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Problems Faced by Antiretroviral (ARV) Drug Users in Kathmandu

Karki J,[1] Shakya S[2]

[1]Nepalese Army Institute of Health Science, College of Nursing, Kathmandu, [2]BPKIHS, Dharan, Nepal.

ABSTRACT

Background: Antiretroviral Therapy (ART) offers an opportunity to improve the prognosis and quality of life of People Living with HIV/AIDS (PLHIV). However, inability to achieve adherence even after drug introduction in Nepal is a matter of concern. Some efforts are to be applied in order to lend a hand to identify and minimize these problems. This study aims to assess the problems faced by antiretroviral drug users attending ART centers of Kathmandu.

Methods: A descriptive study was carried out in Sukraraj Tropical and Infectious Disease Control Hospital, Teku and Bir Hospital in 2071. Non-probability convenience sampling technique was used to recruit 82 respondents. Semi-structured questionnaire was used for conducting the interview.

Results: The overall problems faced by antiretroviral drug users include side-effects of drugs (65.9%), long waiting time (24.4%), unsatisfactory service (4.9%), geographical (68.3%) and financial barrier (25.6%), etc. Few were turned off from social/religious (70.7%) and recreational activities (51.2%). Absence of disclosure (14.6%), lack of spousal support (10.9%), humiliation (34.1%), etc. were also present. Stigmatization materializes as having to lose job (8.5%), feeling of ashamed (30.5%), feeling of isolation (34.1%), etc. Adherence towards medicine was found to be 86.5%.

Conclusions: ART is a long term process and to achieve it rationally, a user has to cope with lots of problems, associated not only with physical health but also with outcomes of psychosocial issue. Further worsening of the situation is due to financial constraints. Policy making, planning and service delivery seek improvement in various steps. Awareness is another demand to end psychosocial discrimination.

Keywords: ARV drug; Kathmandu; problems.

INTRODUCTION

Acquired Immunodeficiency Syndrome (AIDS) has become the most devastating and threatening disease of humans. In the global estimation, PLHIV has increased from 31.0 million (2002) to 35.3 million (2012) within a decade.[1] About 6.1 million people are currently receiving ARV drugs, while 2.4 million HIV-positive pregnant women are receiving ARV prophylaxis for Prevention from Mother-To-Child Transmission (PMTCT).[2] The national estimation of HIV infected adults and child is 55,600 with 0.33% estimated prevalence in adult.[3] NCASC[4] has reported a total of 8,866 clients registered in all ART centers of Nepal till December 2013 with 3,835 in Kathmandu alone.

Some of the problems that people under ARV drugs suffer include short term side effects, discomfort regarding disclosure of HIV status, patient's attitude and belief in treatment efficacy, etc. One of the studies[5] has identified some contributing factors for adherence to be lack of knowledge, social stigma and discrimination, health and hygiene, etc. Other problems included inadequate access to food and nutrition, lack of access to adequate health services, stigmatization and discrimination and inadequate service provision by the care givers.

A study[6] showed the perceived barriers were non-acceptance of HIV status, fear of discrimination and stigma, alcohol abuse, non-supportive home and work environments. The objective of this paper is to assess

Correspondence: Sujata Shakya, Nepalese Army Institute of Health Sciences, College of Nursing, Kathmandu, Nepal. Email: shaksujata@yahoomail.com, Phone: +9779841463678.

the problems faced by antiretroviral drug users attending Sukraraj Tropical and Infectious Disease Control Hospital, Teku, and Bir Hospital.

METHODS

This study used cross-sectional descriptive design to find out the problems faced by the ARV drug users. The sample consisted of 82 ARV drug users from Sukraraj Tropical and Infectious Disease Control Hospital of Teku (STIDCH), Kathmandu and Bir Hospital, Kathmandu. Semi-structured questionnaire was developed for the interview including socio-demographic, medical information and questions related to factors affecting ARV drug use. The questionnaire was translated in the local language (Nepali) and pretested in Tribhuwan University Teaching Hospital (TUTH). Non-probability convenience sampling technique was used to recruit the respondents who were above 20 years and had been on ART for more than 3 months.

Written permission was obtained from each concerned institution and the respondents. Data were collected by maintaining confidentiality and anonymity. SPSS version 21 and Microsoft Excel 2007 was used to manage and analyze the data.

RESULTS

More than half (68.3%) of the respondents were of the age 20 to 39 years with median age of 35 years (IQR=30-42) while 54.9% were male. Majority of the respondents (67.1%) were married. About three fourth of the respondents (73.2%) belonged to nuclear family.

Tabel 1. Socio-Demographic Characteristics.

