

## Psychosocial Adaptation and ART Adherence of HIV-infected Adults at an Urban Ambulatory Clinic in Uganda

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### Abstract

**Introduction:** Success of antiretroviral therapy (ART) requires that individuals maintain nearly one hundred percent adherence to the prescribed regimen. Lack of optimal adherence to ART is associated with a high risk of developing mutant HIV strains, and increased risk of HIV transmission. Psychosocial adaptation is associated with positive health behaviors in HIV. In this study, we determined the correlation between psychosocial adaptation to living with HIV and adherence to ART, and determined the factors associated with psychosocial adaptation.

**Methods:** In this cross sectional study, we interviewed 235 HIV-infected adults that receive ART from the infectious Diseases Institute (IDI) clinic and used the Health Related Hardiness Scale (HRHS) to measure psychosocial adaptation. Adherence to ART was determined by self-report of the number of doses missed in the previous 7 days. Pearson correlation was used to determine the relationship between psychosocial adaptation and adherence to ART. Logistic regression was used to determine the factors associated with psychosocial adaptation.

**Results:** Most (60.4%) were females, married or staying with a partner (46.4%) and had some form of employment (74.4%). Participants had a mean age of  $38 \pm 9$  years, had been registered in the HIV clinic for a median period of 6 years, with a mean duration on ART of  $4 \pm 3$  years. A majority (86%) were adherent to ART. HRHS is found to be reliable (Cronbach's  $\alpha=0.83$ ) and participants had a percentage mean adaptation of 85.9%. There was a significant correlation ( $r=0.159$ ,  $p=0.015$ ) between psychosocial adaptation and adherence to ART. Excellent perception of health status (OR=2.36, 95% CI=1.22-4.53,  $P=0.01$ ), very good self-rating of ART adherence (OR=3.35, 95% CI=1.74-6.50,  $P<0.001$ ) and on-time ART doses (OR=2.17, 95% CI=1.06-4.72,  $P=0.39$ ) were associated with psychosocial adaptation.

**Conclusions and recommendations:** There was high adherence to ART and good psychosocial adaptation to living with HIV in an urban Ugandan HIV cohort. Individuals' psychosocial adaptation correlated positively with ART adherence levels. Routine assessment of psychosocial adaptation during follow-up of ART-treated adults could be used to identify risk of non-adherence. Longitudinal studies are required to understand ART adherence levels and fluctuations in psychosocial adaptation during daily lived experiences.

**Keywords:** Antiretroviral therapy; Adherence; Psychosocial adaptation; HIV Patients

### Introduction

The United Nations Joint Program on AIDS (UNAIDS), estimated that as of December 2009, 33.3 million people worldwide were living with Human Immunodeficiency Virus (HIV), compared to 26.2 million in 1999 [1], and more than two thirds (22.5 million) of them live in Sub Saharan Africa. Additionally, the number of people receiving antiretroviral therapy (ART) in low and middle income countries like Uganda increases from 5.2 million in 2009 to 9.7 million in 2012 [2,3]. Although HIV/AIDS still remains a life threatening illness, it has become more manageable with the advent of ART and has allowed individuals to live longer after diagnosis. As a result, the combination ART has transformed HIV into a chronic treatable condition for a significant proportion of people with access to this treatment. However, the need to maintain patients on treatment for decades rather than years, calls for a long-term perspective on antiretroviral therapy. Adaptation to living with HIV may be one of the long term perspectives. Failure to adhere to the necessary ART is associated with faster progression to Acquired Immune Deficiency Syndrome (AIDS) [4]. Therefore successful treatment requires that people with HIV maintain nearly 100% adherence to the prescribed regime [5]. Yet, many individuals on

long-term treatment experience stressors and mental health problems related to HIV as a chronic illness [6]. They, like those with other lifelong health conditions, must adjust to living with their illness as well as the demanding treatment regime. Such adjustments generally involve engaging in health promoting behaviors as well as avoiding risk behaviors.

