SOCIO-CULTURAL FACTORS AFFECTING ADHERENCE TO ANTI-RETROVIRAL THERAPY AMONG HIV POSITIVE WOMEN IN NEPAL

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ABSTRACT: Consistent high level of adherence to Anti Retroviral Treatment (ART) is critical to treatment success**.** A recent study in Nepal revealed that women are seven times less likely to adhere to their treatments than their male counterparts**.** Hence this study explores the influence of socio-cultural factors that affect the adherence to ART among female HIV positive patients in Nepal. A cross sectional study surveying 100% dose adherence in past 4 weeks was conducted among 246 HIV positive female patients enrolled into ART for at least three months from December 2012-January 2013 in Kathmandu, Saptari and Morang district of Nepal. The study revealed that only 66.6% of the respondents reported complete adherence to the treatment. The key factors affecting adherence were; perceived stigma of disclosure (OR= 18.413, p=<0.001), perceived family support (OR = 8.975, p=<0.001), monthly family income (OR=6.371, p=<0.001), medication self efficacy OR= 6.222, p=<0.001), patient provider communication (OR= 4.525, p=<0.004) and total perceived social support (OR = 4.071, p=0.027). The most common reason given for missing a dose was memory lapse, either in falsely believing they had already taken their medication or forgetting to take it entirely. In conclusion, the adherence rate among the HIV positive women was found to be 66.6% with memory lapse being the main reason for it. Patient's perceived stigma of disclosure and perceived family support were major factors affecting adherence to ART. Adherence supportive programs such as mobile phone reminders, alarm clocks can be implemented to help them remember. Also, introducing a buddy system for improving social support, tailoring counseling content for vulnerable patients and addressing the patient's fear of disclosure beyond the immediate circle can also be done to increase adherence among the positive women.

Keywords: Anti Retroviral Treatment (ART), Adherence, Socio-cultural factors, HIV positive women, Nepal

INTRODUCTION

Anti Retroviral Treatment (ART) used in the management of HIV infection among people living with the disease helps prolong life by reducing the risk of related illness and death as well as the likelihood of onward transmission. However, consistent high level of adherence is critical for optimal virological outcome and treatment success [1, 2]. Furthermore, it has been documented that females have greater difficulty adhering to ART compared to their male counterparts, mainly associated with depression lack of supportive interpersonal relationships, young age, drug and alcohol use, non-pregnancy, higher number of children etc. [3].

Consistent high level of adherence is vital in preventing development of drug resistance especially among the cheap first line drugs, to decrease the viral load of patients and subsequently get the complete benefit of the treatment [1]. In contradiction, Bangsberg et al. argued that resistance –adherence relationship varied among different antiretroviral therapeutic class, with resistance to single protease inhibitor therapy occurring most frequently at moderate to high levels of adherence [4]. However beyond merely following medical instructions a patient must be having an active discussion with their health care provider about diet and other lifestyle changes for them to be considered adherent to the medication [5, 6].

Adult women (15-49) yrs comprise of 28.2% of the total infected population, as well as 44.8% of all patients currently receiving free ART services in Nepal [7]. Alarmingly, a recent study revealed that these women are seven times less likely to adhere to their treatments than males [8]. This was attributed

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to the various socio-cultural and economic restrictions that women are uniquely subjected to in their daily lives. One of the most common barriers for women is the presence of a child [9]. Stress of depression related with the disease may cause low efficacy and a need of social support which has been significantly associated with low adherence in the past [10-12]. Moreover, lack of decision making power and an inferior position to men are often related to myriad of factors that directly affect adherence to ART [13]. This study aims to measure the level of adherence among HIV positive females in Nepal while further examining the influence of various socio-cultural factors that affect their adherence.

