Impacts of Internal Stigma among the People Living with HIV/AIDS in Bangladesh: An Empirical Account

Sifat E Sultana

1 Department of Social Relations, East West University, Dhaka, Bangladesh

Correspondence: Sifat E Sultana, Department of Social Relations, East West University, Aftabnagar, Dhaka, Bangladesh. E-mail: sifat_tu@yahoo.com

Received: July 23, 2013   Accepted: August 13, 2014   Online Published: September 29, 2014

Abstract

All over the world HIV/AIDS related stigma and discrimination are of growing concern. At the same time self or internal stigma is one of the influential facts that make people living with HIV/AIDS (PLWHAs) to feel ashamed and guilty about their positive status. But the matter of stigma has been largely ignored by the existing policy of Bangladesh. This paper critically assesses how internal stigma contributes to keeping people from accessing HIV prevention, care and treatment services and adopting key preventive behaviors. This qualitative research is based on in-depth interview and case study method, located at Dhaka city, Ashar Alo Society (AAS), a service delivery center for HIV/AIDS patients. This study also revealed that internal stigma forced the PLWHAs to accept and believe that their disease is a moral punishment; they also perceived the disease as a result of their misdeeds. Many participants felt ashamed and tried to hide their status from everybody. Observation showed that HIV is regarded as an invisible contagious disease because PLWHAs hide their diseases even from their wives as a result the wives get infected with the disease in ignorance. These findings enabled us to understand the existing situation of PLWHAs and the impact of stigma and discriminatory behavior on their lifestyles in Bangladesh. The study suggested that the existing situation can be improved by formulating related strategies to reduce stigma and discrimination of PLWHAs.

Keywords: HIV/AIDS, Stigma, Internal Stigma, discrimination, Bangladesh

1. Introduction

Self or internal stigma is a daily reality and continuous strike in the mind of people living with HIV/AIDS (PLWHAs). Stigma is a disrespectful and discreditable issue for PLWHAs which makes them vulnerable and debased. Internal stigma is rooted in the helplessness of PLWHAs and their lack of control over the situation. Internal or self stigma fosters PLWHAs to change their socio-cultural practices due to their positive status. According to United Nations AIDS (UNAIDS), HIV-related stigma and discrimination stand in the way of HIV prevention efforts- they lead people to be afraid to seek out information about how to reduce their exposure to HIV, and to adopt safer behavior in case this raises suspicion about their HIV status (UNAIDS, 2010). PLWHAs are reluctant to provide information about their positive statuses to their close relatives. They worry if they provide the information they will be stigmatized and discriminated and may be their situation will be more critical than the present.

Internal stigma makes PLWHAs feel culpable and embarrassed of their status. As the major responsible factor for HIV/AIDS transmission is unsafe sexual intercourse throughout the world, society believe that PLWHAs are only infected with the virus due to unethical sexual practices which are prohibited in Bangladesh. As Bangladesh owns collectivistic family nature, as a result not only the HIV positive individual is neglected but also their family members suffer the negligence of the society. Consequently, PLWHAs hide their status to avoid social criticism. One USA study found that internal stigma contributes significantly to levels of depression, anxiety and hopelessness in PLWHAs (Lee et al., 2002). According to surveys conducted using People Living with HIV Stigma Index, instances of stigma and discrimination exact profound psychological costs, resulting in feelings of guilt, shame and suicidal thoughts (UNAIDS, 2013). PLWHAs feel an urge to think the disease is the result of their wrong activities. It may lead to loss of hope which makes them physically exhausted and mentally debased.
This may lead to reduction of self confidence, loss of motivation, withdrawal from social contract, avoidance of work and health based interactions and abandonment of planning for the future (UNAIDS, 2011). HIV/AIDS is the debasement of personality and dehumanization of man. PLWHAs have feelings of misery rather than well-being. The world becomes alien to him/her. The Internal stigma makes PLWHAs frustrated and depressed, and leads them to be reluctant to seek care, treatment and services from health care center. In response to experiencing stigma, PLWHAs may adopt protective actions that in turn, tend to reinforce and legitimize internal stigma (Brouard & Wills, 2006).

