ZAMBIA HIV Leadership through Accountability

THE PEOPLE LIVING WITH HIV STIGMA INDEX

ZAMBIA

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Network of Zambian People
Living with HIV/AIDS (NZP+)

GNP+ GLOBAL NETWORK OF
PEOPLE LIVING WITH HIV

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CSO	Central Statistics Office
FBO	Faith-based organisations
GIPA	Greater Involvement of People Living with HIV/AIDS
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV/AIDS
IPPF	International Planned Parenthood Federation (IPPF)
MOH	Ministry of Health
NAC	National AIDS Council
NGO	Non-governmental organisations
NZP+	Network of Zambian People Living with HIV
PLHIV	People living with HIV
PMTCT/PVT	Preventing Mother-To-Child-Transmission of HIV (now increasingly referred to as ‘prevention of vertical transmission’)
SPSS	Statistical Package for the Social Sciences
SRH	Sexual and Reproductive Health
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
WHO	World Health Organisation
ZARAN	Zambia AIDS Law Research & Advocacy Network (ZARAN)
ZDHS	Zambia Demographic and Health Survey

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Aids Fonds finances scientific research, provides prevention and treatment for vulnerable groups and fights for the rights of people with HIV.

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Executive Summary

HIV-related stigma and discrimination is widely recognised as a barrier to accessing HIV prevention, treatment and care services in Zambia, yet there are still notable gaps in measuring its extent and generating sufficient evidence to inform the design and implementation of effective stigma-reduction interventions. This study aimed to measure the extent of HIV-related stigma and discrimination experienced by people living with HIV, and to document its various forms in Zambia.

Methodology

This study, conducted by the Network of Zambian People Living with HIV/AIDS (NZP+), used the People Living with HIV (PLHIV) Stigma Index to conduct interviews, following the standard standard methodology and process developed which can be found at www.stigmaindex.org

Data was collected from 854 PLHIV drawn from two districts, Lusaka urban and Mkushi district (rural). The majority of respondents were female (56.7%, n=481) and approximately 60% live in a city or large town, approximately 20% living in a small town or village, and 20% living in rural area. Initially respondents were recruited from among people living with HIV attending selected health centres to receive ART in selected facilities; however, during the study, other people attending these facilities, who were not taking ART, were also interviewed.

Major Findings

The study found that HIV-related stigma was prevalent and an ongoing part of the lives of people living with HIV in Zambia. People reported experiencing stigma and discrimination in variety of settings, including places of worship, in their local communities, within the household, workplaces and health care facilities.

The study sample included people identifying as belonging to key populations, including men who have sex with men, being gay or lesbian, sex workers, people who use drugs and ex-prisoners. While 30% of the respondents identified with ever having belonged to a key population; the number of respondents belonging to any one group was small[1], affecting the extent to which the results can be generalised to other people living with HIV belonging to each of the key populations.

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[1] Prisoner or ex-prisoner (14.8%), sex workers (6.6%), migrant workers (3.8%), internally displaced people (2.6%), members of indigenous group (0.7%), people who use drugs (0.6%), men who had sex with men (0.6%), transgender people (0.6%), refugee or asylum seeker (0.2) and gay/lesbian (0.1%).

Nevertheless, the study has generated important evidence of the existence of men who have sex with men, gay men and lesbians, and people who use drugs among people living with HIV in Zambia; as well as highlighting the needs other key populations living with HIV, including prisoners, sex workers and migrant workers.

The effects of poverty on the study sample of people living with HIV are clearly evident. Most respondents report food insecurity, ranging from a low of 83.8% in large towns/cities though to 95.2% in small towns or villages. Furthermore, over one quarter of respondents across all locations are unemployed with higher levels reported in rural areas (nearly 35%), and unemployment being more pronounced among women. One quarter of respondents reported that children who have been orphaned due to AIDS live in their household; while 85% (n=703) of respondents reported having children. Of this number 692 felt confident enough to answer the question as to whether any of their children were known to be HIV positive with 25.9% (n=179) reporting having one or more HIV-positive children.

Other major findings concerning the experiences of people living with HIV by area are outlined below with the full findings presented in the **Conclusion**.

Exclusion

About 30% of the men and 36% of the women reported having been excluded from social activities; and one quarter reported exclusion from family or religious activities this in the last 12 months.

More than half the respondents stated that they had been gossiped about and/or verbally insulted, harassed and/or threatened about in the past year, and over one third reported being physically harassed or threatened

Access to work and health and education services

Some 16.5% of the respondents had been refused employment because of their HIV status, and 39.3% reported losing a job or some other source of income at least once on account of their HIV status in the previous 12 months.

Though respondents were recruited through health care facilities, 8% still reported difficulties in accessing certain health services, or being denied them.

Internalised stigma and fears

Internalised stigma was prevalent amongst the sample. Over 60% of male and 40% of female respondents blame themselves; nearly 60% of respondents feel ashamed, over 50% feel guilty and over 40% have low self esteem.

More than one in ten respondents report feeling suicidal.

Over 70% of respondents decided not to have (more) children because of HIV status.

Rights, laws and policies

Amongst the respondents 10.4% (n=89) reported experiencing forced medical procedures, while 4.8% reported detention, isolation, being quarantined or segregated.

Of those who reported that their rights had been abused and had sought legal redress, over half reported that nothing had happened.

Over 80% of respondents did not know or were unsure of the reason for HIV-related stigma and discrimination they had experienced. The most commonly reported reason why respondents felt that they had been stigmatised or discriminated against was that they believed that people feared infection from them (10.4%).

Effecting change

Less than one in five respondents felt that they had any influence at the national programmatic level or on local or national policies.

Perceptions of the most important strategies for addressing stigma and discrimination varied according to the number of years respondents had been living with HIV. For example: The provision of emotional, physical and referral support was more important for respondents with fewer years of living with HIV compared to those who had been HIV-positive for 15 or more years.

While advocacy for the rights of people living with HIV was considered a priority by more than one third of those who had lived with HIV for 9 years or less, its importance steadily declined among respondents who reported living with HIV for more than 10 years.

Testing and diagnosis

Nearly one quarter of men and more than one third of women were symptomatic at time of HIV diagnosis.

Human rights violations associated with involuntary HIV testing and being tested without any counselling[2] remain a challenge, as do the cost, time and distance in accessing HIV testing services.

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[2] More than 10% of young people and people over 50 years of age, reported having been tested without any counselling at all.

Disclosure and confidentiality

Self-disclosure by respondents of their HIV-positive status was highest to health care workers (78.4%), other people living with HIV (72.6%) and other adult family members (72.3%).

Two thirds of respondents had disclosed to their husbands, wives or partners, while 5.3% indicated that their sexual partners were not aware of their HIV status.

Some 3.9% of respondents reported having injecting drug partners who were unaware of their status.

Over two thirds of respondents described disclosing their HIV status as an ‘empowering experience’.

Treatment

Overall, access to ART was not a problem with nearly 90% accessing ART, which can in part be ascribed to the sample being almost exclusively drawn from among people attending health centres providing ART.

Over half (59%) of respondents reported having discussed sexual and reproductive health, emotional well-being and other similar subjects with a healthcare professional in the last year.

Having children

Nearly a third of respondents indicated that they had not received any reproductive health counselling since diagnosis.

Of those responding to the question 12.5% of women in lowest income bracket and 6.3% of women in the highest income bracket reported having been pressured to terminate a pregnancy in the previous 12 months.

Nearly a quarter of women from rural areas and small towns/villages, along with 7.7% of women from large towns/cities did not know that prevention of vertical transmission was possible.

These results reinforce the call for sustained efforts to support the reproductive aspirations of people living with HIV, with greater emphasis on strategies for preventing vertical transmission of HIV.

Recommendations

Among the sample there was prevalent food insecurity, low socio-economic status, including low levels of employment, and internalized stigma, high rates of being fearful about the ways they were perceived and treated in the community (with reported examples of stigmatising and discriminatory treatment), and one in ten respondents feeling suicidal. As such, psychosocial and socioeconomic support must clearly be a priority for NZP+, civil society, National AIDS Council and the Government. Concerted efforts are required to promote positive living and provide psychosocial and socioeconomic support including training opportunities for people living with HIV to become peer educators, capacity and network building, including sensitization training on rights, counselling, training, and income generation.

NZP+

Disseminate the findings of this study to the Government, NACC, civil society, UN agencies and donors.

Take into account the heterogeneity of people living with HIV in developing and implementing interventions to address stigma and discrimination.

Given the fact that over one third of respondents were unsure whether they had suffered violation of their rights as people living with HIV in the previous 12 months, it is recommended that sensitization training for people living with HIV on their rights be undertaken and human rights literacy programmes be instituted..

Intensify education efforts with people living with HIV on positive health, dignity and prevention.

Advocate for the creation of a supportive legal and policy environment to challenge rights violations experienced by people living with HIV, including key populations.

Advocate for the inclusion of more people living with HIV in policy-making fora and in the development and drafting of relevant legislation.

Encourage people living with HIV to be actively involved in developing and implementing stigma and discrimination reduction efforts, including within the HIV-positive community.

Civil society

Take into account the heterogeneity of people living with HIV in developing and implementing interventions to address stigma and discrimination.

Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.

With nearly one quarter of men and more than one third of women being symptomatic at time of diagnosis, invest more in promoting voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.

Without clear policies and guidelines targeting groups such as sex workers, prisoners, men who have sex with men and people who use drugs, it is difficult to provide effective and appropriate interventions. Therefore, advocacy for the creation of a supportive legal and policy environment should be high on the agenda of efforts to challenge rights violations experienced by people living with HIV.

Support the active participation of people living with HIV in the development of laws, polices and guidelines.

National AIDS Council

Take into account the heterogeneity of people living with HIV in developing and implementing interventions to address stigma and discrimination.

With nearly one quarter of men and more than one third of women being symptomatic at time of diagnosis, investment more in promoting voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.

Given that there is a low level but consistent pattern of denial of rights to people living with HIV in health care settings[3]:

- revise pre- and in-service training curricula to enhance the capacity of health providers to provide non-judgmental and non-discriminatory services to people living with HIV; and
- review and update, if needed, protocols to ensure they are rights-based and include pre-service training for health care workers as well as in-service training refresher

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[3] For example:

Some 8.4% of respondents (n=68) reported being denied access to health services.

Some 9.7% reported having been denied family planning services as a result of their HIV status, while 11.8% indicated that they had been denied sexual and reproductive health services.

Nearly 10% of low and high income respondents and over 15% of middle income ones avoided going to a local clinic, and approximately 5% across all income levels avoided going to hospital.

10.4% of respondents (n=89) reported experiencing forced medical procedures.

12.5% of women in lowest income bracket and 6.3% of women in the highest income bracket reported having been pressured to terminate a pregnancy in the previous 12 months.

courses for health providers, managers and other health facility staff, as well as strengthen supervision to foster non-judgmental and non-discriminatory practices towards people living with HIV.

Scale up the provision of correct information and appropriate options for the sexual and reproductive health for people living with HIV, including on information and services for the prevention of vertical transmission, across all locations.

Support SRH and HIV linkages, including the integration of SRH services for people living with HIV into HIV programmes.

Support the active participation of people living with HIV in the development of laws, polices and guidelines.

Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.

Intensify stigma reduction interventions that promote the involvement of community leaders, religious leaders and labour representatives.

Undertake and/or support research to strengthen the evidence base, including:

- Qualitative studies on the extent of stigma and discrimination within key populations.
- Studies on the denial of sexual and reproductive health services to people living with HIV.

Government

Take into account the heterogeneity of people living with HIV in developing and implementing interventions to address stigma and discrimination.

Take the lead in creating a policy and legal environment that will safeguard the rights of people living with HIV and specifically address HIV-related stigma and discrimination.

Support the active participation of people living with HIV in the development of laws, polices and guidelines.
Support broad-based social and community awareness raising and mobilization as part of efforts to eradicate stigma and discrimination against people living with HIV and key populations, including through a human rights-based approach, addressing HIV-related myths.

Zambia

Prioritize HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in national strategic planning, funding and programmes, including support for scaled up implementation of promising programmes.

Include HIV-related stigma and discrimination indicators as part of the national AIDS response M&E systems to monitor and evaluate progress over time.

Introduction

Addressing stigma and discrimination is critical to achieving Governments' commitments to universal access to HIV prevention, treatment, care and support as outlined in the 2001 Declaration of Commitment on HIV[4]. Stigma and discrimination often lead to silence, denial and feelings of blame. As a result, those affected opt to delay or avoid accessing services such as prevention, counselling, testing, treatment, care and support. In Zambia, mitigating stigma and discrimination is listed as one of the strategic objectives under the *Intensifying Prevention* theme in the 2006-2010 National HIV and AIDS Strategic Framework (NAC, 2006[5]).

Background on HIV-related stigma and discrimination

Stigma is 'an attribute that is deeply discrediting' and results in the reduction of a person or group 'from a whole and usual person to a tainted, discounted one' (Goffman, 1963). Thus, the ultimate effect of stigma, as noted by Goffman, is the reduction of the life chances of the stigmatised person through discriminatory actions.

Discrimination involves treating someone in a different and unjust, unfair or prejudicial way, often on the basis of their actual or perceived belonging to a particular group. It consists of actions or omissions that are a result of stigma and directed towards those individuals who are stigmatised. In other words, discrimination is 'enacted stigma' (IPPF, 2008; UNAIDS, 2005). However, a person may feel stigma towards another but s/he may decide not to act in a way that is unfair or discriminatory. Discrimination can occur at different levels: individual, family, community or national (UNAIDS 2005).

HIV-related stigma often builds upon and reinforces other existing prejudices such as those related to gender, sexuality and race. For example, the stigma associated with HIV is often based upon the association of HIV and AIDS with already marginalised and stigmatised behaviours such as sex work, drug use and same-sex and transgender sexual practices (UNAIDS, 2005). HIV-related stigma affects those living with HIV and, often, those who with whom they are associated, such as their partners or spouses, their children or other members of their households.

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[4] http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf

[5] Progress and challenges can be found in the country report at http://www.unaids.org/en/dataanalysis/monitoringcountryprogress/progressreports/2010countries/zambia_2010_country_progress_report_en.pdf

Zambia

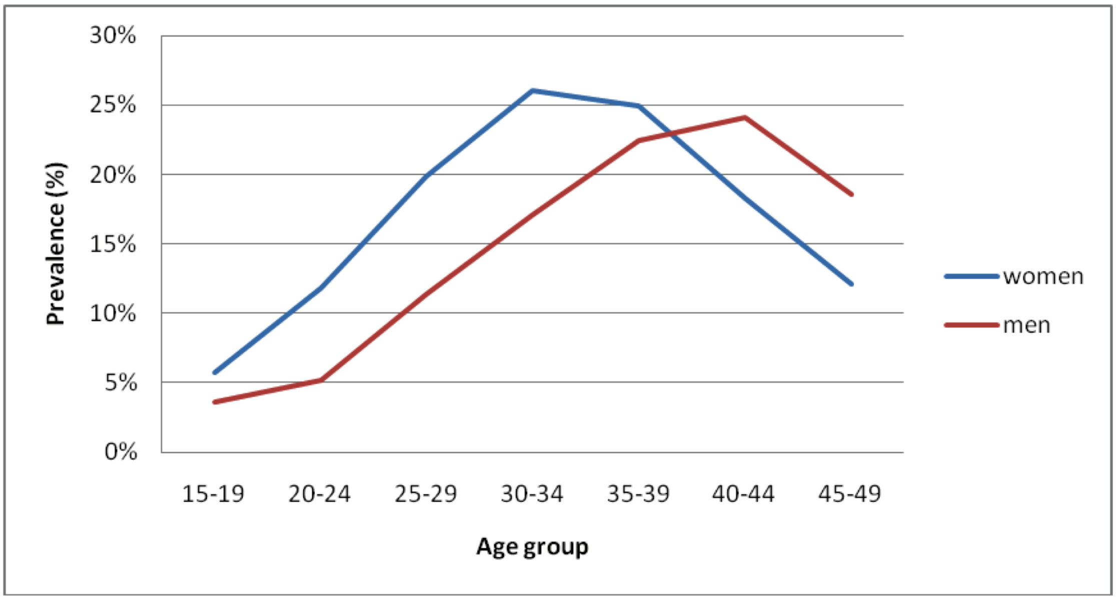
Internal stigma, also referred to as 'felt' stigma or 'self-stigmatisation' is used to describe the way a person living with HIV feels about him/herself, particularly if he/she feels a sense of shame about being HIV-positive. Internal stigma can lead to low self-esteem, a sense of worthlessness and/or depression. Internal stigma can also result in a person living with HIV withdrawing from social and intimate contact.

