NATIONAL COUNCIL OF PEOPLE LIVING WITH HIV (NACOPHA)

THE PEOPLE LIVING WITH HIV
STIGMA INDEX REPORT
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Acronyms/Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBO	Community Based Organizations
GIPA	Greater Involvement of People Living with HIV and 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
MSM	Men who have sex with men
NACOPHA	National Council for People Living with HIV/AIDS
NGO	Non-Governmental Organisation
PLHIV	People living with HIV
PVT	Prevention of Vertical Transmission (sometimes referred to as Mother-To-Child Transmission)
SRHR	Sexual Reproductive Health Rights
TDHS	Tanzania Demographic and Health Survey
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
WAC	World AIDS Campaign (WAC)

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Executive Summary

The People Living with HIV stigma index is both a new research initiative and tool that was developed in partnership between the International Planned Parenthood Federation (IPPF), two networks of People living with HIV: the Global Network of People Living with HIV (GNP+) and the International Community of Women living with HIV (ICW), and The Joint United Nations Programmed on HIV/AIDS (UNAIDS).

The tool was rolled out in Tanzania in 2010 and 2012 with the aim to assessing the extent of stigma and discrimination relating to HIV from PLHIV point of view, while at the same time advocating about the key barriers and issues perpetuating stigma and discrimination among PLHIV. The tool was implemented in five (5) regions namely Kilimanjaro, Kibona, Iringa', Keera and Dar-es-salaam whose selection was based on the past and present prevalence rates. The study process was lead by the People living with HIV who also were the centre of the process as both interviewers and interviewees. The PLHIV acted as drivers of how the information was collected, analyzed and used. Respondents in this study were the adult women and men living with HIV 18 years and above. A total of 2205 of PLHIV from all 5 regions participated in the study. Tanzania has a generalized epidemic with prevalence rate of 5.3 % among all adults aged 15-49 years, by the end of 2012, Tanzania had an estimated 1.5 million people living with HIV and approximately 86,000 new HIV infections (Spectrum, 2013).

Stigma index tool was implemented as a cross section study, and was divided into three main sections covering perceptions of self and internal stigma as well as specific examples of stigma or discrimination in different settings such as at home, community, workplace, religious and health care setting. Some of the key areas explored in the research tools included the causes of stigma and discrimination; access to work and services; internal stigma; rights, laws and policies; effecting change; disclosure and confidentiality, treatment; having Children; and overcoming stigma. All participants were asked to respond to the Questions based on their experiences in the last 12 months. Ethical clearance for conducting research was sought from the National Institute of Medical Research (NIMR). Data analysis was done using SPSS for Windows and answered key areas of concern as was written in the objectives of the stigma index study. The stigma index guidelines were used to guide the whole process of data analysis and reporting.

A total of 2205 respondents, among whom 596 were from Dar es Salaam and 1609 were from other 4 regions. Nearly two thirds (57%) were females and 43% were males. Major findings from the study show that over three quarters (76%) and two thirds (65%) of respondents from other regions and Dar es Salaam respectively were self employed while 14.% and 18% in other regions and DSM respectively were not employed and not working at all. Over two thirds (64.8%) from other regions and 63.8% (from Dar es Salaam) of respondents have an average number of 1-4 children aged 1-14 years old living together in the same households indicating high burden of care among PLHIV at household level. more than half (52.9%) of respondents from DSM reported to have had 1 or more days without food.

Acts of exclusion for stigmatization and discrimination experienced by PLHIV were prevalent and are common in the community. Being gossiped, verbally insulted, exclusion from social, family as well as religious activities were the leading forms of stigmatization whereby Dar es Salaam indicated high levels of stigma (49.7%) as compared to (39.4 %) from other regions, females experienced more gossiping than males counterparts in both regions. More than 56% (from other regions), and 45.5% (from Dar es Salaam) showed that the main reason for stigmatization is that people have fears of getting infected due to lack of knowledge and misconception on how HIV is transmitted.

Expressing outcomes of stigmatization and discrimination, respondents suffered internal stigma and reported that they experienced low self-esteem, blamed themselves and felt ashamed, decided not to have (more) children, decided not to have sex, chose not to attend special gathering, and not to get married; afraid of being gossiped, and also were afraid that someone would not want to be sexually intimate with them. Involvement of PLHIV in development and review of policies, laws and guidelines was found to be almost nonexistent; low level of awareness and discussion of laws and policies that protect rights of PLHIV, and inability of PLHIV to effect changes indicated the need for creating enabling environment for empowering the PLHIV through various interventions but more importantly bringing them to the centre of HIV response.

In concluding, it is evident that, the stigma index tool, led and implemented by and for PLHIV, has shown that PLHIV have experienced various forms of stigmatization, both internally and externally. The generated evidence should be used as basis for informing policy advocacy action and programmatic interventions that will influence policy, attitudes, practices and other community actions that will contribute to the elimination of stigmatizations against PLHIV.

Based on the findings, recommendations are made for potential roles that various stakeholders can play at different levels to eliminate stigma and discrimination. The stakeholders must include and engage the PLHIV, Government bodies, Civil Society organizations and Development partners. The key roles that stakeholders will be engaged in may include the following:

- Through NACOPHA, PLHIV should develop and implement participatory advocacy action for legal and policy issues emanated from the study to influence policy and programs that will empower PLHIV on human rights, access to treatment and HIV prevention services, Reproductive health, HIV testing and disclosure, treatment and HIV policy and law literacy.
- It is also important to advocate and mobilize support for PLHIV empowerment targeting the capacity strengthening for both individuals and PLHIV groups through psychosocial

support, economic empowerment, networking, Skills building, policy engagement and advocacy.

- The government is responsible for ensuring enforcement of policies and laws that provide for an enabling environment that will empower PLHIV to access and utilize HIV and health services including information that strengthen their ability to effect changes in the community. The government bodies may include all ministries, departments and agencies that have various relevant roles in responding to HIV, particularly in eliminating stigma and discrimination against PLHIV.
- Civil societies (CSOs), as allies to PLHIV, should engage PLHIV to developing and implement joint advocacy action to influence policy dialogues at various levels in addressing stigma and discrimination.
- CSOs should work to generate and disseminate strategic evidence that can inform policy and interventions in various strategic areas such as community, workplace, policy making and programming as well.
- Development partners are expected to jointly work with government and other stakeholders in the efforts to promote human rights and dignity of PLHIV, including support to the national frameworks that address stigma and discrimination in the country

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1.0 INTRODUCTION

1.1 Background

The People Living with HIV Stigma Index is a new research initiative, driven and implemented by and for people living with HIV /AIDS, to measure stigma and discrimination relating to HIV/AIDS. The initiative was developed and is the result of a partnership between the International Planned Parenthood Federation (IPPF), the Global Network of People Living with HIV (GNP+), the International Community of Women living with HIV (ICW), and The Joint United Nations Programme on HIV/AIDS (UNAIDS). The stigma index has been successfully piloted in a number of countries (South Africa, Kenya Trinidad and Tobago, India) and hence advocated by IPPF, GNP+, ICW and UNAIDS to be scaled up and rolled out in other country levels to get the reality of stigma and discrimination in the specific country context.

Discrimination involves treating someone in a different and unjust, unfair or prejudicial manner, often on the basis of their belonging, or being perceived to belong, to a particular group. It is often viewed as the end result of the process of stigmatization. In other words, when stigma is acted upon (sometimes called "enacted stigma"), the result is discrimination. "Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized." For example, HIV-related discrimination occurs when someone is treated differently (and to their disadvantage) because they are known to be living with HIV, suspected of being HIV-positive, or closely associated with people living with HIV (such as their partner or a member of their household).

Stigma is a sign of disgrace or shame often described as a process of devaluation. If one is stigmatized, one is discredited, seen as a disgrace and/or perceived to have less value or worth in the eyes of others. 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 marginalized and stigmatized behaviours, such as sex work, drug use and same-sex and transgender sexual practices. Moreover, HIV stigma also involves **internal-stigma** which referred to as "felt" stigma or "self-stigmatization". It is used to describe the way a person living with HIV feels about themselves and specifically if they feel a sense of shame about being HIV-positive[1].

Most of studies on stigma among people living which HIV have been done largely at community setting and thus difficult to generalize them as national estimates. This dearth of evidence of the extent of the problem as is experienced by PLHIV lead IPPF and GNP, ICW and UNAIDS to develop this measure to be used specifically for this population. This study was conducted as an empowering experience for people living with HIV involved in the process. The information

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[1] IPPF, GNP+, ICW and UNAIDS (2012). The people living with stigma index: user guide. Accessed on July 2013 at http://www.stigmaindex.org/14/ethical-research/about-the-questionnaire.html

captured generated a wide range of knowledge and best practices in every aspect of the process of data capture, entry and analysis for PLHIV

1.2 Tanzania HIV Context

Tanzania mainland is part of the United Republic of Tanzania which is an East African country covering approximately 945,000 square kilometers and sharing borders with eight (8) countries. Mainland Tanzania is divided into 25 regions, which are further subdivided into 156 district, municipal and town councils. The population of Mainland Tanzania is approximately 43.6 million people as of 2012 (Census 2012) and it accounts for 97% of the country total population, of which 73% live in rural areas and 27% live in urban areas. Nearly half of the population (48%) is below 15 years of age; 49% are aged 15-64 years and 4% are over 65 years.

Tanzania has a generalized epidemic with prevalence rate of 5.3 % among all adults aged 15-49 years, varying ranging from the lowest 1.4% (in Manyara region) to the highest 14.8% (in Njombe region. By the end of 2012, Tanzania had an estimated 1.5 million people living with HIV and approximately 86,000 new HIV infections (Spectrum, 2013). The predominant mode of HIV transmission is heterosexual contact between HIV-infected and uninfected individuals, with sexual transmission accounting for approximately 80% of infections. Vertical infections from mothers to newborns account for about 18% of infections and medical transmission through unsafe blood for approximately 1.8%. HIV prevalence increases with age generally, and women invariably have higher prevalence rates in all age groups compared to men; however, prevalence among young women aged 25 – 29 is 3 times higher as compared to young men

The policy and legal framework in Tanzania characterizes the National HIV response. Tanzania developed its first National Policy for HIV and AIDS in 2001, subsequently implemented by two strategic frameworks which were completed in 2012. In 2008, Tanzania enacted a HIV Prevention and Control Act (HAPCA). In 2010, regulations for HIV Counseling and Testing, use of ARVs, and disclosure were developed and gazette. The regulations provide for protection against forced testing and mandatory disclosure. The National HIV and AIDS Policy (2012) further emphasize the importance of respect for the human rights of PLHIV. Specifically the policy commits to enhancing measures to ensure men, women, boys and girls living with HIV and AIDS are entitled to all civil, legal, and human rights without discrimination based on gender differences or serostatus in accordance with the URT Constitution and other International Conventions.

1.3 About NACOPHA

The National Council for People Living with HIV and AIDS in Tanzania (NACOPHA) is a non-governmental and not-for-profit organization which was founded in August, 2003 and registered in 2005. NACOPHA serves as a unified voice and umbrella organization of all individuals, groups, organizations and networks of People Living with HIV (PLHIV) in Tanzania. It coordinates the efforts of the PLHIV in responding to HIV and AIDS challenges. The followings are the Constitutional objectives of NACOPHA:

- There is a great importance for having a national body to coordinate all the issues involving People Living with HIV and AIDS in Tanzania
- The Council to develop an effective drive in the coordination and management of capacity building, treatment, training and support for PLHIV in the country
- To recognise and support government efforts in the development of policies and strategies in the combat against HIV and AIDS in our society
- To supplement efforts of the government of Tanzania in the developement of policies and strategies in response against HIV and AIDS in the country.
- To ensure that the power of advocacy for people living with HIV and AIDS is enhanced in all processes of developing Policies and different programs containing the spread of HIV in the country
- To consider and establish ways and means for effective participation of PLHIVand those affected by the pandemic in the activities to contain the spread of HIV in the country.
- To establish that PLHIVin the country have a big stake, duty and responsibility for containing the spread of new infections of HIV
- To respond to the articles of the UNGASS Declaration on HIV and AIDS of June, 2001

Presently, NACOPHA both coordinates and works with registered 11 national networks of PLHIV, 128 District PLHIV clusters and over 600 PLHIV support groups in the country under one roof.

