



Impact of Community Support Workers in Rural Ethiopia on Emotional and Psychosocial Health of Persons Living with HIV: Results of a Three-Year Randomized Community Trial

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Abstract

People living with HIV face multiple psychosocial challenges. In a large, predominantly rural Ethiopian region, 1799 HIV patients new to care were enrolled from 32 sites in a cluster randomized trial using trained community support workers with HIV to provide individual health education, counseling and social support. Participants received annual surveys through 36 months using items drawn from the Centre for Epidemiologic Studies Depression Scale-10, Medical Outcome Study Social Support Survey, and HIV/AIDS Stigma Instrument-PLWA. At 12 months (using linear mixed effects regression models controlling for enrollment site clustering), intervention participants had greater emotional/informational and tangible assistance social support scores, and lower scores assessing depression symptoms and negative self-perception due to HIV status. A significant treatment effect at 36 months was also seen on scores assessing emotional/informational social support, depression symptoms, and internalized stigma. An intervention using peer community support workers with HIV to provide individualized informational and psychological support had a positive impact on the emotional health of people living with HIV who were new to care.

(ClinicalTrials.gov protocol ID: 1410S54203, May 19, 2015).

Keywords Community support workers · HIV · Social support · Depression · Internalized stigma

Introduction

Despite the considerable benefits in immunologic status and physical health that HIV patients have achieved from antiretroviral therapy (ART), people living with HIV (PLWH)

still face many psychological and social challenges. These include depression, feelings of internalized stigma (shame or reduced self-esteem due to HIV status), and perceived lack of social support [1–5]. Such factors are significant determinants of overall mental health and quality of life in PLWH, and are related to important outcomes such as HIV treatment adherence [6–12].

Community support workers (CSWs) have been used in multiple settings to improve HIV patient clinical outcomes, including ART adherence and viral suppression, by providing services such as HIV education, peer counselling, and social support [13–17]. The World Health Organization (WHO) strongly recommends that programs for PLWH include community support [18]. Such services may be especially valuable in rural and resource-limited settings, where HIV clinics are caring for increasing numbers of PLWH with limited health care personnel.

In a large and predominantly rural region of southern Ethiopia, we implemented a 32 site cluster randomized trial with a primary objective of evaluating whether individual

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CSWs provided to HIV patients newly entering care would improve retention in care over a 36-month follow-up period [19]. As previously reported, our primary analysis found that this intervention did not result in significant decreases in clinical care gaps or death [20]. However, a second objective of this study was to assess whether having such HIV patients assigned to an individual CSW would lead to emotional health benefits, including an improved sense of social support, and reduced feelings of depression and internalized stigma. This current analysis evaluated whether being paired with a CSW led to significant benefits in the psychosocial well-being of HIV-positive clients to which they were assigned.

