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Assessment of Healthcare Utilisation among Nepali Migrants Living with HIV/AIDS in Mumbai, India

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Abstract: Mumbai being the number one metropolitan city of India is a major recipient of migrants from within the country and also from the neighboring countries especially from Nepal(UNAIDS 2001). More than 5% of HIV/AIDS prevalence among high-risk groups, labor migrantion from to high-risk locations in India is one of the challenges(Nepal HIV Estimates 2003).This paper focuses on the level of medical care, adherence and barriers to care and treatment among Nepali Migrants Living with HIV/AIDS. Quantitative and qualitative approaches have been adopted to elicit more information about the different aspects of healthcare utilization among Nepali migrants. The universe of this study is Nepali single, male migrants in the age group of 18 to 50 years in the city of Mumbai. Purposive and Snowball Sampling was used on the basis of the characteristics of the population.The factors like the area of residence, type of occupation, management of health institution, absence of identity proof and absence of the caretaker in the hospital are important barriers to care and treatment. This study suggests that the Government should focus on the improvement of healthcare utilization policies for the easy access of services for migrants in India.

Keywords: Nepali migrants, HIV/AIDS, Healthcare utilization, Adherence, ARV treatment.

Introduction

Mumbai being the number one metropolitan city of India is a major recipient of migrants from within the country and across the country especially from Nepal. Migration and HIV/AIDS are well established global phenomenon; migration is one of the causes for the spread of HIV virus (UNAIDS, 2001). In fact, in the present scenario, it is increasingly identified that the migrant population is more vulnerable to HIV/AIDS than the non-migrant population. Therefore, there is a need to focus on the interlinks of migration and HIV/AIDSspecially on the aspects of healthcare utilization of migrants living with HIV/AIDS. It has been observed that in the western far zone of Nepal HIV/AIDS is known as Mumbai diseases (Karkee and Shrestha, 2005). It is also found that HIV prevalence among labor migrants primarily to cities like Mumbai in India is higher, and when they return to Nepalhave spread the infection among the women folk in some districts of far west Nepal. HIV/AIDS is a serious health concern in Nepal. With more than 5% of HIV/AIDS prevalence among a high-risk group, labor migrants to high-risk locations in India is one of them. It is one of the challenges for policymakers and programmers to prevent the spread of infection to the general population (Nepal HIV Estimates 2003). According to a survey in the far western district Kilali of Nepal, it has been noticed the HIV infection found among

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those who migrated to Mumbai was 6.1% (New Era, 2006). Moreover, a report of the Integrated Bio-behavioral Survey of 11 districts of far west and mid far west of Nepal found that prevalence rate of HIV was 5.1% among migrant returnees who have visited Maharashtra in India and 1.4% who have not been there (Integrated Bio-behavioral Survey, 2006). All these surveys show that Indo-Nepal migration is a common phenomenon. Nepali migrants are into high-risk behavior, they are getting an infection of HIV in India mainly in Mumbai and it spreads into Nepal in some of the districts of western, far western and mid-far-western zones. Therefore, it is important to study the level of healthcare utilization among HIV positive Nepali migrants in Mumbai and the hurdles in the healthcare utilization for Nepali migrants living with HIV/AIDS in Mumbai.

In a transnational world with a free flow of labour and capital, there is an increase in cross-border migration. In the recent past, there has been a growing flow of labour into India particularly from Bangladesh, Nepal, Pakistan, Sri Lanka. Interestingly, it is in this region that the rise of HIV has turned into an epidemic and a major public health concern. According to UNDP (2010), it is estimated that in South Asia alone that there are 2 to 3.5 million people lived with HIV AIDS. Globally, it is estimated that there are 33.3 million people who have been adversely affected by this endemic. In a paper titled, 'Vulnerabilities of Movement: Cross-Border Mobility between India, Nepal and Bangladesh,' Samuel et al (2011) argue that mobility by itself is not be considered a vulnerability for HIV occurrence but the conditions under which certain migrant groups from lower socio-economic backgrounds live and migrate make them most susceptible to the deadly infection. Multiple studies on the association of and various linkages between migration and HIV incidence have been conducted. Mukherjee and Danje (2006) suggest that there is a strong rationale for the migrant-HIV association. The process of migration needs to be understood. Migration often results in the disintegration of the family unit. In the event of male migration, the male member gets separated from his spouse. The male migrant is usually in reproductive age and is sexually active by choice and travels without a spouse or his regular partner. This combined with poor living conditions, working conditions and witnessing risky sexual behavior (RSB) of fellow male migrant members predisposes migrants to seek sexual activity, often with commercial sex workers (CSW) (Mukherjee and Danje, 2006).

