

**DRAFT REPORT
ON
“People living with HIV Stigma Index” study in
Bangladesh**

**Submitted to: UNAIDS, Bangladesh
....., 2009**

**Submitted by: James P Grant School of Public Health
BRAC University, Bangladesh**

66, Mohakhali, Dhaka-1212

Contents

	Page
Acronyms	iii
Acknowledgements	iv
Executive Summary	vi
List of Tables	viii
List of figures	ix
Chapter 1- Introduction	1
1.1 Definition: HIV/AIDS Stigma and Discrimination	2
1.2 A Review of Relevant Research	3
Chapter 2 Methodology	
2.1 Introduction	7
2.2 Methodology for the Quantitative part of the study	7
2.2.1 Training of the data collectors	12
2.2.2 Data Collection	13
2.2.3 Quality Control	13
2.2.4 Data Analysis	13
2.3 Methodology for the Qualitative part of the study	13
Chapter 3 Findings	
3.1 Introduction	16
Part I- Stigma Index: Findings of the Quantitative Part of the Study	16
3.2 Information about the participants	16
3.3 HIV Testing/Diagnosis	24
3.4 Disclosure and Confidentiality	27
3.5 Experience of Stigma and Discrimination from Other People	31
3.6 Access to Work, Health and Education Services	33
3.7 Internal Stigma (The Way You Feel about Yourself) and Your Fears	34
3.8 Rights, Laws and Policies	38
3.9 Effecting Change	39
3.10 Treatment	41
3.11 Having Children	42
3.12 Problems and Challenges	43
Part II- Results from the Qualitative Phase	44
3.13 Profiles of Participants for the Qualitative Phase	44
3.14 Misconceptions and lack of information	45
3.15 Previous knowledge about HIV/AIDS	46
3.16 No previous knowledge about HIV/AIDS	48
3.17 Discrimination faced	49
3.18 Discrimination from health care givers	51
3.19 Self-stigma	52

3.20	Gender discrimination	53
3.21	Health and mental well being of PLHIV due to stigma and discrimination	55
Chapter 4 - Summary of Findings and Discussion		57
Chapter 5 –Recommendation		60
	Limitations	62
	References	62

Acronyms

AAS	Ashar Alo Society
AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti Retro Viral
CAAP	Confidential Approach to AIDS Prevention
CCDB	Christian Commission for Development in Bangladesh
FPAB	Family Planning Association of Bangladesh
GHF	GEON Health Foundation
HIV	Human Immunodeficiency Virus
ICDDR, B	International Centre for Diarrhoeal Diseases Research, Bangladesh
IDU	Injecting Drug User
IPPF	International Planned Parenthood Federation
JPGSPH	James P Grant School of Public Health
MAB	Mukto Akash Bangladesh
MTCT	Mother to child transmission
NGO	Non Governmental Organization
PLHIV	People Living with HIV
UNAIDS	The Joint United Nations Programme on HIV/AIDS
YWCA	Young Women Christian Association

Acknowledgements

The study “**People living with HIV Stigma Index**” in Bangladesh is an outcome of dedicated work of a large team of people. It is an outcome of collaboration among Ashar Alo Society (AAS), Family Planning Association of Bangladesh (FPAB), James P Grant School of Public Health, BRAC University and UNAIDS Bangladesh. The study got financial support from the International Planned Parenthood Federation (IPPF), The International Community of Women living with HIV/AIDS (ICW), The Global Network of People living with HIV/AIDS (GNP+), and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

We would like to express our deepest gratitude to everyone who assists us in the study, especially the members and staff of AAS, MAB, CAAP, GEON health foundation who gave us continuous support during the entire study period.

Field Research Team Conducting Stigma Index (names listed alphabetically)

Albart Diponkor Biswas, National University

Anil Mallick, AAS

Anwar Parvez, Jahangirnagar University

Dewan Md. Abdus Shafi Azad, University of Rajshahi

Farjana Sharmin Luna, Jahangirnagar University

Jumka Rani, AAS

Kaniz Fatima Tuly, GEON

Khurshedul Alam, AAS

Mahmudul Hasan, Jahangirnagar University

Md. Jahid Ali, University of Rajshahi

Md. Shamiul Alam, University of Rajshahi

Mr. Kajol Kanti Das, MAB

Nahid Fatima, Jahangirnagar University

Nupur Costa, CAAP

Panna Akter, AAS

Sabrina Darain, Jahangirnagar University

Samima Ferthous, University of Rajshahi

Sherine Akter, AAS

Syed Humaun Kabir, GEON

Tony Rodregaz, MAB

Zillur Rahman, MAB

** With Research Managed and Supervised by James P Grant School of Public Health, BRAC University*

Technical Support

UNAIDS

Dan Odallo, Country Coordinator, UNAIDS, Bangladesh

Mr. Tony Michael Gomes, National Consultants, UNAIDS, Bangladesh

FPAB

Dr. Tahmina Mirza
Director AIDS, Family Planning Association of Bangladesh.

James P Grant School of Public Health

Sabina Faiz Rashid, Associate Professor, James P Grant School of Public Health

BRAC

Samir Ranjan Nath, Research Coordinator, Research and Evaluation Division, BRAC

Implementing Agencies

Ashar Alo Society

Habiba Akter, Executive Director, AAS
Md Tauhidul Islam, Project Coordinator, AAS
Sanwar Hossain, Project Coordinator, AAS
Ruhul Rahman, Coordinator- Stigma Index Study, AAS

Mukta Akash Bangladesh

Ms. Mukti, Executive Director, MAB
Saidur Rahman Matabber, Project coordinator, MAB
Md. Razu Ahmed, Peer Counselor
Mrs. Salma Sultana, Office Assistant

CAAP

Dr. Halida Hanum Khandaker, Executive Director, CAAP
Dr. A.S.A Masud, Director Program, CAAP
Suriya Islam, Adherence Counselor, CAAP

GEON Health Foundation

Md. Humayan Kabir, Executive Director, GHF
Kaniz Fatima, Chairperson, GHF

IPPF

Lucy Stackpool Moore, HIV officer, IPPF, London
Aroshi Singh, Program Manager, IPPF, India

Research, Data Analysis and Writing Team:

Tanvir Hasan, Senior Research Assistant, The James P Grant School of Public Health
Nabilah Khan, Research Staff, The James P Grant School of Public Health
Owasim Akram, Research Associate, The James P Grant School of Public Health
Ilias Mahmud, Lecturer, The James P Grant School of Public Health
Elisabeth Lee, visiting intern, The James P Grant School of Public Health
Sabina Faiz Rashid, Associate Professor, The James P Grant School of Public Health
Samir Ranjan Nath, Research Coordinator, Research and Evaluation Division, BRAC

Executive Summary

This report focuses on stigma and discrimination against people living with HIV/AIDS (PLHIV) in Bangladesh. The main aim of the study was to identify actions needed to address HIV related stigma and discrimination. The results of this report will be useful for the government, NGOs, and those working to provide support to HIV positive people; community based organizations and for people living with HIV for any future planning and advocacy to reduce the stigma and discrimination linked to HIV in Bangladesh.

Stigma and discrimination against people living with HIV/AIDS is a pre-existing problem in Bangladesh which continues to inhibit both the physical and mental well-being of those carrying the human immunodeficiency virus. Stigma also deters the strategies intended to prevent the AIDS epidemic from breaking out in Bangladesh. Discrimination against PLHIV has many long term effects, as shown by previous research, it delays HIV testing, restrict adoption of preventative programs, and deter the adoption of preventative behaviors like condom use and HIV status disclosure.

The study employed Quantitative and Qualitative methods, with the quantitative component conducted using a Stigma Index questionnaire (developed by the IPPF, ICW, GNP+ and UNAIDS International Partnership). A total of 238 HIV positive persons were randomly interviewed in the country. The sample size was calculated using the Epi Info software package, as instructed in the user guideline of “The People Living with HIV Stigma Index”. The quantitative survey of the study was conducted in four divisional cities namely Dhaka, Chittagong, Sylhet and Khulna. Each interview was conducted by a PLHIV and an anthropologist. Two key research team members from James P Grant School of Public Health (JPGSPH) continuously worked with the data collectors to ensure quality control during the data collection process in the field. The qualitative component interviews were done with 30 selected HIV positive persons for further detailed discussions on their experiences of stigma and discrimination. In choosing participants for in-depth interview two criteria were used- recommendations from the field data collectors during the quantitative survey and by identifying profiles of underrepresented PLHIV group. Profiles of PLHIV selected for the qualitative phase included Sex workers, Sex worker who is IDU, migrant workers, HIV positive people with HIV+ children, IDUs, prisoners, Unmarried HIV+, Hijra (Transgender) and a HIV positive widow woman etc.

A majority of the 238 participants of this study faced discrimination on revealing their HIV status from their families, friends, communities, colleagues or at health care settings. Some have faced stigma and discrimination from almost everyone in their lives, while others have both been supported and discriminated against by different people in their lives. Some participants chose not to disclose their HIV status to anyone except their HIV peer counselors, in fear of being discriminated against.

Many of the PLHIV were discriminated during HIV testing/diagnosis by the health care providers (doctors, nurses, laboratory technicians etc.). Many of the PLHIV faced discrimination when receiving treatment from government hospitals, local clinics, or from health care providers and as a result some of the respondents (16.8%) decided not to go to a hospital when they needed to do so. A majority of the respondents (84.9%) also decided not to have more children because of their uncertain future. Many of them felt discriminated against when looking for employment, while some of them experienced discrimination from their work colleagues or supervisors and consequently lost their work.

Findings also reveal that the PLHIV suffer from internal stigma. It was found that more than half of the PLHIV blamed themselves for their HIV status while many of them felt suicidal. Because of internal stigma more than three fourths have decided not to get married and remain afraid that someone would not want to be sexually intimate with him/her after knowing their HIV status.

The study also reveals that female PLHIV got more HIV test counseling than male PLHIV and majority of them got both pre and post HIV test counseling; this might be because most of the female PLHIV belong to the mainstream population and got their HIV from their husbands. Unequal gender and power relations, along with higher unemployment rates for females (64%) than for males (19.1%), and poorer educational status for females compared to males, left them much more vulnerable.

More than half of the PLHIV gave support (emotional support like counseling, financial support like providing money or food etc.) to other people living with HIV which they found very important for mental and physical well-being. The main reasons behind stigma and discrimination of PLHIV seemed to be misconception of AIDS as a contagious disease, and the negative connotation attached to the method of transmission of HIV with sexual promiscuity seen as the main cause. Respondents were isolated by their families and friends, excluded from community or religious functions, faced problems getting their children admitted to schools and many other forms of discrimination on revealing their HIV positive status.

Almost 75% of the PLHIV recommended that the most important issue that needs to be addressed by the organizations working with PLHIV and the government is to raise awareness and knowledge of the general people about AIDS and to remove stigma and prejudices which are deeply embedded in society. Recommendations included starting mass campaigns on basic information about HIV/AIDS to reduce the stigma attached to this virus and the AIDS disease. According to the HIV positive people interviewed, the short television advertisements on HIV/AIDS being aired at present generated more confusion and discrimination rather than reducing it. Advertisements portraying HIV as a fatal condition created the impression that being infected by HIV can only mean immediate death. If mass media could be used to impart facts about how to protect one, and if infected, how to continue living positively, it would reduce the fear in people's minds and go a long way towards encouraging people to provide physical and mental support to PLHIV rather than discriminating against them.

List of Tables

	Name of the table	Page Number
Table -2.1	District wise participant location for qualitative phase	14
Table-3.2.1	Age distribution of PLHIV	16
Table-3.2.2	Educational status	20
Table-3.2.3	Occupational status	22
Table-3.2.4	Income status of the PLHIV's family with respect to family size	23

List of Figures

	Name of the figure	Page Number
Figure-3.2.1	Age and Sexual status for the PLHIV's	17
Figure-3.2.2	Living with HIV in years-Male vs. Female	18
Figure-3.2.3	Current relationship status	19
Figure-3.2.4	Disability status	20
Figure-3.2.5	Educational status of the PLHIV-Male vs. Female	21
Figure-3.2.6	Occupational status of the PLHIV-Male vs. Female	23
Figure-3.2.7	Geographical distribution of PLHIV-Urban vs Rural	24
Figure-3.3.1	Reasons for HIV testing among all participants	25
Figure-3.3.2	Decision for HIV testing-Male vs. Female	26
Figure-3.3.3	Why a woman was tested for HIV vs whether they received counseling	26
Figure-3.3.4	Why a man was tested for HIV vs whether they received counseling	27
Figure-3.4.1	Discrimination experienced by PLHIV from specific people – Male vs Female	28
Figure-3.4.2	Discrimination experienced by PLHIV from health care givers regarding privacy problem	30
Figure-3.5.1	Discriminatory behaviour faced by the PLHIV because of his/her HIV status	31
Figure-3.5.2	Discriminatory behavior faced by the PLHIV according to gender because of his/her HIV status	32
Figure-3.6	Change of residence/change of employment	34
Figure-3.7.1	Feelings of the PLHIV because of his/her HIV status	35
Figure-3.7.2	Perception of internal stigma	36
Figure-3.7.3	Event happens to the PLHIV because of their HIV status	37
Figure-3.8	Discrimination faced by PLHIV in relation to rights, laws and policies	39
Figure-3.9	Effecting change	40
Figure-3.10	Present health status of PLHIV	41
Figure -3.13	Profile of study participants for the qualitative phase	45
Figure -3.16	Knowledge of HIV/AIDS among the qualitative participants	48

Chapter I

Introduction

Bangladesh is in the nascent stage of its HIV/AIDS epidemic, as the most recent data indicate an estimated 7,500 persons living with HIV nationwide.ⁱ In total, 1,207 cases of HIV have been identified since the first case in 1989.ⁱⁱ Prevalence estimates suggest that HIV/AIDS remains at less than 1% amongst most at-risk populations.ⁱⁱⁱ

While the vast majority of documented HIV/AIDS cases in Bangladesh are the result of heterosexual intercourse, transmission modes also include intravenous drug use (IDU), mother to child transmission (MTCT), blood transfusion, and male to male intercourse; Populations at greatest risk include sex workers, migrant workers, and IDU, as well as their family members.^{iv} Surveillance of urban IDU in Dhaka City found HIV prevalence increased to 7% by 2006 from 1.4% six years prior,^v effectively creating an epicenter for the epidemic.

Research conducted by International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B) has underscored a number of problematic areas for persons living with HIV (PLHIV), in particular the need to address societal stigma and subsequent discrimination directed at two groups: PLHIV and their health care providers.^{vi} This study advances prior research with an attempt to document stigma and discrimination both quantitatively using the Stigma Index and qualitatively using focused, in-depth interviews experienced by the PLHIV in Bangladesh. The Stigma Index is a partnership initiative between UK Department for International Development, the International Planned Parenthood Federation (IPPF) in partnership with UNAIDS, the Global Network of People Living with HIV (GNP+) and the International Community of Women living with HIV (ICW) to develop an instrument that will be used worldwide to measure the stigma experienced by people living with HIV. This index is first of its kind to be conducted in Bangladesh. The “People Living with Stigma Index” is a project developed and implemented by and for the people living with HIV. The aims of the project are to collect information about the

experiences of people living with HIV related to stigma, discrimination and their right. The information that will gather after implementing the project will be useful in a number of ways- It allows us to document the various experiences of stigma and discrimination faced by the PLHIV in relation to their HIV status within a particular community or country. It will be helpful in comparing the situation of HIV/AIDS related stigma across different countries, to measure changes of the situation on stigma, discrimination and rights of the people living with HIV/AIDS over a period of time. It will also be helpful to provide an evidence base for policy change and programmatic intervention.

This research is a part of multi country study which focuses on stigma and discrimination faced by the PLHIV from the community. The expected benefit of the research is manifold – It will give a present picture of stigma and discrimination linked to HIV in Bangladesh, It will help identifying the barriers to reduce stigma and discrimination exist in the society, It will also explore future needs to reduce stigma and discrimination which will ultimately benefit the HIV infected community in Bangladesh. The findings will have important implications for developing effective HIV/AIDS prevention programs and message for Bangladesh, as well as ensuring PLHIV access to testing and care without discriminatory barriers.

