

# Journeys:

Experiences of Nepalese and Bangladeshi  
cross border migrants living with HIV



LOTTERY FUNDED

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Published by EMPHASIS Regional Secretariat, Kathmandu

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# Acknowledgement

“Journeys: Experiences of Nepalese and Bangladeshi cross border migrants living with HIV” was conducted in Bangladesh, Nepal and India. Numerous organizations and people were involved in the research process.

First of all, we are grateful to Big Lottery Fund, the largest distributor of National Lottery good cause funding in the United Kingdom for its support for the study through the EMPHASIS project implemented by CARE in Bangladesh, India and Nepal.

We acknowledge the involvement of PLHIV self-help group ‘Ashar Alo Society’, ‘Mukto Akash Bangladesh’ and ‘Geon Health’ as they backed up the study by arranging interviews with PLHIV in Bangladesh. Similarly, we are thankful to partner organization of CARE Nepal in Achham and Kanchanpur including Peer Educators and Partner organizations Action Research Center, Anchal Charitable Trust and Bharuka Public Welfare Trust in India for supporting the field level data collection activities.

We would like to acknowledge research assistants in Bangladesh and Aditi Mishra from India and Nur Prasad Pant of Nepal for carrying out the research work with support from M&E managers in respective countries. We would also like to acknowledge the efforts of Bipin Thapa from Gangotri Rural Development Forum, Nepal, Umesh Gahatraj and Yam Nath Yogi, Sanju Wagle from CARE Nepal for their contribution in the study design, assisting field team and presentation of preliminary findings.

We would also like to acknowledge the support of the Overseas Development Institute in designing the study and providing ongoing guidance. The guidance of Senior Project Director and Country Team Leaders of the project during the study were helpful.

Most importantly we are grateful to the participants of this study who provided information without hesitation, given their time and shared their experience and views regarding mobility and vulnerability to HIV.

# Foreword

“Journeys: Experiences of Nepalese and Bangladeshi cross border migrants living with HIV”, a compilation of three different studies conducted in Nepal, India and Bangladesh, reflects the fact that the journeys of migrants especially for those living with HIV across continuum of mobility are challenging.

In the context of general migration discourse, one of the existing facts is that in different forms majority of migrants have to face multiple levels of stigma, discrimination and harassments at source, transit and destinations. For many migrants living conditions are not well especially in destination. For those living with HIV, the journey is even critical because of the challenges in accessing health services including access to ART. For women, the levels of vulnerabilities are deeper and thus are forced to face additional vulnerabilities. While exploring barriers to access to services related to HIV, one of the interesting findings of the study is that availability of treatment, care and support services for PLHIV doesn't always ensure accessibility and it explains the reasons and evidences behind it.

The significance of this study is to bring the issues and challenges around access to services so that it would help stakeholders including the government and civil society to take collective actions accordingly. Meanwhile, EMPHASIS being a regional project on cross border migration, study also captures some of the innovative intervention and facilitation of EMPHASIS in informing, alerting and supporting migrants to access services in the continuum of mobility starting from source, transit and destination. These innovations have added new values and learning in the journey of AIDS response in the region.

The authors of this study, Mirza Manbira Sultana and Navneet Kaur, have tried their level best to consolidate the findings of three different studies conducted in Nepal, India and Bangladesh. I appreciate this effort to capture issues and challenges as well as in sharing some learning from EMPHASIS interventions. In the meantime, I also appreciate entire team in Nepal, India, Bangladesh, partners, PLHIV networks, migrants and stakeholders and reviewers in putting collective efforts at various levels to complete this study.

**Prabodh Devkota**

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# Abbreviations

AIDS	Acquired Immuno Deficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral Therapy
BDT	Bangladeshi Taka
BNP+	Bangladesh Network of Positives+
BSP	Bangle Speaking Population
CAAP	Confidential Approach to AIDS Prevention
CBMP	Cross Border Mobile Population
CHBC	Community Home Based Care
DOTS	Directly Observed Treatment, Short- Course
EMPHASIS	Enhancing Mobile Populations' Access to HIV and AIDS Information Services and Support
FGD	Focus Group Discussion
FHI	Family Health International
GFATM	Global Fund to Fight for AIDS, Tuberculosis and Malaria
HIV	Human Immunodeficiency Virus
HPNSDP	Health Population Nutrition Sector Development Program
IEDCR	Institute of Epidemiology, Disease Control and Research
ID	Identification
IDH	Infectious Disease Hospital
IDI	In-depth Interview
IDU	Injecting Drug User
INR	Indian Rupees
ICDDRDB	International Center for Diarrhoeal Disease Research, Bangladesh
KII	Key Informant Interviews
MARP	Most at Risk Population
MJF	Manusher Jonno Foundation
MSM	Men having Sex with Men
NACO	National AIDS Control Organization
NASP	National AIDS and STD Program
NCASC	National Center for AIDS and STD Control
NHRC	Nepal Health Research Council
NNP+	North Parganas Network of Positives+
NMP	Nepalese Migrant Population
NPR	Nepalese Rupees
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
PPTCT	Prevention of Parent to Child Transmission
RCC	Rolling Continuation Channel
SAARC	South Asian Association for Regional Cooperation
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infections
UNAIDS	United Nations Programme on HIV and AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

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# EXECUTIVE SUMMARY

Enhancing Mobile Population's Access to HIV and AIDS Information (EMPHASIS), Services and Support is a 5-year project funded by Big Lottery Fund, UK. EMPHASIS is implemented in Nepal, India and Bangladesh to address AIDS related vulnerabilities of cross border populations who are moving between Bangladesh, India and Nepal

EMPHASIS is an operations research project and one of the pioneer regional projects to address HIV and AIDS vulnerability among cross border populations. The project aims to address its goals through service provision, capacity building of relevant partners/stakeholders, and advocacy through generating evidence. As part of generating evidence, EMPHASIS developed a research study to investigate the dynamics associated with accessing services for mobile groups who are already affected by HIV and AIDS. This study examines people and questions that were not covered by the EMPHASIS baseline survey that was previously conducted.

Three separate studies were conducted in Bangladesh, Nepal and India. Bangladesh and Nepal first initiated the study aiming to understand the dynamics of HIV infection among migrant populations and also to assess barriers to accessing services at source. In India the study was initiated later, to assess the barriers to accessing services at destination. The prime objective of the study was to present these barriers to services at the regional level among the regional stakeholders. Sharing the findings at South Asian Association for Regional Cooperation (SAARC) could be an important way to initiate dialogue between the governments of Nepal and India to formalize a cross border referral system. Country specific barriers to services will be provided as evidence to inform policy at the national level.

## KEY FINDINGS

The study explores migration scenarios for Bangladeshi and Nepalese migrants with a special focus on AIDS related vulnerabilities.

## CONTEXT OF MIGRATION FOR PLHIV

Overall migration was reported as a livelihood strategy in response to extreme poverty for Bangladeshis. Some migrants reported it as a way to reunite with relatives while most female migrants were accompanying their husbands.

There were three common scenarios for Bangladeshis and Nepalese people living with HIV (PLHIV) regarding HIV infection and seeking health services. One group of respondents returned to their home country with persistent illness. They approached different health facilities to identify the cause of their illness and after many hurdles they found out about their HIV status. This group is now linked with treatment, care and support services in their home country. The second group of respondents sought health care at their destination and has approached private facilities. This group was identified as HIV-positive in India but later returned to their home (in either Bangladesh or Nepal) and has sought treatment services at home. The third group of respondents also had persistent illness and they sought health care in India. This group was later diagnosed in India and now they are accessing treatment facilities in India. There is a fourth group of respondents who are Nepalese migrants diagnosed in Nepal and who came back to India but still access ART from Nepal. This group of respondents has experienced the processes of getting an ART transfer from Nepal to India.

Both Bangladeshi and Nepalese respondents faced additional vulnerabilities as women. There are two recurring scenarios recounted by female Bangladeshi respondents. One group decided to migrate as a survival strategy because they were divorced, widowed or abandoned by their husbands. The other group either went with parents or other relatives or to visit relatives. Among 14 female respondents 3 were trafficked and forced into sex work. In both scenarios, women perceived themselves as being vulnerable to HIV. Among 14 women 11 assumed they contracted HIV from either their migrant husband or their Indian husband.

Among female Nepalese, HIV is a primary reason for poverty. All (8) of the female respondents lost their husbands due to AIDS. All 8 respondents also believed to be infected by their husbands. The economic situation of these women in Nepal has rapidly deteriorated with the loss of the primary income their husbands were providing. Now, these households face the loss of a primary income source with the additional health care costs that come with being HIV positive.

In Bangladesh HIV is still surrounded by misconception and fear among the community and service providers. Those infected with HIV, in order to avoid stigma, choose to conceal their status to their community and also to service providers.

In Nepal, HIV related misconception and stigma is gradually decreasing, reported by respondents. In areas where there is higher prevalence, NGOs have formed community-based organizations (CBOs). The CBOs work to sensitize community and family members of PLHIV to reduce stigma and discrimination. CBO's also provide psychosocial support to PLHIV. As the number of PLHIV has been increased in the study area, CBO activities have also increased and respondents reported a change in the community's attitude toward PLHIV.

## **BARRIERS TO SERVICES**

In Bangladesh, care and support services to PLHIV used to be implemented by PLHIV self-help groups through a funded program. From December 1, 2012 these services, including ART distribution were supposed to be rendered through government hospitals. Despite this, the service modality has not changed. The absence of a sustainable service system is the primary challenge for treatment, care and support for PLHIV in Bangladesh. Additionally, misconceptions and stigma around HIV transmission is high among service providers in Bangladesh. The study shows many PLHIV attempt to conceal their HIV status to service providers.

In Nepal, treatment care and support services have been scaled up under universal care and support at government health facilities. Though services are available, most respondents are unable to access them regularly because of the distance between their home and the health facilities. Additionally, the array of services needed cannot be accessed at a single location. Different facilities provide different services. Different services are also provided on different days.

In India services are scaled up at government and non-government health settings at district and sub-district level. In the big cities like Mumbai, the volume of clients is high resulting in long queues and a lower quality of service. Migrants also face language barriers as the service providers often use their local language. Though there is a system in place clients often wait an entire day to pick up their medication. Additionally, although no identity (ID) proof is required for HIV services, respondents reported that they were asked for identity (ID) proof to access services.

## **EMPHASIS RESPONSES**

EMPHASIS has introduced some services, which are essential to the consistent delivery of treatment, care and support services for people living with HIV (PLHIV). In Bangladesh, EMPHASIS has established voluntary counseling and testing (VCT) centers at government health facilities. These are the first VCT centers at government facilities that are established for targeting the cross border mobile population. Additionally, EMPHASIS has already started to link for HIV treatment across the border from source to destination and destination to source. These are promising examples from a regional project that is helping migrant PLHIV access services at source and destination.

## **CONCLUSION**

The study shows that even when services are available, clients face many challenges to access them especially at destination sites. EMPHASIS as a regional project has demonstrated some strategies to improve cross border linkages. Most significant among them is the ART transfer that has been done through EMPHASIS facilitation. This experience can be utilized to design a formal cross border ART transfer between Indian and Nepalese ART distribution centers. In order to make treatment, care and support accessible to undocumented Bangladeshi's a project-based approach might be required due to the legal context.



Enhancing Mobile Populations' Access to HIV and AIDS, Services, Information and Support (EMPHASIS) is a 5-year project funded by Big Lottery Fund, UK. EMPHASIS is implemented in Nepal, India and Bangladesh to address AIDS related vulnerabilities of cross border populations who are moving between Bangladesh, India and Nepal

Bangladesh and Nepal are low HIV prevalence countries. The prevalence rate is less than 0.01% in Bangladesh and 0.3% in Nepal among the general population. India, although it is considered a low prevalence country with 0.31% prevalence in general population, has the third largest number (2.4 million) of people living with HIV and AIDS (NACO, 2010-2011). The number of people migrating from Bangladesh and Nepal to India has increased in recent decades, with Mumbai being one of the major destinations. Alongside this increase, there is a growing concern that mobile populations are forming a bridge between high HIV prevalence areas of India to low prevalence areas of Bangladesh and Nepal.

In the baseline survey carried out in 2010-2011 in Bangladesh, Nepal and India (Sultana, T. and et al, and S, Wagle and et al 2011), the vulnerabilities of PLHIV in the EMPHASIS region was not explored. As such, it was decided to carry out a separate study on PLHIV to explore the experiences of cross border PLHIV and the barriers they face in terms of accessing services and treatment. The study results will be used as evidence to inform regional advocacy initiatives addressing barriers to accessing ART and care and support for cross border mobile PLHIV.

The study was conducted in Bangladesh among PLHIV respondents of EMPHASIS working area (Jessore and Satkhira) and neighboring cities. In Nepal, it was conducted in Accham and Kanchanpur. In India, the Study was conducted among Nepalese and Bangladeshi people living with HIV in Delhi, Mumbai and Kolkata.

## 1.2 STUDY OBJECTIVES

Three studies were conducted each study having country specific objectives as well as common regional objectives. In order to inform regional policy through the South Asian Association for Regional Cooperation (SAARC), EMPHASIS ensured that there was a common objective aimed at exploring the barriers to accessing HIV and AIDS services among migrant populations. EMPHASIS envisioned these studies as a way to gather evidence to support cross border referral systems for PLHIV. Country specific data will be used to inform policy and advocacy initiatives at the national level.

### Bangladesh

- Explore barriers to accessing ARV and care and support services at source and destination by migrant PLHIV.
- Explore trends of HIV infection in the south west region of Bangladesh

### Nepal

- Explore livelihood and economic activities and opportunities for PLHIV and their family members
- Assess factors determining social exclusion of PLHIV in the community
- Explore barriers to access ARV and care and support services at source and destination by migrant PLHIV.

### India

- Explore barriers to access ART and other care and support services

## 1.3 LITERATURE REVIEW

### HIV /AIDS Scenario

#### Bangladesh

Bangladesh is a low HIV prevalent country with a prevalence rate of less than 0.01% among the general population (9th Round Serological Surveillance). HIV in Bangladesh is concentrated with higher prevalence rates among drug users in Dhaka. Among sex workers the prevalence rate is still relatively low (<1%) except for sex workers in the bordering district Hili where prevalence is 1.6%. Among the sex workers of different bordering districts, the serological surveillance data shows that proportion of sex workers who crossed the border to India and sold sex is highest in Hili. This indicates a link between mobility to India and heightened HIV vulnerability (9th Round National Serological Surveillance, 2011).