Economic migrants face many barriers while accessing health care in a foreign country. These barriers are both due to socio-economic as well as socio-cultural reasons. Given their 'foreign' status, at the local level, these migrants face discrimination or even harassment. Further, migrants in some cases may be under a constant threat of deportation. Financial limitations too exist when it comes to accessing private health care systems. If the migrants are undocumented the problems, see a manifold increase. In terms of state policy, there is a question of health insurance and without this there is a catastrophic financial burden on the migrants. Within the health system, many barriers are about overcoming bureaucratic obstacles and these include completing paperwork and becoming part of registration systems. There are very few alternative care systems available and these were usually private models and that was exorbitantly pricedand well beyond the financial means of migrants. There also exists evidence of widespread discriminatory practices within the health care system itself. The individual-level focused on the immigrant's fear of deportation, stigma, and lack of capital (both social and financial) to obtain services. Many human rights and health rights advocates have studied the situation and some of the recommendations identified were in the papers reviewed included advocating for policy change to increase access to health care for undocumented immigrants,

providing novel insurance options, expanding safety net services, training providers to better care for immigrant populations, and educating undocumented immigrants on navigating the system (Hacker, Anies, Folb, and Zallman, 2015). This study focus on healthcare utilization and the factors which delay the care and treatment of the Nepali migrants living with HIV/AIDS in Mumbai.

Data and Methods

This study is a mixed-method in nature, primarily based on quantitative approach. The attempt is to understand the challenges faced by the Nepali single male migrantsin the age group of 18-50 years, who are affected and infected with HIV/AIDS and taking treatment in Mumbai. These challenges are mainly pertaining to the care and treatment utilization pattern of the same. Therefore, the quantitative method is best suited to present and portray the distinctive knowledge of the frequency of utilization which is being expressed in measurement. In addition, qualitative methods in the form of Focus Group Discussions were carried out to understand the experience of the respondents while availing care and treatment and the meanings they ascribed to their health condition as put forth by them. At the time of the interviews, they were either on duty or living in the community or though not on duty but still at the place of duty because the living arrangement is made by the employers which are attached to the place of employment or in the premises of the place of employment. The intention behind this is they can also utilize their services on the day of the holiday. Since they are single, at least they can occupy one person. Therefore, there were multiple sites of identification of the respondents. It was decided that the study would be located in the city of Mumbai and its suburbs. Since the study includes the Nepali male migrants in Mumbai, such groups could be available in the sites of residential societies, buildings or restaurants. This approach would involve the mapping of the locations of the residential societies, buildings, restaurants as well as Chinese corners of the city. For arriving at the challenges of healthcare utilization, the structured interview method was used with some open-ended and close-ended questions.The interview schedule was developed based on the research questions, the objectives, a review of the literature and the researcher's experience of work with Nepali migrants PLHA (People Living with HIV/AIDS). Purposive and Snowball Sampling was used based on the characteristics of the population of Nepali migrants who are HIV positive.

Approximately a total number of 500 were registered in all till June 2008, at the end of the project. These were registered cases from Mumbai. 20% of this is around 100 cases. Based on the sampling frame, it was decided to interview 50 and to conduct Focus Group Discussions for the rest of the respondents. To arrive at the profile concerning socio-economic and living conditions and healthcare utilization patterns of the respondents and their challenges, all these calculations dependent on the availability and willingness to participate in the study and the rapport developed with the respondents.

The following routes were attempted for approaching respondents

1. One, taking the help of Nepali migrants who were working with and for PLHA as a staff of NGOs who are associated with the respondents as a friend or they might have helped the respondents earlier.

2. Taking the help of respondents who have already been interviewed and who happen to know the other respondents.
3. Directly approaching the respondents by making phone calls if that was made available to the researcher by any such staff of NGO or the relative of the respondents.
4. By making home visits with the prior permission of respondents.

No names of respondents have been mentioned in the research to maintain confidentiality and also the identities of the respondents and key informants are not revealed as the assurance is given by the researcher. The oral consent has been given by the respondents to agree for the interview.

The quantitative data collected in this study was obtained through structured interviews with 50 samples which have led to developing the profile of the respondents and receiving the data of the migration details, healthcare treatment, details of institutional care, details of self-care and home-based cared. This data was analyzed through the SPSS software and frequency and cross-tabulation emerging from this analysis have been interpreted to suggest the findings. For Focus Group Discussion the dialogue was considered as the basis of analysis and the responses received were linked to answer research questions and objectives.

