Social stigma and vulnerabilities of HIV/AIDS-positive people: reconsidering social work education and NGOs’ role in Bangladesh

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Social Stigma and Vulnerabilities of HIV/AIDS-Positive People: Reconsidering Social Work Education and NGOs’ Role in Bangladesh

Md Ismail Hossain, Iftakhar Ahmad, Nafiul Mehedi, Rumina Akter & Tam Chipawe Cane

Author biographies and contact details:

Md Ismail Hossain
Department of Social Work, Shahjalal University of Science and Technology, Sylhet, Bangladesh
Email: ismailscw@gmail.com

Iftakhar Ahmad
Department of Social Work, Shahjalal University of Science and Technology, Sylhet, Bangladesh
Email: iftakharscw@gmail.com

Nafiul Mehedi
Department of Social Work, Shahjalal University of Science and Technology, Sylhet, Bangladesh
Email: nafiuscw@gmail.com

Rumina Akter
Social and Health Care Professionals, Nubah Social Care, London, United Kingdom
Email: ruminaakter121@gmail.com

Dr. Tam Cane
University of Sussex, Essex House, BN1 9RH, United Kingdom
Email: tam.cane@sussex.ac.uk
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Abstract

Despite the low incidence of HIV in Bangladesh, an HIV diagnosis results in stigma and discrimination. Therefore, the study looked at the causes and patterns of social exclusion, as well as strategies for reducing the exclusion of HIV/AIDS patients. It also emphasised the importance of reconsidering social work education and the role of non-governmental organisations in curbing the stigma that these people confront. In this qualitative study, a convenience sampling approach was utilised to select the participants from the NGO, Ashar Alo Society (AAS). The findings are grouped into six themes: exclusion from family and community, access to healthcare, education, and employment, as well as the role of non-governmental organisations in raising knowledge of family and community acceptance. Recommendations include the provision of remote healthcare and support services to combat stigma, as well as the adoption of new NGO efforts to assist PLWHIV in accessing care.

Keywords: Social stigma; Vulnerabilities; HIV/AIDS-positive people; Social Work education; NGOs’ role
Background of the study

Globally, HIV-related stigma is a common social phenomenon (Chambers et al., 2015). Stigma can be enacted, anticipated, or internalised, leading to detrimental outcomes in many respects for infected people with low social support (Thomas et al., 2005; Mehedi & Hossain, 2022). The impact of social stigma may include awkward social interactions, avoidance, exclusion, rejection, isolation, social ostracism, blaming, violence, service denial, physical distance, and indifference. These can be found in the family, the community, in health care, religious institutions, labour sectors, and educational settings (Stutterheim et al., 2009).

HIV has continued to persist as a global public health problem. In 2020, UNAIDS reported that 37.6 million people were living with HIV (PLWHIV) globally. Of these, 35.9 million were adults, and there were 1.5 million new infections and 690,000 deaths from AIDS-related illnesses. Of the 27.4 million PLWHIV accessing antiretroviral treatment, 74% were 15 years of age or older. Since the HIV pandemic began, 34.7 million have died of AIDS-related illnesses, and due to the improvements in treatment, there has been a significant reduction in HIV or AIDS-related deaths worldwide (UNAIDS, 2021). The actual figures for death reductions, however, differ from country to country due to the differences in preventative strategies and, more recently, how countries are performing against the 90/90/90 targets (WHO, 2020; UNAIDS, 2020). Looking at South and East Asian regions, around 5 million people were infected with HIV in 2015, with the majority living in India, Indonesia, Myanmar, Nepal, and Thailand (UNAIDS, 2021). Bangladesh first experienced HIV/AIDS in 1989 (Azim et al., 2008). The number increased from 1,207 to 3,674 in 2007 and 2014, respectively (Sheikh, Uddin & Khan, 2017). According to national case reporting data, out of 5,383 people living with HIV, 1,072 died of HIV/AIDS related illnesses in 2018 (NHMIS, 2018). Recent data shows that 7,900 people live with HIV in Bangladesh, and the figure is gradually increasing. Migration is one of major factor of high transmission of HIV (Khan et al., 2021). Other factors include problems with managing HIV infected people, sexual infidelity, reluctance of taking an HIV test and lower power of women of asking for test to their husband (Kabir et al. 2020). Considering the current population of Bangladesh, these numbers demonstrate a low prevalence, yet there has been a rapid increase and spread (Huq et al., 2020).

While treatment is essential, research suggests that people living with HIV/AIDS encounter discrimination from healthcare staff. Sometimes care providers pay less attention to
HIV/AIDS-positive people, skipping physical examinations or making unnecessary referrals, which worsens the vulnerability of HIV/AIDS-positive people (Yakob & Ncama, 2016). People have no understanding about the treatment and transmission of HIV/AIDS related diseases. For lack of sufficient knowledge, teachers can be less understanding, empathetic, and stereotypical when interacting with HIV-positive children (UNODC, 2009). Isolation and deprivation at schools for HIV-positive children are prevalent, because teachers and parents are unaware of the disease's transmission. Thus, HIV/AIDS-positive pupils are unable to receive a decent education and suffer psychologically as a result of their HIV status.

It is claimed that HIV/AIDS positive people face different social stigmas and other consequences. Other reasons include fear of social scolding and unawareness about the transmission of HIV, which leads to high transmission and increases vulnerability (Nasreen, Shokoohi, & Malvankar-Mehta, 2016). Various misconceptions are prevalent about the transmission of HIV/AIDS. Among many other reasons that escalate social exclusion, the most dominant are: it can be transmitted through saliva, sweat, spit, tears, air, insects, food, water, toilets, swimming pools, clothing, or shaking hands (Das & Islam, 2008) and it can be treated through quarantine (Kabir, 2020).

