

Participation in PLHIV Support Groups: Does it Enhance Behavioural Outcomes?

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Abstract

The role of antiretroviral therapy (ART) in HIV prevention has generated hope for an AIDS-free generation but also interest in behavioural outcomes of people living with HIV (PLHIV). This is from the knowledge that the benefits of ART in terms of enhancing PLHIV health outcomes and preventing HIV transmission depend on PLHIV's behaviours including sexual risk, disclosure, treatment adherence and retention. The purpose of this study was to examine whether PLHIV in Nigeria who participate in support group activities have different behavioural outcomes than those who do not.

A cross-sectional design was used to compare stigma, disclosure, sexual risk behaviors and ART adherence rates of PLHIV who participate in support group activities and those who do not. Respondents were adult PLHIV enrolled in ART from January 1, 2010 to December 31, 2012. Study sites and respondents were selected using multistage probability sampling. Data were collected using a self-administered questionnaire from 1,676 respondents between February and May 2014. Data were analysed using STATA. Univariate analysis was carried out to generate descriptive statistics while Chi-square tests were used to examine if there was any association between participation in support group activities and PLHIV selected behavioral outcomes.

PLHIV who participated in support group activities differed from those who did not in terms of HIV-related stigma ($p < 0.001$), positive HIV status disclosure ($p = 0.005$), ART adherence ($p = 0.021$), and sexual risk behaviors ($p = 0.045$). PLHIV who participated in support group activities were more likely to have less internal HIV-related stigma, disclose their positive HIV status, adhere to ART and live less risky sexual lives. These findings suggest that PLHIV who participate in support group activities are more likely to adopt positive behaviors than those who do not.

Keywords: Social support; Support groups; Participation; Stigma; Disclosure; Sexual risk behaviour; Antiretroviral treatment adherence

Introduction

Research findings which showed that ART is important for HIV prevention has increased interest in interventions that enhance positive behaviors of PLHIV. This is owing to the knowledge that the public health impact of ART in reducing HIV transmission and enhancing treatment outcomes significantly depends on how much PLHIV adhere to the prescribed daily dosing regimens of antiretroviral medicines and reduce risky sexual behaviors.

While HIV/AIDS control programmes have implemented a number of innovations to reduce sexual risk and enhance ART adherence and retention among PLHIV, stigma and non-disclosure of positive HIV status remain daunting challenges [1,2]. There is concern that due to stigma, a significant number of PLHIV in many sub-Saharan African countries do not disclose their positive HIV status to their sexual partners and delay to initiate treatment [2].

ART adherence is required to achieve durable suppression of viral load and thus reduce the risk of HIV transmission [3,4]. Despite various interventions for ART adherence support, recent studies 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% [5,6]. Although there are a number of factors associated with non-ART adherence, most of them are modifiable with appropriate adherence support interventions [7].

Nonadherence to ART has been associated with risky sexual behaviors. In a study in Atlanta, USA, results show that non-adherent 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 [8]. Moreover, other studies have found that ART

reinvigorates sexual desires and sexual activity of PLHIV [9-11]. Thus the need for reducing their sexual risk behaviors to reduce the risk of HIV transmission.

Studies have also shown that sexual risk behavior among PLHIV is associated with individual psychosocial wellbeing. In a prospective cohort study among PLHIV in Tanzania, researchers found that stress over time increases the risk of unprotected sex among PLHIV [12]. This highlights the need for psychosocial interventions such as social support to reduce HIV transmission risk behaviors among PLHIV.

Additionally, research findings suggest that HIV-related stigma and non-disclosure of a positive HIV status undermine efforts for ART adherence and reduction in HIV transmission [2]. Non-disclosure of positive HIV status has been associated with internalized stigma-negative feelings towards oneself because of one's HIV positive status. Stigma causes some PLHIV to remain silent, alienate themselves, opt not to seek healthcare, or hide their antiretroviral drugs (ARVs) from others even when they are faced with life threatening health conditions [13]. In a recent study in rural Nigeria, researchers found a strong association between HIV-related stigma and ART adherence. Respondents with a low level of stigma were more likely to adhere to ART than those with high levels of stigma.

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To reduce sexual risk behaviors and optimize ART adherence, HIV/AIDS programs continue to explore interventions that reduce stigma and enhance disclosure. Social support intervention is one such strategy. This is because some studies have established a link between perceived social support and physical and mental health [14-17]. In Nigeria, PLHIV support groups are the most common and popular way of providing social support for PLHIV.

