

# The Value of Support Group Participation in Influencing Adherence to Antiretroviral Treatment among People Living with Human Immunodeficiency Virus (HIV)

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Received 11 July 2015; accepted 4 September 2015; published 7 September 2015

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## Abstract

Advances in antiretroviral therapy for both Human Immunodeficiency Virus (HIV) treatment and prevention have increased interest in adherence to HIV treatment. This is because the individual patient and public health benefits of antiretroviral treatment (ART) greatly depend on the extent to which people living with HIV (PLHIV) adhere to the prescribed daily dosing regimens. Studies have shown that nonadherence to ART increases drug resistance, morbidity and person-to-person HIV transmission. Public health experts are trying different innovations to enhance ART adherence, including promoting support groups of PLHIV. The purpose of this study was to determine the value of support group participation in enhancing ART adherence. The study used a cross-sectional design to compare ART adherence among PLHIV who participate in support group activities and those who do not. Respondents were adults who were initiated on ART between January 1, 2010 and December 31, 2012. Multistage probability sampling was used to select study sites and respondents. Data was collected using a self-administered questionnaire from 1676 respondents between February and May 2014. Data was analyzed using STATA. Univariate analysis was carried out to generate descriptive statistics, while Chi-square tests were used to examine if there was an association between participation in support group activities and antiretroviral treatment adherence. ART adherence was self-reported by 745/788 (95%) and 814/888 (92%) respondents who had ever and had never participated in support group activities respectively. Among respondents who reported nonadherence to ART, 74/117 (8%) had never participated in support group activities compared to just 43/117 (5%) who participated in support group activities. These findings suggest that PLHIV who participate in support group activities are more likely to adhere to ART

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than those who do not participate. This implies that there is value in participating in support groups by PLHIV in terms of ART adherence.

## Keywords

**Support Groups, Human Immunodeficiency Virus, Participation, Antiretroviral Therapy, Adherence**

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## 1. Introduction

Success in antiretroviral treatment (ART) for both Human Immunodeficiency Virus (HIV) treatment and prevention has rekindled interest in interventions that enhance ART adherence. This is because the public health impact of ART in reducing HIV transmission and enhancing treatment outcomes greatly depend on the extent to which people living with HIV (PLHIV) adhere to the prescribed daily dosing regimens of antiretroviral medicines. There is concern that a significant proportion of PLHIV on ART do not adhere to their ART [1]

According to the World Health Organization [2], adherence to treatment is the extent to which a patient's history of therapeutic drug-taking coincides with the prescribed treatment. The point that separates adherence from nonadherence is defined as that in the natural history of the disease which makes the desired therapeutic outcome likely (adherence) or unlikely (nonadherence) to be achieved. In ART, adherence of  $\geq 95\%$  is required to achieve durable suppression of viral load. ART adherence may be measured in various ways, for example, self-reports, pharmacy refill logs, pill counting, or a combination of these measures. Researchers have identified multiple factors associated with nonadherence to ART. These fall into broad categories including psychosocial issues, economic factors, substance abuse, co-morbidities including psychiatric disease, low health literacy, and medication-related issues. Many of these factors are modifiable with adherence enhancing interventions [3].

Despite various interventions in ART adherence support, recent studies of PLHIV have reported low adherence rates. In a recent cross-sectional study on HIV infected adults attending an ART clinic in Nigeria, results showed an adherence rate of 85%, while a similar study in Ghana put adherence at 38% [4] [5]. A near perfect adherence level of  $\geq 95\%$  is required for the effective suppression of HIV/AIDS virus [6]. Excellent adherence is the cornerstone of successful ART because nonadherence leads to drug resistance, treatment failure and death. Also, nonadherence to ART leads to an increase in viral load and increases the risk of HIV transmission from an infected to an uninfected sexual partner. Nonadherence to ART has been associated with risky sexual behaviors. In a study in Atlanta, USA, results show that nonadherent Men who have Sex with Men (MSM) were more likely to have a greater number of sex partners and engage in unprotected sex than those who were adherent [7]. Also, there is evidence that ART reinvigorates sexual desires and sexual activity of PLHIV; and that few PLHIV practice safe sex [8]-[10].