HIV/AIDS is now considered a long-term illness, and access to antiretroviral therapy (ART) can allow people to lead relatively normal lives (Archin & Margolis, 2014). Unfortunately, very few PLHIV take advantage of the available medical services in Bangladesh. (Venturelli et al., 2015). Many individuals continue to die from HIV/AIDS in the absence of treatment for fear of social scolding. It is important to consider the ongoing stigma, social exclusion, and discrimination in Bangladesh in line with the 2016 undetectable vs. untransmittable slogan (U=U) and the 90/90/90 target for 2030 in Bangladesh. The lack of access to or reluctance to access treatment, and poor adherence levels result in slow progress in U=U in Bangladesh. Moreover, U=U may not be achievable or have a positive impact on people living with HIV quickly unless they start to take treatment as well as adhere to it. As a consequence, it may result in slow PLWHIV in Bangladesh continuing to experience social exclusion.
Understanding social exclusion of HIV/AIDS positive people

Social exclusion is used to describe social division, which mostly refers to persistent, systematic, and multidimensional processes through which people face denial of resources, rights, goods, and services and are mostly unable to participate in the normal relationships and activities open to the majority of people in a society (Muddiman, 1999; Levitas et al., 2007). Social exclusion occurs when different stigmatising factors cause disadvantage. Sociologist Jordi Estivill explained social exclusion more broadly, stating that a society, group, or even an individual establishes and maintains a set of rules that create a differentiation in a society or in a group (Estivill, 2003). This differentiation creates inequalities between different groups of people (Sen, 2000).

The frequency of social exclusion was first felt within Europe, but later it gained momentum beyond that region. In Britain, "social exclusion" was used to explain discrimination in social policy. Later, researchers used it to understand poverty, where people’s inability to participate in customary life was pictured. By contextualising this theory in his work, Duffy (1995) suggests that a lack of effective participation in economic, social, political, and cultural life creates alienation and distance from mainstream society. Estivill (2003) first explored the transferability of the concept beyond the European context. Levitas (2006) found some general issues where the danger of stigmatising certain groups in defining their behaviour or situation is explained with importance.

Research has shown that exclusion exists in the familial, economic, educational, and medical realms of people living with HIV (PLWHIV) (Khosla, 2009). Unemployment leads to transactional sex, and immediate survival needs encourage commercial sex (Rispel & Popay, 2009), which is among the high-risk behaviours associated with HIV/AIDS. For this reason, PLWHIV prefer to isolate themselves and hide their HIV status from relatives for fear of familial neglect and rebuke (Balashundaram et al., 2014), bullying, threats, and public prejudice (Mandela, 2001). As AIDS is a chronic disease, it damages physical well-being, challenges intellectual functioning, and threatens mental health (Kontomanolis et al., 2017). Lack of awareness regarding HIV/AIDS leads to the stigma, discrimination, and social exclusion that overlay the process of violation of human rights.

Contextualising the situation of HIV/AIDS-positive people in Bangladesh, it can be argued that societal values and beliefs exacerbate the stigma and discrimination experienced by people with HIV. Drawing views from different theorists on social exclusion and contextualizing the
situation of HIV/AIDS positive people in Bangladesh, it is found that social stigma leads to exclusion and social exclusion leads to social vulnerability that are explained in the following figure.

**Figure 1:** Social exclusion of HIV/AIDS positive people.

**Social Work Education and NGOs role in HIV/AIDS Prevention**

Academically, social work education provides a solid basis for those interested in studying the HIV/AIDS problem and its consequences. The use of social work methods enables (i.e. case work) this practitioner to help the patients cope with day-to-day challenges. Concerning the nature and being an altruistic professional academic discipline, it emphasises three components of a cross-disciplinary centre point: "HIV/AIDS as a social, racial, and fairness and equality concern; the global HIV/AIDS epidemic in the framework of international social work; and its response to the infected elderly people" (Bowen, 2013). Subsequently, social workers are well qualified, through knowledge and practice, to empathise with HIV/AIDS patients, as well as their families, friends, and so on. It is worth noting that they try to encourage meeting the
clients' best prerequisites (Sweifach & LaPorte, 2007). To address exclusion, the government of Bangladesh has launched various programmes in the areas of HIV/AIDS prevention (Das & Islam, 2008). Along with the government, various non-governmental organisations (NGOs) are working diligently and delivering assistance on the ground against HIV/AIDS (Azim et al., 2008).

It is obvious that non-governmental organisations can assist people living with HIV with their impediments (Cane, 2018). In Bangladesh, NGOs can play a more effective role in medical distribution, medical treatment assistance, and HIV prevention activities such as needle exchange programmes, peer education in HIV prevention, providing presentations, and distributing instructional materials (Amirkhanian et al., 2004). In many countries, non-governmental organisations (NGOs) regularly face a variety of issues and obstructions in carrying out their programmes, such as a lack of accessible funds, official triviality or resistance, and AIDS-related stigma (Hua, Yi & Anderson, 2005; Amirkhanian et al., 2004). However, since NGOs supplement the functions of the government, they may face indifference or unwillingness to take such actions. On the other hand, NGOs dealing with AIDS may provide health education, mobilise people to combat the epidemic, and launch intervention strategies through trained personnel (Hua, Yi & Anderson, 2005, 2005). While government organisations serve outsiders in the community, non-governmental organisations serve people who are vulnerable in society (Crane & Carswell, 1992).

Since 1989, the government of Bangladesh (GoB), together with several domestic and global non-governmental organisations, has been contributing to the HIV/AIDS epidemic in Bangladesh. The GoB put forward a slogan, “Bachte Hole Jante Hobe” (If you want to live, you have to know) to raise public awareness of HIV/AIDS (Hira et al., 2021). Faruk, Begum, and Rana (2017) demonstrated that HIV/AIDS knowledge and understanding in 2014 was around 80%, with males accounting for 90% and females accounting for 70%. According to the 4th National Strategic Plan for HIV and AIDS Response, the objective is to accomplish measures to stop new cases by continuing to increase programme coverage and case identification (GoB, 2019). The government of Bangladesh ensures free distribution of drugs for HIV/AIDS treatment. (Islam, 2022). In addition, a few non-governmental organisations (NGOs) primarily offer counselling, advocacy, and protection of HIV positive patients' rights in Bangladesh. However, very little research has been found that explores the role of NGOs in HIV/AIDS prevention and treatment, and reducing the vulnerabilities of the affected. In this
study, we define NGOs as non-profit organisations that act independently to address HIV/AIDS-related health issues with finances from sources other than the state or government.