We are now frequently having meetings, round table discussion to introduce HIV/AIDS. On the contrary, we seldom discuss about HIV/AIDS related stigma and discrimination in Bangladesh. Bangladesh Government has formulated lots of national STDs and HIV related policies and mechanism to raise awareness about HIV/AIDS, but most of the programs focus on knowledge, attitude and practices of HIV/AIDS. The issue of stigma and discrimination is not a concentrated and priority agenda of Government due to low prevalence rate of HIV/AIDS in Bangladesh. But the condition of Bangladesh is very vulnerable because the high-risk behavioral pattern of the people makes the country susceptible to the disease. The situation can be aggravated at any time due to high-risk factors in Bangladesh such as open borders, poor health services, misconception about the disease and high migration flow. A large number of people migrate every year from our country to everywhere around the world, mostly to middle Eastern countries. Bangladesh, these days, has thousands of sailors, construction workers and other professional groups who work abroad for a time and a continual tide of students and business men returning from overseas (Khan, 2013). But migrate workers have less opportunity to test their HIV or other health related investigation when they come back from their working places. Government is not conscious enough to give priority and importance to this issue which can be devastating for our country within a few years. The HIV prevalence rate is very high especially among the migrate workers in Bangladesh. Moreover, in our country, the number of prostitute women, injecting drug users (IDUs)), transgender person are also very high risk group which makes us more vulnerable and susceptible to the danger. The HIV prevalence rate in Bangladesh is less than 2% at this moment but we are not out of danger because the rate is increasing in a wide scale. According to Bangladesh Demographic Health Survey, the reported number of HIV positive people in Bangladesh increased from 263 in 2003 to 1207 in 2007 and by the end of 2011, the number of HIV-positive people had increased to 2533, an increase of more than double in four years (BDHS, 2011). However, UNAIDS estimates that the number of People Living with HIV (PLWHIV)) in the country may be as high as 12000 (Khan, 2013). It is feared that the HIV epidemic in Bangladesh may emulate the situation in India with a rapidly increasing prevalence of HIV seropositive in high-risk groups spreading to the general population (MOHFW, 2007). The number of HIV/AIDS patients is very high in Indian Territory and the number is increasing day by day. Indian mechanism failed to provide an effective program to cope up with the aggravated situation of HIV/AIDS which most commonly happened due to pronounced stigma and discrimination faced by PLWHAs. Some experts are of the opinion that if the present trends continue in this way then the hiding tendency of PLWHAs reinforces them to involve unsafe sexual practices which are the root causes of HIV/AIDS. Because of the silence surrounding the disease, HIV/AIDS gets warm ambience to breed in excess. The HIV and AIDS related (published) studies done in Bangladesh mainly focused on knowledge, prevalence and reviews on discrimination. However limitations regarding stigma, internal stigma and discrimination still exist in present days. Despite considerable progress in recent years, many projects addressing stigma and discriminations are still small in scale or in the pilot phase (Bround & Wills, 2006).

In view of these contexts, this qualitative study explored and examined how PLWHAs internalize the negative views of community members. The central concern of the study was to observe and document the impact of internal stigma of PLWHAs, leading to feelings of self blame, shame, isolation from community and disruption of family relationship and social responsibilities. The paper is an attempt to frame an understanding of how PLWHAs perceive judgmental attitudes of community members and how their lifestyle is changed because of their positive statuses.