Country Context

Zambia, with an estimated population of 12.2 million, is one of the most affected sub-Saharan African countries with a prevalence of 14.3% among the adult population (CSO, 2008). Prevalence varies across regions, ranging from 7% in North-Western province to 22% in Lusaka province.

In Zambia, HIV disproportionably affects more women than men, with women constituting 57% of the 1.2 million adults estimated to be living with HIV (UNAIDS, 2008). In the 15-19 age group, HIV prevalence for women is 6% and 4% for men. Women aged 20-24 are 2.3 times more likely to be HIV-positive than men of the same age group (CSO, 2008). As shown in below, this trend continues up until the 40-49 age group, at which point prevalence is higher among men than women.

Chart 1: HIV prevalence in Zambia (men and women) by age



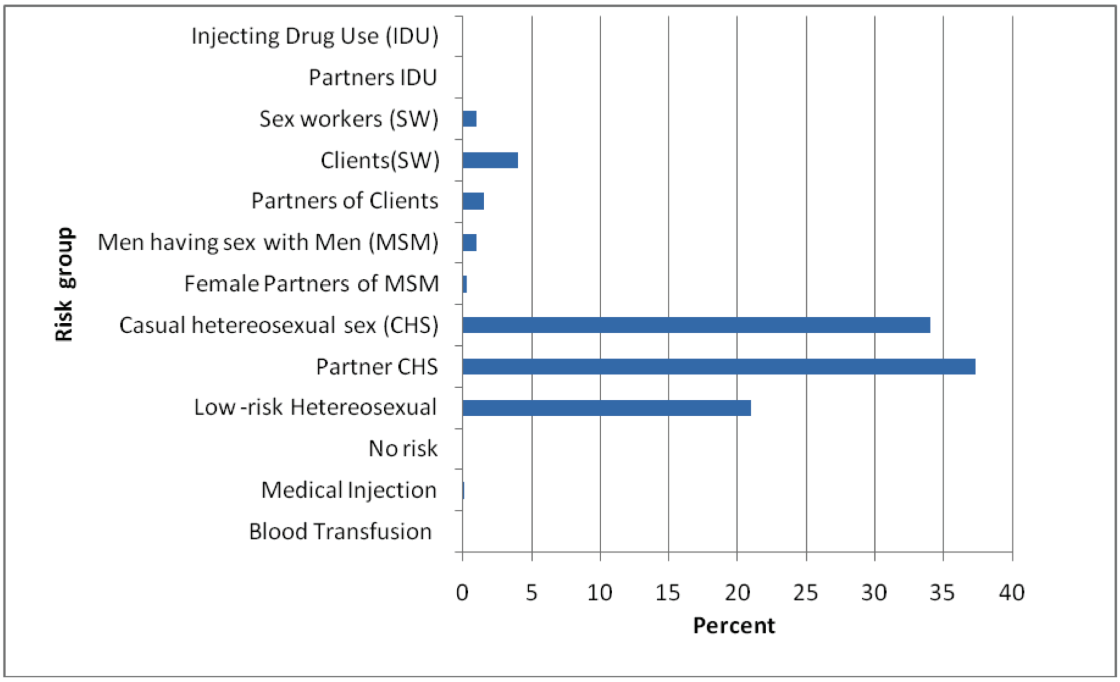
Source: CSO, 2008

For younger women in sexual relationships with older men (NAC, 2006) and for older, married women, financial dependence coupled with the submissive role women are expected to play in a relationship often prevents them from negotiating safe sex despite awareness of HIV.

In addition, gender-based violence involving coercive sex raises a woman's risk of HIV (Turmein, 2003). According to the 2005 Zambia Sexual Behaviour Survey, 68% of all cases of forced sex among female respondents involved a husband or live-in partner, while boyfriends accounted for 25% of all the cases (CSO, 2006). There is a growing number of orphans, currently estimated to be 1.4 million, of whom more than half have been orphaned as a result of AIDS (NAC, 2010).

Data in the public domain[6] states that HIV infection in Zambia is almost exclusively through heterosexual contact (78% of all cases), with 'vertical transmission' during pregnancy, birth or while breastfeeding accounting for a further 21% of HIV infections. However, mother-to-child transmission is expected to reduce through the increased countrywide availability of free of charge services in public health facilities to prevent vertical HIV transmission[7]. All pregnant women accessing antenatal services are routinely screened for HIV under the opt-out approach to provider initiated HIV testing and counselling, and those testing HIV-positive are referred to PVT services.

Chart 2: HIV incidence in adult 'risk behaviour' groups in Zambia, 2008



Source: NAC 2009

The graph above shows that the highest HIV incidence is related to partners of adults involved in casual heterosexual sex (37.3%), followed by people involved in casual heterosexual sex. Furthermore, married or co-habiting couples, considered a 'low-risk'

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[6] As [5] above.

[7] Scaled up PVT services has already resulted in a decline in vertical transmission from 30% (2006) to 12% (2008) (NAC, 2009).

group, in fact have a 21% HIV incidence. Incidence is in the remaining groups. While clients of sex workers have a HIV incidence of 4%, sex workers, men who have sex with men and female partners of men who have sex with men all have a HIV incidence of less than 1%. However, the incidence for men who have sex with men (as well as other key populations) could be understated, given the limited data available.

Since 2005, with support of cooperation partners, the Government has provided free antiretroviral therapy (ART) in all public health institutions. The proportion of people who are both eligible for and able to access ART has increased from 38.9% in 2007 to 68% in 2009 (NAC, 2010). Over the years, the number of public and private facilities providing ART related services such as CD4 counts has increased, resulting in improved services in both rural and urban areas. There are still sub-optimal numbers of children accessing ART, due to challenges in relation to the availability of infant diagnostic tests.

According to the 2009 Zambia Sexual Behaviour Survey[8], levels of HIV-related stigma and discrimination have in general been declining since 2005. Modest positive changes have been observed in proxy indicators to measure the level of stigma and discrimination (CSO, 2010). For instance, the proportion of urban respondents who say a HIV-positive worker should be allowed to work increased from 83% in 2005 to 88% in 2009. Similarly, the proportion of respondents who exhibited accepting attitudes towards people living with HIV increased from 27.1% in 2003 to 34% in 2009.

About NZP+

The study was conducted under the leadership of the Network of Zambian People Living with HIV (NZP+), which was established in 1996 to help improve the quality of life of people living with HIV through the promotion of communication, support and representation of people living with HIV with regard to issues affecting them. To date, it has chapters nationwide in all the districts of the country, with a membership of approximately 100,000. With technical and financial support from local and foreign organisations, NZP+ has been active in challenging stigma and discrimination through initiatives, including advocacy, information provision and building the capacity of support groups to implement anti-stigma programmes.

Objectives

The purpose of this study was to measure the extent of HIV-related stigma and discrimination experienced by people living with HIV, and to document its various forms in Zambia. Stigma and discrimination act as barriers to access to HIV and AIDS services.

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[8] http://www.zamstats.gov.zm/media/zambia_sexual_behaviour_2009.pdf

Specific objectives were to:

- Estimate the level of stigma and discrimination among people living with HIV in Zambia.
- Document the various experiences of people living with HIV regarding HIV-related stigma and discrimination in Zambia.
- Contribute to an evidence base for advocacy, policy change and programmatic interventions to address stigma and discrimination related to HIV.

NZP+ believes it is important to learn from the voices of people living with HIV in order to develop stigma reduction programs that address their specific concerns. This research project supports the principle of GIPA by allowing people living with HIV to plan and conduct a study with other people living with HIV to document their experiences regarding stigma and discrimination. NZP+ believes that the results from the study will provide a powerful advocacy tool regarding stigma and discrimination experienced by people living with HIV and contributes towards universal access to prevention, treatment, care and support in Zambia, Southern Africa and globally.

Methodology

The study used the People Living with HIV (PLHIV) Stigma Index (The Index) developed by and for people living with HIV. This is an initiative of four founding partners working together since 2005 - GNP+, ICW, IPPF and UNAIDS. The Index facilitates collection of information from people living with HIV to:

- enable people living with HIV to document their experiences;
- compare experiences across countries;
- measure changes over time; and
- provide sound evidence for policy and programme interventions.

For more information go to www.stigmaindex.org

Ethical approval: The study protocol and instruments were approved by ERES Converge, a Zambian private IRB (Institutional review board) approved by the MOH to assess and grant approval for in-country research. The study benefited also being conducted as part of a partnership and the research being guided by a lead researcher from the University of Zambia, School of medicine – Prof Seter Siziya.

Sample determination: The study was conducted in 2010, and involved a sample of 854 people living with HIV. Due to resource constraint the l partnership implementing this study were not able to sample across the whole country

Respondents were drawn from two districts. Lusaka urban district was selected as a convenience sample as it is mainly urban. Mkushi district was randomly selected from among rural districts.

Inclusion and exclusion criteria: Initially the selection criteria was people living with HIV attending health centres for ART in selected facilities during the data collection period. However during the study, other people attending health facilities, who were not taking ART, asked to be interviewed. Local implementation teams extended an invitation to participate to avoid feelings of exclusion. Furthermore, the study only included people of 18 years or above.

Training: The interviewers were recited and selected through NZP+ and other PLHIV organisations. All of the interviewers in the study were people living with HIV. Interviewees were trained in undertaking interviews following the PLHIV Stigma Index User Guide suggested outline for such training with further the assistance and input from AIDS Alliance, Zambia. In addition to a the three day session on research and interviewing techniques, exploring what stigma and discrimination meant to the interviewers, interviewees received guidance on dealing with difficult emotional situations and providing sources of advice and information. As part of the training, the questionnaire was also piloted to check its relevance to the Zambian context.

Referral for support for people living with HIV: In certain instances, it was necessary for interviewers to refer participants to local organizations that could meet specific needs. NZP+ District Chapter Coordinators in each research site developed a list of referral organizations for this purpose.

Information sheet and informed consent: Before starting the interview, interviewers ensured that each interviewee provided informed consent. To facilitate this process an information sheet, which had been translated into local languages during the research training, was provided to interviewees.

Data collection: The questionnaire was administered through a one-to-one interview. The interview process on average took 1.5 hours. This did not include the process of getting the informed consent, answering any questions about the study before starting the interview, or (as was often the case) the process of reflecting on the issued raised by the questions and ensuring referrals were in place at the end of the interview.

Confidentiality: Participant names were not noted on the questionnaire. Instead, a unique identifying code was used. Informed consent forms and questionnaires were kept in a locked filing cabinet to which only the team leader had access. Importantly, the only people who had access to completed informed consent forms and questionnaires were the interviewers who collected the data, the biostatistician and the team leader. Data entry clerks only had access to questionnaires during data entry and cleaning. Signed informed consents were not linked to the completed questionnaires.

Data management: Various procedures were carried out once the information was collected, including:

- *Editing:* Questionnaires were checked in the field and again as soon as they were brought to the office by the team leader who made sure they had been completed correctly.
- *Storing:* As soon as the questionnaires were checked by the team leader at the office, they were archived (i.e. securely stored) ready for data entry.
- *Data Entry:* Using Epi Info, data from each questionnaire was entered twice into two separate databases ('double data entry'), by people working independently of each other. The two databases were then validated. Inconsistencies were checked against the original questionnaires and corrected. Epi info was used for initial data entry as it is a freeware package, thus allowing the data entry to be carried out by NZP+.

Data analysis: Data was exported to the Statistical Package for the Social Sciences (SPSS). A reporting template was used to create a list of tables on which this report is based, and to serve as a 'results library' containing all the survey findings, disaggregated by demographic groups most relevant to each question, as well as some key cross-tabulations between questions. These data will be used as a resource for future thematic studies and reports.

Study limitations: The study has a number of limitations, including:

- Though interviewees were recruited from both urban and rural sites resource constraints did not allow for a nation-wide study
- Knowledge of one's HIV-positive status was one of the inclusion criteria. Thus people who may be HIV-positive but do not know their status were excluded.
- The attributes of the study sample, drawn primarily from people living with HIV above the age of 18 and registered with an ART site, may be distinct from people living with HIV who did not meet the selection criteria or opted not to participate.
- As information was elicited through self-reporting; reporting bias cannot be ruled out with regard to sensitive issues such as drug use, sexual orientation and behaviour, or being (or having been) a sex worker. The numbers of those identifying as being part of (or having been part of) certain key populations is not large enough to provide more than a 'snapshot' of the concerns of these communities of people living with HIV.

Despite these limitations, the study presents useful findings to guide further research and inform the design of interventions to address HIV-related stigma and discrimination.

What is in this report?

This report follows the content of the questionnaire and is divided into three Sections:

- **Section 1:** General information about the respondent and her/his household.
- **Section 2:** Reported experiences of HIV-related stigma and discrimination; internal stigma (felt or internalised stigma); the protection of the rights of PLHIV through law, policy and/or practice; and effecting change at household and community levels in responding to stigma and discrimination.
- **Section 3:** Experience of testing, disclosure, treatment and having children.

Conclusions and recommendations are then presented.

Section 1:
Background characteristics and household composition

This Section presents general background information about people living with HIV who took part in the survey. The survey involved 854 respondents, of which 19% (n=162) live in rural areas, 22% (n=188) live in a village or small town, and 59% (n=504) live in a city or large town. Over one third of respondents were aged between 30 and 39 years old (34.9%, n=113) with the sample including more women (56.7%, n=484) than men (42.7% n=365). 5 (0.6%) participants in the study were transgender.

Respondents' educational levels were generally low, with 10% (n=86) reporting no formal education and a further 38% (n=326) reporting primary level education. Secondary school education was the most frequently reported education level of respondents (45%, n=386). Men were more likely than women to have an educational level higher than primary level. For both men and women, the most common relationship status was married and living with a spouse (54.9% of men (n=200) and 37% of women (n=179)).