Results

Healthcare Utilization and the Issue of Adherence

The majority of the Nepali migrants were taking treatment in the public healthcare institutions and very few that are $1/10^{th}$ were taking treatment in the private healthcare institution (Table 1). Those who were taking care of the public healthcare institution they were referred by NGOs. Because these NGOs had a collaboration with public health institutions. The migrants who come into contact with such NGOs were taking treatment in the public healthcare institution. Those who were taking treatment in private healthcare institution they had the fear of disclosing their status. They assumed if they go to public healthcare institution then their other Nepali colleagues will come to know their status and through them, their family members will come to know about their HIV positive status. Secondly, they also felt that in public healthcare institutions they had to wait for a long to take a treatment therefore they preferred to take treatment in private institutions. The majority of them were taking treatment for some months and less than $1/10^{th}$ taking treatment for some years. It could be a positive sign that the majority of them were living in Mumbai for 5-10 years but the treatment has started from the last few months, days or weeks. It means the duration of treatment was relatively less than the duration of stay.

The majority of the respondents were very particular about the CD4 checkup (Table 2). Therefore, there wasa high level of utilization in the CD4 checkup. There was also a high level of regularity in CD4 checkup and the lowest number of migrants did not check regularly but it was essential to have 100% regularity in CD4 checkup since CD4 is a very important component for the patients of HIV/AIDS, because it affects the viral load and immunity of the patients.

Table 1: Medical care for Nepali migrants with HIV/AIDS

Visits to Healthcare Institution	Percentage
Private Healthcare Institutions	10
Public Healthcare Institutions	90
How long had this usual source of care	
Days	10
Weeks	14
Months	58
Year	18
Frequency of visit to health care provider	
Monthly	82
Once in a two month	18
Visit healthcare providers other than the usual source of care	
Yes	10
No	90
N	50

Table 2: Written Information of the CD4 Count Check-Up of the Nepali Migrants Living with HIV/AIDS

Details of the CD4 count percentage of Nepali Migrants	Percentage
Checked regularly CD4 counts	
Yes	96
No	4
How much regular in CD4 count	
NO	6
Less than 6 months	6
Every 6 months	88
Last CD4 count	
More than 500	46
500 and more	32
Don’t remember	22
Lowest CD4 count of all	
less than 500	26
Less than 200	64
Less than 50	4
Don’t remember	6
Most recent CD4 count	
200 - 499	5
More than 500	36
Don’t remember	8
N	50

Table 3: Detailed Information of the ARV Treatment of the Nepali Migrants Living with HIV/AIDS

Utilisation of ARV treatment	Percentage of Nepali migrants taking ARV treatment
Details of ARV treatment	
Yes	92
No	8
When started ARV treatment	
Months	30
Years	62
No	8
From where are you taking treatment:	
Private	8
Public	88
Ever missed or stopped ARV treatment	
Yes	24
No	76
N	50

Majority of Nepali migrants were on ARV treatment and unfortunately the number of missing ARV treatment though it was not very high but not very low also (Table 3). For HIV patients, ARV treatment is a very important factor to control HIV and that is the only treatment in Medical Science to control the effects of HIV. Therefore, the adherence to ARV is expected to be high up to 100% even the single PLHA shouldn't miss the ARV treatment if he is taking ARV. Lack of adherence to ARV treatment harms the health of the patient. Slightly more than half of the respondents utilised the test and the medical facilities given by the health care centers and 42 % did not use it rather they did not utilise or those who utilised among them very few 6% did not remember what treatment they had given (Table 4). It showed how do they perceive the need for the treatment. Though the percentage was very low but in the context of the nature of illness low percentages also have a significant effect. High level of respondents utilising the medical facility.

Table 4: Test Conducted by the Health Care Centers and the Utilisation of Services by Nepali Migrants Living with HIV/AIDS

Tests conducted by Health Care centers	Percentage of migrants
X-Ray	2
Medicines	24
Blood test and X-ray	6
Blood test and Medicine	4
X-ray and medicine	14
Blood Test, X-ray, and Medicine	2
Taken to health care center but don't remember what treatment was given	6
N	50

Table 5: Services Used in a Hospital After Admission of the Nepali Migrants Living with HIV/AIDS

Services	Percentage of the Nepali migrants
Stay in hospital overnight during the last six months	24
Patient in a residential care facility, nursing home or hospital overnight or longer	18
Emergency care room or urgent care center for medical care during the last six months	6
Recent stay Private /Public	
Private Institution	6
Public Institution	38

The level of service utilization was not very high because it involved a need factor. Therefore, staying in a hospital, residential facility or nursing home during the last 6 months for the night, overnight or longer was very low that is 24% and 18% respectively because a majority of them did not perceive the need for admission (Table 5).

Barriers to healthcare utilization

There are few challenges to access health care treatment for Nepali migrants living with HIV/AIDS. Waiting time for the care and treatment is one of the barriers to care and treatment. Very few of the Nepali migrants reported that there was no delay in getting an appointment or getting HIV care, but a high level of migrants utilised the healthcare and treatment despite the delay in appointment for healthcare. Approximately 8-10% did not get any delay in getting treatment or appointment but most of the Nepali migrants reported that they got delayed in getting an appointment for HIV care. The period must be different for less than one hour, one to two hours, or more than two hours, but the level of participation in healthcare utilization was not low (Table 6).