Interventions in Bangladesh are designed to reduce risk and vulnerability of different targeted risk groups, through harm reduction program for drug users and other preventive programs for risk groups such as sex worker, MSM and transgender. As of December 1, 2012 the total number of reported PLHIV in Bangladesh is 2871 and 1204 AIDS cases. (NASP, 2012). Registered PLHIV are eligible to receive ARV (according to CD4 count) from funded programs free of charge.

### Nepal

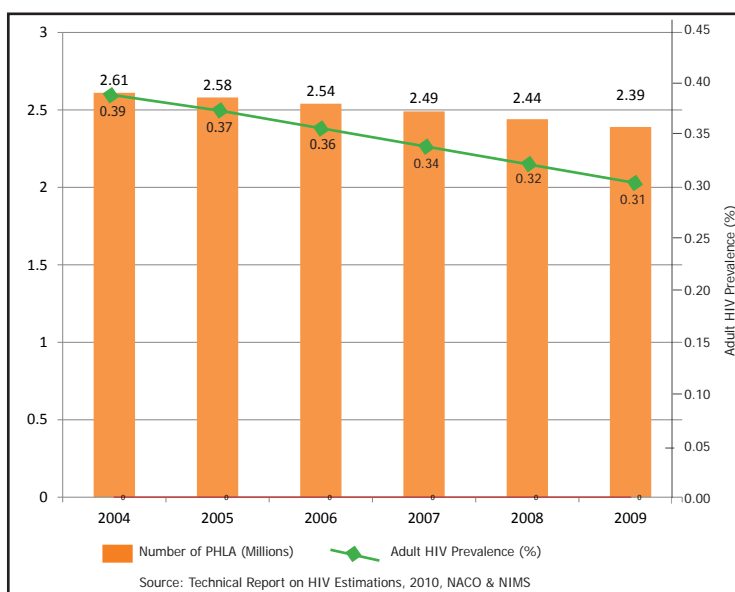
In Nepal the HIV epidemic is concentrated among key populations such as sex workers, IDUs, MSM, transgender and migrants. Until November 25, 2012 a total of 20583 reported cases of HIV were identified. There are approximately 50,287 estimated PLHIV as of 2011. Injecting drug users, who are also sometimes commercial sex workers, and sex workers who migrate or are trafficked to Mumbai are key populations in Nepal. Fifty-eight percent of the HIV infections are accounted key populations. (World Bank, 2012). The government of Nepal also found that in 2008, 41 percent of all HIV cases in the country were among labor migrants (IRIN ASIA,2011) In the district of Achham local people report that migration is the sole reason for the 1.7% HIV prevalence rate in the district(Poucel,CK., et al, 2006).

### India

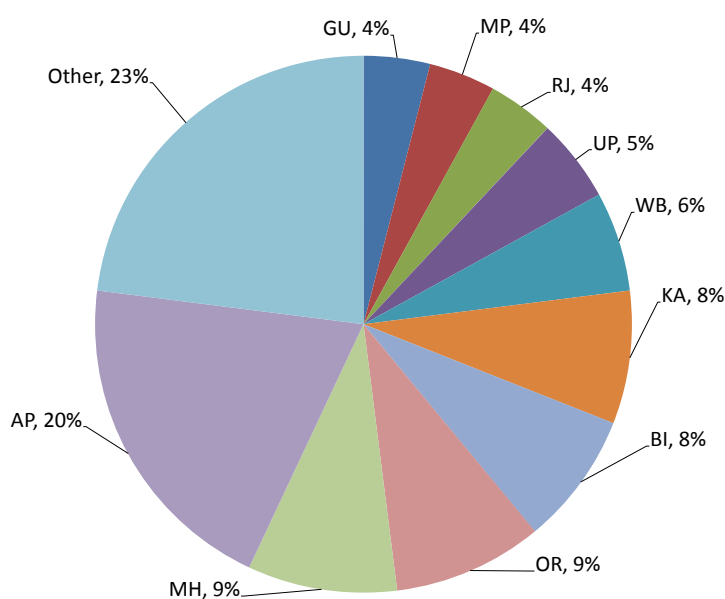
Though India is a country with low HIV prevalence, it has the third largest number of people living with HIV and AIDS; HIV estimates 2008-2009 highlight an overall reduction in HIV prevalence at the national level. There has been a steady decline from 0.41% in 2000 through 0.36% in 2006 to 0.31% in 2009.

The total number of people living with HIV and AIDS in India is estimated at 2.4 million in 2009(NACO 2010).

Variations exist across the states. The four high prevalence states of South India (Andhra Pradesh–0.5 million, Maharashtra–.42 million, (Karnataka–.25 million, Tamil Nadu–.15 million) account for 55% of all HIV infections in the country.



### Statewise Distribution of New HIV Infections, 2009



Three separate studies were conducted in Bangladesh, Nepal and India. Qualitative research methods were used in India and Bangladesh while both quantitative and qualitative methods were used in Nepal. In both Bangladesh and India the number of PLHIV identified was small. Due to the small sample size, the research team decided to employ qualitative methods. In Nepal, the sample size was larger with a total of 281 reported cases in Achham and Kanchanpur. The research team in Nepal decided to use a quantitative survey along with qualitative tools to complement the quantitative findings. This chapter will outline the detailed methods used in each of the three countries.

## 2.1 BANGLADESH

In Bangladesh the study was conducted with the support of the Network of HIV Positive (BNP Plus) of Bangladesh by collecting information from PLHIV enlisted in the networks. The study was focused on selected migrant PLHIV, with the prime samples being from cross border mobile PLHIV(CBMP). Among the cross border mobile PLHIV enlisted in the PLHIV self-help group, around 50 PLHIV were reachable. As the CBMP PLHIV are hard to reach only qualitative methods were used and consisted of in-depth interviews among the PLHIV and Key Informant Interviews of PLHIV self-help group leaders and health service providers.

**Table 2.1.1: Method and Sample Size**

Interview method	Target study group	Number	Area
IDI	PLHIV(CBMP)	20	Dhaka and Khulna
KII	Self-help group leaders	3	Dhaka and Khulna
	Health service provider	2	Dhaka

**Table 2.1.2. Self-help group wise distribution of respondents**

Name of Self-help group	Number of PLHIV
Ashar Alo Society	7
Mukto Akash	8
Geon Health	5
Total	20

Among the five self-help groups of PLHIV, three work in the southwestern region of Bangladesh. Data has been collected from these three organizations. Table 2.2.2 shows that there were 7 PLHIV from Ashar Alo Society, 8 PLHIV from Mukto Akash Bangladesh and 5 from Geon health.

In Bangladesh, 13 case stories of PLHIV from the VCT centers at government health facilities were collected. Those stories were also analyzed to present the findings from the VCT centers.

## 2.2 NEPAL

In Nepal a cross sectional study was conducted, involving both quantitative and qualitative methods. The proposed study was conducted in the EMPHASIS project areas of Achham and Kanchanpur districts. There were a total of 281 PLHIV listed in the project area; 86 in Achham and 195 in Kanchanpur.

**Table 2.2.1: Sample size in Nepal**

Method	Achham	Kanchanpur	Male	Female	Total
Quantitative	49	92	40	101	141
Qualitative	10	10	12	8	20
Total	59	102	62	109	161

A census sampling was applied in this study. All the listed PLHIV available during data collection were approached for interviews. A total of 49 PLHIV in Achham and 92 in Kanchanpur were interviewed. For the qualitative study, respondents were purposively selected from different categories ensuring a mix of different age groups, gender, ethnicity and time since HIV diagnosis. A total of 20 in-depth Interviews were carried out, 10 in each district. Those selected for the in-depth interview were excluded from the quantitative sample.

## 2.3 INDIA

In India, a qualitative study was conducted and a total of 20 in-depth interviews were carried out between Bangladeshi and Nepalese migrant population in Delhi, Mumbai and Kolkata.

**Table 2.3.1: Distribution of Respondent**

Respondent Type	NMP		BSP		Total
	Male	Female	Male	Female	
Location					
Delhi	2	1	--	--	3
Mumbai	5	5	1	4	15
Kolkata	--	--	--	2	2
Total	7	6	1	6	20

## 2.4 TOOLS

A quantitative questionnaire was developed for the quantitative study in Nepal. For the qualitative study, three countries developed separate IDI questionnaires under similar themes.

**Table 2.4.1: Themes covered in the study**

Bangladesh	Nepal	India
Demographic Information	History of migration	ART Transfer from Nepal
Livelihood and employment	Livelihood and employment	Linkages with HIV networks
History of Migration	Attitude toward HIV-positive persons	Nutritional Support
Experience about PLHIV status	Health Situation – Health Service Provision and Access	Legal Support
Societal, experience as a PLHIV	Network Membership and Rights of PLHIV	Discriminatory attitude/Behavior of health service providers

## 2.5 DATA COLLECTION

In Bangladesh, research assistants were recruited for the study. Interviews were conducted, recorded and signed consent had been taken from the respondents. The M&E manager of CARE Bangladesh was also involved in designing the study and leading the research team during data collection.

An Individual consultant was hired in Nepal, and 4 four research associates (2 supervisors and 2 enumerators) were hired and trained by consultant for the study.

In India, an individual consultant was hired who worked on the guidelines, data collection and report writing. The MED Manager of EMPHASIS guided the consultant during the study.

## 2.6 ETHICAL CONSIDERATIONS

CARE received ethical clearance for the study from the Nepal Health Research Council (NHRC). Participants involved in the study were fully informed about the nature of the study, the study objectives, and the confidentiality of the data and the research team obtained full consent for their participation in the study. The potential benefit of participating in the study was explained to all the research participants. Informed consent form was written in simple Nepali and Bangla. This was read out to the respondents and verbal and written (in Bangladesh) consent was obtained.

During the introduction, study participants were told that they could skip any questions they did not wish to answer. At the end of interview they were given the opportunity to make comments or ask any questions to the interviewers. Individual interviews were conducted in a private setting. No one but the interviewer and the respondent were present during the interviews. Interviewers were instructed to terminate or change the subject of discussion if an interview was interrupted. An appropriate time for the interview was planned and if necessary respondents were visited repeatedly.

The confidentiality of all participants enrolled into this study was protected to the fullest extent possible. Tape-recorded interviews have been kept in a locked cabinet and only core research team members have access to them. Recorded interviews were erased following their translation. Prior consent of the participants was obtained to record the interviews. No individual data has been disseminated. No names were entered into the computerized database. Moreover, all researchers have received strict instructions about the importance of maintaining confidentiality.

## **2.7 DATA MANAGEMENT AND ANALYSIS**

All completed structured questionnaires were edited and coded before entering into the computer. Data was entered into the statistical package for social science (SPSS). Before analyzing the data, consistency and range checks were carried out for all the questionnaires.

For the qualitative information, all the data collected from in-depth interviews were translated and transcribed by the note taker.

## **2.8 CONSOLIDATED REPORT**

Three separate PLHIV reports were produced by consultants in Nepal and India and by the Country team in Bangladesh. The consolidated research report has been produced at the Regional Secretariat by the Regional Research Manager of EMPHASIS.



# 3 DEMOGRAPHICS

Migrant PLHIV were interviewed in the EMPHASIS project areas covering both source and destination. This chapter presents the demographic data collected.

## 3.1 BANGLADESH (SOURCE)

17 out of 20 of PLHIV who had migrated to India came from extremely poor families with a household income level ranging from 500 -5000 per month. Only one respondent's income level was 30000-35000 (See Box 3.1.1). Migration for all respondents was cited as a survival strategy. While in India they were able to increase their household income but later faced poverty because of lack of job opportunities and low wages in their home country. One of the respondents used to earn 30000-35000 per month working in the fish business in India. After returning home, the respondent is working as a volunteer in a PLHIV self-help group and has a reduced monthly income of 4000-5000. As a migrant, the respondent was the primary source of income to the family. The family's economic situation has suffered after one or more members have contracted HIV.

BOX: 3.3.1

### Income of respondents

Income	Persons
1000 to 5000	9
6000	2
3000 to 35000	1
Not specific (Agri-labor or homemaking)	8

**Table 3.1.1: Marital Status of respondent PLHIV**

Marital Status	Male	Female
Never married	1	1
Married	4	2
Abandoned		4
Divorced	1	3
Widow		4
Total	6	14

Only two respondents had never been married, one male and one female. Among other respondents one male respondent was divorced; all other male respondents were married. Among the female respondents only 2 are currently married. 11 out 14 are abandoned, divorced or widowed due to HIV. Only one female respondent was never married.

## 3.2 NEPAL (SOURCE)

Table 3.2.1 shows A majority of the respondents (61.7%) are in the age bracket of 31-45 years. Almost two-thirds. (62.4%) of the respondents are Dalit and majority (96.5%) are Hindu. More than half (51.8%) of the respondents are currently married while a significant portion (46.1%) are widowed. It is important to notice that among women 63.4% are widowed. The average household size is 5.2. Around 50% of the respondents are illiterate. About 43% respondents are returnee migrants and 44% are spouses of the migrants while 13.5% are circular migrants. Marital status of PLHIV shows that 46.1% of the respondents were widows or widowers. For 63.1% of the respondents, HIV is the reason behind separation with their spouse.

