

Factors associated with poor social support among Persons Living with HIV/AIDS at the Infectious Disease Institute HIV/AIDS clinic in Uganda, 2019: A cross-sectional study

Sharon Nakamanya Kitibwakye

Department of Pharmacy, Makerere University School of Health Sciences

Freddy Eric Kitutu (✉ kitutufred@gmail.com)

Sustainable Pharmaceutical Systems (SPS) unit, Makerere University School of Health Sciences

Angella Nabakooza Kigongo

Department of Pharmacy, Makerere University School of Health Sciences

Ronald Olum

Makerere University College of Health Sciences

Elizabeth Katana

Infectious Disease Institute, Makerere University College of Health Sciences

Eva Laker

Infectious Disease Institute, Makerere University College of Health Sciences

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Abstract

Background

Social support is known to influence desired health outcomes resulting in decrease in morbidity and mortality. HIV patients with poor social support are at risk of worse health outcomes. Little is known about the determinants of social support in the HIV population in Uganda. This study examined the determinants of social support among HIV patients on Atazanavir-based regimen at the Infectious Disease Institute HIV/AIDS clinic in Uganda.

Methods

We carried out a secondary analysis of data nested in a cross-sectional study to determine the prevalence of clinical jaundice among patients on Atazanavir-based second-line therapy, which was conducted at a specialist HIV center, Infectious Disease Institute (IDI) in Kampala, Uganda from April to May 2019. IDI is a specialist HIV center in Kampala, Uganda with over 7000 patients in care. The primary study consecutively sampled patients on an Atazanavir-based regimen. Social support was assessed by using a 3-item Oslo social scale. Logistic regression was used to determine the association between social support and its correlates.

Results

Data from 236 participants with the mean age of 40 years \pm 11 was analyzed. The majority were females (66.5%) and 34% were married. Up to 16.5% (39/236) had other comorbidities and less than 1% (2/236) were depressed. There was a high level of disclosure of status to either a family member, friend, spouse, or children (94%; 221/236). The prevalence of internalized stigma (4%; 9/236) and depression (2/236; 1%) was low. Only disclosure of HIV status was associated with social support (OR= 4.9, 95% CI 1.1 – 21.3, p-value= 0.038). There was no significant association of age, sex, marital status, education status, religion, other chronic comorbidities, depression, drug fatigue, and stigma with social support.

Conclusion

We found that good/ moderate social support was associated with disclosure of HIV status. However, the relationship between social support and disclosure of HIV status warrants further exploration using qualitative research methods.

Background

Social support networks enhance the performance of implementation programs in people living with HIV/AIDS (PLWHA).^{1,2} They are mainly existent amongst friends, partners, and family members including the patient's children.^{3,4} The support may be categorized into instrumental, emotional, or informational⁵. The extent of this support provided influences the health outcomes of patients.⁶ Poor social support in

PLWHA is significantly associated with low adherence to antiretroviral therapy (adherence < 50%),⁷ retention in care (8.1%),⁸ and disclosure of status (82%).⁹ It has also been found to potentiate mental illnesses such as depression according to a cohort study in the United States of America.¹⁰ PLWHA tend to have negative self-perceptions resulting into inefficiency, poor quality of life, internal-stigma and increased morbidity and mortality.¹¹ In order to counteract these negative effects, the influencers of social support need to be tackled.

In Iran, a study showed that determinants of social support for PLWHA included social network size, sex, and CD4 count.¹² In United States, disclosure was positively correlated with social support in PLWHA.¹³ A randomized clinical trial revealed that social support was not significantly associated with family's social demographics unlike that from friends. Social support provided by friends mainly depended on age, sex, education and employment, income and duration since diagnosis.¹⁴

Limited information is known about the determinants of social support in PLWHA more so in sub-Saharan African. In Uganda, only one study was done on the factors influencing support measured in terms of adherence lapses in PLWHA at a rural health facility in Western Uganda. Social support was positively associated with being female (RR = 0.66, P < 0.001), regular income (RR = 0.28, P < 0.001), food insecurity (RR = 1.79, P < 0.01) whereas negatively associated with depression (RR = 1.53, P = 0.001) and a day-to-day interaction with study participants (RR = 1.55, P = 0.002).¹⁵ Given the different social structures in rural and urban settings of Uganda, determinants of social support in rural settings may differ from those in peri-urban and urban areas. Knowledge on these determinants will aid in development of interventions aimed at improving social support and hence outcomes of PLWHA. Therefore, our study aimed to ascertain the determinants of social support in PLWHA in Kampala, Uganda's capital city.