Zambia

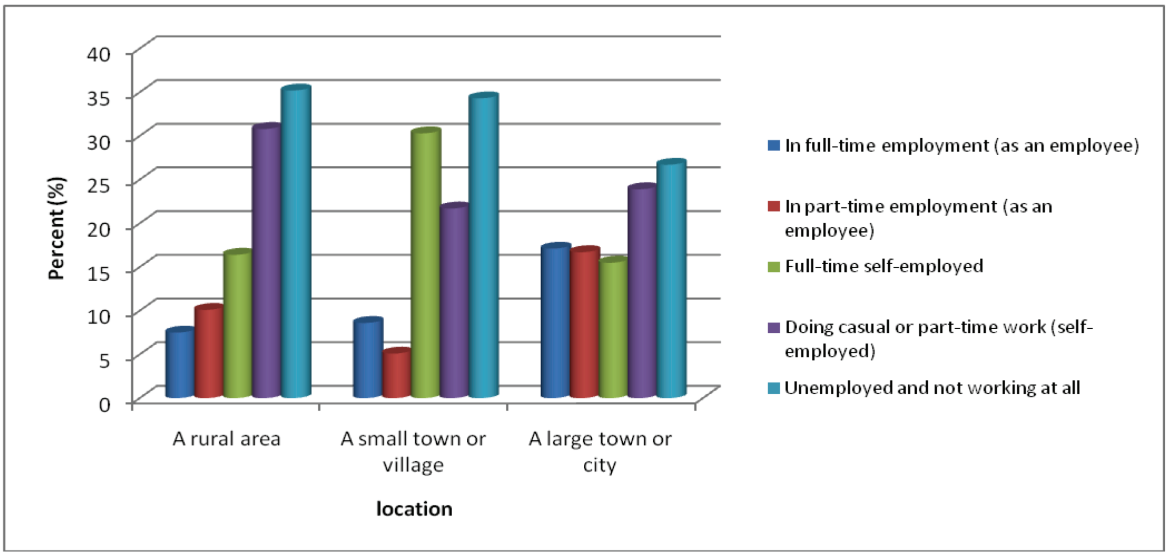
Table 1: Socio-demographic characteristics of respondents (men/women by age)

	Male	Female	Total
Background Characteristic	N (%)	N (%)	N (%)
Age (years)			
15-19	19 (5.2%)	25 (5.2%)	44 (5.2%)
20-24	17 (4.7%)	43 (8.9%)	60 (7.1%)
25-29	42 (11.6%)	84 (17.5%)	126 (14.9%)
30-39	129 (35.6%)	194 (40.3%)	323 (38.3%)
40-49	122 (33.7%)	102 (21.2%)	224 (26.6%0
50+	33 (9.1%)	33 (6.9)	66 (7.8%)
Total	362	481	843
Education status			
No formal education	30 (8.2%)	56 (11.6%)	86 (10.1%)
Primary school	108 (29.6)	218 (45%)	326 (38.4%)
Secondary school	193 (52.9)	193 (39.9%)	386 (45.5%)
Technical college/university	34 (9.3%)	17 (3.5%)	51 (6.0%)
Total	365 (100)	484 (100)	849
Current relationship			
Married with spouse living in	200 (54.9%)	179 (37%)	379 (44.7%)
Married, spouse not living in	16 (4.4%)	16 (3.3%)	32 (3.8%)
In relationship, not living together	32 (8.8%)	56 (11.6%)	88 (10.4%)
Single	51 (14%)	73 (15.1%)	124 (14.6%)
Divorced/separated	28 (8%)	61 (12.6%)	90 (10.6%)
Widow/widower	36 (9.9%)	99 (20.5%)	135 (15.9%)
Total	364	484	848
Residence			
A rural area	81 (23%)	79 (17)	160 (19.6%)
A small town or village	68 (19.3%)	110 (23.7)	178 (21.8%)
A large town or city	203 (57.7%)	275 (59.3%)	478 (58.6%)
Total	352	464	816

Numbers not adding up due to missing data

The graph below outlines respondents' employment status by residency. The proportion of respondents in full-time employment was much higher in the larger towns (over 15%) than in small towns or rural areas (6-7%). However, over one quarter of respondents across all locations were unemployed with higher levels reported in rural areas (nearly 35%), and unemployment was more pronounced among women than men (37.6% and 20.4% respectively). Similarly, more men than women reported being in full-time employment (21.9% compared to 8.4%).

Chart 3: Employment status by residence



In line with the study's objective of identifying the different vulnerabilities of population groups with regard to stigma and discrimination, respondents were asked with which 'key population[9]' they identified. About 70% indicated that they did not belong to any of the categories listed while the remainder identified as belonging to Key populations: ex-prisoner (14.5%), sex workers (6.6%), migrant workers (3.7%), internally displaced people (2.5%), members of indigenous group (0.7%), people who use drugs (0.6%), men who had sex with men (0.6%), transgender people (0.6%), refugee or asylum seeker (0.2%) and gay/lesbian (0.2%).

Despite the relatively small percentages, these findings are important evidence of the existence of men who have sex with men, gay men, lesbians and people who use drugs

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[9] The questions asked in the survey is 'Do you belong to, or have you ever belonged to, any of the following categories? The categories given are Men who have sex with men, Gay or lesbian, Transgender, Sex worker, Injecting drug user, Refugee or asylum seeker, internally displaced person. Member of an indigenous group, Migrant worker, Prisoner (or ex prisoner). Respondents could tick more than one box if appropriate as well as indicating that they had never belonged to any of these groups.

among people living with HIV in Zambia. It was also a learning point for NZP+ who realised that the sampling should have taken into account the stigma experienced by key populations and designed the sampling and the way that it reached out to key populations.

Table 2: Respondents being part of a key population

Key populations	Number	%
Men who have sex with men	5	0.6%
Gay or lesbian	2	0.2%
Transgender	5	0.6%
Sex worker	56	6.6%
Injecting drug user	5	0.6%
Refugee or asylum seeker	2	0.2%
Internally displaced person	21	2.5%
Member of an indigenous group	6	0.7%
Migrant worker	31	3.7%
(Ex) Prisoner	122	14.5%
None of these categories	589	69.8%

Note: the percentages are calculated on those answering the question (n=844)

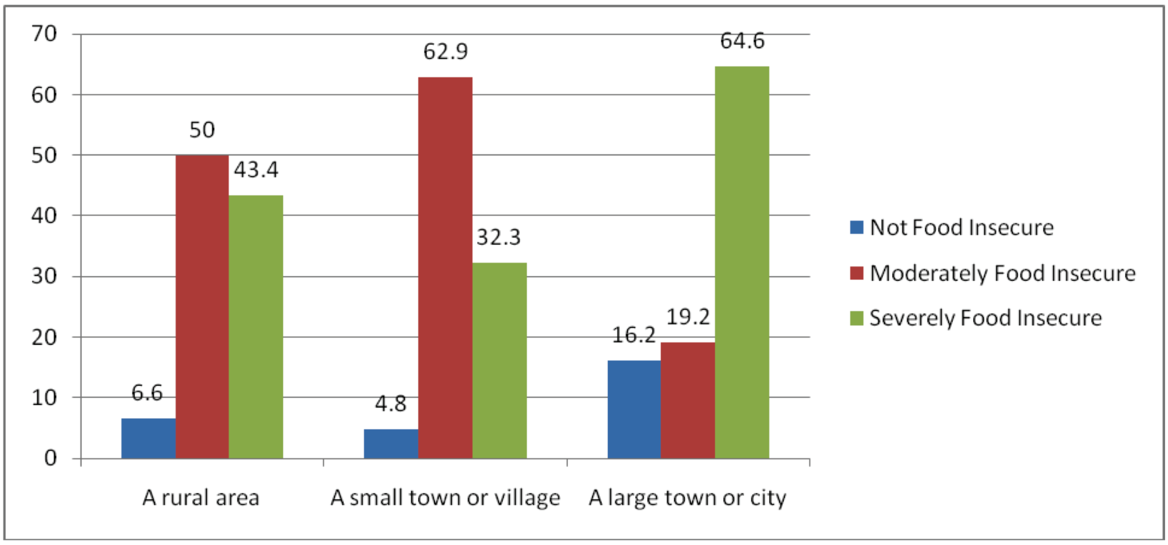
One quarter of respondents reported that children who have been orphaned due to AIDS live in their household with 1-2 orphans per household most frequently reported. There were no significant differences between male and female respondents.

Table 3: Number of orphans living in households of male and female respondents by location

	Male						Female						
	A rural area		A small town or village		A large town or city		A rural area		A small town or village		A large town or city		Total
No of orphans	N	%	N	%	N	%	N	%	N	%	N	%	N
1-2	15	71.4	15	78.9	82	78.8	20	76.9	27	69.2	112	75.2	159
3-4	4	19	4	21.1	19	18.3	5	19.2	9	23.1	26	17.4	40
5 or more	2	9.5	0	0	3	2.9	1	3.8	3	7.7	11	7.4	15
Total	21	100	19	100	104	100	26	100	39	100	149	100	214

Overall food insecurity was prevalent amogst respondents, ranging from a low of 83.8% in large towns/cities though to 95.2% in small towns or villages. However, severe food insecurity was more common among large town/city residents (64.6%) than in small towns (32.3%) or rural areas (43.4%). The results suggest that challenges to access aduquate nutrition are common in all locations.

Chart 4: Household food security by place of residence



Section 2: Experience of stigma and discrimination

This Section comprises five sub-sections: experiences of HIV-related stigma and discrimination; access to work and health and education services; internalised stigma; the protection of the rights of people living with HIV through the law, policy or practice; and effecting change.

2.1 Experience of HIV-related stigma and discrimination

Respondents were asked about their experiences of stigma and discrimination in the previous 12 months. Exclusion from social gatherings or activities was experienced by one third of respondents (n=278), and when disaggregated by gender, women were excluded more often than men (36.4%, n=174 compared to 29%, n=104)

Nearly 36% (n=293) of respondents reported being physically harassed or threatened with little gender disparity (male (33.6%, n=1185) and female (37.4%, n=175), respectively.

Gossip was the most frequently experienced form of stigma and discrimination for the whole sample with over half of respondents (51.8%, n=423) reporting experiencing this. Among the male respondents, 33.9% (n=99) reported experiencing gossip a few times, and 32.5% (n=114) indicated this happened often. Women had also experienced being gossiped about, with 31.9% (n=151) having experienced it a few times, and 38.8% (n=184) often.

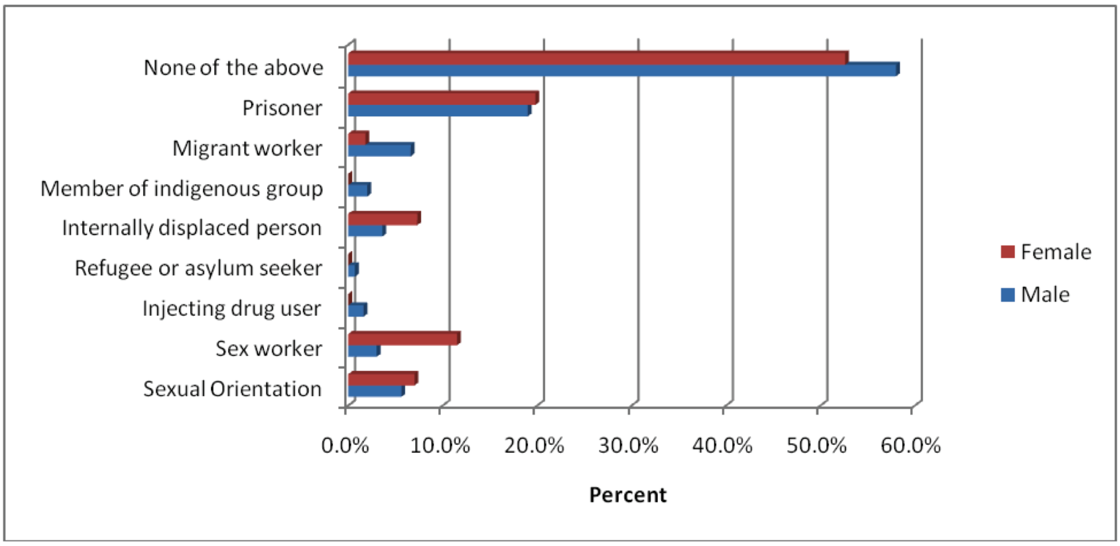
Respondents were also asked to indicate how often they had been subjected to psychological pressure or manipulation by their spouses or partners on account of their HIV status. 11.6% (n=99) had experienced this at least once in the previous 12 months.

Respondents were also asked to indicate if they felt there were reasons other than HIV status for being stigmatised and discriminated against. Over half of respondents indicated none of the reasons other than being HIV positive applied to them. The chart below shows the other reasons for discrimination. Of those respondents who had had experienced stigma and/or discrimination for reasons other than their HIV status, many belonged to key populations e.g. sex workers, internally displaced person or ex-prisoner; men who have sex with men or people who use drugs.

Table 4: Selected forms of discrimination - male and female respondents

		Male		Female		Total	
		N	%	N	%	n	%
In the last 12 months, how often have you been excluded from social gatherings or activities?	Never	254	70.9	304	63.6	558	66.7%
	Once	35	9.8	62	13	97	11.6%
	A few times	51	14.2	70	14.6	121	14.5%
	Often	18	5	42	8.8	60	7.2%
Total		358	100	478	100	836	
In the last 12 months, how often have you been aware of being gossiped about?	Never	97	27.6	105	22.2	202	24.5%
	Once	21	6	34	7.2	55	6.7%
	A few times	119	33.9	151	31.9	270	32.7%
	Often	114	32.5	184	38.8	298	36.1%
Total		351	100	474	100	825	
In the last 12 months, how often have you been verbally insulted, harassed and/or threatened?	Never	172	49.4	222	47.3	394	48.2%
	Once	50	14.4	83	17.7	133	16.3%
	A few times	99	28.4	111	23.7	210	25.7%
	Often	27	7.8	53	11.3	80	9.8%
Total		348	100	469	100	817	
In the last 12 months, how often have you been physically harassed and/or threatened?	Never	233	66.4	293	62.6	526	64.2%
	Once	44	12.5	66	14.1	110	13.4%
	A few times	62	17.7	75	16	137	16.7%
	Often	12	3.4	34	7.3	46	5.6%
Total		351	100	468	100	819	

Chart 5: Reasons other than HIV for being discriminated/stigmatised against

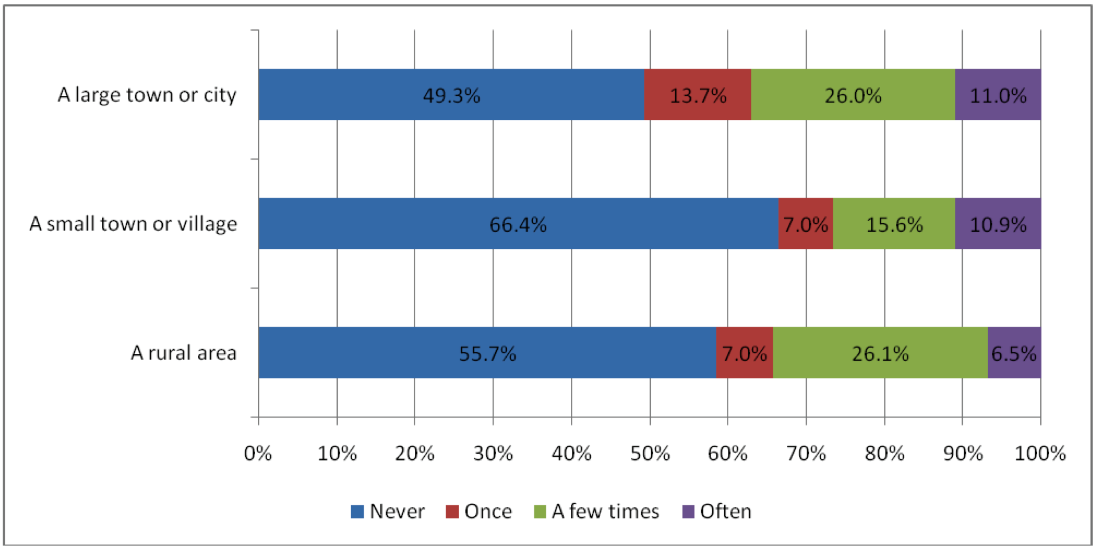


Illustrative quotes why respondents experienced stigma and discrimination for reasons other than HIV

> *'I had an operation that saw my uterus removed hence I can't have a child. Due to this my husband continuously beats me for I can't give him a child.'*
> (Female, large town)
>
> *'It was because of TB.'*
> (Female, rural area)

Respondents were also asked to state how often their spouses or any other member of their household had experienced discrimination as a result of the respondent's HIV-positive status. Although there were minor differences across gender, income group and age among others, the results presented in the graph below show that the proportion of respondents whose household members had been subjected to stigma by association at least once was higher in large towns/cities (50.7%) than rural areas (39.6%) or small towns or villages (33.5%). The proportion of respondents who reported that household members often experienced stigma was nearly equally high among respondents from large towns/cities (11%) as among those from small towns/villages (10.9%).

Chart 6: Discrimination against household members by place of residence



To gain an insight into the prevalence of discriminatory practices within the family setting, respondents were asked to state whether they had experienced exclusion from family activities in the previous 12 months. The table below shows that though 72.6% (n=605) of respondents reported never experiencing this form of discrimination in the last 12 months, over one quarter (27.4%) had. Furthermore, 22 of the 43 respondents between the ages of 18-19 (51.2%) had experienced exclusion on one or more occasions. In all in all other age groups, between 21.6% and 36.9% of respondents had been excluded from family activities at least once. There was no appreciable difference in the findings between exclusion experienced by men and women.

