secondary victimisation inhibit sex workers from accessing justice when abuses occur. It is in this context of abuse by authorities that sex workers experience criminalisation of their work as a citizenship issue, a status that disenfranchises sex workers from seeking accountability and redress as members of a legal community.
- In many of the examples cited, sex workers actively sought out healthcare to ensure safe sexual practices and health. Sex worker respondents also could clearly identify issues that constrain their effective health access, including the refusal of certain health systems and healthcare workers to accommodate for the mobility of sex workers to ensure sustained and effective access to HIV services.
- Ensuring the protection of healthcare users’ confidentiality extends to presumptions that healthcare workers may make about healthcare users’ occupations and was indicated by respondents as being vital to enable sex workers to access healthcare sustainably close to home when they need it.
- Indirect discrimination is experienced by sex workers as significant inhibitions to care through policies or practices of healthcare workers refusing to provide STI or HIV testing

or treatment in the absence of healthcare users' sexual partners. These practices, while potentially neutral in abstract, have disproportionate effects on women and persons particularly vulnerable to HIV such as healthcare workers.

- STI treatment was narrated as being particularly stigmatised among sex worker respondents who described habits of denial of care and verbal abuse, particularly when seeking treatment for STIs.
- Finally, it is distressing to note the experiences of sexual abuse and coercion related by some sex workers in Malawi. These abuses are occasioned in contexts of significant vulnerability of the sex workers as healthcare users. Many of these accounts related experiences of high-risk sexual contact, which aggravates the individual abuse and negatively impacts on public health outcomes.

6.3 Lesbian, gay, bisexual and transgender persons

Introduction

LGBT persons are recognised as vulnerable to HIV. Men who have sex with men (MSM) are particularly vulnerable to HIV. MSM are nineteen times more likely to be living with HIV than the general population and only 5% of MSM worldwide have access to the prevention, care and treatment service they need.³⁵⁸ The WHO defines MSM as “all men who engage in sexual and/or romantic relations with other men.”³⁵⁹ Sex between men and sex between women are criminalised in Botswana, Malawi and Zambia.³⁶⁰

The WHO employs “transgender” as an umbrella term for “people whose gender identity and expression does not conform to norms and expectations traditionally associated with the sex assigned to them at birth.”³⁶¹ The term is inclusive of people who are transsexual, transgender or otherwise gender non-conforming. The WHO further states that the high vulnerability and specific health needs of transgender people necessitate a distinct and independent status in the global HIV response. The United Nations Development Programme (UNDP) has stated that transgender persons face systemic discrimination in trying to access general health services and are highly vulnerable to ignorance or prejudice in seeking healthcare and fear of violent reprisals if healthcare workers breach confidentiality.³⁶² Furthermore, violence, stigma, social exclusion, and discrimination harm transgender persons' health and wellbeing, which deters people from seeking HIV prevention, treatment, care, and support services.³⁶³

³⁵⁸ “Advancing the Sexual and Reproductive Health Rights of Men who have Sex with Men Living with HIV: A Policy Briefing” *Global Forum on MSM and HIV & Global Network of People living with HIV* (2010), 4.

³⁵⁹ Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations, note 2 above.

³⁶⁰ Botswana, Malawi and Zambia have identical provisions in their respective Penal Codes, which criminalise unlawful carnal knowledge (anal sex between men), gross indecency between men, and gross indecency between women.

³⁶¹ Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations, note 2 above.

³⁶² United Nations Development Programme Discussion Paper: *Transgender Health and Human Rights* (2013), available at: <http://www.undp.org/content/dam/undp/library/HIV-AIDS/Governance%20of%20HIV%20Responses/Trans%20Health%20&%20Human%20Rights.pdf>, 17.

³⁶³ As above, 18, citing J Godwin *Legal Environments, Human Rights and HIV Responses Among Men Who Have Sex with Men and Transgender People in Asia and the Pacific: An Agenda for Action* (2010); S Khan et al. “Living on the Extreme Margin: Social

Ensuring that MSM and LGBT persons broadly are able to access appropriate healthcare safely and without discrimination is therefore vital to ensuring effective responses to HIV. In Botswana, Malawi and Zambia, there are minimal verifiable data on LGBT persons, including on stigma and discrimination faced in healthcare.

A 2012 Study by the Government of Botswana sought to assess the population size, HIV and STI prevalence and incidence and risk profiles of MSM.³⁶⁴ HIV prevalence amongst MSM is estimated by government at 13.1%.³⁶⁵ The Botswana government has recognised that stigma and discrimination place HIV-positive MSM at increased risk of HIV.³⁶⁶ In Botswana, transgender activists list a variety of challenges in accessing healthcare in primary healthcare institutions, which includes discrimination and a lack of understanding from service providers.³⁶⁷

In Malawi, a medical professional who was perceived to be MSM, was attacked and reported being fearful of seeking medical attention in the facility where he worked.³⁶⁸ Civil society in Malawi has called on the Minister of Health to issue instructions to personnel in charge of health training to design and implement a curriculum to address discrimination by healthcare workers.³⁶⁹

In Zambia, MSM are repeatedly neglected in government-funded studies despite an acknowledgment of the absence of information on MSM in the context of the HIV epidemic. For example, the Joint Mid-Term Review of the National HIV/AIDS Strategic Framework 2014-2016 does not include MSM in its definition of key populations thereby failing to speak to MSM in its priority interventions and strategies. In Zambia, transgender activists state that there are “no safe spaces for transgender people to interact” and stress the importance of documenting human rights abuses.³⁷⁰

Focus groups

A total of five focus-group discussions were run with persons who self-identify as LGBT. In Botswana, two focus groups were held with LGBT participants – one in Palapye with six LGBT participants and one in Gaborone with seven LGBT participants. In Malawi, one focus group was held with LGBT participants in Lilongwe. In Zambia two focus groups were held: one in Kitwe with 23 LGBT participants and another in Lusaka with twelve transgender participants.

Exclusion of the Transgender Population (Hijra) in Bangladesh” (2009) 27 *Journal of Health Population and Nutrition* 441; “HIV and the Law: Risks, Rights and Health” *Global Commission on HIV and the Law* (2012), available at: www.hivlawcommission.org/index.php/report, 53.

³⁶⁴ Republic of Botswana: Ministry of Health *2012 Mapping, Size Estimation and Behavioral and Biological Surveillance of HIV/STI Among Select High-Risk Sub-Populations in Botswana* (2013), available at: <http://www.fhi360.org/sites/default/files/media/documents/BBS%202012%20Final.pdf>, 29 at para 3.2.1.1.

³⁶⁵ Republic of Botswana *2013 Global AIDS Response Report: Progress Report on the National Response to the 2011 Declaration of Commitments on HIV and AIDS* (2013), available at: http://www.unaids.org/sites/default/files/countrydocuments/file_94425.es..pdf, 20.

³⁶⁶ As above.

³⁶⁷ “Report of the Southern Africa Transgender Advocacy and Capacity Building Summit, 15-17 August 2014, Johannesburg, South Africa” *Transgender and Intersex Africa* (2014), available at: <http://transgenderintersexfrica.org.za/wp-content/uploads/2014/10/summit-report.pdf>, 12.

³⁶⁸ “Human Rights Violations on the Basis of Real or Perceived Sexual Orientation and Gender Identity in Malawi” *Centre for Human Rights and Rehabilitation & the Centre for the Development of People* (2014), available at: http://iranti-org.co.za/content/Africa_by_country/Malawi/2014_CEDEP_Human_Rights_violations_report.pdf, 16.

³⁶⁹ As above, at 22.

³⁷⁰ As above, at 13.

Experiences of stigma and discrimination in healthcare

The most common form of discriminatory behaviour LGBT participants complained of was the use of harsh and abusive language by healthcare workers. Several respondents noted that gay men in particular experienced **verbal abuse**. In many of the descriptions, LGBT respondents stated that healthcare workers had related religious convictions that indicated the healthcare user to be sinful:

“A friend asked me to escort him to get tested; he had makeup on. People were staring at him at the hospital. When we went into the doctor’s office, the doctor asked him whether he was a girl or a boy. My friend answered that he was both. I intervened and asked whether they could just test him so we could leave. The doctor went to call another doctor and they started mocking us by their questions and comments. They insisted that both of us should be undressed and checked, but we refused and that’s how we left without testing.” (LGBT participant – Lusaka, Zambia)

“One participant who is feminine presenting said he went to a clinic with general chest pains. As he was explaining to the attending nurse, she was looking at him strangely at first. She then called in another nurse and started talking rudely about him right there in his presence, laughing about his appearance and ‘gay’ behaviour, his health issue totally forgotten. He told them to mind their business and demanded treatment. She in turn became rude and rough with him. All the time while she was treating him she lectured about God and sin of Sodom.” (Focus-group facilitator – Gaborone, Botswana)

Blaming healthcare users for their health status was frequently related by respondents when recounting dissatisfactory interactions with healthcare workers. In Palapye, a respondent described a nurse blaming him for becoming infected with HIV, by saying that it was punishment for engaging in anal sex. Following the interaction, the respondent ceased using government facilities and only accessed healthcare at private facilities. Due to financial limitations, the respondent no longer accesses healthcare services but claims to “self-medicate” instead.

LGBT respondents, particularly transgender respondents, complained of an **unwillingness by healthcare workers to accommodate their particular healthcare needs**.

“It is difficult to get prescriptions for certain medicines if you are a transgender person. For example, one cannot not buy testosterone. If we cannot get services from one place we try another provider.” (LGBT respondent – Lusaka, Zambia)

Several respondents discussed **concealment of their identities** when seeking healthcare as necessary to access services, but as inhibiting appropriate treatment and prevention services.