PLHIV support groups are comprised of PLHIV who come together to share challenges and experiences of living with HIV. While researchers have reported some benefits of social support to PLHIV—reduced HIV-related stigma, increased HIV disclosure, safer sexual behaviors and ART adherence, there is limited information about the benefits of participating in PLHIV support groups in terms of positively enhancing their behavioral outcomes. The purpose of this study was to examine the differences between PLHIV who participate in support groups and those who do not in terms of four key PLHIV behavior outcomes; HIV-related stigma, sexual risk behavior, positive HIV status disclosure and ART adherence.

Methods

Study design

A cross sectional study design was used to compare HIV-related stigma, positive HIV status disclosure, sexual risk behaviors and ART adherence rates among PLHIV who participate in support groups and those who do not. Data were collected between February and April, 2014. Inclusion criteria for study respondents entailed:

- PLHIV still on ART at the sampled sites
- PLHIV who were initiated on ART between January 1, 2010 and December 31, 2012
- Adult PLHIV (aged 18 and above)
- PLHIV scheduled for ART refill during the data collection period.

Respondents included PLHIV who participate in support group activities and those who do not. Assuming a moderate within-hospital correlation of 0.05 among members of each group and a correlation of 0.025 between-group members led to a design effect of approximately 1.5 with a cluster size of 54 respondents in each of the 30 clusters to achieve the desired power. Based on this, the researchers estimated that they needed to enrol 1,620 PLHIV. Further accounting for 15% non-response, the researchers planned to enrol 1,906 respondents, approximately 64 respondents for each of the 30 sites. This was further rounded off to 70 participants per site.

Study participants were selected using multistage probability sampling. Out of the 15 states with FHI 360 operations, 10 were randomly selected. Thereafter, each supported hospital that met the following inclusion criteria was selected.

- Had at least 200 patients enrolled in ART
- Had active support groups
- Had been providing ART services since at least January 1, 2010.

Out of the 60 hospitals that met the inclusion criteria, the researchers randomly selected 30 hospitals. Once a hospital was sampled, identification numbers (IDs) of all adult PLHIV who met the above inclusion criteria were recorded. This constituted the site

sampling frame. From each site sampling frame, a simple random sample of up to 70 PLHIV were picked using STATA software version 12 to participate in the study.

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). Through technical, material and financial support, the SIDHAS project aims to improve accessibility, quality, and integration of comprehensive HIV/AIDS services in 15 states in Nigeria. Supported ART sites provide comprehensive HIV/AIDS services including HIV testing and counselling (HTC), prevention of mother-to-child transmission of HIV (PMTCT), ART and care and support for PLHIV. To enhance positive living, retention in care and ART adherence, site personnel including counsellors, nurses, doctors and pharmacists provide counselling to all HIV positive patients before initiating them on ART and put emphasis on positive prevention and treatment adherence. Counsellors continue to sensitize both pre-ART and ART patients about the benefits of PLHIV support group participation and interest them to join so as to benefit from continuous adherence support, positive prevention and care services. PLHIV support group members meet at least once a month and participate in activities related to positive prevention, stigma reduction and group psychosocial wellbeing. However, some PLHIV enrolled in care do not participate in activities.

Data collection

Respondents were randomly selected from the sampling frame as they came for their ART refill appointments. Research assistants provided ID numbers of all expected and eligible respondents to the pharmacists. The pharmacists identified sampled patients on the sample list for each day by comparing the numbers on the patient folders 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; instructions for filling the questionnaire; and received completed questionnaires on the same day.

Questionnaire and measures

A self-administered questionnaire was developed and pre-tested for data collection from respondents. The key PLHIV behavioural outcomes considered in this study were HIV-related stigma, positive HIV status disclosure, sexual risk behaviour and ART adherence. The instrument included questions on: respondents' socio-demographic data; PLHIV support group participation; HIV-related stigma; positive HIV status disclosure, sexual risk behavior; and adherence to ART. With the aim of ensuring use of reliable and valid measures for the key study variables, the researchers adopted instruments or relevant items thereof that had been validated in similar contexts.

For purposes of this study, a PLHIV support group referred to a formal association of adult PLHIV who met monthly at a designated place to discuss issues and carryout activities related to HIV/AIDS care and treatment. A PLHIV support group could be health facility or community-based. Participation in PLHIV support group activities was broadly defined as having ever attended a support group meeting. This measure was a binary variable with response options of "Yes" or "No". Additionally, respondents were requested to quantify 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).