The report is outlined in the following way: This chapter provides a definition of HIV/AIDS Stigma and Discrimination and reviews the literature on stigma and discrimination linking with HIV/AIDS. The second chapter discusses methodology. The third chapter presents the core findings, which consist of two parts; the first part focuses on results from the Stigma Index survey and the second part on the qualitative findings from focused in-depth interviews. Chapter 4 includes the summary and conclusion and is followed by recommendations

1.1 Definition: HIV/AIDS Stigma and Discrimination

HIV/AIDS related stigma and discrimination has been widely demonstrated worldwide.^{vii}
^{viii, ix} Goffman (1963) defined stigma as “...a powerful social label, stemming from a

discrediting attribute of the individual which radically changes their social identity.” He notes discrimination is a way “through which we effectively, if often unthinkingly, reduce [...] life chances...”^x In the context of HIV/AIDS, UNAIDS has defined HIV/AIDS related stigma and discrimination as “a ‘process of devaluation’ of people either living with or associated with HIV and AIDS. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Stigma and discrimination breach fundamental human rights and can occur at a number of different levels including: political, economic, social, psychological and institutional.”^{xi} HIV is a catalyst for inherently harmful social labeling followed by discriminatory practices which may create a multitude of obstacles for PLHIV in life and in health care services.

HIV/AIDS stigma and discrimination are addressed by this study in the following specific divisions: self-stigma, guilt by association, and personal stigma. Self-stigma may be understood as the negative perceptions a PLHIV has of his or herself as a result of HIV+ status. Self-stigma can significantly impact quality of life for PLHIV, for example, by causing withdrawal from society. Other considerations include what Powell-Cope and Brown termed ‘guilt by association’^{xii}, or discrimination impacting any acquaintance of the PLWHA, as well as the discrimination directed at the PLWHA him/herself, or ‘personal stigma.’^{xiii}

1.2 A Review of Relevant Research

Stigma and discrimination linked to HIV and AIDS became a major issue of discussion in the first few years of the 21st century. De Bryun (1998) made a discussion paper on HIV/AIDS and Discrimination.^{xiv} Ken Morrison (2006) produced a paper focusing on understanding HIV related stigma and discrimination relating vulnerability, behavior and suggest approaches for stigma reduction^{xv}. An extensive review on internal stigma was described by Pierre Brouard (2006).^{xvi} A report prepared by Laura Nyblade and Kerry Macquarrie (2006) suggested ways to begin the process of quantitatively measuring HIV related stigma; much of the data presented in this report were based on the findings from

a study in Tanzania that tested a number of potential quantitative measures for stigma.^{xvii} Visser et al. (2008) developed three parallel scales to measure HIV related stigma. These three scales were developed to assess personal views of stigma, stigma attributed to others, and internalized stigma experienced by HIV- infected individuals. The stigma scales were administered in two samples; a community sample and a sample of HIV infected women from the same community. A two factor structure referring to moral judgment and interpersonal distancing was confirmed across scales and sample groups. The internal consistency of the scales is acceptable and evidence of validity is reported.^{xviii}

International HIV/AIDS research also largely focused on structural, institutional, and environmental patterns of discrimination, particularly with regard to health care settings. Parker, Easton & Klein (2000) ascertained that structural and environmental conditions can act as barriers or facilitators to HIV prevention programs, calling for interventions to achieve broader social and structural change.^{xix} Through an integrative six country study in Asia, Reidpath and Chan (2005) found structural constraints in health care institutions can encourage discrimination against PLHIV.^{xx, xxi} For example, in India, China and Vietnam, pre-surgery routine HIV/AIDS testing results in PLHIV being operated on last after all other patients. Qualitative interviews revealed that in the absence of proper sterilization supplies, surgeons are not discriminating against PLHIV, but rather are protecting other patients from bloodborne pathogens by operating on PLHIV last.^{xxii}

While a dearth of discrimination research specific to South Asian countries of low HIV/AIDS prevalence exists, relevant data are available for India where 90% of South Asian PLHIV are located.^{xxiii} By comparison, the neighboring countries of Bangladesh, Nepal, Pakistan, Sri Lanka, Bhutan and the Maldives are still in the early stages of their epidemics.^{xxiv} Here, examination of Indian literature on HIV/AIDS discrimination may reveal comparable attitudes and practices towards HIV/AIDS relevant to Bangladesh.

Like most attempts to evaluate discrimination of PLHIV, Indian efforts have focused on structural and institutional examples and have generally not incorporated self-stigma by

PLHIV and/or 'guilt by association.' The majority of research examines discrimination faced by PLHIV in health care institutions. Mahendra et al. (2007) found that health care workers discriminated HIV positive patients by "testing patients for HIV without their consent, disclosing test results to relatives and other health care workers without the consent of patients, labeling of HIV-infected patients' belongings or files, and unwarranted use of precautions to prevent transmission."^{xxv} In many instances, discrimination was a product of institutional constraints; for example, supply shortages. However, further analysis uncovered stigma among health care workers towards PLHIV stemming from misconceptions about HIV susceptibility and patients' class, occupation, or behavioral practices.^{xxvi}

In a study conducted in Kerala, India which looked at existing legislature and actual health care setting practices, J. Elamon (2005) revealed discrimination against PLHIV was manifested in several ways. Refusal to treat based on positive status, different and negative treatment due to positive status, refusal to deliver results of HIV testing, and failure to maintain patient confidentiality were observed, all due to lack of clarity in or enforcement of legislature and internal policies.^{xxvii} Thus, structural and institutional constraints in the health care setting may help to facilitate transformation of stigma into discriminatory practices by health care workers.

Green, Devi, & Paulraj (2007) examined caretaker visits to married PLHIV while admitted in hospitals in India. The researchers developed a simple tool on the basis of relationship and familial distance of caretakers to PLHIV in order to assess stigma and discrimination in the care giving dyad. They assert that the relationship of family members to PLHIV who are absent during hospital admission and stay is a robust measurement of stigma felt by the caretaker, as well as a measure of discrimination against the PLHIV.^{xxviii}

Other environmental constraints which have been explored in India include generalized class discriminations against PLHIV. Kaulagekar and Godbole (2007) examined stigma among the urban Maharashtra middle class, finding that considerable stigma was

elicited in hypothetical situations posed to participants in four areas: attribution of blame, violation of rights, stigma in interaction, and stigma at the workplace.^{xxxix} In a letter to the editor, N. Paul (2006) called for mass education, proper legislation, and continuing medical education in order to combat discrimination, citing India's educated elite as its perpetrators rather than the oft-blamed uneducated and lower classes.^{xxx} These examples illustrate the challenges of tackling HIV/AIDS discrimination at all levels of Indian society.

Bangladesh

The scope of HIV/AIDS stigma and discrimination research in Bangladesh has so far been limited to two notable studies. An HIV/AIDS knowledge and attitudes survey of ICDDR,B staff found 41% of those surveyed believed that PLHIV should not be allowed to work while another 10% declined to answer, prompting a call for increased education and sensitization in employees commonly interacting with PLHIV.^{xxxi} A knowledge, attitude, belief and practice (KABP) study of HIV/AIDS in Bangladeshi overseas workers (1997) found that 29% of workers would not want to continue living with an HIV positive family member, 17% felt PLHIV should not receive health services like other patients, and 95% would not want to work with a PLHIV.^{xxxii}

Prior to these two studies, there have been no in-depth reviews of stigma and discrimination from the perspectives and experiences of PLHIV in Bangladesh. Analysis of real life examples of discrimination are necessary for understanding hardships faced by PLHIV in Bangladesh, which in turn may create barriers to testing and treatment. Proper care for PLHIV includes education about the disease, which may prevent further transmission. Thus, learning about how to prevent and limit HIV/AIDS stigma and discrimination in all facets of PLHIV life through studies such as this have significant implications for the course of HIV/AIDS epidemic in Bangladesh.

Chapter 2

Methodology

2.1 Introduction: This study employed a mixed method approach. In the first part of the study we conducted a quantitative survey following the questionnaire developed by IPPF, ICW, GNP+ and UNAIDS International Partnership. In the second part, in-depth interviews with selected HIV positive persons were conducted to ascertain details of their experiences of stigma and discrimination. In choosing participants for in-depth interviews two criteria were used - recommendations from the field data collectors during the quantitative survey and by identifying profiles of underrepresented PLHIV. The main aim of this section is to describe the methodological issues in detail.

2.2 Methodology for the Quantitative Part of the Study

The objective of the study was to conduct the Stigma Index survey on a random representative sample of people living with HIV in the country. The sample size was calculated based on a recent study by ICDDR, B (Estimating numbers of those most affected by HIV/AIDS in different locations to support efficient service delivery. Capacity building and community mobilization, ICDDR, B., June, 2008) which found that the total number of PLHIV who were alive in the year 2008 to be 736. Thus the total population size was 736. In reality, from the population only 405 HIV positive persons were accessible for interviews according to the partner organizations - Ashar Alo Society, Confidential Approach to AIDS Prevention, GEON Health Foundation and Mukto Akash Bangladesh, - that regularly provided services to registered PLHIV members. The reason for the smaller number being that some of the PLHIV were not traceable or only visited the organization once as year and it would be difficult to find them for interviews; some had not disclosed their identity by registering as members of these organizations; there may be some duplication of numbers with PLHIV registering more than once in different organizations for support and some may have died since the last survey was conducted by ICDDR, B.

Partnership

The Stigma Index is the creation of the collaborative effort of IPPF, ICW, GNP+ and UNAIDS International Partnership. This partnership has come up with a comprehensive tool with focused outcomes ensured the total involvement and empowerment of PLHIVs. Stigma Index was successfully piloted and tested in London under the supervision of this International partnership. To replicate for creating success stories in Asia this partnership has successively organized skill building training at Nepal for country level rollout. Bangladesh UNAIDS country office mobilized the local level partners having capacity and technical expertise on HIV and Reproductive health has come under a country partnership which has been led by AAS for field level implementation. AAS, UNAIDS, FPAB/IPPF and James P Grant School of Public Health, BRAC University has played specific roles and responsibilities to conduct the Stigma Index Bangladesh country rollout effectively as guided by the international partnership.

International Partner Organizations
International Planned Parenthood federation, 1952
IPPF is a global service provider and a leading advocate of sexual and reproductive health and rights for all. It works in over 150 countries - providing and campaigning for sexual and reproductive health care and rights.
The International Community of Women Living with HIV/AIDS (ICW), 1992
The International Community of Women Living with HIV/AIDS (ICW), a registered UK charity, is the only international network run for and by HIV positive women.
, 1986
The Global Network of People living with HIV (GNP+) is a global network for and by people living with HIV. GNP+ advocates to improve the quality of life of people living with HIV.
UNAIDS, 1994
UNAIDS, the Joint United Nations Programme on HIV/AIDS, is an innovative joint venture of the United Nations family, bringing together the efforts and resources of ten

UN system organizations in the AIDS response to help the world prevent new HIV infections, care for people living with HIV, and mitigate the impact of the epidemic.

National Partner Organizations

Family Planning Association of Bangladesh, 1953

As an affiliate of **International Planned Parenthood Federation (IPPF)**, FPAB is the oldest and largest family planning non-government organization in Bangladesh, which pioneered family planning movement in the country. FPAB aims to improve the quality of lives of individuals, by campaigning for sexual health and reproductive right through advocacy and services, especially for poor and vulnerable people.

James P Grant School of Public Health, BRAC University

The James P Grant School of Public Health at BRAC University was established in February 2005. It is the Centre for Gender Sexuality and HIV/AIDS in Bangladesh. The school is running multiple researches in the field of sexual and reproductive health, nutrition, HIV/AIDS related issues, health equity, environment, gender and related fields.

Partner Organizations from the PLHIV Network

Ashar Alo Society (AAS), 2000

AAS is a non governmental organization working for rights, care, empowerment and greater involvement of people living with or affected by HIV/AIDS in Bangladesh. AAS has offices in Dhaka, Chittagong, Khulna Rajshahi and Sylhet.

Mukto Akash Bangladesh (MAB), 2003

MAB is a HIV/AIDS prevention, care and treatment centre run exclusively by people living with HIV/AIDS in Bangladesh. MAB has been functioning in Dhaka since the year 2003.

Confidential Approach to AIDS Prevention (CAAP), 1996

CAAP is a care, treatment and support providing organization, based in Dhaka, providing HIV/AIDS information and carrying out counseling, care, treatment and support to people living with HIV and AIDS.

GEON Health Foundation, 2007

GEON is a national HIV/AIDS organization that works in Khulna to provide peer support and care to people living with HIV and AIDS in Bangladesh.

The sample size was calculated using the Epi info software package, as instructed in the guideline of “The People Living with Stigma Index”. For the quantitative component, a sample size of 252 participants was considered a significant number for a population size of 736. However during the sampling, 278 participants were randomly selected i.e. 10 percent more for size estimate incase of drop-outs, duplication, etc. The PLHIV participants list containing name and details of the PLHIV provided by four partner’s organizations (Ashar Alo Society, Confidential Approach to AIDS Prevention, GEON Health Foundation and Mukto Akash Bangladesh) was used for drawing sample. Using the PLHIV participant list a random representative sample of size 278 was drawn. Ultimately, a survey of 238 respondents was carried out in spite of having 10 % additional in hand. This is because among 278 expected respondents 20 were identified as duplicated cases, 3 of them died and the rest of them did not want to participate in the survey or were not available. However these 238 PLHIV participants well represent the overall demographics of the PLHIV in Bangladesh. Since a random representative sample was used the participants interviewed were from different demographic areas, they were from different ethnicity, or from different religion etc. The study by ICDDR,B (Estimating numbers of those most affected by HIV/AIDS in different locations to support efficient service delivery. Capacity building and community mobilization, ICDDR, B., June, 2008) found that the prevalence of HIV/AIDS is higher in three divisions – Dhaka (35.5%), Chittagong (23.7%) and Sylhet (22.4). The prevalence rate is comparatively low in Khulna division (4.3%) and is followed by Rajshahi division (1.8%) and Barisal disvision (0.7%). In this study, we have covered 140 interview based in Dhaka which is 59% of the total interview and included the participants from three different division (Dhaka, Barisal, Rajshai), 53 interview were conducted in sylhet division which is 22% of the total interview and included the participants from Sylhet, while 45 interview were conducted in Khulna and Chittagong division and is 19% of the total sample (n=238).

A team of 10 anthropologists and 10 PLHIV persons were trained extensively in two phases for the study. The Stigma Index which is a structured questionnaire developed by International Partnership was translated into the native language (Bangla) keeping the original sense and meaning of the English version and the research team reviewed the index to become familiar with the questions.

Following the user guidelines of “The people living with HIV Stigma Index”, all the respondents of the study were 16 years of age or above and/or had no mental disability that impaired their ability to give real, informed consents (user guide, page.11). Prior to the data collection written and verbal consent was taken from all participants. At the very beginning of each interview, the interviewer read out the consent form in Bengali that informed the participant of the intentions and nature of the interview. No personal details were collected from the interviewee.. Only a list of code numbers that were generated through random sampling were provided to the concerned organizations - Ashar Alo Society, Confidential Approach to Aids Prevention, GEON Health Foundation and Mukto Akash Bangladesh - to identify and invite the respondents to take part in the survey. All the interviews took place at four different organizations that work with PLHIV – Ashar Alo Society (AAS), Confidential Approach to AIDS Prevention (CAAP), Geon Health Foundation (GEON) and Mukto Akash Bangladesh (MAB). Great care was taken to ensure confidentiality and privacy at all times. All data and information collected were kept in a locked cabinet and only accessible to the researchers.

The researchers came across many challenges, while collecting the information from the participants. One of the major challenge was to document events related to HIV/AIDS stigma and discrimination as participants willingness to disclose their events varied from individuals to individuals; the PLHIV data collectors plays a major role in this case by disclosing their HIV status to the interviewee at the beginning of each interview. Every data collector team consist of 1 PLHIV and 1 Anthropologist. At the beginning of the research some of the anthropologist data collectors were feared to work in a team with the PLHIV data collectors but after three incentive training they overcome the problem and successfully participated in the data collection process.

As there is a higher chance of not sharing the events happens to the PLHIV because of their HIV status, the research team members were trained as how to develop a

relationship with the interviewee and how to collect information regarding HIV/AIDS related stigma and discrimination. Many of the anthropologist data collectors have no idea on HIV/AIDS and for many of them this was the first time they were doing research on HIV related issue. As a result, at the beginning they have some misconception on HIV/AIDS but the three intensive training help them to overcome the misconceptions on HIV/AIDS related issue. Another major challenge was to ensure the confidentiality of data. The key research team leaders of the JPGSPH worked hard to keep the records confidential throughout the research process.

Since the aim of the research is to document HIV/AIDS related stigma and discrimination and explore ideas on how to reduce stigma and discrimination linked to HIV/AIDS it is important to share the findings of this research to the PLHIV, their support group, community based organization and the general people. For that purpose a national report dissemination plan will be undertake to share the findings. The English report will also translate in local language Bangla so that the general people can easily understand and catch the clear message of the research findings. The four PLHIV network organizations (Ashar Alo Society, Confidential Approach for AIDS Prevention, GEON Health Foundation and Mukto Akash Bangladesh) will share the findings with their network members in the divisional cities. AAS will play a major role to develop and distribute communication and Advocacy material for local level interventions. Folk and Local media will be another approach to reach rural level awareness campaign based on the key findings.