In Uganda, HIV prevalence is estimated to be 6.4% amongst adults

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[7]. Since 2004, there has been a roll-out of free ART which has played a significant role in reducing morbidity and mortality amongst HIV infected patients in Uganda. Currently, about 400,000 HIV infected individuals in Uganda are accessing ART from about 480 accredited ART sites across the country [7]. The Infectious Diseases Institute (IDI) at Makerere University, whose mission is to build capacity of African health systems for the delivery of sustainable, high quality HIV/AIDS care and prevention programming through training, research, and advanced clinical services, is one of the sites where comprehensive HIV care, including ART services, are offered. A total of 7355 clients currently receive ART from IDI [8]. However as the health authorities make all efforts to increase access to ART by HIV/AIDS patients the challenge that come with increased access is ensuring that patients adhere to treatment and engage in health promoting behaviors. This is important in order to ensure prevention of the development of fatal drug resistant HIV strains.

In a study that explored the combined effect of ART regimens and adherence on mortality over time, Lima and others found that individual adherence decreased over time, with the mean adherence shifting from 79% within the first 6 months of starting ART to 72% within the 24 to 30-month period, and a strong association with higher risk of mortality [9]. Other longitudinal studies have also found a decrease in adherence over time [10-12], suggesting that as the chronicity of HIV increases, adherence to ART decreases. These results also highlight the need to develop further strategies to help sustain high levels of adherence on a long-term basis and adapt to living positively and healthy lives while infected with HIV.

As in the case of other lifelong treatments, adherence to ART is a complex and dynamic phenomenon that is influenced by social factors and psychological characteristics of the patient. For instance lack of social support has been associated with lower levels of adherence to ART [13,14]. Personal lack of confidence and negative attitudes toward taking medication has also been associated with reduced levels of adherence [12]. Adaptive living is crucial to help people living with HIV maintain the best possible physical and psychosocial well-being. Persons living with HIV experience ongoing psychosocial stressors, both interpersonal and intrapersonal, associated with diagnosis of a life threatening chronic illness [12,14]. These stressors profoundly affect the individual's quality of life and strain existing coping resources. Persons living with HIV who adapt well and have more positive meaning of the illness experience lower depressed mood [15], such individuals are likely to engage in health promotion behaviors like taking their medication. Despite extensive research on adherence to ART, and mental health problems associated with living with HIV, there is little research on how HIV positive persons psychosocially adapt to living with HIV. The purpose of this study therefore was to assess the relationship between psychosocial adaptation to living with HIV and ART adherence in HIV positive adults and to determine factors associated with psychosocial adaptation.

## Methods

We used a descriptive correlational design to collect data from a sample of 235 HIV adult patients attending the HIV/AIDS clinic at IDI in Kampala, Uganda. The Infectious Diseases Institute (IDI) is one of the centers of HIV care and support in Uganda, extending HIV care to over 30,000 patients. We used systematic sampling to select study patients, and each patient was asked to give signed informed consent. Data were collected over a period of 10 days. The participants included in this study were HIV positive individuals aged 18 years and above

and taking ART at the time of the study. The participants had to have started the ART medication at least three months prior to the time of data collection. Individuals who were too sick, unable to respond to questions, or unable to speak or understand English or Luganda (the most commonly used local language at the study site) were excluded from the study. This study was approved by the Institutional Review Board of School of Health Sciences, Makerere University.

## Measures

The variables measured in this study were demographic and HIV related, psychosocial adaptation to living with HIV, and adherence to ART. Demographic characteristics included the patient's age, marital status, gender, monthly income, education level, employment status, and perception of health status, impact of HIV on daily activities, time since HIV diagnosis, and time since ART initiation. Psychosocial adaptation to living with HIV was conceptualized as the ability of a person diagnosed with HIV to emotionally cope with their condition so that they can maintain some quality of life. Psychosocial adaptation to living with HIV was measured by Health Related Hardiness Scale (HRHS) which consists of 34 items with reliability scores ranging from Cronbach's alpha 0.74 to 0.78 [16]. This scale comprises of three subscales; commitment, challenge and control. These three subscales have been regrouped into two; commitment/challenge and control. HRHS is scored on a 6-point Likert scale and higher scores indicate greater psychosocial adaptation. The scores on the control subscale (14 items) range from 14 to 84 with high scores indicating high control. The 20 item commitment and challenge subscale scores range from 20 to 120, higher scores indicate greater commitment. To avoid response bias, each subscale contains some negatively worded items, as recommended by the authors of HRHS; the scores of the negatively worded items were reversed for analysis. The composite score of the HRHS ranges from 34 to 204. The investigators analyzed the items of the HRHS and found them to be culturally neutral; they were therefore used without any modification.

