

# Perceived Social Support and Associated Factors Among Adults Living with HIV/AIDS Attending ART Clinic at Public Hospitals in Gamo Zone, Southern Ethiopia 2021

Hayelom Berhe<sup>1</sup>, Wanzahun Godana<sup>2</sup>, Negussie Boti Sidamo<sup>2,3</sup>, Gebremaryam Temesgen Birgoda<sup>4</sup>, Lielt Gebresillasie<sup>5</sup>, Sultan Hussien<sup>2</sup>, Selamawit Gebeyehu<sup>2</sup>

<sup>1</sup>Department of Nursing, Hossana College of Health Science, Hossana, Ethiopia; <sup>2</sup>School of Public Health, College of Medicine and Health Science, Arba Minch University, Arba Minch, Ethiopia; <sup>3</sup>Department of Public Health, PHARMA College, Wolaita Sodo Campus, Wolaita Sodo, Ethiopia; <sup>4</sup>Departments of Midwifery, College of Medicine and Health Sciences, Arba Minch University, Arba Minch, Ethiopia; <sup>5</sup>Department of Nursing, College of Medicine and Health Sciences, Wolaita Sodo University, Wolaita, Ethiopia

Correspondence: Gebremaryam Temesgen Birgoda; Negussie Boti Sidamo, Email degnesh31@gmail.com; Hanehalid@gmail.com

**Background:** HIV/AIDS remains one of the world's serious public health challenges. Patients with limited support from their family and community often experience social damage, poor adherence, compliance and are prone to additional psychosocial problems. This study aimed to assess the level of perceived social support and factors among adults living with HIV/AIDS.

**Methods:** Facility-based mixed study (sequential explanatory) design was conducted among 423 adults living with HIV/AIDS attending chronic care follow-up at public hospitals in Gamo zone, southern Ethiopia. Respondents were selected by systematic sampling technique. The bivariable and multivariable ordinal logistic regression was used to determine associated factors. All assumptions applied to ordinal logistic regression including multicollinearity, proportional odds, model fitness and pseudo R<sup>2</sup> were checked. Level of significance was declared at p-values <0.05 and 95% CI.

**Results:** Proportion of perceived social support of participants was 128 (30.7%), 197 (47.2%) and 92 (22.1%) with low, moderate and high levels of perceived social support, respectively. Females [(APOR = 2.42, 95% CI: (1.63–3.58), P < 0.001)], no formal education [(AOR = 0.49, 95% CI: (0.30–0.789), P = 0.004)], fair adherence [(APOR = 2.07, 95% CI: (1.17–3.49), P = 0.006)], no comprehensive knowledge about HIV [(APOR = 0.40, 95% CI: (0.26–0.62), P < 0.001)], and no disclosure status [(APOR = 0.64, 95% CI: (0.43–0.95), P = 0.028] were significantly associated with perceived social support. Qualitative findings revealed that disclosure and adherences involving income generation activities are beneficial to perceived social support.

**Conclusion:** This study showed that one from three of the participants had low perceived social support. Low perceived social support was associated with adherence, disclosure status of individual, educational status and knowledge about HIV/AIDS. Family, friends, health care providers and significant others should provide necessary support and inform people living with HIV/AIDS (PLWHA) about social support.

**Keywords:** perceived social support, HIV/AIDS, adults, adherence

## Background

Human immunodeficiency virus, Acquired Immune Deficiency syndrome (HIV/AIDS) remains one of the world's serious public health challenges. As the World Health Organization reported on HIV in 2018, about 38 million people were living with HIV/AIDS worldwide among these 36.2 million were adults and there were 770,000 AIDS related deaths.<sup>1</sup>

Sub-Saharan Africa is one of the most affected regions with two-thirds of the global new infections. South Africa, Nigeria and Ethiopia are the most affected Sub-Saharan African countries where there is a high rate of HIV/AIDS

infection. In Ethiopia the prevalence in adults aged 15–49 years in 2018 was 1% which is gradually increasing from the national prevalence of 0.9% in 2017.<sup>1,2</sup>

Social support is the help or support that a person receives from people in his or her social networks from various sources, such as family, friends, community, organizations, and coworkers.<sup>3–5</sup> Social support is classified in to actual or perceived support. Perceived social support talks about the insight support that would be available, regardless of whether the support is actually available. Perceived social support is more significant than actual social support in relation to health.<sup>6</sup> It is well known that perceived social support has not only a direct effect on health but also an indirect effect on buffering stress.<sup>7</sup> Moreover, social support is an important aspect in the prevention of diseases, promotion of health, therapeutic compliance and in the process of recovery from illness.<sup>8</sup>

People living with HIV/AIDS have been severely discriminated against, not only by the general public but also by their family members. As HIV/AIDS is a very stigma related disease, people living with it are most repeatedly vulnerable to a lack of social support and poor self esteem. Furthermore, HIV infection can lead to the loss of social, occupational, residential, and economic opportunities.<sup>9</sup> For many people living with HIV/AIDS, social support of any type is limited or nonexistent. This, in turn, predisposes them to psychological problems like depression and anxiety.<sup>10</sup>

