

## **Research Article**

# **HIV Stigma and Discrimination Management in Pokhara, Nepal**

**Ram Prasad Aryal**

Faculty of Humanities and Social Sciences

Pokhara University, Pokhara, Nepal

Email: aryalrampd@yahoo.com

## **Abstract**

*Stigma and discrimination attached to Human Immuno-deficiency Virus (HIV) and Acquired Immuno-deficiency Syndrome (AIDS) are not new issues in Nepal where the issues are often considered to be the outcomes of either extra-marital sexual activities or sharing needles for drug use with people living with HIV (PLHIV). These activities are considered to be outside norms and values of Nepalese societies. Consequently, PLHIV are stigmatized and discriminated against in family and society. There are number of studies on stigma and discrimination attached to HIV and AIDS. However, there are very limited studies on management of HIV stigma and discrimination in Nepal. Therefore, this paper aims to look at HIV stigma and discrimination in general with a view to contextualize these issues, and to examine management of HIV stigma and discrimination in particular after being HIV diagnosed. This study follows qualitative research approach, face to face in-depth interview with 16 PLHIV in Pokhara during the period February-March 2017. This study investigates ways the participants have been able to manage their HIV stigma and discrimination in a greater extent at present with their own individual rigorous efforts, and supports made by local body and organizations/hospitals working in the field of HIV and AIDS as well. This paper has important policy implications, especially in the management of HIV stigma and discrimination in Nepal and other countries with similar socio-cultural contexts.*

**Keywords:** Discrimination, HIV, management

## **Introduction**

This paper follows theoretical framework from the original idea of Goffman's stigma and its strategic management as this framework focuses on social stigma and discrimination (Goffman, 1963). His theoretical framework is still applicable in the field of stigma and discrimination in terms of culturally sensitive issues of health (Carnevale, 2007). At present, practices of giving HIV knowledge and treatment to PLHIV, launching stigma and discrimination reduction programmes, and organizing their social network that have made PLHIV gradually feel reductions in stigma and discrimination in their lives in recent years (UNAIDS, 2015; Stangl, 2010). This study on HIV and AIDS is very important in attaining fast track goals as set by UNAIDS (2015: 4):

*UNAIDS is calling for new Fast-Track targets, which will enable us to focus on where the results can and need to be achieved: stepping up HIV treatment through 90-90-90 targets (90% of people living with HIV knowing their HIV status, 90% of people living with HIV who know their status on antiretroviral treatment, and 90% of people on treatment having suppressed viral loads), and reaching ambitious prevention and stigma reduction targets.*

HIV was identified in Nepal in few people in 1988 and the number of HIV reported cases have increased steadily. There are four major modes of HIV transmission, hetro/homo-sexuality, sharing needles for drug use with PLHIV, parental transmission, and blood transfusion, in the country. An overwhelming majority of PLHIV have been HIV infected due to sexual intercourse, irrespective of hetro-sexuality or homo-sexuality. Internal and international migrations are attributed to increasing number of HIV cases, especially after introduction of multi-party democracy in the country in 1990 (KC, 2004; Joshi, Banjara, Subedi, Sharma, & Karki, 2004; Nepal, 2007). Thereafter, Nepal government emphasised on foreign labour migration to reduce unemployment situation in the country after being Nepal as a multi-party democratic country. Such migration resulted into an increase in HIV infections as a few numbers of emigrants have been HIV

infected due to unsafe sexual behaviour during their stay outside the country (Aryal, 2015; Aryal, Tiwari, Thapa & Pandey, 2011). As of July 2016, there were 28,865 reported cases across the country (National Centre for AIDS and STD Control, 2016). More than three-fifths of the total PLHIV are males in the country and the corresponding figure for females is nearly 40 percent.

HIV is considered as the outcomes of homosexuality, extra-marital heterosexuality, drug using habits that are outside the norms and values in Nepalese society. Consequently, HIV is associated with stigma and discrimination in Nepal (Beine, 2002). However, a general analogy could be made with regard to PLHIV who are living in urban areas are more likely to have access of HIV knowledge and treatment, HIV stigma and discrimination reduction programmes, and other such programmes conducted by government and non-government organizations as these programmes in Nepal are often urban oriented. In this sense, this research focuses on studying the lived experiences of PLHIV in terms of their stigma, discrimination and their management. This paper is intended to identify positive factors that reduce HIV stigma and discrimination after being HIV positive in the Nepalese socio-cultural contexts. There is a very limited research on management of stigma and discrimination with regard to PLHIV, especially in the context of Nepal. Although there have been undertaken some studies related to HIV and AIDS, they have been done from merely positivist approach (quantitative aspects) in which people do not have chance to express their heartfelt experiences. Therefore, this study is important in fulfilling the research gap, capturing the lived experiences of PLHIV on their stigma and discrimination management using qualitative research approach.