1.4 Study Objectives

The purpose of this study was to collect information on stigma and discrimination relating to HIV and AIDS from PLHIV point of view while at the same time advocating for addressing the key barriers and issues perpetuating stigma and discrimination.

Specific Objectives were to;

1. Document the various experiences of PLHIV-related stigma and discrimination in Tanzania
2. Contribute to an evidence base for advocacy, policy change and programmatic interventions to address HIV-related stigma and discrimination in Tanzania
3. Strengthen networks of people living with HIV and AIDS through the partnerships and outreach involved in the research and advocacy process.

2.0 STUDY METHODOLOGY

2.1 Areas of study

Five (5) regions namely Kilimanjaro, Kigoma, Iringa, Kagera and Dar-es-salaam were selected in Tanzania Mainland for the study. The regions were selected based on the past and present HIV prevalence in the regions. Kilimanjaro was selected based on the fact that it has experienced a tremendous drop in HIV prevalence. Kagera was selected because it was the first place where the first AIDS cases were diagnosed and has experienced for a long period of time high prevalence and recently has shown a steady decline. Kigoma was selected based on the fact that it is one among the regions which have maintained low HIV prevalence in Tanzania. Dar-es-salaam and Iringa were selected because these are the regions with highest prevalence rate (**THMIS 2003-2004 and THMIS 2007-2008)**.The mixture of the study aimed at exploring different scenarios of how PLHIV in the selected regions have different experiences of stigma and discrimination.

2.2 Study Design

This was a cross sectional study using the PLHIV Stigma Index Survey Questionnaire to conduct interviews, following the accompanying methodology, available at www.stigmaindex.org

2.3 Study Population

People living with HIV were the Centre of the process as both interviewers and interviewees and as drivers of how the information was collected, analyzed and used. Respondents in this study were the adult women and men living with HIV 18 years and above. A total of 2205 of PLHIV from all 5 regions participated in the study. Participants were obtained from CTCs, PLHIV networks and groups and other places other than CTC and PLHV networks. Between 20 and 25 PLHIV were recruited from PLHIV networks and groups to administer the questionnaires.

2.5 Sample size estimates

Estimation of the sample size was done based on estimated number of PLHIV in Dar es salaam that stood at 175,763 PLHIV (M: **79,093** and F: **96,670**) unevenly distributed in the three municipalities namely Ilala, Kinondoni and Temeke. A probable prevalence of stigma among people living with HIV estimated at 60%, a margin of error of 5% and confidence interval of 95% was used to calculate the sample size as follows:

$$n = \frac{z^2 p\,(100-p)}{\varepsilon^2} = 1.96^2 x60x\,(100-60)/5^2 = 368.8$$

In addition, looking at the design that included three discrete categories as well as possible refusal to conclude questionnaire, and the newness of gathering such data to contribute to about a 40% possible of loss of quality data for which we added 147 persons per group. This added to the sample to 516 persons. This was rounded up to 600 persons to be interviewed in each region. Snowball sampling was used to identify study respondents.

2.5 Data collection tools

The Stigma Index questionnaire is the primary research tool that was used for quantitative data collection from the study respondents for measuring HIV related stigma and discrimination among People Living with HIV. The tool is divided into three main sections covering perceptions of self and internal stigma as well as specific examples of stigma or discrimination in different settings such as at home, community, workplace, religious and health care setting. Some of the key areas explored in the research tools included the causes of stigma and discrimination; access to work and services; internal stigma; rights, laws and policies; effecting change; disclosure and confidentiality, treatment; having Children; and overcoming stigma. All participants were asked to respond to the Questions based on their experiences in the last 12 months. The questionnaires were administered by the PLHIV who received orientation as research assistants on the tool before starting to implement the tool.

2.6 Data management and analysis

As soon as questionnaires were administered, the supervisor undertook quality checks while in the field, which involved checking the informed consent forms had been filled in, that referrals (where asked for had been followed up on) and that they had any discrepancies in the response (missing data, responses not following the logic of the questions) had been corrected or noted. The questionnaires were then sent to the central data management centre at NACOPHA OFFICE. The data entry clerks were trained on how to enter data. All questions were properly coded to maintain a consistent interpretation and analysis of the findings. All data were entered data in a database using the SPSS statistical software package for analysis.

2.7 Ethical issues

Ethical clearance for conducting research was sought from the National Institute of Medical Research (NIMR). Before entering into actual interviewing, each respondent was requested to fill in the consent form as their acceptance to participate in research and provide the required information voluntarily. Respondents were at liberty to either respond or not, to any question that they felt to do so.

2.8 Limitations

The results of this study cannot be generalized to represent the general population as respondents were recruited from PLHIV networks, care and treatment centers (CTCs) and other support groups of individual PLHIV. Conclusions made were drawn from the quantitative data that was collected

3.0 STUDY RESULTS AND INTERPRETATION

3.1 Background Characteristics and Household Composition of PLHIV

This section presents results of general background information about the survey participants.

Table 1: Distribution of Respondents by Selected Regions

Region	Male n (%)	Female n (%)	Total n (%)
Iringa	149 (16%)	242 (19%)	391 (18%)
Kigoma	134 (14%)	267 (21%)	401 (18%)
Kilimanjaro	106 (11%)	294 (23%)	400 (18%)
Kagera	169 (18%)	248 (20%)	417 (19%)
Dar es Salaam	393 (41%)	203 (16%)	596 (27%)
Total	**951**	**1254**	**2205**

Table 1 above, shows that, overall, majority (56.8%) of all respondents were females while 43.2% were males. Nearly one third (27%) of all participants were from Dar es Salaam city and other regions almost contributed equal proportions (18%) of study respondents. It should be noted that even if the total number of respondents added up to 2205, these were classified into two groups of Dar es salaam (N=596 respondents) and other regions (N=1609) for comparison since the study was carried out first in Dar es salaam and followed by other four regions. Combining these two might have time variations effects on results hence the team decided to do separate analysis for comparison. Moreover, it has also to be noted that respondents were free not to answer specific questions hence the numbers in the next variables may not add up to full samples. In cases where scripts were unclear or data responses were missing, then the answers to these questions were excluded from the analysis.

Table 2: Age and Sex Distribution of Respondents by Regions

Age group	OTHER REGIONS			DSM		
	Male n (%)	Female n (%)	Total n (%)	Male n (%)	Female n (%)	Total n (%)
15-19	27 (4.9%)	35 (3.3%)	62 (3.9%)	4 (1.0%)	8 (4.0%)	12 (2.0%)
20-24	30 (5.4%)	73 (7.0%)	103 (6.4%)	20 (5.1%)	15 (7.4%)	35 (5.9%)
25-29	38 (6.8%)	103 (9.8%)	141 (8.8%)	47 (12.0%)	24 (11.9%)	71 (12.0%)
30-39	158 (28.5%)	370 (35.3%)	528 (32.9%)	158 (40.3%)	68 (33.7%)	226 (38.0%)
40-49	189 (34.1%)	301 (28.7%)	490 (30.5%)	136 (34.7%)	56 (27.7%)	192 (32.3%)
50+	113 (20.4%)	167 (15.9%)	280 (17.5%)	27 (6.9%)	31 (15.3%)	58 (9.8%)
Total	**555**	**1049**	**1604**	**392**	**202**	**594**

The data in table 2, shows that majority of respondents were from the age group between 30-49 years, followed by those in the age of 50+ years from all regions participated in the study. However, from other regions majority (35.3%) in the age group of 30-39 were females while most of respondents from Dar es Salaam were males from the same age group. Very few young people 19.1% (from other regions) and 19.9% from Dar es Salaam) in the age between 15-29 years participated in the study. These results imply that there is potential age variation between adults and youth in accessing HIV services from CTCs, PLHIV networks and support groups that provide psychosocial support to PLHIV from both urban and rural areas.

Table 3: Respondents' Years Living with HIV

	OTHER REGIONS			**DSM**		
Years with HIV	**Male n (%)**	**Female n (%)**	**Total n (%)**	**Male n (%)**	**Female n (%)**	**Total n (%)**
0-1	81 (14.5%)	107 (10.2%)	188 (11.7%)	32 (8.2%)	15 (7.4%)	47 (7.9%)
1-4	210 (37.6%)	385 (36.7%)	595 (37.0%)	132 (33.8%)	72 (35.6%)	204 (34.4%)
5-9	181 (32.4%)	397 (37.8%)	578 (35.9%)	66 (16.9%)	33 (16.3%)	99 (16.7%)
10-14	57 (10.2%)	122 (11.6%)	179 (11.1%)	142 (36.3%)	67 (33.2%)	209 (35.2%)
15+	24 (4.3%)	33 (3.1%)	57 (3.5%)	19 (4.9%)	15 (7.4%)	34 (5.7%)
Total	**558**	**1050**	**1608**	**391**	**202**	**593**

Over half of respondents (50.7%) from other regions and (50.1%) have lived with the virus between 1-9 years. Unlike other regions, about 40.9% of respondents in Dar es salaam have lived with HIV for 10-15+ years. However, majority of respondents (37.7%) from other regions appeared to have lived with HIV for 1-4 years while most from Dar es Salaam lived with HIV for 10-14 years (35.2%, n=209).. Living with HIV for many years may influence one's attitudes and experience on stigmatization in the community against people living with HIV. Strategies and interventions against stigma and discrimination may also differ between those living in Urban and rural, and those living with HIV for many or few years.

Table 4: Status of Current Relationship

Current relationship	**OTHER REGIONS**			**DSM**		
	Male	**Female**	**Total**	**Male**	**Female**	**Total**
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Married and living together	247 (45.6%)	305 (29.3%)	552 (34.8%)	81 (20.7%)	81 (40.1%)	162 (27.3%)
Married but temporarily living/working away	11 (2.0%)	29 (2.8%)	40 (2.5%)	17 (4.3%)	8 (4.0%)	25 (4.2%)
In a relationship but not living together	50 (9.2%)	133 (12.8%)	183 (11.6%)	47 (12.0%)	29 (14.4%)	76 (12.8%)
Single	135 (24.9%)	260 (25.0%)	395 (24.9%)	108 (27.6%)	52 (25.7%)	160 (26.9%)
Divorced/separated	34 (6.3%)	67 (6.4%)	101 (6.4%)	37 (9.4%)	7 (3.5%)	44 (7.4%)
Widow/widower	65 (12.0%)	248 (23.8%)	313 (19.8%)	102 (26.0%)	25 (12.4%)	127 (21.4%)
Total	**542**	**1042**	**1584**	**392**	**202**	**594**

While many respondents reported being married and living together for both Dar es Salaam (27.3%) and other regions (34.8%), the second largest group said that they are living single (24.9%) in Dar es Salaam and (26.9%) in other regions. However, majority females from other regions (23.8%) were widows as compared to Dar es Salaam (12.4%). This implies need for couple focused HIV testing and counseling, gender transformative HIV programming, empowerment and legal and social protection interventions for women living with HIV. Although there was no significant difference among those living single both in Dar es Salaam and other regions, there is need to consider the sexual and reproductive health needs and rights of men and women living with HIV to ensure there is equitable access to quality comprehensive HIV services

Duration of relationship with husband/wife/partner

The largest group of respondents had been in relationship for 1-4 years between 27.9% (other regions) and 37.55% (Dar es salaam)

