

## Exploration of better policies and programmes to improve socioeconomic status of HIV-affected individuals in Nepal: a qualitative study.

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### Abstract

The first case of HIV/AIDS in Nepal was reported in 1988. Since then, the HIV epidemic has moved from a 'low prevalence' to a 'concentrated epidemic' among injecting drug users, sex workers, and male labour migrants who travel between Nepal and India. Objectives of this study were to explore major problems faced by people living with HIV/AIDS (PLHIV); policy gaps, and recommendations of better policies and programmes to improve the current situation of PLHIV in Nepal. 18 in-depth interviews were conducted in Kathmandu in August 2016. A thematic analysis approach was applied to the information provided. Results of the study revealed that assistance provided to PLHIV by governmental, non-governmental and international organizations was limited. One-third of the participants reported that PLHIV could not continue their job, were not offered employment (33.3%), and they were removed from their job by employers after finding out their HIV status (27.8%). One-third reported different types of stigma and discrimination towards PLHIV, including self-stigma. Over a fifth reported that children affected by HIV/AIDS were discriminated in schools by teachers, fellow students, and school administrators. The study concludes that PLHIV are still facing a number of social and economic problems in Nepal. Although free treatment services are said to be available, they are not completely free. Stigma and discrimination are still highly prevalent in villages compared to cities, and among female compared to male PLHIV. Therefore, specific policies and programmes are recommended to relevant stakeholders to improve the socioeconomic status of PLHIV in Nepal

**Keywords:** Health Policies and Programmes, HIV/AIDS, Nepal, qualitative study, socioeconomic improvement, stigma and discrimination.

*Accepted on June 30, 2018*

**Abbreviations:** AIDS: Acquired Immunodeficiency Syndrome; ART: Anti-retroviral Therapy or Treatment; CT Scan: Computed Tomography Scan; FNCSI: Federation of Nepal Cottage and Small Industries; FSWs: Female Sex Workers; GO: Governmental Organisation; HIV: Human Immunodeficiency Virus; INGO: International Non-Governmental Organisation; MLM: Male Labour Migrant; MRI: Magnetic Resonance Imaging; MSM: Men who have Sex with Men; MSW: Male Sex Worker; NCASC: National Centre for AIDS and STD Control; NGO: Non-Governmental Organisation; P: Participant; PLHIV: People Living with HIV/AIDS; PWID: People who Inject Drugs; STD: Sexually Transmitted Diseases; STI: Sexually Transmitted Infection; UNICEF: United Nations Children's Fund; VDC: Village Development Committee

### Background

Since the first Nepalese case of HIV/AIDS was reported in 1988, the nature of the HIV epidemic has gradually moved from being a 'low prevalence' to a 'concentrated epidemic' [1] among people who inject drugs (PWID), male and female sex workers (MSWs/FSWs) and male labour migrants (MLMs) who travel between Nepal and India. The national estimates of HIV infection suggest that the actual number of HIV/AIDS

cases in Nepal is 40,000, which is higher than reported cases of 26,702 [2].

HIV/AIDS causes multiple problems to people living with HIV/AIDS (PLHIV) [3]. If a member of a household is infected by HIV/AIDS, the family not only faces the burden of treating the ill person, but also the loss of the productivity of the ill person due to the time taken by other family members to support the ill family member. Therefore, the household level impact of HIV/AIDS also includes treatment and productivity costs [4]. If the HIV-infected people die due to opportunistic infection, their experiences, skills and knowledge built up over a period of years will die with them [5]. If they were the breadwinners, the family will struggle to fulfil daily needs. Scarce resources can be utilized during the period of ill health, so poverty increases as the household's leader dies.

In the findings of previous studies, it is evident that HIV-affected households generate relatively lower household income than HIV-unaffected households [6, 7], and the burden of treatment is significantly greater in HIV-affected households than in HIV-unaffected households [8]. HIV/AIDS is one of the most stigmatised diseases in the world [9]. The stigma and discrimination related to HIV/AIDS not only emotionally

affects the HIV positive individuals, but also affects them economically [10]. Separation from families and communities, loss of employment, restrictions on movement and activities in communities are reported as stigma and discrimination related to HIV/AIDS, which have economic consequences. These types of discrimination generally limit PLHIV's economic capacity to generate a decent livelihood [11]. Similar findings were reported in a study by Poudel in Nepal [12]. According to the study, the majority of the HIV-affected individuals and households face catastrophic and impoverishing impacts due to the disease. However, there is no policy in place to protect the HIV-affected people or prevent households sinking into poverty [12].

A number of multi-lateral and bilateral organisations are working on HIV/AIDS prevention, support and treatment initiatives in Nepal, including: behavioural change communications; condom promotion; Sexually Transmitted Infection (STI) control; HIV testing and counselling; as well as surveillance, care and treatment. Different factors, such as poverty, political instability and gender inequality, combined with low levels of education and literacy make the prevention and treatment of HIV/AIDS challenging in Nepal [13]. Although the global funding for the HIV/AIDS programme has increased significantly during the past decades, most people living with, and at-risk of, HIV/AIDS do not have access to necessary services for them [14] and they are living in poor socioeconomic conditions [12]. The effect of HIV/AIDS is especially severe on poor households. Moreover, the effects can also be catastrophic and may also be an important poverty generating factor for non-poor households [15].

Stigma and discrimination are associated with HIV/AIDS, which have a severe impact on HIV positive individuals and households. Therefore, HIV positive people do not want to be tested or disclose their HIV status to other members of society. This may result in not seeking treatment [16] or seeking treatment far from home where the individual is unknown by others [12, 17]. This affects income as well as the expenses of the households. Similarly, stigma and discrimination also affect the coping mechanism of the household against the disease. In Tanzania, approaches to tackle stigma have largely focused on knowledge, attitudes and responses of individuals [16, 18]. Research indicates that approaches to tackle stigma require interventions on policy, societal, health system, and individual levels [16, 19].