**Table 3.2.1: Socio-Demographics of Nepalese Respondents**

Variables	Number/category	Female	Male	Total (%)
Age (in years)	20 years or less	2(2.0)	0(0)	2 (1.4)
	21 – 30	18(17.8)	5(12.5)	23(16.3)
	31 – 45	64(63.4)	23(57.5)	87(61.7)
	46 – 60	17(16.8)	10(25.0)	27(19.2)
	61 and above	0(0)	2(5.0)	2(1.4)
Ethnicity	Dalit	63(62.4)	25(62.5)	88(62.4)
	Brahmin	4(4.0)	3(7.5)	7(5.0)
	Chhetri	34(33.7)	12(30.0)	46(32.6)
Religion	Hindu	97(96.0)	39(97.5)	136(96.5)
	Buddhist	2(2.0)	1(2.5)	3(2.1)
	Christian	2(2.0)	0(0)	2(1.4)
Marital status	Never married	3(3.0)	0(0)	3(2.1)
	Married	34(33.7)	39(97.5)	73(51.8)
	Widow, widower	64(63.4)	1(2.5)	65(46.1)
Household size	1 to 5	--	--	89(63.2)
	6 to 10	--	--	47(33.3)
	11 or above	--	--	5(3.5)
Education	Illiterate	57(56.4)	13(32.5)	70(49.6)
	Primary schooling	18(17.8)	15(37.5)	33(23.4)
	Secondary schooling	7(6.9)	12(39.0)	19(13.5)
	Adult literacy	19(18.8)	0(0)	19(13.5)
Place of residence	Achham	41(40.6)	8(20.0)	49(34.8)
	Kanchanpur	60(59.4)	32(80.0)	92(65.2)
Types of respondent	Returnee migrant	31(30.7)	29(72.5)	60(42.5)
	Circular migrant	10(9.9)	9(22.5)	19(13.5)
	Spouse of migrant	60(59.4)	2(5.0)	62(44.0)
Total		101(100)	40(100)	141(100)

**Table 3.2.2: Income of Nepalese Respondents**

Variable	Income level	Frequency	Percent
Income range	Less than 500	42	30.9
	500 to 999	16	11.8
	1000 to 1499	17	12.4
	1500 to 1999	6	4.4
	2000 to 2499	11	8.1
	2500 to 2999	2	1.5
	3000 to 3499	10	7.4
	3500 to 3999	1	0.7
	4000 to 4499	5	3.7
	4500 to 4999	3	2.2
	5000 or above	16	11.8
	Don't know	7	5.1
Total		136	100.0

Nearly one-third (30.9%) of the respondents of the quantitative respondent have income less than NPR 500 per month. 83.1% of the respondent have income less than 5000 per month. Nearly one in every ten (11.8%) of the respondents have income NPR 5000 or more.

## Quantitative

In order to triangulate the findings from the quantitative study, 20 in-depth interviews were conducted; 10 each in Achham and Kanchanpur. Among the respondents 8 were widowed women and 12 were married men. All the women had lost their husband due to AIDS. Among the respondents, two men were circular migrants who still regularly migrate to India, 10 are returnee migrants (male) and 8 are spouses (female) of migrants. The monthly income for 11 migrants (including spouses of migrants) is below NPR 5000 per month. The remaining 9 respondents earn more than NPR 5000 per month. All the female respondents interviewed had a minimum income of (1000-4000) which was not enough to keep their family alive.

### 3.3 INDIA (DESTINATION)

Among the 20 respondents in India, 9 were male and 11 were female, one was unmarried, 13 married and 6 were widows. The majority of migrants were engaged in labour intensive jobs. Due to poor pay, they have to work day and night. They work in various sectors. The following table outlines the reported sectors in which they work.

**Table 3.3.1: Marital Status of Respondent**

Marital status	Frequency
Married	13
Widow	6
Unmarried	1

BOX: 3.3.1

“I WORK DAY AND NIGHT”

One of the respondents, echoing responses of many others, told how one has to work throughout the day to earn money. To elaborate on the routine work one of them:

5AM to 7 AM – Car Washing

9AM to 6 PM—Car Driver

8 PM to 5 AM—Security Guard

**Table 3.3.2: Job Status of Respondent**

Job Status	Frequency
Restaurant worker	1
Factory worker	2
Watchmen	3
Driver/Car cleaner	3
Housekeeping	4
Dependent on family	3
NGO worker	3
Day Labor	1
Total	20

The respondents reported earning between, 3000 to 10000 a month. One female respondent found to have no source of income, as she is a widow and recently (two weeks before the interview) became paralyzed, after knowledge of her sero-status. She has two children. Her parents and brother live in India as well. During the interview, she reported that due to her illness the family had to spend 20000 rupees at the hospital. At the time of interview, the respondent was in a very critical health condition but unable to go to the hospital because of their dire financial situation.

### 3.4 SUMMARY

Both Bangladeshi and Nepalese respondents reported low household incomes. Female-headed widow families in Nepal have incomes within 1000-4000 rupees (qualitative). One noticeable demographic factor is that in Bangladesh 11 out of the 14 women interviewed were divorced, abandoned or widowed. In Nepal 63.4% of the quantitative female respondents were widows and all female qualitative respondents were widows in Nepal. 63.1% (n=141) of respondents cited AIDS as the reason of death for their partners.

# MIGRATION SCENARIOS OF PLHIV 4

This chapter discusses the different migration scenarios of the PLHIV respondents at source. It also explores migrants' experience as a person living with HIV at destination and presents the diversified experience of both Nepalese and Bangladeshi migrants.

## 4.1 BANGLADESH (SOURCE)

Migration history and PLHIV status varies significantly according to sex of the respondent. The scenarios analyzed are disaggregated by sex.

For respondents living in the bordering district of Bangladesh, migration to India is not always a livelihood strategy. Family and relationships at the other side of the border sometimes also work as the determining factor for migrating to the neighboring country. These factors also contribute to heightening the risk of HIV and AIDS at the destination country. Among the 6 male migrants 2 of them who went to India got married there. Among those 2, one went to meet his mother in India leaving his first wife and children in Bangladesh. His mother in India insisted him to marry an Indian woman of her choice, and he did so. His second Indian wife later died of an unknown illness. Another male respondent went to meet his aunt in India after having a serious argument with his father (See Box: 4.1.1). One female respondent's original home was in India and she stayed in India during her childhood. Later they migrated to Bangladesh. As they had land and relatives in India they visited them often.

Also among the female respondents who went to India with their parents during childhood, both were brought up in India, and got married there. Later one of them was sold to a pimp in India with the promise of a high paying job. The other respondent returned to Bangladesh after her husband's death. Two female respondents went to India to work with relatives. Upon arrival, they were married to Indian males arranged by their relatives. There are other examples of women migrating to India with a cousin or another family member with the aim of getting a better job, but instead they ended up marrying an Indian or being forced by relatives or brokers to engage in sex work.

Mobility to India is also seen as a "rite of passage" for Bangladeshi's living in the bordering districts. One respondent was 8 years old when she went to India; She was angry with her parents, so she left home with her friends and went to India (See Box: 4.1.2). There she and her friends were kidnapped and sold to a brothel. She was rescued by the anti trafficking organization "Rights Jessore" at the age of 12. After coming back she was diagnosed as a HIV positive while in the custody of "Rights Jessore". (The respondent was a bit reluctant to share the entire story)

The treatment scenarios shows among the 20 respondents 3 were initially diagnosed in India, all others were diagnosed in Bangladesh. All except one is accessing treatment care and support from Bangladesh. The rest of the migrant respondents (both male and female) came back to Bangladesh with persistent illness and being diagnosed as HIV-positive at Bangladesh.

Among the PLHIV respondents, 4 have currently more than one family member who is HIV positive.

### Box: 4.1.1

*"Samiul (pseudonym) is a peasant who works under his father. His aunt lives in India. He went to India 2/3 times to visit his aunt. Once he had an argument with his father, and he went to India leaving his wife and daughter behind. In India, he suffered from a stomachache and had to undergo an operation. After his operation he returned to Bangladesh, later falling sick. He later got an HIV test that came back positive.*

### Box: 4.1.2

*Mina said (pseudonym) "I was angry with my parents so I left home with friends and went to India".*

## 4.2 NEPAL (SOURCE)

### Quantitative

The quantitative data shows that all the available PLHIV in the districts of Achham and Kanchanpur during the time of interview had family members with a history of migration. Among the quantitative respondents 42.5% were returnee migrants, 13.5% were circular migrants (still migrating) and 44.0% were spouses of migrants.

83.7% of the quantitative respondents received an HIV and AIDS test in Nepal while 16.3% were tested in India. Only 10.6% of the respondents tested out of curiosity while 31.2% went because their spouse either tested positive or died. The remaining 54.6% got tested because of persistent illness.

### Qualitative

Among the qualitative respondents 10 out of 12 male respondents had a history of migration to India. For one male respondent his first wife had also migrated to India in the past. Among the 10 male respondents, 3 were diagnosed while they were in India. Three of the respondents returned to Nepal after their diagnosis. Among the 3, one respondent got diagnosed in Mumbai while donating blood. The other two respondents went to the doctor in India because of persistent illnesses.

One of the respondents who was diagnosed in India reported, *“Doctors in Indian hospital said; in Nepal, organizations like CARE Nepal, WAC Nepal help HIV infected people, medicine is available and treatment is also good in Nepal”*. So after his diagnosis, he returned to Nepal and started treatment.

Among the 8 male respondents who were diagnosed in Nepal, one said he traveled to India again for work. One respondent had persistent illness. Later he had a gland operation in India but had persistent symptoms and returned to Nepal where he was diagnosed with HIV. One respondent's wife and children tested HIV-positive in Nepal after learning of their status he came back and also tested positive. None of the male migrants had experiences with accessing ARV or any other care and support service while in India. All of the female respondents had their HIV tests in Nepal, while 5 of them got VCT and were diagnosed with HIV after their husband's death.

Among the male respondents, 5 of their wives are also HIV-positive. Two have HIV-positive children. For the female respondents all of their husbands died either from unknown diseases or from AIDS. One female reported that all six of her children tested positive and all of them were diagnosed after her husband's death (See Box: 4.2.1).

Among the female respondents, 6 out of 8 had accompanied their husbands to India. The remaining 2 respondents had husbands who migrated alone.

Female and male migrants' stories show that male migrants used to stay at the destination alone without family. Six female respondents visited their husbands at destination but did not stay there the whole time; they stayed either for a few months or a few years. 3 out of the 11 male migrants mentioned that they have visited sex workers while in Mumbai, being influenced or encouraged by friends (See Box: 4.2.2). One mentioned about having relationship with a neighborhood girl on a regular basis.

#### BOX: 4.2.1

*Lujhari (pseudonym) is a Nepali female living with HIV, she lives in Kanchanpur Nepal. Her husband used to work in Mumbai 12 years ago. All of a sudden her husband died. This changed her life. Her children were small and she faced many challenges educating her children. She frequently fell sick. She was diagnosed with TB and received DOTS therapy. It was not cured which forced her to seek VCT from a mobile camp. After VCT, she knew she and all of her 6 children were HIV positive. She feels her husband also died of AIDS. Now her son is the main breadwinner of the family. He is now working in Surat, India. He sends 3000 rupees every three months. She also works on daily wages as an agricultural laborer. She has managed to keep her family alive with this income.*

#### Box 4.2.2

*One male Nepali respondent said “friends called me Hijada (transgender) if I refused to go to brothel”.*



### 4.3 INDIA (DESTINATION)

Among the Nepalese respondents interviewed in India, there were 5 female respondents and 7 male respondents. Among the 5 female respondents, 4 were widowed due to AIDS. One widow remarried. Therefore, 2 respondents are currently married. Only one woman came to India alone and lived with relatives. She got married to a Nepali man in India. The other respondents arrived in India after marriage. One woman interviewed in India, reported that she resides and gets her medicine from Nepal. She started ART in India but when her mother-in-law was sick, her husband arranged an ART transfer from India and she returned to Nepal and continues her treatment there.

There are 7 male Nepalese respondents; among them 3 have experienced transferring ART. One had accessed ART transfers from India to Nepal and then returned to India and was able to transfer and access ART in India. He reported that since he did not have the ART number written in the transfer letter he had to go back to Nepal to bring the ART number. After that his ART was transferred to India

Among the 7 Nepalese men, 4 have their wives living with them in India. The remaining 3 have spouses reside in Nepal. One respondent mentioned his wife often shuttles between India and Nepal in order to stay with him.

Among the Bangla speaking respondents, only 2 were actually from Bangladesh. One came to India after her husband abandoned her. She needed to work to survive and support her three children, so she went to India and was forced into sex work. Her story shows that after diagnosis in a clinic she was enlisted with an organization that arranged hospitalization for her. All of the organizations where she sought health care initially asked for her Voter ID card. She was enrolled in ART and received treatment with a reference letter from the first hospital she was admitted to (See Box 4.3.1). The other female respondent went to India with husband after marriage. She and her husbands as well as their younger child are HIV-positive. She started ART from India but later stopped because of financial reasons.

Among the other 5 Bangla Speaking respondents, 3 are currently living in Mumbai but their home is in Kolkata. The other two respondents (mother and daughter) are still living in Kolkata. Only one male Bangla speaking PLHIV was interviewed in destination and is also from Kolkata.

Nepali migrants can work in India under the Indo/Nepal friendship treaty of 1950. According to the treaty, the two countries provide similar rights to the citizens of the other except for voting rights. Despite the treaty, Nepalese often face discrimination while working in India. Nepalese respondents were often not aware of their rights and entitlements. Responses indicate that although no Voter ID card is required to access HIV and AIDS care and treatment services hospitals still required a Voter ID card. Although services are available in government hospitals 2 Nepalese migrants reported receiving an HIV test from private clinics. The cost of an HIV test at a private clinic for one respondent was 250 and for the other one 750 Indian Rupees. Respondents reported seeking health care at private clinics rather than government hospitals for other health problems as well.

#### Box: 4.3.1

*Ruma (pseudonym) is a Bangladeshi woman. She has three children. Her husband left her and married for the second time after her third child was born. In order to survive with her children she migrated to India leaving her children in Bangladesh with her mother. She was forced to engage in sex work at a bar in Dombivali, Mumbai. She has lived in Mumbai for the last 10-11 years. She had fever; allergy and headache three years ago that made her go to the hospital where she was eventually tested for HIV. The test came back with HIV positive and she was referred to an organization named Adhaar, which supports people living with HIV. With the help of Adhaar, she was admitted in Jyothi hospital. There she had her CD4 test done. In both Jyothi and Adhaar they asked for official proof of residence in India. Now she is accessing ART from Dhirubai hospital. She has a ration card but didn't want to show that in fear of getting identified as a PLHIV. Now she is living with a man who is paying her rent. Her son and grandson live with her. Her Daughter –in-law left her son when she came to know about Ruma's HIV status.*

## 4.4 SUMMARY

The Bangladeshi accounts shows that although migrating to India has economic benefits many Bangladeshis choose to go there because of kin relations. Once in India the reality always did not match with the respondents actual intentions. As such, some female respondents also reported getting married to Indian male instead of looking for livelihood option. These female respondents' story shows marrying Indian men increased their vulnerability to HIV and AIDS. Women also reported being trafficked while in India or while traveling from Bangladesh to India.

