

# Social Landscape of the Magnitude of Health Care Needs & Barriers in Accessing Health Care among the PLHIV Attended in NGO Clinics of Dhaka City

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**Abstract:** Introduction: HIV/AIDS is an worldwide public health concern, over the past years data reflects the variance in epidemic concentration from high, medium to low across countries, however, the social dynamics and adversity around the PLHIV still remain an agenda to explore. In Bangladesh since, the first HIV positive case in 1989 till date, the HIV prevalence remains low (0.1%) in the general population. While current global trends show stabilizing or decreasing epidemics in many high-prevalence countries, Bangladesh has had a >25% increase over the past decade and 1.5 % new cases over past year among high risk groups ( IDU).The prevailing stigma and discrimination are strong barrier for accessing health services and information's and the community support for PLHIV needs. Methods: This is a descriptive cross sectional study, the focus was on both quantitative ( n=100 PLHIV) and with high emphasis on qualitative to capture in-depth insights of health care needs and barriers, the data recorded, and interpreted through matrices, graphs, charts and story base. For surfacing the PLHIV stigma, UNAIDS Stigma checklist on the essential stigma indicators were applied. The qualitative method also includes Focus Group Discussion ( 3,FGD audio taped and transcribed), 2 case stories, 1 expert group consultation, 7 in-depth interview done with the clinics manager , providers and program people engaged in HIV interventions. Results: Of the 100 PLHIV clients interviewed the male 63.64% and female 36.44% and of them 70% married and rest 30% percent either single, widow or divorced. The education status is around 18.2 % received no formal education, Primary 23.4 %, secondary 35.5% and higher secondary 20.9% and only 1.8 % with bachelor level or even higher degree. The occupation predominates traditional work, house wife, regular job and business 34.5%, 21.8 %, 27.11% respectively. Around 96.4% repeated service seeker whom 7.6% came more than once and around 92.5% came to clinic several times and only 2.7% is first time service seeker. The diagnosis made within two years of whom the male 24.3% and female 25% respectively where as 25.7% male and 13% female diagnosed within six to ten years period and a very few 2.9 % even later ( ten years and above). The type of service received mostly Opportunistic Infection (35.5%) and ARV (83.6%), STI (17.3%), pain relief (30%), Gastric (32.7%), and a significant percentage (80.7%) received counseling services. Further service needs includes high response 70 % on social care support like emotional, legal & spiritual, Financial support 30.9 % , other essential Reproductive Health (RH) care (22.7%) and even their capacity building (40%) . Regarding barriers the fear of disclosure both at home (67.3%), and at community (51.8%), 21.8% stated about side effects and 12.7 % shared refusal from health clinic a significant percentage 42.7% also reasoned stigma & denial as barriers to access clinics. Conclusion: Most common view points around the barriers to health care access are like service denial, provider's attitude factor, distance, service hour, long waiting, and imposed service fees. Comprehensive service needs are often denied such as dental care, eye care, other RH service needs, including common medicines like vitamins, eye drops, mental health care, children support health care and education support, transportations, food and nutrition supports. To overcome the clinical level barriers, most importantly the health care providers need proper training/orientation and there should be provision of comprehensive and quality service package for PLHIV linking with other care and support services through Government and NGO clinics in an accessible and affordable manner which can be a true evidence of Public Private Partnership (PPP).

**Keywords:** IDU (Injecting Drug User), PLHIV ( People Living With HIV and AIDS), Stigma, Barrier, Accessible, Affordable, Public private partnership (PPP)

## 1. Introduction

HIV/AIDS considered to be one of the emerging Public health concern worldwide while over the past years data reflects there are countries which are in a high concentration epidemic situation and countries where the number of People Living with HIV is gradually increasing, although there are few countries who could limit their further increase with the advent of specific intervention , treatment following the guiding frame of Universal access to health care and prevention. [1]

In Bangladesh the first HIV positive case was identified in the year 1989 [2], afterwards, the number of people living with HIV showing an increasing trend every year. According to the UNAIDS estimate, there are 7,700 (4,900-16,000) PLHIV in the country [2] corresponds to a total prevalence of only 0.005%. According to the sero surveillance report among the high risk /MARP (Most at

Risk Population) the over all HIV prevalence rate is increasing and already crossed to the limit of concentrated epidemic among the injecting drug users groups ( IDU) , which is about 10% ( percent ) in one part of Dhaka and in certain other pockets also increasing in alarming rate which already crossed 14%, [1] this indicates a potential future risk of increasing trend among the general population. New data presented at the National AIDS Congress in Dec 2012 revealed a prevalence of 0.07% among pregnant women at Sylhet did not have any known risk factors such as migration history or blood transfusion [2].

In Bangladesh, for the last couple of years, HIV prevalence remains low ( 0.1%) in the general population and also (<1%) among the most at risk population unlike female and male sex worker, Men who have sex with Men (MSM) and transgender individual only 0.3%, but the associated risk behavior heightened their potential risk to become HIV positive in course of exposures [3] since MSMs are highly

networked, so, if HIV were to emerge, it could spread very rapidly in this population, if prevention & care efforts are not adequately scaled up.

According to the PLHIV client estimation based on their reporting and accessing VCT services the report present (2014) there 3674 of total HIV cases of whom 563 have been already died and total 1204 have developed AIDS, While current global trends show stabilizing or decreasing epidemics in many high-prevalence countries, Bangladesh has had a >25% increase over the past decade and 1.5 % new cases over past years [2]. There is no scope of complacency from these figure since, most cases go unreported because of stigma and also there is very limited capacity for HIV testing facilities.

It is important to mention that, with these limited number of HIV positive cases still they lack in accessing information and health services (both treatment & Care) while suffer from various opportunistic infections and other health problems. There are provision of Antiretroviral medicine for 1500 clients in the year 2015-16, according to the Govt. service sources, but the regularity of supply of such drugs and the total management which includes medication to side affect management is still poorly managed. The prevailing stigma and discrimination in the society often caused as a strong barrier for accessing health services and information's according to the various needs of PLHIV. There are very limited number of health care facility sites available where there is provision of VCT services and also other medical care for the PLHIV [3]. It has become an important priority for the policy makers to understand the Public Health aspect of the magnitude of such health care needs, health seeking behavior and availability of services to better address the PLHIV there by concentrate and limit the spread and risk of further increase of HIV case burden in a resource poor health care settings of country like Bangladesh.

### 1.1 Research objective

- 1) Obtain information on the socio demographic status of PLHIV attending the clinic
- 2) Identify the common health care needs among the PLHIV who have accessed services in the clinic
- 3) To find out the different type of barriers encountered by the PLHIV in accessing health care
- 4) Explore provider perception regarding the types and causes of health care barriers for PLHIV access to services
- 5) To understand the complexity of the barriers PLHIV have for accessing health care and recommend way forward for better access to health care.

### 1.2 Methodology

This is a descriptive cross sectionals study among the PLHIV, a mixed methodology applied to get information from respondents. For the quantitative data the respondents selected who are either registered already or attending in the NGO clinic. Since the health care settings are limited in number within the country where the services for PLHIV are mostly available in Dhaka city, such case the facility sites

are purposefully chosen where the services are available like the PLHIV NGO clinics in greater division of Dhaka in the country. In order to access the optimum number of PLHIV clients from health care setting the interview process also includes a prior consultation with the clinics manager to obtain optimum number of HIV positive clients. There are certain PLHIV Self Help Group (SHG) NGO clinics where there are specific designated days (members day) allocated for PLHIV clients while they come to the clinic and participate in the social day and simultaneously also avail health services, the most data collected during that period. The client enrollment frequency are considered from the past three months enrollment from the client registration book.

The study focus was on both quantitative as well as qualitative where much weight -age given to qualitative data process, like FGD, Case story, In-depth interview (IDI), Key Informants interview (KII) done so that the in-depth insights of health care needs and barriers can be explored and recorded [4,5] and qualitative data interpreted through data displays in the form of matrices, graphs, charts and description and case narratives.