Methods

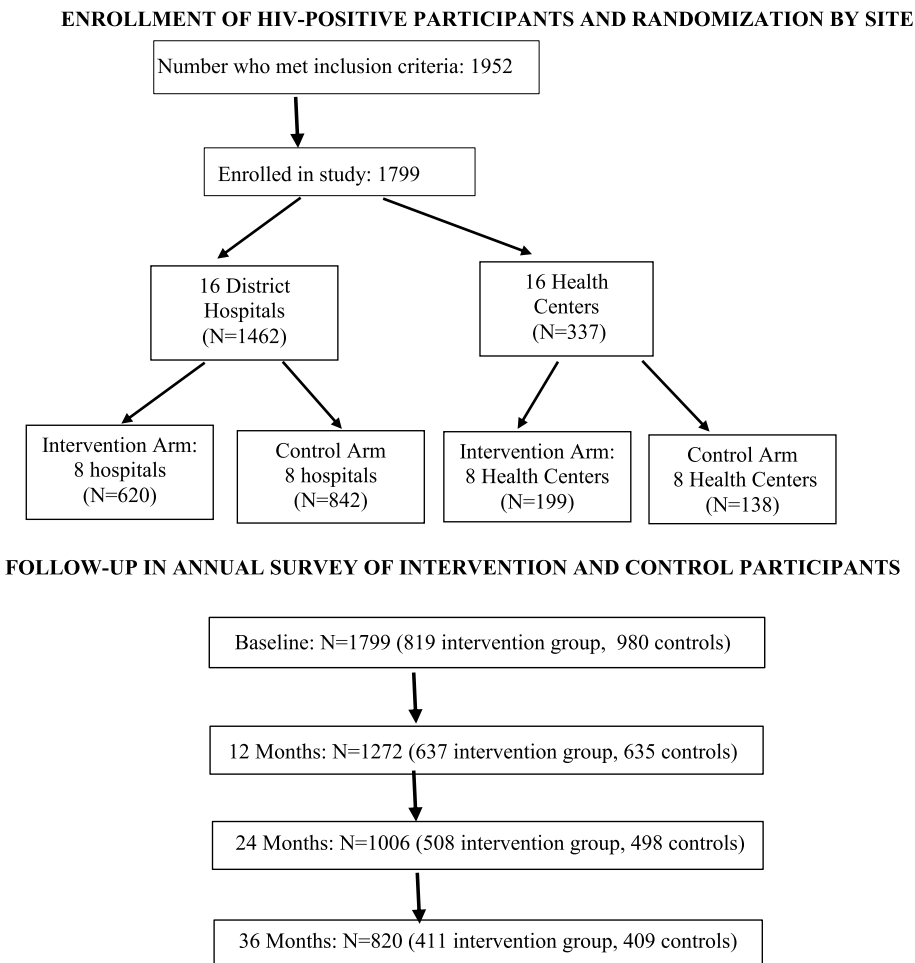
Study Setting and Participants

This study was conducted in the Southern Nations, Nationalities, and Peoples’ Region (SNNPR) of Ethiopia, one of Ethiopia’s most rural major regions. In 2020, Ethiopia had

an estimated 622,326 PLWH, of whom 47,373 were living in SNNPR [21]. Ethiopia’s decentralized health care plan includes primary care health centers, typically staffed by health officers or nurses, and district hospitals where staffing typically includes physicians. Within SNNPR, all public sector HIV clinics were enumerated, and 16 district hospitals and 16 health centers providing care to the largest numbers of PLWH were identified; eight district hospitals and eight health centers were randomly allocated to the intervention arm, and eight hospitals and health centers to the control arm (Fig. 1) [19, 20].

Because failure to retain in care is greatest in the first 6 months after ART initiation, our inclusion criteria were new enrollment in HIV care at one of the 32 participating hospitals or health centers within the previous 3 months. Recruitment was done sequentially from among all patients attending each clinic who met inclusion criteria. As described elsewhere [19], the initial approach to participation in this study was made by the HIV clinic nurse at the end of a patient’s medical visit; those who indicated potential interest were then referred to a study coordinator who explained the study in more detail and obtained informed

Fig. 1 Enrollment of HIV-positive patients, randomization by site, and annual follow-up of intervention and control participants through 36 months, in Ethiopian Community Support Worker Study (N = 1799)



consent. Of 1952 PLWH who met inclusion criteria, 1799 (92%) enrolled after meeting with study coordinators; 819 were enrolled from intervention sites and 980 from control sites [19, 20] (Fig. 1).

Standard of Care

All participants were seen during their HIV clinic visit by a medical provider who reviewed the patient's medical history, performed a brief assessment, ordered or reviewed laboratory tests, and either dispensed or wrote prescriptions for ART refills. Task shifting has been practiced in many Ethiopian HIV clinics, with various routine clinical and ART responsibilities shifted from doctors to health officers or nurses; patients with severe cases are referred to physicians at hospital levels [22, 23]. In some clinics, lay peer health workers may assist with tasks such as adherence counseling or defaulter tracing.

Intervention

PLWH receiving care at intervention sites were assigned a CSW living with HIV, who was also from the same geographic area. Details on selection, training and supervision of CSWs have been previously published [19]. In brief, local PLWH associations were consulted on initial recruitment of CSW candidates, with final selection of 71 CSWs based on observation of performance during a training workshop that contained education about HIV and ART, plus counselling strategies based on motivational interviewing principles [24]. Responsibilities of the CSWs included health education on HIV-related topics such as ART and adherence. CSWs also provided personal counseling and social support, including on feelings of helplessness and acceptance of one's HIV status. The original study protocol called for CSWs to meet with clients in community settings weekly for the first 3 months, and then 2–4 times/month as clients became more stable; however, as detailed elsewhere, some meetings occurred at most only once a month at clinic sites, and in some cases even less often [20]. CSWs met regularly with a project supervisor to review performance and discuss challenges working with clients; they also received periodic refresher trainings on HIV-related topics.