Lack of social support has a harmful effect on health, increasing the risk of morbidity and mortality through a variety of mechanisms both physiological and psychosocial. In the general population, unsatisfactory social support has been linked to the sub-optimal function of multiple physiological systems including the cardiac, immune, and endocrine systems.<sup>11</sup>

Perceived social support has been presented to be associated with more positive and less negative effects in people living with HIV and AIDS.<sup>12</sup> People living with HIV and AIDS who are satisfied with the amount of support available to them experience lower negative self-image about being HIV positive, less psychological distress, a higher quality of life, and high self-esteem.<sup>13</sup>

However, those adults living with HIV who perceive low levels of social support often experience a reduced quality of life, social damage, increased psychological suffering, increased risk-taking behaviors, poor adherence, and high exposure to additional psychosocial susceptibilities.<sup>14</sup> Additionally, in the absence of social support from their social environment, people living with HIV/AIDS (PLWHA) are exposed to a variety of stressing situations like marital problems, losing their job and financial challenges, which are related with an increased risk of developing psychological disorders such as depression, anxiety, guilt and loneliness.<sup>15</sup>

Both the WHO and president's emergency plan for AIDS relief (PEPFAR) promote peer support groups facilitated by trained PLWHA to address the special needs PLWHA have and their partners.<sup>23</sup> The mentor mother support group model is also a key strategy to improve maternal wellbeing among women living with HIV.<sup>24</sup>

In different literatures, less social support and fear of disclosure are the most important and repeatedly reported socio-cultural challenges in both low and high income nations and received very little attention.<sup>25</sup> There were important factors like income generating activities, residence, economic status, and clinical condition of patients like stage of HIV, ART regimen and others that were given little attention, but the characteristics are expected to be different across the populations and groups.<sup>26</sup> So, the current study, aimed to examine the practice of social support among adult PLWHA and explore the levels of perceived social support which were not well assessed by previous studies.

## Methods

### Study Setting

The study was done in Gamo Zone, Southern Nations Nationalities and People's Region (SNNPR). Arba Minch Town which is the capital city of Gamo Zone, located about 502 kilometers (kms) south of Addis Ababa. The total population of the zone was 1,659,310, of whom 879,782 were women.<sup>27</sup> There are five public hospitals and 8 health centers totaling 13 public health facilities providing ART services for HIV/AIDS patients. From five hospitals found in the zone two are former hospitals and three of them had grown from health centers to hospitals recently, these are namely AGH, Chench, Gerese, Kemba and Selam-ber respectively. There are 3268 people living with HIV/AIDS in Gamo Zone who use the ART service in public health facilities. Among those PLWHA, 2566 used the ART service in 5 public hospitals, from this 2352 are adults. The study was conducted in Gamo Zone selected public hospitals.

## Study Design

Facility based cross-sectional study supplemented with qualitative approach was applied from July 15 to September 10, 2020.

## Population

All adult PLWHA who were enrolled to HIV chronic care follow-up at Public Hospitals of Gamo Zone were the source population and the study populations were those clients in the follow up clinic during the data collection period. For quantitative study, all adult PLWHIV who were greater than 18 years old and enrolled to HIV chronic care follow-up at Public Hospitals of Gamo Zone during study period and who knew their HIV status before 1 year and above were included in the study. In case any client who is not volunteer to participate or not ok to sign consent were excluded in the study in addition to those who were critically sick to respond the questions.

## Sample Size Determination and Sampling Technique

For a quantitative method: sample size was calculated through single population proportion based on the following assumption. The proportion of low perceived social support ( $p$ ) of 50%, with a 95% level of confidence and 5% margins of error  $n = Z^2 \frac{p(1-p)}{d^2}$ ,  $n = \frac{(1.96)^2 * 0.5 * (1 - 0.5)}{(0.05)^2} = 384$ , by considering non-response rate 10%, the final sample size became 423. The lists of public health facilities in Gamo Zone were obtained from the zonal health bureau. From all the five hospitals respondents were sampled and a proportional allocation method was used to assign the number of adult HIV patients to each hospital based on their number of cases reported by considering chronic cases of HIV with respect to their follow-up appointment and newly diagnosed cases in the preceding 2 months. Finally, a systematic sampling technique was applied to select 423 study participant adult HIV patients attending ART clinic in the selected public hospitals. The sampling interval ( $K$ ) in each facility is obtained by dividing the total number of adult PLWHA in two month ( $N$ ) to the sample size allocated to respective hospitals ( $n$ ). Then the first participant was selected randomly for an interview.

For the qualitative method the minimum number of participants planned to interview was at least 10 participants. But the in-depth interview of participants continues until achieving data saturation. The selection of participants was based on purposive sampling. Participants were recruited purposively on their year of experience in the diagnosis and treatment of HIV/AIDS. Selections of participants were continued until a point of saturation of information reached.