### **Data and Methods**

This paper follows a qualitative research approach with a view to examining the lived experiences of stigma, discrimination and their management in PLHIV in the Pokhara, Nepal. This is one of major cities affected by HIV and AIDS in the country. There is a dearth of research

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among PLHIV in the city on stigma and discrimination management though some other studies on HIV and AIDS have been conducted by various organizations/institutions (such as New Era, 2009) from epidemiological perspectives. This research aims to undertake a deeper understanding of the lived experiences of PLHIV. The research area of HIV and AIDS in Nepal is regarded as culturally sensitive issue (Nepal & Ross, 2010). The field work was carried out for data collection through hospitals and organizations, maintaining confidentiality of 16 participants by using their pseudonyms during the period February-March 2017. With an understanding of qualitative research, this study utilised a semi-structured questionnaire with a framework of various themes to be explored, drawing on the lived experiences of research participants (Bryman, 2012). Ethical approval was gained from Pokhara University Research Centre (PURC) and Institutional Review Committee (IRC), Pokhara University. After completion of data collection, the field data were translated from Nepali into English. This study used a thematic analysis, examining the responses provided by participants in the research field (Braun & Clarke, 2006). The field data were analysed using a meaning-making approach based on socio-cultural understandings of the Nepalese society.

## **Results and Discussion**

### **Results**

#### Stigma and Discrimination

Some PLHIV, especially males, have been stigmatized and discriminated in both family and society due to their sexual behaviour outside marital union. In general, PLHIV who were HIV infected due to sexual behaviour outside marital union are often stigmatized and discriminated at home and in their society. In this regard, one of male participants, who was HIV infected around eight years ago, shared his experiences on stigmatization and discrimination in his family and society like this way:

*Villagers do not want to be close with me, thinking of disease [HIV] transmission. They say that they do not eat feast at any party at my*

*home...My children and wife do not behave me well like before [Prior to HIV infection]. They do not prefer me to stay at home. It is also okay for me to stay outside home. It does not matter as it is necessary to work for livelihood anywhere else.*

He also shared his experiences on how he was HIV infected while working in India, outside the country like this way:

*When my friends proposed me to visit somewhere else for entertainment, I told them not to go anywhere else. They insisted me to go and drink wine, a little bit far from my place of residence. I said to them, "I do not drink [wine]". But I was insisted. We drunk wine. Then, they told me to go to their room [friends' place of residence]. They insisted me telling, "Let us go, cook and eat meat and fish". We reached there and found that there were such persons [commercial female sex workers]. They said to me, "They are our own relatives and you do not have any problem [HIV transmission]". I added that there have been problems [HIV transmission and its effects on stigma and discrimination]. They repeated me that I did not need to be afraid. Then, I had sexual intercourse.*

In this study, many PLHIV, both males and females, feel stigma after being HIV diagnosed and do not want to disclose their HIV status to their family and society. One of females living with HIV, uttered that she felt deep stigma when she was identified as being HIV positive in the course of giving birth to her baby at hospital. When doctors and nurses came to her and told her HIV positive status after her blood test, she tried not to disclose her HIV status. She shared her experiences with regard to stigma like this way:

*They [doctors and nurses] convinced me so much about the situation [HIV diagnosed]. They made me aware of the situation. I cried a lot that time, but what I should do. Things happened already and I could do nothing for the situation. After all they asked me to call the nearest relatives. I told them [nurses] to call my father*

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*[father in law] because if mother came to know about this she would tell to everyone but father would not tell anyone. So, in my mind father [father in law] came at once. After that I called my father [father in law] ... I felt so sorry for myself. I thought, "If someone knows about me, they will hate me. Now, I think I don't have anything to live in this world. My life is empty. What can I do although I am alive? There is no meaning of my life".*

Likewise, another female living with HIV, expressed her stigma by not disclosing her status to other people except her mother in law at home in this way:

*They [neighbours and other people] still don't know it [HIV]. My husband told me not to tell them. If my husband died before telling to relatives, the situation would be worst. So I have told about our disease [HIV] to mother-in-law. Several times we have gone to take medicine, informing mother-in-law. Many years ago my husband became very sick. So, I have told her about this. But others are not informed about it.*