Available literature suggests that HIV-related stigma and nondisclosure of a positive HIV status are major obstacles to ART adherence and reduction in HIV transmission [1]. Nondisclosure of one's positive HIV status has been associated with internalized stigma-negative feelings towards oneself because of HIV positive status. Stigma makes some PLHIV remain silent, alienate themselves, and opt not to enroll in health care services, or hide their antiretroviral drugs (ARVs) from others even when they are faced with life threatening health conditions [11]. In a recent study in rural Nigeria, researchers found a strong association between levels of stigma and adherence to ART. Respondents with a low level of stigma were more likely to adhere to their treatment than those with high levels of stigma [12].

In order to optimize ART adherence, researchers and the public health community continue to explore interventions that reduce stigma and enhance disclosure. Social support interventions are one such strategy. Some studies have established a link between perceived social support and physical and mental health [13]-[16]. Also, social support has been found to promote psychological adjustment in people with high stress due to chronic health problems like HIV/AIDS [17]. In Nigeria, PLHIV support groups are the most common and popular way of providing social support for PLHIV. According to Fanelli & Moyo [18], a PLHIV support group is an association of PLHIV who come together to share challenges and experiences of living with HIV. It is believed that PLHIV who participate in PLHIV support group activities accrue individual and group benefits. Individual benefits include general supportive counselling, ART adherence counselling, and peer support for addressing other

HIV-related needs. Group benefits include education/information on HIV/AIDS management, group psychotherapy and experience sharing.

While a number of studies report protective benefits of perceived social support for PLHIV, for example, reduced HIV-related stigma; increased HIV disclosure; safer sexual behaviors; and ART adherence, there is little information about the value of social support group participation in enhancing ART adherence among PLHIV. There remained a gap in the knowledge; whether PLHIV who participate in support group activities are different from those who do not, in terms of adherence to ART. The purpose of this study was to determine the value of participation in PLHIV support groups in ART adherence.

## 2. Methods

### 2.1. Study Design

A cross sectional study was designed to compare ART adherence rates among PLHIV who participate in PLHIV support groups and those who do not. The researchers preferred a cross-sectional design because time and resource constraints precluded a longitudinal design. Data was collected between February and April, 2014. Study respondents included adult PLHIV who were initiated on ART between January 1, 2010 and December 31, 2012, were still in care at the sampled sites, and available to participate in this study. These included both PLHIV who participate in PLHIV support group activities and those who do not. A multistage probability sampling method was used to select study participants.

### 2.2. Study Setting

The study was carried out in Nigeria, in ART sites supported by the Strengthening Integrated Delivery of HIV/AIDS Services (SIDHAS) project implemented by Family Health International (FHI 360). The SIDHAS project aims to enhance accessibility, quality, integration and government ownership of comprehensive HIV/AIDS services in 15 states in Nigeria. The supported ART sites provide comprehensive HIV/AIDS services to the population from their respective catchment communities. The services include HIV testing and counselling (HTC), prevention of mother-to-child transmission of HIV (PMTCT), ART, and care and support for PLHIV. To enhance retention in care and ART adherence, hospital nurses, doctors and pharmacists provide adherence counselling to all HIV positive patients before initiating them on ART. Adherence counsellors continue to sensitize both pre-ART and ART patients about the benefits of PLHIV support groups and encourage them to become members so as to benefit from continuous adherence support, positive prevention and care services. PLHIV support group members meet at least once a month and carryout activities related to positive prevention, stigma reduction and group psychosocial therapy. Not all PLHIV enrolled in care participate in PLHIV support group activities.

### 2.3. Data Collection

A self-administered questionnaire was developed, pre-tested and used to collect data from the respondents. Most questions were adopted from instruments validated and used in similar settings. A few additional questions were developed to enlist responses peculiar to this study. The questionnaire included questions on: respondents' socio-demographic data (adopted from ORC Macro); PLHIV support group participation (developed by the researchers); and adherence to ART (adopted from a previously validated tool [19]).