A recent study by Poudel et al. reported that there are severe economic impacts of HIV/AIDS due to stigma and discrimination associated to it, on HIV-affected individuals and households in Nepal [12].

HIV-affected households might use different coping strategies to cope with the burden of illness, such as using savings, selling assets, taking out loans, borrowing from others, re-defining roles in the household, hiring labour and taking children out of school. These can resolve problems in the short term but can increase poverty of households in the long run [10].

There have only been a few studies related to the economic issues of HIV/AIDS conducted in Nepal. One of the latest studies

conducted by Poudel et al. has provided more detailed insights of economic burden of HIV/AIDS at household level. The majority of HIV-affected individuals and households are facing catastrophic (56%) and impoverishing (23%) impacts [12]. A study by Puri et al. only assessed the direct costs of HIV/AIDS treatment in some cities of Nepal [20]. Likewise, a small study by Thapa reported direct costs of visiting a hospital to take anti-retroviral therapy (ART) medicine in Kathmandu valley and the monetary value of time taken while visiting the hospital [21]. However, none of the aforementioned studies recommended strong policies to improve the socioeconomic status of the HIV-affected individuals and household by consulting key informants from governmental organisations (GOs) or national and international non-governmental organisations (NGOs, INGOs) working for HIV positive people and representatives from PLHIV. Moreover, all HIV related policies, guidelines and strategies were focused on prevention and treatment of the infected people, not on improvement of socioeconomic status of HIV-infected individuals and households [22-27]. Therefore, there was a need for a study to further explore the socioeconomic problems faced by HIV positive people, assess knowledge gaps in HIV related policy, and explore suitable policy recommendations for the GO and NGOs working in the HIV/AIDS field to improve socioeconomic status of HIV-affected individuals and households in Nepal, which are filled by this study.

## **Methods**

This is a qualitative research study, and in-depth interviews were conducted to obtain information from the participants. Kathmandu valley was purposively selected for the study because it is the capital of Nepal and all types of HIV-positive people, such as PWID, MSM, FSWs, MLMs were available there. There were many NGOs and INGOs (International non-governmental organisations) working in the field of HIV/AIDS, as well as central level government officials in HIV/AIDS prevention, control, treatment and policy making based there. Therefore, Kathmandu valley was suitable for this purpose. Leaders from GOs, NGOs and INGOs working with HIV-affected people, and representatives from the HIV positive people were interviewed. A purposive sampling method was used in the study to select the organisations and to recruit the participants, because there was specific criteria for the selection of organisations or groups (e.g. working in the field of HIV/AIDS) [28] and the participants (e.g. who are  $\geq 18$  years of age; who have  $\geq 5$  years of experience in working in GOs, NGOs or INGOs working in the HIV field, and HIV positive people who have  $\geq 5$  years of HIV infection history and have knowledge about socioeconomic problems faced by HIV-affected individuals and households) [28]. The representatives from the most at-risk groups, such as people who inject drugs (PWID), female sex workers (FSWs), and clients of sex workers/migrant workers [1] were selected from the PLHIV group.

The information was collected from 18 representative sample participants (11 males and 7 females) from different organisations, such as: the National Centre for AIDS and STD Control (NCASC); Shukraraj Tropical and Infectious Disease

Hospital (also called Teku Hospital, which is the main government hospital where most of HIV-positive people from Kathmandu valley get treatment) NGOs and INGOs working in the field of HIV/AIDS, and both men and women living with HIV (PLHIV). The sample size was determined by the saturation level of the information. The word ‘saturation’ in the sociology research field was first used by Glaser and Strauss [29] in their book ‘The Discovery of Grounded Theory: strategies for qualitative research’. According to them, saturation is achieved when no additional information is received from the extra participants of the study. As the researcher gets similar instances over and over again, he or she becomes empirically confident that information is saturated [29, 30]. Since the aim of the research was not very broad, the data saturation level was obtained by 18 participants. The information was collected in August 2016 after securing ethical approval from Liverpool John Moores University (LJMU) and the Nepal Health Research Council (NHRC). The information was collected using an interview schedule which was piloted with three participants before conducting the main study, and modified according to their responses. The in-depth interviews were recorded by using a voice recorder after getting formal consent from the participants. The interviews were conducted in the counselling room of Teku Hospital, the NCASC office, NGO and INGO offices, which were closed rooms to maintain confidentiality of the information provided by the participants [31]. All the interviews were translated and transcribed by the co-investigator (ANP) and verified by the principal investigator (PS). A thematic analysis approach was used to analyse the information [32]. First of all transcripts were read and re-read several times; themes and sub-themes were highlighted by using a colour coding system. Next, similar themes and sub-themes were grouped into broad themes which are included in the paper. All of the important quotations are presented in the paper.

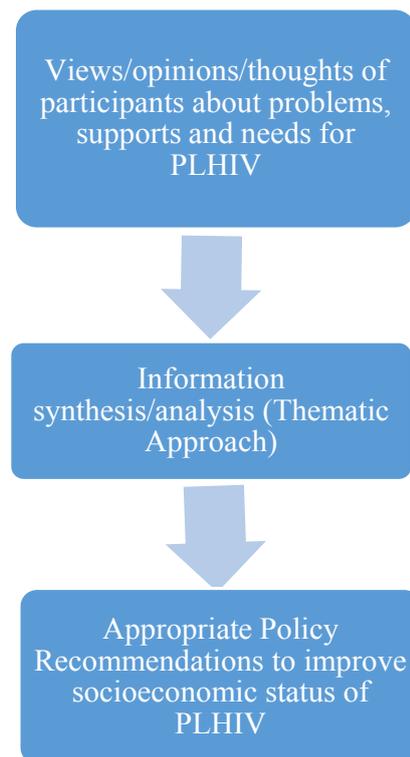
The information collected from the participants was kept in a safe and locked area. Anonymity and confidentiality were maintained from data collection to the research dissemination phase of the study. Figure 1 shows the research process used.