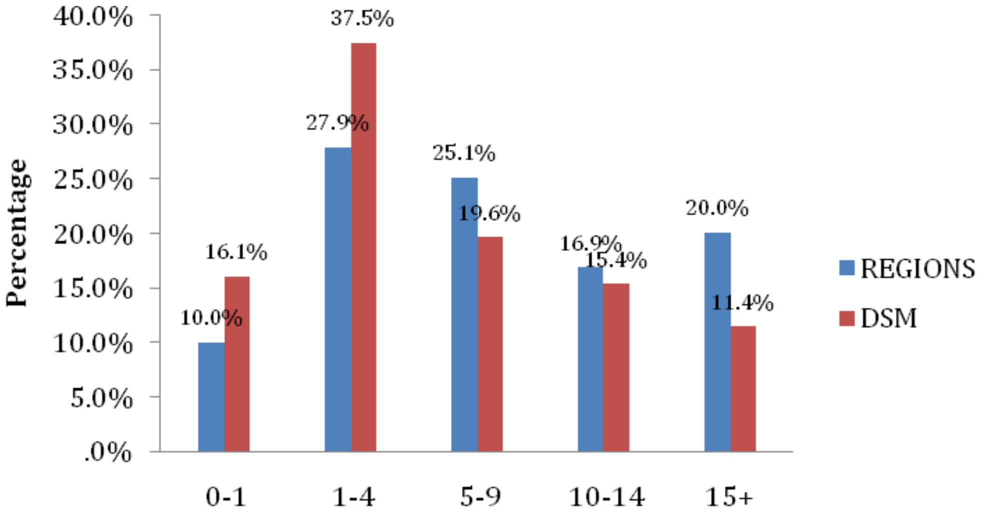

Figure 1: Years in relationship

It terms of being sexually active, most of respondents (85.3%) from DSM are more sexually active than those from other regions (74.3%). Further analysis detected those who are sexually active from other regions are males (80.7%, n=442) while in DSM more females are sexually active (91.9%, n=181%). It had also been found that most of respondents from both regions do not belong to marginalized groups (key populations) such as men who have sex with men, sex workers, lesbian, drug users etc. These findings may indicate that key populations are not well covered by HIV and AIDS services or they are still not able to disclose their status freely. Moreover, only 4% of all respondents from both DSM and other regions had physical disability.

Most of respondents completed their primary education i.e. 87.6% (n=1289) from other regions and 93.4% (549) are from Dar es Salaam. The employment profile of respondents is shown in the following table.

Table 5: Respondents' employment status by sex by regions

STAUS	OTHER REGIONS					DSM				
	Male		Female		Total	Male		Female		Total
	n	%	n	%		n	%	n	%	
In full-time employment (as an employee)	36	6.6	27	2.6	63 (4%)	25	6.4	20	9.9	45 (7.6%)
In part-time employment (as an employee)	45	8.2	49	4.7	94 (5.9%)	36	9.2	18	8.9	54 (9.1%)
Working full-time but not as an employee (self-	169	30.8	333	32	502 (31.6%)	127	32.3	58	28.6	185 (31%)

employed)										
Doing casual or part-time work (self-employed)	230	42	477	45.9	707 (44.6%)	130	33.1	75	36.9	205 (34.4%)
Unemployed and not working at all	70	12.8	156	15	226 (14.2%)	74	18.8	32	15.8	106 (17.8%)
Total	**550**		**1042**		**1592**	**392**		**203**		**595**

While over three quarters (76%) and two thirds (65%) of respondents from other regions and Dar es Salaam respectively were self employed, hardly 14.% and 18% in other regions and DSM respectively were not employed and not working at all. The results indicate that majority of PLHIV have low income and may subject them to poverty that might interfere with other HIV interventions such as care and treatment services that target to improve lives of PLHIV.

Table 6: Number of people per age category living with Dependents

Age profile	**# of children Living together With dependents**	**OTHER REGIONS**			**DSM**		
		Sex			**Sex**		
		Male	**Female**	**Total**	**Male**	**Female**	**Total**
Children Aged 1-14	1-4 children	333 (60.1%)	706 (67.3%)	**1039 (64.8%)**	269 (64.4%)	111 (54.7%)	**380 (63.8%)**
	5-14 children	11 (2.0%)	27(2.6%)	**38 (2.4%)**	7 (1.8%)	7 (3.4%)	**14 (2.8%)**
Youth aged 15-19	1-2 youths	197(35.6%)	413(39.4%)	610 (38.1%)	186 (47.3%)	86(42.4%)	272(45.6%)
	3-5 youths	32(5.8%)	39(3.7%)	71(4.4%)	27 (6.9%)	11 (5.4%)	38(6.4%)
Adult aged 20-24	1-2 people	126(22.7%)	271(25.8%)	397 (24.8%)	157 (39.9%)	58(28.6%)	215(36.1%)
	3-5 people	11(2.0%)	17(1.6%)	28 (1.7%)	13(3.3%)	11(5.4%)	24(4.5%)
Adult aged 25-29	1-2 people	89(16.1%)	142(13.5%)	231 (14.4%)	103 (26.2%)	65(32.0%)	168(28.2%)
	3-5 people	9(1.6%)	18(1.7%)	27 (1.7%)	8(2.0%)	7(3.4%)	15(2.5%)
Adult aged 30-39	1-2 people	122(22%)	216(20.6%)	338 (21.1%)	158 (40.2%)	92(45.3%)	250(41.9%)
	3-8 people	3(0.5%)	11(1.0%)	14(0.9%)	17 (4.3%)	4(2.0%)	21(3.5%)
Adult aged 40-49	1-2 people	122(22.0%)	203(19.3%)	325(20.2%)	151 (38.4%)	78(38.4%)	229(38.4%)

	3-8 people	4(0.7%)	1(0.1%)	5(0.3%)	8(2.0%)	3(1.5%)	11(1.8%)
Adult aged 50+	1-2 people	88(15.9%)	175(16.7%)	263(16.4%)	105 (26.7%)	60(29.6%)	165(27.7%)
	3-8 people	4(0.7%)	3(0.3%)	7(0.4%)	6(1.5%)	3(1.5%)	9(1.5%)

Over two thirds (64.8%) from other regions and 63.8% (from Dar es Salaam) of respondents have an average number of 1-4 children aged 1-14 years old living together in the same households, followed by 1-2 youths aged 15-19 years old for both other regions (38%) and Dar es Salaam (45.6%). The results imply that PLHIV have dependents like other people hence the need for universal access to care and treatment for PLHIV so that they can live longer and take care of their families. It should also be noted that the age group of 1-14years is a school age (primary education).The loss of their parents due to AIDS related deaths is more likely to contribute to school drop outs. Interventions to support children to access primary education, increasing households' income, improving health of PLHIV and other psychosocial support to PLHIV and affected households are critically important.

Number of Orphans living with respondents

Majority of respondents live with 1-3 orphans and most them (35.7%) are from Dar es Salaam. The following figure shows percentage of orphans reported to have lived with respondents

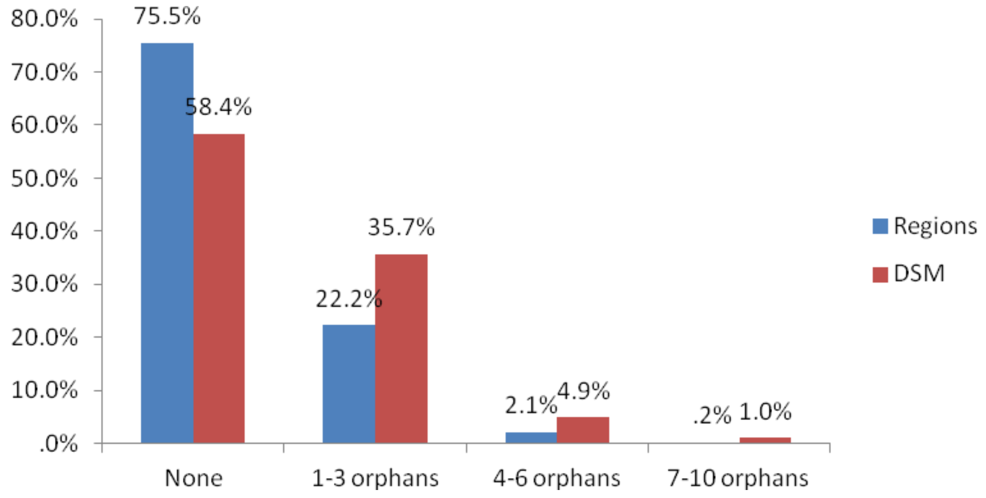

Figure 2: Number of orphans lived with respondents by regions

Distribution of respondents from where they live

All respondents from DSM are found in the city and from such instances were not classified by where they live. However, since other regions have rural and urban characteristics, respondents from these regions where classified as either they are from rural, small town/large village or large town/city. Majority of interviewees from other region lived in rural area (43.8%, n=700), 39.5% live in small towns and 16.7% live in large town. The figure 3 below shows distribution of respondents by the place where they live.

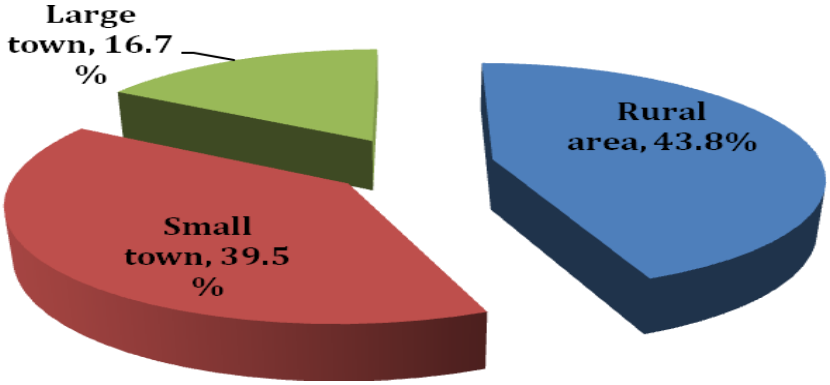

Figure 3: Distribution of Respondents by place where they live

Income levels of Respondents

Income levels of respondents were classified according to their income earned per day. Those who earned below 1 USD (equivalent to Tshs.1500/= by October 2012 when the survey was conducted) were classified under extreme poverty, those who earned between 1 and 2 US$ (Tshs 1500 – 3000/=were classified between extreme and poverty line, and those who earned above 2 USD per day were classified as above poverty line. It was found while over one third (37%) of respondents from DSM earned below 1US$ (extreme poverty), majority (86%) from other regions were above poverty line (86%). This may be associated to the fact that most of the respondents did not have reliable income as most of them were self employed. The results indicate that PLHIV in Dar es Salaam (or in urban areas) are more affected with poverty as compared to those living in rural areas and all this may have implications on other HIV interventions to PLHIV. Addressing income poverty is of great paramount. The figure 4 below shows level of income of respondents by regions.

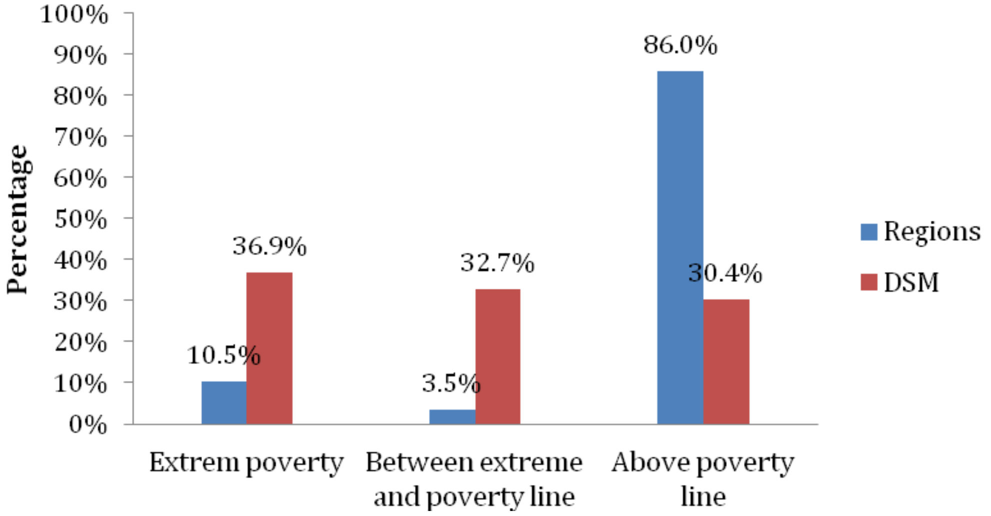

Figure 4: Income Level of Respondents by Regions

Food Security

About 29.5% (n=469) of respondents from other regions reported to have had 1 or more days without food in the past month while more than half (52.9%) of respondents from DSM reported to have had 1 or more days without food. This indicates that respondents from DSM have high food insecurity compared to those from other regions. Food security and nutrition are very critical in addressing PLHIV needs, particularly on improving treatment adherence and the general health and well-being.