METHODS

A cross sectional study among female patients aged 18 years or older and enrolled into ART for at least three months was conducted from December 2012-January 2013 in Nepal. A pretested structured questionnaire was administered among 251 HIV positive women with five not responding to the full questionnaire. These five were excluded from any further analysis, as well as pregnant, co-infected with TB and/or Hepatitis and women with advanced stages of the disease. The ART centers at *Sukra Raj Tropical and Infections Disease Control Hospital* of Kathmandu, *Sagarmatha Zonal Hospital* of Saptari and *Koshi Zonal Hospital* of Morang district were chosen purposively for their large patient number and feasibility with formal permission. Also, coordination with a care house providing shelter and support to the HIV positive patients was done to recruit participants in the study from the Eastern region. All the patients visiting the three ART centers along with the ones residing in the care house during the study time frame were selected and asked for their verbal consent to participate in the study, without any sampling. Ethical approval was sought from the Ethical Review Board of Mahidol University along with a formal permission from the National Center for AIDS and STD Control (NCASC), Nepal.

The dependent variable - adherence to ART was defined as "patient not missing a single dose of ARV drugs in the entire 4 weeks prior to participating to the researcher administered questionnaire." Accordingly, the respondents were classified as 'adherent'- not missing a single dose in the past four weeks and 'non-adherent'- missing at least a single dose in the past four weeks. Adherence and socio-demographic variables were measured using an adapted and shortened version of the self-reported Adult AIDS Clinical Trial Groups (AACTG) adherence instrument. Additionally, the study used the shortened, translated version of family and friends subscale of Multidimensional Scale of Perceived Support of Zimet [14] with the response scale shortened from the 7 point scale to a simple 3 point scale with "agree", "undecided" and "disagree". The subscale for each category- friends and family was calculated separately with scores ranging from 3-9 each. The higher the score the level of perceived social support was labeled to be higher, using mean score as the cut-off point. HIV Treatment Adherence Self Efficacy Scale (HIV-ASES) was also adapted and shortened for calculating self efficacy among the respondents. The original scale has 12 items on a response scale ranging from 0 (''cannot do at all'') to 10 (''completely certain can do''). However, due to the difficulty of administering a large response scale while being administered from the researcher, the response was shortened simply to 0 (''cannot do at all''), 1(can do) and 2(''completely certain can do'') with six questions. The scores ranged from 0 to 12. Higher the score, higher was the self efficacy for adhering to the medication. The participants scoring 12 were categorized as having optimal self efficacy. Also, the stigma of disclosure among the patients was measured using the translated disclosure domain of the Berger's HIV Stigma Scale. This subscale consists of 10 questions and each of them were scored as; strongly disagree = 1, disagree = 2, agree = 3 and strongly agree = 4; with the seventh item on the scale scored inversely. The scores ranged from 10-40, with mean score used as the cut-off point. Finally, patient provider communication was measured using three questions; whether they could ask all queries without any hesitation, whether the provider answered every question asked and whether they understood the answers given.

Epi data was used for questionnaire development and coding. Statistical Package for the Social Science (SPSS) version 16.0 was used for statistical analysis. A p-value of less than 0.05 was used to define statistical significance. Chi square test was used for univariate analysis of each variable with the adherence to ART. The significant variables were then put into a multiple logistic regression with enter subcommand to measure influence of these variables concurrently.

RESULTS

From a total of 246 female respondents interviewed, 66.6% of the respondents said they had not missed a single dose in the last four weeks (Figure 1). Only 100 respondents (40.7%) reported that they had

