Towards Effective Management of HIV Prevention, Treatment and Care (PTC) Services among Sexual Minority Groups in Rwanda

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Abstract

Effectiveness of national HIV prevention, treatment and care (PTC) services is evaluated on the potential to provide access to services by all groups in the country. This paper addresses systemic barriers that limit access to HIV PTC programmes in Rwanda by lesbian, gay, bisexual and transgender (LGBT) persons, and the real health needs of these people. Proposals and practical solutions to ensure equality and change are advanced. The findings are from CBO social workers working with sexual minority groups, government health officials and leaders of sexual minority groups from the City of Kigali. A total of 46 respondents out of the expected 60 returned a survey questionnaire, a response rate of 77%, and 12 key informants answered interview questions. Data was analysed using descriptive statistics and content analysis. National HIV PTC programmes in Rwanda do not effectively reach sexual minority groups. Services do not address the real needs of sexual minority persons; nor do they promote materials and strategies appropriate to them. Health care providers do not respect the rights of LGBTI persons and openly promote disempowering environments for these groups. The vast resources spent on national HIV PTC services should be planned to provide LGBT-friendly services in a safe and empowering environment. LGBTI people need legal support and a voice to promote their rights to health care.

Key Words: LGBTI; HIV PTC Services; Sexual Minority Groups; Rwanda

Introduction

Sexual minorities in Rwanda include persons who profess to have sexual interest in people of both sexes (bisexuals) or people of the same sex (homosexuals). This group includes LGBT persons. Statistics indicate that sexual minorities are on the increase in Rwanda [1]. While neighbouring countries such as Uganda and Tanzania have legislation that curtails the freedoms of LGBT persons, Rwanda is among the few countries in East Africa that promote their rights and freedoms. Rwanda is among the 57 states that signed the UN Declaration on Sexual Orientation and Gender Identity, and one of the six African countries that signed the UN Report on Sexual Orientation and Gender Identity [2].

However, human rights violations on the basis of sexual orientation still persist in Rwanda. In particular, these include verbal and physical violence as well as extortion by the Inkeragutabara (reserve force of the Rwanda Defence Forces), arbitrary arrests by the police and arbitrary detentions at Gikondo Centre [3]. This scenario is attributed to the influence of religions and rigid conceptualisation of culture on public opinion. This scenario has consequently led to the perpetuation of human rights abuses against LGBT persons and sex workers. The ultimate consequence is the increased and unaddressed vulnerability of LGBT persons to various human rights violations, including verbal and physical abuse, denial of access to basic services and discrimination. This is happening amidst the existence of the Rwandan constitution that explicitly provides for protection against sexual minorities and that prohibits all forms of discrimination [4].

Being lesbian, gay, bisexual or transgender is still viewed as going against the order of nature and normally generates a lot of controversy among the general public in Rwanda. Currently, men and women who have sexual preferences other than heterosexual ones generate anxiety and disorder in the community [3]. These people are not viewed as persons with the same human rights and social responsibilities as heterosexual Rwandan citizens. As a result, they find it difficult to access rightful services.

Accessing health services is a right for all Rwandans. Most health services are accessed free of charge in government hospitals (Rwanda government, 2009). However, statistics indicate that LGBT persons in Rwanda are finding it hard to access HIV and AIDS PTC services [3]. While the national HIV prevalence rate stands at 3%, the prevalence of HIV among sexual minorities is estimated to be above 7% [4]. This scenario implies that the current national HIV PTC programmes do not reach sexual minorities. The majority of LGBT persons in Rwanda are in positions of dependence and inferiority, and this makes it a challenge to access general health services [5]. This paper provides information that can be used to evaluate the relevance of national HIV prevention programmes to
sexual minority groups in the areas of promoting access to sexual health services, the personality of service providers, the existence of a safe and empowering environment, addressing the vulnerability and dependence of sexual minorities and building the capacity of civil society organisations (CSOs) to empower LGBT persons.