“The problem is that we don’t even go there. If we do, we don’t go as our authentic self. We go there under an umbrella of someone else. ... It has to do with the fact that we are attended to, but not in the way we would want to. ... I would give an example of a situation where you’ve got anal warts,

you don't even know how to explain that to them, so you end up giving them some form of things for them to give you some medication that is closer. ... Others do not go there, but opt to self-medicate.” (LGBT respondent – Kitwe, Zambia)

“I had an STI in 2012 and I went to the clinic to seek help. But I was told I would not be treated until I went with my partner. And so, here I was in pain and yet the clinician was busy asking for my partner. So I ended up lying so I could get the help I so desperately needed. So now I think, for me it felt like the structures in these institutions, the doctors themselves, it makes me question the kind of training that they have. I understand why they have to ask for a partner for them to treat you, I get that these are public resources and they want to have the most impact with the limited resources. But at what cost will they optimise resources, at the cost of losing a life?” (LGBT respondent – Kitwe, Zambia)

It is noted in this context that in all focus groups, LGBT participants raised treatment-avoidance behaviours, indicating a preference to avoid accessing treatment for fear of the disclosure of their sexual orientation or gender or other forms of discrimination. In Lilongwe, Malawi, some participants described this behaviour as a form of self-stigmatisation.

Several respondents related difficulties in relation to the insistence of healthcare workers that HIV and STI testing or **treatment is conducted together with one’s sexual partner**. Some related examples of healthcare workers refusing to test or counsel homosexual partners together. In Gaborone, for example, an LGBT participant described asking for an HIV test at an HIV testing centre. The respondent asked if he would be permitted to bring his (male) partner, so that they might receive counselling together. He was refused.

“My friend and I are both transgender persons. We decided to go and each test for HIV. The counsellor assumed we were a couple and insisted on doing couple counselling and testing. We told him that we were not a couple but he insisted, stating that he could not attend to one of us but both of us since we were a couple. We both got counselled and tested as a couple.” (LGBT respondent – Lusaka, Zambia)

My friend and I went to Kabwata Market to test for HIV at a VCT booth. We told them we were a couple and they refused to test us, stating that they cannot test people in a same-sex relationship.” (LGBT respondent – Lusaka, Zambia)

A number of NGO and CBO respondents interviewed described concern for LGBT persons accessing healthcare, in that there was a tendency for healthcare workers to **report LGBT persons to the police**. In Malawi, a transgender respondent related that he feared accessing care at state-owned facilities being under the impression that the healthcare workers would call the police. The respondent stated that he prefers instead to access private care, but conceals his sexual orientation even when accessing private care. While no examples were given by LGBT respondents of being reported to the police by a healthcare worker, some had experienced threats of being reported to the police:

"I asked [the sister in charge], 'Do you serve the key population?' and I also asked her what she meant by key populations. She said, 'children, women and old people'. And I was like, 'Let me more specific. Do you treat lesbians, gays, transgender or bisexual people?' And she was like, 'If a thief who came to my house to steal come here to seek a service, I would serve them. And afterwards, I would hold them by the hand and hand them over to the police. I would do the same with those people you are talking about.'" (LGBT respondent – Kitwe, Zambia)

Some respondents had experienced being **refused treatment** by healthcare workers on the basis of their actual or perceived sexual or gender orientation. In other cases, particular services were denied to respondents, such as sexual and reproductive healthcare services, when healthcare users' gender identities did not match the healthcare worker's expectations:

"I had a fight with my brother after he found out that I dated boys. He was hitting me and kicked me on the testicles so I had to go to the hospital when the pain wouldn't go away. I explained to the doctor what had happened and as soon as I disclosed that the fight was over my sexual preference the doctor's attitude changed. He stopped listening and started lecturing me, saying that I deserved the beating, that in fact my brother should have cut my testicles off. He stopped treating me right there and then and told me to leave him, telling me I deserved worse for doing 'unnatural things'. I left and went to a pharmacy and was given painkillers." (LGBT respondent – Gaborone, Botswana)

"I went to hospital for treatment and I was told to go home and change my clothes. I was told to put on clothes that reflect my sex." (LGBT respondent – Lusaka, Zambia)

"I identify myself as a male person. I escorted two of my female friends to UTH for cervical cancer screening. I decided to also screen for cervical cancer. But because of the way I was dressed and probably the way I carried myself, the nurse refused to screen me. She said I do not have penetrative sex, and therefore there was no need to screen for cervical cancer." (LGBT respondent – Lusaka, Zambia)

A significant concern that emerged for LGBT respondents, was not only the **failure to observe confidentiality** by healthcare workers with regard to their health status, but also the failure to observe confidentiality with respect to their gender identity or sexual orientation following healthcare access:

"[O]ne of my trans sons had ulcers. ... I found he was in very bad shape. I could not afford to take him to a private clinic as I was broke, so I took him to Chainda clinic. There wasn't a long queue. The issue then was how do you identify this person because he was using his chosen name and his gender? Apparently when he went for check-up, the clinical officer asked him to take off his shirt, and because he was pre-op there were still breasts. So, because of that, the conversation in the clinic became about his gender identity and

not that he was sick. The clinical officer came out of the treatment room and started sharing his details carelessly so that the whole clinic now was wondering who this person was.” (LGBT respondent – Kitwe, Zambia)

“I went to the clinic to get some medication. Later on I met the counsellor and the nurse that attended to me at a local drinking place/bar and they started discussing my status with their friends.” (LGBT respondent - Lusaka, Zambia)

Some respondents related experiences of healthcare workers **refusing to properly examine** them, or to touch them, or conducting themselves in a manner that indicated a sense of disgust towards them, including refusing to make eye contact and using what were felt to be excessive precautions when undertaking examinations.

In relation to HIV-specific services, one respondent related being given **inferior counselling** services following the revelation of their sexual preference. A transgender respondent was refused treatment in the **absence of HIV testing**:

“I went for HIV test. I wasn’t counselled, but was asked a few questions about my sexuality and sexual practices e.g. if I was sexually active and if I use condoms. When I asked whether the counselling is over, the counsellor said to me, ‘We don’t counsel people like you.’ The person who went in before me had spent about 25 minutes, but I went through everything in less than 10 minutes.” (Transgender respondent – Lusaka, Zambia)

“I went to the University Teaching Hospital (UTH) and I was told they couldn’t treat me until I underwent an HIV test. The counsellors started talking to me about same-sex relationships and counselled me on this basis although I’m not in a same-sex relationship.” (Transgender respondent – Lusaka, Zambia)

Why are we discriminated against?

Respondents were asked to reflect on why they thought they were discriminated against. Most explained that social patterns of discrimination in the community were reflected in the attitudes of healthcare workers. These attitudes were described as caused by ignorance, fear and prejudicial attitudes founded in religious and traditional, cultural beliefs.

Access to accountability and redress

When asked if any respondents had complained about discriminatory treatment, a few instances of direct confrontations with healthcare workers were related, none with satisfactory outcomes:

“I remember when I was at university going to the CBU clinic and telling the nurse ‘bane nshili bwino’ [‘I am not well’] and she started asking me funny questions, ‘ala nail shouta nukuba trainesha’ [‘I shouted at her and taught her a lesson’]. But the end result was that I did not receive the service that I needed. So I ended up scared to go to the next clinic because of fear of being discriminated against. The moral of the story is that all I needed

was health care, and here I was having someone wanting to preach to me.”
(LGBT respondent – Lusaka, Zambia)

A few respondents related examples of escalating a complaint to a healthcare worker’s superior, with varying levels of satisfaction with the outcomes:

“My friend was admitted to hospital for 3 days. During medical examination by the nurse, the nurse forced my friend to move from the male ward to the female ward. We had to call the doctor, who intervened and directed that the patient should remain where he was.” (LGBT respondent – Lusaka, Zambia)

“I explained to the person in charge but my issue was not addressed. He was also biased. At first he reassured me that he would address the matter but when I went back for feedback, he passed the same comments as the counsellor I had complained about.” (LGBT respondent – Lusaka, Zambia)

When asked why respondents did not complain about discriminatory healthcare, several reasons were related. In Zambia, in particular, respondents were frustrated with the suggestion of making a complaint, relating that in the context of criminalisation of same-sex sexual acts, the prospect of complaining was unfeasible:

“But for us, that is a far-fetched conversation that may be irrelevant right now. So I go and report that I am a gay man who got anal warts through anal sex with a man and when I went to Chamboli Clinic the doctor refused to attend to me? That sounds ridiculous coming from my lips, unless I want to end up more than sick but also end up in prison.” (LGBT respondent – Kitwe, Zambia)

Other respondents described that they did not know where or how to complain:

“We don’t know what healthcare providers are expected to do by law and we don’t fully know our rights. Sometimes family and friends discourage us from complaining.” (LGBT respondent – Lusaka, Zambia)

In addition, respondents gave examples of failed efforts to complain in the past by themselves or others making them reluctant to complain because it would not have any meaningful result:

“[A] testing centre in Palapye refused to test a lesbian couple together. The participant said that they made a decision to test together and went to the centre, disclosed their sexual orientation and the fact they wished to be tested together as partners. The testing officer declined, saying that the Botswana law did not recognise them (lesbians), so they could not be tested as partners. They complained and in the end the coordinator of the centre tested them herself after much discussion where everyone in the centre got involved, including other patients. Confidentiality about their sexual orientation was compromised but none in the centre seemed to be even aware that ethics were being breached. The coordinator tested them together reluctantly and did not even bother to offer pre-testing counselling.”

Both of them went away feeling angry and abused, but did not take the matter further. They never went back to test with their partners. Participant said she didn't feel that making the report would make a difference, in any case they both had no idea where else to go to make a complaint." (Focus-group facilitator – Palapye, Botswana)

Significantly, many respondents raised concerns over the confidentiality of their health and sexual and gender orientation as inhibiting accessing redress. Respondents in Palapye stated that a consequence of complaining about inadequate healthcare could include, for example, losing one's job if one's sexual orientation was revealed in the process. Other respondents feared their sexual orientation being revealed to family members or the community if they complained:

"I didn't report the incident to anyone, because as soon as my father found out he went to the hospital and started asking the doctors to find a cure to convert me from being gay. I had thought that by not reporting I would be spared the public humiliation, but after that it became common knowledge as the whole hospital talked and gossiped about me. I was even afraid to go to any clinic after that. I was insulted and confronted about my sexual orientation by complete strangers on the streets. I also didn't report the doctor because I didn't know where to go. I knew little about my rights and so I let it go. I, however, felt angry, and disillusioned for a long time." (LGBT respondent – Gaborone, Botswana)

Respondents gave ideas of what they would need in order to enable them to access complaints processes. This included:

- Guaranteed confidentiality from the complaints mechanism;
- Immunity from criminal prosecution when laying complaints of human rights violations;
- Improved access to legal aid services for the LGBT community;
- A complaints mechanism that specifically deals with the issues faced by the LGBT community;
- Secret complaints options through suggestion boxes and helplines;
- Clear guidelines on how to report a complaint and what to expect from the process;
- Information on the ethical and legal responsibilities of healthcare workers; and
- Clear sanctions for discriminatory behaviour by healthcare workers to ensure the complaints process can work as an effective deterrent.