To measure HIV-related stigma, the short version of the stigma measurement tool developed by Berger et al. [18] was used. The tool had been tested and found reliable and valid with Cronbach's Coefficient Alpha of more than 0.75 on all dimensions. When re-validated during questionnaire pre-testing, the selected items had a Cronbach's coefficient Alpha of 0.80 for internal stigma and 0.92 for external stigma. Two dimensions of HIV-related stigma were measured: (i) internal stigma, defined as negative feelings towards oneself because of being HIV positive; (ii) external stigma, defined as perceptions of being negatively viewed by others because of the person's HIV positive status. During data analysis, items in each subscale (internal and external stigma) were coded and scored. Scores for subscales were obtained by simply adding raw values for individual items.

Disclosure was defined as having revealed one's HIV positive status to a sexual partner/spouse, HIV positive child (by parents or caregivers), and co-worker, friends or healthcare provider. HIV status disclosure was measured by asking questions about whether respondents had disclosed their HIV positive status to the above categories of relations and confidants. Respondents who answered in affirmative to the questions were considered to have disclosed, while those who answered in negative were considered as not having disclosed. In addition, respondents were asked questions related to disclosure to their sexual partners (for sexually active respondents) or to any other person (friend, family member, support group member, co-worker, etc.) for non-sexually active respondents. These additional questions were needed to examine who PLHIV had disclosed to as this has significance in terms of reducing HIV transmission.

Sexual risk behavior was defined as practicing sex that puts the sexual partner at risk of getting infected with HIV. Even though all respondents were HIV positive, risky sexual behaviors expose their sexual partners to HIV infection, hence the interest in knowing whether and with whom PLHIV practice unsafe sex. Sexual risk behavior was measured by asking questions that required respondents to indicate whether in the past 12 months, they had or had not been involved in known risky sexual practices such as: sex with sexual partners outside marriage/cohabitation; sex with commercial sex workers; and unprotected sex without knowledge of the HIV serostatus of the partner. Respondents were expected to say "Yes" or "No". Response values were summed up to get the total number of Yes and No answers per group. These scores were compared among PLHIV in the two study groups.

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: (i) "Did you miss your antiretroviral dose yesterday?" (ii) "Did you miss your antiretroviral dose the day before yesterday?" (iii) "Did you miss your antiretroviral dose three days ago?" These questions were adopted from a tool developed and validated by Gagne and 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 non-adherence score. With the non-adherence 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.

For questions requiring socio-demographic information, the

researchers reviewed several tools used for similar studies and adopted relevant items and measures that had been validated in the HIV/AIDS and African contexts. In particular, items were extracted from questionnaires used in carrying out Demographic and Household Surveys in various countries in Sub-Saharan Africa. The adopted instruments/items were combined into one questionnaire with different sections.

Data analysis

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

Ethical approval

Prior to data collection, the researchers obtained ethical clearance and approval from 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, the Department of Higher Degrees, University of South Africa, and the FHI360 Protection of Human Subjects Committee in North Carolina, USA.

Results

Socio-demographic characteristics of the respondents

A total of 1,676 respondents participated in the study. Of these, 66% (1,111) were females while 32% (523) were males. Forty two respondents (2%) did not indicate their gender. At least 75% of the respondents (1,259) were below 45 years of age. The median age of respondents was 37 years (IQR 31-44). More than half of the respondents were married (57%), 44% had completed secondary education and at least 68% were self-employed. The majority of the respondents were Christians (77%). Almost two-fifths (636) were initiated on ART in 2010 while 29% (488) and 33% (552) started in 2011 and 2012 respectively.

Membership and participation in PLHIV support groups

One-third of the respondents indicated that they were members of a support group, 8% had been members but had dropped out, 6% had ever participated in support group activities but had never been members, while 53% had never participated in support group activities. As participation in support group activities was defined as having ever attended at least one support group meeting, 47% (788) of respondents were considered to have ever participated in PLHIV support group activities against 53% (888) who had never.

Socio-demographics of respondents by support group participation status

Table 1 shows that PLHIV who participated in 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. Support group participation was similar among respondents aged 31-44 years and those aged 45-80 years. However, PLHIV aged below 30 years were less likely to participate in support group activities than those aged between 31 and 44 years as well as those over 45 years. Men were more likely to participate in support

group activities than women and PLHIV who practiced traditional religion were more likely to participate in support group activities than those who practiced Christianity and Islam (Table 1).