**Problem**

National HIV and AIDS PTC programmes in Rwanda have since 2012 striven to achieve universal access to HIV and AIDS services and to provide care and treatment for HIV and AIDS to all people in need of treatment [3]. Despite these efforts, the HIV prevalence rate among sexual minorities remains higher than the national average [4]. This implies that national HIV and AIDS programmes may not be reaching sexual minorities [6]. Studies [1] still show that sexual minorities remain socially disadvantaged in Rwanda, making their access to HIV and AIDS PTC services difficult.

Hence the key questions for this study were:

1. What systemic challenges prevent sexual minority groups from accessing HIV PTC services?
2. What is needed to have friendly HIV PTC services for sexual minorities?

The above questions are examined under five themes that are the thrust of this study. The themes are: The promotion of access to sexual health services among sexual minorities; the personality of service providers; the existence of a safe and empowering environment; addressing the vulnerability and dependence of sexual minorities; and building the capacity of CSOs to empower LGBT persons to fight for their rights.

**Status of HIV PTC Management Programmes in Rwanda**

Since HIV and AIDS were discovered in Rwanda in 1983, relentless efforts have been put into controlling its spread and impact. Rwanda has made a number of commitments at global and national levels to fight HIV and AIDS [1]. At global level, Rwanda has acceded to international treaties that include SGDs, whose target 6 is to halt and reverse the spread of HIV and AIDS and to achieve universal access to the treatment of HIV and AIDS for all who need it. On the national scene, Rwanda has national programmes intended to increase HIV and AIDS awareness among the population, promote the use of condoms and PMTCT as a preventive measure, as well as the provision of nutritional aids to those already infected and living with the pandemic [4].

The Rwandan head of state and the first lady have been personally involved, through their leadership, in the fight against HIV and AIDS. Recently, the Rwandan government restructured the coordination of AIDS control activities by creating the NACC [1], whose objective is to promote a multi-sectoral approach and strengthen cooperation. TRAC (2009) was also established to strengthen the health sector’s capacity to respond to complex issues and to improve its capacity to provide appropriate medical services in relation to AIDS. Currently, safe blood transfusion services are provided by the National Blood Transfusion Centre through a total of 22 sites [7]. The STI control programme is active and ARV drugs are available on the market.

These achievements do not match the current state of affairs with regard to HIV PTC among minority and marginalised groups. Marginalised groups do not generally access HIV prevention services. For instance, only 20% of the adult women compared to 40% of the adult men were found to have used condoms when they had high-risk sex [1]. When HIV testing is considered, high levels of inaccessibility are evident among LGBT individuals. A survey on HIV prevalence in Rwanda conducted in 2013 showed that 76% of gay men and 78% of lesbian women had never had any HIV test [1].

**Methodology**

The respondents in this study included CBO social workers working with sexual minority groups, senior health officials working in national HIV and AIDS programmes and leaders of sexual minority groups from the City of Kigali. A total of 46 respondents out of the expected 60 returned the survey questionnaire, giving a response rate of 77%. A closed-ended questionnaire was administered to the respondents and eventually a variety of analyses were conducted to explore the research questions postulated above. Twelve key informant structured interviews were also conducted with leaders of sexual minority groups to supplement quantitative information.

The researcher purposively selected respondents whom he thought had first-hand information on the research questions. Interviews with key informants were done through face-to-face and email exchanges as well as on the Web.

LGBT leaders were selected from groups in Kigali. Although this research sought to collect information from LGBTI persons in Rwanda, it faced limitations in accessing inter-sex persons and information relating to them. So the findings are limited to LGBT Rwandans.

The questionnaire and interview guide collected information on gaps in sexual health services for sexual minorities, the personality of service providers, the existence of a safe and empowering environment, the vulnerability and dependence of sexual minorities and the capacity of CSOs to empower LGBTI persons. In the questionnaire, the respondents indicated whether they disagreed or agreed to statements that measured each of the five issues that were being investigated. Responses were made on a Likert scale on which 1 represented ‘strongly agree’, 2 ‘disagree’, 3 ‘not sure’, 4 ‘agree’ and 5 ‘strongly agree’.