When respondents were asked what the desired outcomes would be from an effective complaints process, the unanimous response was a process that resulted in behaviour change and/or, where necessary, changes in policy and law. For some respondents this was expressed as wanting to see improved access to healthcare services and seeing changes in the attitudes of healthcare workers. Some respondents stated that they wanted clear and enforceable consequences to result for healthcare workers, which should include the prospect of the healthcare worker apologising to the victim of discrimination. Lastly, some respondents stated merely that they wanted to assert their rights, suggesting that the process of complaining was an end in itself.

What is needed for change?

When asked what was needed to change the prevalence of stigma and discrimination in healthcare, focus-group respondents stated clearly that legal and policy reform, particularly in the decriminalisation of consensual same-sex sexual conduct was the indispensable first step. Respondents noted that having complaints mechanisms with clear processes and enforceable outcomes would also assist. Some respondents noted the need for NGO and CBO partners to be strengthened in their capacities to respond to instances of discrimination in healthcare.

Sensitisation and training were stated to be required on three levels: for healthcare workers, for healthcare users, and for the broader community. Respondents stressed in particular that healthcare workers need to have ethics and human rights and the particular needs of the LGBT community built into professional training. Some respondents stressed the need for training to enable healthcare workers to better deal with issues of privacy and confidentiality of healthcare users.

Some respondents suggested that the solution to discrimination in healthcare was to assist LGBT healthcare users to better censor the information shared with healthcare workers to ensure that accessing care does not result in harm.

Conclusion

- A worrying pattern of discrimination described by LGBT respondents manifests in the repeated statements by respondents of treatment avoidance – either in respondents not seeking healthcare at all or in concealing treatment and counselling needs in order to ensure their sexual orientations and gender identities are not exposed.
- Respondents described accessing healthcare in terms that indicated significant hostility and threat of social persecution and legal prosecution. The threat of healthcare workers reporting LGBT healthcare users to the police was identified by respondents as a significant concern.
- LGBT respondents described, in examples of denial of care and verbal abuse, repeated instances of healthcare workers moralising to them as healthcare users and also gender-policing respondents' conduct (for example by insisting on clothing changes that match the healthcare user's biological sex) at points of care.
- Like sex workers, the social context of criminalisation of same-sex sexual contact, inhibits LGBT persons not only from accessing treatment in the form, time and manner that is required in order to be effective, but also from accessing accountability and redress when violations occur in healthcare.
- The importance of healthcare workers observing not only confidentiality with respect to healthcare users' health status, but also their sexual orientation and gender identity is therefore closely linked to ensuring those most vulnerable to HIV are able to access healthcare equitably.
- Lastly, it should be strongly stressed that LGBT respondents had significantly limited expectations about accessing healthcare or justice in the context of criminalisation of same-sex sexual acts. Even if immunity from prosecution or confidentiality was secured

for complainants experiencing healthcare discrimination in a particular system, it is likely that, in this context, that LGBT persons will remain underserved and excluded from effective healthcare access and also from holding violators to account for breaching lawful entitlements to appropriate care.

6.4 Women living with HIV

Introduction

Some studies show that women in sub-Saharan Africa are significantly more likely to experience HIV-related interpersonal discrimination than men.³⁷¹ In Botswana, studies indicate that entrenched gender inequities perpetuate the HIV/AIDS epidemic.³⁷² In Malawi, gender inequality, harmful gender norms and economic vulnerability, amongst others, are recognised as exposing women to heightened risk and vulnerability to HIV.³⁷³ Discrimination in healthcare is commonly reported amongst women living with HIV in Malawi.³⁷⁴ Zambia's gender equality index rates at 0.623 – ranking it 136 out of 148 countries in terms of gender equality.³⁷⁵

Focus groups

Two focus groups were held with women living with HIV: one with fifteen participants in Chiradzulu, Malawi, and another with twenty participants in Kabwe, Zambia.

Chiradzulu is a town in the Southern District of Malawi, where approximately 90% of the population subsists on farming.³⁷⁶ Chiradzulu has benefitted from years of enhanced HIV interventions by Médecins Sans Frontières.³⁷⁷ Women living with HIV respondents in Chiradzulu expressed concern about the imminent departure of Médecins Sans Frontières from its work in the district, being worried that the Ministry of Health would not be able to take over services effectively.

Kabwe is Zambia's second-largest city, and is located in the Central Region in the Copperbelt area. Formerly a zinc and lead mining town, Kabwe retains high levels of soil and water contamination.³⁷⁸

³⁷¹ M Neuman et al. "Experiences of Stigma, Discrimination, Care and Support among People Living with HIV: A Four Country Study" (2013) 17 *AIDS Behav* 1796.

³⁷² "Epidemic of Inequality: Women's Rights and HIV/AIDS in Botswana and Swaziland – An Evidence-Based Report on the Effects of Gender Inequity, Stigma and Discrimination" *Physicians for Human Rights* (2007), available at: http://www.essex.ac.uk/armedcon/story_id/botswana-swaziland-report.pdf.

³⁷³ UNDP *Assessment of Legal, Regulatory and Policy Environment for HIV and AIDS in Malawi* (2012), 31.

³⁷⁴ As above, 32.

³⁷⁵ Zambia Country Report: Monitoring the Declaration of Commitment on HIV and AIDS and the Universal Access, as note 311 above.

³⁷⁶ Médecins Sans Frontières, Malawi, and the Ministry of Health and Population, Chiradzulu District, Malawi *Antiretroviral Therapy in Primary Health Care: Experience of the Chiradzulu Programme in Malawi Case Study* (2004), available at: <http://apps.who.int/iris/bitstream/10665/43063/1/9241592427.pdf>.

³⁷⁷ See, for example, "Antiretroviral Therapy in Primary Health Care: Experience of the Chiradzulu Programme in Malawi Case Study, as above; "Malawi: Ten Years Ago, MSF Launched ARV Treatment for its HIV patients" *Médecins Sans Frontières* (2011), available at: <http://www.msf.org/article/malawi-ten-years-ago-msf-launched-arv-treatment-its-hiv-aids-patients>.

³⁷⁸ See: "The World's Worst 2013: The Top Ten Toxic Threats" *The Blacksmith Institute* (2013), available at: <http://www.worstopolluted.org/docs/TopTenThreats2013.pdf>, 16.

Experiences of stigma and discrimination in healthcare

A prominent feature of discriminatory conduct described by women living with HIV was the **failure of healthcare workers to obtain proper informed consent** before administering treatment, including **failing to explain treatments and diagnoses**. Respondents were particularly distressed about changes in ART regimes without explanation, involuntary HIV testing when accessing antenatal care, and women living with HIV being placed on contraceptives without their knowledge:

“There are many times that I have gone for review and the doctor just writes a prescription without finding out how I am. Sometimes, I am asked how I’m feeling and I explain the discomfort that I experience and the doctors don’t explain what’s causing certain illnesses. They just write a prescription.”
(Woman living with HIV respondent – Kabwe, Zambia)

“I was on certain [ART]. The clinic changed this drug combination which was working well. They said everyone with a CD4 count above 400 were supposed to change their drugs. I got the new drugs, but I reacted badly to them. I went to the hospital to complain about the new drug, but I was told that I must just continue with the drugs and that side effects would go away. I don’t understand why the drugs I was on before were changed.”
(Woman living with HIV respondent – Kabwe, Zambia)

“Some HIV-positive expecting mothers are put on family planning without their full knowledge or consent. I have a deaf friend who was put on family planning without her full and informed consent.” (Woman living with HIV respondent – Kabwe, Zambia)

“Although this practice has reduced in some places, in other places it is still rampant. Pregnant women are forced to test for HIV in order to receive antenatal services.”

“Yes. At Kasanda Clinic, they test you for HIV before providing family planning to you. Anyone who wants to receive family planning services has to test for HIV.” (Women living with HIV respondents – Kabwe, Zambia)

In Zambia, the practice of providing **preferential treatment** to relatives and socio-economically empowered members of the community was described as commonplace:

“The system in our clinics in Kabwe is that [ART] drugs are only given on selected days and they are only given to the first 20 or so people to arrive at the clinic. We wake up very early, around 03:00 hours on the days we are scheduled to collect our medicines. But the clinics have a habit of allowing their friends or relatives to jump the queue and collect their drugs, which means we have to wait the following week to try again. This practice is very bad at Kabwe General Hospital.” (Woman living with HIV respondent – Kabwe, Zambia)

Instances of being ignored or healthcare workers refusing to treat healthcare users were typically related by respondents in relation to **intersectional grounds of vulnerability**, including socio-

economic status and disability:

“My friend, who is HIV-positive and a wheel-chair user, went for review to Kitwe General Hospital, but she was late by a few minutes. She was then referred to Wusakile Hospital. She didn’t have an appointment but she had missed the slot for getting drugs by one. She was number 21. It was so sad because they refused to make an exception for her and yet they make for their friends and relatives and it’s so difficult for her to move from one place to another.” (Woman living with HIV respondent – Kabwe, Zambia)

“People with money or some high social status like members of the defence forces always get attended to immediately. The rest of us are ignored despite waking up early to try and be in the queue on time. They don’t even care to explain why other people are skipping the queue. (Woman living with HIV respondent – Kabwe, Zambia)

Also in Zambia, women living with HIV respondents described frustrations with general processes implemented by healthcare facilities, ostensibly to manage health-service delivery in the context of personnel shortages:

“Some hospitals have started a practice that can be classified as inferior. At Mahatma Ghandi and Kasanda Clinics for example, they have formed six groups of ten people to collect [ART] drugs for everyone in their groups. Only one person can collect the drugs in that month and they distribute them to the others. Then they rotate the person to collect drugs. This is a group of patients and not caregivers who are offered no prior training. If a member of the group is sick, the team leader at the time must accompany this person to the clinic for examination. The clinics have therefore cut down on the number of patients they are seeing for review and only see patients when they are sick.” (Woman living with HIV respondent – Kabwe, Zambia)

In a 2013-2014 Zambian government study, 34% of women respondents cited “rude attitudes among health workers” as a problem inhibiting access to healthcare.³⁷⁹ Women living with HIV respondents in both Chiradzulu and Kabwe, described experiencing **aggressive attitudes and derogatory language** used by healthcare workers. A respondent in Chiradzulu, Malawi, described going to a health facility to get medical attention and overhearing a healthcare worker stating: “Let her get treated first for she is a dead person walking.” Another respondent was shouted at by a healthcare worker to go away, exclaiming that he (the healthcare worker) is not the one who infected the respondent with HIV.