2. Theory and Method

In order of priority the impacts of internal stigma of PLWHAs, Goffmans’ theory of stigma is used as theoretical framework in this study. Goffman defined stigma as “…a powerful social label, stemming from a discrediting attribute of the individual which radically changes their social identity” (Goffman, 1963). Stigma is related to those diseases that are fatal, incurable and extreme. In social situations with an individual known or perceived to have a stigma, we are likely, then, to employ categorization that do not fit, and we and he are likely to experience uneasiness (Goffman, 1963). And since the stigmatized person is likely to be more often faced with these situations than are we, he is likely to become the more adept at managing them (Goffman, 1963). Goffman’s
primary concern was, however, not with such long-term adjustments, but rather with the way in which stigma bearers interact with normal (the non-stigmatized) when they are in one another’s immediate physical presence, ‘whether in a conversation like encounter or in the mere co-presence of an unfocused gathering.’ Goffman identified three strategies—passing, covering and withdrawal—, which are employed to cope with a stigmatizing attribute in social encounters. These strategies are not unique to stigma bearers but whereas they may be employed occasionally be normal when their identity is threatened; they must be employed continually by stigma beaters. According to Goffman a discrepancy in such a situation may exist between an individuals’ virtual and actual identity. These discrepancy, when known about an apparent, spoils his social identity, it has the effect of cutting him off from society and from himself so that he stands a discredited person facing an unaccepting world (Goffman, 1963). In the context of HIV/AIDS, stigma and discrimination as “a process of devaluation” because in some cases, as with the individual who has HIV, he may continue through life to find that he is the only one of his kind and that the entire world is against him. HIV has been stigmatized because it can be fatal and therefore causes fear; it is often associated with behavior that is already stigmatized, such as sex work, infection is seen as the result of “choices” made by an individual (e.g., the “choices” to have unprotected sex or to share needles to inject drugs) and it is seen as punishment for “deviant” behavior (Bollinger, 2002).

The study uses a qualitative research method as HIV/AIDS related stigmatization and discrimination itself is a sensitive issue and is assumed more sensitive when it is linked up with the stigmatized behavior and lifestyle of PLWHAs. As the issue is more concerned with the quality and meaning rather than measurements, the qualitative method has been employed to present an interpretative analysis on the representation of internal stigma towards PLWHAs.

2. Method

2.1 Study Design

This was a qualitative study in which in-depth interview and case study were conducted to collect information from PLWHAs. These methods supplemented each other to get the overall picture of stigma and discriminatory behavior of PLWHAs. In-depth interview and case study are used for the triangulation of findings, thus enhancing the interpretation of the data and facilitating the researchers’ ability to validate information as the study evolved.

2.2 Study Setting

An organization, named “Ashar Alo Society” (AAS) which was included in the study has been actively working with PLWHAs in Bangladesh. PLWHAs across Bangladesh have easy access to this organization. It promotes care, free treatment with pre/post test counseling and support to the PLWHAs, as well as vocal for the right to non-discrimination.

2.3 Sample Size

Working with hidden populations makes it nearly impossible to use standard random sampling techniques (Habib, 2009). Both male and female HIV-positive respondents were selected using purposive sampling techniques from the study sites in order to gain in-depth information about stigma and discrimination towards PLWHAs. 50 in-depth individual interviews and 10 case studies were conducted to collect the data directly from the respondents. Out of fifty 30 interviewees were male and 20 were female. Case study following a checklist
was used to understand the overall situation of PLWHAs. Six case studies were based on males and four on females. In-depth interviews and case studies were held separately for men and women. Purposive sampling has been implied in two ways- firstly, through recommendations from the official staff of AAS and secondly, those who expressed interest at the NGOs included in the study. Face-to-face interviews were conducted by the author proficient in local vernacular and a recorder was used to record the interviews. In this regard, rapport was built by involving gatekeepers prior to interviewing to maximize the extent of findings. The study was conducted in the office of the AAS. It took almost three months and the interview session lasted about three hours per day.

2.4 Data Analysis

This paper is prepared based on the transcripts of in-depth interview and findings of the case study. In this study, the pre-test was conducted among PLWHAs in AAS in order to test the effectiveness and suitability of the research instrument. The semi-structured interview technique was slightly revised in the light of the experience gathered from these interviews, considering how the respondents react to the question. A general inductive approach was used to analyze the data. Responses on the open-ended items were examined and coded. Then, responses compiled on a word processor and responses with similar characteristics or patterns were categorized together. The qualitative assessment included:

1. Thematic content analysis
2. Transcription of discussion
3. Coding of information framework according to key points of focus
4. Analyzing the coded information
5. Presenting the qualitative information in report form.

The length and intensity of the interview session greatly increased the validity and reliability of data in the study.

2.5 Ethical Clearance

Before proceeding for data collection, the proper authorities of AAS were formally approached for permission. After having permission, the desired respondents were informed about the purpose of the study and their informed consent were taken. Participants were assured that confidentiality would be maintained. Therefore, the name of the study participants were kept anonymous.