**Results**

Table 1 shows that the majority of the participants were male (61.1%), and more than half of the participants were from 41-50 years of age (55.6%); 27.8% participants were from GO and Teku hospital, and the same proportion were from the PLHIV group. Different themes emerged from the information provided

*Table 1. Participant’s characteristics.*

Characteristics	Number (N)	Percentage (%)	
<b>Gender</b>	Male	11	61.1
	Female	7	38.9
<b>Age group</b>	31-40 years	6	33.3
	41-50 years	10	55.6
	51 and over	2	11.1
<b>Representation</b>	GO and Teku hospital	5	27.8
	NGOs	4	22.2
	PLHIV group	5	27.8
	INGOs	4	22.2



*Figure 1. Research process.*

by the participants. The findings of the studies are discussed under these sub-headings:

**Provision of Services by Nepalese Government to PLHIV and their families**

The majority of the participants (88.9%) reported that anti-retroviral therapy medicine (ART) is available free of charge from 65 government operated ART centres in Nepal. More than two-thirds of participants (66.7%) reported that most of the diagnostic test services (such as CD4 count, viral load and total blood counts) are available free of charge in the government hospitals. The government has also provided nutritional support to pregnant women with HIV/AIDS (11.2%); free food and bed services to admitted patients (11.2%); small scale livelihood support programmes in some districts (11.2%); awareness raising programmes (11.2%), and lobbying to donor agencies (11.2%). Moreover, management programmes for opportunistic infections (5.6%), and drug impacts tests on people living with HIV/AIDS (PLHIV), have also been conducted by the government.

One participant reported: “The government has provided all the services free of cost to the HIV positive and their families. For example-medicine. Medicines are free; and lab tests are done at the beginning in 14 days and every month thereafter for three months, these are also free. Later also, which need to be done in every 6 months, whether it is CD4 or viral load, all these tests are done by government free of cost” [P5, Female, 47 years, Staff Nurse].

The ‘HIV Bill’ was prepared by representatives from the HIV Control Board, lawyers, NGOs, NCASC, and Ministry of Health. However, it has not yet been forwarded from the cabinet

for approval. There has been some progress about the rights of the PLHIV and third gender in the constitution of Nepal. Space has been provided to write third gender or other gender in such important documents (such as for Nepalese Citizenship or passports). Moreover, the issue of LGBT (Lesbian, Gay, Bisexual and Transgender), which is the most at-risk group of HIV/AIDS, has been included in the new constitution.

According to a participant: “We have also started to prepare an ‘HIV Bill’..... We have tried to make this in coordination with HIV/AIDS Control Board, people working in law, NGOs, NCASC, health ministry..... the government has provided citizenship by recognising us, this is very welcoming pace of the government. And, they have also included us in our passport, by allowing us to write other sex. In the constitution they have included LGBT in article- 12, ‘right to citizenship’ and article 18- ‘right to equality’ and article 42- ‘social justice’” [P1, Female, 35 years, NGO].

Although the government has conducted the aforementioned programmes and activities, some of the participants complained that the government does not have time to think about PLHIV, and has not helped their families. Although nutritional support used to be provided for PLHIV before, since 2015 it has been stopped.

A participant said:

“Government hasn’t done anything, in my view. They have given this ‘ART’. I don’t know where they have given from. It is free. Lab tests are free. There are no other things. If MRI, CT scan need to be done, the (HIV) infected (people) need to pay by themselves. There are no other supports.....” [P12, Female, 43 year, PLHIV].

### ***Provision of Services by NGOs/INGOs to PLHIV and their families***

NGOs and INGOs mainly work in HIV prevention and support PLHIV for treatment [33,34]. Most of the NGOs are operated by specific risk groups which have their own organisations working for the benefits of their members, including raising issues to the government if necessary. For example, sex workers, LGBT, drug users and other HIV positive people have their own organisations. Some of the organisations are working in the treatment and support of HIV-infected people in care centres, such as for opportunistic infections, nutrition, and training.

There are a number of INGOs working in Nepal to support HIV-infected people and their families. These include: Save the Children, FHI360, UNICEF, and the AIDS Healthcare Foundation (AHF). These organisations are conducting HIV prevention work to reduce new HIV infections, and treatment support to PLHIV [34] with the help of The Global Fund. FHI 360 has been working to reduce gender-based violence to help to prevent HIV transmission [35]. UNICEF work with adolescents and their programmes have helped to control and prevent HIV among them [36].

More than half of the participants (55.6%) reported that the

CABA (Children Affected by AIDS) programme conducted by Save the Children has economically supported HIV-infected children (who are below 15 years of age) [37]. They have provided NRs 1000 (US\$ 9.4) per month to support for their education, nutrition and other needs. However, all participants agreed that there is no such support for HIV-infected adults or their families.

A participant reported: “As far as I know, to the children affected by AIDS are given certain incentives, but there is no any socioeconomic support to the HIV-infected adults..... if they (children) are less than 15 years old and infected with HIV, he/she will get NRs 1000 per month to support for education and other needs... according to CABA guidelines” [P2, Male, 50 year, INGO].

It was reported by 44.4% participants that some of the diagnostic tests which are not provided free of charge by the government, such as MRI and CT scans, are provided by an INGO called AIDS Healthcare Foundation (AHF) free of charge. Some of the participants (22.2%) also reported that food and shelter for caregivers or visitors of patients are provided by NGOs and INGOs.

A participant mentioned: “They (AIDS Healthcare Foundation) support for MRI and CT scan for those patients who are poor. Other support by AHF is, for the visitors (caregivers). Patients come to us and there will be visitors too. Our hospital provides food for the patients who are admitted. .... AHF provides two meals form hotel for visitors of the patients too” [P5, Female, 47 year, staff nurse].

Some of the participants (27.8%) reported that NGOs and INGOs are providing transportation support for poor PLHIV. However, it has been reported that the coverage of the support to the needy PLHIV is very small.

