

# Towards an AIDS free generation: Is stigma still an issue in Zambia?

## Results from a legal environment assessment of the HIV/AIDS/TB program of the Churches Health Association of Zambia

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### Abstract

This paper reports on HIV related stigma based on results from an HIV legal environment assessment (LEA) within the Churches Health Association of Zambia HIV/AIDS program. We conducted 9 Focus Group Discussions and 20 Key Informant Interviews with key HIV/AIDS stakeholders that included representatives from network of Zambian people living with HIV. We administered a Survey Questionnaire to 337 people living with HIV (PLHIV) and 233 health workers. Quantitative data were analyzed using SAS v9.4; qualitative data was analyzed using QRS NVIVO version 11.0 Pro. Internalized stigma ranged between 20.8% and 31.8% of PLHIV; more among females than males. About one third (31%, n=104) of the 337 participants reported that they were aware of being gossiped once, a few times, or often; more among females than males. 62.3%, 63.1%, and 55.1% of the 233 health workers said it was somewhat true or certainly true that in their catchment areas, PLHIV struggle to have an HIV test because of stigma, were hesitant to start ART due to stigma; told them that they had challenges taking their ARVs because of stigma respectively.

### Introduction

Zambia continues to bear one of the highest HIV burden globally,<sup>1,2</sup> but the country is committed to controlling the HIV/AIDS epidemic by 2021 and ending the threat of HIV/AIDS as a public health issue by 2030 as per the National AIDS Strategic Framework 2017-2021.<sup>3</sup> Zambia is also committed to international strategies towards an AIDS free era, such as the UNAIDS 90-90-90 Goals.<sup>4</sup>

To achieve the 2030 agenda for Sustainable Development, to which Zambia is a party, in 2016, world leaders committed to achieving a number of specific goals, which include the elimination of HIV-related stigma and discrimination by 2020.<sup>4</sup> The reduction/elimination of stigma and discrimination are human rights issues that are critical to the success of any HIV/AIDS program. As the AVERTing HIV and AIDS notes on its website, "it is now widely recognized that HIV and human rights are inextricably linked. A lack of respect for human rights drives the HIV epidemic and increases its impact, while at the same time HIV undermines progress in the realization of human rights."<sup>5</sup> A human rights based approach to HIV/AIDS prevention, care, treatment and support is therefore highly advocated for all HIV/AIDS programs. This entails an intervention framework that aims at addressing the impact that HIV and human rights have on each other and covers the following three main areas: Human rights laws and treaties, political declarations, and human rights principles in HIV programming.<sup>6</sup> The Global Commission on HIV and Law's report produced in 2012 provided essential evidence that protective legal environments improve the lives of people living with HIV and reduce vulnerability to HIV infection. It also found evidence that stigma, discrimination, punitive laws, police violence and lack of access to justice continue to fuel the HIV epidemic.<sup>7</sup> One of the key activities to translate the recommendations of the Global Commission on HIV and Law is the conduct of legal environment assessments (LEAs) by the UN member countries. The United Nations Development Program (UNDP) has therefore been supporting countries to conduct LEAs. LEAs offer opportunities to look at priority HIV, legal and human rights issues. This includes a specific focus on reviewing the legal and regulatory framework in the HIV context with respect to stigma and discrimination; women and gender; children and young people; and intellectual property law and access to HIV treatment.<sup>8</sup> This paper reports some results of a LEA conducted between June and September 2017. The paper focuses specifically on HIV related stigma as a human rights issue in the context of HIV and AIDS programming in Church administered health institutions in Zambia.

### Materials and Methods

#### Study Design

Cross-sectional study, utilizing both qualitative and quantitative methods. This was a narrower and modified form of legal environment assessment (LEA).

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Contributions: GB, Conceptualized and designed the study, developed the study protocol and data collection instruments, recruited and trained data collectors, supervised the data collection, developed the quantitative data analysis plan, analyzed the qualitative data, compiled the study report, and developed the manuscript. DMM, conceptualized and designed the study, reviewed the study protocol and data collection instruments. Participated in the training of data collectors, reviewed and provided input into the study results, study report and the manuscript. YS, KSS, conceptualized the study; reviewed and provided input into the study report and the manuscript. WML, reviewed the study protocol and data collection instruments, wrote the sample size section of the study protocol, calculated the sample size, analyzed the quantitative data, reviewed and provided input into the study report and the manuscript.