3. Findings and Discussion

3.1 Perception of Self

The majority of the PLWHAs suffer from internal stigma. They revealed to have considered AIDS as a moral punishment, and a curse for them. Because the root cause of HIV/AIDS is unprotected sexual intercourse throughout the world, PLWHAs try to understand what other people think about them, how society imagines and judge about them. They want to judge themselves by seeing themselves reflected in other people’s attitudes and behaviors toward them and by imaging what people think about them. Societal view is just like a mirror for PLWHAs. This reflected image may make PLWHAs feel very bad and guilty about themselves because they see themselves as rejected by family members, relatives and peers. PLWHAs are forced to believe that they carry the virus because they have done something wrong and they deserve it. Most usually, these wrongs are related to unethical sexual intercourse and non sanctioned activities, such as extra-marital sex or injecting drug use. Being a conservative nation with a Muslim majority population, not only are promiscuity and extra-marital affairs looked down upon, pre marital sexual relationships are also severely frowned on (UNAIDS Bangladesh, 2008).

Internalized HIV-related stigma experience is the stigma effects on the PLWHAs; as it is internalized into their self-perception and sense of identity; impacting on the persons’ perceptions and how they interact in the world (Blessed et al., 2013). PLWHAs feel they have nothing to do for their family. They have disappointed others and have brought bad luck and shame on their family members. Sometimes, they exhibit profound anxieties about infecting others. Some respondents revealed that they are afraid of infecting their family members especially their loved ones and youngest members of the family. PLWHAs think that they are not allowed to share their drinks and foods with others. The results regarding self perception suggest that more than half of the PLWHAs vehemently blamed themselves for their HIV status. HIV positive people who accept society’s negative characterizations may blame themselves for the intolerance of others, feeling that they deserve mistreatment (Herek et al., 1998). In extreme cases, this has led to some of them thinking about committing suicide due to their status. One respondent revealed that she was not allowed to mix with others because of her positive status and she thinks it will be better to die. Some respondents in this study also revealed that they were treated by societal members just like a pet animal or things, not as a human being. PLWHAs feel completely hopeless as
they think that they are going to die and they have nothing to offer for the society. They believe this disease just as a result of their misdeeds and their existence becomes meaningless.

3.2 Fear of Disclosure

PLWHAs face discrimination, social rejection after disclosing their HIV status. Most participants reported that providing information about their positive status was very difficult because of the fear of judgmental attitudes and social ostracism. It is generally recognized that HIV status disclosure is a complicated matter that involves many components, including patients’ HIV status notification, the decision of whether to disclose and the decision of whom to disclose to (Kalichman et al., 2003). Thus the issue of disclosure has created another mental pressure among PLWHAs because our traditional Bangladeshi culture does not approve pre or extra marital relationships. People of our country think HIV/AIDS means normlessness that can be transmitted only by sexual intercourses and if one is HIV positive that means it is the result of their misdeeds. PLWHAs fear if they disclose the status then they will be less respected and isolated from others. They regard this as a sin. One who had sex before marriage is severely criticized and socially narrowed. PLWHAs refrain themselves from disclosing this to others and live in silence. Participants in this study also revealed that because of fear of stigma they try to hide that they are taking medicine Anti-retroviral (ARV) for their disease. Some of the respondents are reluctant to take medicine or even to use safe precautionary method for sexual intercourses because they fear if they do so, they will be caught by their life partners. They have to tell lies all the time in order to hide their status. This tendency debases their morality. Perhaps this is why, when they weigh up the costs and benefits of disclosing, or choosing certain individuals to disclose to and not others, they do so to mitigate these bad reactions, and thus minimize the actual stigma and discrimination that they would receive (Linda, 2013).

A few participants reported that they disclosed to certain close people for certain needs. The most common targets of disclosure were family members like the life partners, parents, children and close friends. PLWHAs had disclosed mostly to family members (collectively) and partners more than to friends and other persons (Shalely et al., 2006).