Adherence was measured by asking participants to remember the number of missed doses of their medication in the previous 7 days, doses taken late in last 7 days and self-rate of how adherent they have been over the last one month on a likert scale ranging from very poor to excellent. Self-report measures have been found to be valid and reliable in measuring adherence to ART [17].

## Data Management and Analysis

Data collected was checked for completeness, cleaned and analyzed using Stata version 10 to generate descriptive statistics and examine relationships between adaptation to living with HIV and ART adherence. The mean, median, range and standard deviations were computed for descriptive statistics of the continuous variables. The categorical variables were described in form of frequencies and percentages. The relationships between adherence and psychosocial adaptation were evaluated with Pearson's *r* coefficients. The confidence level of 95 percent was used and the results with *p* values of less than 0.05 were considered significant. To assess the reliability of HRHS, scale reliability analysis was performed. Cronbach's alpha which is a coefficient of reliability was reported. To determine factors associated with psychosocial adaptation, bivariate and multivariate logistic regressions were performed. We established a cut off for use in grouping participants as adaptive or maladaptive using roc curve analysis. In so doing, we divided the HRHS scores into deciles and got the score that corresponded to the highest correlation coefficient. This score was then used for logistic regression analysis to find predictors of psychosocial

adaptation. Following bivariate analysis, plausible variables, and those with p values of 0.2 or less were entered in the multivariate logistic regression model. All p values were two tailed and statistical significance was set at 0.05.

## Results

### Description of the Sample

Of the 264 patients sampled, 235 (89%) consented to join our study. Not having enough time to be interviewed was the main reason for refusal to participate in the study. Majority of the patients (60.4%) were female, married or staying with partner were (46.4%), and had mean age of 37.7 years (SD=9.12). Majority 128 (54.4%) had at least secondary education, and 211 (90%) had at least one child. About two thirds of the participants 154 (65.5%) perceived themselves to be in good or excellent health status. Participants had been registered and attending this HIV clinic for an average of 6.8 years (SD=4.97) and had taken ART medication for 4 years (SD=3.08). Other socio-demographic characteristics are shown in Table 1.

### Adherence to ART

The majority 202 (86%) of the HIV positive adults had not missed any ART dose in the previous one week, 175 (74.5%) did not take any ART dose late and about half 113 (48%) rated their adherence in the previous one month as very good or excellent (Table 2).

### Psychosocial adaptation

The health related hardiness scale which was used to assess psychosocial adaptation in this study had an internal coefficient of 0.83. Out of the maximum expected total score, participants in this study scored a mean of 175.5 (SD=17.27).

Variable	Frequency ( n=235)	Percentage (%)
Gender		
Male	93	39.6
Female	142	60.4
Marital status		
Never married	46	19.6
Married/staying with partner	109	46.4
Divorced/separated	39	16.6
Widowed	41	17.4
Highest Level of education		
No formal education	13	10.2
Primary	94	40
Secondary	81	34.5
Advanced level	13	5.5
Higher institution	34	14.5
Number of children		
None	24	10.2
One to two	64	27.2
Three to five	102	43.4
Six to eight	26	11.6
More than eight	19	8.1
Self-perception of health status		
Poor	14	6
Fair	70	29.8
Good	120	51.1
Excellent	31	13.2

Table 1: Background and Health status information of study participants.

Adherence Measure	Frequency (n=235)	Percentage (%)
Seven day 100% adherence		
Adherent	202	86%
Not adherent	23	14%
One month personal rating		
Poor/Fair	13	5.6%
Good	109	46.4%
Very good	88	37.4%
Excellent	25	10.6%
Took ART>2 hours late in past seven days		
No	175	74.5
Yes	60	35.5

Table 2: Distribution of respondents by different adherence to ART measures.

Health related hardiness Scale	Missed doses		Doses taken >2 hours late	
	Pearson correlation	P-value	Pearson correlation	P-value
Composite scale	-0.159	0.015	-0.257	<0.001
Control sub scale	-0.042	0.52	-2.158	0.015
Commitment/ challenge sub scale	-0.218	0.001	-2.74	<0.001

Table 3: Pearson correlation analysis for HRHS and adherence to ART of HIV positive adults as measure by number of doses missed and doses taken more than 2 hours late in the previous seven days.