Socio-Demographic Characteristics	Frequency (n=82)	Percent (%)
Age (in years)		
20 - 39	56	68.3
40 - 59	24	29.3
60 and above	2	2.4
Sex		
Male	45	54.9
Female	37	45.1
Ethnicity		
Janajati	41	50.0
Brahmin/Chhetri	29	35.4
Dalit	5	6.1
Madhesi	5	6.1
Others	2	2.4
Marital status		
Married	55	67.1
Unmarried	11	13.4
Divorced/Separated	5	6.1
Widow/Widower	11	13.4
Family Type (n=82)		
Nuclear	60	73.2
Joint	22	26.8

Table 2. Education and Occupation.

Educational and Economic Status	Frequency (n=82)	Percent (%)
Educational Status		
No education	10	12.2
Can read and write	18	22.0
Primary	16	19.5
Secondary	22	26.8
Higher secondary	12	14.6
Bachelor and above	4	4.9
Primary Occupation		
Service	26	31.7
Agriculture	16	19.5
Labour	13	15.9
Business	8	9.8
Others	13	15.8
Unemployed	6	7.3

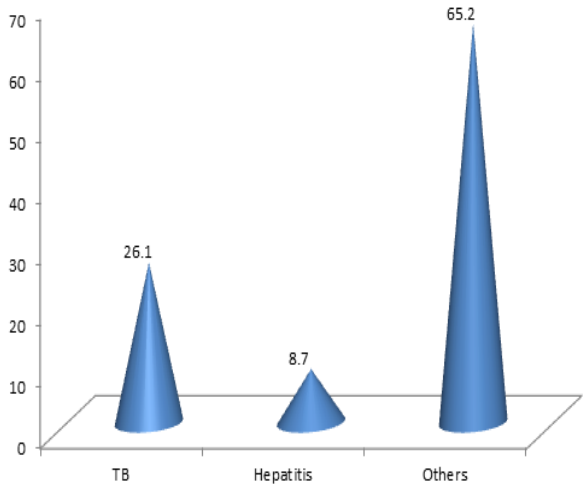

Figure 1. Comorbidity

One-fourth (26.8%) had completed secondary level education and 22% can only read and write and had no formal education. The most common primary occupation

was found as service (31.7%) and only 7.3% were unemployed (Table 2).

Only one quarter of the respondents (28%) suffered from some health problems with 26.1% of them suffering from TB. Other category includes number of health problems which are negligible in percent. These include low back pain, cough, fever, gastritis, diabetes, headache, joint pain, menstrual disorders etc.

Table 3. ART Adherence

Adherence to ART	Frequency	Percent (%)
Ever missed pills (n=82)		
Yes	22	26.8
Reason for missing pills (n=22)		
Forgot to take them	12	54.5
Forgot to get medicine from health center	2	9.1
Because of medicine's side effects	2	9.1
I don't think this works properly	1	4.5
Others	5	22.7
Adherence percentage (n=82)		
≥ 95%	71	86.5
80 - 94%	10	12.2
< 80%	1	1.2

Self-reported adherence of ≥ 95% was identified among 71 (86.5%) respondents. Respondents' reason for irregularity in taking medicine in this research was "forgetting to take medicine" in 54.4%.

Table 4. Access to ART Center

Access and visit to ART center	Frequency	Percent (%)
Distance to ART center		
Far	56	68.3
Very far	18	22.0
Within walking distance	8	9.7
Able to afford the costs		
Yes	61	74.4

Only 9.7% of the respondents responded that the ART centers are within walking distance (Table 4). However, public transportation facilities do not seem to be playing significant role in creating problems for the ARV users in the valley. Only 25.6 % had complained about their financial constraints to bear the cost for treatment.

Tabel 5. Support from Others.(n=82)

Disclosure and support	Frequency	Percent (%)
Disclosed to spouse (n=60)		
Yes	55	91.7
Spousal support (n=55)		
Yes	49	89.1
Support from others (n=70)		
Always	28	40.0
Most of the time	20	28.6
Occasionally	16	22.9
Never	6	8.6

As shown by findings in Table 5, 89.1% of those who had disclosed their status to their partners had received support from them. Forty percent always received support from their family, friends, colleagues or community/neighbors while 8.6% never received any form of support.

Table 6. Stigma and Discrimination

Stigma and Discrimination	Frequency	Percent (%)
Relation with family after HIV (n=64)		
Good	32	50.0
Satisfactory	26	40.6
Not good	6	9.4
Ever being treated differently/humiliated (n=82)		
Yes	28	34.1
Experienced humiliation* (n=28)		
Peer circle/social group	16	57.1
Home	11	39.2
Community/Neighborhood	6	21.4
College/work place	3	10.7
Health facility	1	3.6
Frequency of experiencing (n=28)		
Always	2	7.1
Most of the time	10	35.7
Occasionally	15	53.6
Cannot say	1	3.6

The study also revealed the information about the stigma and discrimination felt by the respondents (Table 6). It shows that half of the respondents (50%) had good relationship with the family members (other than spouse) after being diagnosed as HIV and 9.4% did not

have good relationship. The current study revealed the perceived presence of stigma and discrimination among 34.1% of respondents. Among these, most had faced it in their peer circle or social group i.e. 57.1% and least in health facility i.e. 3.6%. They had been humiliated occasionally (53.6%) in those areas.