Women in this study also tend to keep silence about their HIV status. Some of the PLWHAs faced stigmatized attitudes from their closest ones (e.g. from their family members, their husband/partners) while others faced judgmental attitude from outside of their families. Main barriers to disclosure for women are fear of infidelity accusations, abandonment, discrimination and partner violence (Medley et al., 2004). One respondent revealed that he had not told anyone outside his own family. He did not mix much with his neighbors and did not attend any social programs. He was even reluctant to be involved in any issue and always remained isolated. Hence, no one raised question about his sero-status. He said that he could not anticipate how local people would react with him if he provided his sero-status identity to them. It would be best for him to keep it secret.

3.3 Internal Stigma and Women

According to Paxton within the family and the community, women are significantly more likely to experience personalized stigma than men, including ridicule and harassment, physical assaults and being forced out of their homes (Paxton, 2005). The situation of women is very vulnerable because they face greater stigma and discrimination than men in our society. Women in our society are not equally treated with men. Bangladesh is completely a patriarchal society where all of the organization is male oriented. In Bangladesh, women are disadvantaged group more than male in regards to education, health facilities and economic condition. Women have few opportunity and scope to take their own decision especially for the cases of safe negotiation of sexual intercourses. Because of the lack of power to control their own lives they are frequently infected by their husband with HIV virus. They have not enough resources to cope with the situation. Our society expects that women should be involved only for their household and reproductive activities. They are not encouraged to participate in public life. Parents think women are just the burden of their family and they want to marry their daughter in an early age. A 16 years old female participant stated that she was infected with HIV after her marriage. When she was 13 years old she got married and her husband was abroad for a long time. Her husband was sent back from Kuwait after two years being infected with HIV, and then she also found that she was HIV positive after HIV test. She faced pronounced maltreatment from her in law’s house after the death of her husband. Even her mother in law claimed, her misdeed is responsible for the virus. The scenario of women is the same throughout Bangladesh because women have less access to education, empowerment and decision making right. It has been found that, most of the married women have been infected with the virus by their husbands. In the recent report published by UNFPA, it was stated that sex within the bondage of marriage is not always safe and cannot give protection against HIV infection (Khandaker, 2013). Women do not usually have the power to negotiate safer sex with their partners even if they suspect or know that they are involved in risky behavior for
HIV and STIs (UNICEF, 2007). Because of widespread stigma and discrimination, it is difficult for HIV-positive women to access and use sex related health services, even if such services are made available for them. Most of the respondents reported that nurses misbehaved with them when their HIV status was disclosed. Nurses and official staff of the hospitals also teased them for being HIV status. One female respondent reported that a nurse or a medical staff asked her after her test what have she done that has caused her this disease. Married women who were infected by their husbands, i.e. majority of whom are male migrant workers in the case of Bangladesh, are often scorned, mistreated and even evicted from their in-laws home when their HIV status becomes known (Ickovics et al., 2007). Female PLWHAs seems to be one of the vulnerable groups, who are facing diverse forms of stigmatized attitude from community.

HIV-positive women face mental, physical and emotional abuse by their husbands. Most women with HIV may think their identity, status and self respect have been damaged. They felt shame and guilt and blamed themselves. In some cases, it is reported that female spouses also tend to keep silent even if they are infected by their husbands, as they don’t believe they have many options open to them if they were to leave their husbands. However if the husbands are infected by their wives, it was mentioned that many choose to abandon their wives and leave them to manage on their own (UNAIDS Bangladesh, 2008).

HIV positive women feel vacillates to access treatment and support from health care centers due to fear of stigma and discrimination. In developed nations, PLWHAs have their individual choices of whether to disclose their status, whom to disclose to and why and why not. But in Bangladesh we failed to provide a clear policies regarding confidentiality because still now it is a sensitive and taboo topic which discourages people to discuss publicly. This leads to HIV-positive women to deny taking precaution and medicine that can be identify them as being ill. Women are afraid that disclosing their HIV-positive status may result in physical violence, expulsion from their home or social ostracism, or their property being seized after their partner died. (UNAIDS Bangladesh, 2008).

Women living with HIV/AIDS are frequently referred to as ‘vectors’, ‘diseased ‘and ‘prostitutes’, but these terms are seldom used with infected men (Nadinda et al., 2007).