Respondents were selected randomly from the sampling frame as they came for their ART refill appointments. The research assistants provided the ID numbers of all expected and eligible respondents to the pharmacists. The pharmacists identified clients on the sample list for each day by comparing the numbers on the patient folders or pharmacy order forms and requested them to meet with the research assistants. Research assistants met the referred clients and sought their consent to participate in the study by going through the informed consent form with each eligible respondent. After obtaining informed consent, research assistants provided questionnaires to consenting respondents; provided instructions for filling the questionnaire; and received completed questionnaires on the same day.

### 2.4. Measures

For purposes of this study, a PLHIV support group referred to a formal association of adult PLHIV who met

monthly either at a health facility or designated place in their community to discuss issues and carryout activities related to individual, group and community management of HIV/AIDS. A PLHIV support group could be health facility or community-based. Membership was defined as being formally registered with a particular PLHIV support group. Participation in PLHIV support group activities was measured as: 1) Having ever attended a PLHIV support group meeting; 2) attending monthly support group meetings. Participation in PLHIV support group activities was thus broadly defined as both being a member and having ever participated in PLHIV support group activities. This measure was a binary variable with response options of Yes or No. Furthermore, respondents were asked to indicate their frequency of participating in monthly PLHIV support group activities over the past 12 months. Responses were grouped in 1 - 5 (low participation) and 6 - 12 (high participation).

The key outcome variable was ART adherence. ART adherence was measured using a three-day drug recall. The following questions were asked to measure the frequency of antiretroviral doses missed in the past three days before the study: 1) “Did you miss your antiretroviral dose yesterday?”; 2) “Did you miss your antiretroviral dose the day before yesterday?”; 3) “Did you miss your antiretroviral dose three days ago?”. These questions were adopted from a tool developed and validated by Gagne & Naccache [19]. Respondents were asked to indicate by Yes or No whether on any of the past three days they had missed their morning/lunch or evening/dinner doses (for those not yet on fixed dose combinations) or their daily dose (for those on fixed dose combinations). After coding, these values were summed up to get the total number of doses missed in the past three days, divided by the expected number of doses and multiplied by 100 to get the nonadherence score *i.e.* percentage of doses missed in the last three days. With the nonadherence score, adherence was calculated and defined as <5% of doses missed. Therefore, we created a dichotomous variable for adherence: “YES” for taking  $\geq 95\%$  of prescribed antiretroviral drugs versus “NO” for taking <95% of prescribed antiretroviral drugs in the last three days before the study.

## 2.5. Data Analysis

All statistical analyses were performed using STATA software (Statacorp. 2011). Descriptive statistics such as median (Interquartile Range; IQR) were used to summarize continuous variables while categorical variables were summarized as proportions. Chi-square test was used to test for associations between categorical variables. P-value < 0.05 was considered statistically significant.

## 2.6. Ethical Approval

Before data collection, ethical clearance and approval were provided by the Institutional Review Board (IRB) of the University of Nigeria Nsukka, which is accredited by the Nigeria Federal Ministry of Health’s Research Ethics Council and the FHI360 Protection of Human Subjects Committee in North Carolina, USA.

## 3. Results

### 3.1. Socio-Demographic Characteristics of the Respondents

A total of 1676 PLHIV participated in this study. The questionnaire response rate was 82%. Of these, 66% (1111) were females and 32% (523) were males, while 42 (2%) did not indicate their sex/gender. At least 75% (1259) of respondents were below 45 years. The median age of respondents was 37 years (IQR 31 - 44). More than half of the respondents were married (57%), 44% completed secondary education, and 68% were self-employed. The majority (77%) of the respondents were Christians. Almost two-fifths (636) started ART in 2010 while 29% (488) and 33% (552) started in 2011 and 2012 respectively. **Table 1** summarizes the socio-demographics of respondents.