## Operational Definitions

Level of perceived social support: There are 3 categories low, moderate and good perceived social support defined as low (less than 60), moderate (60–79) and good (more than 80).

Psychosocial wellbeing: Is a sum of physical well-being, psychological well-being, emotional well-being and functional well-being and it is a score in FACT-G, between 0–72. The cut off point of the summated values of each items measuring patient care using the demarcation threshold formula  $((\text{highest total score} - \text{lowest total score})/2) + \text{lowest total score}$ . Participants were categorized as having poor well-being if they score 0–36 and good psychosocial well-being if they score greater than 36.

Adherence Status: If the participant misses  $\geq 9$  doses during the month ( $<85\%$  of the prescribed doses) s/he has poor adherence, if the client misses 4–8 doses during the month ( $85\text{--}95\%$  of the prescribed doses) s/he has fair adherence and if the patient has taken  $>95\%$  of the prescribed ( $<2$  doses missed) doses correctly s/he has good adherence.

## Data Collection and Procedures

For the quantitative method: A structured, pretested questionnaire was used to collect the quantitative data through face to face interviewing technique and medical charts were reviewed. The questionnaire was developed by reviewing different literature experts from different specialties who were invited to control the validity of the tool. The questionnaire was translated to Amharic, then back to English language by a language expert to check for its consistencies. Ten diploma and degree holder health professionals from another health facility, based on his/her experience of data collection and communication skills with clients for data collection and two supervisors based on their language skill and

supervision experience, were assigned. After getting written and informed consent from the study participants, background information and possible factors were collected in the form of a questionnaire. The questionnaire comprised of socio-demographic characteristics of the study participants, clinical characteristics, behavioral and HIV related items and psychosocial wellbeing questions demanded for social support. To assure the reliability of the data collected study participants were assured about the confidentiality of their responses and well informed on the purpose of the study.

For the qualitative part, an in-depth interview data collection method and in-depth interview guide for participants was used with flexible probing technique. The in-depth interview was carried out by the principal investigator with one assistant who tape recorded the interview. In-depth interview guide and field notes was used to record relevant information.

## Data Quality Control

For quantitative data: A one day training course was given for data collectors and supervisors concerning the research objective, data collection tools and procedures, and interview methods that are supposed to be applied during data collection. Prior to the commencement of the actual data collection process, the questionnaire was pretested on 5% of the actual sample size done outside of the study area in Sikela and Shecha Health Centers and the validity and reliability of the questionnaire was checked. After the questionnaire is pretested, some grammatical errors, missed terms and modification of sentences were made to avoid any confusion. The collected data were submitted on daily regular basis to supervisors and the data were checked for completeness, consistency and any error was corrected before the start of the next day's interview. Qualities of data collection were ensured through close supervision of the data collectors by the principal investigator. In addition, the data were thoroughly cleaned and carefully entered into computer for the beginning of the analysis.

For qualitative data: The qualitative data were organized and transcribed in to Amharic, then translated back to English language.

## Data Processing and Analysis

For quantitative data: The data was checked for completeness and consistency and then it was coded, entered and stored into a computer using EpiData version 4.2 software and exported to SPSS version 25 for analysis. The data were cleaned using SPSS by running frequently and checking for consistency. Descriptive statistics were done to assess basic client characteristics using frequencies, percentage, summary measures, tables, and graphs were used to describe respondents' results.

All assumptions applied to ordinal logistic regression, including multicollinearity, were checked by using variance inflation factor ( $VIF > 10$ ), proportional odds, assumption was checked by tests of parallel lines, and model fitness information  $<0.05$  by observing the final model and goodness of fit model Pearson's chi-square test result  $>0.05$  and pseudo  $R^2$  test using the Nagelkerke value was checked. Bivariable and multivariable ordinal logistic regression model was fitted to identify factors associated with outcome variable. Initially, bivariable logistic regression analysis was performed between dependent and each of the independent variables. Variables having p-value of  $\leq 0.25$  in bivariable ordinal logistic regression analysis was selected as candidates for multivariable ordinal logistic regression analysis. Associations between outcome variable and independent variables were reported by using adjusted odds ratio and its 95% CI, and variables having p value less than 0.05 in multivariable logistic regression model were considered as statistically significant.

The qualitative data: Were analyzed with the view of gaining the types of social support that participants perceive from their peer facilitators and what conditions hinder or facilitate their perceived social support. Data were transcribed in Amharic, then translated back to English language then coding and category/family was formed. Finally, the data were analyzed manually using a thematic analysis approach.

## Ethical Consideration

Ethical clearance was assured prior to data collection from the Institutional Review Board of Arba Minch University, College of Medicine and Health Sciences. Authorization was obtained from the Health Bureau of Arba Minch Town Administration and Directors of all health facilities. Information was provided to clients by data collectors after they were asked for willingness and verbal and written consent was obtained after they were all briefed why the study is needed and they were informed that they have a full right to participate or not. Privacy and confidentiality was

maintained throughout the data collection, analysis and result dissemination. Additionally, safe approaches like using glove, masks, keeping distance and hand sanitizer was applied to prevent corona transmission during data collection. Besides, this study was conducted following the Declaration of Helsinki, and all ethical and professional considerations were followed throughout the study to keep participants' data strictly confidential.