Table 6: Time Spending in Getting Treatment by the Nepali Migrants

Aspects Related to Time Spent in getting Treatment	Percentage of migrants living with HIV/AIDS
Whether to get an appointment for HIV Care	
No	8
More than an hour	44
One to two hours	36
Two and more hours	12
How long does it take to get HIV Care	
No	8
More than one hour	44
One to two hours	36
Two and more hours	12
How long do they have to wait from arrival to actually getting the Care	
More than one hour	16
One to two hours	52
Two and more hours	32

Table 7: The association of lack of family support with care and treatment

	Yes
Thinking of going back to a native place and continuing further treatment	80
Lack of family support making more trouble	76
Thinking to bring your family to take care of you	42

Absence of family or lack of family support was also one of the barriers to care and treatment of Nepali migrants, therefore the majority of them were thinking to go back to native place and continue the further treatment and even, those who did not want to go to native place for the treatment they were having the fear of stigma in the family (Table 7). Similarly, a majority of the migrants felt that lack of family support was creating more trouble. It was true that the majority of the migrants did not want to bring their family to take care of them, fear of stigma is one of the reasons to avoid the family and in addition to this most of the migrants didnot have the residence, they were living in a group. Most of them were not on rent and living inthe workplace. Therefore, they did not want to bring their family to take care of them.

It is necessary to emphasize the factors which emerged as barriers to care and treatment. Some of them are sources of barriers to care and treatment. There were three major sources of barriers to care and treatment for Nepali migrants, they were- 1) the area of residence for the group mates who were living in the area of residence. These were leading factors collaborate with barriers to care and treatment for Nepali migrants living with HIV/AIDS, 2) area of occupation are characterised by an informal sector which usually offers the jobs for the migrants, and 3) the management of health institute pointed out by Anderson and Newman (1995) in their theory of healthcare utilization. The first two sources were the interrogative components and stimulation of stigma and fear of isolation. The third source was flourishing of the circumstances of adjustment all these sources propound the opportunities if the development of circumstances raise the tension of the patients and disturbs the routine of the patients. Area of residence incorporates friends, relatives, group members, co-workers, etc., they were very often coming into contact with Nepali PLHA in some or the other way. Therefore, coincidently they knew many things of PLHA. On the other hand, PLHA tried hard to avoid to take medicine in the presence of their group members to harbour their HIV positive status due to fear of stigma.

The area of occupation confined to the demands of the employers rather than the formal rules and regulations. It is characterized by irregular leaves, stick to terms and conditions otherwise, it may result in loss of employment. Thus, it was creating a condition of stress and strain for Nepali migrants living with HIV/AIDS. The management of health facilities denotes a slow bureaucratic process, refusal of treatment on time in the absence of identity proof, a lot of paperwork, lack of interest on the part of the health personnel treatment. Besidesthese,delay in treatment in the absence of an accompanied person and language barrier also palyed an important role. Apart from these sources of barriers,some other factors were visible and they played a vital role in seeking treatment such as living alone, self-blame, avoiding family, addiction of alcohol and tobacco etc. These factors very often emerged to be the reasons for the barriers to care and treatment for PLHA. The sources of barriers are mutually inclusive and are interlinked with each other.

Conclusion

There were interesting insights, that delaying appointment didn't lead to denial of care or discontinuation of care. As far as the services used in the concerned hospitals, the level of utilisation of services in the hospital was very low but it was attributed to the need of the patients. Moreover, there is no specific policy for cross-border migrants concerning healthcare treatment in India therefore the policy for the host population is being applied to the migrants. Some of the aspects of this policy may delay the treatment of the HIV positive migrants, therefore, the study will impel the state to take steps to modify the policy for migrants especially for HIV positive migrants on humanitarian ground. This study also laid the ground for further research.

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References

Karkee, R., and Shrestha D.B., 2006, HIV and conflict in Nepal: relation and strategy for response. *Kathmandu Univ Med* J 4(3): 363-7.

Mukherjee, K., and Danje, A., 2006, Needs assessment for reducing vulnerability to STI/HIV among Nepali migrants in Mumbai/Thane. Mumbai: Tata Institute of Social Sciences (TISS) Projects.

National Centre for AIDS and STD Control Ministry of Health His Majesty's Government of Nepal March, 2004, National Estimates of Adult HIV Infections Nepal.

New Era, 2006, Integrated bio-behavioral survey among male labor migrants in 11 districts in western, and mid-far western regions of Nepal.

Samuels, Fiona, 2011, Vulnerabilities of movement: cross-border mobility between India, Nepal and Bangladesh.

UNDP Regional HIV, 2010, HIV AIDS and Mobility in South Asia.