### 3.2. Membership and Participation in PLHIV Support Groups

One-third of the respondents indicated that they were members of a PLHIV support group, 8% had been members but had dropped out, while 6% had ever participated in PLHIV support group activities but had never been members. Approximately 53% of respondents had never participated in PLHIV support group activities. As participation in PLHIV support group activities was defined as both being a member and ever participated in PLHIV support group activities, 47% (788) of respondents were considered to have ever participated in PLHIV

**Table 1.** Socio-demographic characteristics of respondents (N = 1676)\*.

Characteristics	Frequency	Percentage
<b>Gender</b>		
Female	1111	66
Male	532	32
None response	42	2
<b>Age category</b>		
18 - 30	411	25
31 - 44	848	51
45 and above	385	23
None response	32	1.9
<b>Education</b>		
Completed primary	580	35
Completed secondary	737	44
Tertiary	267	16
Other	92	5
<b>Religion</b>		
Christianity	1288	77
Islam	356	21
Traditional	15	1
Other	17	1
<b>Source of income</b>		
Farming	306	18
My spouse	102	6
Office work	272	16
Trading/business	844	50
Unemployed	62	4
Non response	90	6
<b>Marital status</b>		
Currently married	947	56
Living with a sexual partner	29	2
Single	332	20
Widowed/separated	365	21
None response	3	0.2

\*All percentages presented were calculated based on N = 1676.

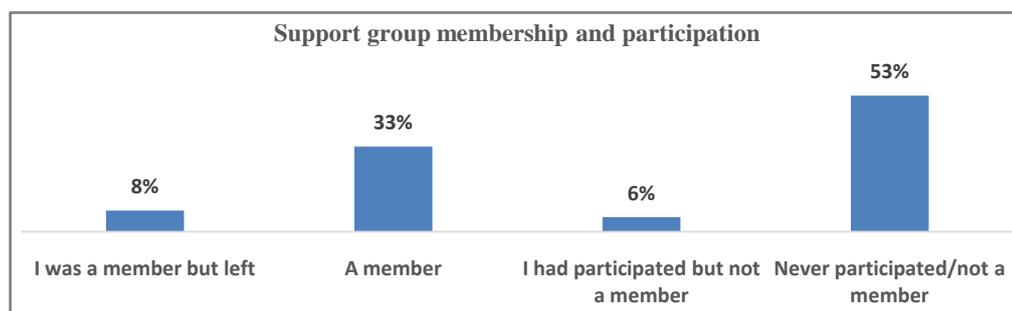
support group activities against 53% (888) who had never. This is summarized in [Figure 1](#).

### 3.3. Socio-Demographics of Respondents by Support Group Participation Status

The analysis in [Table 2](#) shows that PLHIV who participated in PLHIV support group activities did not significantly differ from those who did not, in terms of levels of education ( $p = 0.748$ ) and source of income ( $p = 0.067$ ), but significantly differed in marital status ( $p \leq 0.001$ ), age ( $p \leq 0.001$ ), sex ( $p = 0.029$ ) and religion ( $p = 0.034$ ). PLHIV who were not married (single, widowed, separated or divorced) were less likely to participate in PLHIV support group activities than those who were married or living with a sexual partner (37% vs 67%). PLHIV support group participation was similar among respondents aged 31 - 44 years (49%) and those aged 45 and above (50%). However PLHIV aged below 30 years were less likely to participate in PLHIV support group activities than those aged between 31 and 44 years as well as those over 45 years (21% vs 54% vs 25%). Despite there being more HIV positive women than men, men were more likely to participate in PLHIV support group activities than women (51% vs 45%). PLHIV who practiced traditional religion were more likely to participate in PLHIV support group activities than those who practiced Christianity and Islam (80% vs 47% vs 46%).

### 3.4. Comparison of ART Adherence Rates by Support Group Participation Status

Respondents' responses to questions about adherence to ART were scored to measure their rates of adherence.