There were semi structured questionnaire and in-depth interview designed to obtain maximum information's according to the objectives and variables. To dig out the status of stigma in course of lifestyle and living the UNAIDS Stigma checklist on the essential stigma indicators were applied [6,8]. To further authenticate those information there were also Focus Group Discussion (FGD), expert group consultation and case stories, included which were helpful to well capture the information realities, the interviews are also audio taped and transcribed [7].

### 1.3 Sampling

The non-probability sampling method like Purposive and Convenience sampling used through a systematic technique where based on the availability every clients enrolled in the clinic on the day of interview were included as respondents. There were 100 PLHIV who were subject to the semi structured interview and UNAIDS Stigma checklist [6,8] and 3 FGD (each 7-9 members) conducted, and 7 KII (key informants Interview) and IDI taken with the providers along with an expert group consultation which was represented by all relevant stakeholders engaged in PLHIV policy level to program. There were two (02) Case stories captured through an in-depth discussion with the PLHIV woman [7].

### 1.4 Result of the study

Of the 100 clients interviewed the frequency analysis in (Figure 1 & 2) shows that the majority 63.64% (percent) of HIV/AIDS positive people are male and the rest 36.44% (percent) are female of them 70% (percent) are married and 10.9% (percent) are still single and among women 14.5% percent are widowed, and a few cases, 4.5% (percent) of them are divorced or cohabiting. Regarding their education status stated in (Table 1, Figure 3) a significant percentage has received either Primary 23.4% (percent), secondary 35.5% (percent) and higher secondary 20.9% (percent) education and around 18.2% (percent) received no formal

education. On the contrary a few of them 1.8 % (percent) found to be with bachelor level education or even higher degree. The occupation status also widely varies among the respondents as shown in (Table 2, Figure 4) 21.8 % (percent) as House wife, 14.5% ( percent) in regular job, 13.6% (percent) in business, and around 6.4% & 9.1% (percent) are as daily labor and farmer, also a significant percentage (34.5%) of them also belong to other engagement which includes various traditional works either at home or outside which are non-paid labor.

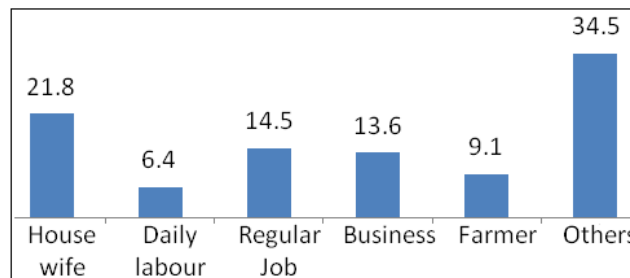


Figure 4

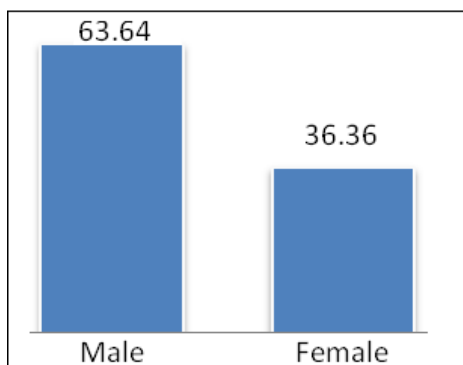


Figure 1

While investigating their Health seeking behavior (Table: 3, Figure 5 & 6) a significant percentage 96.4% ( percent) found to be repeated service seeker and only 2.7% ( percent) stated that this is first time they came to seek care. Among the repeated service seeker 7.6% ( percent) came more then once and around 92.5% (percent) came to clinic several times. [9]

Table 3: Is this your First time to clinic

Yes	2.7
No	96.4
No Response	0.9

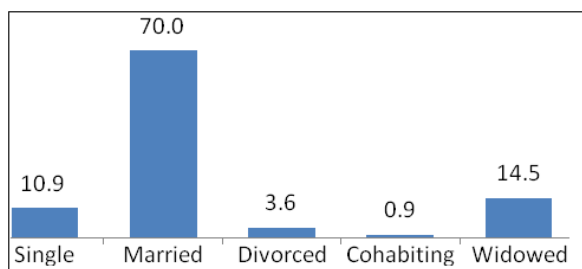


Figure 2

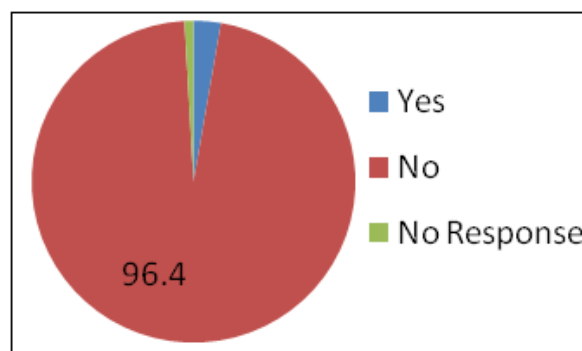


Figure 5

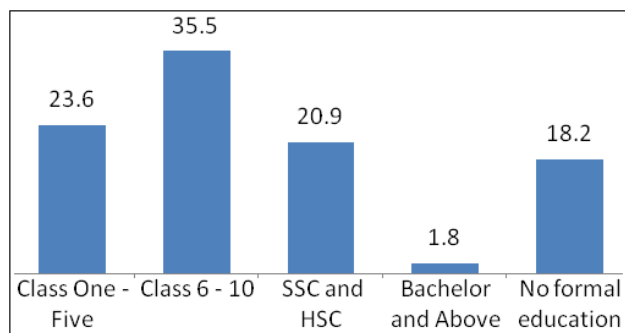


Figure 3

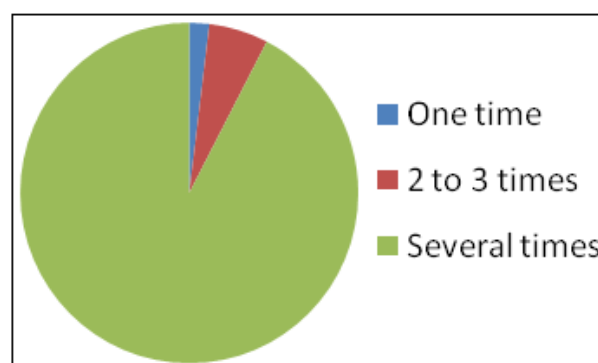


Figure 6

Table 1

Class One - Five	23.6%
Class 6 - 10	35.5%
SSC and HSC	20.9%
Bachelor and Above	1.8%
No formal education	18.2%

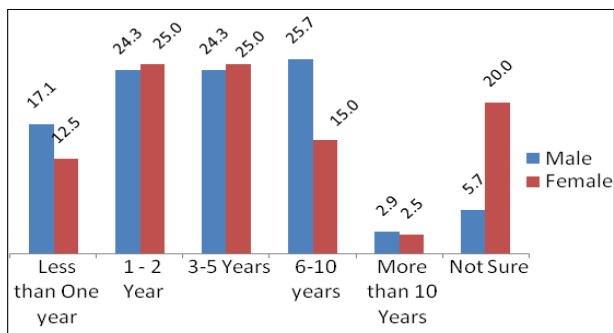
Table 2

House wife	21.8 %
Daily labor	6.4 %
Regular Job	14.5 %
Business	13.6 %
Farmer	9.1 %
Others	34.5 %

Regarding the duration of illness and gender wise segregated data reveals the fact (Figure:7) that most of the respondents found to be diagnosed even within one to two year or even later within three to five years time, the percentage varies between the male 24.3% ( percent and female 25% (percent) respectively. Also a significant percentage 25.7% ( percent male) and 13% ( percent female) found to be diagnosed HIV positive even within six to ten years' period and very few 2.9 % to 2.5% (percent) are diagnosed even later (ten years and above). Among female respondents a significant percentage 20% (Percent) also found to be unsure about their duration of illness [10].