Based on the study data, there are two scenarios of treatment, care and support. One group of Bangladeshi respondents came back to Bangladesh with persistent illness and is now accessing treatment care and support in Bangladesh. The other migrant respondent group was diagnosed with HIV in India and is now accessing treatment in India. This group had difficulty accessing services because at every health facility proof of ID was required even when they had reference letter from an NGO.

The stories of Nepalese respondents show that male Nepalese decided to migrate to improve their livelihood. The female respondents accompanied their husband or went there with relatives and got married in India.

For Nepalese respondents there are four major scenarios of accessing treatment and care. One group came back home after being diagnosed and continued treatment and care in Nepal. Among those who came back to Nepal and started treatment some returned to India again but continued taking ARVs from Nepal. Another group opted to access treatment, care and support in India. The fourth group opted for an ART transfer from Nepal to India or from India to Nepal.

### Overall Treatment, Care and Support Scenarios of migrants

Migrant PLHIV returned back to Nepal/Bangladesh from India, with persistent illness/while at home they learned about their status at source and didn't go back to India and currently taking services from source country

Migrant (Nepalese/Bangladeshi) PLHIV learned about status in India and accessing ART and other services in India

Migrant (Nepalese) PLHIV learned status in India and started ART and other services in Nepal. Went back to India and continued service from Nepal.

Learned status in India but came back to source country and is accessing services in source country

A group of Nepalese migrants who were accessing care and support from India received ART transfer and started taking ART from India and also one took transfer from India to Nepal.

# EXPERIENCES OF WOMEN 5

This chapter highlights the experiences of Bangladeshi and Nepalese women as migrants and as PLHIV.

## 5.1 BANGLADESH

The study data also provides evidence supporting the idea that women have specific and unique vulnerabilities due to socio cultural norms pertaining to the South Asian continent. Social norms in South Asia often prevent women from working outside the home, their movements are restricted, and they are controlled by early marriage. Breaking these norms leads to social stigma and women being termed as “bad” or “kharap” women. Women’s sexuality is usually under the control of their husband, and they are often perceived as the property of their husband. In contrast, men can have multiple marriages, which is permitted in Islam also not prohibited in Hinduism (Tahmina and Moral, 2004). Such social norms not only restrict women’s mobility, but also their abilities to access knowledge and information in the external world. As such, women with limited knowledge and exposure can be easily misled and exploited. Many women are deceived and trafficked from Bangladesh to India and forced into sex work.

The Bangladeshi female respondents of the study have similar stories, as such, out of the 14 female respondents, 3 were trafficked. Among 3, one respondent was trafficked at an age of 8 and rescued from a brothel in India. These women were vulnerable at different stages in their lives (See Box 5.1.2). The respondents’ stories show that even as sex workers men wanted to marry and utilize them as an income source (See Box 5.1.1). On the other hand 11 female respondents reported no other sexual partners other than their husbands. Five of them reported that their husbands migrated to India for work, 4 of them got married to Indian husbands; and two of the respondents’ husbands married another wife in India. Therefore, these women were particularly vulnerable to range of risks, including contracting HIV.

*BOX 5.1.1: RITA (pseudonym) is a Bangladeshi women who was exploited by her husband, neighbor, pimp, broker and faced multiple challenges at different stages of her life*

*“Rita got married at the age of 12 (she used to live in India with her parents and got married there) and, became a mother of two children at an early age. After several years of marriage her husband became mentally ill and he used to come and go a lot. With limited other options, she started working as household maid; there she was sexually harassed by her employer. She wanted to get a better job which would improve her quality of life, so she listen to one of her neighbors who promised her a better job. She left her children with her mother and went with the neighbor and then found that she was sold to a pimp. She was raped and forced into sex work as a profession. After one year she wanted to leave that place and asked the pimp for her money. Pimp gave her only 2000 Indian rupees as her savings, after her food and room rent. She went home to see her children with that small amount of money. After going home her sister-in-law insulted her for not bringing any money even after working for one year. She felt very bad and came back to the brothel again. She wanted to start her own business. One Nepalese sex worker told her that she would require to save money and pay advance to rent a room on her own. She borrowed 20000 INR to pay the advance and rented a room on her own. She had to pay the rent, repay her loan and save money for her children. In order to pay off her expenses she saw many clients (7/8) a day to save money. Meanwhile she sent her mother and children back to Bangladesh. She saved some 2 hundred thousand BDT and with the help of a broker crossed the border to Bangladesh. While crossing the border she gave the money to the broker. After reaching Bangladesh broker gave her the money back, but later she realized the broker had stolen half of her savings. She felt very upset as she saved that money to build a house for her children. She built a house with the remaining amount in Bangladesh.*

*In the brothel she met one Bangladeshi client who wanted to marry her. She got married to that client. Her husband went to Bangladesh and kept on insisting her to come back to Bangladesh. After that she fell sick and tested positive for HIV in a private clinic in India. She thought she was going to die. She came back to Bangladesh and with the help of a relative she learned about “Mukto Akash” the PLHIV self-help group. She received counseling there and learned that she can live if she accesses the right treatment. When she returned to Bangladesh her husband came to meet her. He wanted her to sell her house and give him her money. She understood that he had no interest in her and wanted her money. She left him and now works as an office helper in assistant office and earns 3500 BDT per month in Bangladesh. She takes care of her children and mother with that income.*

These accounts indicate that many women were either widows (4) abandoned (4) or divorced (3) by their partner after they were diagnosed with HIV. On the other hand, out of the 4 PLHIV men who are married, only one PLHIV reported his wife left him after learning of his status and later wanted to come back to him.

The data shows that 11 out of 14 female respondents are abandoned / divorced or widowed. Among the 3 widows one was identified as a PLHIV with her husband. The other two had husbands who died of unknown diseases and they later tested as HIV positive. Among the women who were abandoned, three were abandoned after their husbands learned of their HIV status. Among the divorced respondents, two got married and divorced at an early age. One was divorced by her first husband and remarried in India but her Indian husband sent her home when she was sick. There are two reported cases of female migrants who married in India and were later sent back to Bangladesh when they fell ill (See Box 5.1.3).

Also 8 out of 14 female respondents were dependent on their husbands or family for livelihood. Although 4 of them work as household maids, they receive very little income (300-500 BDT) per month. Out these 8 female respondents 6 are either divorced, widow or abandoned.

## 5.2 NEPAL

Women's vulnerability to HIV in Nepal has both a social and economic dimension. The marital status of women shows that all 8 respondents were widows, and 4 women were diagnosed with HIV after the death of their husband as they were facing persistent illnesses. In one family, the woman was diagnosed as HIV-positive along with 6 of her children. All of her children are HIV positive (See Box 5.2.1). After receiving counseling and learning about HIV, they believe the cause of their husbands' deaths was AIDS.

All of the widows mentioned above now they manage their household on their own and have monthly incomes ranging from NRs1000-4000. Among the 8 women, one is working as a counselor and another works as a peer educator in an NGO. Others earn their livelihood from daily wages working as agricultural laborers (See Box 5.2.1) and from cultivating

### Box: 5.1.2

*I grew up by wearing the used cloth of relatives. Poverty forced me to go to India. I didn't get anything in this world. I didn't find happiness, peace, home, and husband. Only got the disease.... Shoma (pseudonym) Bangladeshi women involved in sex work ... said*

### Box: 5.1.3

*Shampa a Bangladeshi female, (pseudonym) went to India (Kolkata) 6-7 years ago with her cousin. Her cousin promised her parents that she would arrange a good marriage for her in India. As she went with her cousin she didn't have any expenses. Her brother-in-law arranged her marriage with one of his Indian friends. Her husband was a driver. Once she had an abscess on her chest, her husband told her that he was embarrassed to take her to a doctor for the abscess. So he sent her to Bangladesh for treatment. After treatment, she went back to India with a fish smuggler. At that time she was 7 months pregnant, when she went back she found that her husband went to Saudi Arabia for work. So after her child's birth she came back to Bangladesh with her daughter. Her daughter was sick since birth. She was suffering from fever and cold. At an age of 5 months her daughter died. Shampa started feeling weak. In two months after her daughter's death, she suffered from recurrent TB and was not getting better. At the suggestion of one neighbor, she went to a VCT center managed by a PLHIV self-help group and was diagnosed as HIV positive. Her husband used to send her money as long as her daughter was alive. After her daughter's death he didn't send her any money. Now Shampa is living with her parents.*

### Box 5.2.1

*Pari (pseudonym), a Nepali woman, who was first diagnosed as a PLHIV before her husband. Her husband was working in India at that time. Later he was also diagnosed as HIV positive. He died 11 months before this interview. He used to earn 11000 Indian rupees per month. Now Pari is the main breadwinner with three children. She has a small piece of land. The production is not enough to feed her children, therefore she works in a stone-grinding factory for a daily wage. Her health condition does not permit her to work regularly. She earns 1000-1500 Nepalese rupees per month. She has trouble doing labor-intensive work so her son helps her with her daily household chores*

*Sanji (pseudonym) a Nepali widow, was diagnosed as a positive 9 years ago. She was diagnosed HIV positive after her husband. Now she is a widow with 2 children. She has a buffalo and three Katha's of land. Production from the land is insufficient for her family. As she has no other income source she cannot provide necessary stationeries for school to her children. Sometimes she does not have the bus fare to go to the ART center. She seeks monetary help from NGOs such as NAWA ASHA, NARI SACHESTANA, and NNSWA.*

small land. The income they have now is insufficient to support their families (See Box 5.2.1). Their stories show how they struggle to manage their households alone and raise the children with their limited income. Their poor health condition is often a barrier for them to work hard.

The respondents also discussed the difficulty in accessing ART because of the distance of the ART centers and the necessary transportation costs. Two respondents mentioned that they had to seek monetary support from NGOs working for PLHIV. One respondent said she often travels to the hospital by foot. (See Box 5.2.2).

**BOX: 5.2.2**

*“My husband has spent his life in India, where he worked as watch man. He had good earning that time. We built a house in Choukhuttee with his earning.”*

### 5.3 INDIA

In India there were 5 Nepalese female respondents all of whom contracted HIV from their husbands. Among them, 4 are widows of HIV positive husbands and have stayed in India after their husband's death. Among the Nepalese women in India, 2 have husbands who have married a second wife.

The economic situation is often bleak for Nepalese women living at destination. One woman is living in the Nepalese Migrants Lodge opened by Congress Party (Ruling party in India).

One widow reported being in critical condition. She required health care but none of her relatives were taking her to the hospital, they could not afford the costs (See Box 5.3.1)

Among the Bangladeshi respondents, one female at destination also reported forced involvement in sex work. Her younger son lives with her but her family members at source don't have any knowledge of her work in India. They are also unaware of her HIV status.

**BOX: 5.3.1**

*Shely's (pseudonym) husband died of HIV+ 2-3 years ago. She has two children. After his death she went to the Civil Hospital and got herself checked along with her two children, She was diagnosed as HIV+. Her CD-4 count was okay at that time and she was very fit and healthy. She thought she was fine and therefore did not go for any follow-up visits. Suddenly, 2 weeks ago she fell ill. She started complaining of immense weakness and she was hospitalized. Many tests were done and medicines prescribed. This cost them Rs.20,000 including conveyance and her food etc. This entire cost was born by her family (father and brother –lives in India) presently her lower body is totally paralyzed. She cannot feel when she wants to go the toilet. The doctors are now telling her to shift to Sion hospital but nobody from her family can support her financially.*

### 5.4 SUMMARY

The case stories in this chapter illustrate how Bangladeshi women migrants often face exploitation, which increases their vulnerability to HIV and AIDS. The decision to migrate, at times was driven by extreme poverty. Contracting HIV caused these women to face even greater challenges as they were often abandoned / exploited by their husbands and families left alone to support themselves.

In case of Nepalese respondents, all were widows of PLHIV and their husbands were the main source of income. Their Husband's death due to HIV increased the Nepalese women's economic vulnerability.



# 6 EXPERIENCES AS A PLHIV

This chapter highlights the experience of stigma and discrimination faced by PLHIV in the three countries. It also illustrates how PLHIV coped with the HIV related stigma and discrimination and if it was a barrier to accessing services.

## 6.1 BANGLADESH (SOURCE)

In Bangladesh, HIV is surrounded by fear and misconceptions. As a low prevalent country with a concentrated epidemic, programs are focused on key populations such as sex workers, MSM and transgender. The HIV vulnerability of migrants has become part of policy maker's discussion only very recently (2011/2012) especially after the EMPHASIS baseline dissemination and a process of project design regarding migration and HIV and AIDS is ongoing (initiated by UNAIDS), while the 'traditional' high-risk groups are socially excluded, migrants are not typically socially excluded. However, the fear of being discriminated against because of their HIV status has led to reluctance to disclose their status.

Respondents who were migrants themselves mostly learned about their status after they came back home. They either came back with a persistent illness or they became sick after coming back. The experience and the hurdles faced to find out the actual cause of illness is depicted by many migrant stories (See Box 6.1.2). In the end after being counseled and supported by the self-help groups, all of the respondents (18), except two have disclosed their status to their family; 11 have still not disclosed to their neighbors. Five out of those who did disclose to the wider community and family have faced discrimination and social exclusion, e.g. however, after discussion with the PLHIV self-help group (see Box 6.1.1) their situation has improved. Only one respondent noted that although the neighborhood knew his status, they did not show any discriminatory behavior. Among the two respondents who have not yet disclosed their status to family, one is from a middle class background and has high income and the other one is MSM.