A participant reported: “NGOs/INGOs in Nepal have supported some of the PLHIV’s transportation costs with donor’s fund. For example, if a PLHIV need to come to Nepalgunj or Dhanghadi for CD4 count from Rolpa or Rukum, they have to spend NRs 2000 to 4000 rupees for transportation. In such situation if they could not afford 2-4000 rupees, NGOs/INGOs help for transportation. If they have to come to Kathmandu from the ART centre for further investigation, they are supported as a ‘referral support’ for transportation” [P2, Male, 50 year, INGO].

Participants noted that NGOs have also conducted HIV prevention programmes (22.2%), nutritional support to PLHIV (16.7%), awareness raising programmes (16.7%), as well as supporting to keep PLHIV at hospital for observations (16.7%). It has also been reported that NGOs/INGOs provide home-based or community-based care to PLHIV.

A participant said: “While talking about NGOs/INGOs, INGOs have brought resources but NGOs have more focussed on community home based care. They go to their (HIV Positives) home and look after their families too, provide nutritional support, helping for children education, which government has not done or did not manage to do, programmes like these are conducted by NGOs” [P4, Male, 45 years, NGO].

Other reported programmes conducted by NGOs and INGOs for PLHIV in Nepal include: creating demand of health services; bringing resources from donors; reaching people who are not accessible to the government; providing medicines which are not available in the government hospitals; working on behavior change of people; providing home-based and community-based care; providing shelter for needy people; providing legal support to PLHIV; conducting income-generating activities, and providing employment to a number of people (albeit in small numbers).

Although NGOs/INGOs are conducting a larger number of support work for PLHIV and their families, some of the participants felt that there are still limitations of the services provided. The participants reported that not all PLHIV are getting nutritional support, the coverage of programmes are not wide, and not all children are getting support for education and nutrition.

A representative from an NGO said: "Not all the HIV positive people are getting nutritional support and not all children are provided education support too. Who are in the city, who have got good access, only they are getting ..... It is difficult to say what percentage of them are getting such supports because we don't have valid data, but I think up to 10-15% might be getting these" [P4, Male, 45 year, NGO].

### **Economic Aspects**

**Economic problems faced by PLHIV and their families:** Although Nepal is a low income country [38], poverty is highest among the HIV-affected poor families. The economic burden is high among the PLHIV, who are already in the low or lower-middle income category due to different reasons [15]. These reasons according to this study include- they cannot continue their job due to their illness or opportunistic infections (33.3%), they are not given employment because to being HIV positive (33.3%), and they have been removed from their job either due to their absences or for being HIV positive (27.8%). Some of the participants also reported that they cannot work as before due to lack of physical strength which caused loss of productivity (16.7%), and employers provide lower wages to them as being HIV positive (11%).

A participant said: "..... if know to others (employer or work colleagues) that they are HIV positive, they are removed from job. These problems are continue. Due to this, although they are capable ..... they have to leave their job. ....In addition, if one member of the family is already HIV positive, and the same person is their income generating person, then, if that person is removed from the job, they have to live in an economically depressed condition" [P11, Female, 32 year, staff nurse].

PLHIV need to check their CD4 count and viral load periodically. Therefore, they cannot go outside Nepal for their employment; and are not allowed by rule to go to Gulf countries to take a job; they cannot conduct small business as they do not have capital for investment, and they cannot stay in their original village if it known that they are HIV positive due to stigma and discrimination.

A participant stated: "HIV mostly affects migrant workers between Nepal and India. .... If they go to India, they have to take ART, they have to do regular check-up. Due to these problem, they could not manage to go India..... Economic burden occur due to this. .... If they go to India, if need to come in every month (for ART), it is not possible" [P14, Male, 36 year, PLHIV].

Some of the participants reported that PLHIV are of a productive age group. Therefore, the economic loss is high because of their productivity losses.

One participant reported: "The most HIV infected (people) are over 15/20 years old, which is a productive age group. This age group earn income and feed their family members. If the earning person infected with HIV, then their family's income source is affected" [P2, Male, 50 year, INGO].

Some of the participants said that there is lack of economic plan or programmes to support the PLHIV and their families, although other components such as treatment, prevention and awareness raising programmes are available to them.

A participant said: "..... one things is missing, while targeting HIV-infected.....We have more focussed in prevention and treatment parts, we mobilise our resources on these parts. But, their economic part, how this is affected and how this could be improved, it is missing" [P2, Male, 50 year, INGO].

**Programmes of Government to reduce economic problems:** Although there were programmes for HIV prevention, treatment and care; there was no any programme implemented by the Government to improve the economic status of PLHIV and their families. However, a handful of districts (10 out of 77 districts) had supported PLHIV to improve their skills by proving trainings and other supports with the help of Federation of Nepal Cottage and Small Industries (FNCSI). Therefore, there were lack of economic programmes and supports from government sector to the PLHIV and their families in Nepal.

**Improvement of economic status of PLHIV and their families:** A number of suggestions were provided by the participants to improve the economic status of the PLHIV and their families. Half of the participants reported that provision of a job to the PLHIV or employment for their family is the best option to improve economic status, for them and their families. Likewise, 38.9% of participants reported that skill development training, or an interest-free or low-interest loan (33.3%) will be helpful to improve economic status of PLHIV and their families. Some of the participants reported that skill development training along with an interest-free loan would be very effective to improve economic status (11%).

A participant reported: "To improve economic status, it would be better if they (PLHIV or their families) are provided job. They should be supported for investment, for example for agriculture, or for a shop. They can do something and feed themselves. It would be better if that happened" [P12, Female, 43 year, PLHIV].

Some of the participants suggested the need to conduct a feasibility assessment before providing any kind of training or support to PLHIV. This is because they believe that programmes without including the clients' interest will not be successful (P1, P6, P18). The participants provided a number of interesting suggestions to improve the economic status of PLHIV and their families. One participant (P7) suggested that an electronic card system will be useful to track the record of services provided to the PLHIV, as well as provide economic support. This system will also help find out the exact number of PLHIV reported to date, which can reduce management costs incurred to provide the variety of services to them.