In this study, a few PLHIV, especially females, shared their experiences on family, societal and institutional discriminations. Some PLHIV, especially females, were discriminated at home. In this regard, one of female participants, who was separated from home, could not stay with family members due to HIV and had to be away from her husband's home. Even her son and daughter scolded her to go away from her family. She uttered her experiences of family discrimination like this way:

*When family members knew about me [HIV status], they quarrelled with me. My son and daughter scolded me. I also told them I did not need you. I did a lot of struggle to grow you up. I decided to leave the family and to go out. I left home, reached there [A Place], and worked in road construction site...When I spent outside home for few years, separating from family, I would have such behaviours [sexual intercourse].*

Likewise, a widow female living with HIV has faced societal and institutional discrimination after being HIV diagnosed. In regards to discrimination made by her neighbours, her comb was anonymously passed on to others in her village. She came to know that her neighbours did not use it to comb their hair, thinking that HIV could be transmitted from that comb. Likewise, her son did not have an opportunity to study in school because of her HIV positive status though her son was not HIV infected. She shared her experiences on discriminations like this way:

*I heard one of my villagers threw away my comb that I used because of my HIV status. They thought that HIV could be transmitted from that comb. My elder son stopped studying because villagers used to say his father [her husband] died due to HIV positive. While going to school also, everybody began to tell such things. His friends used to discriminate him and did not want to stay together on same bench. They did not want to play together as well. They even used to tell the teacher to give him torture, physical punishment and so on. So, my son left study after completing class VII.*

She also shared another institutional discrimination she faced while going to hospital for her daughter's treatment like this way:

*Once I went to hospital with my daughter as she was suffering from fever. There was a heavy crowd of people at hospital. I was one of PLHIV but my daughter is not infected with HIV. As soon as my turn came, doctor put gloves in both hands even though he was already informed that my daughter is HIV negative. I felt so bad in this case. Doctors know that HIV does not transmit by hands. Furthermore, they didn't have to check up me, but for my daughter. In that condition I felt so much pain in myself. They have already known that my daughter is not HIV positive. Hence such action made me so sad because they were treating a large number of people without gloves. This was one of the misbehaviour shown by doctor to me.*

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### Management of Stigma and Discrimination

Many PLHIV have concealed their HIV status to protect themselves from stigma and discrimination. They have been able to perform their responsibilities without disclosing their HIV status. For example, a married female participant who has been living with her family where father and mother in laws also stay, shared her experiences of stigma management. When her PLHIV friends living with HIV want to come her home, she avoids such visit from her friends, thinking of relatives and neighbours may guess about her HIV status like this way:

*Sometimes friends [PLHIV] make a field visit at the interval of 15 days. I suggested them not to come [her home]. After that they have not come too. I told them such things because if there are other people like me then they [relatives and neighbours, HIV negative] will obviously guess me [HIV positive]. Everybody [among PLHIV] will know about my problem. I told them not to come rather if any problem arises I would call them. I also told them to provide their contact numbers. After that no one visits our home.*

Sharing lived experiences after being HIV diagnosed among PLHIV seems to be a way of reducing stigma, and it also provides an opportunity of transcending their relationship with each other. PLHIV can enjoy sharing their experiences of HIV and its related issues of stigma and discrimination with their friends living with HIV. It enhances their HIV knowledge and importance of having medicine to prolong their life span. For example, a female participant shared her lived experiences like this way:

*We are given chance to meet friends like us who have been living with HIV. At one of organisations in Pokhara, a sister who cooks food for us is also HIV positive. She consoles me not to take any tension. I am very happy with her and her friends [PLHIV] when I go there [Pokhara]. We don't have to take care of taking food item and can take anything as per our wish. The thing is that we have to take medicine regularly for life time. We can also stay alive as long as that of HIV negative people. This made me very much happy. We*

*have to take medicine daily and don't have to do anything else [refraining from any food item]. We remember such things and take medicine daily.*

Family cooperation and consoling to PLHIV in their family seem to be a conducive environment to stay in their family. Of course, family cooperation makes PLHIV comfort to cope with challenges related to HIV stigma and discrimination outside their home. One of female participants, whose husband died due to HIV, shared her experiences on how PLHIV's family members cooperate her with regard to HIV in this way:

*Luckily, my children don't say anything. Brother-in-law, sister-in-law, and mother-in-law also don't say anything. If they told me bad or hated me, I would feel bad and nervous. They tell me, "Although you have HIV, don't feel so. Do your work, earn for children and sustain your life. It does not matter even though you are HIV infected".*