Methods

This study was conducted as a sub-study for a cross-sectional study assessing the prevalence of clinical jaundice and its association with treatment adherence among patients on atazanavir-based second-line (in press). The study protocol was approved by Makerere University College of Health Sciences and institutional review boards.

Study setting

The study was carried out at Infectious Diseases Institute (IDI) located in Mulago, Kampala. Infectious Diseases Institute is a non-governmental Organisation (NGO) specializing in infectious diseases. IDI ART (Antiretroviral Therapy) clinic had 7783 active PLWHA as of October 2019. This study was conducted from April 2019 to May 2019.

Participants' Selection and Sampling

This study enrolled 236 study participants. Inclusion criteria for participation in the study were 1) age 18 years and above, 2) Taking ritonavir boosted atazanavir (ATV/r) for at least 3 months, and 3) Attending IDI ART clinic in April and May. Consecutive sampling was used to select study participants. Data was collected through face-to-face interviews administered by trained interviewers.

Measures

Dependent variable

Social support was the dependent variable in this study. It was measured by using an empirically standardized 3-item Oslo social support scale (OSSS-3). This instrument has 3 questions which include number of people the study participants counted on in case of great personal problems, the concern people show towards the study participants and the easiness with which the study participants obtain support from their neighbors. The scores from this questionnaire range from 3 to 14. These scores were categorized as 3–8, 9–11 and 12–14 and labelled as poor social support, moderate social support, and strong social support respectively. This categorization was based on its effectiveness in previous studies.^{16,17} For analytical purposes the outcome variable was considered on a binary scale – poor social support versus strong and moderate social support.

Independent variables

The independent variables included socio-demographic characteristics such as age in years, sex, tribe religion, education level, marital status, and substance abuse; duration on ART; comorbidities: hypertension, tuberculosis, diabetes; disclosure (yes or no); depression; stigma score and discrimination; alcohol consumption; cigarette smoking; abuse of other drugs and time interval between diagnosis to start of ART.

Duration on ART of the study participants was obtained from an IDI's patient software ICEA.

Stigma score and discrimination were measured by using the stigma scale for chronic illnesses 8-item (SSCI-8). This instrument was empirically validated for use on both internalized and enacted stigma as a single model.¹⁸

Depression was assessed by using Patient Health Questionnaires (PHQ) 2 and 9. PHQ 2 consisted of 2 questions with a total score of 6. Individuals who had a sum score of 3 or greater were administered the PHQ 9 questionnaire¹⁹. PHQ 9 questionnaire consisted of 9 questions and total scores ranged from 0 to 27. Scores for each individual were summed up to give an overall depression score. Participants had a probable diagnosis of depression if they scored 5 and above. Depression was further categorized into mild, moderate and severe depression.

Disclosure

of status was defined as having ever told anyone about your HIV status. It was assessed by asking “Have you ever told anyone about your HIV status?” Yes or no was the response to this question.

Study size

The sample size was calculated using Cochran formula²⁰. Using an estimated population of 871 PLWHIV on ATV/r regimen at IDI, 50% estimated prevalence of clinical jaundice since no study has been conducted in a similar setting, 5% acceptable margin of error at 95% confidence interval, a sample size of 270 was calculated. The original study enrolled only 236 participants. We were able to analyze data for all these participants

Data analysis

The collected data was analyzed using Statistical Package for Social Sciences (SPSS) software version 23. Descriptive statistics for continuous variables were mean (standard deviation) and median (interquartile range) for parametric and non-parametric conditions respectively. Frequency distribution tables, pie charts and percentages were used to summarize categorical data. We performed logistic regression analysis to determine the factors associated with poor social support among PLHIV with a significance level of 0.05. We conducted a bivariate logistic regression analysis for each variable and social support to determine the association. Variables with p-values less than 0.2 were fitted into a multivariable logistic regression model²¹. Non-significant variables were only considered in the final model if prior studies have associated them with social support. We used both stepwise forward entry and backward elimination methods to obtain results. Results were expressed as odds ratios (OR) and their 95% confidence intervals (CI). Factors with $p < 0.05$ were considered statistically significant. The final model was tested for goodness of fit using the Hosmer Lemeshow test.