Table 5: Exclusion from family activities in last 12 months by age

	Never	Once	A few times	Often	Total
Background Characteristic	n (%)	n (%)	n (%)	n (%)	N
Age (years)					
18-19	21 (48.8)	4 (9.3)	14 (32.6)	4 (9.3)	43
20-24	43 (71.7)	5 (8.3)	11 (18.3)	1 (1.7)	60
25-29	86 (68.8)	12 (9.6)	17 (13.6)	10 (8)	125
30-39	240 (75.5)	18 (5.7)	38 (11.9)	22 (6.9)	318
40-49	174 (78.4)	13 (5.9)	24 (10.8)	11 (5)	222
50+	41 (63.1)	4 (6.2)	15 (23.1)	5 (7.7)	65
Total	605 (72.6)	56 (6.7)	119 (14.3)	53 (6.4)	833

Similar results were observed with regard to exclusion from religious activities with 27.4%,

(n=228) of respondents reporting exclusion at least once in the past 12 months. In instances religious and family exclusion converge as one respondent observed:

> *'There was a funeral of my late brother. I was not informed about it [and] when I asked they said I had nothing to contribute, the church would not want me there anyway and hence there was no reason to inform me about it.'*
> (Female, rural area).

Table 6: Exclusion from religious activities in past 12 months

	Never	**Once**	**A few times**	**Often**	**Total**
Age (years)	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**N**
Age (years)					
18-19	36 (85.7)	1 (2.4)	3 (7.1)	2 (4.8)	42
20-24	45 (76.3)	6 (10.2)	7 (11.9)	1 (1.7)	59
25-29	100 (80.6)	9 (7.3)	8 (6.5)	7 5.6)	124
30-39	267 (84.8)	23 (7.3)	18 (5.7)	7 (2.2)	315
40-49	192 (72.7)	12 (5.5)	12 (5.5)	3 (1.4)	219
50+	48 (72.7)	7 (10.6)	6 (9.1)	5 (7.6)	66
Total	605 (72.6)	56 (6.7)	119 (14.3)	53 (6.4)	833

2.2 Access to work and health and education services

This sub-section focuses on the extent to which access to accommodation, work, health and education services were influenced by respondents' HIV positive-status.

HIV testing as part of pre-employment screening is prohibited under a government policy. However this policy[10] is more honoured in the breach than the observance, and though it is government policy, pre-employment testing is not explicitly prohibited in law[11]. However it has been held[12] that mandatory testing without consent is unconstitutional[13]. Within this study 16.5% of respondents (n=92) reported having been refused employment or work opportunities on account of their HIV status in the last 12 months. The percent of respondents who had lost their jobs or some other source of income at least once in the previous 12 months was over double (39.3%, n=231), demonstrating the very real existence of HIV-related stigma and discrimination in the workplace.

Additional findings include:

- With regards to accommodation, some 45.2% (n=376) of respondents had been forced to change their place of residence or been unable to rent accommodation at least once in the past 12 months.
- With regard to education opportunities, 8% of respondents (n=50) reported having been dismissed, suspended or prevented from attending an educational institutional on account of HIV status.
- With regards to access to health services, some 8.4% of respondents (n=68%) reported being denied services (including dental services) in the past 12 months.

Where applicable, respondents were also asked whether they had experienced challenges in accessing family planning and other sexual and reproductive health services in the last 12 months. Some 9.7% (n=83) reported having been denied family planning services as a result of their HIV status, while 11.8% (n=101) indicated that they had been denied sexual and reproductive health services.

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[10] http://www.usaid.gov/our_work/global_health/aids/Countries/africa/zambia.pdf.(at page 2) refers to this policy but also states 'Zambia does not have many laws and regulations specifically protecting PLWHA against discrimination' and that 'knowledge of human rights and discrimination laws remains very low, especially in rural areas'.

[11] Information provided by Zambia AIDSLaw Research & Advocacy Network (www.zaran.org)

[12] Information from ZARAN: 'in a recent (2010) court case two ZAF (Zambian Air Force) employees were tested without their consent. As part of the outcome of this case the High Court ruled that mandatory testing for HIV was unconstitutional.

[13] Details of the ruling are available at http://www.zaran.org/index.php/news-a-press-releases/114-mandatory-testing-unconstitutional

Table 7: Access to work health and education services in the previous 12 months

Category	Response	N	%
In the last 12 months, have you been refused employment or a work opportunity because of your HIV status?	Yes	92	16.5
	No	464	83.5
Total		556	
In the last 12 months, how often have you lost a job (if employed) or any other source of income?	Never	357	60.7
	Once	107	18.2
	A few times	103	17.5
	Often	21	3.6
Total		588	
In the last 12 months, how often have you been forced to change your place of residence or been unable to rent accommodation?	Never	456	54.8
	Once	194	23.3
	A few times	139	16.7
	Often	43	5.2
Total		832	
In the last 12 months, how often have you been dismissed, suspended or prevented from attending an educational institution?	Never	582	92.1
	Once	41	6.5
	A few times	8	1.3
	Often	1	0.2
Total		632	
In the last 12 months, how often have you been denied health services because of your HIV status?	Never	737	91.6
	Once	34	4.2
	A few times	28	3.5
	Often	6	0.7
Total		805	100

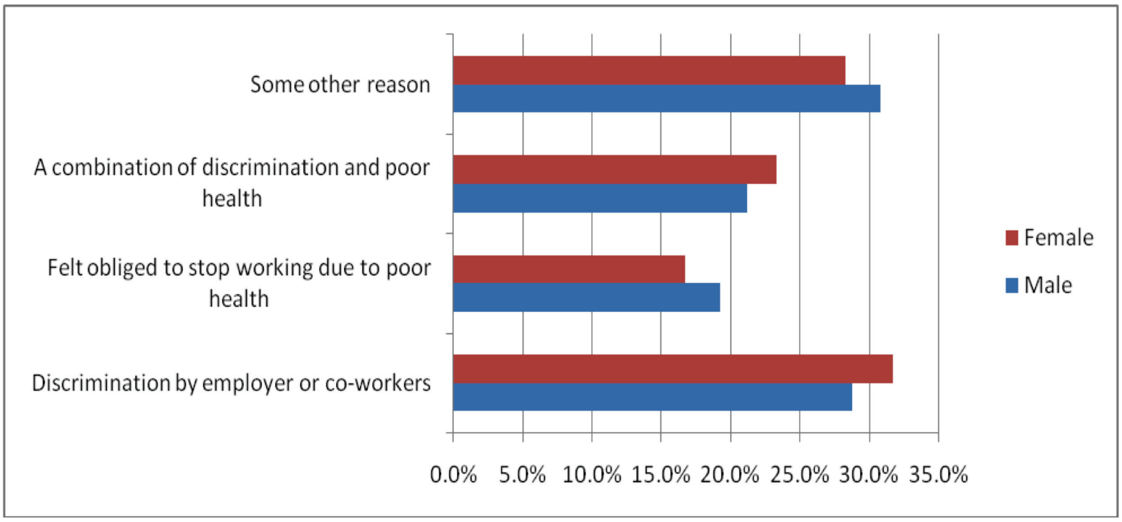
Stigma and discrimination in the work place

> *'I was demoted from work, when I was found to be HIV-positive. The public service commission helped to resolve the issue upon reviewing the case, and I was reinstated and promoted at the same time.'*
> (Male, large town)

> *'My friends at the market wanted to chase me because I was HIV-positive. Other people living with HIV and the market leadership helped resolve the issue.'*
> (Female, large town)

Respondents who reported being denied access to work were asked the reason why they thought this had occurred. For nearly 30% of male and over 30% of female respondents, discrimination at the hands of employers and co-workers was cited as the reason, with over 20% of both genders citing a combination of discrimination and poor health, and over 15% citing poor health. Over 25% of both genders cited other reasons, which should be investigated further.

Chart 7: Reasons for denial of access to work, male and female.



2.3 Internalised stigma and fears

This sub-section focuses on identifying forms of internalised stigma among respondents. The results show that internalised stigma was prevalent among both men and women. Over 60% of male and 40% of female respondents blame themselves; nearly 60% of respondents feel ashamed, over 50% feel guilty and over 40% have low self esteem. Furthermore, over 10% of both male and female respondents, more than one in ten, report feeling suicidal. These findings highlight the important role of psychosocial support to improve the mental well-being of people living with HIV.

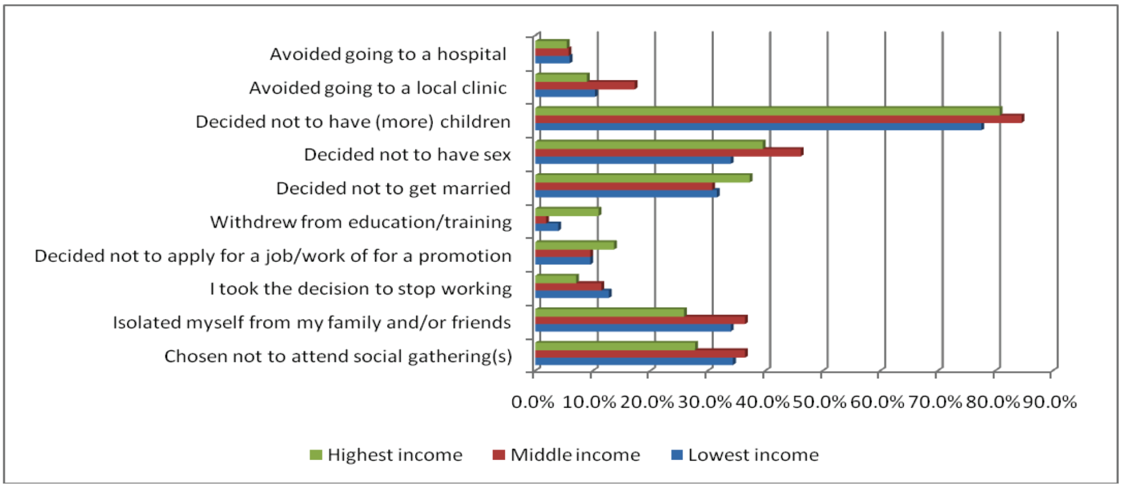
Table 8: Internalised stigma experienced by respondents

		Feelings because of HIV status							
		I feel ashamed	I feel guilty	I blame myself	I blame others	I have low self-esteem	I feel I should be punished	I feel suicidal	Total
Male	Number	159	167	174	71	121	37	40	365
	%	43.6%	45.8%	47.7%	19.5%	33.2%	10.1%	11.0%	
Female	Number	225	206	166	177	167	51	63	484
	%	46.5%	42.6%	34.3%	36.6%	34.5%	10.5%	13.0%	
Transgender	Number	1	4	1	1	-	-	-	5
	%	20.0%	80.0%	20.0%	20.0%	-	-	-	
All	Number	385	377	341	249	288	88	103	854
	%	45.1%	44.1%	39.9%	29.2%	33.7%	10.3%	12.1%	

The **Chart 8** below shows respondents' decisions, disaggregated by income level, not to engage in some activities because of their HIV-positive status. The most frequently cited reaction, over 70% of respondents irrespective of income group, was the decision not to have children. Furthermore, over 30% opted to abstain from sex or marriage; and over 25% stayed away from social gatherings or isolated themselves from friends and relatives.

Internal stigma also affects access to health care. Nearly 10% of low and high income respondents and over 15% of middle income ones avoided going to a local clinic, and approximately 5% across all income levels avoided going to hospital.

Chart 8: Things respondents did because of their HIV status



Respondents level of fear of being gossiped about, verbally insulted, physically harassed and/or threatened, and physically assaulted is shown in the table below. Overall, 91.7% of respondents (n=589) feared being gossiped about; significantly higher levels of fear than verbal insult (57.6%, n=370), physical harassment and/or threat (46.7%, n=300), and physical assault (40.5%, n=260).

Table 9: Fears experienced by respondents by various background characteristics

	Things fearful of				
	Being gossiped about	Being verbally insulted, harassed and/or threatened	Being physically harassed and/or threatened	Being physically assaulted	Total
	n (%)	N (%)	n (%)	n (%)	n
Gender					
Male	263 (73.9)	159 (86.6)	128 (46.4)	110 (39.9)	276
Female	326 (89.1)	211 (57.7)	172 (47.0)	150 (41.0)	366
Total	589 (91.7)	370 (57.6)	300 (46.7%)	260 (40.5)	642
Age (years)					
15-19	32 (84.2)	26 (68.4)	22 (57.9)	19 (50.0)	38
20-24	43 (86.0)	35 (70.0)	24 (48.0)	23 (46.0)	50
25-29	94 (92.2)	57 (55.9)	52 (51.0)	42 (41.2)	102
30-39	214 (87.7)	137 (56.1)	119 (48.8)	101 (41.4)	244
40-49	139 (88.5)	86 (54.8)	64 (40.8)	51 (33.5)	157
50+	41 (83.1)	29 (59.2)	19 (38.8)	22 (44.9)	49
Total	563	370	300	258	640
No. of years living with HIV					
0-1 years	135 (91.8)	94 (63.9)	79 (53.7)	59 (40.1)	147
2-4 years	296 (88.9)	179 (53.8)	145 (43.5)	126 (37.8)	333
5-9 years	99 (79.2)	76 (60.8)	61 (48.8)	63 (50.4)	125
10-14 years	24 (96.0)	15 (60.0)	11 (44.0)	9 (36.0)	25
15+ years	7 (87.5)	4 (50.0)	4 (50.0)	3 (37.5)	8
Total	561	368	300	260	638
Key population					
Men who have sex with men	4 (80.0)	3 (60.0)	1 (20.0)	2 (40.0)	5
Gay or Lesbian	2 (100)	1 (50.0)	1 (50.0)	1 (50.0)	2
Transgender	4 (100)	1 (25.0)	1 (25.0)	1 (50.0)	4
Sex worker	48 (88.9)	33 (61.1)	37 (68.5)	22 (40.7)	54
Injecting drug user	5 (100)	3 (60.0)	3 (60.0)	1 (20.0)	5
Internally displaced person	16 (84.2)	10 (52.6)	11 (57.9)	8 (42.1)	19
Refugee or asylum seeker	2 (100)	2 (100)	2 (100)	2 (100)	2
Member of an indigenous group	5 (100)	3 (60.0)	3 (60.0)	2(40.0)	5
Migrant worker	25 (92.6)	16 (59.3)	14 (31.9)	12 (44.4)	27
Prisoner	70 (78.9)	55 (61.1)	33 (36.7)	32 (35.6)	90
None of these categories	384 (76.3)	244 (57.0)	194 (45.3)	176 (41.1)	428
Total	565	370	300	259	640

Numbers do not equal due to missing data

2.4 Rights, laws and policies

This sub-section focuses on awareness of the 2001 Declaration of Commitment on HIV[14] and knowledge of national laws and policies, as well as violations of rights experienced in various settings.

In the Declaration of Commitment, Governments affirmed that the realisation of human rights and fundamental freedoms for all is essential to reducing HIV vulnerability. Human rights are legally guaranteed by human rights law, which exists to protect individuals and groups from actions that interfere with their freedom and dignity, and promotes access to the things that help people realise their rights. Human rights law exists at the international level (e.g. treaties and covenants) and at the national level (e.g. constitution, bill of rights, domestic laws).

While there are no HIV-specific laws which concern discrimination against people living with HIV (NAC, 2010), Zambia does have laws and regulations to protect vulnerable populations such as women, youth and migrants. It is a signatory to a number of international treaties and declarations related to the protection of the rights of people living with HIV, and there are a number of national policies and guidelines that govern HIV service delivery.

More than half the respondents (57%, n=487) indicated that they had not heard of the Declaration of Commitment on HIV; while of the 43% (n=367) who had, some 49.6% (n=182) reported having read or discussed its contents. The results regarding knowledge of national policies which provide protection for people living with HIV show a similar pattern: 55.6% (n=475) of respondents were not aware of such policies; while of the 44.4% (n=379) who were aware, less than half (47.1%, N=178) had read or discussed them.