3.2 Experience of Stigma and Discrimination

This section of the questionnaire comprises of five sub-sections namely exclusions; access to work, health & education services; internalized stigma and fear; rights, law and policies; and effect change. The following are the results for each sub-section.

3.2.1 Exclusion

General stigma and discrimination

Respondents were requested to share their experiences of stigma in the past one year. Major forms of stigma and discrimination experienced by PLHIV (from both locations) included having been gossiped, verbally insulted, exclusion from Social, family as well as religious activities. Overall, Dar es Salaam indicated high levels of stigma (49.7%) as compared to (39.4 %) from other regions. These results imply that there is more stigma related actions in Dar es Salaam urban areas than it is in the other regions. The data also indicate that more females were being gossiped than male in both regions. No qualitative data was available to triangulate why this variation. The information calls for more investigation to explain the disparity. Figure 5 shows proportions of respondents who experienced some forms of stigma or/and discrimination.

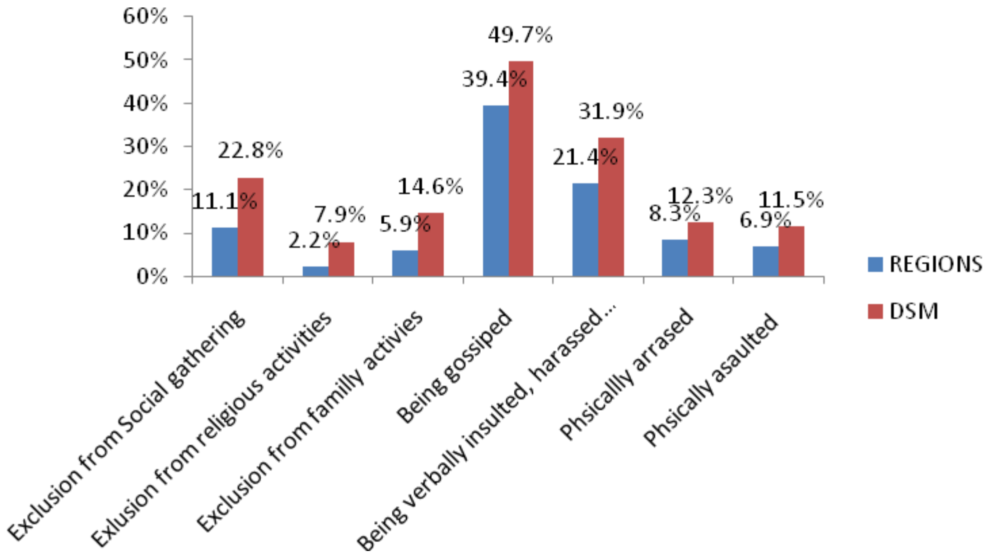

Figure 5: Types and proportions of stigma and or discrimination experienced by respondents

Table 7: Perceived reasons for experienced HIV-related stigma/discrimination

Perceived reasons	**REGIONS**			**DSM**		
	Male	**Female**	**Total**	**Male**	**Female**	**Total**
People are afraid of getting infected with HIV from me	55 (24.9%)	139 (30.3%)	194 (28.5%)	94 (23.9%)	46 (22.7%)	140 (23.5%)
People don't understand how HIV is transmitted and are afraid	61 (27.9%)	132 (28.7%)	193 (28.4%)	88 (22.4%)	43 (41.2%)	131 (22.0%)
People think that having HIV is shameful	42 (19.2%)	93 (20.3%)	135 (19.9%)	74 (18.8%)	27 (13.3%)	101 (16.9%)
Religious beliefs or "moral" judgments	5 (2.3%)	1 (0.2%)	6 (0.9%)	20 (5.1%)	11 (5.4%)	31 (5.2%)
People disapprove of my lifestyle or behavior	2 (0.9%)	10 (2.2%)	12 (1.8%)	4 (1.0%)	3 (1.5%)	7 (1.2%)
I look sick with symptoms associated with HIV	15 (6.8%)	28 (6.1%)	43 (6.3%)	21 (5.3%)	13 (6.4%)	34 (5.7%)
I don't know/I am not sure of the reason(s	77 (35.2%)	149 (32.5%)	226 (33.3%)	27 (6.9%)	11 (5.4%)	38 (6.4%)

Table 7 above indicates that Fear of getting infected with HIV, lack of understanding how HIV is transmitted and shame related to having HIV were the most leading reasons for the existing stigma and Discrimination. Both Dar es Salaam and other regions had the same pattern of reasons. Looking sick with clinical features of AIDS, and Religious beliefs 'moral judgments' also prevailed as reasons for stigmatization.

Overall, the findings show that the main root of stigmatization is embedded in the inadequate knowledge on how HIV transmits as people still have fears of getting infected with HIV. Perceived ill health associated with HIV and moral judgments against PLHIV suggest for social interventions to address negative attitudes against PLHIV

Effects of HIV related Stigma and discrimination

Respondents were asked to indicate effects of stigma and discrimination on their daily life in the past twelve months. It was found that patterns of discrimination are similar both in Dar es Salaam and other regions. While in Dar es salaam, more discrimination appears to be in sexual rejection (17.2%, n=97), psychological pressure by husband/wife/partner (15.7%, n=88), and discrimination from members of household (15%, n=87), in other regions high proportion of discrimination reported to be psychological pressure by husband/wife/partner (15%, n=235), followed by sexual rejection (12.5%, n=197), and members of household (8.8%, n=139). The results may imply, stigma and discrimination acts are more prevalent in Dar es Salaam than in other regions The figure below summarizes the effects of stigma and discrimination as experienced by study respondents.

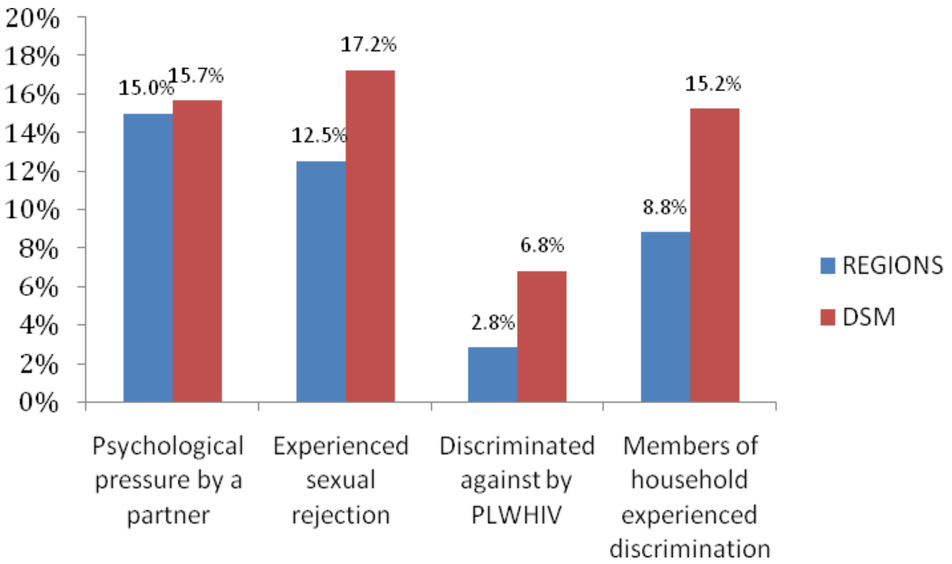

Figure 6: Effects of stigma and discrimination as experienced by PLHIV by regions

3.2.2 Access to Accommodation, Work, Health and Education Services

Access to Accomodation and Work

In the last year, majority of responents from Dar es salaam were forced to change residence/unable to rent accomadation (30.5%, n=181) and lost a job or soucre of income 29.6 %, n=143). In other regions, majority of them lost job/source of income (22.1%, n=315) and also forced to change residence/unable to rent accomadation (11%, n=176).

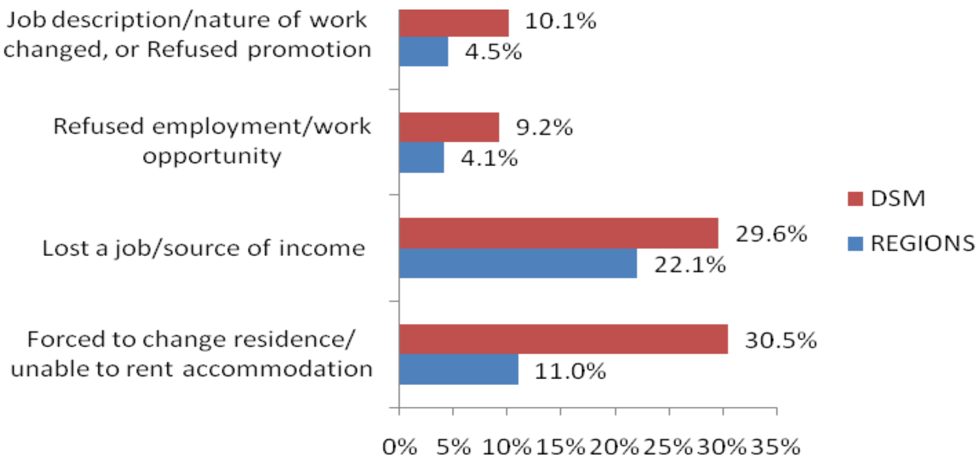

Figure 7: Access to accommodation and Work

Access to Education, Health and Dental Services

Although access to education, health and dental services by PLHIV was generally seen to be not affected, a certain proportion of respondents 8.7% (n=18) from Dar es Salaam reported having been denied of health and dental services due to being infeceted with HIV. on the hand, about 2.7% (n=39) of respondents from other regions reported that their were suspended or prevented from attending schools due to HIIV infection.. Figure 8 below summarizes the access to education, health and dental services by PLHIV in the past 12 months.

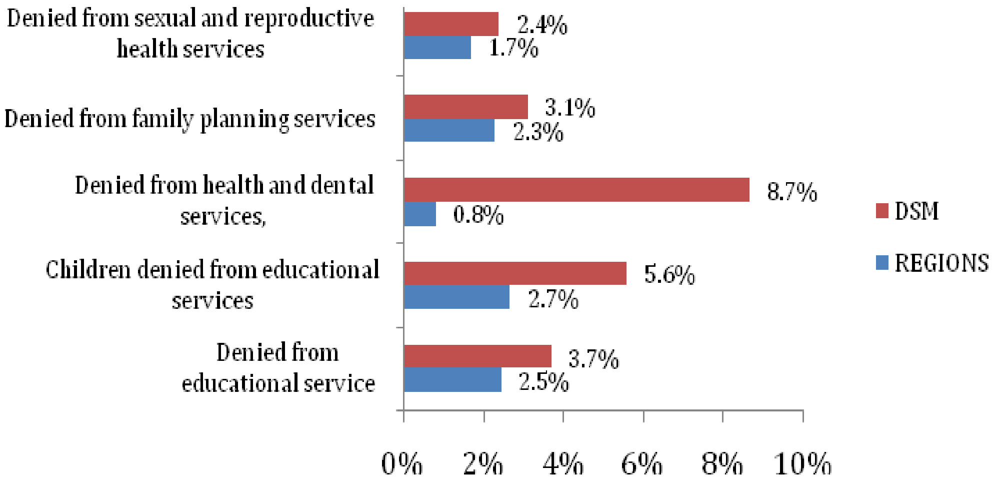

Figure 8: Access to education, health and dental services

Reasons for exclusion/denied from work and accommodation

Respondents were mostly forced to change place of residence due to other reasons apart from HIV status (n=72, 38.7%) and also were mostly refused from employment or a work opportunity due to HIV status (n=153, 48.3%). Forced to change place of residence or unable to rent accommodation due to HIV status were more pronounced in female than in males while refused from employment or a work opportunity were more pronounced in males than females (**Table 8**). Further analysis show that loss of job/source of income was mostly influenced by stop working due to poor health status for all regions (i.e. 40.2% (n=129) in regions and 24.8% (n=34) in Dar es salaam) while change of job description or the nature of your work, or refused promotion was mostly influence by both discrimination and poor health status (38.9%, n=28).