**Table 4:** Type of services availed from clinics

Type of service (Multiple response)	N=100
Treatment for opportunistic infections	35.5
ARV	83.6
Treatment for other sexually transmitted diseases	17.3
Pain relief	30.0
HIV Counseling and testing	80.9
Gastric relief medicine	32.7
Vitamin	3.6
Diarrhea	0.9

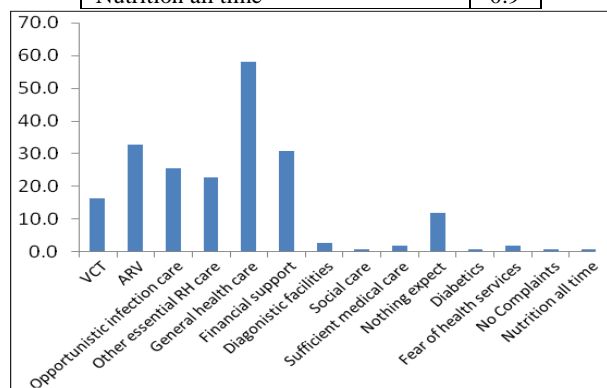


**Figure 7**

The frequency data shows (Table:4) regarding the type of health care often they received from the clinics mostly Opportunistic Infection (35.5%) and ARV (83.6%) , STI (17.3%), pain relief (30%) Gastric (32.7%), and a significant percentage (80.7%) received counseling services. [10,12]. While exploring their further service needs in (Table 5, Figure 8) it appears to be quite similar with disease areas other than the social care supports like Financial support (30.9 % percent), other essential Reproductive Health, RH care (22.7%, percent) including nutrition and Diabetic care (1.8% percent) respectively.

**Table 5:** Type of service Need

VCT	16.4
ARV	32.7
Opportunistic infection care	25.5
Other essential RH care	22.7
General health care	58.2
Financial support	30.9
Diagnostic facilities	2.7
Social care	0.9
Sufficient medical care	1.8
Nothing expect	11.8
Diabetics	0.9
Avoid Fear of health services	1.8
No Complaints	0.9
Nutrition all time	0.9



**Figure 8**

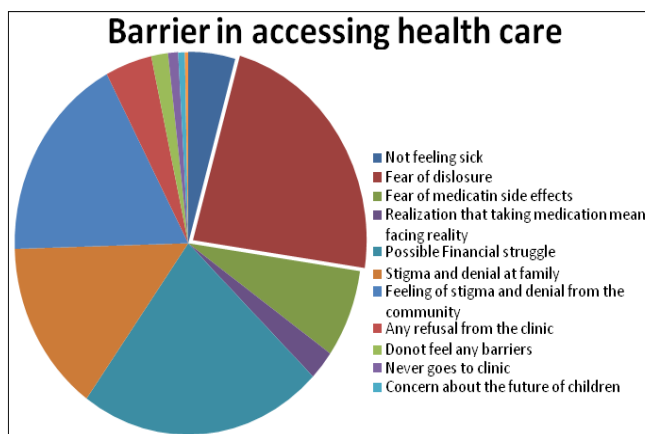
**Table 6:** What are the other needs to be available for a PLHIV (Multiple response accepted)

Health care needs	68.2
Emotional needs	57.3
Spiritual needs	25.5
Nutritional needs	84.5
Social needs	70.0
Capacity development needs	40.0
Day to day needs	16.4
Financial/grant needs	86.4
legal support needs	57.3
Right to express of the disease	0.9
All medical facilities from all other hospitals	0.9
Family counseling	0.9

While the PLHIV were asked to give their free opinion on the other service needs apart from health care the majority of them responded the health care (68.25%, percent) either nutritional (84.5%, percent) or any other health service on the top of the needs. Similarly there was high response on their social need (70 % , percent), financial /grant need (86.4%, percent), emotional and legal support (57.3%, percent), spiritual need (25.5 % , percent) even a significant percentage (40%) also wanted to have support for their capacity building [10,11,12].

**Table 7:** Common Barriers accessing care

Barriers (Multiple Response)	N=100
Barriers of different types for accessing Health care	Percentage
Not feeling sick	12.7
Fear of disclosure	67.3
Fear of medication side effects	21.8
Realization that taking medication mean facing reality	7.3
Possible Financial struggle	66.4
Stigma and denial at family	42.7
Feeling of stigma and denial from the community	51.8
Any refusal from the clinic	12.7
Do not feel any barriers	4.5
Never goes to clinic	2.7
Concern about the future of children	1.8



**Figure 9**

Among the respondents the most commonly appeared barriers for accessing services as shown in Frequency data in the following (Table 7, Figure 9), the majority faces the fear of disclosure both at home (67.3%, percent) and from community (51.8%, percent). 21.8% (percent) stated about medication side effects and 12.7 % (percent) shared regarding the refusal from health clinic as well. Among the

respondents receiving health care a significant percentage 42.7% (percent) reasoned stigma & denial as barriers to access clinics. [13,14]

### 1.5 Expert group consultation: PLHIV health care needs, stigma, discrimination and denial.

Further investigating the providers perspectives at different angles while they provide and manage care and support services for PLHIV from different community with diverse socioeconomic status, it has been noticed that, regarding the issue of stigma, denial, discrimination always have a common face inside the family, community and society irrespective of social status. From the in-depth interview findings with the provider of different tiers like Chief Executive of SHG, the Project Coordinator, Medical consultant, Medical officer and Counselor, the major insights and perspective drawn were that, every provider having association with PLHIV service and care for more than five years. They mostly have received trainings at least four to twelve week (4-12 weeks) duration except the counselor for VCT service who is found to be an hands on learner, have no formal training during the period of consultation. They all echoed in same tune regarding the barrier issues while the PLHIV accessed health care to them and explained their views and experiences on the perceived barriers of PLHIV at different levels starting from family, community and at clinic level.

### 1.6 Barriers at Family level

Immediately after the diagnosis and disclosure of their HIV Positive status in most cases the family level barriers appeared to be in different form but atypically similar in nature for all other PLHIV [10,13]. They shared about the acceptance problem, and deprivation of family resources and supports and the inherited property as well. The stigma and discrimination appeared to be so cruel that, they often face difficulties in accessing health care, taking medicine at home and also going for repetitive treatment and follow up. The deprivation and denial of the property and inheritance become very common to the family affairs and in most cases they are thrown away or separated from sharing the common kitchen [10,15].

### 1.7 Community level Barriers

In case of community and societal level such barriers are more deep routed unlike family, starting from an avoidance look, point fingering the person, causing personal attack, isolating purposefully, denial of education and other supports like health care, job and participation of any social activities, like marriage ceremony, social club, funereal and similar social gatherings [10]. Their children's irrespective of their

## 2. Case Story-1

### A spell of Weeping of a Tormented soul:

When Farida Parveen a women of 27 years with her two sons of their tender age (8 years and 5 years) started to ventilate herself, it was an heartbreaking feel to take that snapshot hearing of her life and realities. The painful story began from the moment, while she was recognized with the HIV virus and herself alone started down the road of her journey through life. Her husband used to work at Saudi Arabia for five years and she used to stay in her joint family with in-laws. She herself and her youngest son suffered from long repetitive illness, then she had to admit at P.G hospital and got the HIV test done where she was diagnosed HIV positive after about two years of prolong sufferings. Then she was referred to Ashar Alo Society a Self Help NGO which is the great umbrella shed for all PLHIV in Bangladesh [12]. She got the support from AAS to get her husband & children also tested as well. Luckily they all found to be HIV negative of course a happy feelings for her being a wife and a mother which clearly glowed in her face while sharing! **But for her, it is a different story of pain taking!** Her fate turned to an opposite rude reality, she become a persistent victim of domestic violence, punished every day & night by beating inhumanly, assaulting in various way, using abusive word, depriving herself and the kids from everything around her, that happened from her very dearest and nearest ones like husband, in-laws [13]. Although she has disclosed these facts to the Counselor of AAS to offload her heavy feelings that was not enough to take care of her total deprivation in everyday life and living. **Only Ray of Hope** she has found from AAS that, she can escape her situation and stay for some period at AAS dormitory, where they will arrange her possible legal support. However, this didn't bring much light to her life way since, she was very much afraid of the "after math" and consequences she will have to face along with her two sons while sought such legal support in a cultural context as she vowed on to me "Pls never ever try with that, let me live with whatever is my fate"

AAS arranged her regular treatment which include mental and social support and also affirmed her to arrange further support to help her skill improvement for engaging any tangible earning for bearing her living expenses by herself. She has also shared that, currently she has acquired skill on handicraft activities, she can operate sewing machine and she is ready to work for managing her children's financial security. The reality is all this kind of support [12] arranged may will impact upon to minimize her sufferings **but nobody will count on her weep of the tormented soul**, the shattered mind of the boys who are the companion warrior of her fighting for life and living!