As the table below shows, the most frequent form of rights violations experienced was that none of the examples presented had ever happened to them (82%, n=700). However, 10.4% of respondents (n=89) reported experiencing forced medical procedures, while 4.8% reported detention, isolation, being quarantined or segregated.

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[14] http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf

Table 10: Incidents experienced by respondents in the previous 12 months

Violation	n	%
Forced to submit to a medical procedure or health procedure (including HIV testing)	89	10.4
Denied health insurance because of HIV status	4	0.4
Arrested or taken to court on HIV-related charges	9	1.1
Had to disclose HIV status to enter another country	7	0.8
Had to disclose HIV status to apply for residence or nationality	6	0.7
Detained, quarantined, isolated, segregated	41	4.8
None of these things happened to me	700	82.0

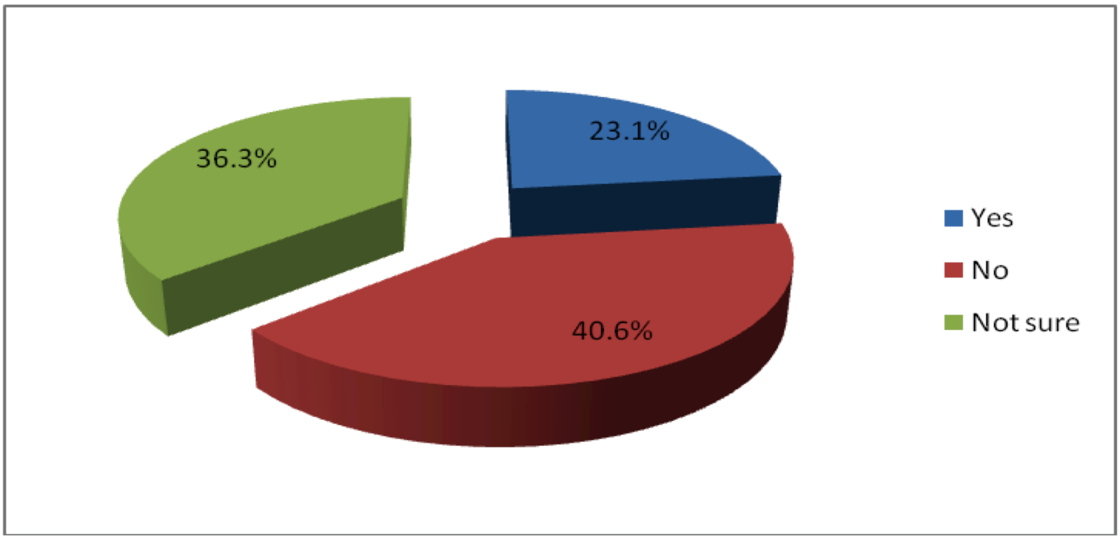
Does not add up to 100%, multiple response allowed

In some instances, violations extended to people associated with respondents, as was the case in the following account:

> *'The family members to my late husband wanted to force me to take the children for VCT. People living with HIV sensitised them on HIV and AIDS and told them that no one had the right to force anyone to do an HIV test.'*
> (Female, large town)

The **Chart 9** below shows that 36.3% of respondents, over one third, were unsure whether they had suffered violation of their rights as people living with HIV in the previous 12 months, suggesting that many people living with HIV could benefit from sensitisation and knowledge about what their rights are.

Chart 9: Respondents' experience of violation of rights in the previous 12 months



Of those who reported that their rights had been abused and had sought legal redress, the majority (51.6%, n=33) reported that nothing had happened; while less than 20% reported that the matter had been dealt with (18.8%, n=12) (Evidence from other studies on HIV-related stigma and discrimination show ignorance is one of the main underlying causes (Stutterheim et al., 2008; CSO, 2009). In this study, 82% (n=700) of respondents did not know or were unsure of the reason for HIV-related discrimination; however, the most commonly cited reason was respondents believing that this was due to other people's fear of being infected (10.4%, n=89)).

Table 11: Respondents' perceptions of why others stigmatized

	n	%
People are afraid of getting HIV from me	89	10.4
People don't understand how HIV is transmitted	4	0.4
People think that having HIV is shameful and they should not associate with me	9	1.1
Religious beliefs or 'moral' judgments	7	0.8
People disapprove of my lifestyle or behaviour	6	0.7
I look sick with symptoms associated with HIV	41	4.8
I don't know/I'm not sure if the reason(s)	700	82.0

Multiple responses permissible

2.5 Effecting change

This section explores respondents' reactions to incidents of stigma and discrimination; awareness of potential sources of assistance when confronted with stigma and discrimination; and participation in policy reform on HIV-related stigma and discrimination.

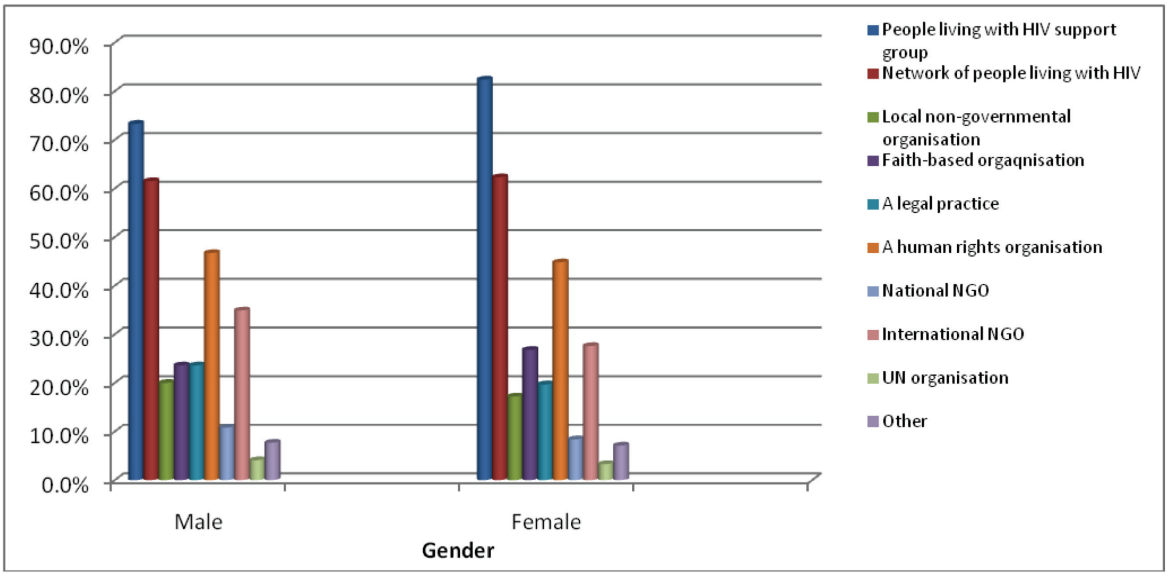
Among the respondents, 40.7% (n=333) reported being a member of a support group and/or network of people living with HIV. Respondents were also asked to indicate whether in the previous 12 months, they had been involved (as a volunteer or employee) in a programme or project providing assistance to people living with HIV; 69.1% (n=591) reported that they had not been involved in any such initiative; while 30.9% (n = 263) had.

Similarly, most respondents (90.1%, n=768) indicated that in the previous 12 months, they had not been involved in efforts to develop legislation, policies or guidelines relating to HIV. Further analysis revealed a clear difference in legislative or policy level participation between members and non-members of support groups. 60 (17.9%) of those who reported being part of a support group (n=333) had been involved in such activities whilst this was only reported by 2.1% (n=11) of the 521 who were not part of a support group.

The **Chart 10** shows respondents' knowledge of different types of organisations or groups providing support to those experiencing stigma or discrimination. Among both male and female respondents, support groups for people living with HIV were the most frequently cited entity to approach (more than 70% and 80%, respectively); followed by slightly more than 60% of male respondents and a similar percent of female respondents reporting knowledge of a network of people living with HIV; and over 40% knowing of a human rights organization. Each of the remaining types of organisation, including human rights organizations, local and national NGOs, FBOs and legal services, was mentioned by less than 50% of respondents.

These findings should be interpreted with caution, due to the potential effect of selection bias on the composition of the sample and also the possibility of respondents opting for responses considered more appealing to the interviewer.

Chart 10: Respondents knowledge of organisations to go to for assistance



Of the respondents who reported being aware of potential sources of help, only 21.2% (n=162) had approached any of them regarding an incident of stigma and discrimination.

Respondents were asked if they had confronted, challenged or educated someone who was stigmatising and/or discriminating against them. 419 (50.4%) of the 832 respondents to this question reported that they had done so. The percentage reporting taking such action was nearly double among members of a support group or network compared to non-members (71.2% and 36.6% respectively). When disaggregated by education level, among respondents, those who responded in the affirmative included 26.7% of respondents with no formal education, 44.8% of those with primary education, 59% with secondary education, and 59.2% with technical college or university education, suggesting that the likelihood of taking action increases with the level of education.

The study also sought to gain insight into various forms of stigma and discrimination by asking respondents to document specific incidents and include details about any measures they had taken to resolve the issue. The following are some of the responses:

> *'I have not tried to deal with stigma issues but I am in the process of calling my relatives so that we can resolve [the matter]. My in-laws don't want me because I am HIV-positive.'*
> (Female, large town)

> *'The landlord decided to evict me from his house immediately he knew that I was HIV-positive.'*
> (Male, rural area)

> *'My neighbour's children fought with mine and the neighbour said that my children are like so because of my illness.'*
> (Male, large town)

> *'I wanted to shift into a bigger house, but the headmaster stopped me because I am HIV-positive. I went to higher education authority (District Education Officer) and reported the matter and I was given a bigger house.'*
> (Male, large town)

> *'Someone told a man who wanted to marry me that I was HIV-positive. I took the matter to the courts of law and the Legal AID Clinic for Women (NGO) and this issue has not yet been resolved.'*
> (Female, large town)

> *'My family members never wanted me to get married when I tested HIV-positive. My fellow support group members helped resolve the issue and the family members were sensitized and told that I had the right to marry.'*
> (Female, rural area)

572 of the 784 respondents to the question (73%) reported having provided some form of support to other people living with HIV in the previous 12 months. Emotional support (in the form of counselling, sharing personal stories and experiences) was the most common type of assistance reported (by 498 of the 572, 87.1%), providing physical support (such as running

errands and providing food or money) was reported by 104 people (18.2%) and 141 (24.7%) indicated that they had provided a referral to other services[15].

Table 12 focuses on respondents' feelings of being able to influence policies, laws and programmes. Nearly 40% of respondents felt able to influence local projects to benefit people living with HIV (39.8%, n=340) and legal/rights matters affecting people living with HIV (37.6%, n= 321). However, less than one in five respondents felt that they had any influence at the national programmatic level (12.4%, n=106) or on local or national policies (18.5%, n=158 and 16.7%, n=143, respectively). Furthermore, over one third (34.1%, n=291) of respondents felt unable to influence any of the areas mentioned.

Table 12: Areas of policy and programs that respondents felt they could influence

Aspect	N	%
Legal/rights matters affecting people living with HIV	321	37.6
Local government policies affecting people living with HIV	158	18.5
Local projects to benefit people living with HIV	340	39.8
National government policies affecting people living with HIV	143	16.7
National programmes/ projects to benefit people living with HIV	106	12.4
International agreements/ treaties	14	1.6
None of these things	291	34.1

Chart 11 outlines respondents' recommendations, disaggregated by age, regarding the most important things organisations should do to address stigma and discrimination.

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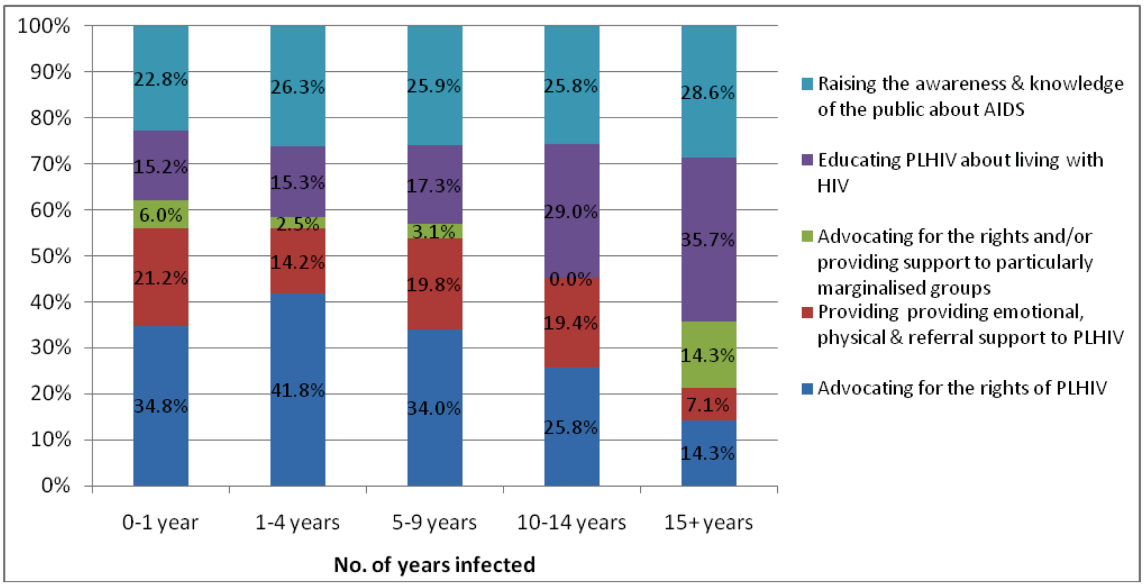
[15] Respondents could report more than one type of support they had provided hence the %'s not adding up to 100%

Chart 11: Respondents recommendations for addressing stigma and discrimination, by number of years living with HIV



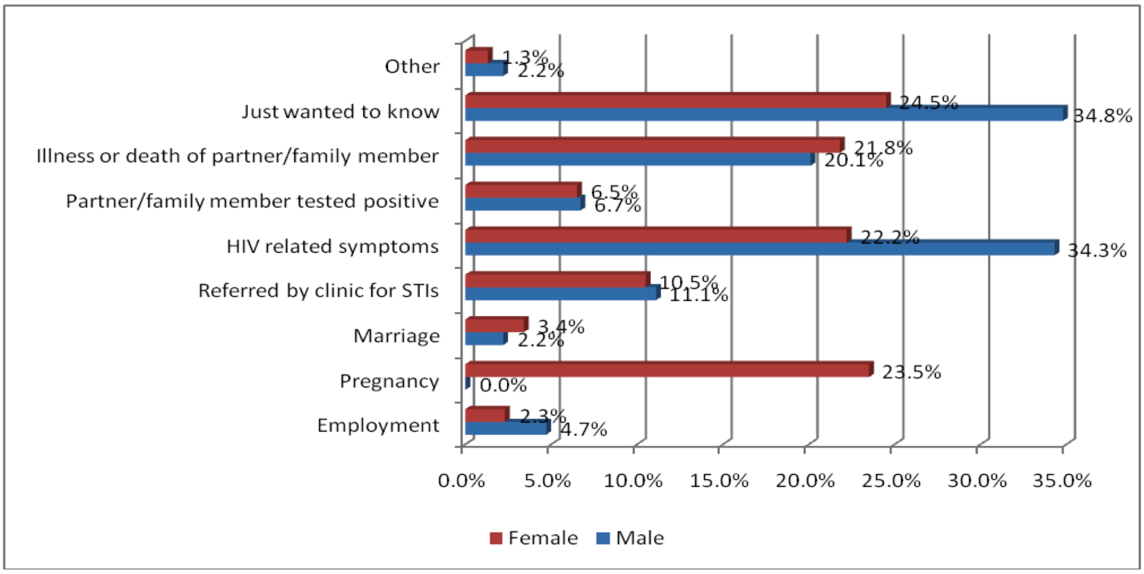
Perceptions of the most important strategies for addressing stigma and discrimination varied according to the number of years respondents had been living with HIV. For example, the provision of emotional, physical and referral support was more important for respondents with fewer years of living with HIV (e.g. 21.2% for those 0-1 years) compared to those who had been HIV-positive for 15 or more years (7.1%). Also, while advocacy for the rights of people living with HIV was considered a priority by more than one third of those who had lived with HIV for 9 years or less, its importance steadily declined among respondents who reported living with HIV for 10-15 year (25.8%) to less than 10% for those HIV-positive for 15 or more years (7.1%). Across the five age groups of people living with HIV, advocacy for the rights of key populations was the least mentioned. This was probably on account of the small number of respondents who identified themselves with a key population, and is in keeping with the low priority accorded these populations within the HIV response.