In Kabwe, Zambia, respondents had experienced healthcare workers **refusing to touch** them, and conducting themselves in a manner indicative of disgust towards women living with HIV:

“I worked for Kara Counselling for 13 years as a caregiver. A nurse came to work with us for one year. She separated the mugs in the kitchen and

³⁷⁹ Central Statistical Office Zambia: *Demographic and Health Survey 2013-2014* (2015), available at: <https://www.dhsprogram.com/pubs/pdf/FR304/FR304.pdf>, 133.

labelled the ones for nurses as 'for nurses only'. When she was asked why she did this, she said many caregivers were HIV-positive and she did not want to risk contracting HIV." (Woman living with HIV respondent – Kabwe, Zambia)

Women living with HIV respondents did not complain directly of **non-consensual status-disclosure** or healthcare workers **gossiping**, but instances of this were apparent from respondents' descriptions of their frustrations with the attitudes of certain healthcare workers.

"At the Kabwe General Hospital there is a nurse who brags about how she has saved many lives and mentions people's names; particularly names of people who are known in the community. When she meets a patient in the corridors of the clinic, she announces to others who are waiting to be attended to that she counselled that person and they are alive today because of her." (Woman living with HIV respondent – Kabwe, Zambia)

Lastly, in both Malawi and Zambia, women living with HIV respondents described the **segregation of HIV-related health services** as a stigma and discrimination risk that in some cases inhibits community members from accessing services. Respondents from Chiradzulu reported that a day was set aside once a week for the ART clinic. This practice, they explained, has exposed them to stigma and discrimination. Respondents suggested that there should not be a specific day for the ART clinic and that HIV services should be offered as "primary health care under one roof." Through this method, the respondents felt they could also access other services or treatment on the same day, and with the same healthcare provider, instead of getting appointments to come again for other services. Respondents were concerned that the treatment they were receiving was not as comprehensive as possible and essential services were sometimes left out such as taking blood pressure and weight measurements.

"Our clinic, Nkungu Clinic, is divided into segments where those of us on ART have our own section for ART. When my friend tested positive and was due for ART, I encouraged her to come with me to the clinic to get her drugs. She refused to come because the ART clinic is a stand-alone building at the clinic and it is open for everyone to see those who accessing its services." (Woman living with HIV respondent – Kabwe, Zambia)

Why are we discriminated against?

When asked why healthcare workers might discriminate against women living with HIV, respondents acknowledged that a contributing factor was the overburdened health system, which may overwhelm healthcare workers and compromise the quality of the care they receive. In addition, they identified ignorance-driven fear of both healthcare users and healthcare providers as being a contributing factor.

Access to accountability and redress

The women living with HIV respondents in Chiradzulu said they would not know where to complain except through Health Advisory Committees. The respondents said they did not know what their rights were so found it difficult to know when their rights were being violated.

In Kabwe, respondents stated that in general they did not complain about mistreatment and discrimination because some of the conduct is simply routine and respondents feared being victimised by being ignored or denied treatment:

“If we complain about the segregated ART centres, we may not have ART services as they may completely stop offering them or there would be delays in order for them to restructure their services.” (Woman living with HIV respondent – Kabwe, Zambia)

Some instances of seeking redress and accountability were related. A Malawian woman living with HIV respondent described an example of seeking accountability for mistreatment as a collective of people living with HIV who were accessing ART services. The respondent, who was actively involved at an ART clinic in Chiradzulu, was denied treatment together with other ART clients for no apparent reason. The respondent, together with other ART clients, mobilised themselves and went to complain to a village headman who referred them to the Traditional Authority. The Traditional Authority, together with local Health Advisory Committee members, called the healthcare provider to a round-table meeting. The healthcare provider was allegedly rude and dismissive towards the complainants, the Committee and the Traditional Authority. Following the meeting, the healthcare provider started victimising the respondent who had mobilised others to report her to the authorities. No further consequences resulted from the complaint.

In both Malawi and Zambia, respondents related isolated instances of direct confrontation with healthcare workers. A respondent from Chiradzulu gave an example of a successful direct confrontation with the healthcare worker. The respondent was concerned that her HIV viral load was increasing, which was confirmed after testing. In seeking to address the increase in her viral load, the respondent sought medical assistance. She related that the clinician told her to “just accept her medical condition as [you are] already dead.” The respondent said that she continued to demand treatment and was eventually provided with appropriate treatment.

Other examples of direct confrontations were less successful:

“I went to the hospital to collect my [ART]. The nurses were late in reporting for work and when they finally came, they were sitting in the nurses’ room chatting. They later started allowing their friends to skip the queue and they attended to them. I went to complain that I have been waiting too long and the nurse told me in local language that the medication I’m on is confusing me, and making me insane.” (Woman living with HIV respondent – Kabwe, Zambia)

In one example from a respondent in Kabwe, the escalation of a complaint at facility-level was successful in achieving behaviour change from an individual healthcare worker:

“I complained at a health centre. They were asking personal and health issues of patients in the queue, in the presence of other patients. Patients were not free to respond to some of their questions as they were not asking them in a private space. I told the nurse that what they were doing was wrong and she ignored me. I called the Clinical Officer in charge of the clinic

and the nurse who was collecting this information from patients and I asked the Clinical Officer to speak to her about my concerns in my presence. I later followed up to see how the nurse was doing and she apologised to me. My complaint was verbal, but the clinic was able to address my concern.”
(Woman living with HIV respondent – Kabwe, Zambia)

When women living with HIV respondents were asked what they wanted to achieve from a functioning complaints process they stated that they wanted to see a change in attitude from healthcare providers and to receive respectful treatment as healthcare users. Where possible, they wanted to receive apologies for mistreatment and changes in policies where needed. Lastly, they stated that compensation would be appropriate in cases of serious abuse.

What is needed for change?

Respondents were asked to reflect on what was needed to change patterns of stigma and discrimination in healthcare settings. In Kabwe, respondents stated that a well-disseminated complaints procedure for healthcare institutions which is accessible by community members was needed. They suggested in addition that support groups must report to a central place, which follow up the complaints on healthcare users’ behalf. People living with HIV should be empowered to advocate for their rights in support groups. Respondents from Kabwe stated in addition that the suggestion boxes in some clinics could be better used to lay complaints and that healthcare facilities need to review the contents of the boxes regularly and take action on complaints. Respondents in Chiradzulu expressed a desire for a special committee to be put in place to address issues when their rights were violated.

In both Chiradzulu and Kabwe, respondents stressed the importance of educating and sensitising all stakeholders on healthcare users’ rights, legal systems and complaints processes.

Conclusion

- Access to information and the integrity of the informed consent process emerge as important features of experiences of discrimination related by women living with HIV. Respondents were slow to offer examples of non-consensual treatment or failure to provide information as examples of what they thought was discrimination. But when asked directly on these experiences, women living with HIV respondents appeared to have many experiences of healthcare workers presuming that women living with HIV lack the capacity to decide on their healthcare needs, or lacked the need for information on their health status.
- Many of the examples cited by women living with HIV respondents highlight the intersectionality of women’s vulnerability to discrimination. Women who are disabled or socio-economically marginalised appear to be far more susceptible to abuse.
- In addition, women living with HIV described several instances in Zambia and Botswana of segregating and identifying practices by healthcare institutions and healthcare workers. These were described to exacerbate stigma against people living with HIV and inhibit health-seeking behaviours. Respondents’ strongly voiced preferences for integrated healthcare services and more holistic treatment options.

6.5 Persons with disabilities

“This happens all the time, the assumption that you are not able to do anything just because of one’s disability. We value our independence and like to manage our own lives where we are able to but healthcare workers disregard this and do not support our differently able/disabled bodies. I can make all of life’s choices if I am given adequate information about my body.”
(Person with disabilities respondent – Gaborone, Botswana)

Introduction

In Botswana, 2011 figures estimate that persons with disabilities account for about 2.92% of the population.³⁸⁰ The prevalence of disability in Malawi is by some estimates indicated at 4.18%.³⁸¹ Several surveys indicate that significant portions of the population in Malawi are not able to access the health services they need³⁸² and that people with disabilities face heightened vulnerability to HIV.³⁸³ In Zambia, persons with disabilities experience discrimination and restrictions in access to HIV treatment and care.³⁸⁴ Persons with mental disabilities experience pervasive discrimination and stigma in healthcare settings in Zambia.³⁸⁵

Focus groups

Three focus groups were held with persons with disabilities. One focus group was held in Gaborone, Botswana with nine participants. In Zambia, two focus group discussions were held with persons with disabilities in Ndola, comprising eight and nineteen participants respectively.

While the facilitators sought to identify and include persons with mental disabilities, in the end only persons with physical disabilities were available to participate in the discussions.

Experiences of stigma and discrimination

“Where we live, when going to Kabushi clinic, one side has stairs and the other side which is accessible is locked, so stairs are a barrier. They lock the accessible part of the building. When we go to the clinic they do not consider that a disabled person needs to be attended to quickly ... We rarely have strength to stand. When you look at hospitals we know our women have the right to family life but they face a lot of difficulties when they are expecting.