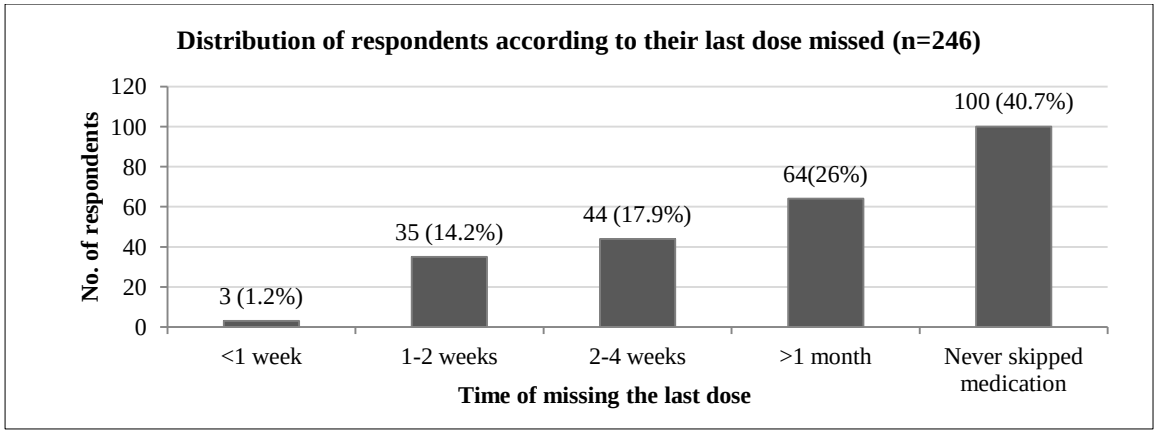

Figure 1 Number and percentage distribution of the time of the last dose missed

never missed a single dose since the start of their treatment, although the questionnaire failed to ask the length of duration of the patients receiving the ART. The most common reason given for missing a dose was memory lapse, either in falsely believing they had already taken their medication or forgetting about taking it entirely (47.6%). Even among the women surveyed who regularly took their doses, few did it on time. This was followed by miscellaneous reasons for their negligence which were usually socio-cultural in nature (29.3%). Some reported that they had been locked out of their houses by landlords afraid of the disease, and thus were unable to access their medicine. Some reported violent spousal fights resulting in medicines being thrown away. Others simply said they had been too depressed to take the medication.

The mean age of the respondents was 31.76 years with almost half of the respondents having either no formal education or completing less than primary level (46.7%). Two-fifths of the respondents had monthly family income of less than 7000 NRs (40.7%) and most worked outside their homes for pay (82.1%). More than half were married (54.5%) but only 103 of the respondents had any children living with them (Table 1).

Furthermore, more than half of the respondents said they did not drink or smoke (61.8%), whereas about one-fifth of the respondents only drank alcohol (19.5%). Also, although majority of the respondents had tested their CD4 count in the last six months (89.4%) only one-tenth of the respondents had both CD4 count test and Viral Load Test (10.2%) done in past 12 months.

Additionally, assessment on perceived social support (friends and family), medication self efficacy, patient-provider communication and perceived stigma of disclosure was completed. Almost two-thirds of the respondents had a high perceived family support (63%) while only a little over half the respondents had high perceived friends support (53.3%). Also about two thirds had optimal medication self efficacy (64.2%), and more than three-quarters had optimal communication with their providers (78.5%).

Factors associated with adherence

After conducting chi-square test among all variables, only 9 were significantly associated with adherence (Table 2). Multiple logistic regression was carried out among these variables (adjusting with all the significant variables from Table 1, there were no confounders) and only 5 remained significant in the final model: perceived stigma of disclosure (OR= 15.76, p=<0.001), perceived family support (OR = 3.405, p=0.004), monthly family income (OR=5.214, p=<0.001), medication self efficacy OR= 5.878, p=<0.001) and patient provider communication (OR= 3.663, p=0.010). Personal behavior (smoking and drinking), educational level and perceived social support were not significant.

DISCUSSION

The overall adherence rate of the women for one month was found to be 66.6% which is considerably less than that of the previous study conducted in Nepal among both men and women at 85.5% of adherence rate to ART [8]. Another study conducted in Far-west region of Nepal reported >95% adherence of 84% of the respondents [16]. This can be attributed to the fact that women find it more difficult to adhere to the treatment regimen than men [17, 18]. Moreover, this study involved participants receiving treatment outside of the ART center (residing at the care house), which can also account for lower rate of adherence.

Contradicting other studies, age and active use of alcohol was not found to be associated with

Table 1 Distribution of the variables studied and factors associated with ART adherence among HIV positive women in Nepal