**Figure 1.** Proportion of PLHIV who belong to and participate in PLHIV support group activities.

**Table 2.** Socio-demographics by support group participation status.

Variable	Support group participation				p-value
	NO		YES		
	n	%	n	%	
<b>Gender</b>					
Female	611	55	500	45	<b>0.029</b>
Male	262	49	270	51	
<b>Age category</b>					<b>&lt;0.001</b>
18 - 30	248	60	163	21	
31 - 44	430	51	418	54	
45 - 80	192	50	193	25	
<b>Education</b>					0.748
Completed primary	305	53	275	47	
Completed secondary	374	51	363	49	
Tertiary	141	53	126	47	
<b>Marital status</b>					<b>&lt;0.001</b>
Currently married	467	49	480	51	
Living with sex partner	15	52	14	48	
Single	195	59	137	41	
Widowed/separated	209	57	156	43	
<b>Religion</b>					<b>0.034</b>
Christianity	685	53	603	47	
Islam	193	54	163	46	
Traditional	3	20	12	80	
<b>Source of income</b>					0.067
Farming	154	49	158	51	
My spouse	60	59	42	41	
Office work	140	51	132	49	
Trading/business	441	52	403	48	
Unemployed	42	68	20	32	

Respondents who scored  $\geq 95\%$  were considered adherent while those who scored below 95% were considered nonadherent. Overall, 1559 (93%) of the respondents were found adherent and 117 (7%) not adherent. Generally, there was no significant difference between respondents' socio-demographics and their rates of adherence to ART except for marital status. Respondents' self-reported adherence was highest amongst married respondents (93%) and lowest amongst respondents living with sexual partner but not married (79%).

Adherence to ART amongst PLHIV who participated in PLHIV support group activities was reported by 745/788 (95%) respondents while adherence among PLHIV who never participated in PLHIV support group activities was reported by 814/888 (92%) respondents. These findings suggest that PLHIV who participate in PLHIV support group activities are more likely to adhere to ART than those who do not participate ( $p = 0.021$ ). The frequency of attending PLHIV support group activities has no association with ART adherence ( $p = 0.461$ ),

and neither does the year of ART initiation ( $p = 0.512$ ). **Table 3** summarizes respondents' socio-demographics, PLHIV support group participation status and ART adherence.

#### 4. Discussion

Membership of support group offers the opportunity for PLHIV to participate in their care at both the facility and community level. The finding that only 33% of PLHIV were members of a PLHIV support group is not significantly different from an earlier study in Uganda which put the figure at 30% [20]. Also, some of the reasons for nonparticipation are similar to findings of a previous study in South Africa. In this study, the reasons given for nonparticipation include lack of time (35%), lack of information about benefits of PLHIV support groups (29%), not wanting others to know the respondent's positive HIV status (14%), lack of transport (6%), and having other sources of support (5%). In the South Africa study, the major reasons for nonparticipation in PLHIV support groups were given as: 1) perception that attending PLHIV support group activities would be disclosing their positive HIV status to other people; 2) lack of knowledge of associated benefits; and 3) perceptions that PLHIV support groups lack skills and resources to provide effective psychosocial or other support needed by PLHIV [21]. The apparent low patronage of PLHIV support groups could also be associated with another finding in this study which shows that only 16% of PLHIV consider PLHIV support group members as their major