**\*(For the sake of the PLHIV confidentiality the identity was not declared but the case captured with due consent)**

HIV status are in most cases dropped out from the school after the parents are being diagnosed positive.

### 2.1 Clinic Level Barriers

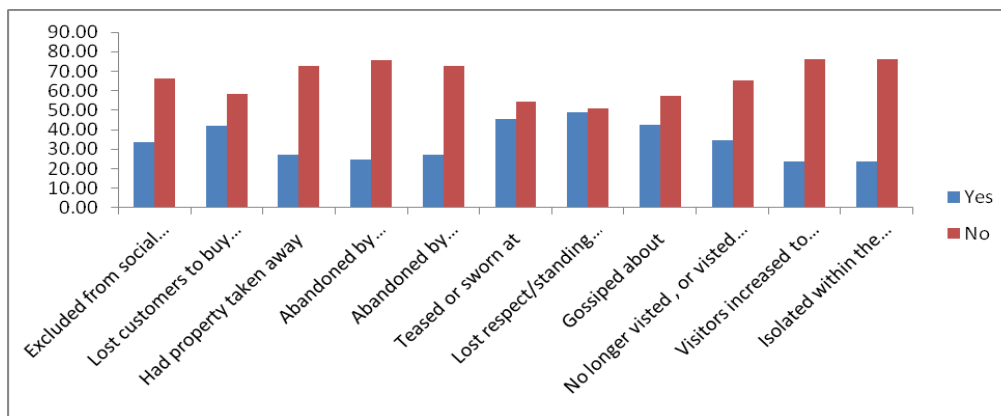
At clinic levels these barriers have a little different face for instance, apart from the Self Help Group NGO in most cases

the clinics denied their access to health care. The providers lack in motivation, fear factors associated to extend support, stigma and discrimination become strongly visible while offering health services and they are poorly attended by the clinics because of the inadequacy of information, inadequacy in logistics, universal precautions, medicine supply and providers incompetency to treat and counsel PLHIV and in some cases not having any surgical and other service back up for them [15] to extend some minor surgical procedure like, stitching abscess draining etc.

**Enacted Stigma: Community level**

**Table 10**

UNAIDS stigma checklist N=100	Yes	No
Excluded from social gathering	33.60	66.40
Lost customers to buy his/her produce goods or lost a job.	41.80	58.20
Had property taken away	27.30	72.70
Abandoned by spouse/partner	24.50	75.50
Abandoned by family/sent away to the village	27.30	72.70
Teased or sworn at	45.50	54.50
Lost respect/standing within the family and/or community	49.10	50.90
Gossiped about	42.70	57.30
No longer visited, or visited less frequently by family and friends	34.50	65.50
Visitors increased to check them out	23.60	76.40
Isolated within the household.	23.60	76.40



**Figure 12**

**a) Perspective regarding the common causes associated to barriers**

While sharing the provider perspective, at home level the barriers they encounter from the family members in their everyday life and living are mostly due to the absolute ignorance and fear factor associated with the disease itself. The family members in most cases lack in accessing information on HIV/AIDS and often are convinced with superstitions misconception rather having curiosity to avail correct information's [10]. It is very obviously coming out from their view point that the family members are most cases not sensitized and aware of the disease rather afraid to get infected which could be overcome through access of information and repeated motivation and sensitization at that level [10].

In the community and society level the causes relate to such barriers are similar like the prevailing superstitions and misconception, lack of access to information and awareness and sensitization at that level and also rumor associated with the fear of infectivity [10], and the stigma and death attached to HIV/AIDS.

Whereas at clinic level the causes associated to the barriers are in most cases Doctors are not trained and motivated enough for handling cases and also not protected with pre exposure prophylaxis services from the clinic level to handle clients. In some cases providers also suffers from stigma of losing clients after the PLHIV case disclosure. Moreover, at clinic level the services are not properly packaged like with access to information's, service availability, equipments and

logistics, medicine, provision of universal precaution, OT (Operation /surgical) services along with the free blood screening facilities which quite often a discouraging factor for the clients to seek segregated service at different place while they are already surrounded with an heighten of stigma factors around [11, 1].

**b) View point to overcome barriers at different level (Home, Society and clinic)**

While drawing their insights regarding the means and way forward to overcome those barriers at different level the providers put their opinion on the facts that, at family level there are enough scope for doing awareness and sensitization activities engaging them with HIV information, care and services also some basic human rights matters [10]. Once they are educated on the transmission and prevention of HIV/AIDS they will be able to overcome their fear, misconception and denial attitude to their family members. The clinic providers also shared that the programs like Greater Involvement People with HIV AIDS (GIPA), [16] will also open up an opportunity to engage them meaningfully in HIV care giving services through proper training and awareness.

In order to overcome barriers at community and society level they viewed upon having repeated community awareness and sensitization activities as an inclusive part of HIV program might be of help. Moreover, engaging different stakeholders and elites in such sensitization activities would be much value add. In their opinion the PLHIV empowerment activities through their training, and

engaging and organizing them as member of Self Help Group (SHG) arrange their participation in community meetings and gatherings as a part of social inclusion can be the easy solution to overcome societal barriers. Accessing right information in a right way through advocacy can be useful to dispel community stigma and will be helpful to bridge the gap between PLHIV and the others in the community [16,17].

## 2.2 Perspective on service improvement at health care setting to minimize the barriers

There were several suggestions regarding the improvement of service level to overcome the clinical level barriers to access health care of PLHIV, most importantly the health care providers like doctors, nurses, counselors and paramedics invariably need proper training/orientation and awareness to handle HIV clients, [10, 17]. There should be a provision of primary information and services at all health care settings and the comprehensive service package for PLHIV case management and care also a need. The follow up with an established proper referral mechanism for linking other care and support services to satisfy their needs also an essential consideration [12]. The comprehensive clinics should be also properly equipped with logistics, equipment and O. T facilities if possible so that, the clients can avail one stop services for them, and the clinic also need to pay proper attention to the provider safety net such as universal precaution, pre exposure prophylaxis availability at the work settings [10,11]. There should be some provision of extended services like Nutritional support for infected and affected, legal support, Job arrangement, IGA activities which will eventually helpful to reduce clinical and community stigma as well [12,17,18] and these findings equally supports the quantitative information.

## 2.3 In-depth interview findings with the Key Informants

In order to obtain the deeper purview of their Health care needs and common barriers the PLHIV often face at personal sphere of family, community and health care clinic level, a total five (05) in depth interview were taken from the PLHIV NGO clinics at different tiers.

### In-depth insights are drawn from the service providers SHG NGOs : Ashar Alo Society, and Mukto Akash

Interview were taken from the Coordinator, Medical Consultant & Counselor AAS, and Executive Director and program Manager of Mukto Akash, all have been engaged with PLHIV services more then five (05) years and they have training on PLHIV care not less then one month except the counselor who is yet to be trained on PLHIV issues. While investigating the barriers associated to health care for PLHIV they all equally shared the view that the access of health care is always faced with different barriers and difficulties. It starts at family level while they are diagnosed positive. Although the barriers at different levels appears with a similar notion of stigma and discriminatory attitude attached to it, these barriers in most cases quite common at different layers starts from family, Society and institutional health care settings but also are distinguished in selective cases [10,17,20], the findings also authenticate the quantitative reports.