Data Collection

All participants were followed for 36 months, or until such time as they died, transferred to another HIV clinic, or were lost to follow-up [19]. At enrollment and every 12 months thereafter, participants completed a health survey. The survey was prepared as a scan-able bubble survey form using Amharic font and was verbally administered by a trained study coordinator. In developing the survey, items were

translated into Amharic, back-translated, and pilot tested. Items included demographics, date of first learning HIV status, feelings of social support and companionship, internalized HIV stigma, and physical and mental health symptoms. From the participants' HIV medical record, each year clinic-based data clerks abstracted information including CD4+ count and WHO HIV clinical stage, date of each clinic visit, and (if known and applicable) date of death or transfer to another clinic [19, 20].

Psychosocial Measures

Perceived social support was assessed using two domains from the Medical Outcome Study Social Support Survey (MOS-SSS): emotional/informational (EI) support (eight items assessing provision of emotional support and guidance/advice), and tangible assistance (TA) support (four items assessing provision of material aid or assistance) [25, 26]. For each domain, responses for each statement indicating perceived receipt of positive support from someone if needed were scored from 0 (none of the time) to 4 (all of the time). Possible scores were 0–32 for the MOS-SSS EI domain, and 0–16 for the MOS-SSS TA domain.

Depressive symptoms were assessed by the 10-item Centre for Epidemiologic Studies Depression Scale (CES-D-10) [27, 28]. Responses indicating depressive feelings in the previous week were scored from 0 to 3 for each item, with possible scores on the scale between 0 and 30. Participants were asked about feelings of internalized stigma in the last 3 months, using the five negative self-perception items drawn from the HIV/AIDS Stigma Instrument-PLWA (HASI-P) [29, 30]. Items indicating negative self-perception in the past 3 months because of HIV status were scored from 0 (never) to 3 (most of the time) for each item, with possible scores for the five item scale between 0 and 15.

Analysis

Results for all scores are presented using descriptive statistics (mean and standard deviation) for continuous variables; baseline results for each scale include Cronbach's alpha scores. Treatment effects (TE) (the estimated difference between intervention and control arms) were calculated using linear mixed effects regression models, with separate models fit for each of the four dependent variables; 95% confidence intervals (CI) were calculated for each TE to provide information about whether the bounds of this CI estimate include the null hypothesis of zero difference between intervention and control groups (e.g., $TE=0$) [31].

Repeated outcomes were included for each individual (12, 24, and 36 months). The baseline (0 month) value of the dependent variable was included as a covariate in the model and we adjusted for clustering due to enrollment site as well

as repeated observations in a 3-level model (visits clustered within subjects clustered within clinics). Additional analyses tested an interaction between follow-up time and TE; if no significant interaction was identified, an overall TE across the entire 36 month study duration was calculated and presented. Additionally, for each of the dependent variables, we fit follow-up year specific models to assess the effect of intervention on the dependent variable at 12, 24 and 36 months, adjusted for baseline scores. Individuals with missing data for any variable in the analysis were excluded from analysis. Degrees of freedom were based on the number of clusters, adjusting for the number of factors in the model. All models were fit in Stata V17 [32].

Results

Study Participants

From October 2015 through April 2017, of 1952 PLWH who met inclusion criteria at participating sites, 1799 (92%) enrolled in this study after meeting with a study coordinator; 819 were from intervention sites and 980 from control sites [19, 20]. Seven hundred thirty-three (41%) were male and 1066 (59%) were female; the median age was 30 years. Forty-nine percent were married, 15% were single and 35% were widowed, divorced or separated; 26% had no schooling, 47% attended some primary school, and 26% secondary school or higher. Sixty-six percent first learned their HIV status within 2 months prior to enrollment, and 18% within the previous 3–12 months. Forty-one percent entered the study with WHO HIV clinical stage III or IV disease. Of 1421 persons with a baseline CD4+ count in the medical record, the median value was 263 cells/mm³; 39% had a CD4+ count < 200 cells/mm³.