## Results

### Socio-Demographic Characteristics

A total of 423 adult HIV patients attending ART clinic in public health facilities were invited into the study. Of these, 417 adult HIV patients participated in the study making a response rate of 98.5%. The majority of participants were females 243 (58.3%) and the mean ( $\pm$ SD) age of respondents was 39.2 ( $\pm$ 7.32) years, among which 46 (11%) were in the 18–29 year age group and 18 (4.3%) were above 50 years age group. The majority of participants 255 (61.2%) were married and more than half 260 (62.4%) were urban residents. The majority of respondents 173 (41.5%) had completed secondary education and above (Table 1).

### Clinical Characteristics Related Factors

The mean known duration of HIV infection was  $6.97 \pm 4.2$  years, and the majority of the respondents 266 (63.8%) do not know the mechanism of how they became HIV positive. Of the 417 patients, more than two thirds 301 (72.2%) of the respondent partners' HIV status was known. Among them 223 (53.5%) of the partners are HIV positive status. Regarding the nutritional status of the patients, two third of them 284 (68.1%) were categorized as well nourished. On the other hand, their current CD4 count 176 (42.2%) was  $>500$  cells/mm<sup>3</sup> (Table 2).

### HIV Related Factors

Out of the total 417 respondents 251 (60.2%) had comprehensive knowledge about HIV/AIDS transmission, care and treatment. The majority, 232 (55.6%), had no discriminatory attitude. Majority 259 (62.1%) of them disclosed their HIV status to others (Table 3).

### Behavioral Related Factors

Among the respondent, 402 (96.4%) of the study participants had no smoking habit and 286 (68.6%) never drank alcohol before and 384 (92.1%) had not chewed chat/khat in their lifetime (Table 4).

### Psychosocial Factor

Respondents reported a relatively high score in functional wellbeing ( $M = 9.91$ ,  $SD = 5.591$ ) and social wellbeing ( $M = 8.04$ ,  $SD = 5.697$ ) assumes second place followed by emotional wellbeing ( $M = 6.66$ ,  $SD = 5.786$ ) and physical wellbeing ( $M = 2.82$ ,  $SD = 3.015$ ). The mean and standard deviation of the total psychological wellbeing was 27.62 and 14.99 respectively. Respondents who reported below the mean score of psychosocial wellbeing were 307 (73.6%), while those who reported above the mean score of psychosocial wellbeing were 110 (26.4%). This indicates that respondents who reported below the mean score of psychosocial wellbeing outnumber those who reported above the mean score of psychosocial wellbeing.

Influence of social support on physical, emotional and social wellbeing, social support was reported to increase the psychosocial well-being of HIV-positive caregivers.

A 46 year old male respondent:

...When someone advises me with something that she/he experienced, and you see that she/he is doing well... you will also have hope that you will also get past that situation that you are facing right now....

Another 32 year old female adherence supporter:

...tangible support (money and materials) is very important for me to have my own business and to activate my own tasks. So money is very important for me in addition to that when somebody gives me advice and provides me with new information's regarding my situation and else hopefully I become happy and feels strong.

**Table 1** Socio-Demographic Characteristics of Adult PLWHA Attending ART Clinic in Public Hospitals, Gamo Zone SNNPR Ethiopia, 2020 (n = 417)

Variables	Category	Frequency(n)	Percentage (%)
Sex	Female	243	58.3
	Male	174	41.7
Age of respondent	18–29	46	11
	30–39	184	44.1
	40–49	169	40.5
	≥50	18	4.3
Place of residence	Rural	157	37.6
	Urban	260	62.4
Educational status	Unable to read and write	124	29.7
	Primary education	120	28.8
	High school and above	173	41.5
Marital status	Single	30	7.2
	Married	255	61.2
	Divorced	43	10.3
	Separated	36	8.6
	Widowed	54	12.9
Income status	≤2500	272	65.2
	>2500	145	34.8
Occupation	Government employee	89	21.3
	Farmer	70	16.8
	Merchant	74	17.7
	House wife	93	22.3
	Daily laborer	59	14.1
	Drivers and students	32	7.7
Number of household members	≤4	246	59
	>4	171	41

## Perceived Social Support

Among 417 adult HIV patients interviewed in the current study, from the overall proportion of perceived social support almost half of the proportion of participants, 197 (47.2%), had a moderate level of perceived social support, while 128 (30.7%) and 92 (22.1%) had low and high levels of perceived social support respectively.