The participant stated: "If all of them (PLHIV) are provided an electronic card, they could get their services from anywhere they want. Their data should be kept in the electronic system and we will be able to assess 'who got what' by looking their database. Here .....hospital also provides services, NGO has given, INGO has also given and there are many reports. The heads are counted many, but the real HIV infected people who are actually needy, did not get the services. A lot of money are spent on management. If the electronic system is introduced, they could be seen from anywhere about the service provided to HIV infected. If this is done, it would be so good. Who is left out also could cover, the people who got more could be stopped" [P7, Male, 51 year, PLHIV].

Another participant (P18) highlighted the microfinance model to improve the economic status of PLHIV and their families. A group of 8-10 PLHIV can be formed in a village or town. Then they should be provided with a seed capital of NRs 200,000-400,000 (US\$1,873-US\$3,746). After that, the group will decide who will take the loan from the seed money to conduct a business. After some time they can return the capital with a small amount of interest (which is decided by the group). This will help to increase the income of the PLHIV and their families, help track them for treatment adherence, and will be sustainable in the long run.

The participant stated: "In my view, government or NGOs, they can make a group of PLHIV in a village or in a Village

Development Committee (VDC) or in a district. And bring them to the microfinance, provide them a seed money. If you give once, that will be enough..... It is a one-time investment. You need not to provide big amount of money, there won't be possibility of cheating too. So, make a group, provide a money of 2-4 lakhs (NRs 200,000-400,000). The group will decide who does what business, or what work, and they invest there. They will pay very minimum amount of interest and return to the group. The total fund will increase due to the interest. If the fund will increase then other people also get chance. The group will recommend to whom to invest, to whom not to, how to get back if the money stuck by a member. Or, how to bring in track if a person took money and did not work. All these things are done by the group. If we do this, then PLHIV will be self-sustained. Other things is, that will be a better for treatment linkage. If anyone lost from a place, that person can be tracked from the group by asking other group member" [P18, Male, 38 year, INGO].

The participants also provided a number of suggestions regarding the economic improvement of the PLHIV and their families. These are listed in Table 2:

### Social Aspects

#### Social problems faced by the PLHIV and their families:

The majority of the participants reported that perception of the general population to PLHIV has changed within the last 15-20 years. Nepalese people have increased acceptance of PLHIV, and realised that HIV is a disease like any other. However, the participants agree that there are still different forms of stigma and discrimination (33.3%). PLHIV are discriminated at their home, in their community, in hospitals, in schools, and at the work place. Children in school are discriminated by their friends and teachers (22.2%), sometimes they are removed from their schools (22.2%) or are not enrolled (16.7%). The participants reported that they were aware about such news from the media such as radio, TV, and newspapers. Some of the participants (27.8%) reported that stigma and discrimination is higher in villages than cities. HIV/AIDS is also called 'Bambiya disease' (imported from Mumbai, India) in the villages. Some of the

**Table 2.** Additional themes from participants to improve economic status of PLHIV (Note: 'P' in parentheses means 'participant', therefore, 'P7' means 'participant number 7').

Themes	Responses (participant's ID)
Policy and Plan	Government should focus on HIV bill, should make law and should implement/monitor it (P1, P7), existing policy should be implemented (P17), support priority should be given to needy PLHIV in policy (P10)
	Employment issue should be included in plan (P10), employment quota reservation for PLHIV (P1) or PLHIV should get priority for job (P11)
	Need to provide social support package (P2), provide subsidy or other support (P4),
	Strict law for corruption (regarding budget use for HIV) (P13)
	Prioritise poverty alleviation fund to PLHIV (P18)
	Decentralisation of comprehensive treatment services (P10, P18)
Monitoring	Should get support for treatment (p12)/ support for expensive diagnosis and treatment (P14),
Collaboration between NGOs and Government	Monitoring of programmes conducted by NGOs (P13)
	Training by NGOs/INGOs, and capital support by government (P1)
Treatment and capacity building	Coordinated work with health sector and economic sector (P2), conduct integrated (treatment + income generating activities) programmes in a unified manner (P8, P18)
	Make them capable so that they can sustain (P3)/ provide treatment and make them capable (P5)
Create working environment	Provide working environment (P5), provide conducive environment to return to their own place (P9), keeping or returning them in their original place (village) (P3), stigma and discrimination should be eliminated (P11), PLHIV should not be remove from job (P16)
One Door Service	All programmes should be conducted by government, or all support should go through the government or hospital (P13, P17)

participants (22.2%) reported that PLHIV feel self-stigma and do not wish to attend social gatherings and ceremonies.

A participant said: “.....they are disrespected in society, and they felt inferiority, and they do not want to attend in social activities as uninfected people do. .... due to stigma and discrimination they could not participate with confidence and dignity. Due to that they will feel humiliation, and they get mental health problem, this type of situation exists.....if we look at this social aspect, while looking 5-10 or 15-20 years back, it has been improved a lot. But still the news (related to discrimination) are coming in media. While looking at the social life of HIV-infected children.....They are removed from school, adults are removed from job being HIV-infected” [P2, Male, 50 year, INGO].

PLHIV are still discriminated by health workers in private or government hospitals (16.7%). Some of the health workers do not want to touch HIV positive patients, some of them send such patients to another hospital with a fake reason, and some of them use double gloves and masks although these are not necessary. Some participants highlighted discrimination by health workers in the hospitals or clinics: “While going for treatment, if they say ‘I am HIV positive’, then they are referred to another clinic/hospital by showing fake reasons, (they) refuse providing ART services, such reports also come to us...” [P3, Male, 56 year, Government Official].

“In some cases, if they go to seek treatment services, some of the clinics say that they do not provide health services to HIV positive people. Some of them charge double rate to HIV positive (for treatment) than non-positive. Although they (Health workers) need not to touch their (HIV positives’) body fluid, they use double gloves to touch them. They use double masks, goggles. .... If they know patients is HIV positive, they use everything double” [P11, Female, 32 year, Staff Nurse].