There is a negative significant correlation ( $r=-0.159$ ,  $p=0.015$ ) between number of ART missed doses and psychosocial adaptation to living with HIV (Table 3). Using roc curve analysis, the highest correlation corresponded to a psychosocial score of 172. Using this score as the cutoff for psychosocial adaptation as the outcome variable, excellent one month adherence (AOR 3.35, 95%CI 1.74-6.5  $p<0.001$ ), having taken no ART dose more than two hours late (AOR 2.17, 95%CI 1.06-4.72,  $p=0.039$ ) and perceiving own health status as good or excellent (AOR 2.36, 95%CI 1.22-4.53  $p=0.010$ ) were associated with psychosocial adaptation at multivariate logistic regression. Other factors associated with psychosocial adaptation at bivariate logistic regression are shown in Table 4.

## Discussion

We found that a high proportion (86%) of HIV infected patients receiving antiretroviral therapy had excellent adherence to their ART and had not missed any dose in the previous seven days. High levels of adherence to ART in Uganda has been reported in other studies [18-20] among adult HIV positive patients taking ART. Similarly, other studies in Sub Saharan Africa have reported higher proportions of HIV adults being highly adherent to ART. Overall data from the meta-analysis of patients' self-reports indicated that a pooled estimate of 77% was adherent to ART [21]. Adherence to ART among the respondents in this study could have been the result of psychosocial resources provided to them. For example, most patients at IDI are encouraged to disclose their HIV status, join social groups and are availed with ongoing counseling. There are also adherence counselors who specifically talk to patients found to have problems taking their ART medications. Although majority of the HIV individuals on ART in Uganda and Sub Saharan Africa in general are optimally adherent, the few non-adherent individuals play an important role in the success of ART. Lack of optimal adherence to ART has been associated with a high risk of developing mutant strains of the virus [22], and higher levels of HIV in the seminal and cervical secretions which may increase the risk of HIV transmission [23]. In fact, earlier research demonstrated

Variable	Bivariate			Multivariate		
	UOR	95% CI	P-value	aOR	95% CI	P-value
Age (years)						
≤ 37	1.00			1.00		
>37	1.94	1.16–3.26	0.012	1.67	0.87–3.20	0.163
Marital status						
No partner	1.00			1.00		
Staying with partner	0.635	0.37-1.08	0.092	1.63	0.87–3.05	0.243
Education						
< Secondary	1.00			1.00		
≥ secondary	1.62	0.96-2.71	0.069	1.21	0.64–2.22	0.587
Perceived health status						
Poor/Fair	1.00			1.00		
Good/excellent	1.51	0.90–2.54	0.11	2.36	1.22–4.53	0.010
Duration with HIV(years)						
≤5	1.00			1.00	1.00	
>5	3.13	1.79–5.46	<0.001	1.69	0.80-3.56	0.167
Duration on ART (years)						
>4	1.00			1.00		
≤4	1.73	1.03-2.92	0.038	0.90	0.44–2.00	0.88
Monthly income						
≤250000	1.00			1.00		
>250000	1.33	0.78–2.25	0.90	1.03	0.55–1.95	0.913
HIV impact on daily activities						
>4	1			1.00		
≤4	1.07	0.64-1.79	0.801	1.55	0.79–3.00	0.211
7 days 100% ART adherence						
Not adherent	1.00			1.00		
Adherent	2.36	1.34–4.14	0.003	1.32	0.54–3.46	0.507
One month adherence						
Poor/good	1.00			1.00		
Very good/excellent	2.92	1.32–6.45	0.006	3.35	1.74–6.50	<0.001
Took ART>2 hours late						
Yes	1.00			1.00		
No	4.82	2.77–8.39	<0.001	2.17	1.06–4.72	0.039

**Table 4:** Bivariate and multivariate logistic regression of predictors of psychosocial adaptation score equal to or above 172.

the significance of a maintaining an almost perfect adherence to anti-retroviral drug regimens in order to decrease morbidity and mortality, and to improve the quality of life of HIV-infected persons [24,25].