2.2.1 Training of the data collectors

10 pair of data collectors was trained to conduct the survey. Each pair consisted of 1 PLHIV and 1 Anthropologist. The 11 peer PLHIV data collectors (out of 21) are members of four PLHIV organizations and were selected by partner organizations (Ashar Alo Society, Confidential Approach for AIDS Prevention, GEON Health Foundation and Mukto Akash Bangladesh). James P Grant School of Public Health hired 10 anthropologists to help the PLHIV during the interview. Three intensive trainings were conducted throughout the process. The first and second training focused on the quantitative phase of the study and covered interview techniques, preliminary

understanding of the aim of the survey, basics on HIV and HIV related stigma and discrimination, mock interviews and role plays, and pre-testing of the questionnaires etc. The first training was held at the YWCA auditorium, Dhaka in August, 2008. The second training was held at James P Grant School of Public Health from 14th October, 2008 to 18th October, 2008. Both training programs were facilitated by FPAB, JPGSPH and UNAIDS with support from all the organizations who involved their PLHIV and non PLHIV staff. The third training focused on the second, qualitative phase of the study. The most efficient interviewers and data collectors (6 pair out of 10) from the quantitative phase were chosen for this training to learn to conduct further in-depth interviews.

2.2.2 Data Collection

The quantitative survey of the study was conducted from the 28th Oct, 2008 to 12th Nov, 2008 in four divisional cities namely Dhaka, Chittagong, Sylhet and Khulna. Each interview was conducted by a pair of interviewers (one PLHIV and one anthropologist). Two key research team members from JPGSPH worked continuously with the data collectors to ensure quality control during the data collection process. The qualitative survey of the study was conducted from the 24th Nov, 2008 to 1st Dec, 2008. We covered 30 interviews in this phase. Profiles of PLHIV selected for the qualitative phase included sex workers, sex workers who are IDU, migrant workers, HIV positive people with HIV+ children, IDUs, prisoners, unmarried HIV+, Hijra (Transgender) etc.

2.2.3 Quality Control

The quality control included two steps (1) cross-checking answers between each pair of data collectors (1 PLHIV and 1 Anthropologist) immediately following each interview and (2) Following each interview two key research team members from JPGSPH reviewed answers to ensure consistency.

2.2.4 Data Analysis

Epi-Info version 3.5.1, a computer software package was used for data entry and analysis for the quantitative part of the study. Qualitative phase results were obtained manually.

2.3 Methodology for the Qualitative Part of the Study

The qualitative study was conducted from November 24th to December 1st in several locations around Dhaka City. A qualitative interview method was used with questions that were guided yet broad-ranging to minimally direct both the data collector and the respondent in identifying and sharing in-depth experiences of stigma and discrimination. After explaining the interview topic and process, the participants were asked to sign informed consents. Lastly, after further discussion and consent of the participants, 25 of the 30 total in-depth interviews were recorded.

As this qualitative study is the second phase of the Stigma Index, the qualitative study participants were derived from the same sample population as the quantitative study. The qualitative respondents were selected through purposive sampling. Participants were recruited through purposive sampling in two ways (1) through recommendations from field data collectors, and (2) by identifying profiles of underrepresented PLHIV groups. During the quantitative data collection of the stigma and discrimination study, respondents were selected through random sampling- field data collectors were trained to identify respondents who may have experienced greater stigma and discrimination, and had shown a willingness to share their experiences for research purposes. Participants were further selected by assessing the profiles of the randomly selected respondents of the Stigma Index quantitative study, identifying the underrepresented groups of PLHIV. Of the 30 respondents, 5 were outside the quantitative survey population and among them 1 did not belong to the HIV positive peer-support groups' network. However, this one was selected from a group considered to be in high risk of becoming infected with HIV. The rest of the participants were recruited by HIV counselors at AAS, CAAP, GEON, and MAB. The respondents of the study traveled to Dhaka for the in-depth interviews from various districts of Bangladesh.

Table 2.1: District wise participant location for qualitative phase

Location	No. of Participants
Dhaka	11
Sylhet	5
Chittagong	2

Narayanganj	2
Savar	1
Ashulia	1
Gazipur	1
Jatrabari	1
Madaripur	1
Khulna	1
Rajshahi	1
Tangail	1
Netrokona	1
Munshiganj	1

Each in-depth interview was conducted by one interviewer and one anthropologist data collector. Except for one respondents, the interviewees were all people living with HIV, who were both comfortable revealing their statuses and who also belonged to the HIV positive peer-support groups' network in Bangladesh, as per International Partnership guidelines for the stigma index (Stigma Index guideline, page.7). Revealing the statuses of the interviewers provided a supportive environment for the respondents, and helped to create a safe environment in which the respondents felt comfortable openly discussing their experiences of stigma and discrimination. The supporting data collectors were all anthropologists who were further trained to collect qualitative data after their training and collection of quantitative data for the stigma index. After selecting the most efficient interviewers and data collectors from the quantitative study, these six pairs went through a day-long further intense training on qualitative data collection methods. During both the qualitative and quantitative trainings, each pair of interviewer and data collector were additionally taught how to support one another throughout the interview process and given instructions on dealing and referring emotionally distraught respondents to HIV counselors.

All interviews were conducted in local, Bengali language with questions taken from a Bengali questionnaire being asked by an interviewer while the data collector took notes of interviewees' responses. At the very beginning of each interview, the interviewer read

out the consent form in Bengali informing the participant of the intentions and nature of the interview. The consent form also specified that the participant could choose not answer any question and could also ask to end the interview at any time. If the interviewee understood all parts of the consent form, they were asked to give either their verbal or written consent to start the interview. The interviewer and interviewee signed the consent form except when the participant gave only verbal consent. Then the interviewer alone signed the form. A further consent was needed to use tape recorders at each of the 30 interviews. Only 5 respondents chose to not allow their interviews to be recorded, the rest 25 interviews were recorded and later transcribed.

Chapter 3

Findings

3.1 Introduction

This chapter first presents the data obtained through the Stigma Index survey and consists of mainly quantitative findings. The part I (findings from the quantitative part) provides information on respondents' profile and is followed by the type and extent of stigma and discrimination faced by the PLHIV in different areas (e.g. in HIV testing /diagnosis, disclosure and confidentiality, experience of stigma and discrimination from other people, media, access to work, health and education services, internal stigma and fears among the PLHIV, their health condition, access of treatment facility etc.). The part II includes the results from the qualitative part of the study

Part I - Stigma Index: Findings of the Quantitative Part of the Study

3.2 INFORMATION ABOUT THE PARTICIPANTS

The total number of PLHIV who participated in this study was 238. Out of 238 PLHIV, 152 were male (about 64%) and the rest (36%) were female. Most of the PLHIV (110 out of 238) were from the age group 30-39 years. Table 3.2.1 presents the age distribution of the PLHIV

Table 3.2.1: Age distribution of PLHIV

Age of the Respondents	Frequency	Percentage (%)
Age 15-19	1	0.4
Age 20-24	17	7.1
Age 25-29	38	16.0
Age 30-39	110	46.2
Age 40-49	58	24.4
Age 50+	14	5.9
Total	238	100.0

50% of males were from the 30-39 years age group and 38.7% of females were from this age group. (see Fig.3.2.1). The proportion of female PLHIV was higher for the age group 20-24 years and 25-29 years than male PLHIV. Only 1 PLHIV was from the age group 15-19 and was a female.

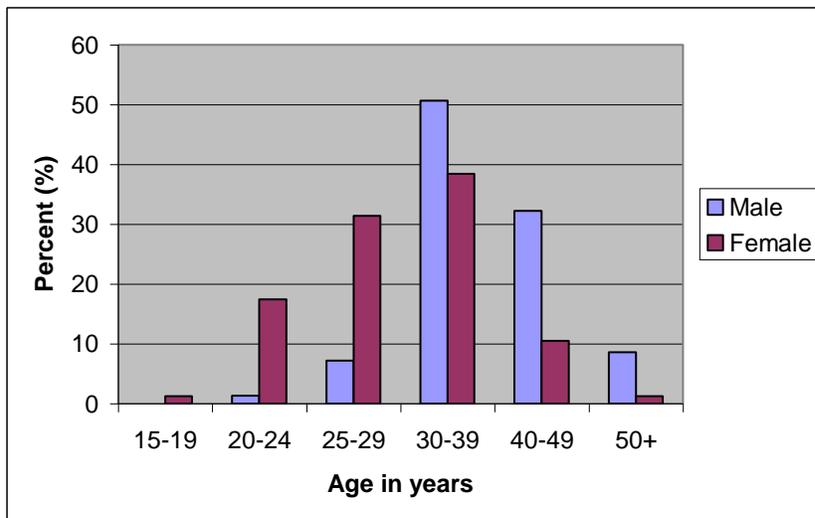


Fig.3.2.1: Age and Sexual status of PLHIV's

Most of the PLHIV (119 out of 238) of this study belong to the mainstream population (i.e. those who did not categorize themselves as part of any specific group). The other categories of PLHIV surveyed categorized themselves as migrant workers (35.7%), injecting drug users (9.20%), and sex workers (1.30%) etc.

Out of 238 PLHIV, the proportion of PLHIV living with HIV for 1-4 years was higher among the females (55.8%) than for the males (50.7%). In accordance, the proportion of PLHIV who had been living with HIV for more than 10 years was 8.5% for the males and 2.3% for the females. Fig.3.2.2 presents living with HIV in years of PLHIV according to gender.

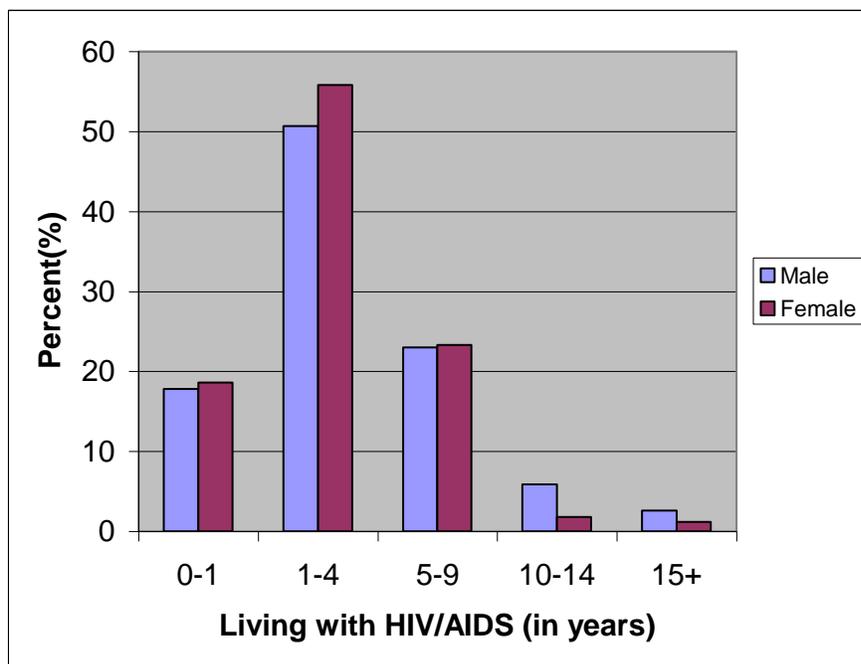


Fig.3.2.2: Living with HIV/AIDS in years-Male vs. Female

Among all PLHIV (n=238), 66.38% were married or lived together as husband/wife/partner living in the same household, while 2.94% were currently married

or lived together as husband/wife/partner but living/working away from household. Fig.3.2.3 shows the percentage of different categories according to their relationship status.

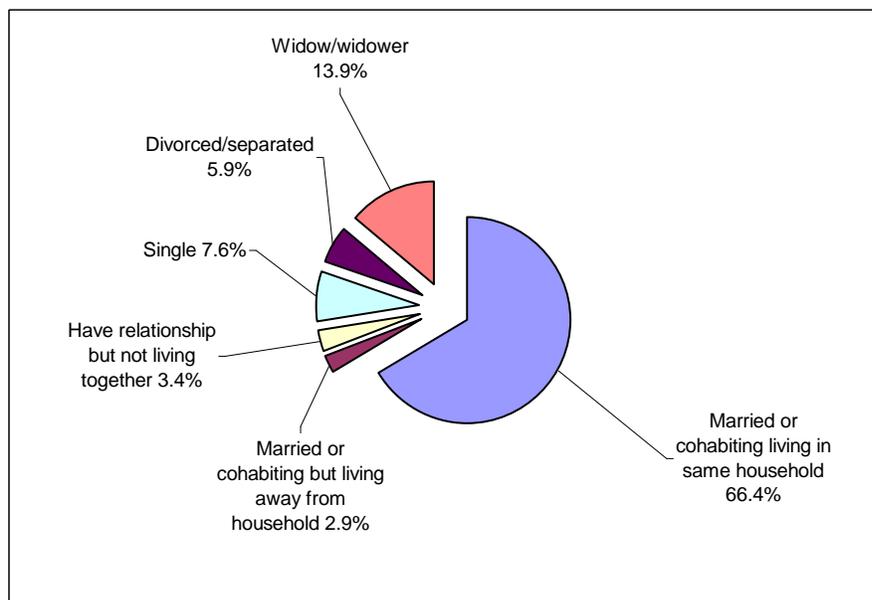


Fig.3.2.3: Current relationship status

Among all PLHIV (n=238), 220 were married for sometime or had lived together at some time in their lives and from them, 196 out of 220 had a child. Of these 196 PLHIV with children, 4 never got their children tested; and children from 171 PLHIV were HIV negative while 21 were HIV positive.

Out of 238 PLHIV, 16.80% were physically disabled (Disability not including general ill health related to HIV/AIDS) which was higher than the national figure (The Government of Bangladesh (GOB) surveys in 1998 estimated a national prevalence rate of disability at 1.60%)^{xxxiii}. The disability status of the PLHIV is shown in Fig.3.2.4.

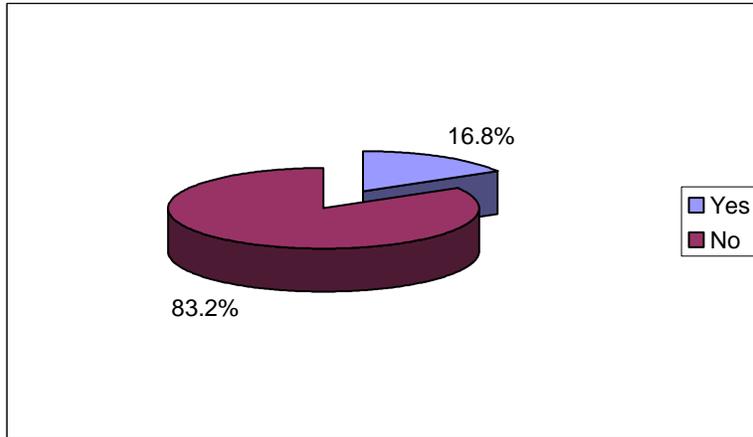


Fig.3.2.4: Disability status

Out of 238 PLHIV, only 11.3% PLHIV completed their technical college/university level education whereas about 23% did not have any formal education. Table 3.2.2 presents the frequency of PLHIV by educational status

Table 3.2.2: Educational status

Educational status	Frequency	Percentage (%)
No formal education	54	22.7
Primary school	66	27.7
Secondary school	91	38.2
Technical college/university	27	11.3
Total	238	100

The educational status for the female PLHIV was extremely poor compared to male in every aspect of educational levels, with the exception of secondary school. Fig.3.2.5 shows the educational status of PLHIV with respect to gender.

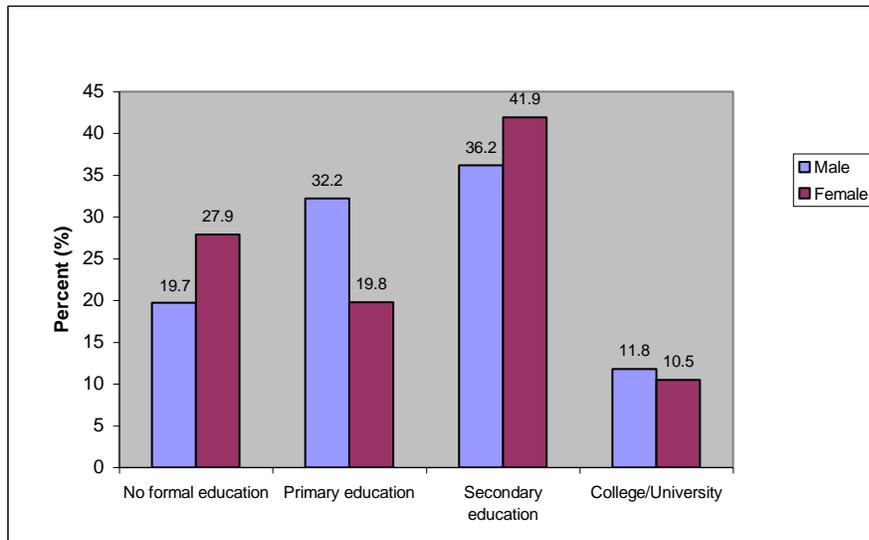


Fig.3.2.5: Educational status of the PLHIV-Male vs. Female

The employment status of the PLHIV is an important factor because it represents a picture of their social status. The common sources of employment are shown in Table 3.2.3. This table shows that a large number of PLHIV (84 out of 238) were unemployed and not working at all. The proportion of PLHIV working in full time self employment was higher than the other group who were involved in any type of work.