Of the entire cohort, by 36 months, 161 (9%) were known to have died, 242 (13%) had known transfer of care to other clinics and 3 (<1%) withdrew from follow-up; additional participants were lost to follow-up and could not be reached for follow-up interviews. Of those entering the study, 1272 (71%) completed the 12 month survey, 1006 (56%) the 24 month survey, and 820 (46%) the 36 month survey. The numbers of intervention and control participants surveyed at each 12 month interval are reported in Fig. 1. As previously reported, those who died, transferred or had a gap in clinical care (> 90 days from a scheduled clinic visit, including those lost to follow-up) did not significantly differ between intervention and control groups [20].

Emotional/Information Social Support

For the eight items from the MOS-SSS EI domain, the mean baseline score for all participants was 13.9, with Cronbach's

$\alpha=0.98$. Mean EI scores for intervention and control participants at baseline and annually through 36 months are reported in Table 1, and illustrated in Fig. 2a. At every year after enrollment, mean EI scores were higher for intervention compared to control participants. The greatest increase in the intervention group was from baseline to 12 months (from 12.9 to 21.6) after which increases from baseline were positive but much smaller.

In a linear regression mixed model accounting for site, TEs from baseline comparing intervention to control groups showed a higher emotional support in the intervention than the control arm after the first 12 months (5.9, 95% CI 1.4, 10.4), as well as at 24 months (5.1; CI 0.1, 10.1) and 36 months (7.2; CI 1.0, 13.5) (Table 2). The TE for EI scores did not significantly differ over time ($p=0.227$), and a model for emotional/informational support for the entire study period, accounting for repeated measures for each participant, was calculated. In this overall model, those in the

Table 1 Mean scores on social support, depression and internalized stigma scales upon enrollment (baseline), and on 12, 24 and 36 month follow-up surveys for intervention and control group participants, Ethiopia Community Support Worker Study

Measurement scale	Intervention Mean (SD)	Control Mean (SD)
MOS-SSS-EI domain scores		
Baseline (N= 1793)	12.9 (10.4)	14.8 (11.1)
12 months (N= 1267)	21.6 (9.5)	16.2 (12.1)
24 months (N= 1005)	22.8 (8.7)	17.2 (12.7)
36 months (N= 817)	23.4 (8.5)	18.2 (12.6)
MOS-SSS-TA domain scores		
Baseline (N= 1797)	8.1 (5.5)	8.1 (5.8)
12 months (N= 1266)	11.4 (5.1)	9.3 (6.1)
24 months (N= 1005)	11.8 (4.7)	9.7 (6.2)
36 months (N= 814)	11.9 (4.3)	10.7 (5.6)
CES-D-10 depression scores		
Baseline (N= 1798)	12.2 (6.3)	11.1 (5.8)
12 months (N= 1269)	5.9 (3.6)	9.0 (6.8)
24 months (N= 1005)	5.5 (3.9)	9.2 (7.5)
36 months (N= 815)	5.3 (3.9)	8.6 (6.9)
Negative self-perception (internalized stigma)[†]		
Baseline (N= 1791)	4.3 (4.2)	3.6 (3.6)
12 months (N= 1267)	1.5 (2.1)	3.3 (4.6)
24 months (N= 1004)	1.8 (2.4)	3.4 (5.0)
36 months (N= 814)	1.9 (2.2)	2.8 (4.8)

MOS-SS Medical Outcome Study Social Support Survey; *EI* emotional/informational support domain; *TA* tangible assistance support domain; *CES-D-10* 10-item Centre for Epidemiologic Studies Depression Scale; *SD* standard deviation

[†]Assessed by items from the HIV/AIDS Stigma Instrument-PLWA (HASI-P)

Fig. 2 a–d Mean scores for intervention and control group participants upon baseline enrollment, and on 12, 24 and 36 month follow-up surveys for: Medical Outcome Study Social Support Survey (MOS-SS) Emotional/informational (EI) support domain (a); MOS-SS Tangible assistance (TA) support domain (b); 10-item Centre for Epidemiologic Studies Depression Scale (CES-D-10) (c); and negative self-perception (internalized stigma) assessed by items from the HIV/AIDS Stigma Instrument-PLWA (d); Ethiopia Community Support Worker Study