On the medical outcome survey of social support scale summary, mean scores were lowest for positive social interaction (possible scores for scale = 3–15) the mean score was 9.9400 (standard deviation = 3.18028) and affectionate support (possible scores = 3–15), the mean score was 10.0600 (standard deviation = 3.49571), followed by tangible support score (possible scores = 4–20), the mean score was 14.9952 (standard deviation = 3.95224) and emotional/



**Table 2** Clinical Characteristics of Adult PLWHA Attending ART Clinic in Public Hospitals, Gamo Zone SNNPR Ethiopia, 2020 (n = 417)

Variables	Category	Frequency	Percent
Method/way of contracting	Sexual contact	93	22.3
	Blood contact	40	9.6
	Blood transfusion	16	3.8
	Unknown	267	64.0
Duration of HIV Diagnosis	≤10yrs	326	78.2
	>10yrs	91	21.8
Status of partner	HIV-positive	223	53.5
	HIV-negative	78	18.7
	Unknown	116	27.8
WHO clinical stage at enrollment	Stage 1	252	60.4
	Stage 2	165	39.6
Recent CD4 cell count(cells/mm3) (Within 6–8months)	≤500	221	53.0*
	>500	176	42.2*
Nutritional status BMI	Under-weight	56	13.4
	Over-weight	77	18.5
	Normal	284	68.1

informational support score (possible scores = 8–40), the mean score was 28.1175 (standard deviation = 7.74678). Each items response with their percentage is mentioned in Table 5.

The significance of specific social support provider characteristics was a theme during interviews with both male and female respondents. Tangible support and informational support are more importantly mentioned than the other social supports.

For example, one female respondent spoke of her very special connection with a neighbor who provided her with both instrumental help and companionship, and helped her deal with physical and psychosocial wellbeing.

Another 21 year old female participant said that:

...I get a support from many peoples. Mainly my sister is my all sources. She expend's all my cost and support me. When we talk about the help and support I am not interestingly preferable with tangible support (money) and other physical matters over

**Table 3** HIV Related Factors of Adult PLWHA Attending ART Clinic in Public Hospitals, Gamo Zone SNNPR Ethiopia, 2020 (n = 417)

Variables	Category	Frequency	Percent
Knowledge about HIV transmission, care and treatment	Have comprehensive knowledge	251	60.2
	No comprehensive knowledge	166	39.8
Discriminatory attitude	Has discriminatory attitude	185	44.4
	No discriminatory attitude	232	55.6
Disclosure	Yes	259	62.1
	No	157	37.6

**Table 4** Patient Behavioral Related Variables of Adult PLWHA Attending ART Clinic at Public Hospitals, Gamo Zone SNNPR Ethiopia, 2020 (n = 417)

Variable		Frequency(n)	Percentage (%)
<b>Smoking</b>	Yes	15	3.6%
	No	402	96.4
<b>Alcohol</b>	Yes	131	31.4%
	No	286	68.6%
<b>Chat/Khat</b>	Yes	33	7.9%
	No	384	92.1%

the other supports like providing information, advice, social relation and getting moral. The aforementioned supports are helpful for my future life.

## Factors Associated with Perceived Social Support

The bivariable ordinal logistic regression analyses was done for the relationship of socio-demographic variables, clinical characteristic variables, HIV related variables and individual's psychosocial related variables with perceived social support. The variables with p-value  $\leq 0.25$  in bivariable analyses were a candidate for multivariable analysis.

**Table 5** Responses on Medical Outcome Survey of Social Support Scale for Adult PLWHA Attending ART Clinic in Public Hospitals of Gamo Zone, Ethiopia (n = 142)

Item	1 %	2 %	3 %	4 %	5 %
<b>Emotional/informational support</b>					
Someone you can count on to listen to you when you need to talk	5.0	12.9	22.5	41.5	18.0
Someone to give you information to help you understand a situation	4.3	13.7	19.9	43.6	18.5
Someone to give you good advice about a crisis	3.8	13.7	26.4	38.1	18.0
Someone to confide in or talk to about yourself or your problems	6.7	12.0	21.6	37.4	22.3
Someone whose advice you really want	6.2	13.4	24.7	33.1	22.5
Someone to share your most private worries and fears with	8.6	11.5	28.8	30.7	20.4
Someone to turn to for suggestions about how to deal with a personal problem	6.7	12.9	24.9	35.0	20.4
Someone who understands your problems	7.7	12.9	26.6	31.9	20.9
<b>Tangible support</b>					
Someone to help you if you were confined to bed	4.3	10.3	19.9	38.8	26.6
Someone to take you to the doctor if you needed it	3.4	10.6	19.7	42.7	23.7
Someone to prepare your meals if you were unable to do it yourself	4.8	10.1	20.1	31.2	33.8
Someone to help with daily chores if you were sick	5.0	11.3	19.2	33.3	31.2
<b>Affectionate support</b>					
Someone who shows you love and affection	11.8	12.0	14.4	42.7	19.2
Someone to love and make you feel wanted	12.7	12.7	16.8	42.4	15.3
Someone who hugs you	14.9	14.1	18.0	36.7	16.3
<b>Positive social interaction</b>					
Someone to have a good time with	8.2	15.1	23.0	39.8	13.9
Someone to get together with for relaxation	11.0	13.2	28.1	32.1	15.6
Someone to do something enjoyable with	10.3	13.2	28.1	33.3	15.1
<b>Additional item</b>					
Someone to do things with to help you get your mind off things	4.8	16.3	29.3	36.0	13.7

**Notes:** 1-none of the time; 2-a little of the time; 3-some of the time 4-most of the time and 5-all of the time, %, percent of each likert responses.