Table 3.2.3: Occupational status

Employment status	Frequency	Percentage (%)
Full time employment (as an employee)	46	19.3
Part time employment (as an employee)	9	3.8
Working full time but self employed	49	20.6
Doing casual part-time work (self employed)	50	21
Unemployment and not working at all	84	35.3
Total	238	100

It was found that 21.7% of the male PLHIV were full time self employed where as 15.1% female PLHIV were full time self employed. The unemployment rate was higher for the females than for males, with 64.0% of the female PLHIV unemployed; on the other hand 19.1% of the male PLHIV were unemployed. Fig.3.2.6 shows the occupational status of PLHIV with respect to gender.

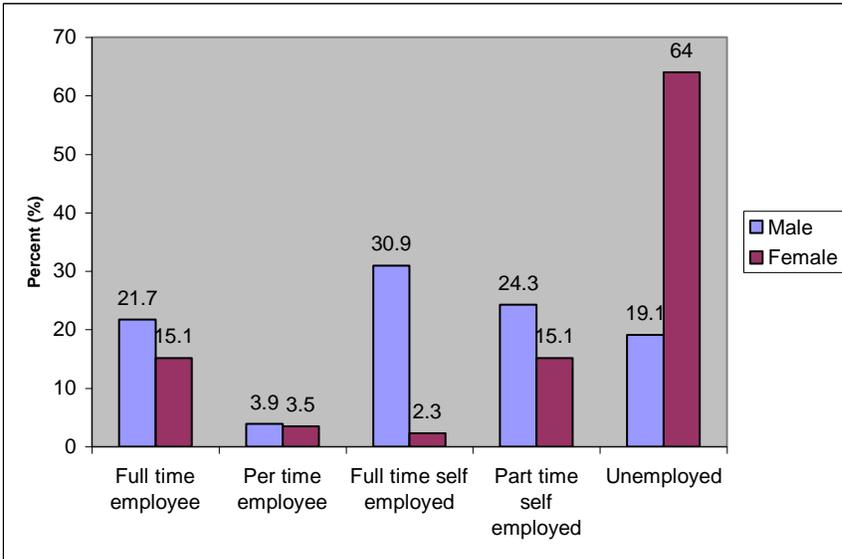


Fig.3.2.6: Occupational status of the PLHIV-Male vs. Female

Family size, as well as household income is also an important factor in determining the social status of the family. For example, if a small family has a high income level, we would expect that family to always have access to food. Table 3.2.4 shows the income status of the household with respect to family size.

Table 3.2.4: Income status of the PLHIV's family with respect to family size

Family Size	Average monthly income BDT 5000 or less (Income\$73 or less)	Monthly income BDT 5001-10000 (Income \$74 - \$146)	Monthly income BDT 10001 and more (Income \$146 or more)	Total
1-4	60	33	12	105
5-6	29	34	12	75
7+	7	26	25	58
Total	96	93	49	238

Majority of the PLHIV (72.7%) were living in rural areas including small towns or villages while 27.3% were living in large towns or cities. The proportions of PLHIV living in different areas are shown in Fig.3.2.7

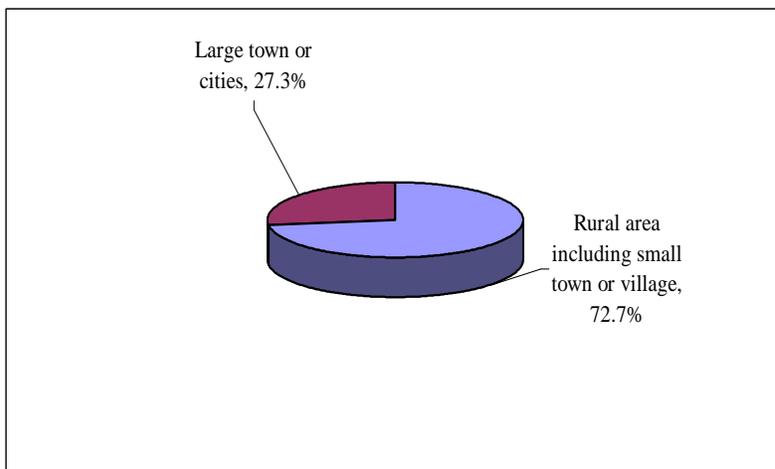


Fig.3.2.7: Geographical distribution of PLHIV – Urban vs Rural

3.3 HIV Testing/Diagnosis

Out of 238 PLHIV, 26.9% were tested for HIV because of their job requirements, while 21.8% were tested because their husband/wife/partner/family member's were found to be positive at some time. Figure 3.3.1 shows the proportion of PLHIV who were tested for HIV for various reasons. Among all the reasons most of the participants were tested

because of employment (about 27%) followed by partner/ family member tested positive.

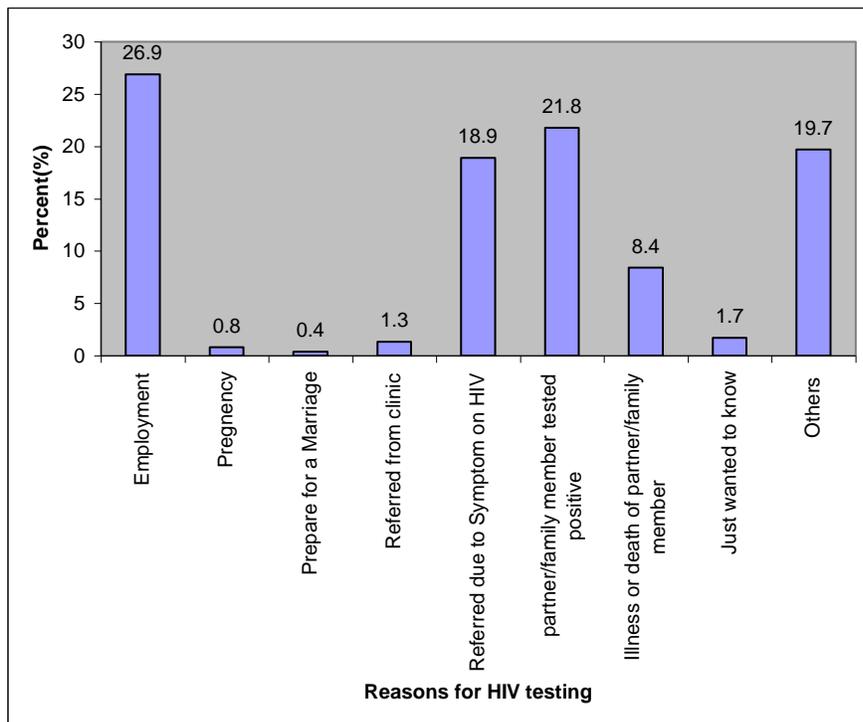


Fig.3.3.1: Reasons for HIV testing among all participants

Among all PLHIV (n=238), 33.6% volunteered for HIV testing. Voluntary testing varied according to gender of the PLHIV with 48.8% of the female PLHIV volunteering for HIV testing, while only 25.0% of the male agreed to volunteer testing. Fig.3.3.2 shows the decision for HIV testing according to gender.

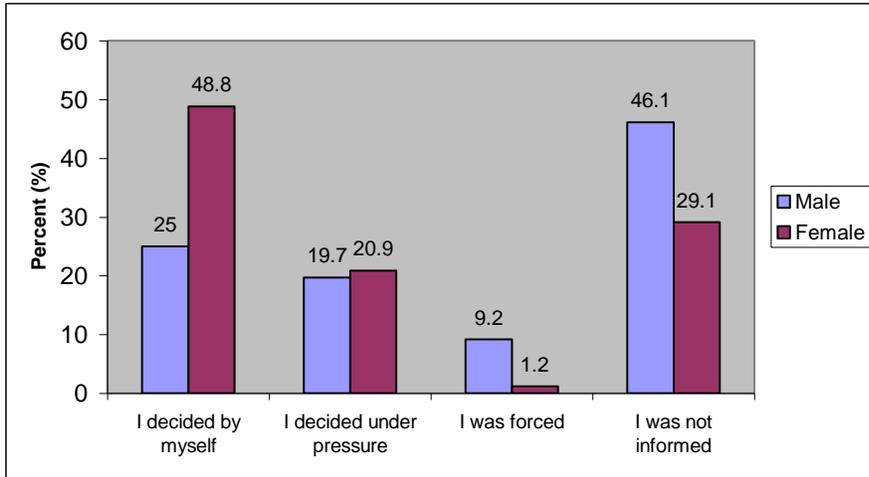


Fig.3.3.2: Decision for HIV testing-Male vs. Female

The following figures show why a man/woman was tested in relation to receiving counseling. These results indicates that regardless of why a man or a woman has testing, in the majority of cases only post test counseling occurs and in many cases for men no counseling takes place at all.

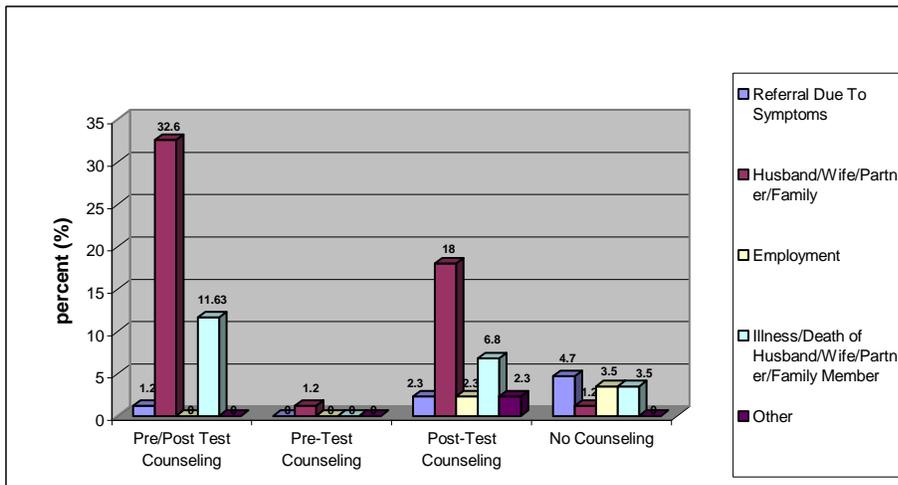


Fig.3.3.3: Why a woman was tested for HIV vs whether they received counseling

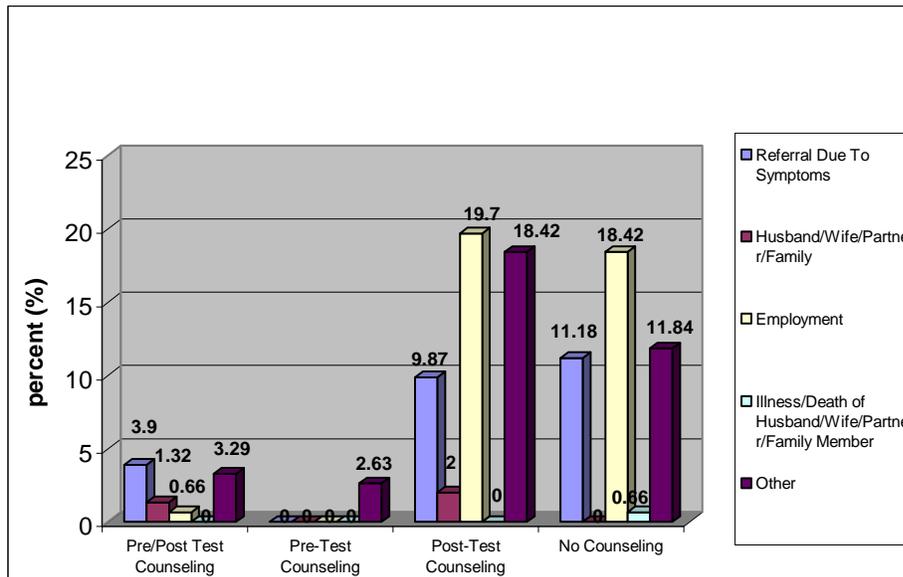


Fig.3.3.4: Why a man was tested for HIV vs whether they received counseling

3.4 DISCLOSURE AND CONFIDENTIALITY

PLHIV faced stigma and discrimination either from the members of their own families or from outside their own families, (friends/neighbors, colleagues/boss, health care providers etc.) The following graph shows the discrimination experienced by the PLHIV from specific people (husband/wife, other adult family members, friends/neighbors, co-workers, employer/boss, religious leader, community leader, health care workers, govt officials).

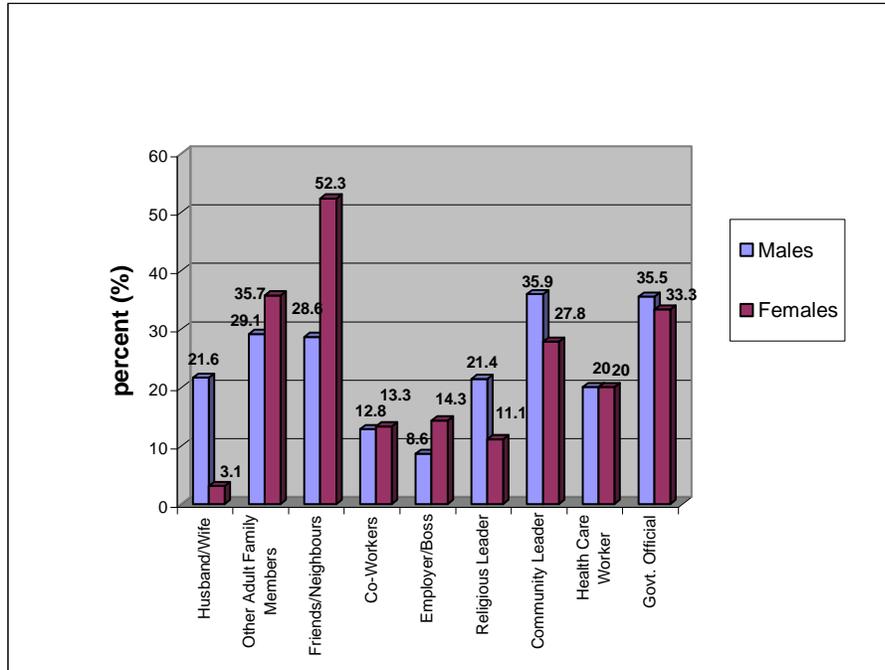


Fig.3.4.1: Discrimination experienced by PLHIV from specific people – Males vs Females

The above results suggest that the female PLHIV faced the highest discrimination from their friends/neighbors while the male PLHIV were discriminated mostly from the community leaders followed by government officials. Out of 238 PLHIV, almost 50% willingly told their husband/wife/partner about their HIV status; but some of them (22 out of 238) did not disclose their status. Among those who willingly told their spouses, 49.20% received supportive behavior from their husband/wife/partner while 14.40% received discriminatory behavior. Many of the PLHIV (42.01%) willingly told family members about their HIV status. Among this group, 8.0% faced very discriminatory behavior. More than 50% of the PLHIV did not disclose their HIV status to the children in their family. The number of PLHIV who willingly disclosed their HIV status to their friends/neighbors was 29 and among them, 2 faced very discriminatory behavior while 5 faced discriminatory behavior

Out of 238 PLHIV, the number of PLHIV who have occupations at present is 122. Among those 122, the proportion of PLHIV who willingly disclosed their HIV status to their co-workers was 15.54%; among them 5.4% faced very discriminatory behavior while 16.2% faced very supportive behavior. The proportion of PLHIV who willingly told their supervisor about their HIV status was 10.92%; among them 3.8% faced discriminatory behaviors. These results suggest that a small proportion of PLHIV were interested in disclosing their HIV status to their colleagues and supervisor regardless of the consequences.

Among all PLHIV (n=238), 22 were injecting drug users. Alarming, the majority (15 out of 22) did not disclose their HIV status to their drug partners. Those who willingly disclosed (5 out of 22) their HIV status did not face any type of discrimination from their drug partners which suggest that HIV positive status does not have any impact on sharing drugs.