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## Sites selection

The sites selection was done in such a way as to ensure a mix of characteristics of various study sites as well as geographic representation within the Churches Health Association of Zambia (CHAZ) HIV program implementation areas. At the time of designing the study, there were 55 CHAZ HIV/AIDS sites implementing both ART and PMTCT in all the ten (10) provinces of Zambia. For cost and logistical considerations, we decided to conduct the study in the four provinces with the highest number of sites (total 30 sites). We selected 25% of these sites (8 sites), proportionately representing each of the four provinces based on the number of sites in each province. From each province we selected 1-3 sites based on the number of sites in each province; including both health centre and hospital, both rural and urban, and also ensuring to include both CHAZ/Mission and Civil Society (CSO) or Private managed sites. In order to accommodate CSO representation we adjusted the number of sites in Lusaka to two; bringing the total number of sites to nine.

## Data collection and data collection methods

Twelve (12) Research Assistants (RAs) with prior experience in both quantitative and qualitative data collection techniques were recruited and trained to collect the data. The team of RAs was led by two experienced Field Supervisors who provided direct data collection supervision and performed quality checks in the field. Below is a summary of the data collection methods:

### Desk review

We conducted a desk review of the current laws, regulations and policies related to HIV and AIDS in Zambia and within the region. This section of the study was not designed to be a systematic review of literature and therefore a detailed description of the literature search methodology is not described here. We however made every effort to search online literature as well as gray literature by consulting with key national and international HIV and AIDS stakeholders as well as legal institutions like the Law Association of Zambia and the Ministry of Justice. The objective of the literature search and desk review was to identify legal and human rights issues related to HIV Globally, within Africa, and in Zambia.

### Focus group Discussions and Key Informant interviews

We conducted nine Focus Group

Discussions (FGDs) with people living with HIV (PLHIV), traditional leaders, religious leaders, traditional health practitioners, and neighborhood health committees (NHCs). We also conducted twenty Key Informant Interviews with various stakeholders, which included representatives from the Ministry of Health (MOH), Ministry of Justice, Ministry of Education, National AIDS Council, Law Association of Zambia, Network of Zambian People Living with HIV, Association of People Living with Disabilities, Human Rights Commission, the Police, Zambia Correctional Services (Prisons) and others.

### Quantitative Survey Questionnaire

For quantitative data collection, we designed a quantitative survey questionnaire administered to a sample of service providers (technical staff) of the CHAZ HIV/AIDS program and a sample of PLHIV on CHAZ antiretroviral therapy (ART) register in the study districts. The survey instruments were designed to quantify the level of stigma in terms of proportion of respondents who experienced stigma as well as quantify the association between stigma and service access (testing and treatment). The questionnaires were pretested to test internal (content) validity and reliability. However, we did not test the questionnaires for external validity.

### Sample sizes and sampling strategy

For the qualitative data collection, the sample sizes we selected were our best estimate of the maximum numbers of respondents to reach saturation or predictability. The sample sizes were determined taking into account cost, time, logistical and analytical feasibility; acknowledging the intense effort needed to collect, transcribe, analyze and report qualitative data. We also reviewed some sample sizes used in similar assessments within the Southern African region and placed our sample sizes within similar limits. With the above considerations in mind, we estimated to conduct up to 10 FGDs sampled proportionately from each of the four study provinces. Key informants were conveniently selected based on a consultative process and snowballing up to a maximum of 30 Key informants. For the quantitative survey, we used two sampling frames: All PLHIV on the ART register as well as all health workers on the HIV/AIDS ART program in the selected CHAZ sites. From each list, we randomly selected the sample using an excel random sampling function. We based our sample sizes on the estimation of a single proportion with a margin of error of +/- 5% and 95% confidence interval. We estimated to

select 376 PLHIV on ART proportional to the number of PLHIV on ART register and 206 CHAZ HIV/AIDS technical staff.

### Inclusion and exclusion criteria

See some reference literature on inclusion and exclusion criteria (<http://www.statisticssolutions.com/participant-selection-in-qualitative-research-part-2/>)

*Inclusion Criteria:* Both male and female aged 18 years and above within target districts.

*Exclusion Criteria:* Children below 18 years; CHAZ Secretariat staff.

### Ethical considerations

This study was approved by the ERES Converge Institutional Review Board (IRB) and authority to conduct the study was granted by the National Health Research Authority (NHRA). We also sought concurrence from the District Health Officers (DHOs) in the study districts. Informed Consent was obtained from all respondents and strict confidentiality was observed; no names were recorded on data collection forms. The research team ensured that study participation was on a voluntary basis and that no undue inducements for participation were made. FGD participants were reimbursed for transport because they travelled from different places to the place of interviews. Key informants and the survey respondents were not reimbursed for transport because the interviewers travelled to the places most convenient to the respondents for the interviews.