### Box: 6.1.1

*In Bangladesh HIV testing services used to be available only by donor funded projects at NGOs or PLHIV self-help organizations. Treatment care and support for all reported PLHIV are rendered through PLHIV self-help group. Whenever a HIV positive person is diagnosed, from the testing center they would be counseled and linked with any one of the five self-help group. The membership with self-help group would ensure treatment, care and support for a PLHIV.*

### Box 6.1.2

*Rahim (pseudonym) a Bangladeshi male went to India visit his mother leaving his Bangladeshi wife and children. In India, as his mother insisted, he got married to an Indian girl. His Indian wife loved him a lot so he decided not to come back to Bangladesh. He understood after sometime that his Indian wife's health was not good. She used to suffer from fever, diarrhea and cholera. After 3 years, he became sick. He had a skin disease and diarrhea. He went to a doctor, there he had blood test. But Rahim's Indian wife brought his report and said he is all right. His first wife came to visit after learning he was sick. The he came back to Bangladesh. He went Khulna for check up but no problem was identified. Doctor at Khulna (divisional city) told him to go India again for treatment. Meanwhile new problems developed. He was losing his eyesight. His Bangladeshi wife took him to India .In India also they approached many doctors in many places. In the end in Kolkata in a clinic he was diagnosed as HIV positive. His Bangladeshi wife neither could understand it properly nor did she believe it. They came back home. His wife approached his sister with the doubt; his sister took both of them to the VCT center managed by FHI in Benapole. There, both she and her husband were identified as HIV positive again. Initially they thought the testing center would kill Rahim and his wife if they find out that they are positives. Counseling at the VCT center helped to change their misconceptions and fear.*

Given the large amount of stigma already associated with MSM, and the fact that they remain a largely hidden population in Bangladesh, an HIV- positive MSM would face added layers of stigma and potentially violence.

The respondents' stories show there is fear of social exclusion and discrimination (See Box 6.1.3) that inhibits them from disclosing their status to society. Six of the respondents shared their story of being discriminated against

by family members. One respondent explains that his brother didn't want to mix with him and live with him so he had to relocate his family from his village and move to the city. He arranged the move with the help of a cousin in the city (Khulna). For 2 respondents, self-help groups arranged community sensitization activities in their locality, improving their social status... Families in most cases (18) have been their prime shelter and source of support (See Box: 6.1.3). One respondent's mother sold her gold earrings and gave her 1800 Taka to go to Dhaka for treatment. One female respondent was abandoned by her husband and now depends on her father. She feels she is a burden to her family. The data shows consistently low levels of HIV and AIDS related knowledge. One respondent thought that at the testing center, people would kill them after learning of their status (she and her husband). After receiving counseling assurance from the testing center she and her husband accessed VCT (See Box 6.1.2). Misconceptions persist among respondents. The youngest respondent's (one who went to India at an age of 8) father expressed that he wants to arrange a good marriage for his daughter when she is cured.

For all respondents, family and PLHIV self-help group staff inspired them to live a healthy life.

Respondents illustrated that many PLHIV conceal their HIV status from service providers in fear of stigma. Key Informant Interviews (KIIs) revealed a story of a respondent who was denied the delivery of her newborn because she disclosed her status to service providers. Even sensitization from doctors didn't work to eliminate the fear from the gynecologists they have approached. The client then had the surgery in a localized hospital concealing her status (See Box 6.1.4).

## 6.2 NEPAL (SOURCE)

HIV as a disease continues to be subject to misconception and fear often resulting in stigma and discrimination in Nepal. The qualitative data in this study shows that while the fear surrounding HIV persists, it is gradually decreasing (See Box 6.2.1.). Seven out of 20 respondents had faced discriminatory behavior, 4 of them explained that the situation has been gradually changing as there are many PLHIV around and all of them are facing similar health problems (See Box 6.2.1).

Increased knowledge on HIV has also led to reductions in fear amongst the broader community. A further 3 respondents state that discriminatory behavior still persists from relatives and neighbors. Even though they are aware about the modes of transmission their relatives fear getting close to them or even touching them. Nine out of 20 reported that they had never faced discrimination. One respondent explains that now PLHIV are getting love and care from other people in their society (See Box 6.2.1).

Knowledge on HIV and AIDS is poor and misconceptions regarding transmission often prevail. Widow female respondents did not know about HIV before they were diagnosed and 5 of them learned it after their husband's death. Now these respondents assume that their husband might have died from AIDS (See Box 6.2.2)

### Box: 6.1.3

*Shoma (pseudonym) said "Initially after knowledge about my status, I got discriminated by neighbors and family members. Neighbors used to prohibit me from going to pond for bath and my siblings used to refuse food that I prepare"*

*Shukla said (pseudonym) my brother takes care of me since me and my daughter have been diagnosed as HIV positive, he is not getting married thinking how his wife is going to treat us."*

One respondent thought that at the testing center, people would kill them after learning of their status (she and her husband). After receiving counseling assurance from the testing center she and her husband accessed VCT (See Box 6.1.2). Misconceptions persist among respondents. The youngest respondent's (one who went to India at an age of 8) father expressed that he wants to arrange a good marriage for his daughter when she is cured.

### Box 6.1.4

*"One PLHIV required a C-section, she came to a service provider, he requested many service providers, but was not able to provide her the required service, later he came to know that she took the service from a localized hospital without disclosing identity—KII reveals"*

### BOX 6.2.1

*Bipin (pseudonym) said...*

*In past, people used to stay away from PLHIV. Now other PLHIV are also having wounds, rashes and nausea. So community is familiar with the problem of PLHIV. Now community understands with medicine PLHIV can live longer.*

*Prakash (pseudonym) said....*

*Though people said that HIV infected should not be discriminated, in practice they are not following that. They even fear to sit close to PLHIV. He also said to the interview as of today you are only person who sits close to me.*

*Nirmala (pseudonym) female widow said....*

*Everybody in the community knows that I am HIV positive; I have openly come before the society. Community has not discriminated me for my status. I feel HIV positive and non-positive is same. There is no change in my life after I go HIV. It was difficult to live with HIV in the past but treatment has given the hope for living a long life and there is no problems living with HIV.*

Once identified with HIV, respondents expressed passing through and emotional crisis. One said he felt that life is worthless and reported attempting suicide. However, with the support of a local Support Group (Nawa Asha), he has got ART and counseling. Now his CD4 is okay and he feels more hopeful than before.

The psychosocial support from local NGOs and NGO developed support group has played a strong role in changing the mindset of the community and PLHIV themselves.

This has brought tremendous change in their attitude towards life. Eight of the respondents are organized into networks and are helping each other leading to a positive change in the attitude of community towards PLHIV (See Box 6.2.3).

The four respondents who talked about change in social position of PLHIV in the community, one among them recalls her past days when she was diagnosed with HIV. She had no hope for life. Now she has some basic knowledge about HIV and AIDS and does not fear disclosing her status. She expressed that HIV can be well managed with HIV drugs and good nutrition. Other respondents also explained why being a PLHIV was difficult before (See Box: 6.2.4).

PLHIV representatives have been offered leading roles in different decision-making bodies. For instance, Shyam Bahadur (pseudonym) is now the chairperson in the school management committee.

In Nepal, respondents also complained about the behavior of service providers. Patients were transferred for ART from one hospital to another (See Box 6.2.5); but the reason for transfer was not clearly explained to the clients. CD4 reports were not provided to clients. For these clients, service providers did not explain to them why they were not getting their reports.

#### Box: 6.2.2

*Ranjit (pseudonym) Said." Since my wife started getting lean and thin, I sent her to Sanfe Hospital for test.. When my wife returned back from hospital, she said that she was diagnosed HIV. I did not believe her so we together went to District Hospital. Finally HIV antibody was seen in both of our blood. We don't know how HIV has been transmitted; I firmly believe that HIV is not transmitted due to our mistake. My parental uncle was also HIV positive; I might have contracted HIV from him while taking care of him."*

#### Box 6.2.3

*Hari Thapa (Pseudonym) has been involved in a community group called Nawa Asha, which has 345 members. The group has received funds from NAPN and government for care and support of PLHIV including education of their children. In the beginning, people used to hate him, however, since he organized a group, managed funds and started supporting other PLHIV, the community perception has gradually changed. Now, he is one of the respectable members in the community. HIV has tremendously changed his life. He just wants to learn new things, teach friends, and expand networks and services. His is a man with passion and a positive attitude now.*

#### Box: 6.2.4

*Geeta (pseudonym) from Achham said...*

*There is no difference between one diagnosed and not diagnosed of HIV. Life has changed a lot. It was difficult to live before. There was hatred and we were marginalized before. But now the things have changed. Now everyone understands. I am self-sufficient and I know how to live happily.*

#### Box: 6.2.5

*I have first started ART in Dhangadi (7-8year back).Then was transferred to Mangalsen and now I am receiving ART from Bayalpata. They took long time to start ART in Bayalpata and behavior of service provider was also not good.*

## 6.3 India (Destination)

AIDS related stigma and discrimination plays a great role in social integration of PLHIV and adherence to services. There are two levels of stigma and discrimination faced by PLHIV respondents: accessing services as a PLHIV and from within the community. While it is expected or hoped that service providers will not have misconceptions regarding HIV, in practice PLHIV reported discriminatory behavior from the service providers as well as from the community.

In Mumbai 7 out of 15 respondents reported discrimination in the hospital or community. One female respondent was scolded for coughing loudly at the hospital. Discrimination faced at the hospital was inappropriate and rude behavior (See Table 6.3.1, 4 out of 20) and denial of treatment and clinical procedures (2 out of 20). One respondent reported he had to leave the hospital because of rude behavior and refusal for ART (See Box 6.3.1).

**Table 6.3.1 Discrimination at community level in India**

Discrimination	Number
Refusal to share property and finance	2
Isolation at home and community	2
Labeling and calling names	5
“Guilt tripping” for burdening the family economy	2
Termination from job/forced resignation	3
Social exclusion and denial to access shared facilities	1
Total	15

At the community level, 2 respondents reported refusals to share property after knowledge of their status by family member. Two respondents faced isolation from their community. One respondent was told to leave his job after his employer learned he was HIV positive. The respondent is now working as a watchman earning Rs 2000. In his current job he has not disclosed his status to his employer for fear of losing his job. As his salary has decreased he is unable to send money to home for the last 3 months.

One respondent disclosed his status to one colleague who disclosed his status to others in the office as a result he was forced to leave the job. His colleagues who he used to spend time with told him to stay separately.

One respondent reported discrimination and harassment from police. Her story shows she was in police custody for 4 months. Initially in the lock up she couldn't take ART for 12 days (See Box 6.3.4.).

There were 9 cases where respondents said they didn't have to face any kind of discrimination. According to one of them it was because he was staying in India for a very long time and therefore they understand the attitude and behavior of people here (See Box 6.3.3).

**Box 6.3.1**

*“As soon as health staff at general health facility got to know that I am HIV-positive, their attitude towards me has changed. It seems that their eyes were piercing my guilt even more”... A male respondent from Mumbai*

**Box 6.3.2**

*“My own mother-in-law detests me. She went out and told the whole community that I have a bad disease.” A female respondent from Mumbai.*

*“Earlier everybody used to come to our house, borrow sugar, tea, milk etc. They used to sit with us and etc. Now the same neighbors change their way when they see us”. Respondent in Mumbai*

**Box 6.3.3**

*One Nepali respondent said “Only because I was literate, I could easily navigate through my process of transfers from Nepal to India...”. Male respondent*

**Box 6.3.4**

*One of the female respondents recounted her 6 month long ordeal with the Mumbai Police. She was held up in jail for more than 4 months. Despite her pleas and requests for release and her medication for her illness, she was unheard. She was kept in jail for 12 days. She was HIV positive. Despite being on ART she had to be without medication for 12 days. Police told her to go through the HIV test again. She was taken to JJ Hospital along with a constable where she was tested positive for HIV. The staff asked for her ART Card. She told the police that it is at her home. She was not allowed to visit her home and get the card rather she was again put in jail. She was asked to give contact details of someone she knew. She gave the number of a person, who used to pay her house rent. She was taken to Dhirubhai Hospital with her papers. There she was recognized and the hospital staff told the police about her condition. Police allowed her to take medicines for 2 months and put her in jail again. A week before her medicine depleted, she was deported out of country and was left at the country border. She went to her home (across border). But she did not want to stay there.*

**6.4 SUMMARY**

There is still widespread misconception and fear regarding HIV transmission at the community level and health service facilities—which is true for all three countries (Bangladesh, Nepal, and India).

In Bangladesh PLHIV fear disclosing their status to their families and community. Facilitation from PLHIV self-help groups have been able to change the attitude of community and families for some instances, but service providers still have fear and misconceptions around providing health service to PLHIV. Therefore, patients approach service centers concealing their status which is risky from prevention point of view.

In Nepal, respondents illustrate how the community environment is changing as a result of facilitation from community support groups which have helped PLHIV re-integrate society.



# 7 BARRIERS TO SERVICES

The prime focus for the consolidated report is to explore barriers to services for PLHIV in the three countries, especially for migrants in India (destination). This chapter explores the country specific barriers to services for PLHIV.

The approach of this three-country report in exploring barriers services was very different. In the case of Bangladesh, the scenario of funding related care and support services were facing a drastic change. Therefore, for Bangladesh this has been one of the major focuses of the study to address the issue. On the other hand, in Nepal and India, government system for care and support is already in place as the number of PLHIV in these two countries are much higher than Bangladesh. Therefore in Nepal and India PLHIV face barriers in accessing the existing system.

## 7.1 Bangladesh

### Care and Support Services for PLHIV

The PLHIV care and support programs in Bangladesh are implemented by PLHIV self-help groups. The first PLHIV self-help group "Ashar Alo" emerged during 2000, since then, another 4 PLHIV self-help groups have been formed. These five self-help groups have also set up the BNP+ network. Among the five self-help groups, three work in the southwest region of Bangladesh, the other 2 work only in Dhaka. The PLHIV study purposively collected data from these three organizations "Ashar Alo", "Mukto Akash", "Geon Health". The care and support programs, distribute ARVs which have been funded by Global Fund through the RCC(Rolling Continuation Channel) project since 2008; prior to then it was funded by the World Bank funded HPNSDP program. The services made available by the self-help groups are mostly ARV distribution, treatment for opportunistic infection, psycho-social support and nutritional supplements.