Table 8: Reasons for exclusion from work and accommodation by sex

Exclusions Criteria	**SEX**	**Reason for Exclusion/denied**				
		HIV status	**Other reasons**	**HIV + Other reasons**	**Unknown**	**Total**
Forced to change place of residence or unable to rent accommodation	Male	16 (23.9%)	28 (41.8%)	18 (26.8%)	5 (7.5%)	**67**
	Female	39 (32.8%)	44 (37.0%)	30 (25.2%)	6 (5.0%)	**119**
	Total	55 (**29.6%**)	72 (**38.7%**)	48 (**25.8%**)	11 (**5.9%**)	**186**
Refused employment or a work opportunity	Male	57 (50.0%)	36 (31.6%)	16 (14.0%)	5 (4.4%)	**114**
	Female	96 (47.3%)	62 (30.5%)	31 (15.3%)	14 (6.9%)	**203**
	Total	153 (**48.3%**)	98 (**30.9%**)	47 (**14.8%**)	19 (**6.0%**)	**317**

3.2.3 Internalized Stigma and Fears

Respondents were requested to identify feelings they had experienced because of their HIV status and their response are shown in the table below:

Table 9: Feelings because of HIV status

Feelings	Male	Female	Total
Felt ashamed	156(28.3%)	309 (29.8%)	465 (29.2%)
Felt guilty	88 (16%)	143 (13.8%)	231 (14.6%)
Blamed myself	194 (35.1%)	291 (28.2%)	485 (30.6%)
Blamed others	65 (11.8%)	142 (13.8%)	207 (13.1%)
Have low self-esteem	249 (45.0%)	446 (42.9%)	695 (43.7%)
Should be punished	30 (5.4%0	56 (5.4%)	86 (5.4%)
Felt suicidal	30 (5.4%)	72 (7.0%)	102 (6.4%)

Respondents showed feelings that they have suffered internal stigma. Majority of them reported that they have low self-esteem (43.7%, n=695), blamed themselves (30.6%, n=485) and felt ashamed (29.2%, n=465)

Respondents were also requested to indicate things they had done because of their HIV status. It has been reported that most respondents decided not to have (more) children (38.4%), decided not to have sex (27.8%) chose not to attend special gathering (18.3%), and not to get married. Detailed responses are shown in the bar chart below;

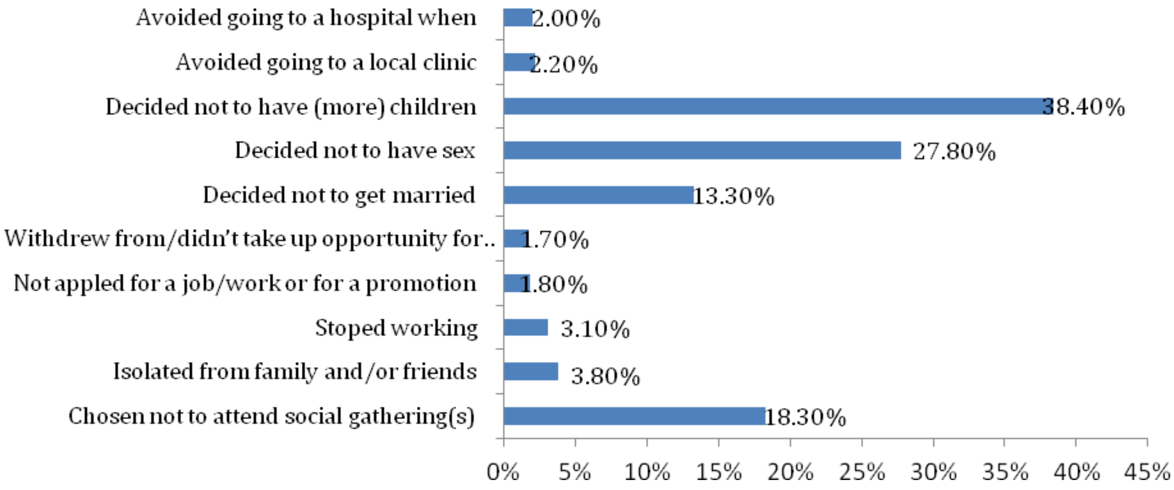

Figure 9: Things respondents avoided due to HIV status

Fears

Respondents also shared fears they had related to living with HIV as shown in figure 10 below. Most of them (45.6%) were afraid of being gossiped, and also were afraid that someone would not want to be sexually intimate with them (40.9%).

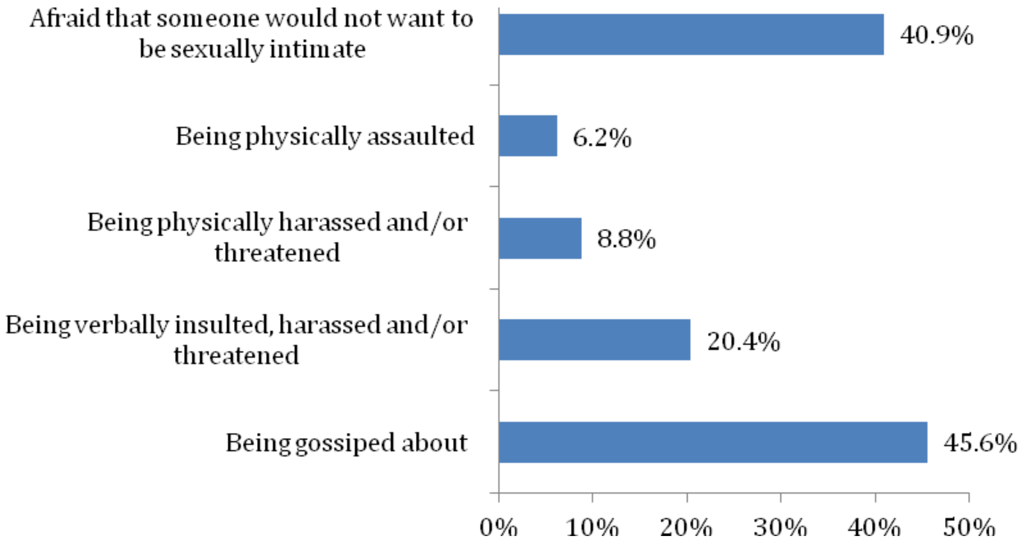

Figure 10: Fears of things happening to respondents as the results of HIV status

3.2.4 Rights, Laws and Policies

Awareness and discussion of laws and policies protecting the right of PLHIV

The table 10 below indicates respondents' awareness and general discussion about laws and policies protecting the right of PLHIV.

Table 10: Awareness and discussion of laws and policies protecting PLHIV

Right,/Law/policy	REGIONS			DSM		
	Male	Female	Total	Male	Female	Total
Heard of the Declaration of Commitment on HIV/AIDS, which protects the rights of people living with HIV	231 (41.9%)	356 (34%)	587 (36.8%)	237 (61.2%)	130 (64.7%)	367 (62.4%)
Ever read or discussed the contents of declaration of Commitment on HIV/AIDS, which protects the rights of people living with HIV	84 (33.3%)	145 (37.7%)	229 (35.9%)	126 (43.9%)	66 (40.7%)	192 (42.8%)
Ever heard National law/policy or set of guidelines which protect(s) the rights of people living with HIV in Tanzania	200 (38.5%)	296 (29.7%)	496 (32.0%)	237 (69.9%)	114 (64.8%)	351 (68.2%)
Ever read or discussed National law/policy or set of guidelines which protect(s) the rights of people living with HIV in Tanzania	108 (43%)	137 (37.4%)	245 (39.7%)	134 (49.6%)	68 (53.1%)	202 (50.8%)

Overall, results on Table 10 above indicate low level of awareness and discussion of laws and policies that protect rights of PLHIV, and wide disparity between other regions (rural areas) and Dar es Salaam (Urban areas). While more than two thirds of respondent from Dar es Salaam (62%) and (68%) have heard about International Declaration on Human rights and national policies and laws that protect PLHIV respectively, less than half (36%) and (39.7%) of respondents from other regions were aware of the same.

Reading the Declaration, law and policies on the protection of human rights for PLHIV seem to be more prevalent in Dar es Salaam (42.8% and 50.8% respectively) than it was reported from other regions (35.7% and 39.7%). Women in rural areas are far below than men in accessing this information.

Rights

Respondents were requested to indicate if their rights have been compromised in the past twelve months because of their HIV status. Although most of respondents reported to have their rights not compromised in the past 12 months, some forms of force submission of medical/health procedures were reported. Such practices may compromise with one’s rights to confidentiality and voluntary HIV testing and disclosure of the testing results. Overall responses are shown in the graph below.

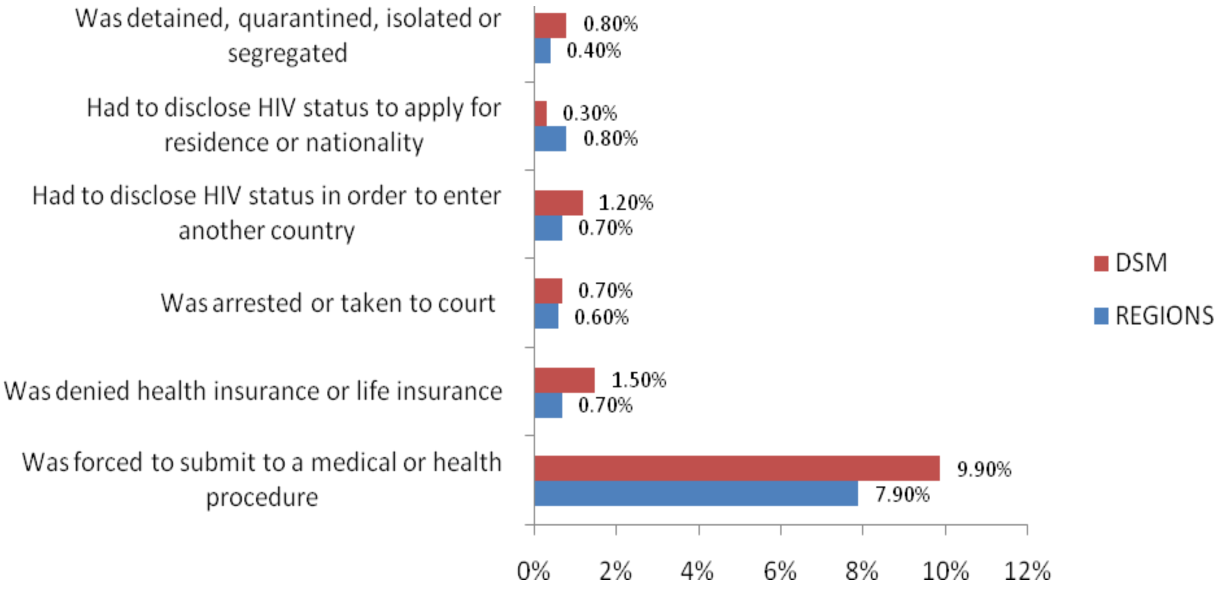

Figure 11: Respondents' compromised rights

Abuse of Rights and Legal Redress

About 7% (n=111) of respondents from Regions and 15.7% (n=88) from Dar es Salaam stated that their rights had been abused. Of those abused, only 14.6% and 12.5% from other regions and DSM respectively tried to get legal redress for abused rights. Reasons for majority not taking legal redress were not well captured. Moreover, 50% from other regions and 17.8% from Dar es Salaam tried to get a government employee(s) to take action against an abuse of their rights. Some other 5.2% from other regions and 14.3% from Dare s Salaam reported to have tried to get a local or national politician to take action against an abuse of their rights. It is critically important to have interventions that will increase literacy on human rights among PLHIV and empower PLHIV on how best to demand and access institutions or instruments that can support PLHIV to gain their abused rights with focus on community structures strengthening, refresher training or regular orientation of health providers, social workers, employers, law enforcers, judiciary as well as community gatekeepers.