### 2.3.1 The Commonly faced barriers Home / Family Level

The first and foremost is the issue of acceptance of the PLHIV status and denial from family resources and supports which are most common in every cases. These denial can be of various type like mere ignoring, denial of sharing foods, clothing's, beds, spaces and also denial of participation and taking role in any family matters, programs, social activities, decision making, denial of supporting medical care, including the denial of property inheritance [10] which also synchronize the quantitative findings.

### 2.3.2 The Neighboring and community /societal level barriers

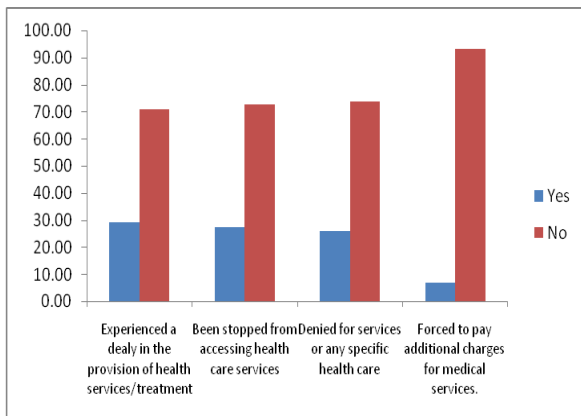
At the community outsets the denial and discrimination occurs in different angle, in most cases the PLHIV have a strong fear of disclosure of their status as they are heavily point fingered for such status [14, 15]. The crude face of the social stigma appears to be in various form of social treatment like, the over curiosity about the positive person, personal attack & isolation, refusing participation in any social matters, refusal of children from good schools, refusal of engaging in formal jobs and other social opportunities [10,19,20].

### 2.3.3 At clinical Service level barriers

To access clinical care the barriers are not always associated with stigma and denial it can be reasoned by financial inability, remoteness of service center, the institutional stigma mostly attached to the providers motivation and skill, inadequate information's and logistics availability in the clinics.[17,18]. Although at the clinic level it differs from the complete denial and discrimination of PLHIV medical care and information in the formal health care settings. In opposite instances there are few Self Help Group clinics which are designated institution for PLHIV so the PLHIV peoples where the service are not much denied and discriminated, rather they face denial in different mode, like denial of getting medicines according to the prescribed types and doses [11,12,21]. They often get Antiretroviral (ARV) but quantity may not adequate to fill up the whole months medication need, and also these medicine is dispensed need base only over the prescription counter. So PLHIV client have to be physically present every time which in some cases not possible for PLHIV as they fail to seek repeated care to the clinic because of family level discrimination and non-cooperation and also in some cases the SHG clinics are located at far place to access regular care. They are often denied with comprehensive needs of their medical care like dental care, eye care, other RH service needs and in case medicines like vitamins and other common medications are often denied because of the unavailability and inadequacy of supply[12,22,23]. Moreover, the PLHIV can also receive indoor medical care from very selective Govt. hospital and Private clinics which are also often lacks in effective services and regular supplies.

**Enacted Stigma -Clinical Level****Table 9**

UNAIDS stigma Checklist (N=100)	Yes	No
Experienced a delay in the provision of health services/treatment	29.10	70.90
Been stopped from accessing health care services	27.30	72.70
Denied for services or any specific health care	26.00	73.60
Forced to pay additional charges for medical services.	7.00	93.00

**Figure 11****2.3.4 Common reasons associated to the Barriers**

While searching deep to the reasons attached to these barriers for health care access at different level, the most common were the lack of knowledge and information about the disease transmission and risks which even in many cases enveloped with the complete ignorance, misconception, fear factor and curiosity of different form which are enacted as discriminatory forms behaviors in the society. The inherent opportunistic attitude of the family members and societies are much visible while the PLHIV suffers this disease and the question of deprivation of land and resources comes into effect.

At the Health care settings, such barriers may start from the lack of information and awareness & appropriate orientation and training at staffs and providers level [10,11]. There is often institutional stigma highly matters with the refusal of PLHIV due to the prevailing fear, misconception about the transmission risk, exposure risk and also they are afraid of losing other clients if the PLHIV are entertained. In cases there are just lack of motivation factor which compliments others factors like absence of pre-exposure prophylaxis drug for the providers, the inadequacy of trainings and logistics and even required medicines for PLHIV including ARV and other drugs.[22, 23]

In the clinics there are also information and service inadequacy like in the two SHG clinics the only health care services available are the very needed care for PLHIV like the Anti Retroviral Medicine (ARV) Opportunistic infection care, counseling, and referral provision for other services like Reproductive health, GH and legal supports. Although there are certain very essential services offered from these two clinics which are very unique approaches like dormitory (Half way home service), income generation activities) both grant and skill transfer as well, designated members day so the PLHIV can avail tremendous opportunity to cross share and ventilate themselves in every month social day (members day). All the findings are complimentary across the diverse level of investigations made in the study.

**2.3.5 Major means to overcome barriers**

According to the opinion of the service providers the prime important solution to the access barrier is the sensitization and awareness raising, mass media campaigning of HIV/AIDS at home, community and institutional level in order to dispel the stigma which eventually will act upon the access issue [17]. They have further opined that integrating HIV counseling and basic care at both public and private health care settings along with provision of repetitive orientation and training can further compliment to remove institutional stigma, however, in such situation the provider safety net is another issue to be taken care of with a provision of post exposure prophylaxis at those health care settings[12,22]. In every PLHIV health care settings demands the major investment and program emphasis to the comprehensive service provision, adequate supplies of medicine, logistics and equipment and also backed up by flow of information and counseling services[11]. Doctors viewed upon the issue of stigma and access denial that the activities orchestrated to penetrate the community and societal analogy is extremely important where there are many instances apart from community awareness and sensitization unlike community self-help organization, community care giver role, self declare status as Role model and right base activities played crucial role in reducing stigma and discrimination. It appeared as a common view to every providers who were interviewed, they strongly believe that, the barriers to health care access can be of various nature but exterminating the route is extremely crucial and according to them, the PLHIV issue needs to be considered in a mainstreaming way rather marginalized focus of ongoing programs. So that, the PLHIV will be entitled and embraced with the access of every basic societal amenities (Health, Food, Jobs, education & shelter [12, 15,25] thereby the accessibility and expansion of the information and quality health care service barriers will be taken care of.



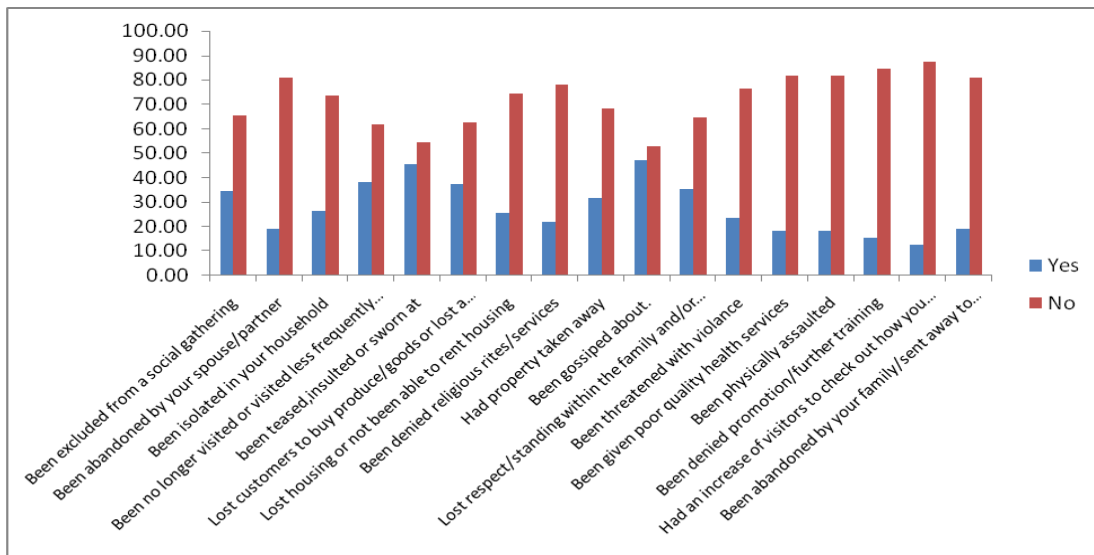


Figure 10: Enacted stigma: Individual level (UNAIDS stigma Index)