### Barriers to access services

#### Travel Costs

Geon Health members require travel to the capital city Dhaka for ARV and CD4 services. The ARV service delivery organization Confidential Approach to AIDS Prevention (CAAP) used to provide bus fare and accommodation for the PLHIV who traveled each month. This travel and accommodation services have been discontinued recently. Interviews with key informants reveal that since the majority of PLHIV come from low-income groups, managing this cost is difficult for them (See Box 7.1.2).

#### HIV transmission related stigma among service providers

There are still widespread misconceptions and stigma among health service providers. According to one key informant, "one patient required dialysis service, the patient bought the service from a privatized hospital (IBN SINA) concealing her status". These examples presents heightened risk factors for general populations on the other hand the PLHIV would not be able to take the service after disclosing status. There are many instances when PLHIV, fearing that they would be declined services, have had received services concealing their status (See Box 7.1.3).

#### Box 7.1.1

*Mukto Akash and Geon Health have their office in Khulna (Divisional City of EMPHASIS working area)-has 1427 members.*

*"Mukto Akash" organizes a member day per month in order to share PLHIV experiences with each other and monthly check up by doctor. They distribute the ARV at that day in the Khulna office (Divisional city of the South West).-has 460 members.*

*"Geon Health" member's requires to come to capital city Dhaka for ARV, member day is organized in Khulna.-has 33 members.*

#### Box 7.1.2

*PLHIV of Geon health says" We used to get travel and accommodation arrangement previously while going to Dhaka for treatment, now we only get a bus ticket and no local transport cost is given, and no accommodation is provided as funding has been decreased".*

### Box 7.1.3

Shamima (pseudonym) is a PLHIV, who needed surgery treatment for her gynecological and appendix removal, she consulted three gynecological service providers but none agreed to provide surgery treatment for the gynecological problem. While doing surgery for the other problem (appendix removals) one of her ovarian tube was found to have burst and she needed immediate surgical procedure by a gynecologist to save her life. Doctors in a board meeting decided to involve one gynecologist without letting him/her know Shamima's HIV status. One gynecologist was found in the end who had done surgical procedures on PLHIV before and she did the procedure and saved her life.

### Centralized Service and Inadequate Government initiatives

In Bangladesh, treatment, care and support related services such as ARV distribution, CD4 count, VCT, PPTC etc are rendered through privatized service centers such as ICDDRBL PLHIV self-help groups, FHI 360, CAAP etc, and through donor funded projects in the capital city Dhaka.

There had been very limited services available at government health settings. The services established so far at government health facilities are not sustainable. According to key informants, "a PLHIV not only need ARV or OI treatment, but also because PLHIV can suffer from all diseases like a general patient, general treatment facilities are also required". (See Box: 7.1.4).

#### Box: 7.1.4 Key informant comment

"If we cannot provide the necessary services to the PLHIV by providing them necessary health services, why to give them a death sentence by letting them know their status"

Another example of lack of commitment is the CD4 machines installed in the Government Health facility. The government has recently provided CD4 machines at 8 government health settings in 5 Divisional medical college hospitals and 3 other hospitals in Dhaka. But so far, service is only functional at one service center in Sylhet (See Box 7.1.5).

### Box 7.1.5 Government Health Settings: The CD4 Count experience

8 CD4 machines were purchased for 5 Divisional Government Medical colleges and 3 other hospitals in Dhaka (Dhaka, Khulna, Chittagong, Barisal, Rajshahi medical college hospital and IDH, BSMMU, IEDCR hospital in Dhaka). Among these CD4 machines, only one machine at Sylhet (divisional city) Medical College Hospital is currently functioning. This experience shows that Sylhet Medical College Hospital authorities were not ready to start the service, saying staff was not trained and reagent was not available. Even when the reagent was delivered, hospital staff required sensitization from PLHIV organization to start the process. The provision of continued services for the PLHIV of Sylhet region required a continuous push from the PLHIV self-help group.

### The Uncertainty of Funded Interventions

The health services available for PLHIV is dependent on funding and is not demand driven, mostly supply driven. Funding for certain services are not sustainable and are available on an ad-hoc basis.

One example is the global fund supported program for ARV and Care and support services, which has been discontinued from November 2012; previously it used to be rendered through PLHIV self-help groups funded by HPNSDP program of the government. As the Global Fund support discontinued suddenly the government was compelled to re-think the issue to manage care and support service for the PLHIV.

### Limitations of Future Care and Support Plans

The government of Bangladesh planned to render the ARV distribution from 5 district level hospitals. The service at the government hospitals was initially planned to start from November 1, 2012, but it was delayed and started on December 1, 2012. Also although the funding mechanism has changed from Global Fund to the government, the service modality has not been changed (i.e. from self-help group to government hospital).



## 7.2 NEPAL

### Care and support services for PLHIV

The government of Nepal plans to provide care and support for PLHIV following the Millennium Development Goal and UNGASS declaration. Under Universal Access, care and support services have been scaled up at the district level. Major PLHIV treatment, care and support services such as ART, CD4 count, VCT, PMTCT are designed to be delivered through government health facilities. VCT, CHBC (community home based care) and prevention programs are implemented by NGOs. Yet geographical location, economic conditions of the respondents and distance are the prime barriers to accessing these services.

Kanchanpur respondents are accessing ART from Mahakhali Zonal Hospital and Seti Zonal Hospital, while Achham respondents are accessing ART from District Hospital (Mangalsen/Achham District Hospital), Bayalpata and Doti Hospital (See box 7.2.1 and Table 7.2.1). Among these hospitals only Bayalpata Hospital is non-government. However, 16 out of 20 qualitative respondents are taking ART medications. Among the quantitative respondents 12.6% have accessed STI services and 22% have utilized VCT services from NGOs.

**Table 7.2.1: Distribution of ART patients**

Name of Hospital	Frequency	Percentage
Mahakali Zonal Hospital	50	43.8
Seti Zonal Hospital, Kailali	25	21.9
District Hospital, Achham	19	16.7
Bayalpata Hospital, Achham	17	14.9
Doti Hospital, Doti	2	1.8
Simi G.G. Hospital, India	1	0.9
	114	100

Some qualitative respondents of Achham went to Bayalpata (4) hospital which is a private hospital; the second preference is Mangalsen (2), which is a government hospital. Among the respondents of Kanchanpur, the majority went to Mahakhali (4) hospital followed by Seti Zonal (2) hospital.

### Barriers to Services

#### Financial Difficulties

The income levels of the quantitative respondents show that 55.1% have an income ranging from 500 to 1500 Nepalese Rupees per month. Only, 11.8% have an income more than 5000 rupee. Qualitative respondents reported similar income levels, which are largely insufficient to provide for the household.

The quantitative findings show that among respondents who have stopped ART, 35.8% of them stopped because of financial problems (See Box: 7.2.2). While reporting about problems related to treatment, poor economic condition was also spoken about as leading to problems in accessing services.

The qualitative respondents report that they have to travel a long distance, more than 50 km to reach the nearest hospital. The transportation costs are between NPR 200 and NPR 400 per visit in Kanchanpur, while it takes hours to reach health facilities in Achham. Some of the respondents in Kanchanpur reported that they borrow money or sell food crops to manage the transportation costs.

#### Long Waits

In Nepal prime HIV related services such as ART, CD4 count, PMTCT, OI services are rendered through government facilities but not all services are available in the same place. Also services are not available every day. For example, ART is provided once a week (might vary) and CD4 counts are available twice a month. Therefore, there is an overflow of patients on those designated days and patients repeatedly complain about waiting for hours to get the services they need.

#### Box 7.2.1

##### Location of Hospitals

Mahakhali Zonal Hospital –Kanchanpur

Seti Zonal Hospital-Kailali /Kailali 60 KM far from Kanchanpur

District Hospital Achham-Achham

Doti Hospital-Doti /45Km from Achham

Mangalsen Hospital-Achham

Bayalpata Hospital- Achham

Simi GG Hospital, India

#### Box 7.2.2:

Among the quantitative respondents 114 are under ART, and 7 stopped taking ART multiple times and 7 stopped for once. One of the prime reasons behind stopping ART was financial difficulty (35.8%).

1. The governments made a commitment to United Nations in 2006 to scale up the AIDS response. In the political declaration countries committed to provide Universal Access to HIV prevention, treatment, care and support services to all who is in need by 2010.

## Quality of Service

**Table: 7.2.2 Respondents by level of satisfaction towards services received**

Variable	Very Satisfied	Somehow Satisfied	Not Satisfied	Total
STI	21 (43.8)	27 (56.2)	0 (0.0)	48 (100.0)
VCT	18 (35.3)	32 (62.8)	1 (1.9)	51 (100.0)
CD4	22 (26.5)	68 (66.7)	7 (6.8)	91 (100.0)
PMTCT	8 (42.0)	11 (58.0)	0 (0.0)	19 (100.0)
ART	42 (30.0)	72 (70.0)	0 (0.0)	114 (100.0)
OI	11 (31.4)	24 (68.6)	0 (0.0)	35 (100.0)
DOTS	7 (15.6)	38 (84.4)	0 (0.0)	45 (100.0)

Respondents expressed mixed impressions regarding the quality of services. Quantitative respondent expressed overall satisfaction for the services such as STI, PMTCT, and ART. The level of satisfaction is highest for STI (43.2%), followed by PMTCT (42%), and VCT (35.3%). Respondents expressed dissatisfaction related to CD4 (6.8%) and VCT (1.9%) services.

Two qualitative respondents expressed their dissatisfaction regarding CD4 count service and mentioned that they didn't receive their CD4 reports and don't know their CD4 count. Three respondents also expressed that the behaviors of the health service providers were unsatisfactory (See Box 7.2.3).

At times the service mechanism was not clear to the clients and the service providers didn't explain it to them clearly. Therefore, respondents complained that they didn't receive CD4 report, or that ART didn't start.

### Box 7.2.3

*Mahesh (pseudonym) is a migrant worker in India. He came back to Nepal after his wife and daughter were diagnosed as HIV positive. He was also diagnosed HIV positive. He is still a circular migrant. He had done his CD4 count 13 times. He complained that the hospital staff never provided the report to him. He is on cotrim, but not on ART. He wants to start ART. He is not all satisfied with the services. Mahesh thinks health workers should change their behavior.*

### Availability of Services

Qualitative respondents shared their challenges to accessing ART and CD4 counts. Among the 20 respondents, 11 reported a negative experience. Three respondents from Achham had done their CD4 count in Dhangadi, which is 300 Km away from Achham and 60 Km from Kanchanpur. In order to receive CD4 service from Dhangadi (Seti Zonal Hospital), people from Achham would have to travel about 18 hours by bus.

One respondent shared that CARE Nepal covered his transport costs to travel to Dhangadi. One Achham respondent also mentioned seeking treatment from Doti Hospital instead of Achham District Hospital as she was very sick and the hospital in Achham didn't have beds available. Now she accesses ART from Doti.

### Limited /One Combination ART drugs

In Nepal only a limited combination of drugs are available. Respondents termed it as "only three drug combination". Respondent also mentioned that even if a patient develops side effect with these drugs there is no alternative, either they have to continue or they have to quit (See Box 7.2.4).

### Box 7.2.4

*Sumi (pseudonym) is a HIV infected widow. She started ART one year after her CD4 count was done. But after one month she had allergy in her skin and she stopped ART as per advice of the doctor of Achham District hospital. Now she is taking iron, vitamin and cotrim.*

## 7.3 INDIA

### Care and support services for PLHIV

In India under NACP III program of the National AIDS Control Organization (NACO), ART services for PLHIV are made available at medical colleges, district hospitals and non-profit charitable institutions providing care, support and treatment services for PLHIV. Additionally, counseling and follow up on treatment adherence services are provided through community care centers. (NACO) Like other health service, migrant PLHIV do not need to provide ID proof to obtain treatment services, though an address proof of residence of the city or district is required. Although there is availability of services and in principle no ID is needed, Nepalese and Bangladeshi migrants nevertheless face obstacles in obtaining services.

Among the 20 IDI respondents, 11 respondents went to private practitioners first or for a recheck for getting themselves tested. All respondents mentioned that they have received pre and post counseling.

A major barrier for accessing services in both Delhi and Mumbai is the shortage of staff at the hospitals compared to the number of patients whom they need to attend to. According to respondents, this leads to long waiting times, inadequate time provided per patient and the provision of inadequate information. Additionally, given the long waiting time, a day off work each month is necessary leading to a loss of wages, which has negative economic consequences for an individual.

## **Barrier to Services**

### **Long waits**

Respondents who are taking ART in India (Delhi and Mumbai) reiterated the problem of standing in long queues for getting ART. On the allotted day for collection of medicines, nearly 300-400 people are in a queue with only one doctor available for check-up and one window to get medicines. This makes the patient weak and tired. There is no proper sitting arrangement for patients. Drinking water and toilet facilities are also not available. In conditions like these they have to get accompanied by somebody else (generally a family member). This leads to one day of employment loss for both of them hence a cut in their salaries as well for that particular day. Respondents report that the collection of medication leaves them so tired that they don't have energy to go for work the next day as well. This also results in patients deciding not to collect the medicines and therefore increased dropout rates.

### **Inadequate time given by ART counselor because of insufficient staffing levels**

Some of the respondents mentioned that even though they were counseled well for HIV, there should be more time given to counseling. One of the respondents from Mumbai reported that the dosage was not properly explained or possibly she did not understand the way it was explained and she ended up consuming 4 pills a day instead of 2 pills. This led to severe illness and weakness, resulting in hospitalization. Thus there is need of adequate counseling time given to all the patients.

Also there is only one counselor who is available during the day of medicine collection. This results in long lines and a lot of waiting. Thus many patients leave without proper counseling leading to uncertainty about dosage as well as lack of adherence.

### **Discouraging attitude of staff**

Out of 20, eight respondents mentioned that they have experienced negative behavior from the health staff. One of the widows who is severely ill expressed how the attitude of hospital staff in the general ward changed towards her as soon as she was diagnosed with HIV. She also expressed how they do not provide clarity in the whole process and they get irritated if asked for second time.