Section 3: Experience of testing, disclosure, treatment and having children

This Section comprises four sub-sections: testing and diagnosis; disclosure and confidentiality; treatment; and experience of having children.

3.1 Testing and diagnosis

Chart 12: Reasons for testing for HIV



Among the respondents, the proportion of men and women who reported taking a HIV test just to know their status is similar to that of men and women who tested because of HIV-related symptoms (24.4% and 34.8% compared to 22.2% and 34.3%, respectively). With nearly one quarter of men and more than one third of women being symptomatic at time of diagnosis, this suggests that more investment should be made in promoting voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.

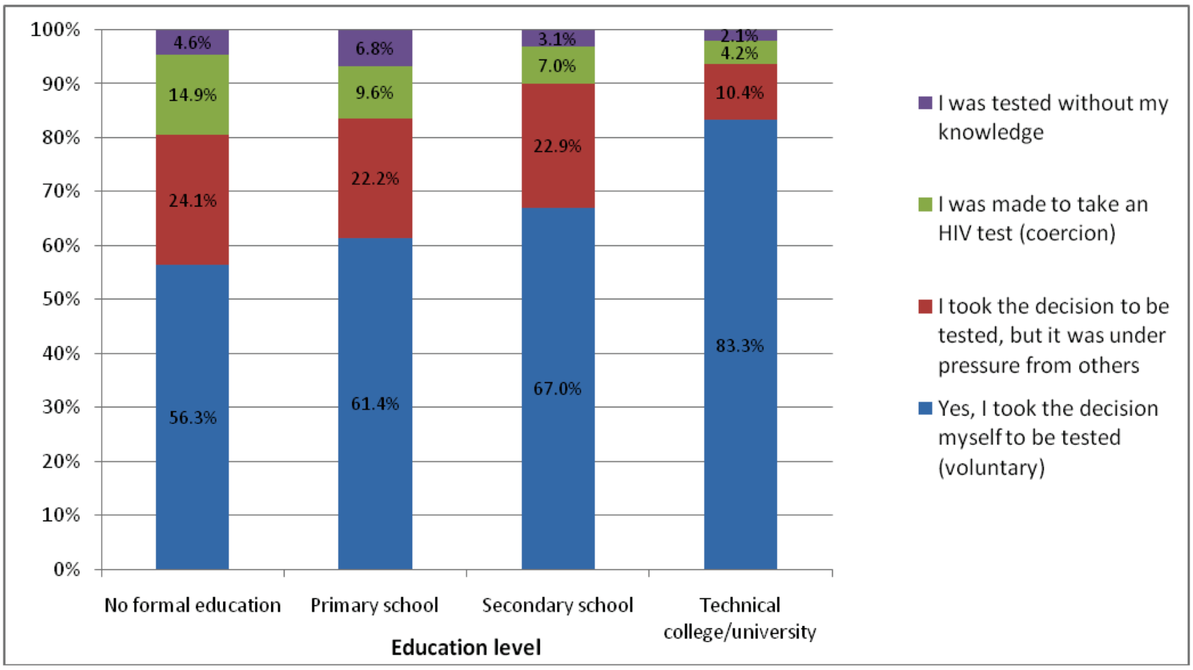
Human rights violations associated with involuntary HIV testing remain a challenge in Zambia. Although there is a national HIV and AIDS policy that clearly states that HIV testing should be voluntary, 73 of 839 respondents (7.8%) reported testing under coercion.

Challenges respondents faced in the course of accessing HIV testing services:

> *'There is only one place to get tested from, so it takes too long for one to get tested.'*
> (Male, rural area)
>
> *'The distance to the testing centre is long and the staff have only two days in a week to attend to those that want to test for HIV.'*
> (Female, small town)

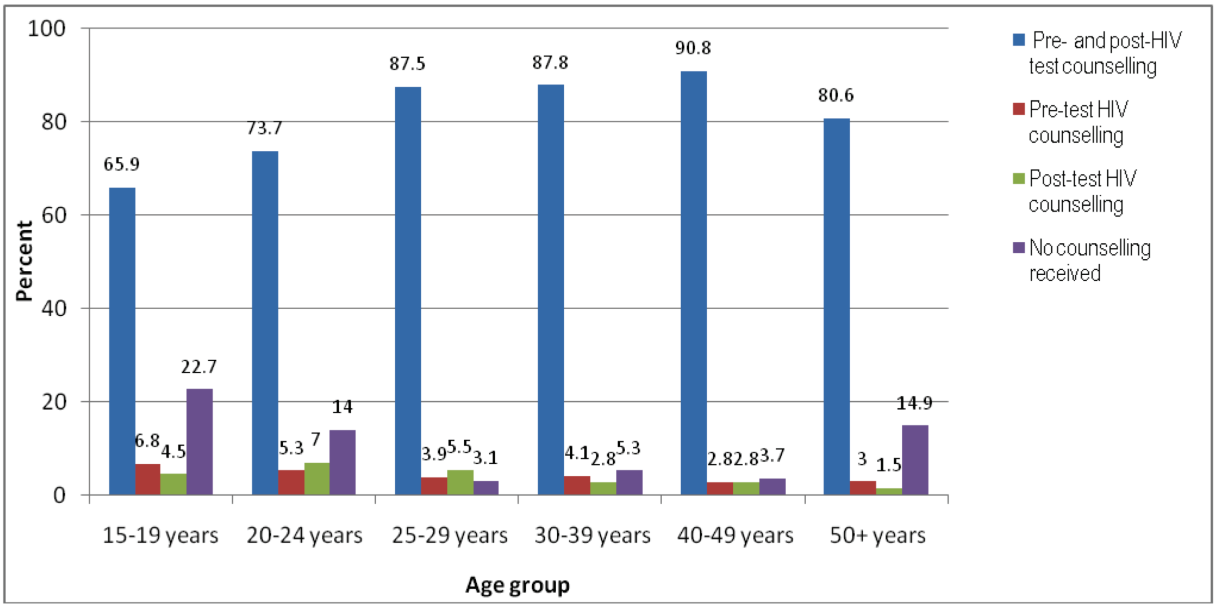
Chart 13 shows the motivation for taking a HIV test, disaggregated by education level. While the proportion of respondents who voluntarily took the test was high in all groups; it was higher among respondents with secondary and tertiary level education (67% and 83.3% respectively) in comparison to those with no formal education or primary school level education (56.3% and 61.4% respectively). Conversely, testing under coercion/pressure was more likely to be reported by respondents with lower levels of education (e.g. 39% for those with no formal education and 21.8% for those with primary education, compared to 29.9% and 14.6%, respectively, for those with secondary and tertiary level education), suggesting an association between the two variables.

Chart 13: Motivation for taking HIV test, by education level



National guidelines on HIV testing in Zambia require the provision of both pre- and post-test counselling irrespective of the test result. Respondents were asked to indicate whether they had been counselled at the time they took the HIV test. Most respondents irrespective of age group reported receiving both pre- and post-HIV test counselling. Some people, including more than 10% of young people and people over 50 years of age, reported having been tested without any counselling at all, suggesting that adherence to the national guidelines remains a challenge.

Chart 14: Whether counselling received when taking HIV test, by age group



3.2 Disclosure and confidentiality

The results presented in sub-section 2.3 show that irrespective of gender, age, location and identification with key population, being gossiped about is what respondents generally feared most. To a large extent, this fear is linked to disclosure and confidentiality. A person's decision about who to inform about his or her HIV-positive status is therefore partly influenced by perceived reactions. **Table 13** shows to whom respondents disclosed their status and the manner in which it was done.

Table 13 Who respondents disclosed their status to and manner in which it was done.

	I told them	Someone else told them with my consent	Someone else told them without my consent	They don't know my HIV status	Not applicable	Total number of eligible respondents
Your Husband /wife/ partner	552 87.6%	18 2.9%	16 2.5%	44 7.0%	198	630
Other family members	607 74.4%	56 6.9%	63 7.7%	90 11.0%	24	816
Children in your family	340 49.0%	23 3.3%	55 7.9%	276 39.8%	140	694
Your friends/neighbours	216 28.9%	38 5.1%	200 26.7%	294 39.3%	70	748
Other people living with HIV	601 75.2%	25 3.1%	60 7.5%	113 14.1%	29	799
Co-Workers	181 36.9%	15 3.1%	92 18.7%	203 41.3%	337	491
Your employers/bosses	178 49.4%	14 3.9%	28 7.8%	140 38.9%	452	360
Your clients	156 33.5%	20 4.3%	53 11.4%	237 50.9%	360	466
injecting drug partners	6 0.7%	3 0.4%	31 3.9%	761 95.0%	801	801
Religious leaders	230 35.2%	71 10.9%	71 10.9%	281 43.0%	172	653
Community leaders	88 16.9%	39 7.5%	61 11.7%	332 63.8%	293	520
Health Care Workers	648 81.0%	61 7.6%	55 6.9%	36 4.5%	27	800
Social Workers/Counsellors	459 66.5%	55 8.0%	78 11.3%	98 14.2%	130	690
Teachers	31 11.4%	10 3.7%	16 5.9%	215 79.0%	550	272
Government Officials	29 13.2%	9 4.1%	6 2.7%	176 80.0%	605	220
The media	18 10.5%	4 2.3%	2 1.2%	148 86.0%	653	172

Please note that the % in each of the rows is calculated against the total number of eligible respondents, this being the number in the total sample who felt the question applied to them. Where the number of eligible respondents plus the number of respondents who did not feel the question applied to then does not add to the total sample size (854) this is due to missing or unclear responses which were excluded.

Ideally, the counsellor-client relationship is associated with high levels of mutual respect, openness and confidentiality. However, a number of respondents as part of qualitative follow up conversations indicated that they feared disclosing their HIV status to their counsellors as outlined below:

> *'In most counselling centres there so many trainee counsellors hence there is no guarantee for confidentiality.'*
> (Male, small town)
>
> *'I think they should not employ counsellors who drink beer. They break confidentiality in bars.'*
> (Female, large town)

Respondents were further asked about the reactions of these people when they first knew about their HIV status. The **Table 14** below shows perceived reactions, with categories ranging from very discriminatory to very supportive.

Table 14: Reactions to disclosure of HIV- positive status

Groups	Very Discriminatory	Discriminatory	No different	Supportive	Very supportive	Not applicable
Your husband/wife/partner	12.8	9.3	8.8	21.8	19.2	28
Other adult family members	11.7	14.4	13.8	31.5	18.5	10.1
Children in your family	3.2	3.6	19.8	19.7	15.7	37.9
Your friends/neighbours	13.3	19.2	17.4	13.9	4.1	32.1
Other people living with HIV	1.4	0.8	9.3	47.7	25.1	15.6
People who you work with	5.1	7.1	9	11.4	4.3	63.1
Your employer(s)/boss(es)	5.7	4.5	4.9	11.5	6.1	67.3
Your clients	1.7	2	12.3	13.7	4.2	66.1
Injecting drug partners	0.1	0.1	0.9	0.9	1.7	96.3
Religious leaders	3.7	3.3	15.4	21.2	11.6	44.8
Community leaders	2.3	5.3	16	8.3	4	64.2
Health care workers	2.7	5.1	9.9	49.1	26	7.3
Social workers/counsellors	1.5	1	13.3	42.5	19.1	22.6
Teachers	0.4	2.2	3.5	3	2.6	88.3
Government officials	1	0.7	2.6	1.7	3.1	90.8
The media	0	0	1.5	2	2.6	93.9

In terms of supportive and very supportive reactions, health care workers (75.1%) and other people living with HIV (72.8%) were reported by respondents as being the most supportive.

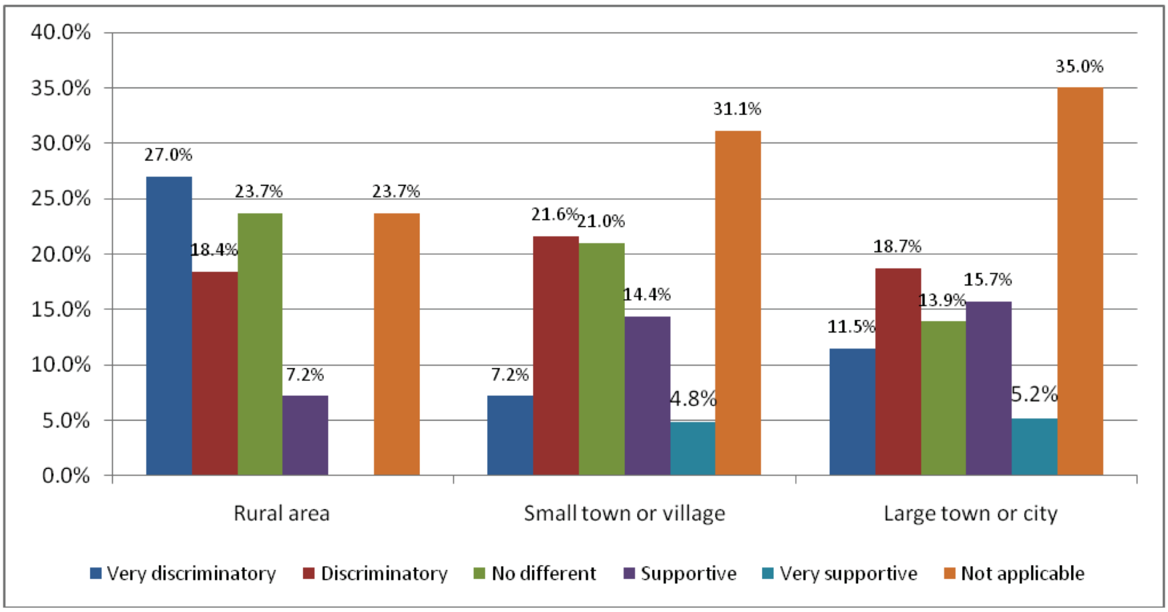
Husbands, wives and partners were also rated as having very supportive and supportive reactions (19.2% and 21.8% respectively), but also very discriminatory reactions (12.8%) – almost as high as friends and neighbours (13.3%).

> *'My husband ran away from home and went to his relatives to stay with them, so I had to seek help from the support group. I was referred to NZP+ for help, but I decided to confront my husband.'*
> (Female, large town)

> *'The parents to my wife told her that she couldn't stay with me because I had HIV, the church helped to resolve the issue and I'm still with her.'*
> (Male, large town)

There were no major differences in reported reactions between age, gender, income group and education. However, the reactions of friends and neighbours appeared to vary with the respondent's area of residence. For instance, 27% of rural respondents reported very discriminatory reactions among friends and neighbours, more than double that of respondents residing in a large town or city (11.5%). As **Chart 15** shows, none of the respondents residing in rural areas reported very supportive reactions from friends and neighbours, an indication of the existence of HIV-related stigma even in communities traditionally seen as closely knit and with strong social support systems.

