

Knowledge, Difficulties and Motivations associated with Anti-Retroviral Medication Adherence in Patients with HIV/AIDS

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ABSTRACT

Introduction: Patients' medication taking behavior can be influenced by multiple factors. Such factors can vary between settings and patients. Gaining an insight into difficulties encountered by the patients and their motivation to take medications can aid in developing strategies to promote adherence.

Objective: To explore patients' knowledge regarding their Anti-Retroviral therapy, and investigate difficulties and motivations associated with ART consumption.

Materials and Method: Face-to-face interviews were conducted with patients who came to refill their prescription of anti-retroviral pills, in ART Clinic of Sukraraj Tropical and Infectious Disease Hospital, using structured questionnaires.

Result: Participants were mostly male (64.22%) and aged between 22-49 years (93.58%). Knowledge about ART varied from good to moderate in the majority (81%). About 44% of patients depended on the shape and size of container/ pills for identifying their ARV pills, and 53% perceived it difficult to take their medications as prescribed. Lack of easy access to medications, fear of disclosure and financial problem were the most reported difficulties associated with consumption of anti-retroviral medications.. Almost 57% of patients reported that they would avoid taking their medications in front of others; 14% of the patients reported missing their ARV pills over last month. Desire to living long and healthy life and prevent opportunistic infections motivated patients to take medications. Few felt they had no choice but to take their medications.

Conclusion: Appropriate strategies to increase patients' knowledge, simplify regimen and to motivate them to take medications regularly is necessary to facilitate adherence to ART in this population.

Keywords: Adherence; anti-retroviral therapy; difficulties; HIV/AIDS; motivation.

INTRODUCTION

Acquired Immunodeficiency Syndrome (AIDS) is a disease of the body's immune system caused by Human Immunodeficiency Virus (HIV), a retrovirus that is transmitted through body fluids.^{1,2} Infection with HIV renders patient infectious for life. Since the very first case of HIV/ AIDS in the United States in 1981,³ it has now become a major epidemic. It is estimated that everyday over 6800 persons are infected with HIV and over 5700 persons die from AIDS. HIV has already caused an

estimated 25 million deaths worldwide.³ Sub-Saharan Africa lies as the epicenter of HIV/ AIDS epidemic, accounting for 67% of the global total of 32.9 million people living with HIV and for 75% of AIDS deaths in 2007.^{3,4} Asia is the second hardest hit. An estimated 4.9 million people lived with HIV in 2007, in Asia. The highest national HIV infection in Asia is found in South East Asia.^{4,5} Nepal had its first HIV case diagnosed in 1988. The epidemic highly increased in the mid 90's. As of 2007, the total number of HIV infections is 70, 256.⁶

Anti- Retroviral Therapy (ART) for HIV management involves use of anti- retroviral (ARV) medicines to inhibit multiplication of HIV for disease control.⁶⁻⁹ In 1996, the World Health Organization introduced Highly Active Anti- Retroviral Therapy (HAART), which incorporated the use of 3 or more ARV drugs in the ART regimen to tackle resistance observed with mono or dual therapies and to increase effectiveness.^{3,8,10} There has been an increasing need identification to control the epidemic; and following Millennium development goal (2015) to reverse the epidemic by 2015,³ several plans, policies and programs have been developed, implemented and strengthened in different parts of the globe. More people now has access to HAART.

Availability of drugs to the patients, however, alone cannot guarantee therapeutic success. Adherence to ARV regimens is an important determinant of both the degree and duration of virologic suppression. Whilst optimal adherence has been reported to increase the likelihood of virologic control which is essential for reducing HIV associated morbidity and mortality, poor adherence, has been associated with increased possibility of virologic failure, which can ultimately lead to development of resistance and limit the effectiveness of ART.^{8,11}

Different factors influence patients' adherence to therapy.¹² These factors can vary with variance in settings and social, cultural, educational background can play role in determining the predictors. It is therefore essential, that factors be determined for specific setting. Identifying what facilitates and what hinders patients' adherence to ARV therapy is important to facilitate medication taking. There are limited studies in Nepal that informs how patients with HIV/AIDS feel about their medication, their knowledge and factors that influence their medication taking. In order to address the gap, this study aims to shed light on patients' knowledge of their medications, the difficulties faced by the patients in relation to consumption of ARV pills and what motivates them to take their pills.