A very small number of PLHIV willingly disclosed their HIV status (12 out of 238) to religious leaders with only 1 facing discrimination. Similar results were found when PLHIV willing disclosed their HIV status to community leaders, with 9 PLHIV willingly disclosing their HIV status and only two facing discrimination.

A very small proportion of the PLHIV (19.7%) willingly informed the health care providers about their HIV status and among them, 4.3% faced very discriminatory behavior while 6.4% faced discriminatory behavior. PLHIV also faced discrimination from health care givers (for example, a doctor, a nurse, counselor, and laboratory technicians) in a sense that, these peoples did not maintain the privacy. Figure 3.4.2 shows the discrimination faced by the PLHIV from health care givers regarding privacy problem.

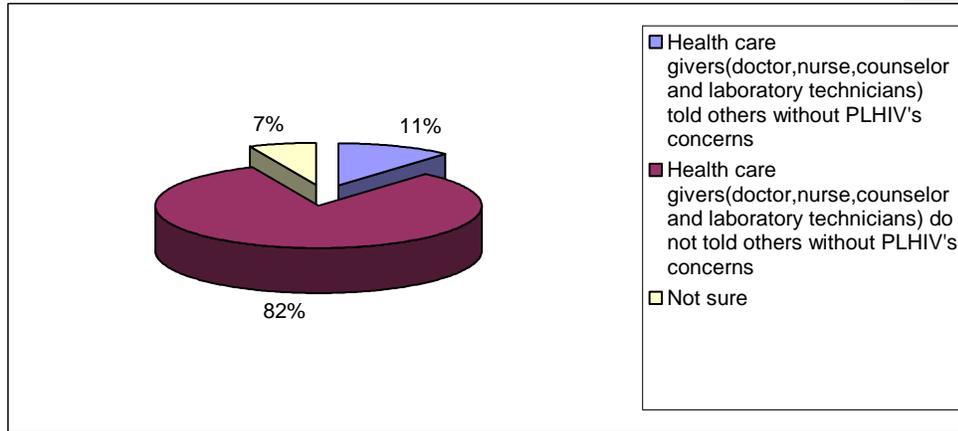


Fig.3.4.2 : Discrimination experienced by the PLHIV from health care givers regarding privacy problem

A large proportion of PLHIV willingly disclosed their HIV status to their social workers/counselors (57.6%) with none of them reporting any type of discrimination.

Out of 238 PLHIV, only 2.5% willingly told their teachers about their HIV status with none of them reporting any type of discrimination. Out of 238 PLHIV, only 15 willingly disclosed their HIV status to government officials, with 1 faced a lot of discrimination and 2 others faced discrimination. Among all PLHIV (n=238), only 22 PLHIV willingly disclosed their HIV status to the media with 1 reporting very discriminatory behavior while 3 reported discriminatory behavior.

The results on disclosure and confidentiality about HIV/AIDS suggest that many of the PLHIV faced discrimination after disclosing their HIV status and the discrimination level varied from individual to individual. Some of the PLHIV faced discrimination from their closest ones (e.g. from their family members, their husband/wife/partners etc.) while others faced discrimination from outside their own families (e.g. friends/neighbors, religious leaders, co-workers/supervisors, health care providers, family planning workers etc.).

3.5 EXPERIENCE OF STIGMA AND DISCRIMINATION FROM OTHER PEOPLE

Respondents were asked whether they experienced any stigma and discrimination (verbal insults, harassed and/or threatened, physically harassed and/or threatened, sexual rejection etc.) from others in the last 12 months while involved in social gatherings or activities, religious activities or family activities. The following graph shows the numbers for each type of discriminatory matter regarding the respondents HIV status.

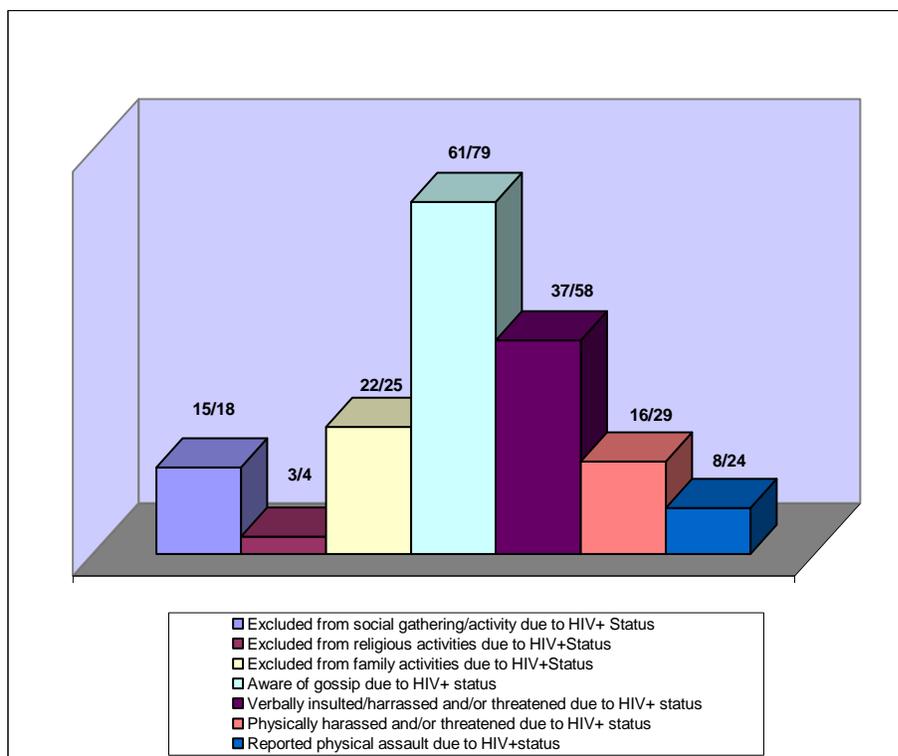


Fig.3.5.1: Discriminatory behavior faced by the PLHIV because of his/her HIV status

The 'n' for each of these variables is different but the trend is evident in that, when PLHIV reported some type of discriminatory behavior, they most often reported that it was due to their HIV status. For example, 18 people said they had been excluded from social gathering/activities at one time and among them 15 were because of their HIV status.

The discrimination severity does not vary according to the gender of the respondents. Almost all of the discrimination types are same for both male and female. Figure 3.5.2 shows the stigma and discrimination faced by the PLHIV from others in relation to their gender status

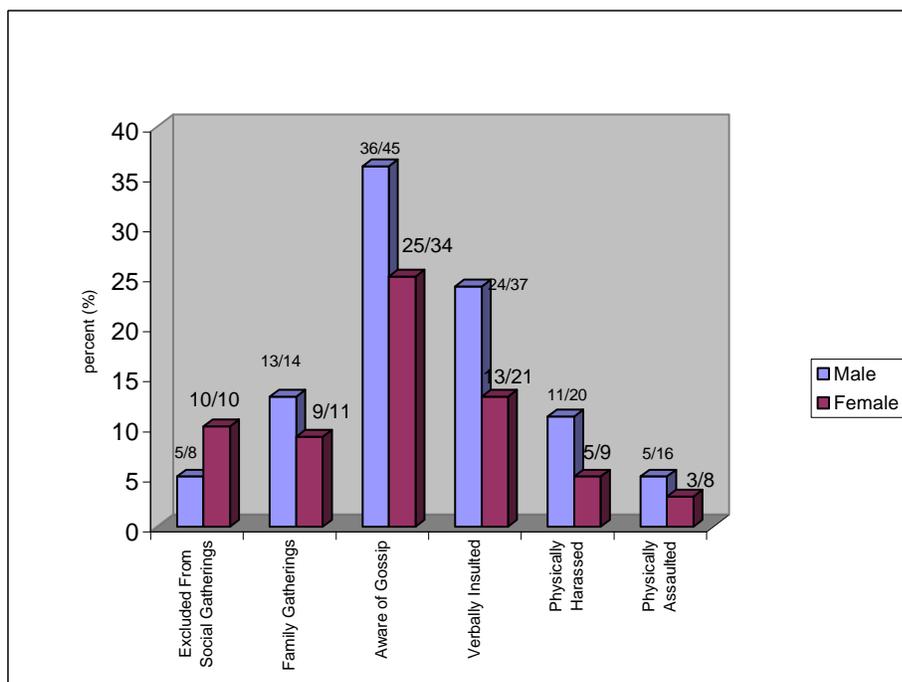


Fig.3.5.2 : Discriminatory behavior faced by the PLHIV according to gender because of his/her HIV status

A small proportion of PLHIV (7.6%) were excluded from social gatherings or activities (e.g. weddings, parties, clubs etc.) and among them 77.7% reported that it was due to their HIV status. The number of PLHIV who were excluded from their family activities (e.g. eating, cooking together, and sleeping in the same room) was 25. Among these 25 PLHIV, 19 reported that it was due to their HIV status and 3 were excluded because of both HIV and for other reasons. These results suggest that the PLHIV not only face discrimination from various facets of society but most importantly, they may face discrimination from their own family members.

Out of 238 PLHIV, the proportion of PLHIV aware of being gossiped about was 33.19%. Among them, 69.6% knew that the gossiping occurred because of their HIV status and 7.6% because of both HIV status and for other reasons.

It was found that the PLHIV were insulted both verbally and physically, and also harassed and/or threatened by others. Out of 238 PLHIV, 24.37% were verbally insulted, harassed and/or threatened by others. Among them, 58.62% were because of their HIV status and 5.2% were because of both HIV and for other reasons. 12.18% of PLHIV were physically harassed and/or threatened by others and among them 48.27% were because of their HIV status, 6.9% because of their HIV status and for other reasons.

Out of 238 PLHIV, 24 were physically assaulted by someone. Among them 8 were assaulted because of their HIV status. Among all PLHIV (n=238), 26 were under psychological pressure or manipulation by their husband or wife or partner and among them 10 faced pressure/manipulation very often. Out of 238 PLHIV, 5.62% experienced sexual rejection because of their HIV status.

3.6 ACCESS TO WORK, HEALTH AND EDUCATION SERVICES

Respondents were asked whether they faced any type of discrimination in relation to their access to work, health and education in the last 12 months. The following graph shows the discrimination experienced by the PLHIV in getting their access to work, in getting health services etc.

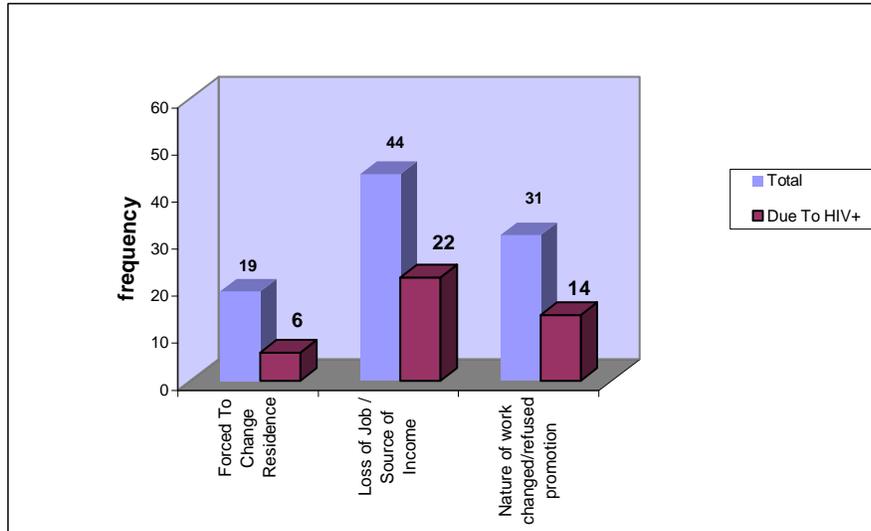


Fig.3.6 : Change of residence/change of employment

Out of 238 PLHIV, 28.20% lost their job (if employed) or another source of income, among them, 43.2% because of their HIV status while 6.8% because of both HIV and another reasons. The proportion of PLHIV who were refused employment or a work opportunity because of his/her HIV status was 9.27%. The proportion of PLHIV whose work changed, or who were refused a promotion, as a result of his/her HIV status was 20.26% (if employed) and among them 10% because of discrimination by his/her employer or co-worker due to their HIV status.

Out of 238 PLHIV, 7.98% were forced to change their place of residence or have been unable to rent accommodation. Among them, 21.1% was because of their HIV status and 10.5% was due to both HIV status and other reasons. 10.55% PLHIV's families experienced discrimination as a result of having a PLHIV in their household.

3.7 INTERNAL STIGMA (THE WAY YOU FEEL ABOUT YOURSELF) AND YOUR FEARS

Self stigma is another important fact that forced many of the PLHIV to feel guilty and tense about their status and themselves. Among all PLHIV (n=238), 69.7% felt shamed because of their HIV status, 59.2% felt guilty, and 63% blamed themselves. The proportion of PLHIV having low self-esteem because of their HIV status was 52.9%. A small proportion of PLHIV (27.3%) felt that they should be punished and 21% felt suicidal. Fig.3.7.1 shows the own feelings of the PLHIV for different categories.

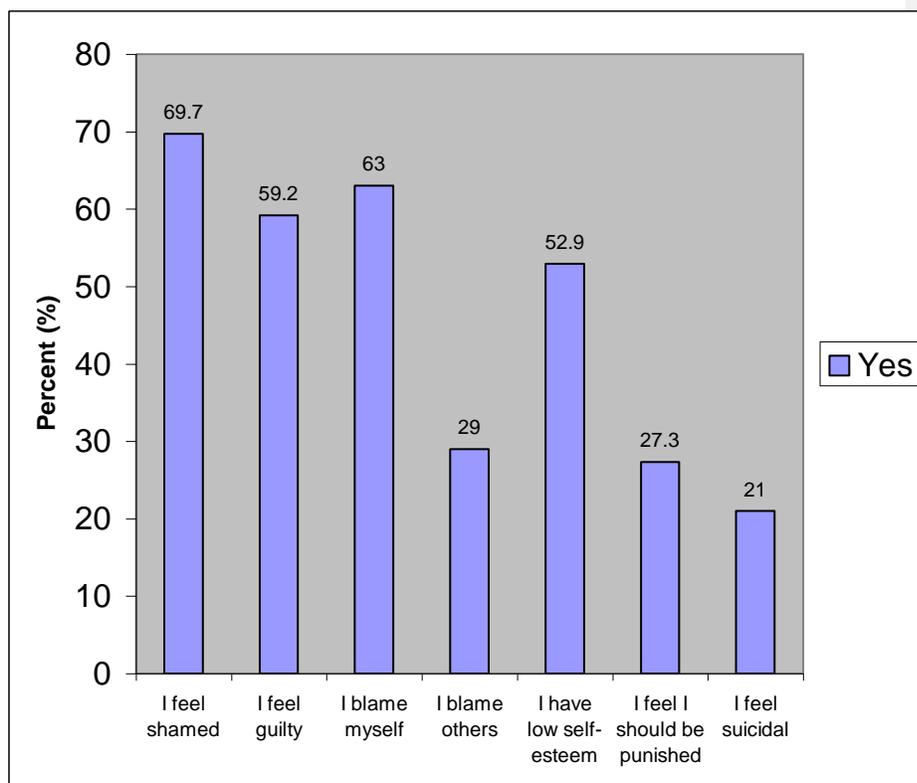
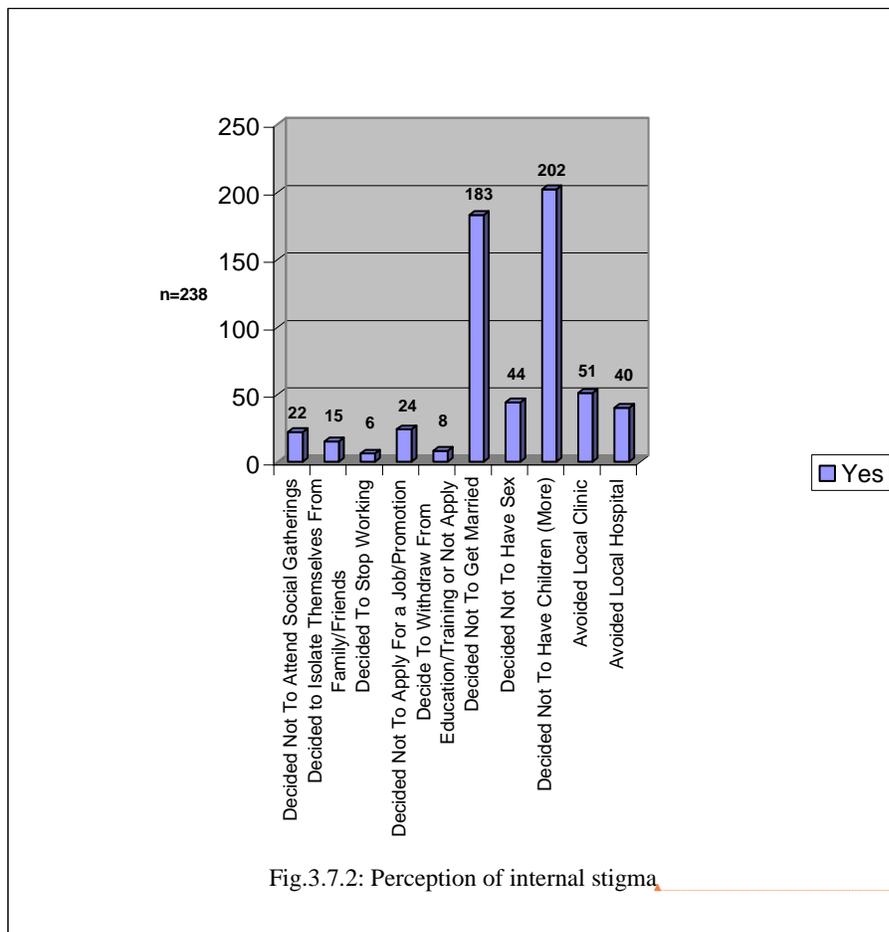


Fig.3.7.1: Feelings of the PLHIV because of his/her HIV status

Among all PLHIV (n=238), 9.2% took the decision not to attend any social gatherings while 6.3% decided to isolate themselves from their family and/or a friends. Because of internal stigma 2.5% of the PLHIV decided to stop working while 10.1% decided not to apply for a job/work or for a promotion. Most of them (76.9%) also decided not to get married and not to have sex (18.5%). A large proportion of PLHIV (84.9%) decided not

to have any more children while 21.4% avoided going to local clinic when they needed to and 16.8% avoided going to a hospital even when required. Most of the PLHIV (75.6%) were afraid that someone would not want to be sexually intimate with him/her because of their HIV-positive status.