**Research objectives**

The main aim of this study is to explore the role of NGOs in reducing the vulnerability of HIV/AIDS-positive people. To obtain general information, this study has focused on the following specific objectives:

i. To explore the social stigmas against HIV/AIDS-positive people;
ii. To identify the process of social exclusion of HIV/AIDS-positive people and its impact on social vulnerability;
iii. To understand the role of NGO interventions in combating the challenges of HIV/AIDS patients;
iv. To reconnoitre the social work education in reducing social stigma and vulnerabilities of HIV/AIDS patients.

**Materials and Methods**

**Sample selection and data collection**

A qualitative approach and a case study method have been applied to conduct the study in Sylhet City, Bangladesh. Sylhet is the region that holds the highest number of immigrant people, and HIV/AIDS infection rates among labour migrants in the region are constantly on the increase (Sheikh, Uddin & Khan, 2017). It is reported that, 24.7% of HIV can be found among migrant workers or those working overseas who then return to the country and contribute to the spread of the disease (Kabir et al. 2020). Since PLHIV keep their status secret, it is hard to find them without the help of the different institutions or organisations dealing with them. In Sylhet City, there is an NGO named Ashar Alo Society (AAS) that has been working with such a group of people for a long time. Hence, we contacted the AAS Sylhet centre and collected a list containing a total of 765 HIV/AIDS-positive people who had registered by taking services from the centre. For interviewing 15 PLHIV, we followed convenience sampling to select respondents because this is a common strategy of nonprobability sampling where respondents are selected based on their availability. To get real descriptions of the issues, 10 guardians and community members were asked to answer our questions. As we concentrated on knowing the NGO roles targeting PLHIV, we conducted key informant interviews with
AAS officials. The selection of respondents from a multi-section of society helps to get a diversity of perspectives on the given research problem (Pallas & Nguyen, 2018).

<table>
<thead>
<tr>
<th>Sources of data</th>
<th>Number of participants</th>
<th>Techniques of data collection</th>
<th>Objectives addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS people</td>
<td>15</td>
<td>In-depth interviews</td>
<td>Vulnerabilities of HIV/AIDS people</td>
</tr>
<tr>
<td>Guardians/community people</td>
<td>10</td>
<td>Key informant interview</td>
<td>Perception of HIV/AIDS</td>
</tr>
<tr>
<td>AAS Officials</td>
<td>5</td>
<td>KII</td>
<td>Ways of providing services</td>
</tr>
</tbody>
</table>

The data collection process was directly observed and guided by the first and fourth authors, who are social work academicians (Bangladesh) and practitioners (UK), respectively. For collecting data, we prepared open-ended questions addressing a number of issues, including socio-biographic information of the respondents, such as gender, age, and education; social stigmas that PLHIV experience in their family; their vulnerabilities in their family, community, and in different sectors, including education and employment; and the behaviour patterns of family members and people in the community. Regarding employment, we asked PLHIV about their sources of income to identify their present occupational status and get a clear picture of their earnings, as they may not disclose their income data. Respondents from different age groups participated in the study. Since the research project was conducted in English, accordingly the research tools were prepared to keep the meanings intact. However, the participants were asked in Bangla so that they could respond comfortably. The data collectors were native of Bangla language and also fluent in English language. Therefore, they efficiently transcribed the data into English. The data was analysed thematically and themes were generated from the data. The data collection was undertaken in the participants’ convenient places.

To ensure trustworthiness, we showed the analysed data to some of the participants, who approved it. All of the researchers observed the process of the study and cross-checked the data for reliability. Furthermore, two qualitative research experts validated the coding, documenting, and overall procedure of the research. This study followed the ethical guidelines of the Research Center of Shahjalal University of Science and Technology in Sylhet,
Bangladesh. Besides, the researchers strictly adhered to the guidelines of the Declaration of Helsinki. Furthermore, the researchers submitted a formal application to the AAS outlining the research and all of the ethical principles that would be observed, as well as an explanation of the data sharing agreement. Then, the AAS evaluated and approved the researchers' data collection procedures.

Before interviewing the participants, the researchers explained the goal of the study, how the findings are intended to be used, and how the study can help HIV/AIDS-positive people in Bangladesh. The researchers then guaranteed them rigorous adherence to the confidentiality of information. Verbal consent was taken from some PLHIV who could not sign, and written consent was taken from all other respondents who had a minimum level of education. The researchers were highly sensitive to the patient’s HIV/AIDS status when asking questions. The researcher maintained the anonymity of the respondents by using pseudonyms, keeping their records secured, and concealing their identity. Respondents were also assured that they could withdraw their participation from the study at any time.