Chart 15: Reactions of friends and neighbours to respondent's disclosure of HIV status, by location



Some 9.4% (n=76) of respondents had not disclosed their status. Of the remaining 734 people who answered this question 75.7% (n=556) said they had ultimately found this an

empowering experience, whilst 24.3 % (n=178) had not. For some respondents, disclosing one's status carried practical benefits:

> *'Disclosing HIV status to one or two people is good. People can collect medication on your behalf.'*
> (Male, rural area)

However, some respondents had negative views about disclosure, for example:

> *'Disclosure cost my marriage so to me it was not beneficial.'*
> (Male, large town)

> *'I find it difficult to disclose for I don't know what reaction I will meet. I don't know how confidential my counsellor will be.'*
> (Female, large town)

3.3 Treatment

In most countries in which the Stigma Index has been implemented, the sampling methodology used involves a mixture of respondents accessing ART and HIV care, and those who are not. This is part of wider aspiration that the sampling (as far as is possible within the resource constraints and known epidemiological profile) can reflect/be representative of the known community of people living with HIV within a country. As already discussed, the Zambian sampling strategy was initially to interview those people already accessing ART, as well as including those attending centres where ART was available but who were not yet accessing it. As such the Zambian data is skewed and may be providing a more favourable assessment of the situation regarding the availability, and accessibility if HIV health care and health care services within the country than is actually the case.

Respondents were asked to provide information on how they perceived their current health, their access to treatment for opportunistic infections and their experiences of sexual and reproductive health information in health care facilities.

As perhaps could be expected considering the sample was predominantly those accessing health care facilities with good access to ART provision only a small number described their health as poor (3.5%,n=29).

Table 15: Respondents perception of their health

In general, how would you describe your health at the moment? (Tick one box only)

		Excellent	Very good	Good	Fair	Poor	
Male	Count	48	134	121	44	12	359
	%	13.4%	37.3%	33.7%	12.3%	3.3%	
Female	Count	70	149	167	72	17	475
	%	14.7%	31.4%	35.2%	15.2%	3.6%	
Transgender		2	0	1	2	0	5
		40.0%		20.0%	40.0%		
TOTALS	Count	120	283	289	118	29	839
	%	14.3%	31.4%	35.2%	15.2%	3.5%	

Of those accessing ART, the highest percent was among those respondents from large towns/cities (80.4%) followed by those in rural areas (73.1%) and the lowest was among those residing in a small town or village (55.9%) (**Chart 16**). In addition, fewer people living in a large town/city reported not knowing whether they could access ART or not, compared to respondents from a rural area or small town. ART access was highest among those aged 30 to 39 years (78.7%) followed by 62.5% in the over 50 age group and 58.1% among 15 to 19 year olds.

Chart 16: Respondents on ART, by location

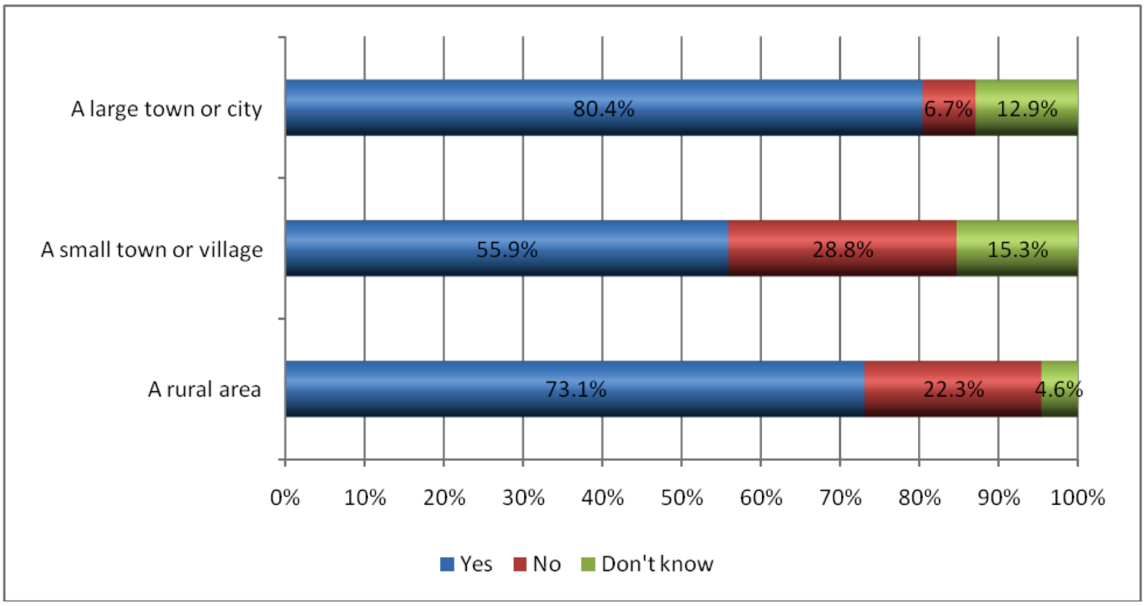


Table 16 shows the percentage of respondents who reported receiving some form of HIV-related treatment by gender. Overall, access to ART was not a problem with nearly 90% accessing ART. Even among those yet to commence treatment, a majority of respondents (77.9% of the men and 72% of the women) indicated that they could access ART. Furthermore, over 70% of respondents indicated that they were taking some medication to prevent or to treat opportunistic infections.

Table 16: Access to ART and treatment for opportunistic infections, by gender

Category	Response	Gender				Total
		Male		Female		
		N	%	n	%	n
Are you currently taking antiretroviral treatment?	Yes	327	91.3	419	88.0	746
	No	31	8.7	57	12.0	88
Total		358	100	476	100	834
Do you have access[16] to antiretroviral treatment even if you are currently not taking it?	Yes	226	77.9	279	72.1	504
	No	35	12.1	59	15.2	94
	Don't know	29	10.0	49	12.7	78
Total		290	100	387	100	667
Are you currently taking any medication to prevent or to treat opportunistic infections?	Yes	256	73.8	326	70.3	582
	No	91	26.2	148	29.7	229
Total		247	100	464	100	811

Numbers not adding up due to missing values

The levels of satisfaction were generally high, with one respondent describing ART as a saviour. Treatment-related challenges mentioned by respondents mostly related to side-effects, pill burden and the duration of treatment, suggesting that more investment in treatment literacy could improve adherence and heath outcomes.

Treatment-related challenges:

> *'The time of taking the drugs is too long. It would be better if some cocktail could be formulated to be taken may be once per month.'*
> (Male, rural area)

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[16] In this context access means that antiretroviral treatment is available and free or the respondent can afford it.

> *'It's challenging taking ARV's daily. Better formulations need to be found.'*
> (Male, large town)
>
> *'Stavudine[17] is giving a lot of problems. My legs are becoming swollen. I feel like stopping taking ARV's.'*
> (Male, small town)

More than half the respondents (59.3%, n= 489) reported having constructively discussed sexual and reproductive health, emotional well-being and other similar subjects with their health providers in the previous 12 months. While over two thirds (69.4%, n=579) of respondents reported having had a constructive discussion on HIV treatment options.

3.4 Having children

This sub-section focuses on respondents' experiences regarding reproductive options and sexual and reproductive health services. Female respondents were asked additional questions relating to pregnancy and infant feeding practices.

Altogether, 85% (n=703) of respondents reported having children, with no discernible difference across the income groups or by gender. Respondents were also asked about having children known to be HIV-positive **Chart 17** shows that the percentage of respondents with HIV-positive children was much higher among those who reported living with HIV for longer periods. For example, some 60% of those who reported living with HIV for 15 years or more indicated having HIV-positive children, compared to only 13.2% of those living with HIV for 1 year or less. While these results may reflect scaled up prevention of vertical transmission services and programmes; these results also reinforce the call for sustained efforts to support the reproductive aspirations of people living with HIV with greater emphasis on strategies for preventing vertical HIV transmission.

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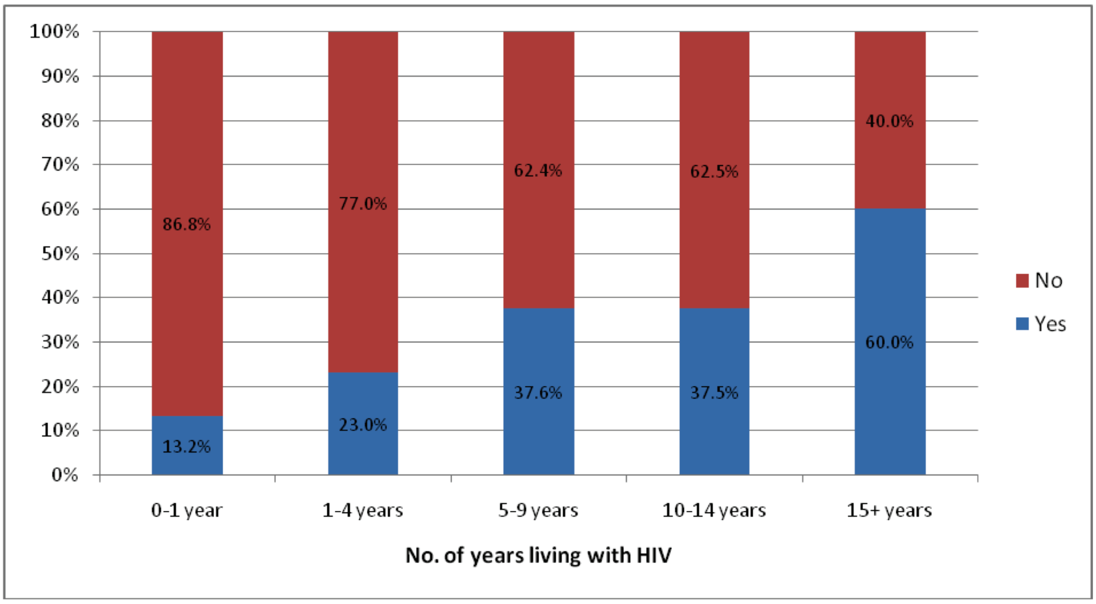
[17] Stavudine is also known as Zerit (brand name) or d4T.

Chart 15: Respondents with HIV-positive children, by number of years living with HIV



Reproductive health counselling plays an important role in the effectiveness of HIV prevention strategies, particularly those focusing on vertical transmission and serodiscordant couples. Of the 818 respondents to this question 134 responded that this question did not apply to them. Of the remaining 684, 111 of 288 men (38.5%) and 120 of 396 (30.3%) of women reported never having received counselling on reproductive options

Female respondents were asked to indicate if they had experienced coercion from a health care professional in relation to termination of a pregnancy (abortion) in the previous 12 months.

407 women answered this question (of the total number of women in the sample[18]) and of these 96 (31.1%) said the question did not apply to them – i.e. they either had not been pregnant in the previous 12 months or had not had a conversation with a health-care provider about pregnancy in the previous 12 months. Of the remaining 309 women, 5.2% (n=16) had experienced pressure to terminate a pregnancy (abortion) in the previous 12 months.

Female respondents were also asked about access to services to prevent vertical HIV transmission. Surprisingly, **Chart 18** shows that more respondents from rural areas (61.2%) reported receiving interventions to prevent vertical transmission compared to 52.6% of respondents residing in large towns/cities and 41.4% of those living in small towns or villages. In terms of access to services to prevent vertical HIV transmission, 11.5% of those living in small towns or villages stated they did not have access, compared to 8.6% of

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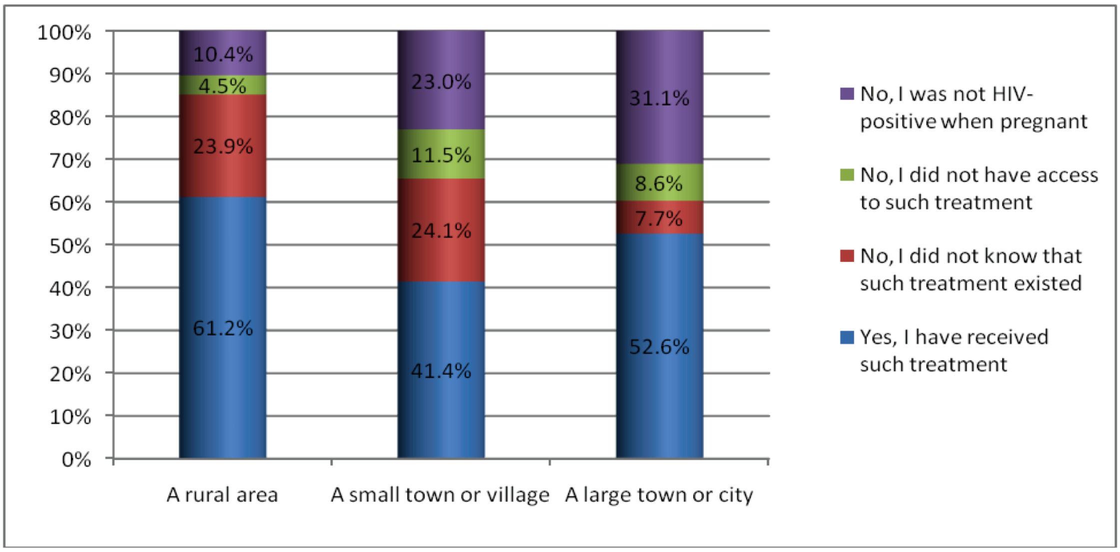
[18] Respondents were free NOT to answer any question, however it is not clear from the scripts whether the response rate to this question at 83.7% (405 of 484 women taking part) was due to respondents electing not to answer the question or missing data – i.e. the question not being asked.

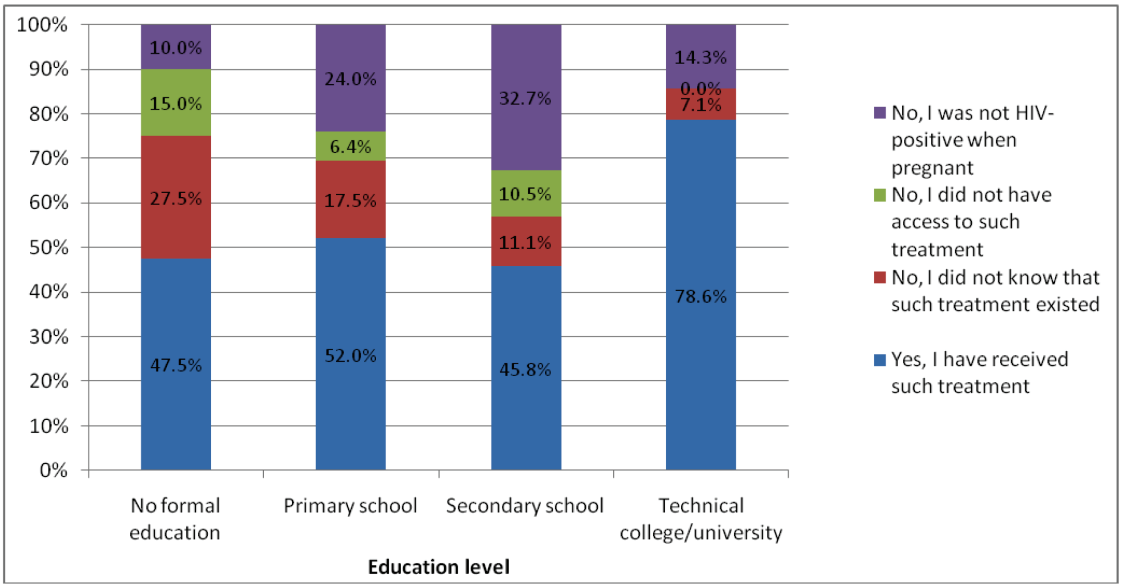
respondents from large towns/cities and 4.5% of rural areas. Furthermore, nearly a quarter of women from rural areas (23.9%), and small towns or villages (24.1%), along with 7.7% of women from large towns/cities did not know that such services exist. Clearly, more needs to be done to improve knowledge of and access to prevention of vertical transmission services in all settings.

Chart 18: Access to services to prevent vertical transmission, by location



Tertiary level education were associated with access to services to prevent vertical transmission. Among those eligible for the service, uptake was highest among women with technical or university education (78.6%), compared to between 40% and %0% for all other levels (**Chart 19**).

Chart 19: Access to services to prevent vertical transmission, by level of education



The results showed that, in general, being HIV-positive did not of itself deter women from exercising their right to bear children. The qualitative responses from respondents regarding reproductive options revealed that a major concern was the cost of infant feeding options (e.g. formula milk). There were also concerns about the well-being of their children once the parents died.