### **Limited access to medicines**

The respondents said that the government only provides free ART. There are often other medicines prescribed by the doctor that have to be bought by themselves from the chemists. The respondents clearly stated that they do not buy medicines from outside, as they are costly.

### **Accessing services from different points within a hospital**

Another important concern shared by a majority of respondents was the amount of time and running around they have to do in the hospitals as departments are at different corners of the hospital. Respondents reported that the patients who are new and unaware of the location of departments leave without getting a particular service. (See Box 7.3.1).

### **Language Barrier**

Respondents from Mumbai faced a language barrier. The hospital staff speaks in Marathi instead of Hindi, which is unfamiliar to them (See Box 7.3.1).

#### *Box 7.3.1 "I couldn't find ART center in the hospital"*

*An HIV positive man from Mumbai remembered how he had to go to the hospital alone and get his tests done. When he tested positive he was sent for counseling. He says "maine aspatal mein ART centre bahut dhoonda par nahi mila" (I tried hard to find the ART centre in the hospital premises but couldn't find). He asked hospital staff as well but they spoke fast and in half Marathi, which he couldn't understand. Therefore, he left without getting counseling done.*

*"Being illiterate I couldn't understand the directions"*

*One of the respondents, who now work as a social worker helping people affected with HIV, was illiterate and unaware about HIV when he was first diagnosed. He narrated his story of leaving the hospital without getting his CD-4 count and ART pre-counseling done. He said he was not able to understand the directions given by staff. Also he couldn't locate the various departments he was being sent to. He described the whole day as an ordeal as he had to keep running from one department to another and at the end of the day he left without any results.*

### Travel cost

Another problem restated by the respondents was the travel expenditure (to ART centre) they have to incur to get the medicines they need. About Rs 50 to Rs 300 is spent on travel from their home to the hospital for one day. They have to buy food as well as it takes almost one whole day to collect medicines. The respondents are daily wage earners. From their limited income they also have to send money home. This leaves little for them to sustain themselves in an adequate manner. So sometimes they chose to drop ART (See Box: 7.3.2).

When asked why they do not travel by trains (there are intercity trains in Mumbai that is the low cost public transport), they replied saying trains are packed and they feel very unwell after the claustrophobic journey. Additionally, most of the times there is no place to sit.

### Poor financial status

All respondents echoed the need for monetary support in order to improve their quality of life. Out of 20 respondents 6 are widows who are working themselves or are dependent on their children. They said that all the money they earn is spent on rent, water, electricity, daily food items and education of their children. This leaves them with no money to eat fresh fruits and vegetables, have fresh juice and a healthy lifestyle.

As mentioned previously, migrants have to work day and night in order to sustain themselves. A respondent from Delhi, therefore, works as a driver and does car washing during the day and works as watchman during the night hours. Another respondent works as caterer, with his working hours being 9 am till 2-3 am (Box 7.3.3).

### ID proof

Although ID proof is not a mandatory requirement in order to access HIV treatment, care and support in India, a residence proof of the city they are staying is required. If a person cannot arrange residence proof, a reference letter from an NGO or local influential organization mentioning that the client will continue taking ART is supposed to work. But respondents reported that health facilities asked for ID even if they had reference letter from NGO.

#### Box: 7.3.2

*“Seema (pseudonym) Stopped ART because its costs her husband to lose one day wage”*

*Seema took ART from a hospital in Mumbai for four months. She has not taken ART for the past two months. She says she has to take out one whole day just to get ART. With a small child at home she does not get time to visit the hospital every month. Her husband needs to accompany her to the hospital and that means a day wage loss for him too. They also need money to travel to the hospital, which they don't have. In addition, they have to deal with problems related to basic living. They get water at a particular time, so they have to be in the long queue during that time otherwise they won't get water for the day. Their house frequently gets demolished by MCD (because dwellings in the area are illegal constructions) with no other place to go.*

#### Box 7.3.3

*“My children left their education to sustain our living”*

*A widow from Nepal described how her young children had to let go of their studies and start earning in order to get food in the family. Because they are not qualified, the income is just enough to sustain the house. She pleaded for financial assistance during the interview.*

*“My daughter is exploited when she goes to work”*

*Another widow who is fighting a legal battle in India to claim her husband's belongings is living in a makeshift place for Nepalese where she and her daughter are harassed and asked for wrong favors. Her daughter is very young but has to earn for their basic needs.*

## 7.4 SUMMARY

Bangladesh as a low HIV prevalent country has PLHIV care and support through funded programs managed by PLHIV self-groups at large. Government initiated care and support systems such as OI management and the training of service providers has not been consistent. Also because services are made available through limited funded programs they are not sustainable; therefore programs are facing transitions all the time. PLHIV treatment, care and support services are also centralized at the capital city making it difficult for people living in rural areas to access them.

The government of Bangladesh took initiative this year to try and transition the global fund provided services for treatment, care and support. The Government's plan was ambitious and it was not successful in transitioning all the services in time creating a major challenge for the future of treatment care and support for PLHIV in Bangladesh.

In Nepal Care and support services are available at government health facilities. It seems the services are gradually taking place but there are shortages and inconsistencies. There is limited availability of CD4 count services in certain districts and not all services are available at the same facility. Therefore the distances of service center and transport costs are described as the major hurdles faced by respondents in accessing consistent and quality services. Additionally, accessing different drug combinations is another obstacle that often results in people having difficult side effects making adherence a challenge. Other obstacles included long waiting hours, rude behavior of staff and a lack of confidentiality.

In India PLHIV treatment, care and support is available in government and NGO service facilities at district and sub district level. But in the big cities such as Mumbai, the major problem for care and support is the large number of clients. Therefore, patients face difficulty in receiving services. Allotted service time per patient remains minimal. Patients have to spend a good amount of money on travel costs, and then wait for a long time in a queue to take ART. As the economic conditions of the clients are not good, they chose to drop ART against losing a day's salary. Another barrier to access services for Nepalese and Bangladeshi migrant is that often health facilities ask for ID proof or residence proof when they attempt for the first time to access services.

# EMPHASIS INTERVENTIONS 8

This chapter describes the interventions that EMPHASIS has introduced for migrant PLHIV at source and destination. The prime focus of this chapter is to explore which EMPHASIS initiative has been most beneficial to migrant PLHIV and their families and how they can be improved. These findings will provide directions to establish similar interventions in the future.

## 8.1 VCT AT GOVERNMENT HEALTH SETTINGS BY EMPHASIS

WHO and UNAIDS issued guidance on provider-initiated HIV testing, where HIV counseling and testing (HTC) is a critical entry point to life-sustaining care for people with HIV, a key element of treatment and essential for prevention of vertical HIV transmission. (WHO,2010).

The civil surgeon working in the health management authority in the EMPHASIS working area of Jessore and Satkhira expressed the need for having a VCT facility targeting undocumented migrants. It is also a requirement as a strategy to the policy makers, to identify migrant PLHIV in areas where there is high mobility between Bangladesh and India, to have an understanding of the HIV vulnerability of undocumented migrants. In response to the demand, EMPHASIS provided support to establish two VCT centers at Satkhira Medical College and Jessore Government Hospital in 2012. The support provided by EMPHASIS ranged from renovating the lab to building a room for the counselor and providing testing kits and other equipment. The implementing partners have also recruited two counselors; the counselor position is a new addition in these hospitals.

Apart from the provision of the above, EMPHASIS has also provided VCT training organized as a joint collaboration with ICDDR, B. They recruited VCT counselors; hospital and Upazilla health complex doctors and nurses were trained on voluntary counseling and testing. Also, in order to increase awareness around VCT and HIV, VCT orientation training was organized at the government hospitals.

The VCT centers started testing from May 2012. Since May 2012 up to March 2013, a total of 671 people have been tested and 17 people have been identified as positive. All of those who tested positive have families with histories of migration to India. The PLHIV case stories show that 4 families have more than one PLHIV. For these report initial 13 PLHIV case stories has been used. Among the 13, 7 are female and 6 are male, also three are children, two male children and one female child. All the PLHIV have at least one family member who has migration history. Out of 7 female PLHIV, 3 were trafficked to India for sex work by broker or husband; one got married to Indian husband and the other two females were married to migrant husbands. The migrant scenarios are similar to those of in-depth interviews.

EMPHASIS attempted to link these PLHIV with treatment, care and support services through PLHIV self-help groups. Eight were linked with the service and amongst those, five are getting ART under self-help group management. Identification of 13 PLHIV with a family history of migration has been turned out as a successful intervention for the project. The migrant's story provides evidence of AIDS related vulnerabilities of undocumented mobile populations.

## 8.2 LINKING PLHIV FROM DESTINATION TO SOURCE FOR SERVICES

One Bangladeshi couple was diagnosed by EMPHASIS in Mumbai. The wife was receiving ART from May 2012. The couple had regular communication with EMPHASIS project in Mumbai and were linked with EMPHASIS in Bangladesh, when they planned to come back to Bangladesh. The couple was linked with VCT and ART services at Jessore through EMPHASIS>

## 8.3 CROSS BORDER ART TRANSFERS

Despite being diagnosed in India there are cases of Nepalese respondents who are taking ART from Nepal. Among those, two were diagnosed in India and were accessing ART from hospitals in Nepal. The respondents then were transferred to an Indian hospital for ART (Box 8.3.1 and Box 8.3.2).

The respondent of ART transfer case 1 had facilitation of NGO from both source and destination. The partner NGO of Nepal arranged the transfer certificates and team in India arranged a reference letter for the respondent. It was a two-way facilitation; therefore his transfer was much easier.



**Box 8.3.1 (ART transfer case 1)**

Ram Bahadur (given name) has been living in India since 1988. He was diagnosed as HIV positive in Nepal in 2007. He started ART in Nepal. After 3 years he was feeling better and also financial problems motivated his return to India. He used to go to Nepal every 2 months for ART. This put a lot of financial strain on him. Ram's brother Ranjit was one of the ORW working with EMPHASIS in Delhi. Ranjit got in touch with the partner NGO working in Nepal with the help of the India country team. The partner NGO in Nepal arranged ART transfer for him and sends it to India team through email. Ram with the test results and ART transfer paper and reference from partner went to the GTB hospital and got a CD4 test done and resumed ART at GTB hospital Delhi.

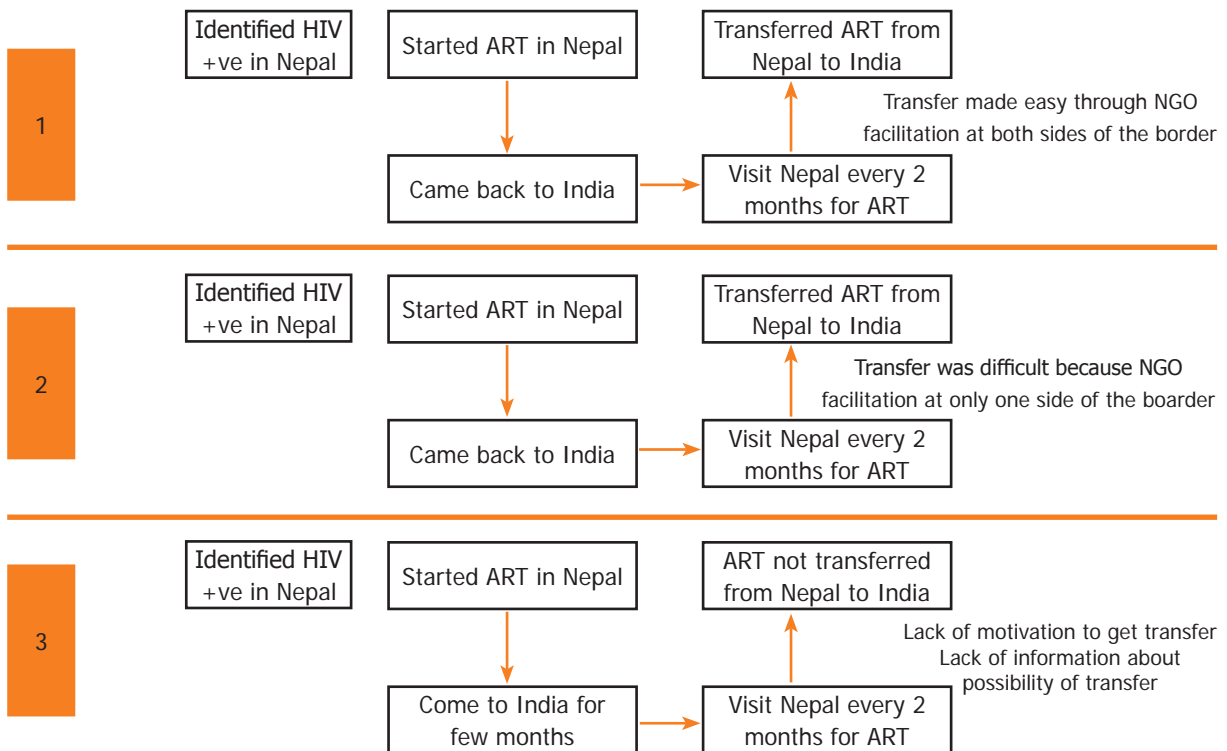
**Box 8.3.2 (ART transfer case 2)**

Jeet Singh (given name) has been living in Delhi since 1991. He had gone for a medical checkup through his company to get health clearance for going abroad. In that medical test he was tested HIV positive, in 2004. After knowledge about his status he went to Nepal and had the HIV test done on his wife. She was also positive. Initially he was not on ART. Later he started ART from Nepal. Later he asked for a transfer letter from service center in Nepal. For the transfer letter he had to travel back and forth between Nepal and India many times. During that time he got associated with EMPHASIS partner in Delhi and got associated with DNP+. With the help of partner NGO he was enrolled for ART in India.

The respondent of ART transfer case 2 had arranged transfer letter by himself. An NGO at destination helped him with reference letter and got him enrolled in ART at a hospital in Delhi.

The case stories show two different scenarios of transfer. If there is two-way facilitation the transfer process is much easier and incurs less hassle for the client. Also it can be said that though transfer is possible there are not any formal systems between the ART institutions of Nepal and India. EMPHASIS experiences can help develop a formal referral system between the ART institutions of both countries. Therefore, a formal referral process can expedite the ART transfer and reduce hassle for the migrant (See Box 8.3.3).