### Definitions and types of HIV related stigma

HIV related stigma has been defined as a process of devaluation of people either living with or associated with HIV and AIDS.<sup>9</sup> Stigma can be perceived, enacted, or internalized.<sup>10</sup> Perceived stigma refers to felt or imagined devaluation from individuals and/or institutions.<sup>11</sup> Enacted stigma refers to actual occurrences of discrimination,<sup>12</sup> while internalized stigma is self-shaming or self-blaming narrative that is adopted by a stigmatized individual.<sup>13</sup> Enacted stigma may also be referred to as experienced stigma, which means exposure to acts of discrimination, devaluation, and prejudice.<sup>14</sup>

### Data analysis

Quantitative data entry was done using TeleForms®, a program that allows for paper copies of data collection forms to be scanned into a computer and verified by a data entry specialist. The data was then analyzed using SAS v9.4 by calculating frequencies.

Qualitative data entry and analysis was carried out with QRS NVIVO version 11.0 Pro using thematic analytic techniques. Audio-recorded data was transcribed by three transcribers and verified by the Study Coordinator. One research assistant did the coding and the Principal Investigator verified and recoded the themes and carried out the analysis.

## Results

### Sample description

A total of 337 PLHIV were enrolled into the study; 100 were males and 237 were females, most (58.8% or 198/337) were aged 40 years and above (Mean age was 41.4 ± 11.1 years). Over half (54.3% or 183/337) were married; 35.9% (121/337), 25.2% (85/337), and 16.6 (56/337) were farmers, small-scale entrepreneurs, or unemployed respectively. Most of the PLHIV respondents (63.8% or 215/337) had been living with HIV for at least six years.

We enrolled 233 HIV service providers (health workers) in total; out of which 79 (33.9%) were males and 153 (65.7%) were females; the sex of one respondent was not recorded. Sixty-four percent of the service providers interviewed were nurses and 10% were doctors. Majority (67.8%) of the service providers were 30 years and above in age. Most (69.5%) of the service providers interviewed had been working in their respective professions for 4 years and above; with 71.7% of the nurses having worked for over 10 years. About sixty-three percent (146/233) of them had been providing HIV services for at least four years.

### Is HIV related Stigma still an issue?

Between 20.8% and 31.8% of PLHIV respondents reported some level of HIV related *internalized stigma*, including low self-esteem. Table 1 below summarizes the levels of internalized stigma among males and females; showing more internalized stigma among females than males, except for self-blame which is much higher among males.

The results of this study also show that there is still a fair amount of HIV related *perceived stigma*. About one third (31%, n=104) of the 337 participants reported

that they were aware of being gossiped once, a few times, or often. Among the 100 males, 23% reported being gossiped about once, a few times or often; among 237 females, 34.2% reported being gossiped about once, a few times, or often (Table 2). More than three quarters (76%) of 101 respondents who reported being gossiped said they were being gossiped because they were HIV positive.

Table 3 shows that according to 233 HIV service providers interviewed stigma has had a negative impact on HIV testing, ART initiation, and ART adherence: 62.3%

**Table 1. Internalized stigma among PLHIV by sex.**

Variable (combined responses: Occasionally, quite often, frequently, nearly all the time)	Males N=100 % (n/N)	Females N=237 % (n/N)	All Subjects N=337 % (n/N)
I feel ashamed	14 (14/100)	40.8 (56/237)	20.8 (70/337)
I feel guilty	20 (20/100)	24.0 (57/237)	22.8 (77/337)
I blame myself	31 (31/100)	23.2 (55/237)	25.5 (86/337)
I blame others	17 (17/100)	38.0 (90/237)	31.8 (107/337)
I have low self-esteem	20 (20/100)	29.1 (69/236)	26.4 (89/336)
I feel I should be punished	6 (6/100)	3.8 (9/237)	4.4 (15/337)
I feel suicidal	2 (2/98)	7.6 (18/237)	5.9 (20/335)

**Table 2. Experience with stigma and discrimination among PLHIV by sex.**

Variable (combined responses: once, a few times, often)	Males N=100 % (n)	Females N=237 % (n)	All Subjects N=337 % (n)
Excluded from social gatherings or activities	1 (1)	5.5 (13)	4.2 (14)
Because of HIV status: %(n/N)	0.0 (0/1)	38.5 (5/13)	35.7 (5/14)
Excluded from family activities	1 (1)	3.0 (7)	2.4 (8)
Because of HIV status: %(n/N)	0.0 (0/1)	33.3 (2/6)	28.6 (2/7)
Aware of being gossiped about	23.0 (23)	34.2 (81)	30.9 (104)
Because of HIV status: %(n/N)	81.8 (18/22)	74.7 (59/79)	76.2 (77/101)