Variables	General distribution	Category of adherence		χ^2 (*p-value*)
		Adherent	Non adherent	
	n (%)	n (%)	n (%)	
Age group (Years)				
<32	140 (56.9)	41 (50)	99 (60.4)	0.122
≥32	106 (43.1)	41 (50)	65 (39.6)	
Mean=31.76,S.D=5.846, Min=20, Max=52				
Education level				
No education or up to Primary level	115 (46.7)	56 (68.3)	59 (36)	<0.001*
Lower secondary or higher	131 (53.3)	26 (31.7)	105 (64)	
Monthly family income level (NRs)				
Poor (<7000)	100 (40.7)	52 (63.4)	48 (29.3)	<0.001*
Not Poor (≥7000)	146 (59.3)	30 (36.6)	116 (70.7)	
Employment status				
Works for pay outside home	202 (82.1)	66 (80.5)	136 (82.9)	0.638
Works /doesn't work outside home	44(17.9)	16 (19.5)	28 (17.1)	
Marital status				
Single	55(22)	20 (24.4)	35 (21.3)	0.010*
Married	135(55)	35 (42.7)	100 (61)	
Widowed /Divorced	56 (23)	27 (32.9)	29 (17.7)	
Presence of living children				
Yes	103(41.9)	29 (35.4)	74 (45.1)	0.144
No	143(58.1)	53 (64.6)	90 (54.9)	
Alcohol consumption and smoking (past 4 weeks)				
Both (drinking and smoking)	15(6.1)	10(6.1)	5(6.1)	0.001*
Neither drinking nor smoking	152(61.8)	112(68.3)	40(48.8)	
Only smokes	31(12.6)	11(6.7)	20(24.4)	
Only drinks	48(19.5)	31(18.9)	17(20.7)	
Utilization of services				
Both (CD4 and VLT)	25(10.2)	0 (0)	25 (15.2)	NA***
Only CD4	220(89.4)	82 (100)	138 (84.1)	
Only VLT	1(0.4)	0 (0)	1 (0.6)	
Perceived social support-friends				
High (≥6.78)	131 (53.3)	30(36.6)	101(61.6)	<0.001*
Low (<6.78)	115(46.7)	52(63.4)	63(38.4)	
Mean = 6.78, S.D = 1.9, Min = 3, Max = 9				
Perceived social support-family				
High (≥7.28)	155(63)	26 (31.7)	129 (78.7)	<0.001*
Low (<7.28)	91(37)	56 (68.3)	35 (21.3)	
Mean = 7.28, S.D = 2.04, Min = 3, Max = 9				
Medication self efficacy				
Optimal (=12)	158(64.2)	28 (34.1)	130 (79.3)	<0.001*
Less than optimal	88(35.8)	54 (65.9)	34 (20.7)	
Mean = 11.36, S.D =1.66, Min =5, Max =12				
Patient-provider communication				
Optimal	193(78.5)	49 (59.8)	144 (87.8)	<0.001*
Less than optimal	53(21.5)	33 (40.2)	20 (12.2)	
Stigma of disclosure				
High perceived stigma (≥28)	212 (86.2)	78 (95.1)	79 (48.2)	<0.001*
Low perceived stigma (<28)	34(13.8)	4 (4.9)	85 (51.8)	
Mean=28.71, S.D.=2.86, Min=20, Max=39				

Note: p <0.05*, Pearson's goodness of fit >0.05; ***NA = Not Applicable, since the variable has 0 value in one of its category

Table 2 Final model of multiple logistic regression for adherence to ART among HIV positive females of Nepal

Factors	Adjusted OR	95% CI		*p-value*
		Lower	Upper	
Monthly family income (NRs)				
<7000	1			
≥7000	5.214	2.209	12.308	<0.001**
Marital status				
Divorced/Widowed	1			
Single	4.781	1.431	15.973	0.011*
Married	1.417	0.554	3.622	.467
Perceived social support-family				
Low	1			
High	3.405	1.469	7.890	0.004**
Medication self efficacy				
Not optimal	1			
Optimal	5.878	2.597	13.302	<0.001**
Patient-provider communication				
Not optimal	1			
Optimal	3.663	1.362	9.854	<0.010*
Perceived stigma of disclosure				
High	1			
Low	15.766	4.947	50.244	<0.001**

Note: p <0.01**, p <0.05*, Pearson's goodness of fit >0.05. Reference group "0" was "non-adherent" and "1" was "adherent"

adherence [19-22]. However, similar to other research conducted among male and females, education, marital status and family income (economic status) were significantly associated with adherence to the treatment [23-26]. Women from a lower socio-economic status were found five times more likely to miss their doses compared to women from higher socio-economic status. Poverty is also associated with many other predictive factors such as education, social support, awareness and ability to pay for associated costs of healthy living. A meta-analysis conducted by Falagas et al. [25] reported that seven out of 14 reviewed studies found a patient's level of income to be associated with their adherence to ART.