**Table 6** Multivariable Ordinal Regression Analysis of Factors Associated with Perceived Social Support Among Adult PLWHA Attending ART Clinic at Public Health Facilities in Gamo Zone, July 23–September 9, 2020 (n = 417)

Variables		PSS			APOR	95% Wald CI for APOR		P-value
		LSS	MSS	HSS		Lower	Upper	
Sex	Female	95	109	39	2.419	1.63	3.58	<0.001*
	Male	33	88	53	1			
Age	≤45yrs	80	140	64	0.705	0.47	1.07	0.098
	>45yrs	48	57	28	1			
Educational status	No formal education	44	36	44	0.485	0.30	0.79	0.004*
	Primary education	20	63	20	0.893	0.57	1.41	0.624
	Secondary & above	28	98	28	1			
Place of residence	Rural	59	61	37	0.99	0.67	1.51	0.977
	Urban	69	136	55	1			
Adherence to ART therapy	Poor	24	20	13	1.520	0.85	2.71	0.155
	Fair	35	30	11	2.067	1.17	3.49	0.006*
	Good	69	147	68	1			
Disclosure status	Yes	63	134	62	0.641	0.43	0.95	0.028*
	No	65	62	30	1			
Knowledge about HIV	Yes	52	132	67	0.403	0.26	0.62	<0.001*
	No	76	65	25	1			
Discriminatory attitude	Yes	61	89	35	0.1.17	0.80	1.7	0.414
	No	67	106	57	1			
Psychosocial wellbeing	Poor	87	151	69	0.85	0.55	1.31	0.46
	Good	41	46	23	1			

**Note:** \*A statistically significant variable at  $p < 0.05$  in multivariable ordinal logistic regression analysis.

Multivariable ordinal logistic regression was used to control the confounding effect and the strength of the association was reported in the proportional odds ratio with a 95% confidence interval. The  $p$ -value  $< 0.05$  was considered statistically significant in multivariable analysis. The results of bivariable analyses revealed that sex and age of the respondent, educational status, place of residence, adherence to ART therapy, disclosure of one's own HIV status, knowledge about HIV transmission, care and treatment, discriminatory attitude and psychosocial wellbeing of the respondent were found to be significantly associated with perceived social support (Table 6).

Sex and age of respondents, educational status, place of residence, adherence to ART therapy, disclosure of one's own HIV status, knowledge about HIV transmission, care and treatment, discriminatory attitude and psychosocial wellbeing of the respondents were candidates for multivariable analysis having a  $p$ -value  $\leq 0.25$ . However, by multivariable analysis, using ordinal logistic regression analysis, female gender, educational status, adherence to ART therapy, knowledge about HIV transmission, care and treatment and disclosure of one's own HIV status were found to be statistically significant.

Accordingly, the likelihood of getting low perceived social support is two times more likely among females compared to males (APOR = 2.42, 95% CI: (1.63–3.58),  $P < 0.001$ ) when educational status, adherence to ART therapy, disclosure and knowledge about HIV are held constant.

The likelihood of getting low perceived social support is around 51.5% lower among those with no formal education compared to those who attended high school and above (APOR = 0.485, 95% CI: (0.30–0.79),  $P = 0.004$ ) when gender, adherence to ART therapy, disclosure and knowledge about HIV are held constant. Compared to educational status of above secondary school, primary education is not significant, so above secondary education and primary education do not have any significance in their level of perception to social support.

The likelihood of getting low perceived social support is 2 times higher among fairly adhered respondents compared to those with good adherence therapy (APOR = 2.07, 95% CI: (1.17–3.49),  $P = 0.006$ ) when gender, educational status, disclosure and knowledge about HIV are held constant. Compared to adherence to ART therapy, good adherence and poor adherence is not significant, so good adherence and poor adherence does not have any significance in their level of perception to social support.

The likelihood of getting low perceived social support was 40% less among those who disclosed their status (APOR = 0.64, 95% CI: (0.43–0.95),  $P = 0.028$ ) when gender, educational status, adherence and knowledge about HIV are held constant.

The likelihood of getting low perceived social support was 60% (more than half) less likely among those who have comprehensive knowledge about HIV transmission, care and treatment compared with those who do not have comprehensive knowledge about HIV (APOR = 0.40, 95% CI: (0.26–0.62),  $P < 0.001$ ) when gender, educational status, adherence and knowledge about HIV are held constant.