2.4 Findings of the FGD

The in-depth understanding of the various aspect of the access barrier have been further explored through FGDs among the respondents in three different sessions where the discussion have been facilitated and followed to authentify the findings associated to the semi structured interview and in-depth interviews. The findings are relatively similar around issue of access barriers to Health care, the major focus of the discussion was mostly relevant to the commonly encountered barriers, their personal experiences of discrimination and service denial, even further dig down to the facts of provider’s attitude factor, distance, service hour, long waiting, and imposed service fees [22,23.24]. The groups genuinely viewed about their feelings and experiences while seeking health care, the very first kind of the access barrier starts from stepping out of

and its get even more complex while seeking repeated care and also while the carry medicine with them. Even though they manage to come out of home, then the barriers often they face are related to transport, distance and locations of the clinic which is too far in most cases. While reaching service centre these turns into different form unlike, being teased, negligence from the nurses and providers, sometimes even long waiting and unnecessary harassment, repeated visits requires to get the service and investigations reports. In several cases they face the inadequacy of medicine and are told to buy from the pharmacy where they face another form of denial and discriminations [3,9.24 ].

The common medical cares although reachable in some health care settings, however, facility to access food, medicine and little allowance in a monthly basis along with a monthly card system is very much expected in the service lists. Getting to know about other private and Govt. medical and hospital care supports it is a far-reaching fact when in most cases they prefer to hide their conditions to avoid the access barriers of various angles.

Table 8

UNAIDS stigma Index N=100	Yes	No
Been excluded from a social gathering	34.50	65.50
Been abandoned by your spouse/partner	19.10	80.90
Been isolated in your household	26.40	73.60
Been no longer visited or visited less frequently by family and friends	38.20	61.80
Been teased, insulted or sworn at	45.50	54.50
Lost customers to buy produce/goods or lost a job	37.30	62.70
Lost housing or not been able to rent housing	25.50	74.50
Been denied religious rites/services	21.80	78.20
Had property taken away	31.80	68.20
Been gossiped about	47.30	52.70
Lost respect/standing within the family and/or community	35.50	64.50
Been threatened with violence	23.60	76.40
Been given poor quality health services	18.20	81.80
Been physically assaulted	18.20	81.80
Been denied promotion/further training	15.50	84.50
Had an increase of visitors to check out how you are doing	12.70	87.30
Been abandoned by your family/sent away to the village	19.10	80.90

*“Atimes I feel like to commit suicide to escape my sufferings or I get engaged to unfair means to manage money for my living”.*  
FGD view point

Exploring their service needs which are still unmet, they tend to have more services from same facility sites starting from their medical care, mental health care, children support health care and education support, transportations , food and nutrition supports. Even at some points they found to be very anxious about their social security which they feel to be a responsibility of the county and society as a whole to ensure those services for them as human being. Findings echoed with other countries PLHIV statements as the stated quote shared in the Box highlights.

home where they encounter barriers as such they need to communicate to family members, neighbors where they go

*"Some medicines are very costly ... I need to take money from my brothers but even in spite of having the money medicine is sometimes still not available."*

Fiji

*"I have to do this treatment all my life but no organization can support me all this time."*

Myanmar

*"It is difficult for me to get the medicine. Because transportation costs are high, I have to pawn things first."*

Myanmar

*"Hopefully ARV will be free forever."*

Philippines

(Ref.10)

Tertiary medical university, BSMMU. Deeper to this fact of receiving in patient care which often very limited to their actual service need and is more likely to be difficult in terms of accessing services. **"Taking ART is like pulling Tiger's Tail, you have to keep it once you have started it, otherwise you will be in big trouble"** Lashier participant, MPG [25]

However, in respect to the overall satisfaction to the health care and quality it reveals in the discussion very explicitly that they have not much to share while it comes to the question of satisfied care in most cases there was a very positive notions among the FGD participants except with few occasional cases of misbehavior, wrong attitude by the providers and long waiting. On the reverse discussion around the quality of care they strongly emphasized on providers aptitude and ranges of service availability which they feel to be more improved and widely considered which truly match with the case stories the PLHIV shared.

Currently, they access their medical and everyday health care from some of the private sources like Mukto Akash, Ashar Alo Society, CAAP, AITAM, Jagori, ICDDR, Zeon Foundation and also receive in patient cares from few of the Govt. sources like IDH, Medical college Hospitals and

### 3. Case Story -2

#### Unfolding Truth of A PLHIV Women's Life:

Shaymoli Sarker a woman of 34 year old who have already experienced her widow hood in this age and living a distressed life with extreme stigma and denial due to her PLHIV status. Nobody in her surrounding were sensible enough to feel how it has happened to her as an innocent victim of her loyalty of love in a marital bondage rather the surroundings treat herself brutally blaming and discriminating her status [26]. Shaymoli has two children , son of 16 years old who is already appearing his SSC exam and the daughter is at age of 11 and studying in class V in a local school and it is very fortunate to learn about their HIV negative status which some way lighten her soul to live and fight for life. Her husband Krishna Sarker died in 2006 while working at Saudi Arabia and it was not even known about his HIV status before his death. Although he had repeated symptoms but was often reluctant to sick treatment from Bangladesh whenever he used to visit his wife. After 6 years of his death her wife was tested and diagnosed as HIV positive while she had a long unknown sufferings of chronic symptom like cough, fever and weight loss and finally sought treatment from Mitford Hospital., there she was admitted for six days and then referred to Jagori clinic, icddr for primary counseling and treatment and then to Ashar Alo Society for registering as member of PLHIV team for availing continuous care and support. Her early entry to AAS was one way, a great push to give her relief through counseling and gradually healing up her emotional trauma and it was an avenue for receiving proper treatment which is too costly for her to afford herself. But that was not an end of her story of prolonging sufferings rather was a beginning of a new painful world around her. Currently, She is having several medical symptoms like skin disease, chronic insomnia, nail and eye infections which she requires regular medical care and medicine support , at the moment she is struggling to manage a eye drop (prescribed by the clinic ) which is expensive for her to afford.

Initially, as she used to live in a joint family so the financial matters of everyday livings and savings were collective whatever has been contributed by her husband while he was in abroad. But immediately after diagnosis of her HIV status the whole scenario turned opposite all of a sudden, she was blamed rudely for the disease and tortured by her in -laws repeatedly along with her children and finally thrown away from her "sweet home" which was the only "safe haven" to relate herself with the emotion and love of her late husband. She was even abandoned from her husband's inheritance and finally took shelter to her brother's house where she has been supported in a little way as his brother himself is also struggling for his family with his limited earnings. The crucial part for herself to arrange the livelihood of the children's starting from food, education, medicine, daily expense, clothing's and others for which she is currently over stretching on her brothers earnings. While ventilating herself, she was too emotional to share how much humiliated she feels wanting money from her brother as she shared " At times I feel like to commit suicide to escape my sufferings or I get engaged to unfair means to manage money for my living". With the legal support from AAS and Ain O Shalish Kendra she has already put a file to the District Judge of the local court to claim her husband's inherited small piece of land which is still awaiting decision and she has to pursue through legal doors with patience to attend the hearings in the courts over days. Living through a life of extreme discrimination and denial puts her in a dilemma of living and winning life or surrender to eternal peace and escape this dismay forever!