3.2.5 Effecting Change

Table 11 below summarizes major actions taken by respondents to effect change against discrimination and or stigma.

Table 11: Actions taken to effect change against stigma/discrimination

Action	**REGIONS**			**DSM**		
	Male	**Female**	**Total**	**Male**	**Female**	**Total**
Ever confronted, challenged or educated someone stigmatizing or discriminating against you	164 (30%)	311 (30%)	475 (30%)	198 (50.4%)	122 (60.1%)	320 (53.7%)
Know any organizations/groups that can help in stigma/discrimination	185 (33.6%)	324 (31.4%)	509 (32.2%)	212 (53.9%)	108 (53.2%)	327 (53.9%)
Sought help from any of organizations or groups to resolve an issue of stigma	51 (9.3%)	116 (9.3%)	167 (10.5%)	90 (22.9%)	48 (23.6%)	138 (23.2%)
Have supported other people living with HIV	367 (67.5%)	694 (67.4%)	1061 (67.4%)	315 (80.2%)	162 (79.8%)	477 (80%)
1. Support type (Physical support) provided	59 (16.2%)	94 (13.6%)	153 (14.5%)	48 (12.2%)	26 (12.8%)	74 (12.4%)
2. Support type (Emotional support) provided	132 (36.1%)	232 (33.45)	364 (34.3%)	176 (44.8%)	97 (47.8%)	273 (45.8%)
Currently a member of a PLHIV support group and/or network	223 (41.6%)	446 (44.4%)	669 (43.4%)	0%	0%	0%
Have either volunteer or employee in any program assisting PLHIV	79 (14.4%)	162 (15.2%)	241 (15.2%)	150 (38.2%)	85 (41.9%)	235 (38.4%)
Ever involved to develop HIV legislation/policies/ guidelines	17 (2.1%)	42 (4.15)	59 (3.7%)	66 (16.8%)	36 (17.1%)	102 (17.1%)

Efforts to effect changes among PLHIV and by PLHIV in addressing stigma are still very low. There is also big disparity between Urban (Dar es Salaam) and Rural (other regions) areas. Results in table 11 above show that there is limited capacity of PLHIV to address stigma including little knowledge and capacity to access services from various organizations for support. However, the results also show that there is more cohesion among PLHIV support groups that may be useful sources for psychosocial support for PLHIV, at least nearly half (43.4%) were members of PLHIV support groups but need for more mobilization of PLHV to join such clusters

Involvement of PLHIV in development and review of policies, laws and guidelines was found to be almost nonexistent as only 3.7% (from other regions) and 17% (from Dar es Salaam) reported to have been involved in these processes. Women Living with HIV in the rural areas (2.1%) reported their participation. All this calls for advocacy efforts at all levels of policy and decision making to actively engage or meaningfully involve PLHIV to effect positive results on the lives of PLHIV. Networks of PLHIV need to be engaged in implementing programs that address needs of PLHIV and monitor the progress and outcomes.

A minimum package of benefits and advantages attached to disclosure of HIV test results need to be developed, promoted and advocated for so that it can be used as a tool to mobilize and motivate many others to join efforts of NACOPHA and individual PLHIV in stigma reduction efforts. In the spirit of putting PLHIV at the center of the HIV response, specific programs need to be designed to enable PLHIV to become leaders of change and the decision makers for positive health outcomes

Over two thirds (64.9) and (46.5%) of PLHIV from other regions and Dar es salaam respectively were aware of PLHIV support groups and services networks (64.9%) than other local and international organizations that may offer financial legal, social, moral or psychosocial support to the PLHIV. This is very vital in addressing stigma and discrimination issues as far as human rights and empowerment of PLHIV are concerned. Details are provided in table 12 below:

Table 12: Types of Organization respondents know about

Type of Organization/Group	**REGIONS**	**DSM**
People living with HIV support group	368 (64.9%)	277 (46.5%)
Network of people living with HIV	197 (35%)	320 (53.7%)
Local non-governmental organization	42 (7.5%)	57 (9.6%)
Faith-based organization	155 (27.6%)	104 (17.4%)
A legal practice	95 (16.9%)	111 (18.6%)
A human rights organization	60 (10.7%)	88 (14.8%)
National non-governmental organization	7 (1.2%)	30 (5%)
National AIDS council or committee	29 (5.2%)	144 (24.2%)
International non-governmental organization	1 (0.2%)	21 (3.5%)
UN organization	1 (0.2%)	25 (4.2%)
Other	31 (5.5%)	5(0.8%)

Respondents' Perceived Power to Influence Decisions

Respondents were requested to state if they feel that they have the power to influence decisions in various aspects relating to effect change on rights, stigma and/or discrimination for PLHIV. Their perceived powers are shown in table 13 below.

Table 13: Respondents' power to influence decisions

Factors to be influenced	REGIONS			DSM		
	Male	Female	Total	Male	Female	Total
Legal/rights matters affecting people living with HIV	155 (29.5%)	284 (28.5%)	439 (28.8%)	191 (48.6%)	94 (46.3%)	285 (47.8%)
Local government policies affecting people living with HIV	104 (19.8%)	169 (17%)	273 (17.9%)	193 (49.1%)	86 (42.6%)	279 (46.8%)
Local projects intended to benefit people living with HIV	145(27.6%)	231 (23.2%)	376 (24.7%)	122 (31%)	71 (35%)	193 (32.45)
National government policies affecting people living with HIV	29 (5.5%)	44 (4.4%)	73 (4.8%)	58 (14.8%)	31 (15.3%)	89 (14.9%)
National programmes intended to benefit people living with HIV	51 (9.7%)	114 (11.4%)	165 (10.8%)	1 (0.3%)	1 (0.5%)	2 (0.3%)
International agreements/treaties	2 (0.4%)	4 (0.4%)	6 (0.4%)	0	0	0
None of these things	186 (35.4%)	370 (37.1%)	556 (36.4%)	0	4 (2%)	4 (0.7%)

Overall, results show that PLHIV have limited powers to influence decisions in various forums and programs that affect the lives of PLHIV. Over 53% (from Dar es salaam)of those responded to the various aspects to be influenced agreed to have no powers to influence decisions in legal rights, local projects, national governments policies national programs benefiting PLHIV including International agreements/treaties. The situation was far worse from other regions whereby nearly three quarters (72%) indicated were not able to influence decisions. The results indicate need for prioritizing on the empowerment of PLHIV through implementation of Positive Health and Dignity Prevention program and the GIPA principle in Care, Treatment and Impact mitigation HIV services.

Important issues to address in order to eliminate stigma and discrimination

Respondents were requested to recommend the most important thing which should be done by NACOPHA to address stigma and discrimination. The figure below summarizes the major interventions recommended by respondents.

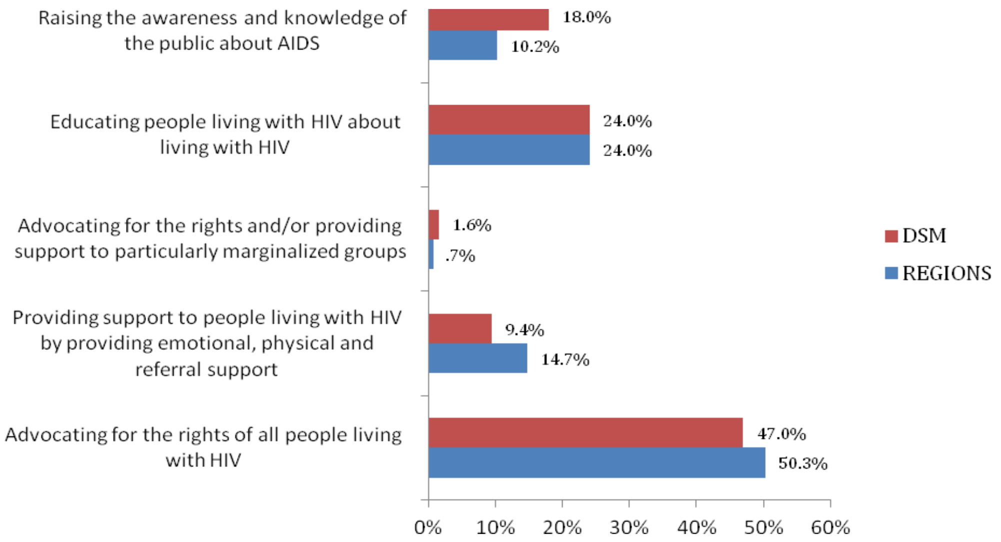

Figure 12: Reported Important intervention to address stigma and discrimination

Figure 12 above shows that PLHIV indicated three priorities that include advocating for the rights of all people living with HIV, educating people living with HIV about living with HIV including treatment efficacy and raising awareness and knowledge of the public about HIV and AIDS as the most important intervention that needs to be done for PLHIV. In developing national strategies, PLHIV need to be involved so that they can have an opportunity to influence planning and programming for the national HIV and AIDS response.

3.3 Experience of testing Disclosure, Treatment and Having Children

This section comprises of four sub-sections which deals with testing and diagnosis, disclosure and confidentiality, treatment, and experience of having children. Every section is reported under the following respective sub-headings.

3.2.1 Testing and Diagnosis

Respondents were requested to indicate the reasons why they were tested for HIV. The following table 14 shows respondents' response.

Table 14: Reasons for being tested for HIV

Reasons	REGIONS			DSM		
	Male	Female	Total	Male	Female	Total
Employment	3 (5%)	5 (5%)	8 (5.0%)	2 (5%)	1 (5%)	3 (5%)
Pregnancy	9 (1.6%)	140 (13.4%)	149 (9.3%)	34 (8.7%)	18 (8.9%)	52 (8.2%)

Prepare for a marriage/sexual relationship	15 (2.75)	16 (1.5%)	31 (1.9%)	3 (0.8%)	1 (0.5%)	4 (0.7%)
Referred by a clinic for sexually transmitted infections	19 (3.4%)	40 (3.8%)	59 (3.7%)	0	0	0
Referred due to suspected HIV-related symptoms	182 (33.1%)	248 (23.8%)	430 (27%)	102 26%)	55 (27.15)	157 (26.3%)
Husband/wife/partner/family member tested positive	39 (7.1%)	52 (5.0%)	91 (5.7%)	0	0	0
Illness or the death of husband/wife/partner/family member	54 (9.8%)	158 (15.1%)	212 (13.3%)	71 (18.1%)	31 (15.35)	102 (17.1%)
Just wanted to know	263 (47.6%)	447 (42.8%)	710 (44.5%)	0	0	0
Other	14 (2.5%)	21 (2.0%)	35 (2.2%)	0	0	0

From table 14 above, the most reported leading reason for HIV testing from other regions was just wanted to know (44.5%) their HIV sero status voluntarily; Dar es salaam data was missing. Others include referrals due to suspected AIDS-related symptoms, (27%) and illness or the death of husband/wife/partner/family member (13.3%). While the most reported reasons for HIV testing among respondents from Dar es Salaam were referred due to suspected AIDS-related symptoms (n=157, 26.3%) and illness or the death of husband/wife/partner/family member (n=102, 17.1%)

Decision to test for HIV test

Respondents were asked if decision to test for HIV status was voluntary or due to other reasons. Although most of respondents (87.8%) in other regions and (67.4) in Dar es salaam took decision to test for HIV voluntarily, a considerable proportion between 12% (from other regions and 32.6% (Dar es Salaam) were tested out of their willingness. The figure below summarizes their responses.