## Findings of In-depth Interview

A total of 8 participants who knew their status for 1 year and above were involved in the in-depth interview (IDI). The results of the in-depth interviews are summarized as follows.

## Factors Influencing Perceived Social Support

The IDI participants identified many factors that influenced perceived social support among men and women. Disclosure of HIV status plays a main role because it integrated with adherence of medication and discriminatory attitudes, finally this is also associated negatively or positively with the person's perceived social support. Where the person does not disclose their status due to fear of stigma and discrimination, fear of blame and unfaithfulness were prominent barriers of perceived social support, in contrast if a person does not disclose their HIV status they may not get the support they need from their family and the community.

A 46 year old male participant said

...I disclose my status to anyone. It has its own negative consequences. As I told you before even my wife leave me alone and my family stigmatizes me but thanks to God now all things are resolved and I live with my wife by supporting each other.

Another 57 year old female adherence supporter said:

...a long time ago, If you disclose your status; people took you as unfaithful person, and also they point their finger at you so you faced a great stigma and discrimination, this makes you to hidden your status to avoid those things. If a person has a high tendency to disclose, s/he helps for himself. S/he develops confidence, it also helps for his medication, s/he can take anywhere without fear and shy anybody. He gets good support from others.

## Disclosure and Adherence Enhances Perceived Social Support

Almost all participants perceived that disclosure and adherence had a positive value for their social support. Most of the participants reported that their family/relatives remind them to take their medication on time.

A 32 year old female said:

...Disclosure was very important! For example, I freely took my medication everywhere even in the home of others then I ask a glass of water and took it; in case if they ask me I told them I am taking ART drug so the people accept and support me. I took medication correctly without missing any pills since my children remind me.

But in contrast with the finding of the quantitative study, due to the fear of stigma and discriminatory attitudes another young lady denies disclosure of her own status to her colleagues and others. A 21 year old female participant said that:

...I don't want to disclose my HIV status, because others they don't understand you and your situation even they may shun you, ostracize you even they might point their finger at you. So that's why I don't disclose my status and I don't want to miss my friends due to this. Whatever the situation we discuss a lot of ideas different information's with my friends but when such like issue (about HIV) is raised I become silent to hide myself.

## Sources of Income, Income Generating Activities, HIV Support Groups and Perceived Social Support

The predominance of HIV/AIDS-impacted members in an open and member-driven setting can lead to meaningful emotional support and tangible assistance to the affected individuals. In this way, there are many economic programs developed with an integration program that includes a broader range of both economic and non-economic activities, such as skill building for income generation and marketing integration. Regarding their source of income and income generating activities and support intake from their surrounding link with social support, most of the interviewees had a positive perspective to community groups and HIV support groups. But they raise primarily the challenge of sustainability.

A 30 year old female participant said that:

...I have no source of income but for living I earn by selling wood. A long time ago, HEWs helps us in different way. We get different information's, advice and support from them. And there is established group that helps us to share together our concerns. The groups fall through because CHWs have different tasks and the groups have different needs. Due to those reasons the group members drift apart. At the beginning time different HIV support groups with collaboration of HEWs they provide us with different materials even they give us money other home inputs like oil, wheat and so on (during holiday time)..... but now a day there is no support.

Another 34 year old male respondent:

...I am a weaver. I support myself by the money I get through weaving and selling it. It is not enough money I get. Sometimes I borrow some money from my neighbors and I return when I get. Many years ago we get some tangible resources from NGOs and the CHWs also provide wide range supports like informational and tangible resources but now a day it is decreased.

Almost all participants had positive values about HIV support groups. HIV support groups can provide confidential spaces where experiences and issues about HIV such as knowledge about HIV, disclosure, adherence and social values are shared.

A 21 year old female participant said that (university student):

...I participate in different clubs and HIV support groups. I get good support from them, they provide me with books, exercise books, soaps, cloths and take me with others to different recreational centers and cities like Hawassa, Langano Lake and others. All in all they provide good support.

A 56 year old male participant said that:

...I was a soldier, now I am retired (pensioner) so I haven't other source of income. What I worry in my life is, I have kidney infection, so I take another medication. I have school Childs but I can't run to do my daily activities to support them. So that is my big obstacle to me. Due to this infection I can't do any other work like security (guard), social works and so on .....

## Discussion

This study assessed the level of perceived social support and identified its associated factors among adult HIV patients attending ART clinics in public hospitals of Gamo Zone. The level of perceived social support was low (30.7%) with 95% CI: (26–35%), moderate (47.2%) and high (22.1%). Females, having no formal education, fair adherence, knowledge about HIV, and no disclosure status were found to be significantly associated with low perceived social support.