3.4 Exemption from Normal Social Norms

Many PLWHAs would exclude themselves from family members, community and from normal social norms and responsibility. They are badly treated by their friends, relatives and even family members in one on encounters. Individuals in various countries in Asia have reported coercion to move from their homes by landlords and refusal of service at food and other business establishments (Human Rights Watch, 2003). Due to the risky factor and negative view of lifestyle choices linked to this fatal disease, HIV/AIDS still remain a taboo topic in our collectivistic and conservative Bangladeshi society. Most of the PLWHAs have been excluded from their social activity due to their sero-status. One respondent revealed that his business faced loss because people feared to come to his shop and, people could not take tea from his shop. Though media has played an important role for spreading the knowledge of HIV, people in our country are less knowledgeable about the various modes of HIV transmission process and prevention. People have the misconception that HIV can be transmitted by mosquito bites, through casual contact and sharing foods. Friends and relative try to avoid PLWHAs for fear of infection and even it is found from this study that family members did not feel comfortable to share their dishes and towels for fear of contagion. A HIV-positive Hindu couple reported that they were severe victim of stigmatized behavior in their family and they were excluded from their normal daily activities and responsibilities. After knowing their HIV status, their family members do not eat together. Their house and bathroom had been separated so that the disease cannot spread. In spite of the NGO members going to their house to counsel, the misconception among them has not gone. They were not allowed to mix with others. PLWHAs were vehemently criticized by societal members. Those who had shared their HIV status reported that their neighbors keep distance after being aware of their HIV status. They are even criticized in gathering. They were deprived of social gatherings (i.e. birthday party, marriage ceremony, the day of mourning etc.). Individuals who disclosed their HIV status to other have been discharged by their daily, routine activities and not allowed to participate in any family or social events. One respondent revealed that his financial support was cut off from his family because of HIV status. The problem is further aggravated when PLWHAs are forced to leave family residences due to sero status. An unbridled rise of this type of discriminatory attitude is stocking up frustration and depression among the PLWHAs. PLWHAs are deviated from their normal social norms which makes them helpless and powerlessness.

The stigmatization severity has grasped also in religious matter. One respondent reported that he faced stigma and discriminatory behavior from the religious leader (Imam) of the mosque of his area. When his HIV status
was disclosed, the religious leader prohibited him to come to the mosque. He fell so much harassed and decided not to attend any religious activity from that day. Not only the individual person who have HIV virus, but also family members continued to suffer negative perception of community member. Because of the low level of accurate knowledge and attitudes regarding HIV/AIDS prevention and transmission in the general population, Community members suspect that the rest of the family members of PLWHAs are also infected. When families are aware of the positive HIV status of one of its own members, they often lie about the illness to avoid community stigmatization (Songwathana et al., 2001).

3.5 Self-Imposed Isolation

Because of fear of refusal and judgmental attitude, many PLWHAs keep their disease information a secret from others, which may cause them to be socially isolated and alienated. PLWHAs would exclude themselves from social activities, family responsibilities and opportunities. Internal stigma forced the individual to avoid public dealings and social interaction. PLWHAs internalize pessimistic societal views, which can lead them to think that they are dehumanized person and they bring bad luck for others. They blamed themselves and felt that they are bad persons, sinners, and they felt like committing suicide for this fatal disease. Self blame was accompanied by other deep fears which an HIV diagnosis evoked: fear of hurting others and the fear of causing pain and suffering to others (Brouard & Wills, 2006).

PLWHAs fear that they will be responsible for infecting others. They also may exhibit profound anxieties about death and dying (Brouard & Wills, 2006). PLWHAs try to keep distance from others which, in turn, prevent them from receiving health care support which can contribute to their mental distress. PLWHAs experience themselves as an alien and, estranged from themselves. When the individual feels powerless against his/her situation, to change or reshape according to his/her wishes, and instead fall a helpless prey to it, an alienating situation arises. In such a situation, the individual may wish to isolate himself. The situation of PLWHAs in this study was so extreme that they alienated themselves from their expected roles and chose to stay separated and not attend family or religious functions. They reported staying inside the house, and isolating themselves in a room all the way in a corner of the house. One respondent revealed that he feel he is not a normal person like others and that’s why he wanted to maintain distance from his surroundings and avoiding making long-term plans for future. This kind of self-imposed isolation led some people to exclude themselves from sexual and loving relationships (Brouard & Wills, 2006).