She further makes clear about importance of HIV medicine and HIV knowledge like this way:

*Previously there was no ART [Anti-retroviral Therapy]. Medicines were also not available. Nowadays there is medicine available. So PLHIV can also work like those normal people [HIV negative people]. If there was no medicine for this disease [HIV], I would also die. Next thing is that people previously had a lot of misconception about HIV. They even thought that mosquito bite could cause HIV transmission. But nowadays they know HIV does not transmit due to this [mosquito bite]. They have knowledge about how HIV gets transmitted. They are aware about this matter. I hope so. They don't hate us nowadays. Brothers-in-law are aware of this matter. So they do not ignore me and hate me. We stay together, eat together and work together. Family members don't take it too much seriously.*

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Many PLHIV have been feeling an inner strength emerged gradually that they are like other HIV negative people, which helps them being felt of reducing self-stigma in a greater extent. When they are able to manage their self stigma with an increasing HIV knowledge, they turn into their responsibilities of rearing children. In this regard, one of female participants shared her experiences as follows:

*Previously I also had willingness to die. But nowadays I don't feel so. I think I have to live for my daughter and son. They are already grown up. I don't feel I have HIV nowadays because I can work like normal people [HIV negative people]. From the last Mangsir [November/December], I started having ART. It has already been one year. Before starting ART I didn't have any problems also.*

Stigma and discrimination attached to HIV depend upon their contextual background of society whether societal people have their knowledge on HIV and AIDS. PLHIV who stay in such a place, where many HIV negative people have HIV knowledge, have not been stigmatized and discriminated in their society. It also depends upon individual physical ability and skills to work with other people living in the society. In this regard, a male participant shared his experiences on stigma and discrimination that he never faced such problems in this way:

*In my society, many people know about me. We have our own Kshetri (one of major castes in Nepal) society. My house is in the district [A district]. Although many people know everything [HIV] about me, they don't hate me. Somebody doesn't still know that I am HIV positive. Sometimes, at village, we cut goat. We always stay together, eat meat and enjoy. Sometimes we together drink wine. Villagers request me to stay with them, eat together and go home. They don't separate me. I am very happy with their behaviour.*

## **Discussion**

In general, degree of HIV stigma and discrimination differs from physical health and earnings. PLHIV who are physically active and can gain their earnings themselves; they are not discriminated in their family and society. In this study, even PLHIV aged 60 years and above who have been working in his farmland equally as his previous ages prior to HIV diagnosis, have not been discriminated against in family and society. Some of PLHIV have worked in their farmland even in old ages in addition to their pension. In such households, neither individual living with HIV nor his/her family members have disclosed their family member's HIV status to their society with a view to maintaining confidentiality. Consequently, such PLHIV have not faced stigma and discrimination in family and society due to HIV as stated in Goffman's stigma theory (1963), and Parker and Aggleton's conceptual framework (2002). In contrast, PLHIV who are weak physically and can not contribute to their family economically; they have been heavily discriminated against in family. In the cases of females who were more likely to be HIV transmitted due to sexual intercourse outside marital status, even their children have scolded such females heavily and have not allowed them to stay together in the family. Likewise, some of males who were HIV infected due to sexual intercourse outside marital union were also not treated well like prior to HIV diagnosis. Thus, how PLHIV have been HIV infected are also matter of concerns with regard to degrees of HIV stigma and discrimination in Nepalese society.

PLHIV who have been discriminated at early stage of HIV positive, immediately after HIV diagnosis, in family and society have been able to manage their stigma and discrimination well at later stage by applying various strategies such as migration, economic independence, hiding and disclosing HIV status, and social service. In this study, migration has been chosen as a better way of managing stigma and discrimination as well as becoming economic independence. Likewise, hiding HIV status in society is another way of managing stigma and discrimination by not disclosing HIV status to anyone outside home, even discouraging other PLHIV who wish to visit home, thinking of that other neighbours would guess about HIV. PLHIV have managed their livelihood, either working in their farmland or becoming service holder or both. This has supported them

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being economically independent and managing stigma and discrimination. Some PLHIV have also served as social worker to help other PLHIV who do not have HIV knowledge and treatment through various organizations working in the field of HIV and AIDS.

## Conclusion

This paper concludes that economic independence is one of major ways of managing HIV stigma and discrimination in Nepalese society while going through life history of each participant in one or other way after being HIV diagnosed. PLHIV in this study have managed their stigma and discrimination by applying various strategies in which economic independence seems to be interlinked with most of other strategies they adopt in their lives.

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