In this study, the proportion of low perceived social support practice was found to be in line with studies done in Gimbi General Hospital, West Ethiopia,<sup>22</sup> Kathmandu Jos-Nigeria and valley-Nepal which was 36.9% and 39.9% respectively.<sup>20,21</sup> However studies conducted in Dublin, Ireland (54%) and Quindío, Colombia (77.1%) reported a higher proportion of low perceived social support than this study.<sup>16,17</sup>

Moreover, these current findings were relatively higher than the studies conducted in tertiary hospital, Nigeria (6.1%), Iran (7.9%) and Aizawl city, India (9.7%).<sup>18,19,28</sup> The reasons behind the difference in the proportion of perceived social support between studies might be explained by the difference in socio-demographic characteristics, cultural differences across the population, and different personal judgments' for perception of the availability of support. In addition, it may be due to the difference of measuring scales of social support plus using different statistical measures to compute the total score of social support.

The likelihood of getting low perceived social support is two times more likely among females compared to males. This finding is consistent with findings in Dublin, Ireland,<sup>17</sup> San Francisco,<sup>29</sup> Nepal and a study in African American families,<sup>30,31</sup> Trichy-India, Iran<sup>32</sup> and Tiruchirapalli, India (but not significantly associated). The possible reason for females to perceive low social support might be due to cultural values such as accusations for transmitting the disease to their husband, shyness, fear of stigmatization, and discrimination prevent women from disclosing their status, not to seek medical support or advice. Furthermore, socio-cultural factors may influence the social support, hope, and quality of life of women participants.

Another finding of this study is that the likelihood of getting low perceived social support is around 51.5% lower among those with no formal education compared to those who attended high school and above. This finding was inconsistent with a result found in Arba Minch in Ethiopia, Ohio State University in the-USA, and Nigeria.<sup>12,21,31</sup> Those studies showed that a high level of education has positive impact on perceived social support. Though, the reason for the current study might be those with no formal education whatever the case they get even a little support they perceive as high and this may be the result of community based policies and strategies in the prior studies.

The likelihood of getting low perceived social support is 2 times higher among fairly adhered respondents compared to those with good adherence therapy. This result was consistent with Kathmandu valley, Nepal and Ahvaz Jundishapur, Iran.<sup>20,25</sup> This might be due to the reason that since HIV/AIDS is one of the chronic diseases that needs close attention every day plus ART therapy is lifelong so those with less adherence might think that they are neglected, which decreases self-esteem, hope, psychosocial wellbeing and their quality of life. Additionally, lack of social support represents a barrier to optimizing chronic HIV treatment. Another study of Ethiopian patients on ART identified social support gaps in a number of areas, and correlated these with poorer physical and immunologic recovery.

Additionally, the likelihood of getting low perceived social support was 60% (more than half) less likely among those who have comprehensive knowledge about HIV transmission, care and treatment compared with those who do not have comprehensive knowledge about HIV. This is also in line with a study conducted in Arba Minch, Ethiopia before.<sup>33</sup> The scope of provision of social support widely skims on the provision of more informational support. Since informational support is one aspect of social support, with a provision of facts and advice to others, clients get help to define and understand their situation and problems. Provision of such informational support to PLWH may help improve their physical, social and mental health.

Another very essential finding of this study is that there is lower perceived social support among those who disclosed their HIV status to at least one social network of 0.6 times (more than half) lower than those who did not reveal their own HIV status to others. This study is similar to studies conducted in Addis Ababa in Ethiopia<sup>34</sup> and Tehran University in Iran,<sup>35</sup> but in contrast with the study conducted in Austria.<sup>26</sup> The possible reason might be that revealing one's HIV status may help other people to provide some emotional, informational and psychological support due to in this finding those

disclosing their status get more support than the others. Another important issue why peoples do not disclose their sero-status is for fear of rejection and stigmatization by their own people.

## Limitations

To sum up, the study has incorporated some variables like nutritional status, psychosocial wellbeing and disclosure status of the respondents and tries to address many other parameters to assess the level of their social support not incorporated in other studies. Using mixed (sequential explanatory) method design (qualitative methods supplement quantitative) is also the other strength of this study. However, this study has limitations that should be noted. Some variables are prone for recall bias and social desirability bias that would underestimate or overestimate the result. Participants were recruited from an HIV clinic, those who learn their HIV status and enter care may differ in multiple ways from those not initiating care.

## Conclusion

This study showed that one out of three of the participants encountered low perceived social support. Low perceived social support was associated with adherence, disclosure status of individual, educational status and knowledge about HIV/AIDS transmission, care and treatment. Findings from the qualitative study also indicated that community health workers, HIV support groups and other governmental and non-governmental supports are necessary for the support of HIV patients.

It would also be meaningful for HIV patients to organize themselves into self-help groups or other like-minded network groups so that they would be able to provide each other with different income generation activities (financial), emotional and other social supports. Also, programs to identify and address social support needs, including those using CHWs, may help facilitate improved physical, emotional and functional health for PLWHA plus they should be able to address the challenges of sustainability to provide care and support for those PLWHA.

## Data Sharing Statement

The data used to support the findings of this study are available from the corresponding author upon request.

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## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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## Disclosure

The authors report no conflicts of interest in this work.

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