PLWHAs in this study chose to avoid loving relationships and to stay out of the public sphere as much as possible. It has a negative effect concerning help-seeking and adherence to treatment. Stigma also isolates families; it can discourage households from registering affected children in national support programs, and further limits access to information, prevention, care, and treatment (Tomaszewski, 2012).

3.6 Coping Mechanisms

Stigma and negative perception of societal people affect the personal coping mechanism of HIV individual and adopt precautionary mechanism to reduce the risk factor for transmission of HIV/AIDS. Stigma and internal stigma completely destroy the internal coping mechanism of PLWHAs and makes the individual susceptible to danger. PLWHAs are typically inclined not to disclose their experiences due to feelings of guilt and shame. In that case PLWHAs are even less likely to share their trauma with their family members and friends. This internal frustration leads them to perform a twister personality in front of others. PLWHAs try to combat HIV/AIDS by concealing their status to others. Perceived stigma and discrimination have been associated with increased prevalence and severity of depression among PLWHAs (Joseph et al., 2004).

Frustration and depression motivate PLWHAs to delay their diagnosis and to adopt a risk free healthy lifestyle. When PLWHAs perceive HIV/AIDS is a fatal, life threatening disease then they do not feel any urge to test, they have no motivation to adopt preventive efforts. Internal stigma makes PLWHAs reluctant to adopt safety measure for themselves and their family members. PLWHAs frequently engaged unprotected sexual intercourses without taking condoms or other safety measures. Even many HIV positive mothers continue to breastfeed their Children due to the avoidance of family observation, suspicion and questions. In this way, few opportunities open for them to cope with the difficult situation and to manage their own health condition by accessing better treatment facilities from health care centers. These results suggests that the perceived self/internal stigma admitted to by PLWHAs negatively affects their overall physical and mental well being and as a result, their decision making processes involving lifestyle choices and access to services (UNAIDS Bangladesh, 2008).

Depression and physical health condition of PLWHAs decline their concentration and attentiveness in the work which also makes them marginalized and debased person. Participants suffered economically, by being written
out of wills of either parents or spouses, or as was more common, by having their properties and money ceased by non-positive family members (UNAIDS Bangladesh, 2008).

Being HIV positive made participants physically weak and instead of compassion and support due to this, they were mistreated and fired from jobs unfairly and without any prior notice (UNAIDS Bangladesh, 2008). A majority of the respondent reported they decided not to have more children and avoiding making long term plans because of their uncertain future.

3.7 AIDS as a Moral Punishment

PLWHAs perceive AIDS as a moral penalty for them. The participants expressed that feeling rejected has caused them sufferings, pain and rage, frustration and irritability, as well as loss of self esteem. The HIV-related stigma that is associated with breaking sexual rules and ethics is heightened by the fact that PLWHAs are deemed responsible for their “deviant” sexual behavior. PLWHAs are seen to possess a spoiled identity that deviates from traditional social norms and morality and which deserves sanctioning. HIV-positive people who accept society’s negative characterizations may blame themselves for the intolerance of others, feeling that they deserve mistreatment (Herek et al., 1998). It is very often seen that the PLWHAs are defamed by their spouses due to their HIV status. A HIV positive male respondent reported that he first disclosed his status to his spouse. His wife, knowing his HIV status, started defamatory attitude towards him. She suspected that her husband might have infected with HIV by extra marital sexual relationship. On that day she threw petrol over the house with an intention to burn it to ashes as to die along with her two children’s. However, he succeeded in blocking her from hitting fire on them. He lived an isolated life in his own house for almost two and a half years. His children were kept away from him. He always used everything separately such as separate bed, soap, bathroom, plate, glass. He suffered a lot due to his HIV status. HIV is a punishment from God for immoral sexual sins committed by humanity and individuals in particular. Those who get HIV are supposed to have sinned.