MATERIALS AND METHOD

Study site: The study was conducted in ART Clinic of Sukraraj Tropical and Infectious Disease Hospital, Teku, Kathmandu, Nepal. The data was collected over a period of about four months, starting from January 2009 to April 2009. The ethical approval for the study was obtained from Nepal Health Research Council, Ethical

Review Board. The study formed a part of postgraduate (Master's) research of the lead author.

Subjects: The people living with HIV/AIDS (PLHA) who came to the clinic (ART center) to refill their prescriptions for ARV medications were requested to participate in the study. The patients met eligibility criteria if they were on ARV medications at the time of interview, had been taking ARVs for at least three months, were at least 15 years old and were able to provide informed consent. Pregnant women and in-patients admitted in the hospital ward who came in for the refill were excluded in the study.

Data collection and analysis: The study involved face to face interviews with the participants. The interviews were based on structured questionnaires designed for the purpose of the study. The questionnaires involved questions to gather general information about the patient, the prescribed medications and missed doses, their knowledge and their perceptions of factors influencing their medication adherence.

Specific set of questions was developed to assess medication knowledge. In addition to the questions, the patients were asked to identify their ARV medications during the interview. The questions used to assess patients' knowledge included:

1. Can you identify ARV drugs amongst other drugs (that you take) ? (Y/ N).....
2. Do you know the name of the drugs? (Y/N).....
 - a. If no, how do you identify your drug?
3. Indicate the name(s) of the ARV medications that you take. Also mention the number of pills that you have to take each day for each of these medications.
4. Do you know how does your medication manage your condition?
5. Did you know about the side effects of ART prior to starting the therapy?

Scoring: For a positive response to each question in 1, 4 & 5, the patients scored '1' point. For correctly naming (question 2) the drug and identifying the regimen, they scored '1' point. The patients also scored (1), if they did not name the medicine but could correctly identify the medication and tell the regimen. Total Score, was therefore: 4. The categorization of Medication

knowledge employed for the study is presented in Table 1.

Table 1: Scoring criteria for evaluation of ‘Medication Knowledge.’

Category	Score
Good Knowledge	4
Moderate Knowledge	3-2
Poor Knowledge	0-1

If the patient could not name the medication (Q. no. 2), his method of identifying the medication was asked. Stated methods of drug identification were plotted in a graph. Descriptive statistics was used to analyze the collected information.

RESULT

A total of 109 patients were interviewed. Of them, 64.22% were male. Overall, participants’ age varied from 22 to 58 years. Majority (93.58%) were aged between 22- 49 years. Most participants (30.38%) had never attended school (no formal education). Only 18 patients interviewed had University level of education. A total of 75 (68.8%) patients were employed (Table 2).

Table 2: Participants’ Demographics

	Participants’ Number (%)
Gender	
Male	70 (64.22)
Female	39 (35.78)
Age (years)	
50-59	7 (6.42%)
40-49	29 (26.6%)
30-39	54 (49.54%)
20-29	19 (17.43%)
Education	
No formal education	33 (30.28)
Education up to class 5	11 (10.09)
Class 6 to 10 (SLC)	47 (43.12)
Higher level of education	18 (16.51)
Employment	
Unemployed	34 (31.2)
Employed	75 (68.8)

Of the employed, most (26.7%) were engaged as a field worker (or a volunteer) in non- governmental organizations providing services to PLHA. Sixteen reported that they had their own business. Female patients were

mostly found to be involved in cottage entrepreneurship activities, such as, sewing, making socks, making cultural garlands and carpet industry (Table 3).

Table 3: Major occupations of the employed participants.