Table 7. Psychosocial Problems Associated With HIV Status.

Psychosocial Problems	Frequency	Percent (%)
Feel isolated in social gatherings	28	34.1
Have to work hard to hide the fact	43	52.4
Lost a job/not get service	7	8.5
Felt ashamed of having HIV	25	30.5
Lost interest in social activities	43	52.4
Feel that life is useless	24	29.3

This study provides the information about the presence of discrimination like losing job (8.5%), emotionally hurt as feeling isolated in family and social gatherings (34.1%), feeling ashamed of having suffered from HIV (30.5%) or needing to work hard to hide the fact of being suffered from HIV (52.4%). (Table 7)

Depressive feeling is another problem associated with HIV/AIDS. It comes either directly with the diagnosis and/or with the stigma and discrimination attached with it. In this study, more than half of the respondents (52.4%) said that they had lost their interest in social activities and more than a quarter (29.3%) felt that their

life had become useless due to the HIV.

DISCUSSION

The co-presences of any other disease along with HIV/AIDS have a direct impact on the health status of ARV user. The study shows various problems faced by the antiretroviral drug users during their daily life. The study also depicts that the comorbid condition i.e. TB was present in 26.1% of the respondents. TB is considered as the leading cause of death in PLHIV. This also seems to be a serious threat and an issue among the respondents in the present study.

Variation in measurement methods of adherence rates makes it difficult to compare with findings in other studies. The self-reported adherence of 86.5% of the respondentswas more than 95%. This is in line with a study done in 2012 which shows the 95% and above adherence to be 85.5%.[9] A study among HIV patients in Kathmandu showed similar adherence (86.7%).[7]About a quarter (26.8%) of the respondentshad missed pills at some time the reason of most (54.4%) being "forgetting to take medicine". This result was in agreement with the findings of another study in which "being busy or simply forgetting" is the leading cause (51%) of non-adherence.[10] Another study also states that the most cited reason for not taking ART according to the prescription as "simply forget".[7]

Distance from patient's residence to service center has major impact on adherence to the treatment. Unavailability of transport facility is one encumber and transport cost acts as another burden for people, particularly in those with low financial support. Despite 90.3 % of the respondents residing far from walking distance, only one respondent was found to be missing regular visit to ART center.

Support from others including family members help the drug users while encountering other physical, financial and social problems, improving treatment adherence, etc. Majority (89.1%) of the respondents had received support from the family members in the study. This was in contrast with the study done in 2012 of which shows that only 39.4% received spousal support.[9] The present study revealed that 34.1% of the respondents perceived presence of stigma and discrimination. This is much similar with the figure of 30.9% found in the study of 2012.

The study illustrates about the psychological effect like feeling of isolated in social gatherings (34.1%), feeling ashamed of having suffered from HIV (30.5%) or needing to work hard to hide the fact of HIV (52.4%) etc. Similarly, the findings of the study done in Vietnam in 2012 identify that non-adherence was associated with low satisfaction level ($P<0.001$), lower score of social connectedness ($P<0.001$) and greater score of social isolation ($P=0.03$).[12] He also mentioned that disclosure may improve adherence but sometimes is associated with increasing risk of loss in business, loss of job, emotional injury, discrimination from others, etc. Depressive feeling is another problem associated with the HIV/AIDS. It comes either directly with the diagnosis and/or with the stigma and discrimination attached with it. In this study, more than half of the respondents (52.4%) said that they had lost their interest in social

activities and more than a quarter (29.3%) felt that their life had become useless due to the HIV.

CONCLUSIONS

Identification and evaluation of problems faced by ARV drug users are important measures for addressing the problems in rational way and achieving goal through ART programs. Antiretroviral drug users have to face various physical, psychological, social and other problems. Among these problems that add to the physical and financial burden, the co-morbid conditions (28%) and side effects (65.9%) are the ones. Psychosocial hindrance caused by disclosure seems to impart negativity in the life of ART users as evidenced by feeling of isolation in family gatherings (34.1%), feeling ashamed of the diagnosis (30.5%), lost social activities (52.4%), etc. Thinking that suffering from HIV is a crime (15.9%) or feeling that life is useless because of HIV (29.3%) especially due to social stigma and discrimination is another difficulty faced by the ART users. Thus, it can be concluded that ARV users in Kathmandu valley are facing different physical, financial, psychosocial problems. Accessibility of satisfactory health services has also been a problem to some extent. Awareness is of vital necessity to eliminate psychosocial discrimination.

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