Figure 3.7.2 summarizes the results regarding internal stigma. It is evident that more than half of the PLHIV blamed themselves for their HIV status while many of them felt suicidal.



Formatted: Font: 12 pt

The proportion of PLHIV fearful of gossiping or harassment was also high. About 21% PLHIV was fearful of being gossiped and about 12% was fearful of being verbally insulted, harassed and/or threatened by others. Figure 3.7.3 shows the percentage of PLHIV fearful of different events (being gossiped about, being verbally or physically harassed etc.) which later happened to them.

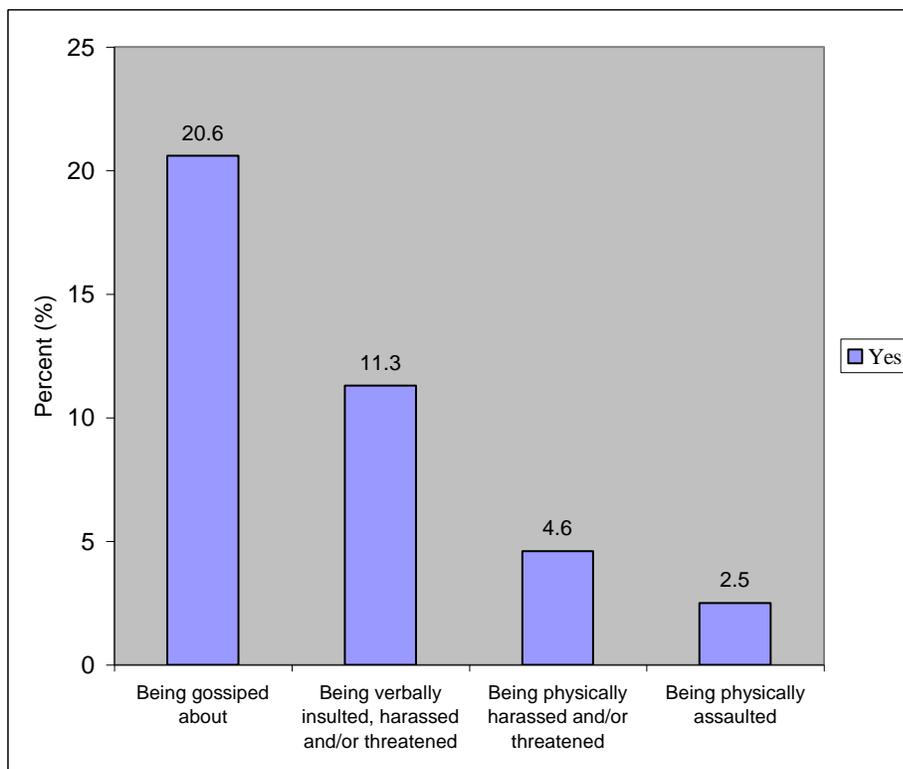


Fig.3.7.3: Event happens to the PLHIV because of their HIV status

These results suggest that the perceived self/internal stigma admitted to by PLHIV negatively affects their overall physical and mental well-being and as a result, their decision making processes involving lifestyle choices and access to services.

3.8 Rights, Laws and Policies

The proportion of PLHIV who had heard the declaration of commitment on HIV/AIDS that protects the rights of people living with HIV was only 8.8%. Of these PLHIV, 28.6% had read or discussed the content of this declaration.

Many of the PLHIV (12 out of 238) were abused for exerting their rights as a person and among them only 1 attempted legal redress and the matter was dealt with. On the other hand a majority of them (4 out of 11) did not attempt to get legal redress due to insufficient financial resources.

Figure 3.8 shows the discrimination faced by the PLHIV in the area of rights, laws and policies. Not many of the 238 respondents reported discrimination in the realm of Rights, Laws and Policies relating to their HIV+ Status. It is likely that the vast majority of the respondents either never interacted with officials in these areas or has not revealed their HIV+ status to these officials.

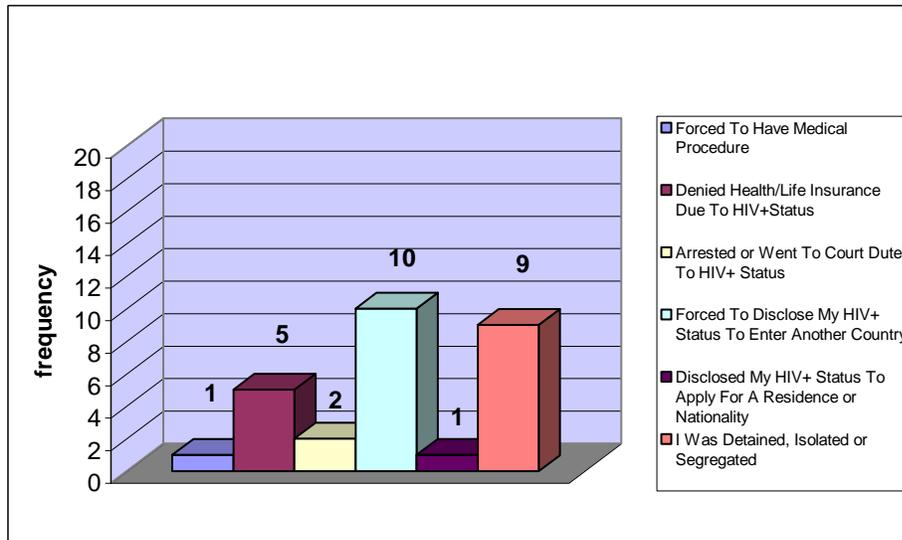


Fig.3.8: Discrimination faced by PLHIV in relation to rights, laws and policies

Formatted: Font: 12 pt

3.9 EFFECTING CHANGE

All of the respondents were currently members of an HIV support group and/or network and most of them were involved in supporting the others. The proportion of PLHIV supporting the other people living with HIV was about 63%, and among them, 82.6% provided emotional support (e.g. counseling, sharing personal stories, and experiences). The proportion of PLHIV who confronted, challenged or educated someone who was previously involved in discriminating against his/her was very small (15.1%). It is likely that they felt that it would be too difficult to change someone's mind and the outcome for them might be further discrimination. Figure 3.9 summarize the results regarding effective change by showing the frequency/outcome of different event (educating someone who was showing discriminatory behavior against the PLHIV, knowledge of PLHIV on different organization that works against stigma and discrimination, providing support to other PLHIV etc.)

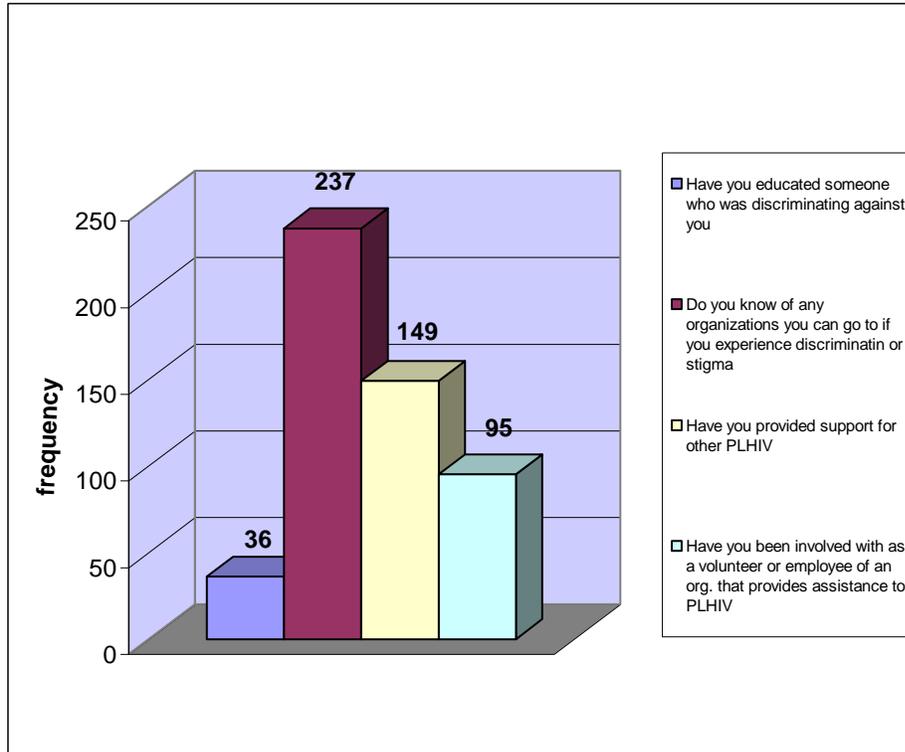


Fig.3.9: Effecting change

Formatted: Font: 12 pt

Almost all of the PLHIV (99.6%) were familiar with some organizations or groups that work against stigma and discrimination and among them 99.2% were familiar with PLHIV support groups and 82.3% familiar with the local non-governmental organizations.

Many of the respondents (39.9%) were involved either as a volunteer or as an employee, in some program or project (either government or non-government) that provides assistance to people living with HIV. Out of 238 PLHIV, only 5.9% were involved in the development of legislation, policies or guidelines related to HIV.

Among all PLHIV, only 14.3% believed that they had the power to influence decisions regarding legal/rights matters affecting people living with HIV. Most of the PLHIV (74.4%) recommended that the most important thing that needed to be addressed by the organization of PLHIV working against stigma and discrimination was to raise public awareness and knowledge about AIDS.

3.10 TREATMENT

Respondents were asked about their present health condition, their treatment facilities and some other health related issues like whether they have the access to medication for opportunistic infections, whether they have had a constructive discussion with a health care professional regarding sexual and reproductive health etc.

Most of the PLHIV reported that their health condition was fair. This figure was 41.2%; on the other hand, 8.8% reported that they were in poor health. The proportion of all PLHIV with their present health condition is presented in Fig.3.10.

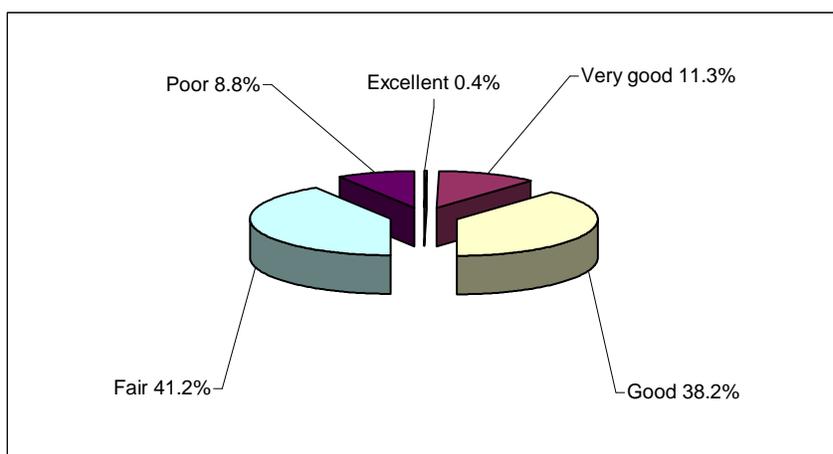


Fig.3.10: Present health status of PLHIV

Half of the PLHIV were currently taking antiretroviral treatment. The number of PLHIV who were in good health and taking antiretroviral treatment was 52 while the number of PLHIV who were in good health and not taking antiretroviral treatment was 39. The majority of the PLHIV (230 out of 238) replied that they had access to antiretroviral treatment and only 7 answered they did not know whether they had an access or not. Only one of the PLHIV, whose health condition was poor and did not take the antiretroviral treatment, reported that she did not have the access to antiretroviral treatment.

Out of 238 PLHIV, 76.9% were currently taking medicine to prevent or to treat opportunistic infections, while 23.1% did not take any medicine. Out of 238 PLHIV, only 1 responded that they did not have access to medication for opportunistic infections but the rest reported that they had the access to medication for the opportunistic infections.

A majority of the PLHIV (189 out of 238) reported that they had constructive discussions with a health care professional regarding their HIV-related treatment options. Among all PLHIV (n=238), 58.4% reported that they had constructive discussions with a health care professional regarding their sexual and reproductive health, sexual relationship, emotional well-being, drug use etc. The number of PLHIV who were in good health and had a discussion with a health care professional regarding HIV related treatment options was 77 while the number of PLHIV who were in poor health and had a discussion with a health care professional regarding HIV related treatment options was 15.

3.11 HAVING CHILDREN

Among all PLHIV (n=238), 220 were married and among them 196 have a child/children. 87.8% of the PLHIV received counseling on reproductive health concerns since being diagnosed as HIV-positive. The counselling program (different national HIV AIDS prevention interventions) extensively includes message regarding PMTCT.

A large proportion of PLHIV (87.8%) also reported that they were never coerced by a health care professional for sterilization. More than half of the PLHIV did not face any types of conditionality on the use of certain types of contraception for receiving their antiretroviral treatment.

A majority of the female PLHIV (50 out of 86) were never coerced by a health care professional for termination of pregnancy/abortion because of their HIV status, also they had never been coerced for type of delivery/giving birth (84.9%) and for infant feeding practices (45.3%). A small number of female PLHIV (10 out of 86) received antiretroviral treatment to prevent mother-to-child transmission of HIV and all of them were informed about healthy pregnancy and motherhood as part of the program to prevent mother-to-child transmission of HIV

This figure is low because the overall health system does not include the PMTCT messages as well as counseling for the reproductive health decision making process. Testing facilities, Doctors concern about pre-testing for maternal health care check up is not currently practiced in Bangladesh due to national low level prevalence.

3.12 PROBLEMS AND CHALLENGES

Respondents were asked to share their belief on some main problems and challenges relating to HIV testing/diagnosis, disclosure and confidentiality about being HIV positive, antiretroviral treatment and having children in Bangladesh. Among all PLHIV (n=238), about 6% of the respondents mentioned that they have no idea on the problems and challenges relating to HIV testing/diagnosis, disclosure and confidentiality about being HIV positive, antiretroviral treatment and having children which is very unfortunate. To analyze the results of this section (Problems and Challenges) we have coded the qualitative information into quantitative data and the analysis was done manually.

Out of 238 PLHIV, about 58% of the PLHIV defined “the insufficient number of HIV testing centers in the cities/areas” as a major problem for HIV testing/diagnosis. Many of the PLHIV (12%) also defined “the cost of HIV testing/diagnosis” as a serious problem. A small proportion of PLHIV (6%) mentioned the problem of getting the right behavior from health care professionals. Some of them said they had to travel to Dhaka for an HIV test which posed a challenge for them.

Among all PLHIV (n=238), more than 40% identified social stigma and discrimination as the main problem for disclosing HIV status. A person living with HIV does not want to disclose their HIV status because of fear of being discriminated against in the society. Many of them (about 9%) mentioned the “confidentiality/privacy problems by health care professionals or from the PLHIV organization” as a major issue that needs to be address.

The main problems relating to antiretroviral treatment are its lack of availability and high price. Among all respondents (n=238) about 23% respondents defined “high cost of ARV” as a main problem while 36% were worried about the “availability of the ARV”. Among all PLHIV 13% said they do not have the access to 2nd line ARV because it is not available in Bangladesh.