Results

Data from 236 study participants was analyzed. Socio-demographic characteristics are summarised in Table 1. The mean age of respondents was 39.9 years (SD = 10.8) and more than half were female (66.5%, $n = 157$). One third of the participants subscribed to Roman Catholic religion (33.2%, $n = 78$). Majority of the participants had completed primary level education (36.4%) and were married (33.9%). Alcohol consumption among the participants in the study was (16.1%) with a low proportion of smokers (1.3%) and other abusers of drugs such as marijuana, khat (2.1%).

Table 1
Socio-demographic characteristics of PLWHA attending the IDI-ART clinic, 2019.

Characteristics (N = 236)	Category	Frequency (n)	Percentage (%)
Age	Mean, standard deviation	39.9	10.8
Sex	Female	157	66.5
	Male	79	33.5
Tribe	Ganda	133	56.4
	Ankole	24	10.2
	Others	79	33.4
Religion	Anglican	67	28.5
	Catholic	78	33.2
	Muslim	39	16.6
	Pentecostal	47	20.0
	Seventh day Adventist	4	1.7
Education level	None	23	9.8
	Primary	86	36.4
	Secondary	95	40.3
	Tertiary	32	13.6
Marital status	Married/Cohabiting	125	53.0
	Separated/widowed	68	28.8
	Single	43	18.2
Alcohol consumption	Yes	38	16.1
	No	198	83.9
Cigarette smoking	Yes	3	1.3
	No	233	98.7
Abuse of other drugs	Yes	5	2.1
	No	231	97.9

Clinical characteristics of the study participants

As shown in Table 2, most participants (93.6%) had disclosed their HIV status. Majority of the participants did not have any comorbid chronic conditions (83.5%). A high proportion of study participants reported to have started ART within one week to one year after diagnosis (47.9%). There was a low proportion of people with depression, (0.85%, n = 2) and (0%) while using the PHQ 2 and PHQ 9 scores respectively. Very few study participants (6.4%, n = 15) had poor social support status (Fig. 1).

Table 2
Clinical characteristics of PLWHA attending the IDI-ART clinic, 2019.

Characteristics (N = 236)	Category	Frequency (n)	Percentage (%)
Duration on ART	Mean (SD)	8.1	4.3
Comorbid chronic conditions	None	197	83.5
	Hypertension	14	5.9
	Diabetes	5	2.1
	Hypertension and diabetes	2	0.8
	Hepatitis B	1	0.4
	Others	17	7.3
Time interval between diagnosis to start of treatment	Immediately	59	25.0
	1 week to a year	113	47.9
	1 to 5 years	30	12.7
	More than 5 years	13	5.5
	Don't remember	21	8.9
Disclosure of HIV status	Yes	221	93.6
	No	15	6.4
Stigma and discrimination (SSC-8)	Yes	9	3.8
	No	227	96.2
Depression: PHQ-2	None/Mild	234	99.15
Depression: PHQ-9	Moderate	2	0.85
	None/mild	236	100
	Moderate/severe	0	0.0
<p>SSC-8–8-item Stigma Scale of Chronic illnesses, PHQ- patient health questionnaire. While using PHQ-2 tool, scores below 3 indicate mild depression and above 3 moderates but not conclusive depression. Administered PHQ-9 tool for moderate depression showed by PHQ-2. Scores 0–4 – no depression, 5–9 watchful waiting, 10–14 – moderate depression, 15–19 – moderately severe depression, 20–27 – severe depression. Social support was assessed using OSSS-3. Scores 3–8 – poor social support, 9–11 – moderate social support and 12–14 – strong social support.</p>			

Determinants of poor social support among persons living with HIV/AIDS

Bivariate analysis

An unadjusted association analysis was conducted to determine the association between socio-demographic and clinical characteristics and social support status among 236 participants (Table 3). Participants belonging to tribes other than Ganda and Ankole were less likely to have poor social support (OR:0.30, 95% CI: 0.09–0.94, $p = 0.039$). Non-Disclosure of one's status (OR: 4.35 95% CI: 1.08–17.52) was significantly associated with poor social support. Marital status and alcohol consumption had low statistically insignificant results.