\*(For the sake of the PLHIV confidentiality the identity was not declared but the case captured with due consent)

#### 4. Recommendation

- 1) In order to make the service provision accessible and affordable at primary level it is wise to arrange health care service provision at government clinics along with NGOs and train the every Thana and Upazilla level doctors accordingly which can be a good example of Public Private partnership.
- 2) There should be proper plan of integration of need base PLHIV services at sectoral program supported by adequate medicine and logistics also proper monitoring mechanism for ensuring quality care of PLHIV both at NGO and Govt. settings.
- 3) There should be some promotional and protection measure from the state to self declared cases in order to spell out stigma and discrimination. From the clients Rights protection point of view there should be some legal protection to address the breach of confidentiality of case disclosure at clinic and workplace and also refusal of services for clients as well .
- 4) Since education status is strongly linked to overweight stigma in such case the education sector engagement is a high priority agenda to get high attention.
- 5) Since there is a social & cultural link to stigma & discriminations around diseases like HIV/AIDS, so further deep level research need to be done to explore the deeper insights around the health care needs & access barrier to support future program.

#### 5. Conclusion

Most common view points around barriers to health care access are like service denial, provider's attitude factor, distance, service hour, long waiting, and imposed service fees. Comprehensive service needs are often denied such as dental care, eye care, other RH service needs, including common medicines like vitamins, eye drops, mental health care, children support health care and education support, transportations, food and nutrition supports. To overcome the clinical level barriers, most importantly the health care providers need proper training/orientation and there should be provision of comprehensive and quality service package for PLHIV linking with other care and support services through Government and NGO clinics in an accessible and affordable manner which can be a true evidence of Public Private Partnership (PPP).

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**Semi structured Questionnaire for the Respondents**

**Date of Interview**

**Site of Interview**

Good morning. We would like to ask you few questions regarding your health status, health care needs and other associated problems you have encountered to access health care services and the services that you have received from this clinic. I would like to ask you some questions about the visit you have just had with this clinic and would be very grateful if you could spend some time answering these questions. I will not write down your name, and everything you tell me will be kept strictly confidential. Also, you are not obliged to answer any question you do not want to, and you may withdraw from the interview at any time. May I continue?"

If the client agrees to continue, ask if she has any questions. Respond to questions as appropriate and put a mark (signature or finger print) below.

**Consent received ( )**

If the client does not agree to continue, thank her and go to the next interview and put a mark (signature or finger print) below.

**Terminated ( )**

**( Obj 1) Socio Demographic & Health Characteristics**

Gender      Male       Female

How old are You (# in completed years) \_\_\_\_\_

What is your Marital status      Single     Married     Divorced     Cohabiting     Widowed

How many years of education have you completed up to now?  
 # years completed \_\_\_\_\_

Less the one year      No response     Never been to school

What is your occupation? House Wife     Daily labour     Regular job     Business     Student     Others

Where do you live/stay?      Village       Metropolitan city

How long have you been living in city?  
 # of years \_\_\_\_\_

Less then one year     Don't remember     No response

What is your total income for last month?  
 Tk \_\_\_\_\_

Don't know     No response

What is your source of income  
 No income     Formal salary     Other grant or support sources

**(Obj 2& 3) Common Health care needs & barriers**

What is the duration of Illness (HIV)  
 < less then one year     1-2 year     3-5 years     6-10 years     More then 10 years     Not sure

How long ago did you learn you were HIV-positive?  
 Less than 12 months     1-4 years     5-9 years     10 years or more     Don't remember

How soon after being diagnosed with HIV or AIDS did you receive HIV related medical care ?

Not in medical care  Immediately after being diagnosed  Within a six months after being diagnosed   
Within 1 year after being diagnosed  When I got sick

Is there anyone else in your household ( family members, partners/spouses, close friends living with you) who is also HIV positive.

Yes  No

Do you have any medical insurance? Yes  No

Do you have regular Doctor for HIV /AIDS Yes  No

Do you have Access to ARV Yes  No

Do you have any difficulty in going to Hospital clinic when want to Yes  No

Do you have any difficulty in going o private clinic when want to? Yes  No

**What barrier or obstacle did you face in accessing health care ?**

- Not feeling sick
- Fear of disclosure
- Fear of medication side effects
- Realization that taking medication means “facing reality”
- Possible financial struggle
- Stigma & Denial at family
- Feeling of stigma & denial from the community
- Any refusal from the clinic

**What would you consider as the major obstacle you faced in receiving health care treatment ?**

- Not feeling sick
- Fear of disclosure
- Fear of medication side effects
- Realization that taking medication means “facing reality”
- Possible financial struggle
- Stigma & Denial at family
- Feeling of stigma & denial from the community
- Any refusal from the clinic

Is this your first time getting to clinic? Yes  No

If no then how many times you have visited to the health care centre ?

One time  2 to 3 times  Several times

What are the Health services you have availed in the last visit

- Treatment for opportunistic infections (e.g. TB, trush, pneumonia, etc)
- ARV
- Treatment for other sexually transmitted diseases
- Pain relief
- HIV counseling and testing
- Others

Are you satisfied with the services you needed: Yes  No

What are the service you have expected to be available in this clinic for your health care

- VCT
- ARV
- Opportunistic Infection care
- Other essential RH care
- General health care (Care for other general diseases)
- Other support services

What are the other needs of services you feel like to be available for a PLHIV ( HIV Postive person )

- Health care needs
- Emotional needs
- Spiritual needs
- Nutritional needs
- Social needs
- Capacity development needs
- Day-to-day needs
- Financial/grant needs
- Legal support need

**Enacted Stigma Related Checklist.**

PLHA Individual level	Have you experienced the followings happen to you because of HIV/AIDS?	Yes	No
	1. Excluded from a social gathering.* 2. Being abandoned by spouse/partner. 3. Being isolated in the household. 4. Being no longer visited, or visited less frequently by family and friends. 5. Been teased, insulted or sworn at. 6. Lost customers to buy product/goods or lost a job. 7. Lost housing or not been able to rent housing. 8. Been denied religious rites/ services. 9. Had property taken away? 10. Been gossiped away. 11. Lost respect/standing within the family and/or community. 12. Been threatened with violence. 13. Been given poorer quality health services. 14. Been physically assaulted. 15. Been denied promotion/further training. 16. Had an increase of visitor to “check out” how you are doing. 17. Been abandoned by your family/sent away to the village.		

Clinical stigma	Had a health care worker refuse to treat you/ denied access to medical treatment or care.	Yes	No
	1. Experienced a delay in the provision of health services/treatment. 2. Been stopped from accessing health care services. 3. Denied for services or any specific health care. 4. Forced to pay additional charges for medical services (e.g. dental care, surgery)		

Provider Level	In the past 12 months, have you seen observed the following happen in this health facility because a client was known to have or was suspected of having HIV/AIDS?	Yes	No
	1. Receiving less care/attention than other patients. 2. Extra precautions being taken in the sterilization of instruments used on HIV positive patients. 3. Requiring some clients to be tested for HIV before scheduling surgery. 4. Using latex gloves for performing noninvasive exams on clients suspected of having HIV. 5. Because a patient is HIV- positive, a senior health care provider assigned the client to a junior provider. 6. Testing a client for HIV without his/her consent. 7. Health care providers gossiping about a client’s HIV status.		

Community Level	Have you experienced the followings happen to you because of HIV/AIDS?	Yes	No
	1. Excluded from a social gathering. 2. Lost customers to buy his/ her product/goods or lost a job. 3. Had property taken away? 4. Abandoned by spouse/partner. 5. Abandoned by family/ sent away to the village. 6. Teased or sworn at. 7. Lost respect/ standing within the family and/or community. 8. Gossiped about 9. No longer visited, or visited less frequently by family and friends. 10. Visitors increase to check them out. 11. Isolated within the household.		

Check-list for FGD with PLHIV

**Names of facilitators, note-taker/s**

**Contextual information**

This sheet will have confidential information identifying informants, and should be stored separately from all other data collected.

1. Identification number of FGD – this number should be used on all pages of notes and transcripts of this FGD

2. Who: number of participants, sex, Age

3. Where the FGD took place

4. When: date and time of FGD

5. Tape recorded? Yes/No

**Check points**

- Researchers to give their names
- Briefly explain the purpose of the FGD
- Ethical issues
- We will not use your name in our documents and your participation will be kept confidential.
- You may withdraw at any time. You do not have to answer every question.
- Are you willing to participate?
- Permission must be given if a tape recorder is being used
- Remind participants that all opinions are welcome and valued.