3.8 AIDS as an Invisible Contagion

AIDS is not a contagious disease; it is not transmitted through dimming swimming in the same pond or even coughing. But it is found from keen observation that it is a contagious disease. It is contagious in this sense that a HIV-positive man who is unknown about his HIV sero-status mixes with all of the people or involves in sexual intercourses without taking any precautions. Some individuals also may fail to change this risk behavior for fear that such change would arouse suspicion and stigma (Brouard & Wills, 2006). This is the cause of infliction. PLWHAs frequently face shame, stigmatized attitudes and discriminations by families and communities. In places where these responses are to rule, many people resist knowing their HIV infection status or are reluctant to change their risky behavior (like sex without any protection) even after knowing they carry the virus, fearing that this would be interpreted as an admission of infection. (Taraphdar et al., 2012).

A 16 years old one female respondent reported that when she was married she had no idea about precautionary measures at the time of marriage. She did not know that her husband kept hidden his HIV status from her. She was inflicted with this virus without knowing anything.

This response clearly depicts the real pictures of our society. In some cases, stigma and discrimination prevents family and community members from providing or accepting care and support. PLWHAs may not always take their drugs at the correct time or in the correct way, in order to conceal their positive status (DFID, 2007).

As a result, stigma and discriminatory attitudes compromise AIDS response and drive the continuation of the spread of HIV around world.

4. Concluding Reflections

According to the theoretically framing of the study, the data consistently and strongly shows that people believe that those with HIV/AIDS get it through sexual intercourses and they perceive HIV/AIDS as a curse and treat the PLWHAs as a deviant person. For these reason, some participants of this study were reluctant to share their HIV status with anyone in fear of being stigmatized and discriminated by their family and community. The silences create a self-imposed isolation from close surrounding which negatively affects the wellbeing of PLWHAs. The silence surrounding this virus and misconceptions about the disease also influences perceived stigma among the PLWHAs. Along with this, given that Bangladesh has a high prevalence of the diseases malaria, the families of PLWHAs also believed that HIV could be transmitted through mosquito, similar to the transmission of the virus causing the disease malaria. For this many PLWHAs became stigmatized and discriminated for HIV positive in family setting.

Due to high risk behavior of man, their female sexual partners are at high risk of acquiring HIV infection. HIV is also more easily transmitted from the male to female due to biological reasons. Female PLWHAs seem to be one
of the marginalized groups, who are facing multiple forms stigmatized attitudes from society in Bangladesh. This is due to both structural and social injustices, inequalities and patriarchal ideologies that push women’s status low down the ladder, as well as because of the HIV positive status of such participants.

The overall situation of PLWHAs forced them feel guilty and shame with regard to their HIV status. This type of emotional pressure and manipulation by family members motivated PLWHAs to accept silent death instead of social criticism or discrimination. A majority of the respondents reported they decided not to have more children or long term plans for life because of their uncertain future. Internal stigma of PLWHAs is an attribute that is significantly discrediting and which, in the eyes of society, serves to reduce the person who possesses it. PLWHAs felt they are the dehumanized and debased person.

It is the high time for us to start thinking more sincerely about new models for counseling, awareness and social change in our response to deal with HIV/AIDS related stigma and discrimination. This study has suggested that along with more counseling, people attitudes need to be changed in order to reduce internal stigma and to help ensure their role in family and community. Media and education campaigns might help to reduce abusive behavior and stress among PLWHAs and their families. Participatory education campaigns can promote positive understanding of the disease and address the root causes of anxiety, fears and tension relating to contagion and ambivalence about sexual difference and so on. Future studies should assess whether providing skills to patients on how to disclose to others and how to cope up with the situation in order to examine this issue in more depth. More studies are needed that look beyond internal stigma for the purposes for HIV treatment and prevention or even eradicate internal stigma at personal level.

Acknowledgements
The author would like to thank all participants who cheerfully answered the queries, and provided information about their experiences. The author pays her heartiest tribute to the organization Ashar Alo Society (AAS) and UNAIDS (Bangladesh office). The author is grateful to the staff of AAS for their support and cooperation.

References


Copyrights
Copyright for this article is retained by the author(s), with first publication rights granted to the journal. This is an open-access article distributed under the terms and conditions of the Creative Commons Attribution license (http://creativecommons.org/licenses/by/3.0/).