Multivariate analysis

Bivariate analysis was performed to rank the relative importance of exposure variables with the outcome variable using crude odds ratios. A stepwise logistic regression model to control the effect of confounding and interaction was performed including all variables. There was no main exposure variable as all covariates with p -values ≤ 0.20 from the bivariate analyses were included in the multivariate model. All independent variables were controlled for as potential confounders in this model. Variables with a p -value of < 0.05 for two-sided tests were considered statistically significant. The final model had disclosure of status and sex of the participant and was tested for goodness of fit using the Hosmer Lemeshow test. The Hosmer Lemeshow test statistic for the adjusted model was 3.47 with a P Value of 0.06 implying that there was no evidence of lack of good fit. Non-Disclosure of HIV status was significantly associated with poor social support (OR = 4.38, 95% CI 1.08–17.62). The odds for poor social support were 4.94 times higher among patients who had reported non-disclosure of status to other people, and this was statistically significant while controlling for all other variables. Though not statistically significant, being female was associated with higher odds of poor social support (OR = 1.42 95% CI: 0.43–4.67). This information is summarized in Table 3.

Table 3

Association between patient characteristics and poor social support among PLWHA attending IDI-ART clinic, 2019.

Variable	Poor social support (n = 15) (%)	Strong & moderate social support (n = 221) (%) ref	Crude OR (95% CI)	P Value	Adjusted OR (95% CI)	P Value
Age (years)			1.01 (0.96–1.96)	0.778		
Duration on ART (years)			0.96 (0.84–1.10)	0.447		
Sex	11 (73.3)	146 (66.1)	1.41 (0.43–4.58)	0.565	1.42 (0.43–4.67)	0.562
Female	4 (26.7)	75 (33.9)			1.00	
Male			1.00			
Tribe	5 (33.3)	128 (57.9)	1.00	0.924		
Ganda	1 (6.7)	23 (10.4)	0.90 (0.10–8.04)	0.039		
Ankole	9 (60.0)	70 (31.7)				
Others			0.30 (0.09–0.94)			
Religion	1 (6.7)	66 (30.0)	1.00	0.174		
Anglican	5 (33.3)	73 (33.2)	0.22 (0.03–1.94)	0.146		
Catholic	3 (20.0)	36 (16.4)		0.064		
Muslim	5 (33.3)	42 (19.1)	0.18 (0.02–1.81)	0.044		
Pentecostal	1 (6.7)	3 (1.4)				
Seventh Day Adventist			0.13 (0.01–1.13)			
			0.05 (0.00–0.92)			

Variable	Poor social support (n = 15) (%)	Strong & moderate social support (n = 221) (%) ref	Crude OR (95% CI)	P Value	Adjusted OR (95% CI)	P Value
Education level	4 (26.7)	19 (8.6)	1.00	0.052		
None	4 (26.7)	82 (37.1)	4.32 (0.99–18.83)	0.063		
Primary	5 (33.3)	90 (40.7)		0.209		
Secondary	2 (13.3)	30 (13.6)	3.79 (0.93–15.40)			
Tertiary			3.16 (0.53–18.95)			
Disclosure of status	3 (20.0)	12 (5.4)	4.35 (1.08–17.52)	0.038	4.38 (1.08–17.62)	0.038
No	12 (80.0)	209 (94.6)				
Yes			1.00			
Alcohol consumption	14 (93.3)	184 (83.3)	1.00	0.325		
No	1 (6.7)	37 (16.7)	2.82 (0.36–22.07)			
Yes						
Marital status	4 (26.7)	39 (17.7)	1.00	0.526		
Single	8 (53.3)	117 (52.9)	0.67 (0.19–2.34)	0.312		
Married/Cohabiting	3 (20.0)	65 (29.4)				
Separated/Widowed			0.45 (0.10–2.12)			
Comorbid chronic conditions	15 (100)	182 (82.4)	1.00		No association	
None	0	39 (17.6)	1.00			
Yes						