PLHIV are removed from their home, community or village. Some of them are removed from their job if they are known as HIV positive, and some of the families abandon them in hospital if the test result of HIV appears positive. In such situations, NGOs also do not keep the PLHIV of any age in their shelter home because they need a signature from family members to keep them in such shelters.

One participant stated: “Organisations (NGOs) also don’t keep the patient who don’t have family member. This is a big problem. Whether that is male or female, if infected with HIV, family member leaves him/her. .... due to fear, he/she doesn’t go home. He/she feels disrespected, ashamed, becomes mentally disturbed. If no one take him/her, what the hospital does? This is happening...” [P16, Female, 32 year, NGO].

Some of the participants (16.7%) reported that women face more stigma and discrimination than their male counterparts. Although they are infected by their husbands, they are not allowed to enter into, or are removed from, their husbands’ home (P9) and not given their share of parental property after the death of their husbands (P1).

A participant said: “In some family, when their son dies,

they (family members) do not allow their daughter-in-law in their home..... After that, they come to NGOs/INGOs. They do not provide property of their (the women’s) share. It has also been seen..... Victims (women) are often infected from males (husbands), according to latest data. But, daughter-in-laws are not given shelter after son’s death” [P9, Female, 40 year, Staff Nurse].

**Programmes of Government and NGOs/INGOs to reduce social problems:** Government, NGOs and INGOs are mainly conducting awareness raising programmes about HIV/AIDS. The government focuses more on providing HIV training to health workers, whereas NGOs and INGOs are organising most of the awareness raising programmes and events. For example, they conduct events on AIDS day, Condom day, street dramas, radio programmes, stakeholders’ meetings, and HIV orientation programmes.

A participant said: “To reduce the social impacts of HIV, NGOs/INGOs have done different events, such as- AIDS day, Condom day and their own district level programmes such as- awareness programme, street dramas, issue discussion by stakeholders, awareness related to gender/sexuality and HIV-infection by radio programmes, stakeholders meeting, orientation programmes, trainings programmes....such events have been conducted by us- NGOs/INGOs” [P1, Female, 35 Year, NGO].

**Reduction of social problems:** The majority of the participants (72.2%) suggested more awareness programmes in order to decrease social problems, such as stigma and discrimination to PLHIV. They suggested that the programmes should be more focussed in villages, with emphasis on ‘how HIV transmits and how it doesn’t’, as well as provide positive messages to people. It was reported that there is still a lack of coverage and right information about HIV and its transmission.

According to a participant: “..... stigma and discrimination are mainly due to lack of knowledge. We have to sensitise every one about HIV. In the beginning we told people how HIV transmits and now we have to highlight them how it doesn’t transmit, to reduce the stigma and discrimination. Because, if we tell them how it transmits and they don’t know how it doesn’t ..... they remember only how it transmits.... Therefore, this doesn’t transmit like it- say while sitting together in society, while eating in the same plate, while using same clothes, while swimming together, while biting by mosquito .....” [P3, Male, 56 year, Government official]. There were some important suggestions by some participants to reduce stigma and discrimination experienced by PLHIV. The government should listen to complaints of PLHIV, should make PLHIVs aware of their rights so that they can claim the rights, and stricter laws against discriminators should be implemented.

A participant said: “...the HIV-infected people also need to be aware about their rights. If they don’t know about their rights, they can’t claim it. When they became capable, when they know about their rights only then they can claim it. Therefore, the family as well as the person itself need to be empowered” [P1, Female, 35 year, NGO].

Some participants suggested including HIV/AIDS and discrimination in the school curriculum with non-discretionary policy implemented in schools, providing the correct information to the community, and providing examples of famous people who are living as HIV positive.

A participant stated: "These (awareness raising information) have to be broadcasted (through TV and radio) to raise the awareness of the people. These have to be written down in the school curriculum (about HIV and discrimination). These should be included in primary class to higher classes. Only then, they will understand about HIV. This will raise the awareness and there wouldn't be stigma and discrimination" [P16, Female, 32 year, NGO]. Some of the participants emphasized the economic improvement of PLHIV to reduce stigma and discrimination. If PLHIV's economic status improves and he or she lives a healthier life for longer, stigma and discrimination will be reduced.

A participant said: "When you are established, then the stigma will reduce itself.....stigma and discrimination will be there when that person won't have anything. When that person starts earning money, and starts earning a status. Then, the stigma and discrimination reduces itself, or disappears. Therefore, we have to think about how they (PLHIV) can be established in the society. If we make them economically strong, stigma and discrimination reduces. This is not only due to money, but it might be due to his capability after getting HIV. Society's perception will be changed- people will not die due to being HIV-positive" [P18, Male, 38 year, INGO].

## **Discussion**

NCASC, under the Ministry of Health, is a government body which is mainly responsible for control of HIV/AIDS and other sexually transmitted infections (STIs) or diseases (STDs) in Nepal. NCASC mainly works on HIV/AIDS prevention, treatment, care and support [39]. NCASC provides ART medicines from 65 treatment and care centres from different districts of Nepal. They provide free diagnostic tests, such as initial HIV tests, CD4 count, viral load and full blood counts (FBC), as well as other minor services [23]. NCASC provides nutritional support to pregnant women, free food and bed to patients admitted to the hospital, and livelihood support in some districts (10 out of 77 districts) through the FNCSI.

The HIV/AIDS and STI Control Board (HSCB), which is under the Ministry of Health, also lobby with donor agencies to get funding and resources for HIV/AIDS treatment, prevention and control. NCASC coordinates and monitors programmes and activities conducted by NGOs and INGOs and other organisations. In the 'targeted intervention' programmes, NCASC works to prevent new HIV infections by behaviour change communication, condom promotion and distribution, HIV testing and counselling, referral to a range of other services for ART, HIV care and support, family planning and sexual health, STIs and tuberculosis [1,27,39,40]. The targeted intervention programmes mainly focus on 'most at-risk groups' like female sex workers (FSWs), people who inject drugs (PWID), men who have sex with men (MSM), transgender (TG)

people, male sex workers (MSWs), and male labour migrants (MLMs) and their spouses [40].