<table>
<thead>
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<th>Variable</th>
<th>Measurement</th>
<th>Percentage</th>
</tr>
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<tr>
<td></td>
<td>Female</td>
<td>34.0</td>
</tr>
<tr>
<td>Age</td>
<td>20-29</td>
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</tr>
<tr>
<td></td>
<td>30-39</td>
<td>27.0</td>
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<tr>
<td></td>
<td>40-49</td>
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<td></td>
<td>50-59</td>
<td>13.0</td>
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<td>Employment</td>
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<td>30.0</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>70.0</td>
</tr>
</tbody>
</table>

Findings of the study

The aim of the study was to explore the three fold objectives; social stigmas towards HIV positive people, process social exclusion and its impact on their vulnerability and role of social work knowledge and NGO interventions in reducing their vulnerabilities. Considering these objectives and the findings are presented in the following three sections:

**Theme one: Social stigmas towards PLHIV**

PLHIV were found to be significantly stigmatised and discriminated against. The research results reveal that the general public has misconceptions concerning PLHIV. They feel that people living with HIV are ethically degraded. They either engage in unlawful relationships
with others or satisfy their sexual cravings through commercial sex. Furthermore, individuals continue to have bad experiences, such as family members condemning and stigmatising them, and positive patients spread the infection through their utensils. These heinous encounters make their lives unbearable.

i. **PLHIV are disgraceful for the family**

The study finds that the identification of HIV is disgraceful for the family members as it results from illegal sexual relations. Consequently, close relatives, including intimate partners of PLHIV, are reluctant to support them once they are diagnosed with HIV. The below statement demonstrates the rejection by the spouse upon HIV+ disclosure:

> I was working away from home in the Middle East for 7 years and had an affair with a woman from Indonesia who was working there with me. Coming back to the country, I tested HIV+ and my wife brought a dramatic change in her treatment of me. She's no longer as intimate with me as she once was (Rashid Mia).

Furthermore, PLHIV face significant social prejudice from family members, who characterise them as a burden on the family. Some family members, like the patients’ immediate siblings, don't want the patients to tell anyone about their HIV status.

> When my brother discovered that I was HIV positive, he prevented me from disclosing my HIV status to anyone. Furthermore, it appeared to me that my brother remained distant from me. It might be his dread of contracting a virus from me, which is excruciatingly unpleasant for me (Ruhel Mia).

ii. **Infidelity**

Most of the participants noted that they were blamed of being engaged in extramarital affairs. Friends, and family members strongly believed that HIV/AIDS cannot be transmitted without the involvement in the illicit relationships other than husbands or wives.
My wife alleged me that HIV/AIDS is a god’s wrath on me because of my extramarital relationship. Consequently, there is always conflicts in my family. I am really tensed about the future of my children.

iii. *HIV is transmitted through using daily utensils.*

As with other studies, more than half of the respondents said that their families and friends believed the myth that HIV is transmitted through utensils. As a result, after disclosing HIV status, family members of PLHIV separate items such as glasses, plates, other utensils, and seats. One of the respondents explained:

After testing with AAS, I found out I was HIV positive. My brothers and parents were frightened after disclosing my HIV status to my family members. For the safety of other members, they separate my usable things. I take my meals in different glasses and plates. My family members do not enter my room (Majid Khan).

Among female respondents, half of the respondents mentioned that their family members do not like them and that they deserve discriminatory behaviour and exclusion. One of the respondents stated:

My husband was a migrant worker. He was HIV/AIDS positive. Consequently, I got infected with this disease. Knowing my HIV status, family members separated my usable utensils, saying this is what I deserved. I even have to use a separate bathroom. I, too, am unable to bathe in the pond (Rukshana Begum).

iii) *HIV/AIDS is not curable.*

A small number of participants claimed that because this disease can never be cured, there is no purpose in undergoing frequent check-ups and they presented themselves as hopeless. Furthermore, healthcare workers such as doctors, nurses, and other support staff in medical settings have demonstrated negative and stereotyped attitudes while dealing with patients afflicted with HIV/AIDS, believing it to be an incurable disease.

I cannot survive as I am an HIV-positive man. I know that my days are limited. When I go for treatment, more people will know about my disease, and it will be a scandal for me. Therefore, it is better to die than take any treatment (Miraj Ali).
The acute fear of scandal experienced by HIV-positive people means they do not seek treatment. They think there is no purpose to taking the drugs as they will only cause more suffering. This self-stigma prevents these people from getting medical care and increases their risk of death.

**Theme two: Social exclusion and vulnerabilities of PLHIV**

HIV/AIDS-positive people are being isolated from their family and community. According to Li et al. (2008), the patients’ HIV positive status causes them to lose their familial identity as well as their social identity. Exclusion in the family and community came up in the findings due to irrational fear, anxiety, and social stigma. Patients experience negligence and a derogatory treatment pattern from their significant others. This theme is comprised of the following sub-themes, which clearly demonstrate how HIV-positive patients are isolated from their families and communities.

1) **Exclusion by family members, relatives and society**

Findings suggest that HIV+ people in this study struggled to disclose their HIV status either to their family members or in the community, due to fear of humiliation. The fear is associated with how disclosing their status to trusted people might result in a breach of confidence that might stretch into the community. The following quote from a respondent explained how it was important to protect himself from family and community humiliation by keeping his status secret.

> When I returned to Bangladesh, I found out I was HIV positive. Firstly, I did not disclose it to my family members. I would think that it is very shameful to let them know about this status. Hearing the disease, they might treat me differently. Later, I shared it with one of my knowing cousins. He forbids me to hide this status (Rahim Uddin).

On the other, female participants face desertion or physical and psychological brutality from their male partners. Among five female respondents who had AIDS, two of them were living in their in-laws’ homes and experiencing negativity from all sides. One of the respondents is living with her parents after being deserted by her husband, as reported below.
I got married 6 years ago. One year later, I became very sick and was admitted to IBN SINA Hospital. But doctors referred me to the Ashar Alo Society after doing some initial tests. AAS found me as HIV+. Soon after that, my in-laws started to blame me, and they did not endure me till the date (Ayesha Begum). Therefore, the HIV/AIDS disease is considered unthinkable for female people. Female patients are deemed more defamatory for their familial status. Therefore, they are treated more harshly than men.

ii) **Exclusion from access to healthcare**

The study found that PLHIV experience greater levels of discrimination from the negative attitudes of healthcare providers in government healthcare institutions, as they often have a lack of understanding and awareness. They have a fear of this disease and its patients. Patients often remain self-discriminated from healthcare due to fear of disclosing their HIV positive status to healthcare providers. Besides, they also suffer from self-stigma, which deters them from getting rehabilitated in mainstream society.