Variable	Poor social support (n = 15) (%)	Strong & moderate social support (n = 221) (%) ref	Crude OR (95% CI)	P Value	Adjusted OR (95% CI)	P Value
Time interval between diagnosis to start of treatment	4 (26.7)	55 (24.9)	1.00	0.882		
	7 (46.7)	106 (48.0)	0.91 (0.25–3.23)	0.984		
Immediately	2 (13.3)	28 (12.7)		0.907		
1 week to a year	1 (6.7)	12 (5.4)	0.98 (0.17–5.69)	0.744		
1 to 5 years	1 (6.7)	20 (9.1)				
More than 5 years			1.15 (1.12–11.19)			
Don't remember			0.69 (0.07–6.65)			

Discussion

Social support is one of the backbones of HIV care as it improves clinical outcomes and adherence to antiretroviral treatment.¹⁵ Therefore, it is important for health systems to ensure strong social support in HIV care. To inform strengthening of social support to PLWHA in Uganda, we examined the determinants of social support in PLWHA at a large HIV care clinic in Kampala. We found that over 90% had moderate-strong social support. Only disclosure of HIV status was found to be significantly associated with social support in PLWHA. These results suggest that encouraging patients to continuously disclose their status to their acquaintances improves social support and consequently clinical outcomes such as reduction in viral load as it improves support from them. This may further enhance their involvement in HIV programs and decrease the burden of stigma in these patients.

These results are consistent with other literature findings. In a study conducted in Southwestern Uganda, more HIV positive women (73.9%) received support from their partners when they had disclosed their status²². In fact, this was validated by a multicenter cohort study in central Uganda which revealed that people who had disclosed their HIV status to spouses had a 17% higher chances of being supported²³. Conversely, a systematic review study in Uganda and Kenya showed that 16.7–86% of women could not disclose their status.²⁴ Barriers to disclosure included fear of its various negative outcomes, some of which included divorce, domestic violence, and anticipated withdrawal of financial support.^{25,26} Efforts to support disclosure of status when deemed safe should be encouraged. Furthermore, different partners should be engaged in the disclosure of HIV status to mitigate the insecurities associated with it. More community-based programs should also be set up to backup this.

Our study was not able to show an association between social support and age, sex, tribe, religion, education level, marital status, alcohol use, smoking, other substance abuse, duration on ART, comorbidities, depression, and stigma score and discrimination. A multicenter study in United Kingdom however indicated that the elderly were less likely to disclose their status leading to poor social support from their partners.²⁷ Our study population was moderately younger, and this could explain why this association was not significant. In a study of PLWHA in Iran, social support was also found to be associated with sex; males were less likely to have strong social support.¹² The differences observed could be due to the different social and cultural contexts in which PLWHA live in.

Both stigma and depression were not associated with social support, an unexpected finding. The prevalence of stigma (3.8%) and depression using the PHQ-2 scale (0.85%) in this study were very small. The study could have been under-powered to determine the association with social support. The lack of association between stigma score and social support is inconsistent with other research findings. Studies have showed a negative correlation between stigma score and social support in PLWHA.^{28,29} Incidentally, the relationship between stigma and depression tends to be bidirectional.^{28,30} Stigma can lead to depression and depression can lead to stigma. The settings of these two studies is also different. IDI routinely provides its patients with emotional support and community centered groups that address stigma unlike the other rural setting. Notwithstanding these results, health professionals should enhance strategies that decrease stigma most especially in rural areas.

Other research studies have demonstrated a bidirectional relationship between depression and social support.^{31,32,33} That is, depression could lead to low social support or low social support could lead to depression. Depressed individuals have been identified as self-isolating which consequently leads to people drawing away from them.³⁴ Another study in Canada showed a negative association between social support and depression. Several studies have documented the success of social support on the negative symptoms of depression.^{35,36} Engagement in social networks has enhanced the physical and mental health of these patients. This could be used as a basis in all HIV treatment programs to improve clinical outcome.