Occupations	No. of participants
Volunteer (HIV related)	20
Business	16
Agriculture	8
Transport related	8
Job/ Services	8
Cottage entrepreneurship	5
Teachers	4
Hotel/ lodge/ café	4
Construction work	2
Total Employed	75

Antiretroviral Therapy

Pill Burden

The number of ARV pills that patients were taking per day ranged from 2 to 9. Patients prescribed with the combination of d4T/3TC/NVP, had the minimum ARV pill burden, as the combination was available as fixed dose combination tablet. Patients who were intolerant to first line regimen and were under second line drugs had higher pill burden. Patients on regimen containing Indinavir had maximum pill burden. Indinavir was available as 400 mg tablet, the prescription constituted 2 tablets to be taken each time on a ‘3 times daily’ basis, plus other drugs.

Other Medications

Of the total, 58 patients (53%) were also taking other medications, for example, medications for treatment and/ or prophylaxis of opportunistic infections. Cotrimoxazole and anti-tuberculosis regimens, were used by the majority. Patients also reported using non- prescription medications, such as, contraceptive pills and herbal medications on an everyday basis.

Patients’ Preferences and Knowledge of ART Preferred Regimen

Sixty one percent of the patients reported that given a choice they will go for once daily regimen. Amongst them, a few preferred bed-time doses. Almost 36% of the patients said that dosing regimen was not a matter of great concern and they would be comfortable with any kind of regimen, provided, the regimens suited them (Figure 1).

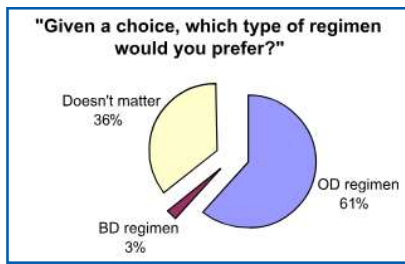


Figure 1. Sample population preference of type of regimen

Patients' Knowledge of Their Medications

Only 28.44% of the patients were able to give correct answers to all the questions designed for evaluating medication knowledge and correctly identify their ARV pills and tell the regimen (Good Knowledge). Majority (52.29%) missed out on one or two questions, showing their lack of knowledge regarding some basic aspects of therapy (Moderate Knowledge).

Table 4: Categorization of the participants based on their 'Medication Knowledge.'

Score	Category	Number of participants	%
4	Good Knowledge	31	28.44
3-2	Moderate Knowledge	57	52.29
0-1	Poor Knowledge	21	19.27
	Total	109	100

Based on the responses to the individual questions, it was found that 71 out of 109 (65.13%) patients knew about the benefit of ARV drugs. 'Benefit of drug' was analyzed based on whether the PLHA understood that ART only controlled and did not cure the disease. 66 (60.55%) reported that they were aware about the possibility of side effects from ARV therapy prior to start of the therapy. Only about 47.70% of the patient could correctly name their ARV medication and regimen. Other identified their medication from the shape and size of the bottles and pills. Some PLHA also responded that the only medications they consumed were those that they collected from the ART center, mostly to be taken once or twice a day, and therefore, had no difficulty in identifying their medications (Figure 2).

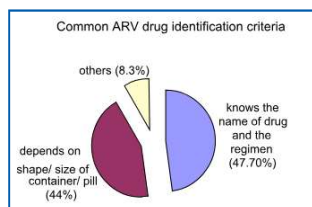


Figure 2: Methods employed by PLHA for identification of their drugs.

Perceived Difficulties, Missed Doses and Motivation for Adherence

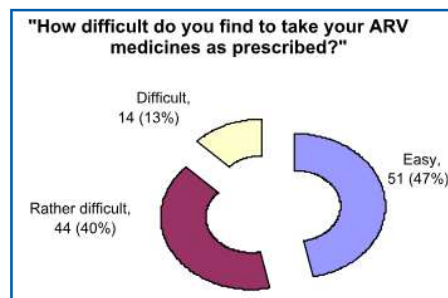


Figure 3: Difficulty level: 'how difficult did the PLHA find to take their medications as prescribed?'