**Table 3.** Association between socio-demographics, PLHIV support group participation and ART adherence.

Variable	Adherence		P-value
	YES	NO	
	N (%)	N (%)	
<b>Gender</b>			
Female	1038 (93)	73 (7)	0.325
Male	490 (92)	42 (8)	
<b>Age Category</b>			
≤30	378 (92)	33 (8)	0.194
31 - 44	798 (94)	50 (6)	
44 - 80	353 (92)	32 (8)	
<b>Education</b>			
Completed primary	537 (93)	43 (7)	0.761
Completed secondary	688 (93)	49 (7)	
Tertiary education	246 (92)	21 (8)	
<b>Marital status</b>			
Currently married	884 (93)	63 (7)	<b>0.014</b>
Living with sexual partner	23 (79)	6 (21)	
Single	314 (95)	18 (5)	
Widowed	335 (92)	30 (8)	
<b>Source of income</b>			
Office work	255 (94)	17 (6)	0.255
Spouse	92 (90)	10 (10)	
Farming	291 (93)	21 (7)	
Trading	790 (94)	54 (6)	
Unemployed	54 (87)	8 (13)	
<b>Support group participation status</b>			
Participation	745 (95)	43 (5)	0.021
Non-participation	814 (92)	74 (8)	
<b>Frequency of participation</b>			
1 - 5 times	227 (95)	11 (5)	0.461
6 - 12 times	391 (97)	14 (3)	
<b>Year of ART initiation</b>			
2010	596 (94)	40 (6)	0.512
2011	455 (93)	33 (7)	
2012	508 (92)	44 (8)	

source of social support. This implies that apart from PLHIV support groups, PLHIV have access to other sources of social support and care.

The finding that people aged below 30 years were less likely to participate in PLHIV support group activities than those of higher age is consistent with young people's health seeking behavior [22]. Generally, in Africa, social norms stigmatize young people and inhibit their health seeking behavior. For example, society does not expect unmarried youths to be infected with sexually transmitted infections such as HIV or to be pregnant because they are generally expected to abstain from sex until marriage. Because of this, young people tend to shy away from places where sexual reproductive health services are provided. This may explain why young PLHIV shun PLHIV support groups which are more patronized by older people. Some programs have responded to this challenge by establishing youth friendly service centers.

The finding that men were more likely to participate in PLHIV support group activities than women (51% vs 45%) is a reflection of gender issues in Sub-Saharan Africa. Generally, African men have more "free" time and disposable income than women. Given that 41% of respondents who do not participate in PLHIV support group activities cited time and money (transport) constraints, it is possible that this is the reason why fewer women than men can afford to participate in PLHIV support group activities.

Study findings indicate that PLHIV who participate in PLHIV support group activities significantly differ from those who do not, in terms of adherence to ART ( $p = 0.021$ ). The finding that PLHIV support group participation is associated with ART adherence is consistent with previous findings which indicate that generally, support from peers, family members or health workers increased ART adherence [23]-[25]. The novel finding from this study is that social support from PLHIV peers, through a PLHIV support group mechanism, has value in terms of ART adherence. This finding is in line with Meaningful Involvement of PLHIV (MIPA)'s principle; that participation of PLHIV in HIV/AIDS prevention, care and treatment enhances their behavior outcomes including reduced stigma, positive HIV status disclosure, reduced sexual risk behavior and ART adherence.

This study presents heterogeneous data from 30 randomly selected health facilities in 10 states of Nigeria spread across five of the six geopolitical zones of the country, thus making the findings generalizable to the whole country. However, the study design had some limitations: Only those respondents who could complete a self-administered questionnaire written in English were included in the study, thus introducing some bias in the selection of respondents. Also, measuring ART adherence was limited to self-reports using a three-day drug recall method; some respondents might have over or under reported their ART adherence-this is inherent in self-behavior. Casual relationships could not be inferred because the study used a cross-sectional design. Further studies addressing these limitations are recommended.

## 5. Conclusion

The study suggests that there is an association between PLHIV participation in PLHIV support group activities and adherence to ART; PLHIV who participate in PLHIV support group activities are more likely to adhere to ART than those who do not participate. While the study's design and methodology did not delve into establishing a casual-relationship between PLHIV support group participation and ART adherence, this finding justifies investments in strengthening PLHIV support groups as one of the mechanisms for promoting social support and enhancing ART adherence among PLHIV. HIV/AIDS programs should invest more in strengthening PLHIV support groups as well as enhancing the social support competencies of PLHIV support group members as part of the strategies for enhancing ART adherence.

## Acknowledgements

SIDHAS State Program Managers, SIDHAS Monitoring and Evaluation Technical Officers, All research assistants, Chief Medical Directors of the sampled hospitals, Lisa Duli, Family Health International, Kenya.

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