³⁸⁰ “Decent work country programme for Botswana 2011-2015” *Report of the Republic of Botswana* (2011) 12, available at: <http://www.ilo.org/public/english/bureau/program/dwcp/download/botswana.pdf>, 3.

³⁸¹ Malawi Health Sector Strategic Plan 2011-2016: Moving towards Equity and Quality, as notes 142, 27 above.

³⁸² As above, 27. See, also, AC Munthali et al. “Non-Use of Formal Health Services in Malawi: Perceptions from Non-Users” (2014) 26 *Malawi Medical Journal* 130.

³⁸³ Assessment of Legal, Regulatory and Policy Environment for HIV and AIDS in Malawi, as notes 331, 37 above.

³⁸⁴ “We Are Also Dying of AIDS: Barriers to HIV Services and Treatment for Persons with Disabilities in Zambia” *Human Rights Watch* (2014), available at: https://www.hrw.org/sites/default/files/reports/zambia0714_ForUpload_1.pdf.

³⁸⁵ A Kapungwe et al. “Attitudes of Primary Health Care Providers towards People with Mental Illness: Evidence from Two Districts in Zambia” (2011) 14 *Afr J Psychiatry* 290; A Kapungwe et al. “Mental Illness – Stigma and Discrimination in Zambia” (2010) 13 *Afr J Psychiatry* 192.

They are discriminated against as if they should not have children and they should not fall pregnant. A lot of them do not even go to antenatal for fear of how the nurses will speak to them.” (Person with disabilities respondent – Ndola, Zambia)

Only one example was raised (in Ndola, Zambia) of a **refusal to treat** healthcare users with disabilities. However, respondents recognised that some healthcare workers were “intimidated” by their disabilities and so would delegate their treatment to other healthcare workers:

“Once I spent the whole day waiting for a doctor, when all I needed was a blood pressure test that needed no specialist. Many are intimidated by our disabilities but some just don’t care to be slowed down, or just don’t want to have to deal with us because of our disability. This is equal to denial of service but it happens frequently.” (Person with disabilities respondent – Gaborone, Botswana)

In both Zambia and Botswana, persons with disabilities respondents strongly perceived the failure of healthcare workers to **recognise them as autonomous persons** as being discriminatory. In Ndola, Zambia, the participant group (despite exhibiting good knowledge and a habit of asserting their rights) became emotional when explaining these behaviours that they felt denied them dignity.

“Doctors do not refuse to treat us when we are sick. The problem is that they treat us like children. The nurses are most troublesome. They usually look at the disability instead of our illness.” (Person with disabilities respondent – Ndola, Zambia)

“Whenever he goes for HIV testing the counsellors treat him like he is doing something he is not entitled to. And once he has an STI they blamed him for it. He told them that he is an adult man with adult sexual needs like any other man. The attitude makes him feel bad and stigmatised so he is ashamed to go for testing or even ask for condoms, which is a real shame because healthcare workers are putting his life at risk by stigmatising him about his sexuality as a man living with a disability.” (Person with disabilities respondent relating an incident experienced by a peer – Gaborone, Botswana)

Person with disabilities respondents described struggles to have their **decisions recognised** by healthcare workers:

“I am partially deaf, so that means I don’t need a hearing aid, but doctors always want to prescribe one for me. They ignore me when I tell them that I don’t need one especially since the volume is never adjusted to suit the partially deaf.” (Person with disabilities respondent – Gaborone, Botswana)

Experiences of being **treated with indignity** included instances that related a sense of superstition or fear when around persons with disabilities. In Ndola, persons with disabilities respondents gave examples of healthcare workers being fearful to touch healthcare users with albinism in particular. Respondents also said that women with disabilities were often neglected during childbirth, as some nurses refused to touch the women, leaving them to clean themselves after birth despite the

women's physical limitations:

"Some people thought they could contract the disability." (Person with disabilities respondent - Ndola, Zambia)

Women with disabilities were highlighted in both Ndola and Gaborone as experiencing particular **discrimination when accessing sexual and reproductive healthcare**. Many respondents stated that healthcare workers frequently slapped and hit women with disabilities during labour. Respondents in Zambia stated that many women avoid accessing antenatal care in anticipation of discrimination. In Gaborone, persons with disabilities respondents said they were often presumed to be victims of sexual assault when accessing sexual and reproductive health services, not as active, consensual sexual partners. The respondents felt their needs, desires and rights to have sexual relationships and found families were delegitimised.

One person with disabilities respondent in Ndola narrated how a nurse slapped her when she went to the hospital for the delivery of her child. "How can such a woman give birth? How could you even do such a thing to yourself?" the nurse asked her. She said the nurse forced her to agree to undergo an operation for delivery. She described, however, how a doctor intervened and examined her and he reprimanded the nurse for taking her to theatre when she was fully able to deliver naturally. The respondent said she nevertheless gave birth to the child without the help of a nurse.

In relation to HIV testing, a respondent from Ndola said "Tatuyako iyo." (Facilitator's translation: "We do not even go there at all"), affirming habits of **healthcare avoidance** due to fear of being discriminated against.

"They accuse us of being difficult, that we are troublesome and because of that we even fear to go to health facilities. [Their] attitude is bad and it tends to stop us from seeking services. We do not even go there. We fear stigma." (Person with disabilities respondent - Ndola, Zambia)

Respondents did not describe significant instances of healthcare workers gossiping about them but did give examples of **derogatory, abusive and mocking language** being used against them by healthcare workers. In Ndola, Zambia, women with disabilities complained that the words used against them when in labour were so degrading that they refused to repeat them during the discussion.

Persons with disabilities respondents in Botswana and Zambia lamented in particular the position of blind and visually impaired persons who were treated as if "they are invisible", especially when bringing an aide with them when accessing care. Respondents related that despite being able to hear and talk for themselves, healthcare workers seldom engaged them directly. Many of these examples were described in relation to **confidentiality failures** by healthcare workers:

"I went to the clinic with my younger sister. When I went to see the doctor I asked her to stay outside. Clearly I wanted my privacy but the pharmacist had no time for me. She could not be bothered to explain the pills to me. Instead she was talking through me as if I wasn't there. This happens a lot, and is very frustrating." (Person with disabilities respondent - Gaborone, Botswana)

Related to this were explanations of multiple instances where healthcare workers provided **insufficient information** to healthcare users and failed to obtain proper informed consent when administering care. In Ndola, when asked on **informed consent**, persons with disabilities respondents did not know that they were even required to consent to treatment, particularly for HIV testing, accepting medication or family planning services. Visually-impaired respondents related difficulty in accessing information. Deaf and hearing impaired healthcare users gave examples of being administered treatment or given medication, without any explanation or informed consent process:

“There are no sign-language interpreters in these health centres and posts. They expect you to write down everything for them to read. What if you are not literate? What if you can’t write because you are too weak to write? Communication with doctors is a big challenge. They end up just giving us panadol even for serious illnesses. One deaf friend of mine was given medicine for high blood pressure instead of been treated for his diarrhoea which he had suffered for three days due to a wrong diagnosis.” (Person with disabilities respondent – Ndola, Zambia)

The failure to make **reasonable accommodation** for persons with disabilities was described by respondents as a form of discrimination. Respondents were able to distinguish “positive” and “negative” discrimination and recognised as discriminatory some healthcare workers’ refusal or ignorance to institute small accommodations to ensure that their rights are respected.

“[They make] false generalisations: we are differently disabled and not the same!” (Person with disabilities respondent – Gaborone, Botswana)

According to persons with disabilities respondents in Zambia, healthcare workers were not willing to explain the contents of medicines dispensed to visually impaired healthcare users:

“For us who are blind, they just shout out the medicine to us without explaining the dosage or even the name of the medicine. They say your relatives will read it for you. But their handwriting cannot even be read by anyone. This means I have received drugs without me agreeing to them.” (Person with disabilities respondent – Ndola, Zambia)

In Botswana, hearing-impaired respondents were frustrated by the absence of any sign language **interpreters** in public healthcare facilities: healthcare users are expected to bring their own interpreters. Hearing-impaired respondents in Ndola demanded that healthcare facilities should employ and train professional sign-language interpreters to ensure that confidentiality is observed.

In the absence of an interpreter to assist, respondents stated that they were **ignored** or not given **information** on their treatment or diagnosis. In Zambia, hearing-impaired respondents said they had never received counselling when testing for HIV and feared humiliation following communication breakdown:

“I went to a clinic by myself and when it was my turn the nurse asked me to go get an interpreter so he could help me. I told [him] that I had no

interpreter and that I was able to read and write, so we could communicate that way. He immediately said it would take too long, as if that was my problem. I refused to move and told him that I was not going away until I got the help I needed. Of course his attitude immediately got rough, and he did not bother to explain what treatment he was prescribing.” (Person with disabilities respondent – Gaborone, Botswana)

Several examples were given of simple **physical assistance being denied**, particularly for women with physical disabilities when accessing maternal healthcare.

“When I was pregnant I was forced by nurses to get onto a very high bed. With my heavy pregnancy and my physical disability they could not give me a stool or adjust the bed. Our clinics do not have facilities that are accessible. A lot of times we have to use stairs and it is a big problem. Even the main hospital has stairs to the main foyer making it difficult to access the lift.” (Person with disabilities respondent – Ndola, Zambia)

Respondents did not describe concerns over the segregation of healthcare users, but in Zambia, persons with disabilities respondents raised concerns about the treatment of persons with mental and intellectual disabilities, particularly their detention and forced treatment.

Why are we discriminated against?

When asked why persons with disabilities were discriminated against in accessing healthcare, respondents in Zambia used the Bemba word “Ichifukushi”, which means “a grudge against persons with disabilities.” Respondents noted that discrimination was driven by ignorance, fear of the unknown and a general tendency to look down on persons with disabilities.