While a study in Brazil showed that there was no association between duration on ART and social support³⁷, some qualitative studies have showed that more support was obtained after a long duration on ART. For example, a study in Kampala showed that the longer PLWHA had been on ART, the more likely they would get materialistic items, care, and other kinds of support.³⁸ This is because people who had disclosed their status had already established strong and wide social networks. However, duration on ART and social support seem to have a bidirectional relationship.^{39,40} Social support has also been demonstrated to improve treatment outcomes in PLWHA by encouraging patients to take their medications and hence greater chance of survival.⁴¹

From our study, social-economic factors like education, religion, and marital status were not associated with and social support ostensibly due to the different cultural context compared to other studies. This

finding is not consistent with the available literature. A study conducted in South Florida showed that participation in religious activities was positively correlated with social support.⁴² The study further went on to demonstrate that PLWHA with many stressors tend to look up to religion to loosen their burdens. This observation explains the dissimilarity observed in this study. Other studies have shown mixed associations between marital status and social support. A descriptive study in Brazil showed no association while³⁷ whereas another study also conducted in Brazil showed that marital status was negatively associated with social support.⁴³

There was no association between substance abuse and social support. This is quite different from literature in which social support has been used to enhance the treatment outcomes of ART in substance abusers.⁴⁴ They could be because in our study only 2.1% were substance abusers in the present study compared to the study in New York. There was also no association between presence of comorbid health conditions and social support in this study. However, it is currently increasingly known that emerging non communicable diseases due to ART need to be addressed.⁴⁵ It has been documented that presence of one comorbidity increases risk for another.⁴⁶ This warrants more care and there should be an integral treatment of HIV and these diseases in all HIV centres.

There were few limitations in this study. Firstly, the sample size calculation was not powered to social support which was a secondary objective of the overall study: therefore, the sample size could have been small leading to failure to detect associations between variables. Secondly, this study was carried out in a single modern setting. However, most HIV treatment in Uganda is received from government hospitals and a few aided by non-governmental organizations. These results may therefore not be generalizable to PLWHA receiving care in public health facilities which may have challenges with the quantity and quality of human resources as regards to HIV care. Lastly, our data was from a cross sectional study and thus couldn't conclude if it's an association or causation.

Conclusion

More than 90% of PLWHA at modern HIV clinic in Kampala have moderate-strong social support. Disclosure of HIV status is the major correlate of social support in PLWHA. PLWHA ought to disclose their status to people of close relations as this increases the support provided to them. Interventions aimed at improving social support should be centered on disclosure of HIV status in PLWHA in addition to other measures. We recommend exploration of this topic using a bigger sample size in both modern and rural HIV settings.

Abbreviations

AIDS
acquired immunodeficiency syndrome
ART
Antiretroviral Therapy

ATV/r
ritonavir boosted Atazanavir
HIV
Human Immunodeficiency Virus
IDI
Infectious Diseases Institute
NGO
Non-governmental Organisation
OSSS
Oslo Social Support Scale
PHQ-2
Public Health Questionnaire-2
PHQ-9
Public Health Questionnaire-9
PLWHA
Persons Living with HIV/AIDS
SSCI
Stigma Scale for Chronic Illnesses

Declarations

Ethics approval and consent to participate

Ethics review was sought from Makerere University School of Health Sciences Research and Ethics Committee.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contribution

NSK contributed towards design of this work, interpretation of data and drafting of this work.

FEK contributed towards the design, interpretation of the findings, review of versions of the manuscripts and finalization of this work.

RO contributed towards interpretation of the findings, review of versions of the manuscripts and finalization of this work.

NAK contributed towards the design of this work.

EK contributed towards analysis and interpretation of data of this study.

Eva Laker contributed towards conception and design and interpretation of data of this study.

All authors read and approved the final manuscript.