**Table 3. Extent to which human rights issues, in particular, stigma and discrimination, could have affected HIV testing, treatment, and adherence for PLHIV: Views of HIV Service providers.**

Variable	Male N=79 % (n/N)	Female N=153 % (n/N)	Not recorded N=1 % (n/N)	All participants N=233 % (n/N)
PLHA in my catchment area really struggle to have an HIV test done because of stigma				
Not true	35.4 (28/79)	39.1 (59/151)	0.0 (0/1)	37.7 (87/231)
Somewhat true	45.6 (36/79)	45.7 (69/151)	100.0 (1/1)	45.9 (106/233)
Certainly true	19.0 (15/79)	15.2 (23/151)	0.0 (0/1)	16.5 (38/233)
After testing HIV positive many PLHA are hesitant to start ART because of stigma				
Not true	38.0 (30/79)	36.6 (56/153)	0.0 (0/1)	36.9 (86/233)
Somewhat true	46.8 (37/79)	46.4 (71/153)	100.0 (1/1)	46.8 (109/233)
Certainly true	15.2 (12/79)	17.0 (26/153)	0.0 (0/1)	16.3 (38/233)
Many of my clients tell me that they have had challenges taking their ARVs because of stigma				
Not true	45.6 (36/79)	46.4 (71/153)	0.0 (0/1)	45.9 (107/233)
Somewhat true	44.3 (35/79)	38.6 (59/153)	0.0 (0/1)	40.3 (94/233)
Certainly true	10.1 (8/79)	15.0 (23/153)	100.0 (1/1)	13.7 (32/233)



said it was somewhat true or certainly true that in their catchment areas, PLHIV struggle to have an HIV test because of stigma; 63.1% said it was somewhat true or certainly true that in their catchment areas, after learning that they are HIV positive, PLHIV were hesitant to start ART due to stigma; and 55.1% said it was somewhat true or certainly true that many clients told them that they had challenges taking their ARVs because of stigma.

However, the 337 PLHIV interviewed did not perceive stigma to have adversely affected their decision to have an HIV test, to start ART or to adhere to ART: 79.8%, 81.5%, and 91.4% said it was not true that they struggled to have a test, to start ART or remain on ART respectively due to stigma (Table 4).

### Experience with stigma, discrimination and violation of human rights in the context of HIV/AIDS:

#### Views from FGDs

FGDs with PLHIV revealed that anti-stigma laws and a lot of sensitization of communities on stigma have resulted in reduced stigmatization of PLHIV.

Text below: Stigma has reduced due to anti-stigma laws and community sensitization.

*"It (anti-discrimination laws) has helped the health personnel to reduce the HIV stigma because once these laws are being implemented to the people, people will be free to or volunteer to go for HIV testing and they'll be able to know their status then they'll be put on ARVs...It has positively helped to reduce stigmatization, these programs with the CHAZ, because of more sensitization, more people now, they have no stigma." (FGD respondents, PLHIV, Monze).*

Despite the reported reduction in stigma, there are some respondents who reported experiencing stigma as illustrated in the text below.

*"I can give an example of myself. After I was tested and found positive, all my family members hated me. No one liked me, even eating, I was eating alone. My children were even taken from me saying that I couldn't be with them because I was positive....." (FGD respondent, PLHIV, Coptic hospital, Lusaka)*

*"..like for me, when I passed to go to grade 8, I was supposed to go to a boarding school but when my mum explained to the school my HIV status the school denied me a place to study there. It also happened when I went to another school and then I had to go the District Education Boards and they had to intervene and that's how I was given a place." (Kalulushi, FGD, PLHIV).*

*"There was this elderly woman in the village who was found to be HIV positive. People in the community started saying that she was an old-aged prostitute, without even asking why such a person would be found with HIV. ....Stigma befell on her and had a really hard time to adhere to her treatment until she eventually died" (FGD, PLHIV, Nyanje hospital).*

*"Recently we had a church member who got sick. The relatives took him to the clinic but when they found out that he was HIV positive, the family just left him at the clinic until the church took it upon itself to take care of him. Unfortunately, that person even passed on 2 weeks ago. Maybe if the family had come close and not distanced him like they did, he would have probably not died" (FGD, PLHIV, Coptic, Lusaka)*