Some problems mentioned by the respondents relating to having children is the lack of support of health care providers and the lack of treatment facilities during delivery (about 9%). Other perceived challenges include: the fear of HIV positive children (about 31%), the uncertain future of the children etc.

Part 2 - Results from the Qualitative Phase

3.13 Profiles of Participants for the Qualitative Phase`

Out of the 30 respondents selected in the qualitative phase - 14 were males, 15 were females and 1 hijra (transgender). Among the 30 respondents, 9 were from the mainstream population (i.e. those who did not categorize themselves as part of any specific group), 1 hijra, 11 were migrant workers, 3 were injecting drug users (IDUs), 5 had a child/children who were also HIV positive, and 1 was sex worker (Fig

3.13). Some of the categories of respondents for this study overlapped, for example a respondent who was identified and asked to participate as a housewife revealed herself to have been a sex worker in the past during the interview***. From the total group of participants, 16 respondents were married, 5 were widowed, 4 were single and 3 divorced, while 2 respondent was separated.

Some common themes emerged from the in-depth interviews relating to the stigma and discrimination faced by PLHIV: (i) misconceptions and/or lack of information about HIV/AIDS that led to stigmatization; (ii) discrimination faced from various sects of society i.e. self-stigma, discrimination from family, friends, neighbours, supervisor/ work colleagues, religious leaders, doctors or health care workers and police or other law enforcement officers; (iii) effects on health and mental well-being of PLHIV due to stigma and discrimination.

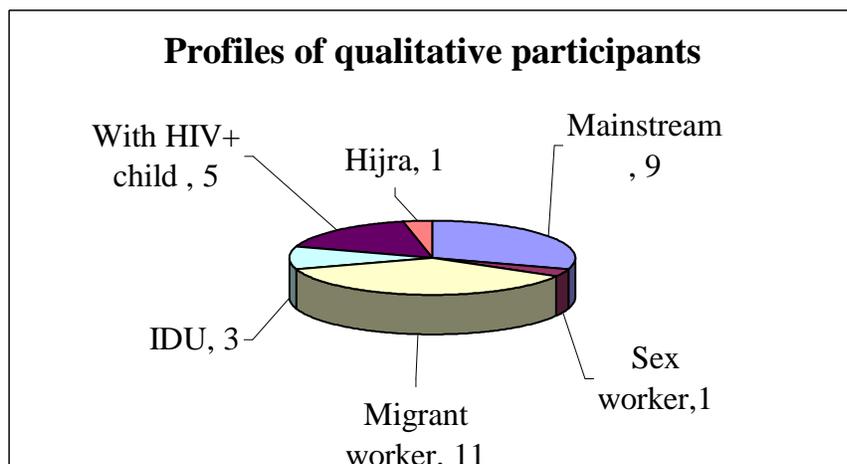


Fig.3.13: Profile of study Participants for the qualitative phase

3.14 Misconceptions and Lack of Information

The study revealed that of the total 30 respondents, 23% knew about the human immunodeficiency virus or had heard of the disease AIDS before they had tested positive

while 40% knew nothing about HIV/AIDS, about 37% had either been misinformed or had only a vague idea about HIV/AIDS before they themselves had tested positive.

3.15 Previous Knowledge about HIV/AIDS

Many of the 30 respondents who had heard about HIV/AIDS, their knowledge ranged between only having previously heard of AIDS as a deadly disease, to actually having information on HIV transmission and protection.

When I heard that I had HIV I became astounded; I thought it was impossible as I had been a member of Badhon (*organization working with Hijra in Bangladesh*) for ten years. I knew and understood about HIV. I never worked without condoms. I didn't work through the back, I would do it only through the front (*i.e. did not partake in anal sex*). I stayed at home, stunned for an entire week. I did not go to work; I did not speak to anyone. (24-year-old transgender sex worker)

I had learnt that HIV could spread through unprotected sex between male and females, when I was in school. I did not know anything other than that. I did not realize that I could have HIV before I tested positive for it. (Female mainstream population)

Misguided Knowledge about HIV/AIDS

Many respondents reported that there was a general lack of information about HIV/AIDS in Bangladesh. They also stated that the information that was available was either given to the public on a negative note, or misguided as the information usually ended being spread through rumors and not based on facts. Hence most people were confused about the risks and methods of transmission of HIV. The silence surrounding this virus and disease, along with the misconceptions about it in the general public, continuously generate the stigmatization of people living with HIV/AIDS. Before joining the PLHIV network, the majority of PLHIV interviewed either had no idea about HIV/AIDS or believed the various 'negative' myths and misconceptions about this disease.

Linking HIV with illegal drugs use, prostitution and promiscuity through public health programs on mass media also lead to the viewing of PLHIV as people who engage in “bad behavior”. For example, the National AIDS and STD Program (NASP) and Save the Children USA distributed stickers and other information material on the World AIDS Day December 1st 2008 with messages that read “Stay away from drugs to save lives – the use of drugs is increasing the risk of getting infected with HIV.” Complicated messages such as these can permanently link HIV to activities like drug use, particularly for those who remain uninformed, and thus not only negatively stereotype all PLHIV but also incite further rumors about the certain ‘lifestyles’ of people living with HIV/AIDS.

I did not know anything about HIV before I tested positive myself. I just knew that people, who have this condition, die. Immoral people get this disease. I have also heard that the train carriages that HIV positive people travel on are burnt later [to avoid contagion from spreading]. I have heard all this from people and on television. (35-year-old female mainstream population)

I did not know any thing about HIV before. But I first saw a sign-board while going to Chittagong airport where it was written, “if you want to live, you have to know”, (*A popular HIV/AIDS media slogan*). But I could not understand at that time what exactly I had to know. (30-year-old male migrant worker)

Then I knew that people die if they have HIV. This is a bad disease and it only happens to bad people. There is no treatment for it. I found out all this from television and other advertisements. (30-year-old female mainstream population)

I did not know much about it before I was found positive myself. I just knew that people die of this disease and this disease is prevalent in Europe and America. (39-year-old male mainstream population)

3.16 No Previous Knowledge about HIV/AIDS

The majority of participants stated that they did not know anything about HIV/AIDS before they themselves tested positive for HIV. Due to the kinds of behavior and lifestyle choices linked with this disease, HIV/AIDS still remains a taboo topic in the conservative Bangladeshi society. Marginalized groups such as injecting drug users, men who have sex with men, sex workers etc. become victims of multiple stigmas as this epidemic tends to begin in these subgroups that are already discriminated against by the larger society.^{xxvii} Until recently, very little information was available publicly on most sexually transmitted diseases including HIV, and even now it is difficult to acquire information about testing centers and health care services for PLHIV.

I did not know anything about HIV before getting the medical test done. (35-year-old male IDU)

I did not have much of an idea about HIV before I was diagnosed myself. I learned about HIV from the doctor who met me at Jagari. (34-year-old male migrant worker)

I did not really know about HIV before, and what I knew I did not understand. (42-year-old female IDU)

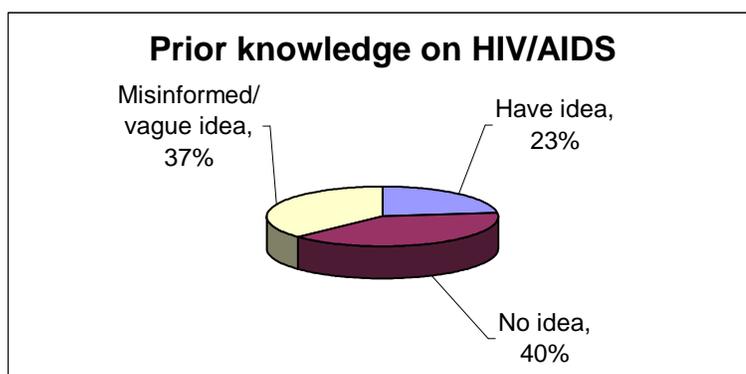


Fig.3.16: Knowledge of HIV/AIDS among the qualitative participants

3.17 Discrimination Faced

Majority of the participants of this study faced stigma and discrimination and the levels of discrimination varied between participants. While some participants faced only discrimination from almost everyone in their lives including their spouses, others received both mental and physical support because of their HIV status from people, and were alternately discriminated against by other people in their lives. Almost all participants indicated the lack of information about the method of HIV transmission, and the negative life-choices linked to this virus as being the major causes of such discrimination.

Family

In many cases, family members became fearful that HIV was contagious and could be transmitted through casual contact like holding hands and hugging, or through the sharing of bathrooms and kitchen utensils. Along with this, given that Bangladesh has a high prevalence of the disease malaria, the families of some PLHIV also believed that HIV could be transmitted through mosquito saliva, similar to the transmission of the virus causing the disease malaria.

My uncle notified the police and other highly placed people in our community about my physical condition. They took my two children and me away and kept us locked in a room in the office for disabled people for 1 month and 2 days. During this time nobody spoke to us or fed us regularly. I then felt like strangling my two children and blaming it on the people who locked us up, so that they would set me free. (30-year-old female mainstream)

All my clothes have been burnt. They [mother and father-in-law] did not allow me to talk to anyone. When I used to cut vegetables they asked me not to because I had a nasty disease. They did not let me eat three times a day and made me work all the time. They didn't even let me go to my husband. (33-year-old female mainstream)

Friends

Many respondents feared sharing their HIV status with anyone outside their own families given that even family members had discriminated against them after finding out. However there were occasions when participants had decided to share their fears, pain and anxiety in search of support from their friends and neighbors, and consequently had been more stigmatized and discriminated against. There were some PLHIV who described having received support and help from both families and friends, but such cases were very rare among this participating group.

Not too many friends know my positive status. And the ones who have found out do not keep in touch with me as often as they used to. (23-year-old female mainstream)

Neighbors

I have an HIV positive friend in Sylhet who could not walk down the roads in his village because of his positive status. People would say bad things when they saw him and would try to beat him up. He used to try to not get out of his house too often. (42-year-old male migrant worker)

My neighbors did not talk to me after I tested positive. I couldn't bathe in the same pond as them. They turned away their faces when they saw me. They did not allow me to keep my clothes with theirs. I couldn't drink water from the same tube well. I was asked to send someone else from my house to fetch water. (33-year-old female mainstream)

Family, Work Colleagues and Supervisors

Participants suffered economically due to discrimination by losing their jobs, by being written out of wills of either parents or spouses or as was more common, by having their properties and money ceased by non-positive family members. Being HIV positive made

participants physically weak and instead of compassion and support due to this, they were mistreated and fired from jobs unfairly and without any prior notice.

I did not get justice when the members of my husband's family captured everything after the death of my husband. They told me that since I am HIV positive, I should not have the need for any property (30-year-old female mainstream)

My colleagues keep their distance [since they know of my status] but my supervisor hasn't said anything. (32-year-old male migrant worker)

I had to do the test in 2001 in accordance to my company rules and I tested positive then. When they informed this to my employer instead of me, my employer went to the immigration office and cancelled my visa. He asked me to go back home but I ran away from him. (45-year-old male migrant worker)

3.18 Discrimination from Health Care Givers

Loss of privacy in health care settings was a common complaint among the participants of this study. Even though there are only a handful of HIV testing centers in Bangladesh, most of the health care givers at these settings are not even trained to provide the required pre and post test counseling. Participants complained of nurses and other health care givers discussing their positive status amongst themselves even before the doctor had shared the information with the patient himself/herself. Participants have also indicated that nurses and other hospital staff only wore gloves when it came to treating the PLHIV.

In an effort to avoid discrimination and obtain access to dental and health care services, PLHIV have admitted to hiding their HIV positive status. Many have also reported turning to tradition healers, homeopathy, religious healers etc. in search of finding a cure for HIV either simultaneously with seeking health services from a doctor, or after being mistreated or ignored by health care professionals in a hospital settings.

The doctor asked me after my test, “What have you done that has caused you this disease?” (30-year-old female mainstream)

A doctor misbehaved with my husband after receiving his test results. The doctor did not keep my husband’s condition private, but also called me and told me that my husband had contracted this unfortunate disease due to his misdeeds while he lived abroad. I felt very bad because I liked my husband and had trusted him very much. (33-year-old female mainstream)

Similarly, participants also reported discrimination and abuse in the hands of law enforcement officers, and feeling powerless and helpless to do anything against the mistreatment.

One of my uncles informed the police about my HIV status. The police took me away and kept me locked in a room. (30-year-old female mainstream)

Police were sent to my shop three-four days after I was found positive. I hid for ten to twelve days but then the police caught me and kept me in the prison hospital. They notified my shop owner who later arranged for my air ticket. The police kept me in chains like a common criminal. They opened the chains when they put me on the plane. (32-year-old male migrant worker)

3.19 Self-stigma

Self stigma admitted the participants to thoughts of suicide on finding out their positive statuses. Their thoughts revolved around their families’ and their own shame in testing positive for a disease that is commonly thought to only be transmitted through sexual relations. Being a conservative society with a Muslim majority population, not only promiscuity and extra-marital affairs looked down upon, pre-marital sexual relationships are also severely frowned on. As a result many participants felt ashamed and were unable to share their distress about their positive status with even people closest to them.

I felt that I am a bad person, a sinner. I felt like committing suicide. (32-year-old male migrant worker)

I thought that I had reached the end of my life when I found out about my positive status. I thought I would die within that day. I was tensed and sorrowful thinking about how my family would function without my income. (28-year old Hijra/transgender)

I felt like killing myself and my two kids many times because after having this disease, a lot of things started to happen to me which I never thought possible. (33-year-old female mainstream)

I think badly of myself now. Sometimes I think it is better to be dead than to live like this. (30-year-old male migrant worker)

3.20 Gender Discrimination

Female PLHIV seem to be one of the marginalized groups described earlier, who are facing multiple forms of discrimination from society in Bangladesh. This is due to both structural and social injustices and inequalities that push women's statuses low down the ladder, as well as because of the HIV positive status of such participants. Women in Bangladesh have very low status in both the private and public spheres of society. Numerous studies have shown that discrimination against women are more prominent in families than against men. Married women who were infected by their husbands, i.e. majority of whom are male migrant workers in the case of Bangladesh, are often scorned, mistreated and even evicted from their in-laws home when their HIV status becomes known.^{xxvii} On the other hand women who are divorced, separated, living alone or even those choosing to not to conceive are also looked down upon by the larger society,

My husband was abroad for a long time before we got married. I heard he tested positive at that time and was sent back to the country, but he married me without revealing any of this. He became sick two months after our marriage and went to India

for treatment. After he was sent back, I saw his medical report and realized that I could have become infected too.

I started to become sick quite often. My in-laws would then scorn my health condition and ask my husband, "What kind of a wife have you brought home? She is always sick!" I became very worried after testing positive. I cried all the time and did not talk to anyone. I always thought about my child and worried about what would happen after I died. This feeling cannot be described in words.

I am divorced and have left my in-laws house. My husband used to torture me and the children in that neighborhood would not play with my child. My husband had gone around telling our previous neighbors about my positive status. They started making comments about me.

Once my child had become critically ill, and when we went to the hospital, I informed the doctor that my child and I were both positive. I wanted the doctor to take precautions against becoming infected themselves. I hoped that my child would receive better service because I had already revealed our statuses, but the opposite ended up happening. The services became worse; they would not come near my child and wear gloves while treating my child. I had to explain to them that this was not a contagious condition.

I also face economic problems. I have been deprived of any property rights because I am HIV positive. I got nothing from my husband or in-laws. I need to take money from my brothers but even in spite of having the money; medicine is sometimes still not available. Some medicines are very costly.

This case story highlights the typical gender biases and mental and emotional abuse young women face when infected by their husbands. Often in these cases, families refuse to accept that the man may be responsible and their anger is directed at the female. In some cases, it is reported that the female spouses also tend to keep silent even if they are infected by their husbands, as they don't believe they have many options open to them even if they were to leave their husbands. However, if the husbands are infected by their

wives, it was mentioned that many choose to abandon their wives and leave them to manage on their own.