The analysis of quantitative data was performed using the Statistical Package for Social Scientists (SPSS). Quantitative data was checked for completeness, consistency and accuracy immediately after it was collected. Data entry screens for quantitative data were developed with all the necessary validation tools to eliminate error that could be introduced at the stage of data entry [8]. The mean response and standard deviation as well as overall rating on each item were calculated. The mean response was taken to show the general view
of respondents on the item. On the basis of Blanche, Durrheim and Painter’s (2008) [9] methods, the more the items on which the respondents generally agreed the higher the level of agreement of respondents on the existence of the issues in the national HIV PTC service programmes. The overall rating showed the general level of agreement or disagreement on the item. This was taken as the predominant view of the respondents on that issue.

Qualitative data was primarily collected through key informant interviews (KIIs) and analysed using a thematic content analysis approach. Themes were developed in accordance with the objectives of the study and expected outcomes. Data was then grouped according to these themes, as a first step towards subsequent interpretations. Pragmatic content analysis (PCA) techniques were adopted from Mugenda and Mugenda (2005) [10]. Concepts were classified according to their probable causes and effects. The intensity with which certain words were used was ascertained. This enabled the researcher to establish why something was said, which subsequently led to understanding the respondents’ perceptions of issues. The general view of the respondents on each theme was used to confirm or indicate divergence with quantitative findings.

Results and Discussion

The results and discussion are presented in five parts under the themes: Gaps in sexual health services for sexual minorities; the personality of service providers; the existence of a safe and empowering environment; the vulnerability and dependence of sexual minorities; and the capacity of CSOs to empower LGBTI persons. Information from the respondents who completed the questionnaire is presented first, followed by that from key informants.

Gaps in Sexual Health Services for Sexual Minorities

The respondents were asked to indicate gaps that they noticed in the available sexual health services for sexual minorities. This was done by indicating the extent to which they agreed or disagreed with the five aspects that signify the existence of good sexual health services for sexual minorities. The findings are presented in Table 1 below.

The findings in the table show that with regard to services addressing the real needs of sexual minorities, the respondents generally strongly disagreed (mean response = 1.1, sd = 2.3). The respondents also disagreed (mean response = 2.1, sd = 3.1) on the prevention services promoting strategies appropriate to sexual minorities. As far as special prevention materials such as dental dams and lubricants being easily accessed by sexual minorities were concerned, the respondents strongly disagreed (mean response = 1.2, sd = 2.6). The respondents were also not sure (mean response = 2.9, sd = 1.5) whether special prevention materials were distributed free of charge to sexual minorities. Regarding LGBT persons accessing prevention training appropriate to their needs, the respondents strongly disagreed (mean response = 1.1, sd = 1.4). The respondents also disagreed (mean response = 2.1, sd = 3.2) on whether LGBT persons easily accessed ARV treatment. Hence, HIV and AIDS as well as sexual health education in the general national HIV and AIDS programmes were not tailored to the needs of sexual minorities. The programmes did not provide appropriate prevention knowledge, materials and services.

A leader from Other Sheep Rwanda said that this was because LGBT persons were marginalised so had low self-esteem and feared to make their unique needs known in public. The key informants further pointed out that HIV prevention packages had been developed for all key populations, but none existed for LGBT persons. A leader of the LGBT persons from HOCA added that there were no campaigns geared towards the HIV prevention needs of homosexuals in Rwanda so they found it difficult to access special materials that they needed to prevent themselves from contracting HIV. LGBT groups were not able to benefit from peer education models that were designed for the general public. The effectiveness of these models depends on training, which the majority of LGBT persons were not able to access. So their knowledge of HIV prevention and management remained limited. The key informants confirmed this when they said that gay and lesbian populations did not participate in training organised by national programmes on HIV and AIDS owing to fear of discrimination and violence from the public and trainers. The key informants further revealed that the existing LGBT groups were mainly based in Kigali and had access only to the general sexual and reproductive health and HIV and AIDS programmes, and that these primarily targeted MSM and gay and bisexual persons. Lesbian and transgender people were not being targeted.