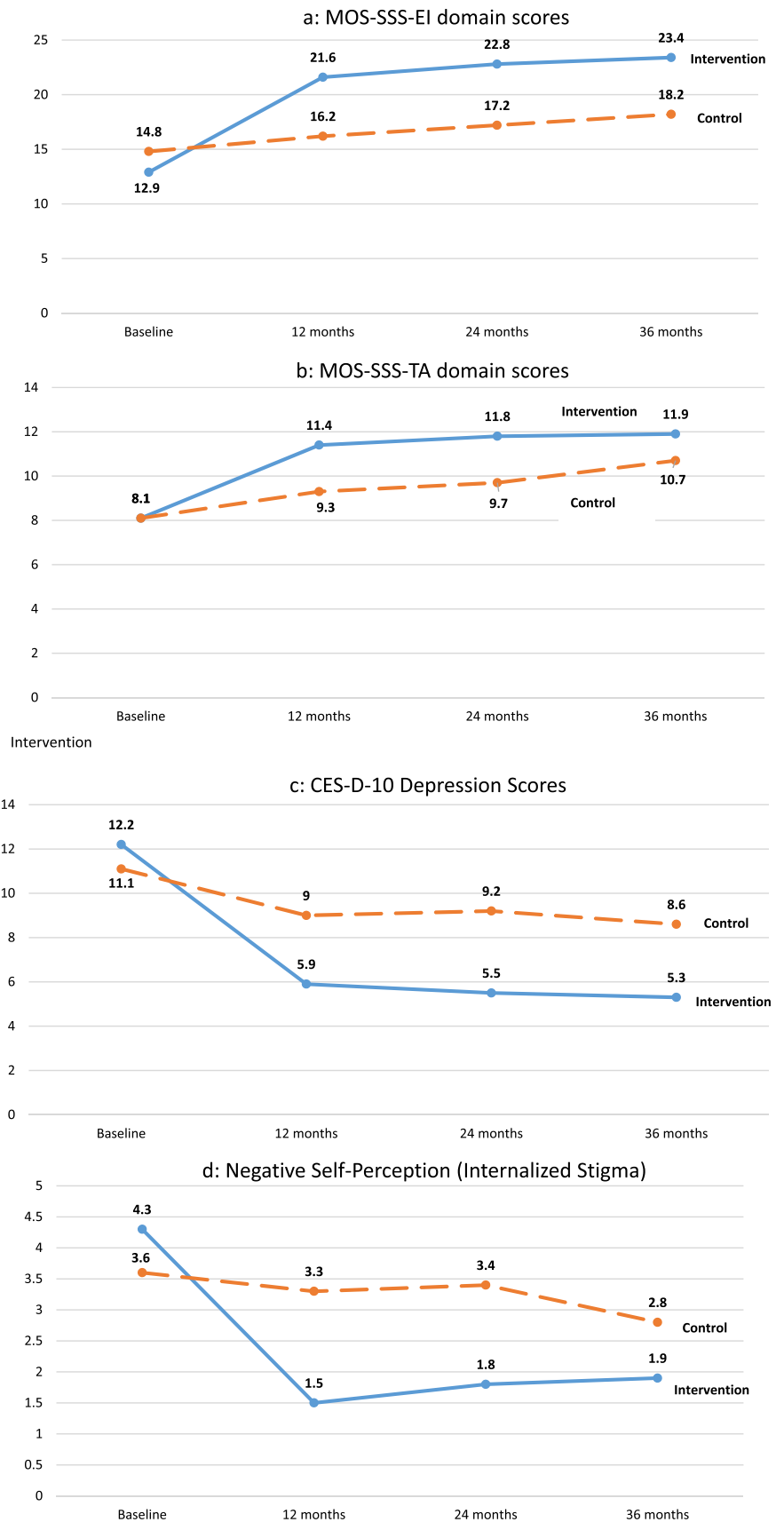


Table 2 Treatment effect with 95% confidence intervals (CI), Ethiopia Community Support Worker Study