**Suggested 'warm ups':**

- How are you all today
- Do you feel good when you see each other in the clinic?
- Suggested discussion topics

**Focus Group questionnaire ( specific objectives)**

**1. Barriers**

Q3.1. What are the barriers you have to encounter commonly while you wanted to have access to health services for yourselves ? Prompt:( Example are provided). Did you face problem Family members? Neighbors? Community Gate keepers? Any other special denial or barriers encountered from home to clinic ?

Q3.2 Are there instances when you have felt particularly unwelcome, uncomfortable, discriminated at an agency? Prompt: (If examples are provided) Did you ever tell anyone at the agency about your experience? (If so, did they respond in a way that helped or made you feel better? Did they respond in a way that made you feel worse?)

Q3.3 While seeking services, have you experienced any problems in trying to get services ?

Probe: (unhelpful attitudes, behaviors, travel a great distance to receive service, transportation problems, inconvenient hours of operation, having to pay a fee for services, unmanageable waiting time to get an appointment or to see a provider once you are there, hassle by staff or other clients, language/cultural barriers)

Probe: Are services less accessible if you have children?

Prompt: Are the services appropriate for you (women, children, adolescents)

**2. Unmet Need**

Q4.1 What services or care do you need, but are unable to get?

Probe: (transportation, food, coordinated appointment schedules, prescription drugs/medication, insurance coverage, benefits?)

Q4.2 What concerns do you have about getting services or care for you or your children in the future?



3. Service availability, Utilization, Access

Q1.1 What are the most important HIV-related services/care you are using now or have used in the last year? (Prompt: medical care, case management, transportation, mental health, substance abuse counseling, support groups, etc.)

Q1.2 What agencies or types of providers are you and/or your children obtaining services from? (For example, AIDS service providers, community-based organizations providing social services, neighborhood clinics, hospitals, etc.)

4. Satisfaction with qualitative services

Q 2.1 Are you satisfied with the particular services you have used? (Prompt: medical care, case management, transportation, mental health, substance abuse counseling, support groups, etc.) Why/why not?

Probe: Are you satisfied with the options you have for services? (i.e., the providers/agencies available) Why or why not?

Q2.2 Are you satisfied with the location and hours of operation of the services you currently use?

Probe: why not, what is reasonable?

Q2.3 Are there instances when you have felt particularly welcome, comfortable, motivated by an agency?

Prompt: (If examples are provided) Did you ever tell anyone at the agency about your experience? What about your provider, if you have one? Or someone else you know who is HIV-positive

5. Care improvement

Q5.1 What would be the single most important change you would suggest to improve services people living with HIV?

Q5.2 If there was one thing you could change about services for people living with HIV, or one recommendation you could make to providers or those serving PLWHA what would it be?

Q5.3 Is anyone in this group or a family member involved with support groups or committees that discuss the planning of HIV care?

Probe: (Title I Planning Council, Title II Consortium, HIV Prevention Community

Planning Group, community advisory boards, spiritual/church group, etc.) If not, would you be interested? What would make it possible for you to become involved?

6. Closing ( Formal thanks and quick moderation of the discussion)

Q6.1 Is there anything else you would like to add? Are there any questions that I can answer before we end the session

Check-list for in-depth interview with the provider

Name of researcher.....

Contextual information

This sheet will have confidential information identifying informants, and should be stored separately from all other data collected.

1. Identification number – this number should be used on all pages of notes and transcripts of this interview.

2. Who: name, age, sex,

3. Where the interview took place

4. When: date and time of interview

Check points

- Researcher to give his/her name
Briefly explain the purpose of the interview
Ethical issues
We will not use your name in our documents and your participation will be kept confidential.
You may withdraw at any time. You do not have to answer every question.
Are you willing to participate?
Permission must be given if a tape recorder is being used

Provider interview Questionnaire

Name of the organization \_\_\_\_\_

Designation of the provider \_\_\_\_\_

How long you have been associated with HIV/AIDS related care ?

< Less than 6 months

- 1-2 year
- 3-4 year
- 5 year or more

Have you had any formal training & orientation related to HIV/AIDs care ? Yes  No

What was the duration of training

- < Less then 4 week
- 6 to 12 week
- 24 weeks or more
- 1 year or more

Do you perceive any kind of barriers associated with PLHIV in accessing Health care? Yes  No

If yes, what are the common barriers you think/perceive they often encounter?

Home/Family level \_\_\_\_\_

Neighboring Community/societal level \_\_\_\_\_

At clinic Service level \_\_\_\_\_

Others If any \_\_\_\_\_

According to you what are the common causes associated with such barriers ?

Home/Family level \_\_\_\_\_

Neighboring Community/societal level \_\_\_\_\_

At clinic Service level \_\_\_\_\_

Others If any \_\_\_\_\_

In your opinion how to improve the better access of PLHIV in health care service ?

Home/Family level \_\_\_\_\_

Neighboring Community/societal level \_\_\_\_\_

At clinic Service level \_\_\_\_\_

Others If any \_\_\_\_\_

**Expert Group Consultation  
Participatory group activity**

**Aim**

To identify barriers and opportunities for access to HIV/AIDS-related treatment.

**Instructions**

**Part 1: Identifying barriers**

- 1) Explain the aim of the activity.
- 2) Present participants with a definition of access to HIV/AIDS-related treatment
- 3) Lead a group in brainstorming about what access to HIV/AIDS-related treatment means.
- 4) Divide the participants into small groups of four to six people.
- 5) Ask each group to brainstorm about the barriers to access to treatment for people living with HIV/AIDS. Ask them to consult discuss and make a consensual list of barriers and write on Flip chart.
- 6) Bring everybody back together and ask each group to share their results by explaining their group work (to represent road-blocks on the path to access to treatment). Encourage the participants to ask each other questions and to make comments.
  - How many major barriers are there to access to HIV/AIDS-related treatment?

- Level the Barriers at Individual, Community and Institutional Road blocks

### Part 2: Classifying barriers

- 7) Write the following headings at the top of separate pieces of flipchart paper: Present to participants what each heading means, in terms of the types of barriers to access to HIV/AIDS-related treatment .
  - Financial
  - Organizational
  - Physical
  - Social
- 8) Working as a large group, classify the barriers that were presented by the small groups (see Part 1 above), by writing each one down under the heading on the flipchart that best describes it.
  - Which are the more common type of barrier ?
  - Which types of barrier might be easier to overcome?

### Part 3: Identifying opportunities

- 9) Divide the participants into Two/four groups.
- 10) Give one of the lists of physical, organizational, financial and social barriers (see Part 2 above) to each group.
- 11) Ask each group to identify which barrier on their list is the most important.
- 12) Ask each group to write the most important barrier at the centre of a piece of flipchart paper. Then ask them to add opportunities to overcome the barrier, by putting them in circles around it. If the opportunity can be addressed easily, it should be placed near to the barrier. If it is difficult, it should be placed further away.
- 13) The Group will finalize their group result of discussion in consensus also ask the groups to share their results. Encourage the participants to ask each other questions and to make comments
  - To what extent can something be done about all of the barriers?
  - Which opportunities would it be suitable for organizations ( NGOs/CBOs ) to tackle

### Aim:

To identify the elements involved in comprehensive care and support for people living with HIV/AIDS.

### Instructions

#### Part 1: Identify the Health care needs

- a) Explain the aim of the activity.
- b) Present participants with a definition of comprehensive care and support

Divide participants into small groups of four to six people.

- 14) Ask each group to brainstorm (based upon their own experiences) on the different elements involved in comprehensive care and support for people living with HIV/AIDS. Ask them to write them on a piece of flipchart paper.
- 15) The Group will finalize their group result of discussion in consensus also ask the groups to share their results. Encourage the participants to ask each other questions and to make comments.
  - Why is it important that care and support for people living with HIV/AIDS should be Comprehensive?
  - What can be the major elements of care and support more important to PLHIV Health care need