In Botswana and Zambia, respondents strongly indicated traditional and religious beliefs as driving intolerance towards persons with disabilities. Even in urban centres like Gaborone, it was explained that many people still believe disability to be a curse or the result of witchcraft:

“Christianity [in the] Old Testament suggests that disability is an indication that one has demons or is possessed by demons or has a curse over them. All of these, it is believed, can be exorcised through prayer. All the time people start conversations with me only to suggest that I have either been bewitched or I am possessed by demons – that I should go to church to have the demons exorcised, which is ridiculous really. But this explains the stigma, the need for parents of disabled children to hide their children, sending them to the cattle posts or farms where they will not be seen.” (Person with disabilities respondent – Ndola, Zambia)

Respondents in Gaborone inferred that the practice of families “hiding” children with disabilities was both a cause and symptom of stigma against persons with disabilities.

Access to accountability and redress

In comparison with other focus-group participants, persons with disabilities respondents in

Zambia described rich and directly confrontational examples of seeking accountability from healthcare workers. All examples were, however, of direct confrontation of the offending party with no instances of engaging any complaints procedures as such. Zambian respondents felt they were perceived by healthcare workers as being troublesome in complaining too much but were unaware of any process external to the health facilities themselves where complaints could be made. In a number of these examples, persons with disabilities respondents were, in contrast to other participant groups, more assertive of their rights:

“I went to a chemist and wanted condoms. This man looked at me as I specified the type of condoms I wanted, but the pharmacists kept looking at me. Then he asked if I use them. He asked about my partner. I asked him if he asks everyone about their partners and that is how he kept quiet. Attitude is bad and it tends to stop us from seeking services.” (Person with disabilities respondent - Ndola, Zambia)

“When I was in Monze town one lady with a disability was made pregnant. At the hospital during examination, the nurse said in Bemba, a Zambian language, ‘tamwilunfyelila uluse?’ [Facilitator translation: ‘Do you not feel pity for yourself?’. I asked the nurse whether she was married. When she said yes, I told her that the other lady also wanted to give birth like her. ‘Are you not married?’ I asked her to say ‘this woman is married just like you’ - and she did. The clinical officer agreed with me that she is human and has the same feelings and she should not be stopped from enjoying her sexual and reproductive rights. The nurse was warned.” (Person with disabilities respondent - Ndola, Zambia)

One participant described an incident with a doctor when seeking an explanation of why his medication had been changed:

“I told him, ‘it is because you did not ask me what drugs I am not friendly with.’ ‘I always react to that drug,’ I told him. ‘You should have asked for my consent to the drug,’ I shouted at him. I said, ‘is it because I am deaf that you wanted to kill me?’” (Person with disabilities respondent - Ndola, Zambia)

A respondent in the Ndola focus group described frustration with this method of seeking accountability, in how persons with disabilities often end up insulting healthcare providers after experiencing mistreatment or discrimination. One respondent provided details of their experience in seeking to escalate a complaint against a healthcare worker at facility-level:

“In 2011, during circumcision, I complained that the nurse left me without showing me where my clothes were. Yet I am blind. How was I to see them? I complained to management but they said they could not do anything as they could not know who did the circumcision. I complained to the sister in charge and got no help.” (Person with disabilities respondent - Ndola, Zambia)

Respondents in Ndola were nevertheless able to discuss and determine together the available

procedures for how ideally complaints should be made. It was agreed that the first step in reporting a complaint would be to start with the sister in charge and then to take it to district medical office. If no help is obtained, then the complaint should be made to the provincial health office:

“The biggest issue is that we have fear. When a medical officer speaks we develop fear. Follow the supervisor. We need to take these matters up so that our rights can begin to be addressed. They have a perception that persons with disabilities are a problem.” (Person with disabilities respondent, Ndola, Zambia)

When respondents were asked why they might not lay complaints when experiencing mistreatment or discrimination, a common response was that of fear of retribution by healthcare workers and future denial of services:

“I cannot take a doctor to court because I will suffer and may never seek health services ever again.” (Person with disabilities respondent - Ndola, Zambia)

Other respondents said they did not know what their rights were or how they could complain:

“We also do not know our rights and how to use them.” (Person with disabilities respondent - Ndola, Zambia)

Respondents in Zambia said an effective complaints process for them could be to use civil society organisations to coordinate a mechanism for lodging complaints so that action could be taken against perpetrators. Zambian respondents emphasised the main purpose of a complaints procedure would be to change laws and policies in order to ensure that persons with disabilities are empowered and so that discrimination in healthcare is prevented:

“We want them to be punished for wrongdoing to deter future offenders so that they develop fear. We need policies to change for the better and laws must become better so that we lead a better life. We need positive discrimination towards persons with disabilities to give them preferential treatment.” (Person with disabilities respondent - Ndola, Zambia)

In Botswana, respondents did not relate any examples of complaining about mistreatment or discrimination. The respondents were, however, unanimous in stating that the desired outcome from a complaint would be to see a change in policy or law. The respondents noted their desire for clear and enforceable consequences for healthcare workers who discriminate against them. Disciplinary hearings should be held with the possibility of the healthcare worker being sanctioned and apologies made to the victims.

In Botswana, respondents indicated distrust about existing complaints procedures, with no confidence that redress would result even if complaints were made. Respondents expressed a sense of resignation towards social condoning of discrimination against persons with disabilities.

What is needed for change?

Persons with disabilities respondents in Botswana and Zambia were asked what they thought was needed to change practices of discrimination in healthcare. In Botswana, respondents stressed the need for updated laws and policies on disability to ensure respect for the rights of persons with disabilities. Complaint procedures should be included in any new legislation.

In both countries, respondents said complaints processes need to be clearly articulated in policy and should provide for effective enforcement. Respondents sought a policy with clear guidelines on ethical conduct of caregivers. It was suggested that healthcare users should be given copies of rules, in a format appropriate to the healthcare user's needs and abilities. Effective access to information was also described as being important for persons with disabilities to make informed decisions on their healthcare, so reducing the reliance on healthcare workers exclusively.

Respondents stressed that information on existing complaints processes must be disseminated to persons with disabilities through representative organisations in simple or local languages, which processes should include opportunities to submit complaints to NGOs working with persons with disabilities. In addition, it was suggested that personnel in community-based mechanisms and the police should be educated on disability rights.

The need for training and sensitisation of healthcare workers, communities and persons with disabilities was strongly emphasised by all focus groups. Training should be inclusive of medical ethics, healthcare users' rights, disability rights, basic sign language, and the obligation to take time to explain issues to persons with disabilities, among others. To this extent, some participants appeared to empathise with healthcare workers who were "lost" and made mistakes.

"It would be good to have perpetrators arrested. But we need not be treated by what I am, but by whom I am. We will die if left behind. We need the rights of persons with disabilities to healthcare to be stuck in public accessible places in the clinic and other healthcare institutions. Health centres should be sensitised on our rights." (Person with disabilities respondent - Ndola, Zambia)

"We need stronger advocacy and [to have] sensitisation in hospitals on disability so that their rights are respected in the healthcare system. Clear awareness raising as they are doing for HIV and AIDS." (Person with disabilities respondent - Ndola, Zambia)

In both Botswana and Zambia, respondents envisaged improvement through the strengthening of civil society advocates on disability rights. In Botswana respondents were aware that the Botswana Council for Disabilities receives complaints as does the Disability Coordinating Office in the Office of the President. Respondents were not confident, however, that either body had sufficient capacity to follow up on complaints effectively, nor to meaningfully reach persons with disabilities in rural areas.

In Zambia, respondents identified the need for community-based organisations to be supported and trained to identify discriminatory conduct and rights violations in healthcare and to refer cases to the appropriate complaints process.

Conclusion

- The narratives of persons with disabilities indicate that extent a failure to provide information and to apply full informed consent procedures is a form of discrimination. Respondents are aware that they are often treated as persons who lack the capacity to decide for themselves and not as autonomous persons. The challenges faced by deaf and hearing-impaired healthcare users were strongly highlighted amongst participants, who described repeatedly being ignored by healthcare workers.
- The manifestation of discrimination against persons with disabilities in healthcare is exacerbated in the context of women's access to sexual and reproductive healthcare services. This not only relates to positive discriminatory conduct but also to failures to reasonably accommodate the needs of women with disabilities to enable them to access healthcare equitably.
- In Botswana, the focus-group facilitator noted that participants were confident about their rights. Persons with disabilities respondents in both Zambia and Botswana raised and engaged in complex notions of positive and negative discrimination and concepts relating to affirmative action. It is noteworthy that persons with disabilities respondents described significantly more assertive practices of seeking accountability and redress when experiencing discrimination. While selection bias and other factors may indeed account for this, the capacity of persons with disabilities to assert their legal rights when experiencing abuses may also be understood in the absence of legal prohibitions against persons with disabilities that otherwise function to constrain other focus-group participants interviewed, such as sex workers and LGBT persons.
- However, the accounts of complaints were usually of direct confrontations with the offending healthcare workers and seldom with an outcome that meaningfully addressed the complainant's needs and frustrations. The absence of an effective, accessible and responsive framework for complaints for persons with disabilities is highlighted in these narratives.
- Finally, it is important to emphasise the absence of the perspectives of persons with mental and intellectual disabilities from the experiences described. This is noted as an issue where further research is needed.

6.6 Poverty and the rural/urban divide

Introduction

“There is also a lot of discrimination on the basis of socioeconomic status. For example, in the line, healthcare workers will be selective about who they attend to first – they assume the poor can’t do anything about it. The higher your status, the more likely you are to complain. Since I complained on behalf of someone else, they are more responsive to me in particular.”

(NGO respondent – Lusaka, Zambia)

Throughout focus groups, key informant interviews and consultations with NGOs and CBOs, a repeated theme emerged on the exclusionary role of poverty and rural location as a systemically-entrenched ground of discrimination for healthcare users in Botswana, Malawi and Zambia. Some studies have shown that increased availability of treatment and services reduces HIV-related stigma and discrimination.³⁸⁶ To the extent that healthcare accessibility is reduced in rural areas, it can be anticipated that higher levels of stigma and discrimination would prevail. To the extent that rural and poor populations are underserved in the allocation and distribution of health resources, this may be identified as a form of systemic discrimination.