NGOs and INGOs have also conducted many programmes and activities for HIV prevention, STI case management, HIV testing and counselling, and condom distribution [41]. NGOs are mainly working as a bridge between PLHIV and treatment centres operated by the government. They reach people from lower socioeconomic groups and create demand for health care, allowing the most at-risk groups access to health facilities, increasing awareness among people, conducting prevention programmes, providing home-based care and treatment support, providing shelters to poor PLHIV, and offering food and shelter to PLHIV during the first two weeks of observation period while initiating ART treatment. They also provide counselling services to PLHIV and their families. INGOs bring resources from outside, and conduct programmes and activities with help of government and NGOs.

Although many programmes and activities are conducted in the field of HIV/AIDS by government, NGOs and INGOs, there are still a number of gaps; PLHIV and their families therefore face a number of social and economic problems [10, 12, 42]. Poverty is highest among PLHIV and their families. The reasons behind this include the inability of PLHIV to continue their job (due to illness), dismissal from their job if their HIV status is known, and the fact that they cannot work as before due to loss of productivity [42-45]. In some cases they are provided with lower wages than HIV-negative people [12].

Although medicine and most of the diagnostic tests are available free of charge, all services are not completely free. PLHIV and their families still need to pay a considerable amount of money for their treatment [42]. Distance and geography are other major problems for PLHIV. This either means the PLHIV having to walk for many hours to reach the treatment centres, or having to pay a considerable amount for their transport [42-46]. Other economic problems faced by PLHIV in Nepal include: the lack of employment; the inability to go to other countries as they have to have a routine check-up, and the need to take regular medicine. Some of the families exhaust all their money and properties in the early stage of treatment before diagnosis. This also hinders other income generating activities by PLHIV and their families. There are no insurance facilities available to PLHIV in Nepal. This puts the majority of HIV-affected families at risk of falling into the 'poverty trap'.

The government of Nepal, NGOs and INGOs are mainly focussed on prevention and treatment programmes of HIV/AIDS and little has been done to improve the economic status of PLHIV and their families [12]. There have been some skill development trainings provided to PLHIV. However, the trainings were not utilised due to lack of capital investment to start a business. Therefore, there is a need for a free or low-interest loan to PLHIV so that that can establish their own business.

HIV/AIDS is probably the most stigmatised disease in the world [9]. Although there are a number of awareness raising programmes conducted by government, NGOs and INGOs,

there is still a considerable amount of stigma and discrimination faced by PLHIV from their family, community, health workers, education providers and employers [12, 31, 47]. Stigma and discrimination is higher in villages than in cities, and females are discriminated more than males [48]. PLHIV are sometimes removed from home by family members and sometimes not given their share of parental properties [48,49]. PLHIV are discriminated at healthcare facilities, and children are discriminated at school either by teachers or by their friends [47]. PLHIV need to leave their villages, either due to self-stigma or due to discrimination from their community. School education is not enough to protect children from HIV as well as discrimination associated with it. A study by UNESCO in Nepal states, "Very little attention is given to incorporate and update healthy lifestyle messages in primary education, nor comprehensive life skills and HIV and AIDS education in tertiary education" [50].

Travelling far for treatment due to self-stigma was also found. Removal from job and not providing job if their HIV status is known by employers are major forms of workplace related stigma the PLHIV face. All these stigmas and discrimination have been reported in different studies in Nepal [11, 12, 42, 47]. Some of the stigma and discrimination are directly related to reduction of economic capacity of the PLHIV or their families. For example, not having a job or being removed from their job, being removed from family or not having access to parental property, travelling far from home for treatment due to self-stigma, leaving their village due to self-stigma or discrimination by villagers, removing children from school or not allowing them to enroll; these are related to either reduction of economic earnings of the PLHIV in the short run, or future earning capacity of their families (children) in the long run [12]. Thus, the social and economic components are interrelated with each other.

Although the treatment facilities in Nepal are said to be 'free', they are not completely free. The PLHIV still need to pay themselves for diagnostic tests, such as MRI and CT scans, as well as medicines for many opportunistic infections, which are not accounted as free medicines. Some NGOs and INGOs are supporting the poor PLHIV for their diagnostic and treatment services. However, this support is not available to every poor PLHIV. Some of the private hospitals take double charges for treatments such as operations or surgeries, whether these are major or minor. The Government of Nepal needs to investigate on this serious issue and need to act on it as soon as possible. Costs of transportation due to remoteness of residence was also a reason for higher treatment charges. Therefore, PLHIV are experiencing economic burdens for their treatment. Most of the PLHIV are already poor; middle-class PLHIV also sink into poverty due to loss of productivity, treatment costs and other reasons. PLHIV who live in far-western regions (Karnali zone) are in very desperate conditions, as they have access to medicine but do not have food to eat. An empty stomach needs food before medicine. The government, NGOs and INGOs therefore need to focus in such remote areas where food is more important than medicine, which is, in fact demands for more food production and increased earnings of PLHIV and their households. There is

no proper policy in place to improve economic status of PLHIV and their families, as all the organisations working in the field of HIV/AIDS (GOs, NGOs and INGOs) mainly focus on prevention and treatment of HIV/AIDS. In Malawi, emphasis has been given on implementation of policies to promote rapid initiation of ART, with weaker implementation of strategies to promote retention in care (e.g. adherence monitoring, home-based care) [51, 52]. A similar finding has been reported for Uganda where policy adoption and implementation have been progressive for HIV testing, treatment, and prevention of mother to child transmission (PMTCT), but often lacking in relation to retention in care [52, 53]. The National Agency for the Control of AIDS in Nigeria (NACA) has produced their own HIV/AIDS stigma reduction strategy, in order to end the epidemic by 2030 [54]. Nepal also needs similar strategies to tackle social problems experienced by PLHIV.