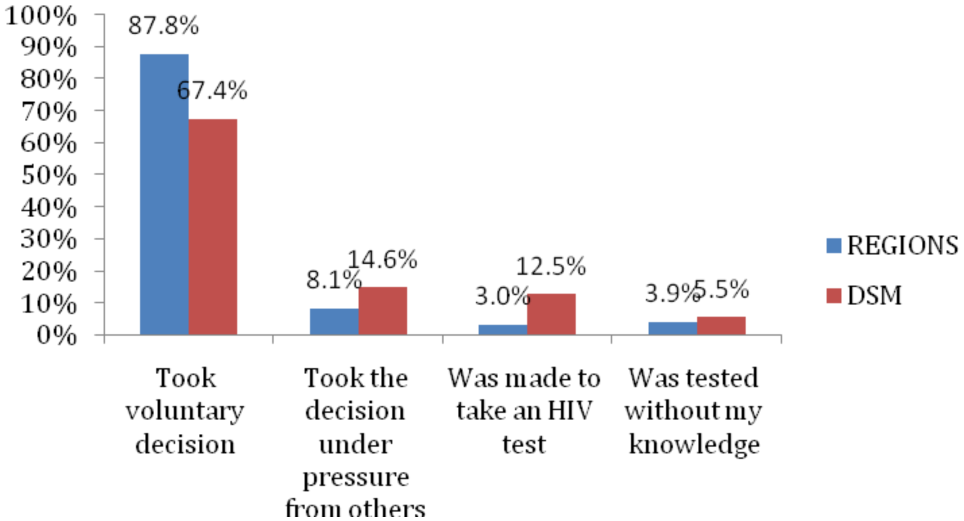

Figure 13: Decision to take HIV Test

Counseling received by people tested for HIV

Figure 14 below shows that, provision of HIV testing services has to a large extent been complied by service providers with HIV testing guidelines as majority of respondents (82.6% - 85%) received both pre and post testing counseling. However, efforts to improve services need to be effected as there are a few respondents who received partial services; without receiving pre or and post test counseling.

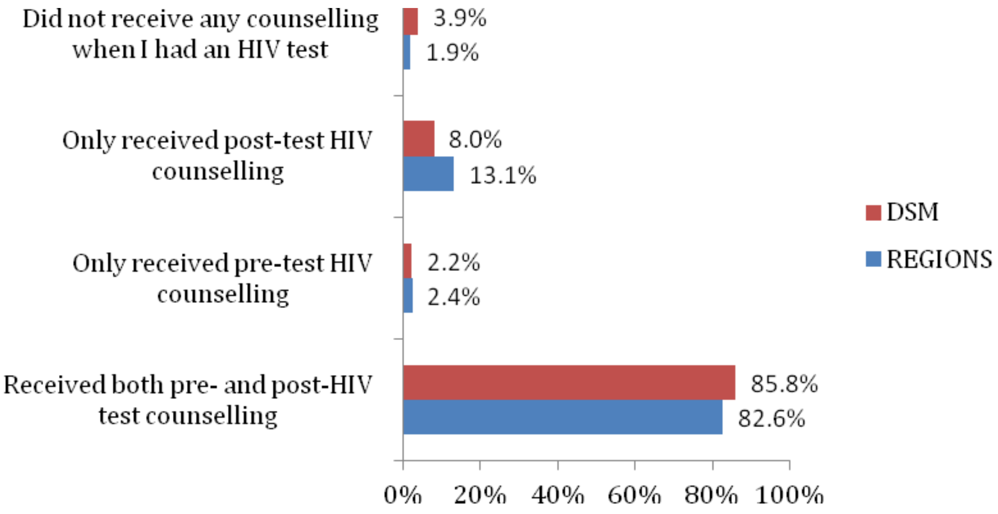

Figure 14: Experience of pre- and post-testing counseling

3.3.2 Disclosure and Confidentiality

Respondents were asked how certain people or groups of people were first told about their HIV status. Findings in table below show that while majority indicated to have disclosed their HIV testing results on their own, practices still exist that disclosure is still difficult to sexual partners, work mates, employers, clients, friends religious and community leaders . This experience is more prevalent in Dar es Salaam than it is from other regions, see table 15 below.

Table 15: Method of HIV status disclosure

To whom status was disclosed	**REGIONS**				**DSM**			
	I told them	**Someone else told them with my consent**	**Someone else told them without my consent**	**They don't know my HIV status**	**I told them**	**Someone else told them with my consent**	**Someone else told them without my consent**	**They don't know my HIV status**
Your husband/wife/partner	789 (86.7%)	50 (5.5%)	22 (2.4%)	49 (5.4%)	334 (82.7%)	10 (2.5%)	16 (4%)	44 (10.9%)
Other adult family members	1057 (77.3%)	127 (9.3%)	72 (5.3%)	112 (8.2%)	0	0	0	0
Children in your family	829 (71.0%)	55 (4.7%)	34 (2.9%)	249 (21.3%)	0	0	0	0
Your friends/neighbors	605 (53.9%)	67 (6%)	146 (13%)	305 (27.2%)	238 (45.9%)	17 (3.3%)	54 (10.4%)	209 (40.3%)
Other people living with HIV	148 (35.8%)	11 (2.7%)	41 (9.9%)	213 (51.6%)	0	0	0	0
People who you work with	1022 (83%)	71 (5.8%)	36 (2.9%)	102 (8.3%)	129 (44.2%)	4 (1.4%)	23 (7.9%)	136 (46.6%)
Your employer(s)/boss(es)	108 (35.1%)	8 (2.6%)	28 (9.1%)	164 (53.2%)	101 (45.3%)	5 (2.2%)	15 (6.7%)	102 (45.7%)
Your clients	104 (21.7%)	13 (2.7%)	39 (8.1%)	323 (69.4%)	49 (18.1%)	4 (1.5%)	10 (3.7%)	208 (76.8%)
Injecting drug partners	15 (12.6%)	1 (0.8%)	1 (0.8%)	102 (85.7%)	0	0	0	0
Religious leaders	455 (47.6%)	59 (6.2%)	38 (4.0%)	403 (42.2%)	152 (34.6%)	10 (2.3%)	14 (5.3%)	263 (59.9%)
Community leaders	461 (46.9%)	98 (10%)	80 (8.1%)	343 (34.9%)	221 (46.4%)	9 (1.9%)	13 (5.6%)	233 (48.9%)
Health care workers	1117 (91.9%)	49 (4%)	11 (0.9%)	48 (3.9%)	507 (91.5%)	8 (1.4%)	8 (1.4%)	31 (5.6%)
Social workers/counselors	543 (61.4%)	71 (8%)	18 (2%)	252 (28.5%)	341 (72.4%)	9 (1.9%)	8 (1.7%)	113 (471%)
Teachers	80	11	23 (6.8%)	224	67	3 (1.4%)	10 (4.6%)	138

	(23.7%)	(3.3%)		(66.3%)	(30.7%)			(63.3%)
Government officials	424 (47.5%)	101 (11.3%)	48 (5.4%)	319 (35.8%)	232 (51%)	5 (1.1%)	9 (2%)	202 (45.9%)
The media	33 (10.4%)	23 (7.3%)	3 (0.9%)	257 (81.3%)	0	0	0	0

Experience of pressure to disclose HIV status

Respondents reported that they were sometimes pressured to disclose their HIV status as shown below;

Table 16: Experience of pressure to disclose HIV status in other regions

Pressure to disclose HIV status	SEX	REGIONS			
		Never	Once	Few times	often
From other individuals living with HIV or from groups/networks	Male	360 (66.1%)	5(0.9%)	43 (7.9%)	137 (25.1%)
	Female	635 (62.1%)	28 (2.7%)	110 (10.8%)	250 (24.4%)
	Total	995 (63.5%)	33 (2.1%)	153 (9.8%)	387 (24.7%)
From other individuals NOT living with HIV	Male	425 (77.4%)	4 (0.7%)	46 (8.4%)	74 (14.5%)
	Female	773 (75.2%)	14 (1.4%)	87 (8.5%)	154 (15%)
	Total	1198 (76%)	18 (1.1%)	133 (8.4%)	228 (14.5%)

Over one third (36.5%) of respondents experienced pressure to disclose their HIV status from other individuals living with HIV or from groups/networks while about 24% experienced pressure from other individuals NOT living with HIV. However, it was also found that about 85.4% of respondents did find that the disclosure of their HIV status was an empowering experience. Investing in empowering PLHIV to disclose their results is of paramount

3.3.3 Treatment

Respondent's current health status

Generally, majority of respondents reported a good health status as only below one fifth of respondents (18.9% and 16.6%) from other regions and Dar es Salaam respectively reported faire health; as well as those who reported poor health status (2.8% and 3.4%) from other regions and Dar respectively as well.). the results may be attributed to access to ART as reported in Table 16. The figure below illustrates reported health status of respondents.

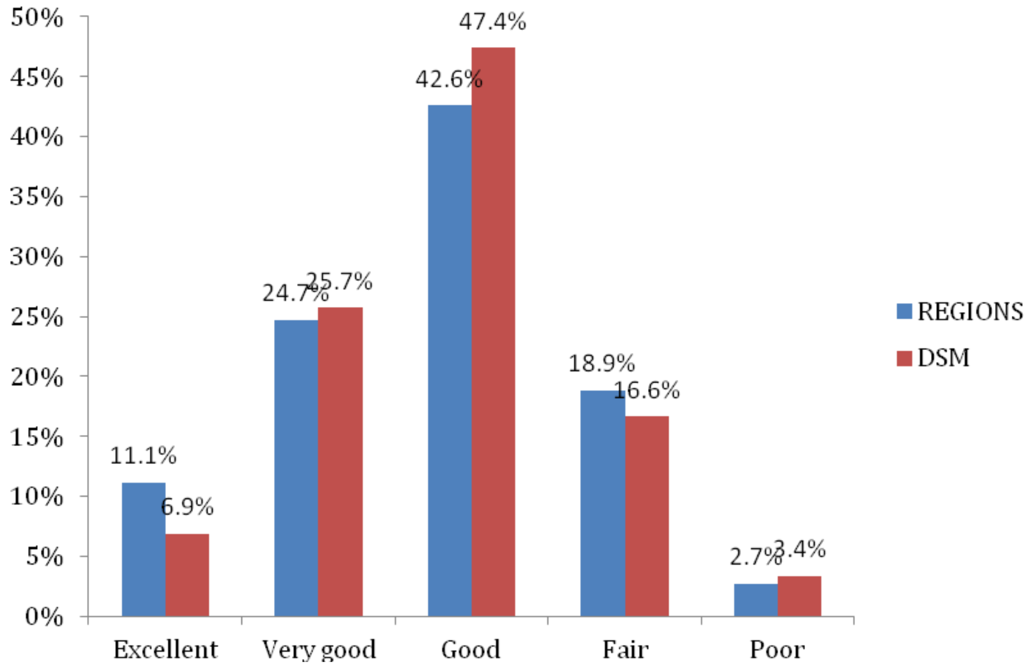

Figure 15: Respondents' current health status by regions

Access to and Use of Treatment and medication

The table below summarizes responses related to use of ARVS, availability, and other related treatment and care for PLHIV.