Sexual minorities also remained disadvantaged in terms of access to HIV treatment. Although the numbers of people gaining access to

| Aspect                                                                 | Mean response | Sd  | Overall rating  |
|-----------------------------------------------------------------------|---------------|-----|-----------------|
| Services address real needs of sexual minorities                      | 1.1           | 2.3 | Strongly disagree |
| Prevention services promote strategies appropriate to sexual minorities| 2.0           | 3.1 | Disagree        |
| Special prevention materials (e.g. dental dams, lubricants) are easily accessed by sexual minorities | 1.2           | 2.6 | Strongly disagree |
| Special prevention materials are distributed free of charge to sexual minorities | 2.9           | 1.5 | Not sure        |
| LGBT persons access prevention training appropriate to their needs     | 1.1           | 1.4 | Strongly disagree |
| LGBT persons easily access antiretroviral (ARV) treatment              | 2.1           | 3.2 | Disagree        |
ARV treatment were generally increasing in Rwanda, the National AIDS Commission (2012) showed that minority groups did not access this service. It was mainly men living with HIV who were found to be accessing ARVs. According to TRAC Plus (2008) [11], in most of the ARV treatment centres in the country, no LGBT person had been registered. A LGBT person from HOCA summed up the situation with regard to ARVs when she said that access to ARVs was a challenge because most of the institutions that are accessible and convenient for most LGBT persons and sex workers did not typically have the ARVs. This had forced the majority of the LGBT persons living with HIV to travel distances that are inconvenient and costly, and that most could seldom sustainably afford.

**LGBT-Friendly Service Providers**

LGBT persons need service providers who understand the challenges they face and can maintain confidentiality regarding their lifestyles. Confidentially has long been recognised as crucial to increasing access to and utilisation of HIV PTC services by LGBT persons [1]. This requires health care professionals and service providers who are trained in managing LGBT persons. To establish these facts, the respondents indicated the extent to which they agreed or disagreed with the four aspects that indicate LGBT-friendly health service provision. The findings are presented in Table 2 below.

According to the above table, with regard to health care professionals striving to meet the specific health needs of sexual minorities, the respondents generally strongly disagreed (mean response = 1.0, sd = 1.4). The respondents also disagreed (mean response = 2.1, sd = 1.1) that HIV and AIDS health care providers maintained strict confidentiality regarding the lifestyles of LGBTI persons and HIV and AIDS treatment in health facilities provided HIV prevention materials specific to LGBTI persons (mean response = 1.6, sd = 1.5). The respondents were not sure whether HIV care providers respected the right to health care of LGBTI persons (mean response = 3.0, sd = 1.6). These findings show that national HIV PTC services do not promote LGBTI-friendly health service provision. Service providers and health care personnel are trained only to provide generalised services that in most cases do not meet the needs of LGBT persons.

This scenario was also confirmed by the key informants. A leader of Pride Ark Kigali said that the national HIV and AIDS PTC programmes made no effort to train health care providers about LGBTI-specific health needs. This led to the majority of health care workers mismanaging and discriminating against LGBTI persons. The key informants further revealed that doctors and nurses on duty asked lots of questions before prescribing treatment for LGBTI persons. As a result, most of them did not want to return for treatment. Homosexuals also had poor access to lubricant gels that existed in small quantities and were not systematically distributed and disseminated with the same consistency as male condoms. A key informant confided that the existing guidelines on the prevention of HIV and AIDS explicitly mentioned facilitation of access to lubricants for female sex workers but excluded male sex workers.

**Existence of a Safe and Empowering Environment**

Discrimination and stigma are currently the major cause and consequence of HIV transmission in Rwanda. So, effective prevention programmes need to have strategies for responding to and eliminating it. This fact was explored using four aspects that indicate a safe and empowering environment for patients in health care facilities. The findings are presented in Table 3 below. The findings in the table above point to lack of a safe and empowering environment for sexual minorities. With regard to whether stigma of minority groups did not exist among health service providers, the respondents were not sure (mean response = 3.1, sd = 2.3). The respondents were also not sure (mean response = 3.0, sd = 2.6) whether discrimination against minority groups did not exist among health service providers in Rwanda. The respondents disagreed (mean response = 2.1, sd = 3.2) regarding whether health