Income generating programmes for PLHIV are profoundly lacking, leaving poor PLHIV in the worst situation. Although the Nepalese Government has provided some skill development training, such as driving, and income generating activities for PLHIV families in some districts through the FNCSI, their coverage is very limited. There was no support from NGOs and INGOs to improve the economic status of PLHIV and their families. Only a limited number of NGOs were trying to establish small businesses (such as printing presses and agricultural farming) to provide employment to PLHIV, skill development training (such as beauty therapy, security/protection, and sewing). The skill development training which needed capital investment was ineffective as it lacked capacity for capital investment. Therefore, they have had a very limited impact.

There are more problems in remote rural areas than in cities, and more problems faced by females than males. There is still existence of a considerable amount of stigma and discrimination towards PLHIV by their families, societies, teachers, friends, employers and health workers, even though a number of awareness programmes have been conducted by different organisations. Self-stigma is also prevalent among PLHIV which hinders use of treatment facilities close to their home, not allowing them to stay and work in their own village, or participate in different social gatherings.

There is a lack of implementation of discriminatory law from the government. The coverage and content of awareness programmes were found to be incomplete and insufficient. There is lack of policy regarding the discrimination of children at school either by teachers, fellow students, or by school administration. Although there is 'national policy on HIV/AIDS in the workplace', it has not been implemented effectively. Although training is provided to health workers, PLHIV are still facing discrimination from health workers in government and private hospitals or clinics. The monitoring of projects and programmes conducted by the government and NGOs show them to be less effective. Availability of limited resources for HIV/AIDS is also hindering availability of services to PLHIV.

## Conclusion

This research concludes that PLHIV are still facing a number of social and economic problems in Nepal. There is an extreme lack of economic support programmes to improve economic status of PLHIV and their families so that they can live a decent life. Based on the findings of this study, the following conclusions and recommendations are made to the GOs, NGOs and INGOs working for PLHIV in Nepal to improve their socioeconomic status:

- The government should prepare a policy to improve economic status of PLHIV and their families. Criteria should be made based on poverty status of PLHIV while selecting the necessary support;
- Skill development training, along with a free or low-interest loan to the PLHIV or their family members, should be provided by GOs and/or NGOs to utilise their skills to look after themselves and their families;
- A need, interest and feasibility study should be conducted by GOs and or NGOs before starting any programmes or activities to enable their success;
- A programme of economic microfinance in the village or town where PLHIV and other people with similar problems (chronic illnesses) live should be implemented by the Government to provide support as a seed capital for investment;
- NGOs or other CBOs should be supported by government and donors to increase employment generation for the PLHIV or their family members;
- Social support packages should be provided by the government to those PLHIV who do not have anyone to look after and don't have any property;
- A biometric card system should be implemented by the government so that PLHIV can get necessary services from anywhere in Nepal, which can also help to monitor the services obtained by them;
- Although there are 65 treatment centres in Nepal, there is a lack of comprehensive treatment facilities available to PLHIV in most of the treatment centres. Therefore, there should be decentralised comprehensive treatment services provided by the government to PLHIV in each treatment centre;
- Treatment services should be integrated with other social and economic support for PLHIV as a cross-cutting issue to improve PLHIV's socio-economic status;
- The 'HIV Bill' (which is already prepared) should be forwarded for approval so that every person with HIV/AIDS can protect themselves, get support if necessary, as well as feel safe physically, socially and economically;
- A safe environment in villages should be created by GOs and NGOs for PLHIV so that they would not need to live in a vulnerable conditions, or in a new place where they have very limited livelihood options;
- Stigma and discrimination have been reduced in the recent years. However, still they are considerably high in villages. Therefore, awareness raising activities and programmes by GOs, NGOs and/or INGOs should be focused in villages by covering issues such as how it is transmitted and how it isn't, how to treat (or behave with) PLHIV, what are the rights of PLHIV, etc.
- Current 'non-discriminatory policy' and 'National policy on HIV/AIDS in the workplace (2007) [55] should be fully implemented effectively by the Government of Nepal;
- There should be a separate policy related to 'school and HIV-affected children' to reduce education-related discrimination to HIV-affected children;
- Ethics in hospitals and health care facilities should be updated and implemented so that treatment costs and discrimination in such places can be reduced;
- The government should build a hospice to keep those PLHIV who are abandoned or who do not have any family members to look after them, because they are the most vulnerable people;
- Women's property rights should be reviewed so that they are not be deprived of getting their share of property, either from their husband or from their family, due to their HIV status;
- PLHIV's rights should be clearly written in government policy so that they can claim the rights if necessary;
- 'HIV/AIDS, PLHIV and their rights' should be included in the school curriculum at a certain class level so that future generations will be more aware about HIV/AIDS and will not discriminate PLHIV, and
- Supportive programmes (as mentioned above) by GOs, NGOs and/or INGOs should be implemented to improve the economic status of PLHIV to elevate their status in their society, so that discrimination towards them is reduced.

Finally, collaboration and cooperation among all stakeholders working in the field of HIV/AIDS is necessary to improve socioeconomic status of PLHIV and their families, to reduce new HIV-infection, to improve care and treatment of PLHIV, to extend life of PLHIV, and to improve their quality of life. Therefore, the government of Nepal should play a leading role in the fight against HIV, as well as HIV-generated social and economic problems. It should lobby with donor agencies for more budgets, and should increase the budget on HIV/AIDS to resolve social and economic problems faced by PLHIV.

## Study Limitation

This study was conducted only in Kathmandu valley, Nepal. Therefore, the results of the study may not be generalised for whole Nepal.

## Acknowledgement

The authors would like to thank all the participants who

gave their valuable time and information for this study. We would also like to thank the Organization for Nepalese Culture and Welfare (ONCW) and Liverpool John Moores University (LJMU) for their supports to conduct this small but important study. We would also like to extend our sincere gratitude to those individuals who have helped directly and indirectly to complete this study successfully.

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