**Scenarios of Transfer from Nepal to India (Diagram 8.3.1)**



The scenario of ART transfer (See Diagram 8.3.1) shows how the transfer process was unclear to the clients, for them it is easier to get ART from Nepal. Therefore there are PLHIV who are not aware of how to approach an ART transfer and what is needed or even if it is available.

### **BOX: 8.3.3**

#### *Process of ART transfer*

*Nepalese PLHIV need to visit the ART centres in Nepal to get the transfer letter.*

*ART centre in India registers the PLHIV as new, thus s/he has to go through the entire process of testing and CD4 count.*

*In Mumbai if the name of the specific ART centre to which transfer is sought is not mentioned they refuse to process.*

## **8.4 LINKING NUTRITION AND SUPPORT SERVICES**

Six out of 20 respondents in Mumbai were linked with charitable organizations where they receive food items like rice, flour, lentil, sugar, biscuits and clothing. Two respondents from Kolkata are associated with North 24 Parganas Network of Positive People (NNP+). They give food items once a month to adult patients and twice a month to children. It includes soybean, rice, lentil and oil. They also give out railway cards that allow free travel by train to access medicines, ART etc.

These people cannot receive government services because they do not have proper documentation. Hence, accessing services from NGOs is their only option. Therefore many of them recommended that it is very necessary for NGO's to collaborate and provide services to those in need. There are other NGOs who offer services but lack outreach and awareness activities that effectively link the target populations with the appropriate NGOs.

## **8.5 CHALLENGES OF EMPHASIS SERVICES**

The EMPHASIS project has also identified inherent challenges to providing services to undocumented Bangladeshi migrants. The major challenges faced by the project are the respondent's priorities as a migrant. EMPHASIS VCT case stories shows among the 13 PLHIV only 8 were linked with services. Out of the remaining 5, two (a husband and wife) were not interested accessing services as the service center is in Khulna (a two hour drive in bus, from Satkhira). Later, however, upon the death of his wife the husband is interested in seeking out services. The other 3 were lost to follow up. Through family the project team learned that they went back to India.

## **8.6 SUMMARY**

The service delivery system EMPHASIS has been able demonstrate, shows that there is a demand for the services. For Nepalese population, these services can be institutionalized if there is initiative from government counterparts. For Bangladeshi impact population a project-based service can be an interim solution.

# 9 CONCLUSION AND RECOMMENDATIONS

This chapter presents the conclusions and recommendations to address the barriers to services for PLHIV in the three project countries. It is also, an attempt to recommend country specific programmatic strategies and advocacy issues to enhance cross border mobile populations' access to HIV and AIDS services

## 9.1 CONCLUSION

The prime focus of this study was to assess barriers to accessing services for migrant PLHIV at source and destination. The study finds that it is important to understand the vulnerabilities of PLHIV as a migrant. Mobility patterns, living conditions at destination and overall socio-economic status have a role to play in heightening HIV vulnerability and increasing barriers to services for migrants.

The study shows availability of treatment, care and support services for PLHIV doesn't always ensure accessibility. Factors such as socio-economic dynamics, health seeking behavior, knowledge and understanding about the services, experience as a women and overall experience as a migrant, can act as a constraint against accessing health services. To understand the barriers to accessing services, it is important to acknowledge the fact that client's priority in general, socio-economic and political position can also constraint his/her accessibility.

The study data shows that prime barrier for the Bangladeshi and Nepalese PLHIV in accessing services is their socio-economic status. It is also contributing to their knowledge and understanding of HIV as a disease. As the clients are from low socio-economic groups, their access to knowledge, level of knowledge, attitude, practice and social positions are very different than those of the program implementers and policy makers. This gap is depicted in stories where Nepalese PLHIV at both source and destination share their experiences and difficulty understanding the service mechanisms (why CD4 report is not shared/ART not started etc) and finding service points in the hospitals. Similarly, Bangladeshi respondents explained their challenges in finding out the actual cause of disease at both source and destination.

Another important factor that constrains access to services is the stigma related to HIV transmission among health service providers. It is very much acute in Bangladesh. In Bangladesh respondents were declined services because they were HIV positive. In India and Nepal service providers had shown different forms of discriminatory behavior, which might have discouraged patients to continue treatment.

EMPHASIS as a project has been able to show some initiative in addressing some of the gaps presented by this study. So far, EMPHASIS has supported the establishment of VCT at government health facilities, ART transfers, and linking Bangladeshi PLHIV from destination to source for services. EMPHASIS has also been able to create enhanced service accessibility for PLHIV through NGO facilitation at destination. These initiatives can guide similar programs in the future to enhance service access of PLHIV at source and destination.

## 9.2 RECOMMENDATION

### Bangladesh

#### Sustainable treatment, care and support services

In Bangladesh the treatment, care and support services for PLHIV are centralized and rendered through PLHIV self-help groups at the capital city and very few divisional cities. A significant change in the service modality is required. In order to bring the required change the government needs to plan capacity building of staff on HIV and AIDS treatment, care and support. To render services from government health settings the facility management and personnel structure requires revision. For example, in order to establish VCT at government facility, a counselor position is required. Service providers who will receive HIV related specialized training needed to be retained in similar health facilities. Arrangement of logistics for HIV and AIDS treatment, care and support are also needed (such as KIT for VCT). One service facility should be able to provide all required services to a PLHIV. A service environment where PLHIV would be able to take treatment support with assurance of confidentiality needs to be created. In order to achieve this, monitoring of service quality is essential.

## **Nepal**

### **Livelihood Support**

In order to address barriers to services in Nepal, the economic and livelihood situation of PLHIV requires attention. Livelihood programs should be designed to support families with HIV positive members. In particular, transportation support to the clinic is needed.

### **More options in first line and second line drugs**

Although in ART guidelines in Nepal has the option for different combinations of first line drugs and need based second line drugs, this is not available at all service centers. The ART guidelines need to be implemented consistently at all service points.

### **Service Availability**

Service availability for selected days of a week or month has made services difficult to access. Considering the concentration of PLHIV in a service area, the facilities should increase their days of services. Additionally comprehensive services should be available at each site to ensure that PLHIV do not have to visit multiple facilities to receive the services they need..

## **India**

### **Cross Border ART Transfer**

For Nepalese migrants the cross border referral transfer can be formalized by initiation from NACO and NCASC. Both organizations can establish a referral system through the health facility with transfer protocol approved by both governments.

### **Service Quality**

Service facilities need to improve their quality of service. Large flow of clients needs to be attended by adequate number of staff. Service providers capacity needs to be built to increase awareness and improve the quality of information they are providing to PLHIV.

### **Paperwork**

Requirements of reference or residence proof should be standardized and all service facilities should follow the same rule.

### **Collaboration between Governments**

For Nepalese migrants two governments (India and Nepal) can have enhanced collaboration and sensitization to ensure access to services for Nepalese migrants at destination.

### **Project Based Service**

For Bangladeshi migrants, since no formal process can be developed, project based facilitation from NGOs can enhance service access for PLHIV. Therefore, a cross border project might be an interim solution to serve undocumented mobile PLHIV.

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### History of Migration:

- We are going to ask you about your travel experiences
- How long did you stay abroad? Do you have any plan to move again and/or to settle permanently abroad? Can you share with us what were the main reasons for coming back in Bangladesh?
- How did you go to your destination? Experience of travel? Travel arrangement? Expenditure?
- What was your destination? If you have been traveling on a regular basis, were you used to going back to the same place or did you travel to other cities/locations?
- What was the work you were involved with? How much you used to get paid? Did your spouse travel with you?
- What he or she used to do?
- Where were your children born? If in India, have you got their birth certificates?

### Experience about PLHIV status:

- When did you first know about your status?(How long ago)
- Have you heard about HIV before knowing your status?
- Where did you get tested? Why did you first test for HIV? Was it free or did you have to pay for the test?
- Can you describe the process to get tested? Probe: How did you know about the availability of ICTC / VCT services? Did you get any counseling? Did you have the relevant documentation? If no, how did you manage? What information/ what did you need to provide? Did you need to provide an ID card? Did you need to provide a proof of residence?
- After getting tested and receiving the information about your HIV status, where were you referred to? Can you describe the following steps?
- Did you tell your family about your status? If yes, would you like to share your experience? Probe: How did your family cope with your status? Did your family have any information on HIV before knowing your status? Where did they seek information? What information did they need?
- How did you cope with your status? What help did you need at that time? Where did you mostly seek for help?  
Is there anyone else in your family, including your spouse and children either here or living elsewhere, who you know are living with HIV? If yes, how many persons in your family, excluding yourself, are living with HIV?

### Societal, experience as a PLHIV:

- How do you think people who are PLHIV, are perceived? What are the attitudes towards PLHIV? In your mind, what are the differences between HIV positive persons and HIV negative persons?
- Have you ever been treated differently by community people or at workplace because you have HIV? How is this manifested? When did you last have problems because your family member has HIV? When was this? Which type of people was involved? How did the others react? What did you do? Was that the only person you have had problems with in the community? Do you know of examples of discrimination from other people's experiences? (Please do not mention any names or details.)
- Some previous studies show that when people find out that they have HIV, some things in their lives can really change. Could you tell us about the ways in which HIV has changed your life? What do you do differently in your life now? What has been the biggest change?
- Is it difficult to live with HIV?
- A: No, it is not difficult: But do you think that it is difficult for other people to live with HIV? Have you ever had trouble related to HIV? When was that? Who was involved? How did other people feel about that? What did you do about it? Was that the only person/time you have had trouble? (Please do not mention names or other details)
- B: Yes, it is difficult: When is it most difficult? When was the last time you had trouble related to your HIV status? Who was involved? How did other people feel about that? What did you do about it? Was that the only person/time you have had trouble? How did you cope with your problems? (Please do not mention names or other details) Thank you for those very valuable responses so far. Is there anything we missed?
- What are the major societal or work place related challenges for a PLHIV in Bangladesh. How do you and your family cope with the challenges?

## Health Situation – Health Service Provision and Access

- How is your health? Is HIV causing health problems for you? Probe on opportunistic infection symptoms of AIDS?
- While in Bangladesh, where do you get medical help and advice? Which doctors/ health facilities do you go? Who else? (If enlisted with the NGO, did you seek health service from any other private source? What was the cost?)
- Have you heard about ARV? Are you on ARV treatment? Since when?
- If yes, did you start your ART in India or in Bangladesh? Probe: Can you please describe the steps you have taken to be enrolled for ART? What documentation did you need to share? Did you need to show an ID card? Did you need to show a proof of residence?
- Have you faced in India or in Bangladesh any challenge to access ART? Have you disrupted your treatment due to challenges in accessing ART? Please would you like to share and describe your experience?
- Do you know the future of ART situation in Bangladesh?(Mention: From November ART will be distributed through government health setting, do you feel comfortable with the change? If not why? Probe: What might happen, what are your fears? What
- If you were on ART in India, did you have to pay for the treatment? In Bangladesh, is ART free or do you have to pay?
- If HIV status has been explored in destination, then where she/he used to seek for health care there? What difficulty did s/he face? At destination / in India, where did you go for health services? Did health workers know that you were a migrant? While in India, were you denied any services or were you treated differently due to a/ your HIV status? b/ your migrant status?
- Would you like to share any difficulty or challenge in accessing health services in Bangladesh or in India/at destination?
- From your experience, is access to health services easier in India or in Bangladesh? Can you explain how it is easier? Probe: When you decided to come back to Bangladesh, did you take your decision considering the access to health services and to services/support available for PLHIV?

## Other services availed

- What other HIV related services have you received in India or in Bangladesh? Probe: care and support, nutritional, psychological, financial, medicine support, PMTCT? From whom, where, since when?
- How satisfied were you with the service you received? (ART, CD4,STI ,VCT,PMTCT,Opportunistic information, Dots service). Can you describe an experience where you were not satisfied of the services? (please, specify if this was in India/destination or in Bangladesh)
- If not received why, what were the barriers or challenges problems?

## Nutrition Status:

- Do you receive food supplementations from NGOs or other programs?
- From Whom, How often do you receive a nutrition support?
- What kind of food supplementation do you receive? Who provides the supplementations?
- Have you ever been treated differently by health staff because you have HIV? How is this manifested? When did you last have problems with health services because you have HIV? When was this? Which health personnel were involved? How did the others react? What did you do? Was that the only person you have had problems with in the health care system? Do you know of examples of discrimination from other people's experiences? (Please do not mention any names or details.)
- What would PLHIV need from health personnel, to make health services easily accessible to them? How could health personnel help the PLHIV more?
- Have you ever been treated badly by the personnel of NGOs who provide services for PLHIV? How is this manifested? When was the last time you had problems at an NGO? Who was involved? How did the other people react? What did you do? Was that the only person you had problems with in an NGO? Do you know any cases of discrimination from other people? (Please do not mention any Names or details here.)

- What would PLHIV need from NGOs and volunteers to make services more accessible to PLHIV? How could the personnel of NGOs help PLHIV more?
- In your opinion what are the main health service challenges for a PLHIV in Bangladesh? How do you think it can be resolved?
- If you have received services from destination as a PLHIV how would you compare the service differences with source?

#### **Network Membership and Rights of PLHIV**

- Are you currently a member of a positive network or support groups? If yes, which, since when, what does it do, how do you benefit, etc.
- While in India/at destination, were you part in any PLHIV network? Can you describe how you got enrolled? Did you face any challenge in this group? Did you face any kind of discrimination as a migrant?
- Are you aware of the rights of positive people? What are they? Do people respect these rights?
- What do you think should be done to encourage safe mobility of positive mobile populations?
- What do you think should be done to make PLHIV and their problems more understandable to our society?
- What could/should the state do to make the life of the PLHIV better?
- Who should offer these services? NGOs, the government, the private sector?
- Which services should definitely be available free of charge for PLHIV?
- In your opinion how HIV infection can be prevented in Bangladesh? What type of program should be initiated?
- What could the PLHIV in Bangladesh do by them to make their lives better? In your opinion how PLHIV's family's life can be improved?
- Would you like to add anything? Is there anything important that we did not discuss? Anything that remained unclear or unsaid
- Thank you very much. Your responses are very valuable to us.



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