Women who had high perceived social support of family were three times more likely to adhere to the treatment, even though a study conducted by Yadav [27] states that the patients have greater non-family support network than family support. This could be due to the fact that in Nepali society women are generally responsible for managing non-financial/ household needs, and thus need greater support from a wider family network. This lack of social networking has been identified as a barrier to adherence [28], which can further indicate the reasons for family support being a big influence in a patient's life. Interestingly, presence of children was not associated with the level of adherence among the patients. Some patients reported that responsibility of a child gave them motivation to stick to their regimen for better health with few even saying that their children reminded them to take their medications on time. This can also indicate the importance of family support, as in Nepal, presence of other family members like mother-in-law or aunts and uncles etc. act as a support system in raising a child. Hence, a mother may not have a sole responsibility for her children. This can help her focus better on her own health and adhere strictly to her treatment.

Self efficacy is another psycho-social variable found to be a predictor of adherence behavior among women in Nepal. Women having optimal efficacy were six times more likely to stick to their treatment irrespective of any obstacle than women without optimal efficacy. This is in accordance to another research study which found that medication self efficacy indicated positive schedule adherence [29]. Also a study by Murphy [22] among HIV positive women with children showed that poor medication efficacy was associated with poor medication adherence. However, the modified self efficacy scale used for this study is not optimal for measuring the self efficacy accurately. Since the questionnaires were administered by the researcher, it employed a self efficacy with only three response scale (0-1) instead of a wide range as is the norm with psychosocial variables.

A considerable number of the women did not understand the answers or instructions provided by the health care personnel easily hence making

patient-provider communication to be another predictive factor for adherence to the treatment. The patients with optimal communication with their provider were four times more likely to stick to their treatment plan compared to patients who did not. This indicates that although everyone receives instructions from their providers, many of the patients are not having treatment plans tailored to their unique needs.

The conservative society of Nepal often paints women with HIV/AIDS with negative stereotypes of sexual deviancy, often leading them to hide their condition out of shame. Perceived stigma of disclosure was found to be the predominant predictor of adherence to ART. Women with lower perceived stigma for disclosure were 15 times more likely to be adherent to ART than women with higher perceived stigma for disclosure. This can be attributed to the fact that most of the women had not revealed their status to anyone outside their close knit circle of friends, family and care providers. Disclosure status was also the chief factor influencing adherence among men and women in a study by Wasti [8].

LIMITATIONS AND STRENGTHS

The threshold for measurement of adherence among respondents is heterogeneous among various studies. For example, studies categorize adherent as 100%, ≥95%, >90 or >80%. Even this categorization differs on the duration it is measured, varying from 3 days, 7 days, 2 weeks, 4 weeks, 3 months and even 6 months. Also, different studies measure adherence by different methods. This study categorizes adherence as 100% over a period of past 4 weeks to categorize a respondent as adherent to treatment. This has made comparison across various studies difficult. Moreover, this study uses a self reported questionnaire as the method of collecting information on dose adherence which is quick and inexpensive, but also highly subjected to social desirability and recall bias [30]. Despite several limitation, the study has highlighted that stigma of disclosure is the main predictor of non adherence. Hence, interventions are needed to address the issue of the patient's fear of disclosure beyond their immediate circle. Also, patient centered discussion regarding the most practical tips for encouraging adherence should be discussed between patient and the provider.

CONCLUSION

Adherence among the women to ART was found to be 66.6%. Family income level, perceived social support-family subscale, medication self efficacy, patient-provider communication and perceived stigma of disclosure were found to be predictive of adherence behavior among the women in Nepal. Health providers should be trained to identify women with low self efficacy or support. The provider may emphasize on specific customized counseling targeting these women to ensure that they stick to their regimen, as well as options like mobile phone alert systems to keep them on schedule. Additionally, stigma of disclosure and perceived family support were found to be the major predictor of adherence. In order to promote better adherence, a 'buddy' system can be introduced to Nepal's HIV positive female population, as a first step in creating a strong support network which helps these women cope with their disease together.

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