## Discussion and Conclusions

The level of stigma observed in this study is still of concern to Zambia, as it aims to control the HIV/AIDS epidemic by 2021 and end the threat of HIV/AIDS as a public health issue by 2030. The good news however is that although our study and the stigma index study by Professor Siziya and colleagues (conducted in 2009) were conducted under different conditions (different sites and sample sizes) there appears to be a reduction in internalized stigma. The study conducted by Siziya and colleagues, reported in 2012, showed that over 60% of male and 40% of female respondents blamed themselves, nearly 60% of all the respondents felt ashamed, over 50% felt guilty, and over 40% had low esteem.<sup>15</sup> Our results show that 31% of male and 23.2% of female respondents blamed themselves, 20.8% of all respondents felt ashamed, 22.8% of all respondents felt guilty, and 26.6% of all respondents had low esteem due to their HIV status. There is evidence that HIV related stigma negatively affects uptake of HIV testing, ART initiation and ART adherence and retention.<sup>16-19</sup> The current level of stigma, though at reduced levels than about 8 years ago, still requires interventions to mitigate its impact on the CHAZ HIV program and the HIV program in Zambia in general. Although PLHIV in this study said they did not perceive stigma to have affected their access to HIV testing, ART initiation or their maintenance on ART, the service providers strongly felt that stigma has had a negative impact on HIV programming. The study shows, for example, that 62.3% said it was somewhat true or certainly true that in their catchment area PLHIV struggle to have an HIV test because of stigma; 63.1% said it was somewhat true or certainly true that in their catchment area after

**Table 4. Extent to which human rights issue, in particular, stigma and discrimination, could have affected HIV testing, treatment, and adherence for PLHIV: Views of PLHIV.**

Variable	Males N=100 % (n/N)	Females N=237 % (n/N)	All participants N=337 % (n/N)
I really struggled to finally have an HIV test done because of stigma			
Not true	86.0 (86/100)	77.1 (182/236)	79.8 (268/336)
Somewhat true	9.0 (9/100)	13.6 (32/236)	12.2 (41/336)
Certainly true	5.0 (5/100)	9.3 (22/236)	8.0 (27/336)
After I was found to be HIV positive I was hesitant to start ART because of stigma			
Not true	89.0 (89/100)	78.3 (184/235)	81.5 (273/335)
Somewhat true	4.0 (4/100)	12.8 (30/235)	10.1 (34/335)
Certainly true	7.0 (7/100)	8.9 (21/235)	8.4 (28/335)
I have had challenges taking my medicine or sticking to the schedule of clinic visits because of stigma			
Not true	93.0 (93/100)	90.7 (215/237)	91.4 (308/337)
Somewhat true	5.0 (5/100)	6.8 (16/237)	6.2 (21/337)
Certainly true	2.0 (2/100)	2.5 (6/237)	2.4 (8/337)

learning that they are HIV positive, PLHIV were hesitant to start ART due to stigma; and 55.1% said it was somewhat true or certainly true that many clients told them that they had challenges taking their ARVs because of stigma. The discrepancy between the perception of PLHIV and that of service providers on the effect of stigma on HIV service access may be explained by the fact that the PLHIV were all on ART and had regular source of HIV care. In one study in Los Angeles USA, researchers found that while experiencing HIV related stigma was strongly associated with poor self-reported access to medical care, stigma was not strongly associated with having a regular source of HIV care. The authors reported that one explanation for this was that stigma might have less of a role in an established patient-provider relationship.<sup>20</sup> Our study sample consisted of PLHIV on the ART register; hence, this was a group of individuals with a regular source of HIV services. Another study conducted in Kwazulu-Natal, South Africa among HIV positive participants taking part in a prospective cohort study found that stigma total score was not significantly associated with loss to follow up (LTFU).<sup>21</sup> The authors concluded that this finding might be consistent with high levels of social exposure to HIV and ART and with stigma affecting LTFU less than other stages of care. Lastly, it is important to note that there is compelling evidence that HIV-related stigma has negative impacts on HIV programming. A recent systematic review with meta-analysis involving 64 studies revealed significant associations between HIV-related stigma and higher rates of depression, lower social support, lower levels of adherence to antiretroviral medications, and access to and use of health and social services.<sup>21</sup> Yet another systematic review of 75 studies involving 26,750 PLHIV in 32 countries worldwide found that HIV related stigma compromised participant's abilities to successfully adhere to ART.<sup>19</sup>

### Study limitations

The results of this study must be interpreted within the following limitations: Although we randomly selected the PLHIV and the service providers within the CHAZ program sites, the results may not represent all the views of PLHIV and the service providers in Zambia. This is also compounded by the fact that we did not test the questionnaires for external validity; meaning we cannot be certain that the results from the sample are a true reflection of the reference population from which the sample was drawn.

In addition, catchments populations served by the church health facilities may be different from the public ones.

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