Participants reported that these professionals were not always willing to provide care for PLHIV. They reported that some doctors in government hospitals are unwilling to talk with PLHIV, and often they are not welcomed or offered appointments. Consequently, most of the respondents avoid local healthcare centres and government healthcare centres. One of the respondents relays her experience:

> I went to the doctor in a government hospital for the next round of treatment because I was HIV positive. Meeting the doctor, I explained my condition exegetically, but he was unoccupied and treated me in a whimsical and disrespectful way. The very arrogant and uncaring attitude of the doctors hurt me very much (Miruj Miya).

It is clearly understood that stigmatisation extends not only from the home into the community, but also from healthcare providers who continue to see HIV/AIDS as a stigmatised illness. PLHIV as well as their guardians believe that they even face exclusion from healthcare centres when they go for any kind of physical examination.

As people have little knowledge of HIV/AIDS and the governmental or non-governmental services available for treating it, they suffer very serious and even fatal conditions. “In most
cases, they come in very late for a diagnosis, once they are very sick. One of the respondents reported:

I am one of the AIDS patients. I got to know it after becoming bed-ridden. As I was abroad, I did not know about local services against it. Some months back, I came to know the sources of those services. As I am taking services from AAS, I am getting well slowly now (Shomuj Miya).

Unfortunately, the lack of knowledge around where to access services for HIV and where to obtain treatment often leads to treatment delays and health deterioration. As said by one respondent:

When I arrived in my homeland with an HIV positive status, I started taking treatment exhaustively. After hearing from a source, I later found that AAS was providing services in this regard. It took almost four months to get them, and in the meantime, conditions got worse.

This study found that some people with HIV hardly ever take treatment, even when their health deteriorates, because of their fear of medicine. However, for those with supportive families, this support plays a crucial role in seeking treatment and hospitalisation when the disease progresses. One respondent explained:

I knew the drugs for recovering from HIV/AIDS were very painful for people to take. First, I did not bother to go for any treatment. Later, I was feeling very bad, thinking that I would die by making myself sicker. Then I started taking medicine from AAS. At first, I became very sick from taking drugs. For this reason, I stopped taking drugs. But my family members again took me here when I became very sick (Abdul Karim).

From this, it is apparent that some PLHIV do not want to take medicine. They think that if they take medicine regularly, it will cause a deterioration in their health. Thus, this belief excludes the PLHIV from accessing healthcare services. Findings suggest that PLHIV fail to come forward for treatment in the first place. One of the respondents stated:

I fear disclosing my HIV/AIDS status to anyone. Initially, I didn’t visit any doctors. If they become aware of my disease, they will let the people know, which a shameful
thing is also for me. When I was in a serious condition, I visited a doctor. He referred me to AAS. I took ART from AAS (Rahim Uddin).

PLHIV fear losing their previous status and companionship in society, which keeps them from seeking treatment.

iii) Exclusion from education
Among the respondents, more than half stated that their children have to face different attitudes from teachers and other students in the school. Sometimes the teachers behave in a stigmatised way, and the children of PLHIV have to hear different words from them about their parents. One of the respondents stated:

I am HIV positive. I have a daughter. But she is HIV-negative. I admitted my daughter to school. She was very attentive and went to school regularly, but after disclosing my HIV/AIDS status in my community, the parents of other children forbade them to get close to my child at school. Thus, my daughter became alone (Hasna Begum).

According to the findings, many do not accept HIV/AIDS-positive people or even their offspring due to persisting stigmas. Misinformation about PLHIV prevents their children from attending school.

iv) Exclusion from employment
In this study, most of the HIV/AIDS-positive people (90%) were unemployed as they were migrant workers abroad. Our findings found that when they obtained employment, they faced discrimination and stigmatisation in the workplace. Most of the time, however, they were not recruited by employers, even in low-class jobs:

I became infected with HIV from my husband. After having HIV/AIDS-positive status, I had to return to my parents’ family. As my parents are not well off, I went looking for a job anywhere to maintain my livelihood and cover treatment costs. But people refused to offer me a job because of my status. So, I could not manage any jobs, not even working as a maid servant. Therefore, I am depressed and waiting for death (Asia Begum).
This study, like others, demonstrates that HIV has an influence on employment and economic status. In addition to stigma, social exclusion and vulnerability are major issues for HIV/AIDS patients.

**Theme three: Role of NGOs**

NGOs are playing a pioneering role in alleviating HIV/AIDS in Bangladesh. Because of their roles in the HIV field, they have become key stakeholders. They are helping PLHIV through peer support groups. According to the workers of AAS, they are working to make the lives of PLHIV meaningful as a whole. AAS provides support services through community engagement and policy advocacy in Bangladesh. Besides providing care and support, NGOs also work to establish rights and empower both those infected with and affected by HIV/AIDS. All of their efforts are aimed at eradicating the social stigma and discrimination caused by HIV/AIDS in society.

i) **NGOs creating awareness for family and community acceptance**

Fear among family members is not the only cause of the exclusion of PLHIV from their family environment. However, we found that a lack of awareness of this disease is fundamental to creating such a fear. Hence, family members are provided with counselling to foster greater awareness regarding HIV/AIDS. In addition, some family and community members who are inclusive and less stigmatising extend their hands to PLHIV. AAS helps with facilitating courtyard meetings under the programme of family and community acceptance. Many respondents agreed with the following:

I would contact AAS authorities if there was a problem in my household. Then they would send representatives to speak with family members. The AAS representatives normalized the situation after extensive discussions with them (Laboni Akhter).

ii) **Reducing social exclusion**

According to AAS officials, PLHIV in this region preferred to get treatment from NGOs due to confidentiality issues. We found that AAS is working to improve family and community acceptance of PLHIV. One NGO worker reported:

After tracing out the HIV+ status, we take care of patients in all possible ways. We also talk to family members and community people in yard meetings and counsel them so that PLHIV get their acceptance (Jahanara Khatun).
They are also preventing mother-to-child transmission. One health worker reported:

We prepare children’s profiles and formulate individual development plans for PLHIV and their children. Thus, we keep people alert about the transmission of HIV/AIDS. Specifically, we also try to increase women’s awareness about the possibility of transmission to their offspring while working in the field (Rabeya Begum).