The United Nations Committee on Economic, Social and Cultural Rights has emphasised the importance of the effect of conditions of impoverishment on the enjoyment of the right to health:

“The right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment.”³⁸⁷

Situation analysis

In **Botswana**, rural settings accommodate around 75% of the population where public healthcare is primarily accessed through mobile stops, health posts and clinics.³⁸⁸ Respondents in this report identified practical limitations that made healthcare access difficult for rural populations, including distance to facilities. In Selebi Phikwe, Botswana, sex worker respondents noted in particular the difficulty of accessing healthcare if they didn’t have an identity card, which was stated to be difficult to access in rural areas or when mobile.

“We’ve heard however about a negative practice wherein people of a certain social class are offered the private ward in our public hospitals, which is wrong. All patients are equal before our public-health facilities whether one is a government minister or street child.” (BHPC – Gaborone, Botswana)

³⁸⁶ S Maman et al. “A Comparison of HIV Stigma and Discrimination in Five International Sites: The Influence of Care and Treatment Resources in High Prevalence Settings” (2009) 68 *Soc Sci Med* 2271; A Farmer & P Castro “Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti” (2005) 95 *Am J Public Health* 53.

³⁸⁷ CESCR *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)* (11 August 2000) at para 4.

³⁸⁸ HA Akinsola “Ethical concerns in nursing practice in Botswana” (2001) 8 *Nurse Ethics* 342.

In **Malawi**, government policy explicitly acknowledges not only the discrimination in healthcare access for impoverished sectors of society but also the greater vulnerability of the poor to threats to their health. The Malawi Health Sector Strategic Plan, for example, draws a link between expanding and improving healthcare and reducing poverty:

“The prevalence of diseases such as malaria, acute respiratory infections and diarrhoea, is higher among poor people compared to those who are rich. Therefore, the successful implementation of the [Health Sector Strategic Plan] will depend to a large extent on the reduction of poverty.”³⁸⁹

The link between poverty and public health is also clearly established in the Malawi Growth and Development Strategy 2011-2016 and in the Malawi National HIV and AIDS Strategic Plan 2011-2016.³⁹⁰ Most of Malawi’s population live in rural areas (some 80%) and experience inequitable access to healthcare:³⁹¹

“Access to [sexual and reproductive health and rights] services is worse in rural areas, as there is inequitable deployment of health personnel, which favours urban areas, [and to] the secondary and tertiary levels of care. This is aggravated by the critical shortage of health workers across the board, but especially [the] shortage of midwives.”³⁹²

The Commission on Social Determinants of Health found in its 2008 report that one of the social determinants of health was the misdistribution and poor quality of healthcare delivery systems.³⁹³

Health systems’ failures also unequally burden the poor. Women living with HIV respondents in Chiradzulu, for example, stated that “sometimes at [ART] clinics they are told to buy medication privately when medicines are not available at the facility due to stock outs.” Most say that they cannot afford to purchase the medication.

Respondents from the Malawi Human Rights Commission, interviewed for this report raised concerns about what they felt was discrimination through the lens of resource constraints. The Commission respondents noted issues concerning the locations of health facilities and investments, disparities in rural/urban healthcare worker staffing ratios, and disparities in healthcare access between the rich and poor despite policy commitments to universal care. An example provided of the discriminatory consequences of resource constraints and misallocation was how women in Lilongwe are at times referred for caesarean sections due to the unavailability of Pitocin, a hormone commonly used to induce or augment labour.

³⁸⁹ Notes 142, 17 above.

³⁹⁰ Malawi National HIV and AIDS Strategic Plan 2011-2016, notes 29, 2 above.

³⁹¹ Gaps in Universal Health Coverage in Malawi: A Qualitative Study in Rural Communities, note 27 above.

³⁹² Republic of Malawi: Ministry of Health *Sexual and Reproductive Health and Rights Policy* (2009), 5. See, also, Malawi Health Sector Strategic Plan, note 142 above: “In particular, access to health care is low among the rural poor and the cost of maintaining better health is high.”

³⁹³ WHO Commission on Social Determinants of Health *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health* (2008), available at: http://apps.who.int/iris/bitstream/10665/43943/1/9789241563703_eng.pdf.

In **Zambia**, the Government's Vision 2030 asserts the right of equality in access to and use of good quality healthcare for all regardless of socioeconomic status.³⁹⁴ Despite this, studies show that the wealthy access public healthcare more than impoverished populations, despite having a lower need for healthcare.³⁹⁵ A 2007 Department of Health study showed that while persons living in urban areas are almost twice as likely to be living with HIV than persons living in rural areas, comparisons of HIV prevalence between 2001 and 2007 by the Department show that the epidemic is contracting in urban areas (with a 3.4% decrease in urban prevalence in that time) while the rural HIV prevalence remained "virtually unchanged" between 2001 and 2007.³⁹⁶ Studies have also indicated lower levels of accepting attitudes towards persons living with HIV in rural areas.³⁹⁷

NGO and CBO respondents described a dual system of care in urban public healthcare facilities where paying "customers" received preferential treatment to those who accessed free services:

"If you don't have money, you will wait in the long queue. But if you pay those people they will treat you and take you ahead of the line." (Sex worker respondent - Lusaka, Zambia)

"At Kabwe General Hospital, the medical personnel have a tendency of keeping people without money for long hours without attending to them. They first attend to people with money, who are often late to come to the Hospital. Some people do not even wait in the queue for collecting [ART], they just walk straight into the doctor's office and collect their drugs; others just make phone calls." (Woman living with HIV respondent - Kabwe, Zambia)

Conclusion

- Whether as intersectional grounds, or independent grounds of discrimination, healthcare users who are poor and/or live in rural areas have reduced access to healthcare services, appear to have greater needs for health services, and are (based on anecdotal evidence) more likely to experience stigma and discrimination in healthcare
- It may be useful to focus advocacy efforts on identifying inequitable allocations and distributions of health resources as discriminatory when addressing policy and budgetary reform.
- In addition, poverty and rural location impacts the accessibility of complaints processes and the choices that complainants may make in using a particular complaints process. In order for complaints systems to be effective as tools for accountability and redress in healthcare, particular consideration needs to be given to the needs of healthcare users who are poor and live in rural areas.

³⁹⁴ Government of the Republic of Zambia: Ministry of Finance and National Planning *Vision 2030* (2010).

³⁹⁵ J Phiri and JE Ataguba "Inequalities in Public Health Care Delivery in Zambia" (2014) 13 *International Journal for Equity in Health*, available at: <http://equityhealth.biomedcentral.com/articles/10.1186/1475-9276-13-24>.

³⁹⁶ Zambia Country Report: Monitoring the Declaration of Commitment on HIV and AIDS and the Universal Access, notes 311, 12 above.

³⁹⁷ Zambia: Demographic and Health Survey 2013-2014, notes 337, 123 above.

6.7 Perceptions of discriminatory behaviour: Complaints mechanisms, NGOs, and CBOs' perspectives

"Discrimination in Botswana's health sector is not prevalent. This finds evidence in the fact that health services are available for free to every citizen, which ensures definite access to healthcare.

Having said that, however, HIV-positive members of Botswana society perceive the existence of special clinics ... as discrimination. This is not fair to the government because clinics that are dedicated to specific ailments have over the years been the norm in Botswana to ensure efficiency and focus. HIV-positive members of our society rather than feel discriminated against should notice the extra mile that the healthcare sector takes for them. To avoid them being in long queues with all sick people, the government has established clinics dedicated to HIV treatment, care and support. The efficient and effective management of pandemics such as HIV calls for separation at times and HIV being the complex virus that it is that needs laboratories and specialists is no exception." (Complaints body respondent - Gaborone, Botswana)

Key informants who were interviewed from complaints bodies had different perspectives on healthcare discrimination than those of key population and vulnerable persons from focus group discussions presented above. Health professions councils and nursing councils in particular tended to take a jaundiced view on the extent to which behaviours complained of as discriminatory by focus-group respondents were indeed discriminatory. For example, these respondents stated that disclosure of a healthcare user's HIV-status to other health professionals was not a breach of confidentiality, whether or not the healthcare users consented to the disclosure.

Health profession and nursing councils also tended to emphasise that segregation, identifying practices, and the use of excessive precautions are necessary procedures and techniques of patient-management and are important for effective data capture. For respondents who made these justifications, it was not raised as a relevant concern that healthcare users perceived these practices as discriminatory or that the practices resulted in social stigmatisation and breaches of healthcare user confidentiality:

"No it is not discriminatory. It is the system. Certain systems must be put in place to make one's work easier. People go to all sorts of clinics - eye clinics, ART clinics, diabetes clinics, etc. These systems are for efficiency." (Complaints body respondent - Lusaka, Zambia)

Nursing councils in particular raised at times the importance of segregation and identifying practices to ease human resource pressures in contexts of significant under-staffing. A number of behaviours identified by focus-group respondents above were justified by nursing councils as unintentional results from capacity constraints. For example, a respondent from a nursing and midwifery council stated that often ignoring a healthcare user was merely the result of implementing a "first-come-first-serve" policy.