Respondents' perceptions regarding child bearing:

> *'At 6 months you stop breast feeding. It is at this point that it becomes a challenge to financially sustain the feeding programme.'*
> (Female, rural area)

> *'I fear dying and being sick every often. The risk of exposing the baby to the virus outweighs [the benefit] of having children.'*
> (Female, large town)

> *'It's good to have a child for you have company and that keeps me from going insane due to the treatment am receiving from my aunt.'*
> (Female, rural area)

> *'It hurts me to think that my last born is HIV-positive. I therefore make sure that she is not exposed to infectious diseases.'*
> (Male, small town)

> *'It is difficult to let someone have unprotected sex with you with high risk of re-infection when trying to have a child.'*
> (Female, small town)

Conclusions

The study found that HIV-related stigma was prevalent and an ongoing part of the lives of people living with HIV in Zambia. People reported experiencing stigma and discrimination in variety of settings, including places of worship, in their local communities, within the household, workplaces and health care facilities. The forms of stigma and discrimination varied depending on factors, including gender, place of residency, level of education, member of key population, and in some cases the number of years living with HIV.

The study sample included people identifying as belonging to key populations including men who have sex with men, gay or lesbian, sex workers, people who use drugs and ex-prisoners. While 30% of the respondents identified with ever having belonged to key populations; the number of respondents belonging to any one group was small[19], affecting the extent to which the results can be generalised to other people living with HIV belonging to each of the key populations. Nevertheless even this absence of data has generated an important lesson; the additional stigma and discrimination which many key populations experience requires additional and targeted efforts by all (including PLHIV organisations) to ensure that their voices are heard and concerns addressed in the response to HIV-related stigma and discrimination.

The effects of poverty on the study sample of people living with HIV are clearly evident. Most respondents report food insecurity, ranging from a low of 83.8% in large towns/cities though to 95.2% in small towns or villages. Furthermore, over one quarter of respondents across all locations are unemployed with higher levels reported in rural areas (nearly 35%), and unemployment being more pronounced among women.

Other major findings of the experiences of people living with HIV by area are outlined below.

Exclusion

- About 30% of the men and 36% of the women reported having been excluded from social activities on account of their HIV status.
- More than half the respondents stated that they had been gossiped about and/or verbally insulted, harassed and/or threatened about in the past year, and over one third reported being physically harassed or threatened

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[19] prisoner or ex-prisoner (14.8%), sex workers (6.6%), migrant workers (3.8%), internally displaced people (2.6%), members of indigenous group (0.7%), people who use drugs (0.6%), men who had sex with men (0.6%), transgender people (0.6%), refugee or asylum seeker (0.2) and gay/lesbian (0.1%).

- Of those respondents who had had experienced stigma and/or discrimination for reasons other than their HIV status, many belonged to key populations.
- Respondents whose household members had been subjected to stigma by association at least once was higher in large towns/cities (50.7%) than rural areas (39.6%) or small towns or villages (33.5%). These results suggest that stigma reduction interventions need to take into account the experiences of those closely associated with people living with HIV.
- Over 70% of respondents reported never experiencing exclusion from family or religious activities this in the last 12 months, though over one quarter had.

Access to work and health and education services

- Some 16.5% of the respondents had been refused employment or other similar opportunities, and 39.3% reported losing a job or some other source of income at least once on account of their HIV status in the previous 12 months.
- About 45.2% of respondents had faced HIV-related accommodation challenges at least once in the previous 12 months.
- Over 90% of respondents reported no problems accessing either education or health services, though 8% reported experiencing one of these.
- Some 9.7% of respondents reported having been denied family planning services as a result of their HIV status, while 11.8% indicated that they had been denied sexual and reproductive health services.

Internalised stigma and fears

- Internal stigma was prevalent among both sexes.
- Over 60% of male and 40% of female respondents blame themselves; nearly 60% of respondents feel ashamed, over 50% feel guilty and over 40% have low self esteem.
- Over 10% of both male and female respondents, more than one in ten, report feeling suicidal.
- The most frequently decision not to engage in some activities because of HIV status was not to have children (over 70% of respondents irrespective of income group). Furthermore, over 30% opted to abstain from sex or marriage; and over 25% stayed away from social gatherings or isolated themselves from friends and relatives.
- Nearly 10% of low and high income respondents and over 15% of middle income ones avoided going to a local clinic, and approximately 5% across all income levels avoided going to hospital.
- Overall, 90% of respondents feared being gossiped about; significantly higher levels of fear than for verbal insult (57.6%), physical harassment and/or threat (46.7%), and physical assault (40.5%). These findings are also reflected among key populations.

Zambia

Rights, laws and policies

- About 60% of respondents were unaware of national laws, policies or guidelines which protect the rights of people living with HIV, and of those who were aware, less than half (47.1%) had read or discussed them.
- 10.4% of respondents (n=89) reported experiencing forced medical procedures, while 4.8% reported detention, isolation, being quarantined or segregated.
- 36.3% of respondents were unsure whether they had suffered violation of their rights as people living with HIV in the previous 12 months, suggesting that many people living with HIV could benefit from sensitisation on their rights.
- Of those who reported that their rights had been abused and had sought legal redress, the majority (51.6%, n=33) reported that nothing had happened; while less than 20% reported that the matter had been dealt with (18.8%, n=12).
- 82% (n=700) of respondents did not know or were unsure of the reason for HIV-related discrimination; however, the most commonly cited reason was people's fear of being infected (10.4%, n=89).

Effecting change

- Among respondents, 40.7% reported being a member of a support group and/or network of people living with HIV with older respondents more likely to be members,
- Nearly 70% of respondents reported that they had not been involved as volunteer or employee in a programme or project providing assistance to people living with HIV in the previous 12 months; while 30.9% had.
- Involvement in HIV legal and policy reform was minimal with only a tenth of respondents reporting being involved in efforts to develop legislation, policies or guidelines relating to HIV in the previous 12 months.
- There was a clear difference in legislative or policy level participation between members and non-members of support groups (17.9% and 2.1% respectively).
- With regards to respondents feelings of being able to influence policies, laws and programmes, 40% mentioned local projects to benefit people living with HIV less than one in five feeling that they had any influence at the national programmatic level or on local or national policies; while over one third felt unable to influence any of the areas.
- Among both male and female respondents, support groups for people living with HIV were the most frequently cited entity to approach for support to those experiencing stigma or discrimination (more than 70% and 80%, respectively). Note: these findings should be interpreted with caution, due to the potential effect of selection bias on the composition of the sample and also the possibility of respondents opting for responses considered more appealing to the interviewer.
- Slightly more than 60% of male respondents and a similar percent of female

respondents reporting knowledge of a network of people living with HIV; and over 40% knowing of a human rights organization. Other types of organisation, including human rights organizations, local and national NGOs, FBOs and legal services, was mentioned by less than 50% of the respondents.

- Nearly double the percent of members of a support group or network had confronted, challenged or educated someone who was stigmatising and/or discriminating against them compared to non-members (71.2% and 36.6% respectively).
- Nearly three quarters of respondents reported having provided some form of support to other people living with HIV in the previous 12 months with emotional support being the most common type of assistance rendered.
- Perceptions of the most important strategies for addressing stigma and discrimination varied according to the number of years respondents had been living with HIV. For example:
    - the provision of emotional, physical and referral support was more important for respondents with fewer years of living with HIV compared to those who had been HIV-positive for 15 or more years.
    - while advocacy for the rights of people living with HIV was considered a priority by more than one third of those who had lived with HIV for 9 years or less, its importance steadily declined among respondents who reported living with HIV for more than 10 years.

Testing and diagnosis

- Nearly one quarter of men and more than one third of women were symptomatic at time of HIV diagnosis.
- Most respondents irrespective of age group reported receiving both pre- and post-HIV test counselling.
- Human rights violations associated with involuntary HIV testing and being tested without any counselling[20] remain a challenge, as do the cost, time and distance in accessing HIV testing services.

Disclosure and confidentiality

- Self-disclosure by respondents of their HIV-positive status was highest to health care workers (78.4%), other people living with HIV (72.6%) and other adult family members (72.3%).
- Two thirds of respondents had disclosed to their husbands, wives or partners, while 5.3% indicated that their sexual partners were not aware of their HIV status.

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[20] More than 10% of young people and people over 50 years of age reported having been tested without any counselling at all.

- Some 3.9% of respondents reported having injecting drug partners who were unaware of their status.
- Friends and neighbours was the category most frequently informed without the respondent's consent (24.4%), followed by work colleagues (11.1%).
- Health care workers (75.1%) and other people living with HIV (72.8%) were reported as being the most supportive after disclosure by the respondent.
- 27% of rural respondents reported very discriminatory reactions among friends and neighbours, more than double that of respondents residing in a large town or city.
- None of the respondents residing in rural areas reported very supportive reactions from friends and neighbours.
- Over two thirds of respondents described disclosing their HIV status as an 'empowering experience'.

Treatment

- Most respondents felt in good health, with 83% describing their health as good, very good or excellent.
- Overall, access to ART was not a problem with nearly 90% accessing ART, which can in part be ascribed to the sample being almost exclusively drawn from among people attending health centres providing ART.
- Of those accessing ART, the highest percent was among those respondents from large towns/cities (80.4%) followed by those in rural areas (73.1%) and the lowest was among those residing in a small town or village (55.9%).
- Among those not yet taking ART, over 70% indicated that they could access ART.
- Treatment-related challenges mentioned by respondents mostly related to side-effects, pill burden and the duration of treatment.
- 59% of respondents reported having discussed sexual and reproductive health, emotional well-being and other similar subjects with a healthcare professional in the last year.

Having children

- One quarter of respondents reported that children who have been orphaned due to AIDS live in their household with 1-2 orphans per household most frequently reported.
- 85% (n=703) of respondents reported having children with 25.9% (n=179) reporting having one or more HIV-positive children The percentage of respondents with HIV-positive children increased in relation to the number of years the respondent had been living with HIV. For example, some 60% of those who reported living with HIV for 15 years or more indicated having HIV-positive children, compared to only 13.2% of those living with HIV for 1 year or less.
- 60% of women and 50% of men reported having received counselling on

reproductive options; though nearly a third of respondents indicated that they had not received any reproductive health counselling since diagnosis.

- 12.5% of women in lowest income bracket and 6.3% of women in the highest income bracket reported having been pressured to terminate a pregnancy in the previous 12 months.
- More respondents from rural areas (61.2%) reported receiving prevention of vertical transmission interventions compared to 52.6% of respondents residing in large towns/cities and 41.4% of those living in small towns/villages.
- Nearly a quarter of women from rural areas and small towns/villages, along with 7.7% of women from large towns/cities did not know that prevention of vertical transmission services existed.
- Uptake of PVT services was highest among women with technical or university education (78.6%), compared with between 40% and 50% for all other education levels.

These results reinforce the call for sustained efforts to support the reproductive aspirations of people living with HIV, with greater emphasis on strategies for preventing vertical transmission of HIV.

Recommendations

Among the sample there was prevalent food insecurity, low socio-economic status, including low levels of employment, and internalized stigma, high rates of being fearful about the ways they were perceived and treated in the community (with reported examples of stigmatising and discriminatory treatment), and one in ten respondents feeling suicidal. As such, psychosocial and socioeconomic support must clearly be a priority for NZP+, civil society, National AIDS Council and the Government. Concerted efforts are required to promote positive living and provide psychosocial and socioeconomic support including training opportunities for people living with HIV to become peer educators, capacity and network building, including sensitization training on rights, counselling, training, and income generation. The issue of building the human rights literacy of people living with HIV , and ensuring that there is access to effective recourse when such violations occur is also of prime importance.

NZP+

- Disseminate the findings of this study to the Government, NACC, civil society, UN agencies and donors.
- Take into account the heterogeneity of people living with HIV in developing and implementing interventions to address stigma and discrimination.
- Given the fact that over one third of respondents were unsure whether they had suffered violation of their rights as people living with HIV in the previous 12 months, it is recommended that sensitization training for people living with HIV on their rights be undertaken as well as programmes and initiatives to build the human rights literacy of PLHIV.
- Intensify education efforts with people living with HIV on positive health, dignity and prevention.
- Advocate for the creation of a supportive legal and policy environment to challenge rights violations experienced by people living with HIV, including key populations.
- Advocate for the inclusion of more people living with HIV in policy-making fora and in the development and drafting of relevant legislation.
- Encourage people living with HIV to be actively involved in developing and implementing stigma and discrimination reduction efforts, including within the HIV-positive community.

Civil society

- Take into account the heterogeneity of people living with HIV in developing and implementing interventions to address stigma and discrimination.

- Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.
- With nearly one quarter of men and more than one third of women being symptomatic at time of diagnosis, investment more in promoting voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Without clear policies and guidelines targeting groups such as sex workers, prisoners, men who have sex with men and people who use drugs, it is difficult to provide effective and appropriate interventions. Therefore, advocacy for the creation of a supportive legal and policy environment should be high on the agenda of efforts to challenge rights violations experienced by people living with HIV.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines.

National AIDS Council

- Take into account the heterogeneity of people living with HIV in developing and implementing interventions to address stigma and discrimination.
- With nearly one quarter of men and more than one third of women being symptomatic at time of diagnosis, investment more in promoting voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Given that there is a low level but consistent pattern of denial of rights to people living with HIV in health care settings[21]:
- revise pre- and in-service training curricula to enhance the capacity of health providers to provide non-judgmental and non-discriminatory services to people living with HIV; and
- review and update, if needed, protocols to ensure they are rights-based and include pre-service training for health care workers as well as in-service training refresher courses for health providers, managers and other health facility staff, as well as strengthen supervision to foster non-judgmental and non-discriminatory practices towards people living with HIV.

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[21] For example:

Some 8.4% of respondents (n=68%) reported being denied access to health services.

Some 9.7% reported having been denied family planning services as a result of their HIV status, while 11.8% indicated that they had been denied sexual and reproductive health services.

Nearly 10% of low and high income respondents and over 15% of middle income ones avoided going to a local clinic, and approximately 5% across all income levels avoided going to hospital.

10.4% of respondents (n=89) reported experiencing forced medical procedures.

12.5% of women in lowest income bracket and 6.3% of women in the highest income bracket reported having been pressured to terminate a pregnancy in the previous 12 months.

- Scale up the provision of correct information and appropriate options for the sexual and reproductive health for people living with HIV, including prevention of vertical transmission programmes and services. across all locations.
- Support SRH and HIV linkages, including the integration of SRH services for people living with HIV into HIV programmes.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines.
- Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.
- Intensify stigma reduction interventions that promote the involvement of community leaders, religious leaders and labour representatives.
- Undertake and/or support research to strengthen the evidence base, including:
    - Qualitative studies on the extent of stigma and discrimination within key populations.
    - Studies on the denial of sexual and reproductive health services to people living with HIV.

Government

- Take into account the heterogeneity of people living with HIV in developing and implementing interventions to address stigma and discrimination.
- Take the lead in creating a policy and legal environment that will safeguard the rights of people living with HIV and specifically address HIV-related stigma and discrimination.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines.
- Support broad-based social and community awareness raising and mobilization as part of efforts to eradicate stigma and discrimination against people living with HIV and key populations, including through a human rights-based approach, addressing HIV-related myths.
- Prioritize HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in national strategic planning, funding and programmes, including support for scaled up implementation of promising programmes.
- Include HIV-related stigma and discrimination indicators as part of the national AIDS response M&E systems to monitor and evaluate progress over time.

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Please note: many of the sources of these references are also available in the relevant footnotes.

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Notes

Disclaimer:

The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination. In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower people living with HIV on human rights related to HIV. Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research subjects, participants have a right to anonymity and to the confidentiality regarding their responses. In addition to the empowerment function, appropriate uses of the data are for advocacy and in order to inform stigma/discrimination reduction programming in the national response to HIV.

This analysis has been made within the framework of the Stigma Index.

The views expressed by individuals quoted within the report are not necessarily those held by the Network of Zambian People Living with HIV (NZP+), the national implementing partnership in Zambia, or the founding partnership of the Stigma Index

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