Psychosocial scale	Treatment effect	(95% CI)*
MOS-SSS-EI domain scores		
Year-specific		
12 months	5.9	(1.4, 10.4)
24 months	5.1	(0.1, 10.1)
36 months	7.2	(1.0, 13.5)
Overall effect across entire follow-up	5.6	(0.9, 10.4)
MOS-SSS-TA domain scores		
Year-specific		
12 months	2.2	(0.3, 4.1)
24 months	1.6	(− 0.3, 3.6)
36 months	1.3	(− 0.8, 3.4)
Overall effect across entire follow-up	1.7	(− 0.1, 3.4)
CES-D-10 depression scores		
Year-specific		
12 months	− 3.7	(− 6.7, − 0.6)
24 months	− 4.3	(− 8.1, − 0.4)
36 months	− 5.2	(− 9.6, − 0.8)
Overall effect across entire follow-up	− 4.1	(− 7.6, − 0.7)
Negative self-perception (internalized stigma) scores [†]		
Year-specific		
12 months	− 2.9	(− 5.1, − 0.8)
24 months	− 3.2	(− 5.8, − 0.7)
36 months	− 3.5	(− 6.6, − 0.5)
Overall effect across entire follow-up	(Not calculated) ^{††}	

Difference between intervention and control participants for changes from baseline in 12, 24 and 36 months mean scores for social support, depression, and internalized stigma scales

MOS-SS Medical Outcome Study Social Support Survey; EI emotional/informational support domain; TA tangible assistance support domain; CES-D-10=10-item Centre for Epidemiologic Studies Depression Scale

*Provides information about whether the bounds of this CI estimate include the null hypothesis of zero difference between intervention and control groups (e.g., treatment effect = 0)

[†] Assessed by items from the HIV/AIDS Stigma Instrument-PLWA (HASI-P)

^{††} Due to significant interaction between treatment and time

intervention arm had EI scores that were 5.6 points higher (95% CI 0.9, 10.4) than those in the control arm.

Tangible Assistance Social Support

For the 4 items from the MOS-SSS TA domain, the mean baseline score for all participants was 8.1 (Cronbach's $\alpha = 0.97$). At every year after enrollment, mean TA scores were higher for intervention compared to control participants

(Table 1, Fig. 2b). The greatest increase in the intervention group was from baseline to 12 months (from 8.1 to 11.4) with small increases thereafter.

In a model evaluating TEs for TA domain scores, those in the treatment arm had greater tangible support than controls after the first 12 months (2.2, 95% CI 0.3, 4.1) (Table 2); TE differences were not significant at 24 and 36 months. The TE for TA scores did not significantly differ over time ($p = 0.528$), and a model for tangible assistance support for the entire study period was calculated. In this overall model, those in the intervention arm had TA scores that were 1.7 points higher than the control arm (95% CI − 0.1, 3.4).

Depression

For the 10 items on the CES-D-10 scale, the mean score at baseline for all participants was 11.6 (Cronbach's $\alpha = 0.84$). Mean depression scores for intervention and control participants at baseline and annually through 36 months show that at every year after enrollment, scores were lower for intervention compared to control participants (Table 1, Fig. 2c). The greatest decrease among intervention participants was from baseline to 12 months (from 12.2 to 5.9), after which incremental decreases continued.

A model comparing intervention to control groups on changes in depressive symptom scores showed fewer symptoms in the intervention arm than controls after the first 12 months (− 3.7; 95% CI − 6.7, − 0.6), as well as after 24 (− 4.3; CI − 8.1, − 0.4) and 36 (− 5.2; CI − 9.6, − 0.8) months (Table 2). The TE on depression scores did not significantly differ over time ($p = 0.640$), and a model for the entire study period was calculated. In this model, those in the intervention arm had overall depression scores that were 4.1 points lower than the control arm (95% CI − 7.6, − 0.7).

Internalized Stigma

For five items from the HASI-P instrument indicating negative self-perception due to HIV status, the mean score at baseline for all participants was 3.9 (Cronbach's $\alpha = 0.84$). Mean internalized stigma scores for intervention and control participants at baseline and annually through 36 months show that at every year after enrollment, scores were lower for intervention compared to control participants (Table 1, Fig. 2d). The greatest decrease in the intervention group was from baseline to 12 months (from 4.3 to 1.5), after which there were small incremental increases.

A model evaluating TEs showed less internalized stigma in the intervention arm compared to controls after the first 12 months (− 2.9, 95% CI − 5.1, − 0.8), as well as after 24 (− 3.2; CI − 5.8, − 0.7) and 36 (− 3.5, CI − 6.6, − 0.5) months (Table 2). Because the TE on internalized stigma scores significantly differed over time ($p < 0.001$), an overall

measure of TE across the entire 36 month period is not presented.