Table 17: Respondents' access to and use of treatment and medication

Treatment/care	REGIONS			DSM		
	Male	Female	Total	Male	Female	Total
Currently Taking ARVs	471 (85.8%)	902 (86.4%)	1373 (86.2%)	279 (71.7%)	144 (71.3%)	423 (71.6%)
Access to ARV even if you don't need it	459 (84.5%)	884 (86.1%)	1343 (85.5%)	145 (37.6%)	68 (34%)	213 (36.3%)
Currently taking any medication to prevent or to treat opportunistic infections	499 (90.1%)	910 (87.3%)	1409 (88.3%)	309 (79.2%)	150 (73.9%)	459 (77.4%)
Access to opportunistic infection drugs even if currently not needed	485 (89.3%)	920 (89.2)	1405 (89.3%)	264 (68.0%)	134 (67.0%)	398 (67.7%)
Had a constructive discussion on the subject of your HIV-related treatment options	211 (38.3%)	405 (39.0%)	616 (38.8%)	166 (42.8%)	80 (39.6%)	246 (41.7%)
Had a constructive discussion sexual and reproductive health, sexual relationship	241 (44.1%)	440 (38.7%)	641 (40.6%)	160 (41.3%)	88 (43.3%)	248 (42.0%)

Although there is relatively high coverage (86.2%) from Dar es Salaam and 71.6% of respondents from other Regions reported currently taking ART including access to other medication to prevent opportunistic infections, more than 59% (Dar es salaam) and 62% (from other regions) were not given opportunity to discuss HIV related treatment options and sexual, and reproductive health. It is important to ensure that there is user friendly environment for PLHIV accessing treatment and sexual and reproductive health services as this is a basic human right to every individual accessing heath services

Moreover, people who reported to take other medication to prevent opportunistic infections were 85.5% (from other regions) and 36.3% (from Dar es Salaam). There is need to do further investigation to understand why there is very low uptake of medication for opportunistic infections in Dar es Salaam irrespective of being nearby HIV treatment and care services.

3.3.4 Having Children

In this sub-sections respondents were asked to share their experiences relating to children and their HIV status including counseling about reproductive health, coercion for termination of pregnancy, method of infant feeding practice, method of giving birth and PMTCT issues. Tables 18 and 19 below summarize all regarding this sub-section.

Table 18: Children issues relating to HIV status

Children and PMTCT issues	REGIONS			DSM		
	Male	Female	Total	Male	Female	Total
Do respondent have a child/children	431 (78.8%)	899 (86.1%)	1330 (83.6%)	326 (83.0%)	151 (75.1%)	477 (80.3%)
Do any of children known to be HIV-positive	79 (18.2%)	180 (20.8%)	259 (20%)	71 (21.6%)	38 (22.5%)	109 (21.9%)
Ever received counseling about your reproductive options	237 (50.6%)	402 (54.5%)	729 (53.2%)	177 (51.6%)	71 (42.5%)	248 (48.6%)
Ever advised not to have a child since you were diagnosed as HIV-positive	43 (8.9%)	162 (17.3%)	205 (14.4%)	51 (14.5%)	27 (15.1%)	78 (14.7%)

On average, one fifth of respondents reported to have children living with HIV. However, more than half of respondents have not received any counseling on reproductive options. Moreover, between 14-15% of respondents were advised to have no children since they were HIV positive. The results suggest policy and programmatic interventions to both PLHIV and Health service providers to ensuring quality access to essential Reproductive health including PMTCT services for PLHIV, particularly to women living with HIV (WLHIV), as well as proper counseling on how best to bear and care children living with HIV. Other intervention should focus on enhancing rights literacy to both PLHIV and health providers

Table 19: Access to reproductive health and PMTCT services

Children and PMTCT issues	REGIONS			DSM		
	Male	Female	Total	Male	Female	Total
Has a health care professional ever coerced you into being sterilized since you were diagnosed as HIV-positive	9 (1.8%)	19 (2.0%)	28 (2%)	8 (2.2%)	6 (3.4%)	14 (2.6%)
Is your ability to obtain antiretroviral treatment conditional on the use of certain forms of contraception	35 (10.5%)	105 (15.3%)	140 (13.7%)	23 (10.8%)	7 (7.9%)	30 (9.9%)
Coerced termination of pregnancy	NA	8 (0.9%)	8 (0.9%)	NA	4 (3.3%)	4 (3.3%)

Coerced on method of giving birth	NA	140 (15.7%)	140 (15.7%)	NA	10 (8.8%)	10 (8.8%)
Coerced infant feeding practice	NA	183 (21.1%)	183 (21.1%)	NA	19 (17.0%)	19 (17.0%)
Ever given drugs for PMTCT	NA	284 (78.5%)	284 (78.5%)	0	0	0
Ever given information about healthy pregnancy and motherhood as part PMTCT	NA	283 (58.1%)	183 (58.1%)	0	0	0

Table 19 above shows that, while a larger proportion (42%) of female respondent reported having never received information on PMTC services, coercion on methods of giving birth, infant feeding options, contraceptive methods were reported at high proportions. Further, nearly 22% did not receive PMTC services. The results on table 18 above indicate violation of human rights and denial of access to essential reproductive health services for both women and men living with HIV. Reproductive health rights of PLHIV must be given due attention both in policy guidelines and direct services provision at health facilities

PMTCT

Prevention from mother to child transmission practices were comprehensively explored in other regions. Data indicate that about 22% of respondents were not given drugs for PMTCT and about 42% were not given information about healthy pregnancy and motherhood as part of PMTCT (Table 18 above). This calls for attention to advocate for increased access for option B+ and health related information for pregnant women living with HIV. Further community awareness is critical to also influence community mobilization for men's involvement and local government support to ensure all barriers to women's access to PMTC have been addressed adequately. Stigma itself is the major barrier, which prevents couples to discuss about this obvious issue in this era. This calls for AIDS competence from among the communities.

CONCLUSION

The stigma index tool implemented in Tanzania was very useful in generating data that show existing levels and forms of stigma and discrimination that PLHIV experience. The data also showed how the lives of PLHIV are affected at individual, workplace and community level as well. The gathered evidence indicated that most of the experienced acts of stigma by the PLHIV from different settings have greatly contributed to the various choices of options for the PLHIV to overcome stigmatizing and discriminating acts. Although the tool was administered by the PLHIV to the fellow PLHIV, the response provided by the respondents indicate that there is high levels of self stigma which can be attributed to the existing stigma from the community against PLHIV. As provided in the most recent HIV and malaria Indicator survey (THM 2012), in Tanzania, over two thirds of males and over three quarters of females have negative attitudes against PLHIV.

The data has also indicated that some forms and experiences of stigma and discrimination are related to social economic differences such as gender, employment, income levels, place of residence (urban and rural), age , marriage as well, that may require various types of interventions in addressing stigma and discrimination. Literacy levels of respondents have to a greater extent influenced response and behavior of PLHIV in accessing HIV services including treatment, reproductive health, PMTCT. Further, results indicated low levels of awareness and engagement of PLHIV in discussing international and national laws, policies and other key information on HIV is major bottleneck to empowering PLHIV with ability, knowledge and skills in influencing policies and decisions at different levels which also affect their engagement in effecting changes in the community. Low level of PLHIV participation in CSOs engagement, particularly at community level is also an issue of concern particularly in engaging PLHIV on advocacy efforts.

The generated evidence calls for the need to create an enabling environment that will set basis and precedence for designing both programmatic and policy interventions that have direct impact on eliminating stigma and discrimination against PLHIV. Various stakeholders, as defined in the National HIV strategic framework (NMSF) that guides the HIV response have key roles to play in addressing stigma and discrimination at different levels from the community to the national levels. Despite the limitations that may be attributed to the study design and methodology, results in the Stigma index tool can at present be the only guiding evidence to various stakeholders in developing strategies and interventions to empower PLHIV overcome Stigma and discrimination, and the PLHIV taking the leadership role both at local and national dialogue platforms responding to the needs of PLHIV in the fight against Stigma and discrimination.

RECOMMENDATIONS

The following recommendations were made basing on the major findings and conclusions that were drawn from this study; and are provided based on the roles that key stakeholders can play in contributing to the elimination of stigma and discrimination against PLHIV

National Council of PLHIV (NACOPHA)

- Facilitate dissemination of the findings of stigma Index at national and district council level and advocate for support from the government to support efforts of PLHIV to eliminate stigma and discrimination both at national and local council's level.
- Develop and implement participatory advocacy action for legal and policy issues emanated from the study to influence policy on PLHIV human rights, access to treatment and HIV prevention services, Reproductive health, HIV testing and disclosure, treatment and HIV policy and law literacy etc.
- Mobilize government, and private sector to generate support to address treatment literacy, policy and laws affecting PLHIV, HIV prevention options, among PLHIV etc
- More funding and Capacity building is required to strengthen the capacity of NACOPHA and Its affiliated networks, NACOPHA clusters to mobilize around their rights and to challenge their stigma and discrimination
- Strengthen networking capacity of PLHIV networks, clusters and support groups to advocate for issues of PLHIV at different levels
- Advocate for integration of Positive Health, Dignity and Prevention framework in the national HIV response for effective engagement meaningful involvement of PLHIV in HIV response.
- Advocate and mobilize support for PLHIV empowerment targeting the capacity strengthening for both individuals and PLHIV groups through psychosocial support, economic empowerment, networking, Skills building, policy engagement and advocacy.
- Empower PLHIV and communities on voluntary HIV sero status disclosure in order to reduce stigma and discrimination for PLHIV
- Conduct further qualitative studies that will generate in-depth understanding of issues that perpetuate stigma and discrimination in order to improve access to HIV services,

policies, laws programs that positively impact on the lives and welfare of PLHIV

- Engage the media to help with creation of open forum to sensitize and educate the public on HIV transmission, access to prevention and treatment, and stigma and discrimination as well

- Advocate for national resourcing of Stigma Index tool for generating strategic information that will inform the national M&E frameworks in the HIV response in policy development, planning, programming, monitoring and evaluation. on measuring outcomes on the fight against stigma and discrimination.

- Strategic information on the prevalence, causes and forms of stigma and discrimination to be used systematically in the "know your epidemic and response analysis"

Civil Society organizations (CSOs)

- Develop and implement joint advocacy action with the PLHIV constituency to address stigma and discrimination issues to protect rights of PLHIV and cohesion and alliance of both PLHIV and CSOs community in the national response as far as Stigma and discrimination is concerned

- Advocate for and maintain policy dialogue platform at national level that will engage other stakeholders to hold the government accountable to policy and law regulation on HIV response that positively impact on the lives of PLHIV

- Engage in generating and disseminating strategic evidence on HIV response that contribute to the national efforts in addressing stigma and discrimination to various strategic areas in the HIV response particularly to the community , work place, policy making and programming .

Government Bodies

Government Bodies include all ministries, departments and agencies. These bodies have various relevant roles in responding to HIV, particularly in eliminating stigma and discrimination against PLHIV. The key movement bodies include Tanzania Commission for AIDS (TACAIDS), Ministry of Health and Social Welfare (MoHSW), Prime Minister's office for Regional administration and Local government (PMORALG), Ministry of Community Development, gender and Children (MCDGC), Ministry of Justice and Constitution affairs, Ministry of labor and Youth development and Ministry of agriculture, Ministry of Education

- Enforce implementation of national stigma and discrimination strategy

- Provide guidance to all stakeholders including government instructions and structures and private sector to ensure representation of PLHIV at various levels of policy decision making and programming particularly on issues that have direct impact on the lives of PLHIV.
- Allocate resources for strategic, coordinated and comprehensive programs to scale up stigma and discrimination interventions to a level to have a significant (tangible) impact.

- Ensure there is equitable access quality and adequate supply of HIV services that are gender responsive and user friendlier including ART, HIV test kits, diagnostics, HIV prevention services and gadgets, PMTCT, family planning, TB NCD such as Cervical Cancer, and other essential health services and medication.

- Engage and provide support for economic empowerment to PLHIV through relevant ministries and local councils to address both income poverty household welfare of PLHIV

- Develop and implement strategies for sustainable food security that will improve access, uptake and adherence to HIV treatment

- Provide for an enabling environment to empower PLHIV to access and utilize information that strengthen their ability to effect changes in the community