We measured adherence to ART using self-report of missed doses, this method has been reported to be less sensitive in measuring adherence compared to objective measures such as MEMS caps and unannounced pill counts [26,27]. However, multiple measures of adherence to ART in a Ugandan setting by Oyugi and others found that all measures were closely correlated with each other (R=0.77-0.89) [18]. In this study, adherence ranged between 91%-94% by all measures and each measure was also significantly associated with the 12-week HIV viral load. There was no significant difference between patient-reported and objective measures of adherence. In sub-Saharan Africa (SSA), where neither the human resources to perform more time-consuming adherence assessment (such as counting of antiretroviral pills or reviewing pharmaceutical records) nor the financial resources to conduct more costly assessment (such as electronic monitoring or monitoring of blood ART concentrations) may be available, some researchers feel that self-report remains the most feasible method of assessing adherence to ART [28]. Self-report adherence is also inexpensive and can be easily and quickly administered. The higher adherence (91-94%) in this study

than 86% in our study could be explained by the fact that adherence was measured by doses missed in the previous 4 days and 7 days respectively. The longer the duration over which adherence is measured, the higher the odds of getting higher proportion of HIV patients missing doses of their ART medication [9-12,29].

### Psychosocial adaptation to living with HIV

The HRHS internal consistency in this study was 0.83 which compares well with the internal coefficient alpha of 0.76 found during its development [16] and is a good reliability score [30]. Cronbach's alpha values below 0.60 are considered poor, values from 0.60 to 0.69 are minimally acceptable, values from 0.70 to 0.79 are moderate or acceptable, values from 0.80 to 0.89 are considered good, and values above 0.90 are excellent [30]. The construct of the scale is measurably comparable to what was originally intended during the development of the tool. The mean composite score (175.24) was computed from the total expected score of 204, this mean score translates into 85.9%. The high psychosocial adaptation score in this study reflects the efforts made by health workers at the study site to address both the physical effects of HIV as well the social and psychological aspects. During data collection we noted that the patients have organized social activities which may enhance their ability to adapt socially to living with HIV.



## Relationship between psychosocial adaptation to living with HIV and adherence to ART

There is a significant negative correlation between the composite Health Related Hardiness Scale and the number of missed doses seven days prior to the interview. The higher the psychosocial adaptation score, the lower the chances that an HIV patient will miss a dose of their ART medication. Psychosocial problems have been reported to affect adherence to ART in other studies. In a study that explored the realities of HIV positive individuals on HAART, psychosocial issues such as depression, low social support and stressful life events were found to be associated with adherence to ART [31]. Furthermore, the level of adherence to antiretroviral treatment by persons living with HIV (PLWH) has been reported to depend on their ability to adapt to the situation of living with HIV/AIDS [32,33]. The correlation between psychosocial adaptations to living with HIV is a plausible one; the patients who are socially adapting to living with HIV will not fear taking their medication even in presence of some other people, they will also find it easy to get some support and reminders from others. It is important to note that forgetfulness is one of the most common reasons for missing ART medication. Once a person is socially adapting and has disclosed to some individuals, they are likely to be supported to remember to take their medications.

## Limitations

The HRHS which was used to assess psychosocial adaptation lacks cut offs to identify participants with poor psychosocial adaptation, it was therefore not possible to determine the prevalence of participants who had psychosocial maladaptation. In addition, we were not able to corroborate adherence measurements with clinical, immunological, or biological outcomes.

## Conclusion

There is a significant relationship between psychosocial adaptation as measured by Health Related Hardiness Scale and adherence to ART among HIV positive adults attending IDI ART clinic. HIV positive persons taking ART should be assessed for psychosocial maladaptation in order to design interventions to promote psychosocial adaptation and subsequently foster adherence to ART.

## Authors' contribution

Tom Denis Ngabirano, Amy Bender, Amsale Cherie, Charles Peter Osingada, and Rose Nabirye Chalo were responsible for the study conception, design, and data collection. Tom Denis Ngabirano, Joseph Sempa, Patrick Mburugu and Damalie Nakanjako. were responsible for data analysis and drafting of the first draft of the manuscript. All authors made critical revisions to the final paper.

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