The NGOs provide services to the guardians of PLHIV to increase awareness so that they are able to support them better. When people come for an HIV test in AAS, they are first provided with pre-counselling and then peer-counselling. In pre-counselling, they are asked some questions and made aware of HIV/AIDS. Through peer-counselling, they are given psychological support from a counsellor who is HIV/AIDS positive. One health worker explained:

A sick person came to our office for testing to determine whether he is HIV positive or not. After completing all the procedures of the test, he was found to be HIV+. Then I talked with him alone in a private room about the disease and found him upset, disrupted, and depressed. I counselled him so that he would not break down and assured him of his recovery (Rokeye Begum).

Among PLHIV respondents, most of them had no idea about HIV/AIDS. When they tested for HIV in AAS and received counselling, they gained knowledge about its transmission and effects.

I can’t think of any other institution that would accept my treatment besides AAS, because the doctors and other healthcare workers in many government hospitals are apathetic towards PLHIV. They have a fear of HIV/AIDS. They do not want to give us service cordially. I get check-ups and medicine from AAS regularly. The service providers are very trusty and helpful there (Shuhel Mia).

Almost all the respondents stated that they get support and advice from NGOs. Due to self-stigma, they do not visit any doctors or healthcare providers privately. They believe they will
be rejected outside of the NGOs. To improve the life status of PLHIV, they provide nutritional, developmental, protective, and educational support. Various counselling services are also arranged in different ART centres to allay the fears and anxiety about the course of the disease among PLHIV.

iii) Providing rehabilitation for PLHIV

We found that AAS provided rehabilitation for people living with HIV as a way to address the gaps in the system and social stigma.

They are providing training on positive living, vocational training, peer education, and life skills training, concentrating on the long-term rehabilitation of PLHIV. Besides these training programmes, there is also a programme of orientation on child rights, child development, and child protection. One AAS official said:

We provide awareness education and campaign support for slum and street children and their parents. The aim of these functions is to ensure the proper development of children of HIV-positive people (Abdur Rahman).

Through this programme, the NGOs provide people living with HIV/AIDS economic support for the education of their children. There are some other programmes designed to empower PLHIV and their family members in their society.

Reconsidering Social Work Education and NGOs roles

As noted earlier, the transmission rate of HIV/AIDS in Bangladesh is increased by returning people from foreign countries, mostly from the Middle East (Urumi et al., 2015). For the time being, the spread of HIV/AIDS infection has amplified beyond this male community to their sexual partners, children, adolescents, and other community members. This trans-group infection advances HIV/AIDS education and practise (Strug, Grube, & Beckerman, 2002). PLHIV have the same rights as all other members in Bangladesh, yet they have to suffer from discrimination, exclusion, and victimisation. Social workers can fight against such injustices (Jaoko, 2014). In Bangladesh, PLHIV get a primary prevention programme and medical care.

As an academic discipline, social work educates professionals in the sphere of health and well-being. Students in social work institutions are prepared to strengthen the healthcare system and
lighten the load of healthcare expenses (Browne, 2017). Yet, with a robust altruist academic and practical understanding of social work, social workers may concentrate on the less visible concerns of HIV/AIDS across the globe. Medical social work, psychiatric social work, clinical social work, and other sub-disciplines of this discipline will be able to directly correspond to the elimination of stigma, discrimination, and vulnerability among these clusters. Social workers’ specialised competencies as well as capabilities are aligned with the crisis mitigation approach (Horevitz & Manoleas, 2013; Ali, Hatta & Azman, 2014). In primary prevention efforts, social workers can empower community members to set their goals regarding this pandemic and play a role in achieving them. They should learn about the values, beliefs, and lifestyles of people by engaging with their community. This will be helpful in creating prevention messages for different social groups. Social workers’ interventions would be crisis-oriented (Ntshwarang & Malinga-Musamba, 2012). Besides, they would help PLHIV and their families make decisions about advanced medical treatment, including antiretroviral therapy, after learning about their prior history of medical care. Identifying uninfected people at risk for HIV/AIDS infection and helping them to eliminate risky behaviours are among the HIV/AIDS social work responses. Infection with this disease has been rapidly increasing in our country in recent years. Hence, the advanced role designed for social workers would be beneficial for PLHIV.

PLHIV suffer from mental illnesses caused by psychosocial, health, biochemical, and/or cognitive stressors (Vance, Struzick & Childs, 2010). For addressing such problems, different kinds of interventions are required. Clinical social work knowledge and skills should be practised with an increased number of PLHIV. While practising with age, intrapersonal resources and personality traits, and emotional optimisation should be incorporated while practicing while aging. Developing skills in interpersonal interaction that produce positive affect will be useful to avoid negative experiences (Zhang & Souleymanov, 2017; Vance, Struzick & Childs, 2010). Thus, they would help their clients formulate their cognitive-behavioral plan in an individualised fashion (Vance, Struzick and Masten, 2008). PLHIV frequently faces stigma, social exclusion, and financial hardship (Zhang & Souleymanov, 2017), which can lead to cognitive stressors such as depression and suicidal ideation, necessitating early intervention for improved emotional and mental health.

According to Riley, Lee and Safren (2017), cognitive-behavioural treatment is a client-centred approach that can improve resilience in people living with HIV (Riley, Lee & Safren, 2017). Through cognitive behavioural intervention, social workers can counsel their clients to
organise their capacities to solve problems and cope with the environment (Ntshwarang & Malinga-Musamba, 2012). They often show intense emotional reactivity resulting from familial and/or social exclusionary processes. Excessive reactivity derived from emotional deficits may cause neurological problems. For the reinstatement of the emotional status of PLHIV, neurocognitive interventions should be implemented (Rich et al., 2020; Tymchuk et al., 2018). Vance and Struzick (2007) highlighted cognitive remediation therapy for the development of cognitive ability in PLHIV. They also emphasise healthy eating habits and a better lifestyle because good nutrition, physical activity, and social stimulation all help to slow cognitive decline.