### Table 2: LGBT-friendly health services provision (n=46)

| Aspect                                                                 | Mean response | Sd   | Overall rating     |
|-----------------------------------------------------------------------|---------------|------|--------------------|
| Health care professionals strive to meet specific health needs of sexual minorities | 1.0           | 1.4  | Strongly disagree |
| HIV and AIDS health care providers maintain strict confidentiality regarding lifestyles of LGBTI persons | 2.1           | 1.1  | Disagree           |
| HIV care providers respect the right to health care of LGBTI persons   | 3.0           | 1.6  | Not sure           |
| HIV and AIDS treatment in health facilities provides HIV prevention materials specific to LGBTI persons | 1.6           | 1.5  | Disagree           |

### Table 3: Existence of a safe and empowering environment (n=46)

| Aspect                                                                 | Mean response | Sd   | Overall rating     |
|-----------------------------------------------------------------------|---------------|------|--------------------|
| Stigma of minority groups does not exist among health service providers | 3.1           | 2.3  | Not sure           |
| Health service providers provide a safe environment for sexual minorities | 2.1           | 3.2  | Disagree           |
| Discrimination against minority groups does not exist among health service providers | 3.0           | 2.6  | Not sure           |
| Health service providers provide an empowering environment for sexual minorities | 1.6           | 1.5  | Disagree           |
service providers provided a safe environment for sexual minorities and whether health service providers provided an empowering environment for sexual minorities (mean response = 1.6, sd = 1.5). This finding points to lack of a safe and empowering environment for sexual minorities in health care facilities in Rwanda.

The key informants also confirmed that stigma of and discrimination against minority groups was considerable among health service providers. The key informants complained that health service providers in public health institutions always breached the privacy of their LGBT patients on the basis of their sexual orientation and exposed them to public humiliation and stigmatisation in health care environments. A leader of an LGBT group called Other Sheep explained that in most cases if one health care professional obtained information that the patient was LGBT, he spread the word among others, which exacerbated discrimination.

Lack of a safe and empowering environment was especially demonstrated by lack of confidentiality among health care workers in national programmes for HIV and AIDS. Confidentiality is crucial to increasing access to and utilisation of health care services by LGBT persons. The leader of Hope and Care said that confidentiality was often lacking among health care professionals managing HIV PTC programmes. Even in health care facilities LGBT persons faced social isolation, which increased their vulnerability to HIV and AIDS.

**Vulnerability and Dependence**

The Rwanda National AIDS Commission (2008) [12] indicates that low social status, poverty and unemployment are some of the factors that have fuelled the spread of HIV in the county. However, being a minority group, LGBT persons in Rwanda are predisposed to poverty and unemployment (Republic of Rwanda, 2009) [7]. This group also largely consists of uneducated and impoverished youth (National AIDS Commission, 2008) [13]. So the majority are economically dependent. This scenario reduces their assertiveness and limits their access to information and services. These issues were explored using four aspects that indicate vulnerability and dependence among minority groups. The findings are presented in Table 4 below.

The findings in the above table show that sexual minorities in Rwanda have limited education and low social and economic status. With regard to LGBTI persons in Rwanda being economically vulnerable, the respondents agreed (mean response = 4.0, sd = 1.3). The respondents also agreed that LGBTI persons in Rwanda were less assertive (mean response = 4.2, sd = 2.4) and had limited access to basic services (mean response = 4.3, sd = 1.6). The respondents were not sure (mean response = 3.1, sd = 1.1) whether the LGBTI persons in Rwanda had limited access to information.

The key informants also revealed that the LGBTI persons in Rwanda faced difficult economic and social conditions that made them more vulnerable to HIV and AIDS. A CBO worker from FAAS intimated that the majority of sexual minorities had limited educational attainment, so they found it hard to understand their rights and subsequently fight for them. It was also evident that most of the LGBT organisations were not able to provide socio-economic empowerment.

**Capacity of CBOs**

A number of CBOs have been created to support sexual minority groups. However, the effectiveness of these organisations depends on their expertise, legal status and the recognition given to them by the local authorities. These issues were explored using four aspects that indicate the capacity of CBOs to support minority groups. The findings are presented in Table 5 below.