Comparison of stigma scores among the two study groups

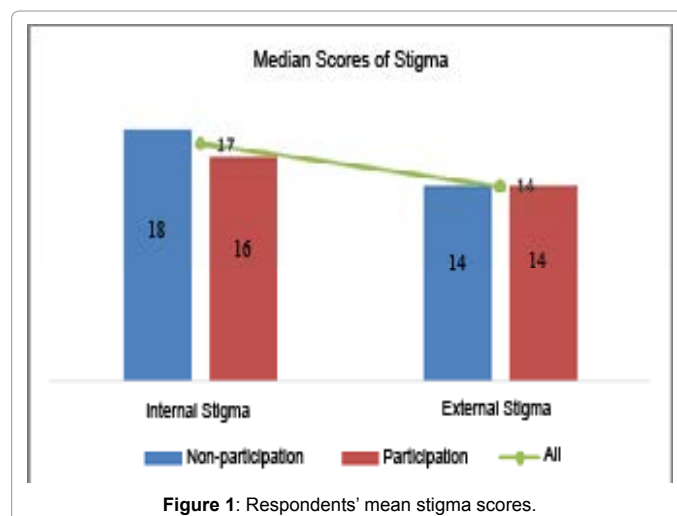
Responses to both categories of questions (related to internal and external stigma) were scored and the median scores of the two study groups compared. Median scores of internal stigma were significantly lower amongst PLHIV who participate in PLHIV support group activities than those of PLHIV who had never participated in support group activities ($p \leq 0.001$). Median scores of external stigma of PLHIV who participate in support group activities were almost similar with scores of PLHIV who do not, ($p = 0.250$). Overall internal stigma was higher than overall external stigma amongst all respondents. Total median stigma scores (internal plus external) of respondents who participate in support group activities and those who do not were not significantly different ($p = 0.88$) (Figure 1).

Comparison of positive HIV status disclosure rates among the two study groups

Overall disclosure was significantly higher amongst respondents who had participated in support group activities than those who had never participated ($p = 0.005$). Frequency of attending support group meetings did not have a dose effect on positive HIV status disclosure ($p = 0.316$) (Table 2).

Comparison of sexual risk behaviors by support group participation status

When sexual risk behaviors of the two study groups were compared, overall sexual risk behavior was higher among PLHIV who had never participated in support group activities than those who had participated; showing that there is a difference between the two groups ($p = 0.045$). There is no difference between PLHIV who frequently



attend support group meetings than those who attend less frequently ($p = 0.498$) (Table 3).

Comparison of ART adherence rates among the two study groups

Adherence to ARVs amongst PLHIV who participated in support group activities was reported by 95% respondents while adherence among PLHIV who never participated in support group activities was reported by 92% respondents. Among respondents who reported non-adherence to ART, 8% had never participated in support group activities compared to just 5% non-adherent PLHIV who participated in support group activities. The findings imply that PLHIV who participate in support group activities significantly differ from those who do not in terms of adherence to ART ($p = 0.021$). The frequency of attending support group activities has no relationship with ART adherence ($p = 0.461$) and the same applies to the year of ART initiation ($p = 0.512$) (Table 4).

Discussion

Belonging to a PLHIV support group provides opportunities for PLHIV to participate in their care both at the health facility and their communities. However, most PLHIV are yet to embrace PLHIV support group activities. The finding that only 33% of PLHIV were members of a support group is not significantly different from an earlier study in Uganda which put the figure at 30% [19].

The finding that people aged below 30 years were less likely to participate in support group activities than those of higher age is consistent with young people's health seeking behavior [20]. 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. Consequently, 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. To address this challenge, some programs have responded by establishing youth friendly service centres.

The finding that men were more likely to participate in support group activities than women is a reflection of gender imbalance in Sub-Saharan Africa. Generally, African men have more free time and money

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

Table 1: Socio-demographics by support group participation status.

Variable	Overall disclosure		P-value
	YES	NO	
Support Group Participation			
Non-participation	510 (75%)	172 (25%)	0.005
Participation	522 (81%)	121 (19%)	
Frequency of participation*			
1-5 times	153 (78%)	44 (22%)	0.316
6-12 times	265 (81%)	61 (19%)	

Table 2: Respondents' disclosure of positive HIV by participation status.

Variable	Total sexual risk behaviour		p-value
	NO RISK	YES RISK	
Support Group Participation status			
Non-participation	507 (69%)	233 (31%)	0.045
Participation	511 (73%)	186 (27%)	
Frequency of participation*			
1-5 times	152 (75%)	52 (25%)	0.498
6-12 times	258 (72%)	101 (28%)	

*Some participants who participated in support groups did not indicate the frequency hence the difference in totals.

Table 3: Respondents' PLHIV support group participation and sexual risk behaviours.