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Figures

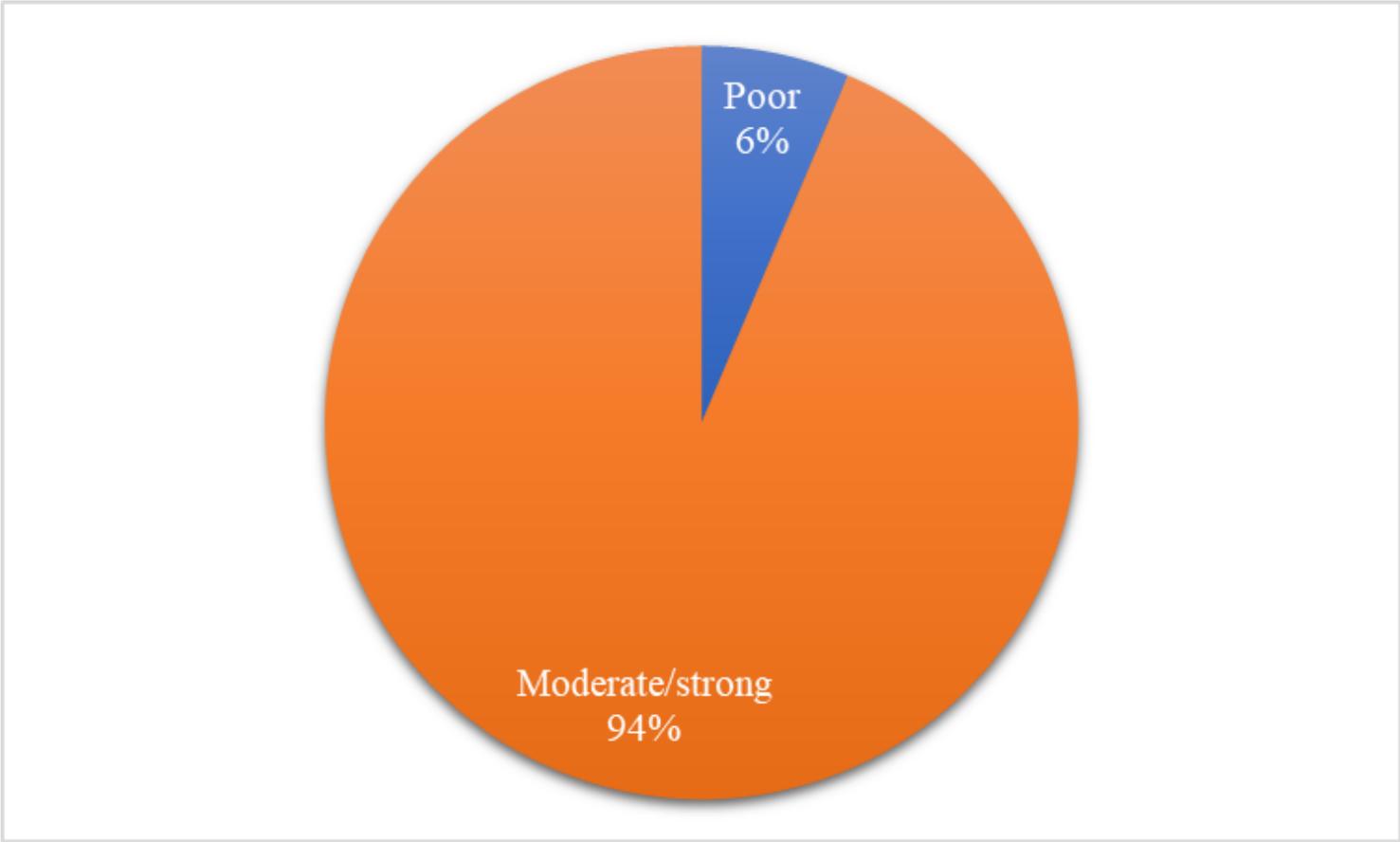


Figure 1

Level of social support among PLWHA attending the IDI-ART clinic, 2019. Note: Social support was assessed using the 3-item Oslo scale of social support (OSSS-3). Scores 3-8 – poor social support, 9-11 – moderate social support and 12-14 – strong social support.