Perceived Difficulties Associated with HAART

Fifty three percent of the patients reported having difficulty taking the ARV medications as prescribed (Figure 3). Patients generally reported that adhering to ARV regimen was difficult at initiation; the medications, they reported, became a routine in a long run.

Difficulties associated with the medications ranged from problems in accessibility to medications to their side effects (Table 5). Patients came to the center for refilling the prescriptions from all over the country. Many reported the costs to come to the center for medications posed difficulties. Despite having an ART center near their place, not all preferred to collect their medication from a nearby center because of the fear of disclosure of their HIV status.

Table 5: Major difficulties in the process of consumption of their ARV medications

Responses	No. of participants	% respondents
No specific problems	51	46.79
Accessibility/ difficult to come to collect the medicines	27	24.77
Difficult to follow the prescribed regimen	12	11.01
Fear of disclosure	10	9.17
Financial problem	5	4.59
Side effects	4	3.67
Total	109	100

Asked if the patients avoided taking their ARV pills in front of others, 56.8% (n=62) responded 'yes' Amongst those who responded 'no' most (n=52) said they do not hesitate because their HIV identity was no more hidden. The others (n=5) reported there was no need to hide the

medications, as people in general wouldn't recognize the medications as ARV pills. The patients who avoided taking their ARV pills from others also reported having difficulty in time adjustment.

Side effects were regarded as difficulties by a few. The findings related to side-effects in this population has been previously published.¹³

Missed Doses

Four, 7, 8 and 15 patients out of 109 reported having missed taking one or more of their ARV pills in last 2, 7, 15 and 30 days respectively (Table 6). While majority reported having missed taking a pill in a specific duration, there was a respondent who reported having missed as many as 12 pills over a month. Reason reported for not taking the medications were forgetfulness in majority of the cases, while the patient who reported having missed maximum number of pills reported that he had taken a wrong medicine from the center and could not come back to change the medication due to personal difficulties, so he avoided taking that particular pill for almost a period of 12 days.

Table 6: Doses of HAART missed by the participants during last 2,7,15 and 30 days.

No. of patients reporting to have missed the doses	Doses missed in	%	
4	Last 2 days	3.7%	1;1;2;1 (=5)
7	Last 7 days	6.42%	4*1; 7;1;1 (=13)
8	Last 15 days	7.33%	6*1; 9; 2 (=17)
15	Last 30 days	13.76%	9*1; 5*2; 12; (=31)

% of patients who missed the drugs in a period of 1 month: 13.76%

Factors Promoting Therapy Adherence

Patients' adherence to ARV pills was mostly found driven by their desire to live long, either for themselves or for their near and dear ones. About 23% of patients reported that they adhered to the therapy to control the disease and to opportunistic infections. About 10% felt compelled to adhere (Table 7).

DISCUSSION

This study explored difficulties faced by the PLHA for appropriately adhering to anti-retroviral medications, and their motivations for sticking to therapy. Furthermore, it investigated patients' basic knowledge about their ARV medications. Patients' preferences of regimen and missed doses in the past month were also explored.

Table 7: Factors motivating PLHA to stick to their therapy.

Responses	No. of participants	% respondents
Longevity/ to live	43	39.45
To control the disease		
progression/ virus growth	16	14.68
For better life/ healthy life	11	10.09
Because the doctor said to/		
had no other choice	11	10.09
For preventing opportunistic		
infections	9	8.26
Felt better after taking		
medications	8	7.34
For family members	7	6.42
Others (to strengthen CD4,		
cannot stop now)	4	3.67
Total	109	100

The sample population consisted of 64.22% male; 93.58% of the sample fell under the age range of 22-49 years. Report as of April 2008 (NCASC), has stated that of out of total cumulative number of HIV positive cases (including AIDS) in Nepal, 68.10% are males and 31.9% are females.⁵ Similarly, the sexually active age group, from 15- 49 years has been categorized as the most vulnerable group for being infected with HIV. Approximately 92.2% of the total HIV cases have been reported to fall

under this age group.⁵ In reference to this figure, the study sample, can considered more or less representative of the total population in terms of age and gender.