In contrast, in a cross-sectional research done in Tanzania, 52.9% of the NGOs teamed up to local bodies, 29.4% with national bodies, and 17.6% with external countries. This implies that the majority of the tested NGOs work in a highly confined setting, with minimal expertise from developmental organisations (Mhando, 2012). However, in Bangladesh, NGOs had carried out approximately 75% of HIV/AIDS preventive, medication, and caregiving efforts on a national scale (Reliefweb, 2014). NGOs became development partners for a long time in the socioeconomic development of Bangladesh (Hossain, Al-Amin & Alam, 2012). In Bangladesh, NGOs intervene in many major areas, including the welfare of children, the development of young people, and HIV/AIDS treatment. Issues related to HIV/AIDS can be dealt with more effectively by having expertise in social work knowledge, tools, and skills. Unfortunately, social work education is rarely considered in this field since the social work profession is yet to be recognised (Hossain & Ahmad, 2020). Major services delivered by such NGOs are medical services for sexual and reproductive health. They offer these services to reduce HIV/AIDS and other sexually transmitted diseases (STDs) in the community.

To serve PLWHIV, NGOs established and expanded HIV testing and counselling (HTC) sites across the country. HTC includes Voluntary Counselling and Testing (VCT) and Provider Initiated Testing and Counselling (PITC) for providing HIV treatment (Kennedy et al., 2013). In addition to that, NGOs can provide various interventions for PLHIV besides counselling and primary treatment. They can design their courses of action with acute care and long-term care for PLHIV. High-risk screening, psychosocial assessment, coordinated patient care, counselling, social education, and community outreach (Segal et al., 2010) should be considered in formulating a long-term intervention plan. NGOs should shed light on social group work practices in working with such stigmatised populations in Bangladesh. It will assist them in creating positive networks between and among AIDS-affected children, adolescents,
young people, and older adults in order for them to solve the problems on their own (Abraham, 2017). The present situation of HIV/AIDS points to the reconsideration of social work education, practice, and NGOs’ roles. Social work educators can examine the deleterious effects of stigma on this population and train social work students with tools to deal with the stigma (Zhang & Souleymanov, 2017).

Social work professionals can take community-based approaches to address health inequalities and social exclusion of PLHIV (Chow & Lou, 2015). Both education and training on such grounds should be provided to make health workers skilled and fit for practice. HIV/AIDS prevention theory, including primary and secondary prevention, should be taught in classrooms and shared during NGO worker training sessions. In Bangladesh, lessons on the HIV/AIDS epidemic are being taught sporadically in some lower grades other than in higher educational institutions. Actually, students in higher grades have more potential to fight against this deadly disease. They may better learn how to help PLHIV and their significant others adjust to this chronic condition.

With matured eyes, they would support PLHIV in assessing their needs while practising in the field. Therefore, initiatives should be taken to familiarise students, care givers, health workers, and client advocates with HIV/AIDS concepts, languages, and theoretical models of behavior change for PLHIV and their families. Innovation theory should be diffused, which focuses on transmitting information regarding HIV/AIDS prevention and treatment over time through the proper channels (Strug, Grube & Beckerman, 2002). To acquire the needed skills and expertise, social work students should have access to organisational opportunities. Novice practitioners and NGO workers need to have diverse knowledge because multidisciplinary functions may appear to be done. Already infected people should be moved to integrated service environments. Developing social work settings, treatment of PLHIV would be more efficient and easier than ever before. Social workers may work as agents of behavioral change alongside other workers, including psychologists, health educators, client advocates, peer educators, etc. Therefore, social work education and practice with PLHIV may have to be focused and reconsidered with common assumptions about work. A segment of social work students should be given specialisation in HIV/AIDS social work so they can contribute to this sector with an advanced set of skills. Workers would need training in accessing integrated systems of support services to help them maintain their caseloads.

Discussion
Our study sought to analyse the stigma and vulnerability of HIV/AIDS-positive people in Bangladesh as well as discover NGO solutions to the challenges that HIV/AIDS patients confront. As a result of the HIV-related stigma, the study discovered weak family interactions and support for HIV/AIDS-positive people. Patients are losing their familial identity due to their HIV positive status (Li et al., 2014). In addition to stigma, irrational fear, avoidance, and neglect of PLHIV are leading to their exclusion from their families. According to the study, the separation of positive patients from their families and communities has made their lives vulnerable in a variety of ways, including isolation and other community engagement. Many studies have found that isolation as a result of one's unique status causes people to become estranged from society, causing long-term problems in family and social life (Hossain & Kippax, 2009; Kumar, Uduman & Khurrana, 1997). PLHIV keep their positive status hidden because disclosing it would make their situation in their family and community untenable. These results are consistent with earlier research that found that disclosing HIV status to family members resulted in a loss of family support (Balasundaram et al., 2014).

This research looked at healthcare for those living with HIV and discovered that healthcare professionals were rude to the patients. In healthcare institutions, PLHIV face hateful attitudes from healthcare personnel. Furthermore, since they are fearful of admitting their HIV positive status, people regularly confront prejudice in healthcare on their own. Consequently, they are denied vital medical treatment. This deprivation is explained in existing literature as a result of misconceptions (Geter, Herron & Sutton, 2018). Das and Islam (2008) also investigated societal stigmas as a result of HIV/AIDS misunderstandings. Internalized stigmas and the incompetence of healthcare personnel in government medical centres cause those with PLHIV to be excluded from healthcare treatment. To address these exclusions, several NGOs, including AAS, play important roles in providing treatment and rehabilitation support.