Some respondents from health professions and nursing councils also sought to draw sharp distinction between behaviour that is discriminatory and that which is “merely” malpractice or unethical conduct. However, none of these distinctions were justified on the basis of differential treatment between groups or persons. In some instances, respondents illustrated a reluctance to engage with the concept of discrimination either as a form of aggravated malpractice or as an independent concept falling within the ethical vocabulary of their respective professions. A failure to conduct a proper informed consent process with a healthcare user was explained, for example, as incompetence and not discrimination:

“In the healthcare setting we speak of negligence, misconduct and malpractice. Discrimination as a concept is not alive in our space.”
(Complaints body respondent – Gaborone, Botswana)

“Discrimination is an attitude not a practice.” (Complaints body respondent
– Lusaka, Zambia)

However, on some issues, health profession and nursing councils expressed strong views on the importance of healthcare users’ rights, even if not engaging in concepts of discrimination and stigma directly:

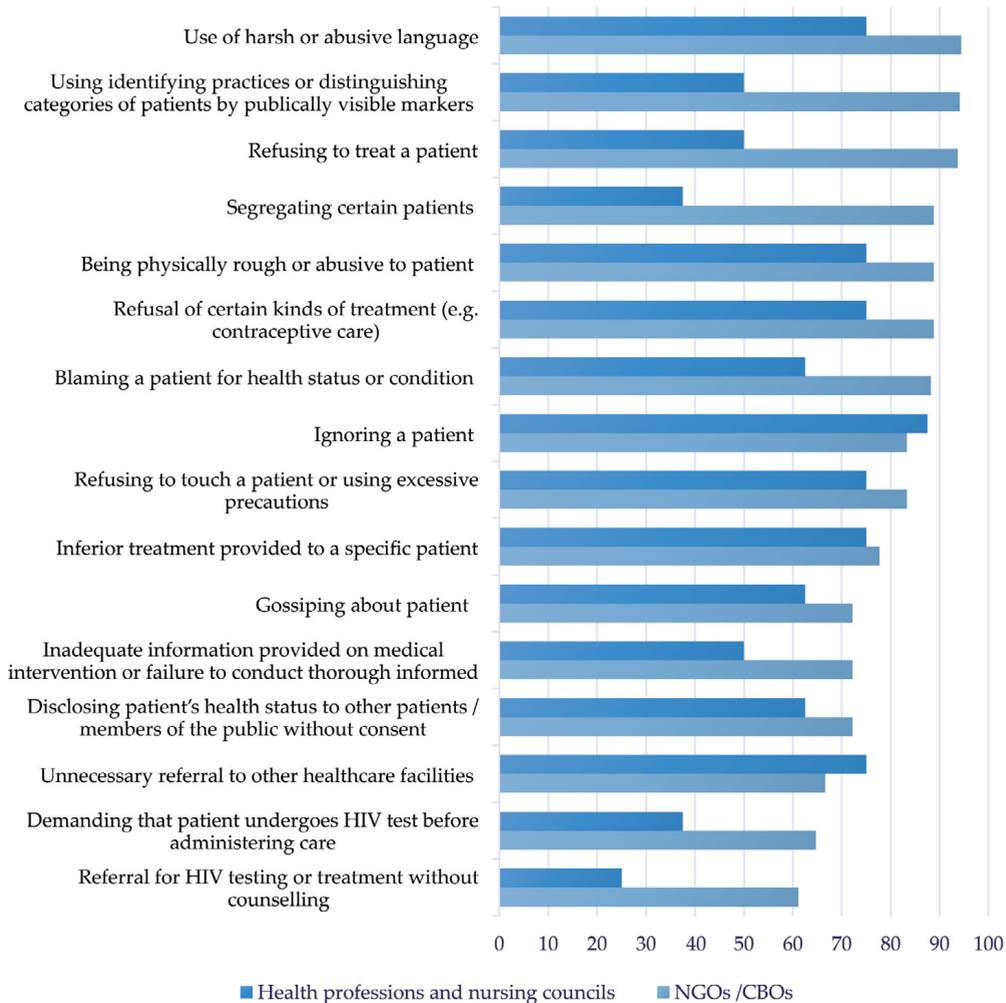
“As long as the patient is breathing or their heart beating, they have the right to be treated.” (Complaints body respondent – Gaborone, Botswana)

“Health facilities are a place for care, comfort and refuge and harsh, abusive language should not be tolerated.” (Complaints body respondent – Gaborone, Botswana)

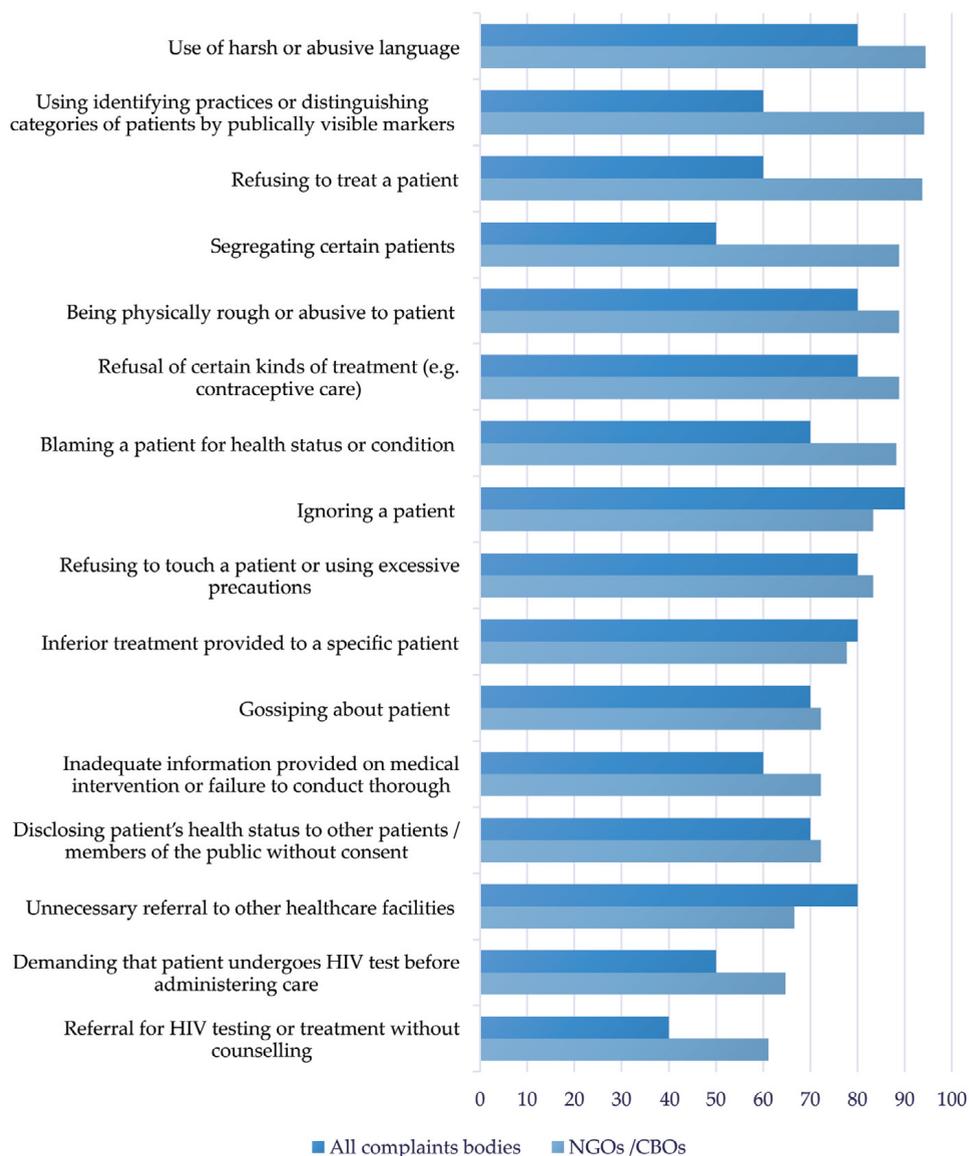
While human rights complaints bodies outside of the healthcare system (such as human rights councils and ombudspersons) tended to be more healthcare user-centred in their assessment of whether certain behaviours in healthcare amounted to discrimination, these bodies were less aware of the particularities of the healthcare environment. Some respondents highlighted the bodies’ inexperience with issues on healthcare in general.

The graphs below illustrate differences in the assessments of whether certain behaviours constitute discrimination in the context of healthcare as expressed by NGO and CBO respondents and complaints body respondents. Respondents from NGOs and CBOs and complaints bodies were asked to indicate whether certain behaviours in the context of healthcare or as enacted by healthcare providers were discriminatory. The graphs (below) show the percentage of respondents who identified the behaviours as discriminatory across the three countries. The difference in assessments of the behaviours’ discriminatory quality is more marked when considering the views of health professions and nursing councils in comparison with NGO and CBO respondents than when including the more generous views expressed by human rights complaints bodies.

Behaviours perceived as discriminatory: Comparing health profession bodies with NGO and CBO perceptions



Behaviours perceived as discriminatory: Comparing all complaints mechanisms with NGO and CBO perspectives



6.8 Conclusion

The experiences described by focus-group respondents indicate anecdotal evidence of pervasive and ongoing discrimination and stigma in healthcare in Botswana, Malawi and Zambia based on a number of grounds including health and HIV-status, gender, sexual orientation, disability, socio-economic status, occupation, and rural location. Worryingly, respondents described direct effects of discriminatory treatment on healthcare avoidance, self-medication, and social alienation.

Respondents described continuity between traditional and religious beliefs held by community members and the attitudes exhibited in conduct towards them by healthcare workers. Despite this, several respondents could relate empathetically to the constraints under which healthcare workers in the public sector function and were able to draw on these pressures as factors which exacerbated discriminatory conduct.

The use of abusive language and practices of dismissive conduct, including failures to properly examine healthcare users before providing treatment, were predominant in participants' descriptions of behaviours perceived as being discriminatory.

Healthcare-user confidentiality was also described as both discriminatory conduct and as an inhibition in health-seeking or accountability-seeking behaviours by respondents. It is important to note that LGBT and sex worker respondents in particular drew attention to the importance of not only health-status confidentiality but also healthcare user identity confidentiality (e.g. that the healthcare user is or is perceived to be an MSM or a sex worker) as central to ensuring that healthcare users can access healthcare safely, appropriate to their needs, and in good time.

Effective and respectful communication between healthcare workers and healthcare users was central to respondents' perceptions of discrimination. When healthcare workers do not conduct proper informed consent, do not accommodate healthcare users' needs to ensure they understand their health conditions and treatment options, and when healthcare workers do not communicate respectfully to healthcare users when operating under resource pressures, these behaviours are marked as discriminatory and are experienced by key populations and vulnerable populations in particular as being dehumanising. Power disparities between healthcare workers and healthcare users seeking to access public-health services, were directly noted by sex workers in particular and indirectly described by all focus groups.

Two areas of particular policy concern are noted. The first was that of healthcare workers denying healthcare users access to STI and HIV testing, counselling and treatment in the absence of (heterosexual) sexual partners. Respondents have described this conduct as functioning to deny access to testing, counselling and treatment.

The second issue, is that of segregation and the use of identifying practices for people living with HIV in Botswana and Zambia. While health professions and nursing councils were insistent on the benign managerial nature of these practices, it must be emphasised that respondents noted these as discriminatory and exacerbating social stigma while also inhibiting health-seeking behaviour. People living with HIV in particular called for integrated services.