The assessment of medication knowledge revealed that only 28.44% of the patients had 'good knowledge' and most (52.29%) had 'moderate knowledge' of their medications. The knowledge of about 19% patients rated poor. Sound knowledge regarding medication is crucial, particularly, in cases where medications are for chronic conditions and the medicines are to be consumed on a regular basis. Especially with possible complications and side-effects associated with the therapy in case of HAART, patients should be properly counseled on different aspects of medicine use, so that they understand the importance of adherence. Studies have demonstrated that better medication knowledge influence patient satisfaction and confidence of patients towards their therapy.¹⁴

Health literacy skills have been defined to be the strongest predictor of an individual health status.¹⁵ When approximately 40 to 44 million adults in the US are reported to be functionally illiterate,¹⁵ the functional literacy in Nepal can be predicted to be significantly lower. Furthermore, the education status of the patients interviewed indicated that most had only had basic/school education. There is no place to assume that patients have ability to understand and be aware of their health, disease and therapy by themselves, and highlights the need to educate patients. This study also indicated that knowledge about medications, for example, the necessity of medications for control of disease and prevention of opportunistic infections motivates patients to take their medications. Need for effective interventions to make better understanding and improving medication knowledge is evident. Furthermore, it was revealed that a major proportion of the patients relied on the shapes and sizes of the pills and/ or the containers to recognize their ARV pills. Changes in the brand leading to change in shape and size of the bottles and pills may cause difficulty for many ARV consumers in identifying their drug and might affect their medication taking. Effective counseling for helping patients identify and understand their medications is also necessary.

The finding that almost 14% of the patients had missed at least one ARV pill within the past 30 days, indicates to patients' struggle to therapy adherence. Easy accessibility to medications, disclosure of their identification as PLHA and financial issues acted as barriers to effective ARV pills consumption. People came to the center from all over the country to refill ARV prescriptions in the center. Those travelling from outside Kathmandu Valley, thus had to incur extra expenses to acquire 'free' medications. In a study that used mainly qualitative methods to find out why and when people do not adhere to ART in Uganda, Tanzania and Botswana, financial difficulty was reported as a major obstacle. Although the patients received ARV drugs free of charge, other related costs (e.g. transport expenditures, registration and user fees at the private health facilities, and lost wages due to long waiting times)

were reported as main obstacles to optimal adherence.¹⁶ Though an ART center nearby is an apparent solution, the provision could not be leveled as a guaranteed solution for all. The problem of accessibility for many is yet complicated by the fact that they have not exposed themselves as HIV/ AIDS patients. Issues with being exposed also led patients to avoid taking ARV pills medications.

Fear of being disclosed or hiding HIV status is not uncommon in PLHA. Because of the perceived societal and moral beliefs about HIV/ AIDS, people are uncomfortable revealing that they are HIV positive. Whilst in some cases, the identity is hidden from the society, in others even the family members are kept ignorant about the HIV status. Disclosure has been identified as an important interpersonal phenomenon and disclosure of one's HIV status is an essential part of the behavior modification required to reduce the incidences of HIV. Difference between disclosure and non-disclosure groups in terms of getting help and social support has been found highly significant.¹⁷ Disclosure not only helps to better control incidences of HIV, but also helps PLHA to become more compliant towards their therapy. Studies have reported that ART users find it hard to take their drugs when they are among people to whom they have not disclosed their HIV status, such as co-workers and friends.¹⁶ The finding seems pretty well suited in our context as well.

CONCLUSION

This study showed that not many patients had a sound knowledge of their ARV pills and a good number depended on the size and shape of the pills or the container for identifying their medications. Furthermore, it was revealed that patients who had not disclosed their HIV/AIDS status avoided medications in front of others. It is therefore necessary that efforts should be targeted to identify and assess the need and knowledge of the patients with HIV/AIDS to ensure that appropriate strategies to promote adherence can be undertaken.

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