Variable	Adherence		P-value
	YES	NO	
Support group participation			
Non-participation	814 (91.67)	74 (8.33)	0.021
Participation	745 (94.54)	43 (5.46)	
Frequency of participation*			
1-5 times	227 (95.38)	11 (4.62)	0.461
6-12 times	391 (96.54)	14 (3.46)	

*Some participants who participated in support groups did not indicate the frequency hence the difference in totals.

Table 4: Respondents' PLHIV support group participation and ART adherence.

than women. Given that 41% of respondents who do not participate in 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 support group activities.

The study found that median scores of internal stigma were significantly lower amongst PLHIV who participate in support group activities than those of PLHIV who had never participated. This finding is consistent with earlier studies, which report an association between support group participation and reduced HIV-related stigma [21]. On the other hand, median scores of external stigma of PLHIV who participate in support group activities were almost similar to scores of PLHIV who do not. Possible explanation for this could be that while it is possible for people to overcome self or internal stigma through interventions such as counselling and disclosure, they have no control over external stigma because it is exerted by other people- it is not from within themselves. Also, participation in PLHIV support group activities inevitably leads to one's HIV status being known, thus opening up for public judgement and perceptions, which may increase the individuals' external stigma. Moreover, HIV-related stigma and discrimination persist as major obstacles to an effective HIV response in

the world, with national surveys finding that discriminatory treatment of PLHIV remains common in multiple facets of life [2].

Disclosure was significantly higher among respondents who had participated in support group activities than those who had never participated. This finding is consistent with previous findings which show that belonging to support groups enhances PLHIV's self-efficacy to disclose their positive HIV status to their sexual partners. In a qualitative study done in Rwanda [22], support group members reported that participating in the support group activities led to positive changes in mental health, positive HIV status disclosure, ART adherence and sexual risk behaviours. However, the support group activities in the Rwanda study had been facilitated by para-professionals who had been trained in trauma counselling rather than PLHIV themselves.

Furthermore, overall sexual risk behavior was higher among PLHIV who had never participated in support group activities than those who had participated implying that there is a slight difference between the two study groups. This finding is related to an earlier study in Kenya, which found an association between social support for PLHIV and reduction in risky sexual behaviors. In a prospective cohort study conducted in Mombasa, Kenya, researchers found that PLHIV who received community-based positive prevention reported reduced risky sexual behaviors compared with those who did not receive the support [23]. The difference between the two studies is that in the Kenya study, social support was provided by community health workers, not PLHIV themselves.

Data from this study shows that PLHIV who participate in support group activities significantly differ from those who do not in terms of adherence to ART- support group participation is associated with ART adherence. This finding is consistent with previous findings, which indicate that generally, social support from family members or health workers increased ART adherence [21-24]. The difference between this study and previous studies is that this study looked at social support from PLHIV support groups.

Overall, the frequency of attending support group activities had no association with any of the behaviour outcomes studied. PLHIV who had been participating in support group activities more frequently had similar behavioural outcomes as those who had been participating less frequently. This implies that the frequency of participation has no significant effect.

The novel finding from this study is that social support received or perceived by participating in support group activities with peer PLHIV has benefits in terms of positively influencing key behavior outcomes of PLHIV: reduced HIV-related stigma, positive HIV status disclosure, sexual risk behavior and ART adherence. This finding is in line with the Meaningful Involvement of PLHIV (MIPA)'s principle-- that participation of PLHIV in HIV/AIDS prevention, care and treatment is valuable in controlling and managing the epidemic.

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 sexual risk behaviors and ART adherence was limited to self-report; some respondents might have over or under stated their behaviors. Casual relationships could not be inferred because the study used a cross-sectional design. Also, the study did not delve into analysing

other factors that could influence PLHIV's behavior outcomes. Further studies addressing these limitations are recommended.

Conclusion

The study findings suggest that participating in support group activities has benefits in terms of enhancing positive behavioral outcomes of PLHIV: PLHIV who participate in support group activities are more likely to have less HIV-related internal stigma, disclose their positive HIV status, reduce sexual risk behaviors and adhere to ART than PLHIV who do not participate. While the study's design and methodology did not delve into establishing a causal- relationship between support group participation and the behavioral outcomes of interest, the findings justify investments in strengthening support groups of PLHIV as one of the mechanisms for preventing HIV transmission and enhancing adherence to treatment and retention in care. HIV/AIDS programmes should strengthen PLHIV support groups as part of the strategies for enhancing effective HIV prevention and treatment.

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Competing Interests

The authors declare that they have no competing interest.

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