(Insert Table 5)

The findings in the above table show that with regard to CBOs supporting sexual minorities being legally recognised, the respondents were not sure (mean response = 3.0, sd = 1.3). The respondents also disagreed that CBOs supporting sexual minorities were not rejected by the local administration (mean response = 2.1, sd = 3.1) and that they were well trained to fulfil their roles (mean response = 2.2, sd = 1.5). The respondents strongly disagreed that CBOs supporting sexual minorities were not persecuted by the local administration (mean response = 1.3, sd = 2.6). These findings...
show that the few CBOs that support sexual minorities in Rwanda are not empowered enough to provide effective support. They are being persecuted and have little legal recognition. This implies that they are not able to access donor funding and support. So, they are not able to have resources and skills required to help sexual minorities access appropriate HIV and AIDS prevention materials and information.

Most of the key informants from LGBT organisations interacted with stated that they were currently not registered and, therefore, not legally recognised. They stated that they had not tried to register their organisations for fear of being rejected and persecuted by the local administration. This had weakened their capacity to acquire training in how to support LGBT persons to meet their needs. The capacity of CSOs needs strengthening if they are to be effective in empowering LGBT persons to fight for their rights to HIV PTC services.

Conclusion and Policy Implications

This paper had two primary objectives: 1) to present the systemic challenges preventing sexual minority groups from accessing HIV PTC services; and 2) to suggest what is needed to have friendly HIV PTC services for sexual minorities. National HIV PTC programmes in Rwanda are yet to reach LGBT persons owing to failure by their management to have tailored initiatives and services to meet these people's needs. The HIV PTC needs of LGBT persons are unique and cannot be met along with the needs of the general population.

In particular, national HIV PTC services do not address the real needs of sexual minorities. They do not promote materials and strategies appropriate to them and health care providers do not respect the rights of LGBT persons. In most public health care facilities, there is open stigma of and discrimination against LGBT persons by health care providers. Public health care institutions promote disempowering environments for these groups. Hence the vast resources spent on national HIV PTC services have not helped them to provide LGBT-friendly services in a safe and empowering environment. LGBT persons need legal support and a voice to promote their rights to health care.

Providing an Enabling Environment

The national HIV response should advocate an enabling environment for the provision of HIV PTC and support services. The government should remove all punitive laws and policies that constitute barriers to universal access to HIV services and commodities. Through mass sensitisation, the government should promote a socio-cultural environment that is safe and empowering for sexual minorities to securely access services without fear of stigma, discrimination or violence.

The Ministry of Health in Rwanda should ensure that HIV programmes, plans and policies promote an enabling environment for minority groups and those discriminated against.

Ensuring Meaningful Participation in the Response

The national HIV strategy should include clear strategies for strengthening the meaningful involvement of sexual minorities in national HIV decision-making, planning and programming. This should include the establishment of mechanisms to institutionalise meaningful involvement and the provision of technical and financial support to enable them to participate in processes that affect their lives and wellbeing.

Integrating HIV within a Sexual and Reproductive Health and Rights (SRHR) Approach

The national HIV strategy should incorporate strategies to promote and ensure the SRHR of sexual minorities. This should include linkages and the integration of sexual and reproductive health and HIV services.

Addressing Stigma of and Discrimination against Sexual Minorities

The national HIV response should define clear strategies to address stigma of and discrimination against sexual minorities living with HIV. HIV programmes should incorporate strategies to halt and respond to all forms of discrimination in order to reduce vulnerability to HIV. The government should ensure universal access to HIV PTC and support services for all minority groups.

Ensuring Accountability for Equality

There should be policies to ensure accountability for commitments to promote equality in the HIV response by strengthening the capacity to coordinate, monitor and evaluate interventions designed to advance equality among government institutions, development partners and CVOs.

The government should ensure that specific actions on equality and interventions are fully costed and budgeted for within the National Strategic Plan (NSP), and that mechanisms are in place to monitor expenditure on equality-related activities in HIV prevention.

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