3.21 Health and Mental well-being of PLHIV due to Stigma and Discrimination

Many PLHIV reported having very low opinion of themselves due to the way HIV/AIDS is perceived by society. PLHIVs themselves referred to having done “bad things” in the past and as a result of their ‘karma’, they were being punished by becoming infected with HIV. Their worries revolved not only around themselves, but also of what society thought of the rest of their family. Many participants of this study shared their sorrows over children and other family members who had been discriminated against by other family members, neighbors and health care providers due to their positive status

Once my brother had become seriously ill and I took him to the Khulna Hospital to be admitted. The doctor, who admitted my brother at the hospital, knew about my positive status from beforehand. And although he admitted my brother, he told everyone that my brother was also positive. I told him to test and check whether my brother was positive or negative. His results came out negative after the test but in spite of this they did not treat my brother. Then we went to another clinic from that hospital. They circulated in the newspaper that a family with HIV positive members had come to them but then they went to a private clinic as they were able to afford it. (23-year-old female with HIV positive child)

I know someone who lives in Gazipur. Nobody invites her to any functions. Neighbors torture her, they don’t allow her kids to play with anyone else’s kids. Her sister-in-law misbehaves with her whenever they have arguments. (30-year-old female mainstream)

Rather than being isolated by the society, some PLHIV in our study have themselves chosen to stay separated and not attend family or religious functions. They reported staying inside the house, and in some cases isolating themselves in a room all the way in

a corner of the house. Many participants themselves reported believing HIV to be a contagious virus, and thus had taken precautions to separate their bowls and glasses from the rest of their families' items. They reported quitting their jobs due to both physical ailments and in fear of discrimination in the work place. Many participants chose to stay out of the public sphere as much as possible.

Even though the majority of the respondents of this study had their health care needs met by doctors attending the PLHIV network offices, some reported loss of privacy, mistreatment, and refusal of treatment of both themselves and other non-positive family members at other health care settings when they had revealed their positive status. The majority of participants faced some amount of discrimination when they went to collect their test results. As a result many PLHIV had chosen to keep their positive status hidden when they required treatment from public or private hospitals and doctors. Many participants reported seeking health services only in extreme situations or turning to traditional healers as a result of past experiences of stigma and discrimination.

When I found out about it after coming back home, I went to an herbal healer (kibiraj) according to my family's advice. The healer was in Banani. I did not let him know that I am HIV positive. He gave leaves from different plants for fever and diarrhea. I went to a general practitioner after being found HIV positive. I did not know about CCDB then. The doctor took Taka 2500 from me and told me to do whatever I wanted to do and to eat whatever I wanted and to be prepared to die soon. He also told me that I could not have sex with my wife or have children.
(32-year-old male migrant worker)

Chapter 4

Summary of Findings and Discussion

The knowledge about HIV/AIDS in Bangladesh is limited. A large proportion of the population has misconceptions and/or a lack of information about HIV/AIDS that has resulted in the discrimination and stigmatization of PLHIV. Even though families provide the majority of support for PLHIV, some families perceive HIV/AIDS as a curse and treat the PLHIV as a family burden. For these reasons some participants of the study have chosen not to share their HIV+ status with anyone except their counselors in fear of being discriminated against or of being stigmatized by their family and society.

Gender discrimination seemed to be an added burden on the shoulders of female PLHIV. Female participants described being thrown out of their in-laws houses, tortured and having their inherited properties and money taken away etc. even in cases where in-laws knew that the participant had become infected with HIV through her husband. Female participants also felt the added pressure from in-laws to become pregnant since they did not know of their son and daughter-in-law's positive status. Participants reported that family members verbally discriminated against them when they could not participate in family activities or perform their daily tasks and chores.

People living with HIV/AIDS have lower income levels than the rest of the population. Some of them lost their job because of their HIV/AIDS status while some of them were forced to resign from their jobs because of poor health. Our research revealed that a large proportion of PLHIV were migrant workers; majority of them reported not even knowing what HIV/AIDS was before leaving the country but almost all of them faced sudden loss of income when they lost their jobs and they were immediately sent back to Bangladesh on testing positive. Many of these participants indicated that they were not even sure about the reasons for being sent back and only understood what it meant to be HIV positive long after coming back to Bangladesh.

Many of the PLHIV interviewed were discriminated against when they attempted to obtain rights as a person living with HIV/AIDS, suggesting that ensuring the rights of the PLHIV is an urgent requirement for their welfare.

The majority of the PLHIV interviewed suffer from internal stigma. Many of them felt guilty with regard to their HIV status. Most alarmingly, many of them felt suicidal, suggesting that along with more counseling, public attitudes need to be changed in order to reduce internal stigma and to help ensure their health and well being.

Sex workers, Hijra and IDU PLHIV groups seemed to face similar types of discrimination for belonging to minority groups who are already looked down upon by the society. Our research included one Hijra, one sex worker and three IDU at the qualitative phase who shared their experience of discrimination from the community. **These marginalized group (Sex workers, Hijra and IDU PLHIV groups) faced a lot of discrimination because of their social status,** so particularly inclusive education and support should be provided to help ensure transmission rates and discrimination are reduced through inclusive education and access to supportive medical and social staff.

It was found that PLHIV were verbally and physically insulted and harassed. Some PLHIV were under emotional pressure and/or manipulation by family members as a result of their HIV status. It is felt that some of this behavior is likely due to a lack of awareness and education about HIV/AIDS suggesting education campaigns might help reduce abusive behavior and stress among PLHIV and their families.

A lack of access to health care services by PLHIV is an issue that requires urgent attention. The majority of PLHIV faced some form of discrimination when attempting to get treatment from a governmental hospital or local clinic, suggesting that adequate training of health care providers (e.g. nurse, doctor, and laboratory technicians) is an urgent requirement.

Participants indicated that misconceptions with regard to causes and methods of transmission of HIV have led to intolerance of PLHIV in society and a variety of forms of stigmatization and discrimination. Participants indicated more measures from government in terms both making the public aware of the basic facts of HIV/AIDS as well as to undertake measures to regularly subsidize antiretroviral drugs and other costly medicines which are essential for the well-being of PLHIV are necessary to reduce the intolerance of PLHIV in society.

In conclusion, much needs to be done by government, donor organizations, NGOs, and those working to provide support to HIV positive people to minimize HIV/AIDS related stigma and discrimination and for that purpose a coordinated plan is necessary.

Chapter 5

Recommendations

Although it is difficult to address all forms of stigma and discrimination linked to HIV/AIDS, it is essential that efforts are made to address some of the key issues.

Stigma and discrimination affect the physical and mental well-being of PLHIV and of their families. It prohibits entire families from being able to earn their regular income, from accessing health care services and from having their children adequately educated. As a result, this behavior hinders their participation in almost all kinds of communal and societal activities. It prohibits information seeking behavior that might result in a better understanding of PLHIV and fosters a status quo and acceptance of discrimination. It prohibits loving relationships between family members and fosters gender discrimination and verbal and physical abuse within the family and within society.

PLHIV blamed themselves for their HIV/AIDS status resulting in many feeling suicidal. Because of internal stigma more than three fourths have decided not to get married and were afraid that someone would not want to be sexually intimate with him/her after knowing HIV status.

It is these key issues (and others) that affect PLHIV, their families and society in general. It is therefore essential that the following recommendations included in a cohesive national program to help reduce the risk of HIV transmission, to improve the lives of PLHIV and to help families cope with the issues associated with a lack of knowledge and education of HIV/AIDS in Bangladesh.

- I. Government run billboards and other mass media campaigns imparting information on the four methods of transmission of HIV could be a first step towards correcting some long term misconceptions about HIV. To reduce the

image of a PLHIV as a sickly person, these advertisements could also be used to make the public aware that anyone could become infected with HIV and erase such ideas as the HIV virus only infecting those who had partaken in “bad behavior” in the past. Thus more media involvement is necessary in pushing positive message on HIV/AIDS and people living with this disease.

- II. Information centers with both information about HIV/AIDS and names and addresses of testing centers are an immediate must. The majority of participants reported going from one medical center to the next in the hope of obtaining an HIV test. All medical staff at designated HIV testing centres require immediate training on how to conduct pre and post HIV test counseling. Staff at all medical centres require urgent training in the areas of emotional sensitivity, tolerance and privacy of medical information. Hospital staff at all medical centres also require adequate medical knowledge in the use of universal safety precautions to reduce risk of infection for all staff and patients.
- III. Civil society participation is a necessary most to handle HIV/AIDS related stigma and discrimination. For this purpose more important role need to play by the social workers/community volunteers for raising awareness about HIV/AIDS.
- IV. Gender inequality is a major contributing factor which increases discrimination and needs to be addressed in the long terms by improving the education and labor force participation of women. The government as well as the NGOs has to play a major role in this regards.
- V. To reduce stigma and discrimination another important recommendation was made repeatedly by the participants. That is, to raise awareness and knowledge of the general population of HIV/AIDS. This can be done through mass media, HIV/AIDS education in schools, community centres and through organized events that include stakeholders in civil society.

VI. Many of the PLHIV were worried about obtaining a regular supply of ARVs and other necessary medications including second line ARVs. Government, donor organizations including all NGOs and PLHIV support groups should work towards ensuring an accessible supply of these much needed medicines.

VII. Efforts should be made to help ensure there is adequate knowledge of HIV/AIDS in the workplace and that sensitivity and tolerance measures are adopted to help ensure PLHIV remain a vital, active contributor in the workforce.

Limitations

Our study had some limitations as we were not able to represent all minority groups of PLHIV living in Bangladesh. Past research has indicated that the population of PLHIV in Bangladesh may actually be greater than the official number. Many people are afraid to get their HIV testing done, and many others who have tested are fearful of coming forward with their positive status. We were only able to recruit our participants (although randomly sampled) through the existing PLHIV peer group network, except for the one Hijra participants.

However, the PLHIV who have participated in our study have given very strong indications of the stigma and discrimination which they have to suffer daily. Almost all participants indicated the misperceptions in society as the root cause of such discrimination. As is clearly indicated by this research, it is only through creating awareness in society about HIV/AIDS will we be able to take the first major steps towards reducing stigma and discriminations against people living with HIV/AIDS.

References:

-
- ⁱ Bangladesh National AIDS Committee(2006). UNGASS Indicators Country Report Template. http://data.unaids.org/pub/Report/2006/2006_country_progress_report_bangladesh_en.pdf.
- ⁱⁱ National AIDS/STD Program(2007). World AIDS Day, Souvenir: Take the lead; stop AIDS: keep the promise. Dhaka: National AIDS/STD Program, Directorate General of Health Services, MOHFW, Govt. of Bangladesh..
- ⁱⁱⁱ Azim, T. et al.(2008). HIV and AIDS in Bangladesh. *Journal of Health, Population and Nutrition*. (3) p311-324.
- ^{iv} ICDDR,B (2008). The HIV/AIDS Programme. Draft Report on estimating numbers of those most affected by HIV/AIDS in different locations to support efficient service delivery, capacity building and community mobilization. Assignment 1: “Care and support for people most affected by HIV and AIDS.” Package #910. GFATM Round 6.
- ^v Azim T, Rahman M, Alam MS, Chowdhury IA, Khan R, Reza M et al.(2008). Bangladesh moves from being a low- prevalence nation for HIV to one with a concentrated epidemic in injecting drug users. *Int J STD AIDS* 19: 327-31.
- ^{vi} ICDDR,B (2008). The HIV/AIDS Programme. Draft Report on estimating numbers of those most affected by HIV/AIDS in different locations to support efficient service delivery, capacity building and community mobilization. Assignment 1: “Care and support for people most affected by HIV and AIDS.” Package #910. GFATM Round 6.
- ^{vii} **Ogden, J., & Nyblade, L. (2005). Common at its core: HIV-related stigma across continents. Washington, DC: International Centre for Research on Women**
- ^{viii} Reidpath, D.D., & Chan, K.Y. (2005). HIV discrimination: Integrating the results from a six-country situational analysis in the Asia Pacific. *AIDS Care*, Suppl 2, 195-204.
- ^{ix} UNAIDS(2007). Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes. A resource for national stakeholders in the HIV response.. http://data.unaids.org/pub/Report/2008/jc1420_stigma_discr_en.pdf.
- ^x **Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. Harmondsworth: Penguin.**
- ^{xi} UNAIDS (2003). Fact Sheet: Stigma and Discrimination. http://data.unaids.org/publications/Fact-Sheets03/fs_stigma_discrimination_en.pdf.
- ^{xii} Powell-Cope, G.M., & Brown, M.A. (1992). Going public as an AIDS family caregiver. *Social Science & Medicine* , 34, 571_80.
- ^{xiii} Green, D.A., Devi, S., & Paulraj, L.S. (2007). Care centre visits to married people living with HIV: An indicator for measuring AIDS-related stigma & discrimination. *AIDS Care*, 19(7): 910-915.
- ^{xiv} De Bryun, T. (1998). “HIV/AIDS and Discrimination: A Discussion Paper”. Montreal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society.
- ^{xv} Morrison, K. (2006). “Breaking the Cycle: Stigma, Discrimination, Internal Stigma and HIV”. Geneva:UNAIDS.
- ^{xvi} Brouard, P., Wills, C. (2006). “ A Closer Look : The Internalisation of Stigma Related to HIV”. United States Agency for International Development (USAID).
- ^{xvii} Nyblade, L., & Macquarrie, K. (2006). Can we measure HIV/AIDS related stigma and discrimination? Current knowledge about quantifying stigma in developing countries. Policy project. Washington : International Center for Research on Women (ICRW) and United States Agency for International Development (USAID).
- ^{xviii} Visser, M., J., Kershaw, T., Makin J. D., Forsyth, B.W.C. (2008). “ Development of Parallel Scales to Measure HIV-Related Stigma”. *AIDS Behavior*, 12: 759-771.
- ^{xix} Parker, R., Easton, D., & Klein, C. (2000). Structural Barriers and Facilitators in HIV Prevention: A Review of International Research. *AIDS*, 14 (suppl. 1) S22-S32.
- ^{xx} Reidpath, D.D., & Chan, K.Y. (2005). HIV discrimination: Integrating the results from a six-country situational analysis in the Asia Pacific. *AIDS Care*, Suppl 2, 195-204.
- ^{xxi} Reidpath, D.D., Brijnath, B., & Chan, K.Y. (2005). An Asia Pacific six-country study on HIV-related discrimination: Introduction. *AIDS Care*, 17(Supplement 2): S117-S127.

-
- ^{xxii} Reidpath, D.D., & Chan, K.Y. (2005). HIV discrimination: Integrating the results from a six-country situational analysis in the Asia Pacific. *AIDS Care*, Suppl 2, 195-204.
- ^{xxiii} Huda, S. (2006). Sex Trafficking in South Asia. *International Journal of Gynecology and Obstetrics*, 94, 374–381.
- ^{xxiv} Huda, S. (2006). Sex Trafficking in South Asia. *International Journal of Gynecology and Obstetrics*, 94, 374–381.
- ^{xxv} Mahendra, V.S. et al. (2007). Understanding and measuring AIDS-related stigma in health care settings: A developing country perspective. *Journal des Aspects Sociaux du VIH/SIDA*. VOL. 4 NO. 2 ; P616-625.
- ^{xxvi} Mahendra, V.S. et al. (2007). Understanding and measuring AIDS-related stigma in health care settings: A developing country perspective. *Journal des Aspects Sociaux du VIH/SIDA*. VOL. 4 NO. 2 ; P616-625.
- ^{xxvii} Elamon, J. (2005). A situational analysis of HIV/AIDS-related discrimination in Kerala, India. *AIDS Care*, 17(Supplement 2): S141-S151.
- ^{xxviii} Green, D.A., Devi, S., & Paulraj, L.S. (2007). Care centre visits to married people living with HIV: An indicator for measuring AIDS-related stigma & discrimination. *AIDS Care*, 19(7): 910-915.
- ^{xxix} Kaulagekar, A. & Godbole, A. (2007). Prevalence of Stigmatizing Attitude Among Urban Middle Class in Maharashtra: Implications for HIV/AIDS Education Strategy. *Indian Journal of Community Medicine* Vol. 32, No. 4.
- ^{xxx} Paul, N. (2007). Discrimination against people living with HIV/AIDS in India: Educated persons as perpetrators. *Journal of Infection*, 54, 103-104.
- ^{xxxi} Islam, M.T., Mostafa, G., Bhuiya, A.U., Hawkes, S. & Francisco, A. D. (2002). Knowledge on, and Attitude Toward, HIV/AIDS among Staff of an International Organization in Bangladesh. ICDDR,B: Centre for Health and Population Research. *Journal of Health, Population, & Nutrition*, 20(3):271-278.
- ^{xxxii} Rahman, M., Shimu, T.A., Fukui, T., Shimbo, T. & Yamamoto, W. (1999). Knowledge, attitudes, beliefs and practices about HIV/AIDS among the overseas job seekers in Bangladesh. *Public Health*, 113, p35-38.
- ^{xxxiv} Ickovics, J., White, K., Stasko, E., Ghose, T. (2007). HIV Related Stigma and Discrimination in Asia: A Review of Human Development Consequences. UNDP Regional Centre in Colombo, p3.
- ^{xxxiii} Japan International Cooperation Agency (2002). Country profile on disability: Peoples republic of Bangladesh, p.10.

(***We categorized the respondents according to the profiles that they were originally purposively selected as, i.e. the house-wife who was previously a sex worker was identified as a house-wife for study purposes.)