HIV/AIDS, like any other debilitating ailment, has financial implications in addition to medical ones (Braveman & Kielhofner, 2006). HIV/AIDS victims are also subjected to prejudice and stigma in the workplace. The majority of the participants' joblessness shows that they are unable to earn a living owing to their HIV positive status, which is represented prominently in their narratives. Unemployment among HIV-positive people is caused by social stigma, discrimination, gender, migration, and isolation, all of which contribute to poorer socioeconomic situations and psychosocial distress (Tujillo, 2010; Despa, 2013). PLHIV is increasingly made up of diverse groups of individuals, including women, people of color, and those with little social support and financial means (Braveman & Kielhofner, 2006). Therefore, they struggle with the challenges of employment. Despite the fact that the right to education is
regarded as one of the most important social and economic rights that assures a person's overall development, PLHIV children face discrimination at school. Hence, educational institutions should design activities to involve all students, regardless of HIV status. Children of PLHIV can benefit from education to learn about HIV infection, prevention, and treatment. In Bangladesh, however, students continue to experience attitudinal discrimination from teachers and classmates. One of the study's distinguishing features is how parents' HIV status leads to their children's educational exclusion. When patients are exposed to the community, their children lose access to education and experience a range of challenges and deprivations. However, researchers in this region place less emphasis on the children of PLHIV who face impediments due to their parents' HIV status. However, Zinyemba, Pavlova, and Groot (2021) observed that children face financial hardship as a result of their parents' diseases and must devote substantial time to caring for them. In Bangladesh, non-governmental organisations (NGOs) contribute significantly in a variety of fields, including HIV/AIDS treatment. Medical services are the most common service provided by such organizations. NGO's assist people living with HIV by forming alliances with them (Abraham, 2017). They also aim to create rights and empower those afflicted with and impacted by HIV/AIDS via community participation and policy advocacy. They contribute to the abolition of social stigma and prejudice by fostering a welcoming atmosphere in the community and society. PLHIV in Bangladesh are given a primary preventive programme as well as medical care. Both governmental organisations (GOs) and non-governmental organisations (NGOs) implement public health awareness campaigns (Urmi et al., 2015), including awareness-raising processions and specific day celebrations, as well as organising HIV/AIDS debates in lower grades of colleges and schools, to raise people's awareness and reduce infection. These are also considered social work responses. They would play a significant role in supporting HIV prevention efforts for PLHIV, such as through coordination of medical treatments that would result in quicker treatment. These social work implications point to the shifting responsibilities of social work academics and practitioners.

**Strengths, imitations, and future research directions**

Interviewing both PLHIV and family members, as well as NGO personnel, provides a diverse set of perspectives and a thorough understanding of the study's key issues. This study distinguishes itself by offering a unique viewpoint. Ensuring that diverse parts of the public participated in this study helped us to comprehend the phenomenon in its individual contexts.
Putting their stories together provides a more complete picture of societal stigmas and the exclusion process of PLHIV. Our research would assist policymakers and development workers in developing care interventions for HIV/AIDS patients, taking into account practitioners' advanced roles. Furthermore, the findings of our study will contribute to social work practise approaches, interventions, and care modelling techniques, research, educational curricula, and policies. Social work agencies and development organizations can create HIV/AIDS-related programs to alleviate the suffering of these stigmatized groups, allowing them to adjust their psychosocial functions and live their lives to the fullest.

Since the study was qualitative in nature, different aspects of PLHIV's life were understood by analysing the narratives of the respondents. Therefore, extensive research with advanced statistical analysis is required to obtain a more detailed picture of the impact. Furthermore, the study was conducted in the Sylhet region, which is home to a significant number of people who work abroad. Given that the majority of the participants in this study were foreign returnees who had been infected abroad, the findings may not be applicable to others who became infected abroad. Hence, it is suggested that research be conducted from other parts of the country, involving a diverse professional group of people. Furthermore, there have been fewer studies on HIV/AIDS from the standpoint of social work; thus, social work academicians should conduct more research to enrich this practice segment.

**Conclusion**

Stigma, discrimination, or exclusion are inevitable outcomes for people diagnosed with HIV and AIDS in Bangladesh. Concentrating on health education and HIV awareness in communities and families, with an emphasis on preventing exclusion, should make a long-term difference. Healthcare systems should be modernised using current technology that allows people living with HIV to obtain services remotely without worrying about being exposed to HIV in the community. Professional training and skill-enhancing activities such as seminars and symposiums can build better capacity among healthcare providers against HIV/AIDS. Research-based activities on STIs and their publication and reporting in mass media can increase civil society's knowledge, understanding, and awareness. Additionally, social or community mobilisation is of the utmost priority to combat the HIV/AIDS pandemic.

Although our study focused on AAS, we argue that NGOs can implement HIV/AIDS prevention programmes reaching wider communities vulnerable to HIV/AIDS and those susceptible to mental health problems arising from HIV stigma and discrimination. Hence,
Community campaigns should be a central focus for creating mass awareness of HIV treatment and preventative work with a clear focus on the inclusion of people with HIV into mainstream services. Action should be taken to encourage different NGOs to work with and offer opportunities to employ people with HIV, whether voluntarily or through paid work. Volunteerism is to be incorporated into social as well as state activities targeting HIV prevention. Partnership-based programmes between GOs and NGOs can be fruitful in this respect.

**Funding**
Not applicable.

**Conflict of interest**
The authors state that they do not have any conflicts of interest.

**Acknowledgment**
The researchers would like to thank the Ashar Alo Society (AAS). We also express our heartfelt gratitude to all of the participants, without whom the study could not have been completed.

**Authors’ contribution**
Dr. Md Ismail Hossain and Rumina Akter contributed to conceptualizing, designing, and collecting the data of the study. Dr. Md Ismail Hossain, Iftakhar Ahmed, Nafiul Mehedi, Rumina Akter, and Dr. Tam Cane prepared the materials, and analyzed the results. All authors made comments on prior drafts of the paper and reviewed and approved the final version.
References