Discussion

In a community randomized trial in which 1799 PLWH were enrolled from 32 HIV clinics in southern Ethiopia, we found that provision of an individualized CSW intervention to HIV patients new to care was associated with important psychosocial benefits. Compared to those in the control group, during the critical first 12 months, intervention participants had significantly greater perceived emotional/informational and tangible assistance social support, as well as reduced feelings of depression and negative self-perception due to HIV status. Sustained benefits among intervention participants were seen through 36 months in reported feelings of emotional/informational support, depression, and internalized stigma.

In our study, self-perceived improvements in both EI and TA social support dimensions were noted among intervention participants during the 1st year, with overall significant improvement in EI scores across the entire 36-month period. Social support can play a critical role in helping individuals cope with stressful life events and ongoing life strains [33, 34], and social support among PLWH can play an important role in promoting physical and mental health, and improved quality of life [7, 35, 36]. Social support can come from many sources, including from peers, friends, family or professional caretakers; social support interventions can be individual or group based, and can be emotional, informational, or through provision of tangible aid [37–39]. In one study, daily home-visits by a community health worker were associated with increases in perceived social support in the 1st year of treatment [40]. Results from our pilot study [41], along with our larger intervention project, demonstrate that less frequent contacts may also be effective; our study also supports longer-term benefits in certain social support domains through 3 years. Provision of social support and social connectedness may be especially important in cultures, including that of Ethiopia, that are highly collectivist, with a strong focus on social relationships, group obligations, and interpersonal harmony [42, 43].

Depression is common among PLWH, including in sub-Saharan Africa [1, 10], and our study found decreases among intervention participants in depression symptoms throughout 36 months, significantly lower than control participants at all time points. Social support and depression are integrally related, and provision of support may help reduce depression and decrease the negative effects of depressive symptoms on health related quality of life [35, 44, 45]. Various interventions have been utilized for depression in PLWH, including medication, and individual or group psychotherapy or

cognitive behavioral therapy [46, 47]. Interventions with trained lay peer counselors have also been utilized to reduce symptoms of depression [48, 49] including one program with daily home visits by a community support worker who provided social support [40]. Our results and other studies support the role trained nonprofessionals can play in providing mental health services to PLWH, especially in resource poor settings.

Internalized HIV stigma represents a process in which a PLWH takes in negative ideas or stereotypes about PLWH and applies it to themselves, such as shame or feelings of worthlessness [50]. Internalized HIV stigma has been associated with greater depression and psychological distress [4, 45, 51], and reported from a number of countries in sub-Saharan Africa [3, 4, 8, 52]. Compared to controls, those in the CSW intervention group had significantly lower scores on negative self-perception due to HIV status at each time point through 36 months. Interventions developed to help reduce internalized stigma include those with educational components, as well as counseling to help PLWH deal with negative emotions, normalize the experience of living with HIV, and acquire problem-solving skills [53, 54]. A number of programs have incorporated peer supporters or counselors who are HIV-positive [41, 53, 55], and benefits of our intervention may have been related to the fact that CSWs were living with HIV themselves and from the same local communities as their clients. Given their background, CSWs could more easily relate to mental health challenges faced by their clients, and provide feedback on how they themselves had dealt with these negative feelings.

This study had several strengths. Validated survey instruments used in other African HIV studies were employed, and surveys were verbally administered in Amharic by trained project staff. Participants were recruited from a diverse mix of small and large district hospitals and HIV clinics, and 92% of potentially eligible HIV patients agreed to enroll in this study [19].

Our study also has several limitations. First, at each annual follow-up, there was a decrease in the number of participants surveyed, with major causes being death, loss to follow-up, or transfer to other clinics. However, our findings have important implications for the psychosocial health of those HIV patients who remain retained in care over time. In addition, as described in our primary analysis [20], the overall rate of death, transfer and gap in clinical care during the 36-month follow-up period did not significantly differ between intervention and control groups, supporting the lack of a substantial bias from differential loss to follow-up between treatment arms. Second, given the potential sensitivity of some questions, some participants may have chosen to minimize reporting negative feelings or attitudes, and self-reported answers may not have reflected actual beliefs [56]. Although we cannot exclude this influence, the consistency

of findings of benefit across multiple psychosocial domains is supportive of an intervention effect. Finally, this project was conducted in a specific and predominantly rural region of Ethiopia, and different interventions may be best suited to address emotional and psychosocial needs of PLWH in different settings. However, this study's findings have relevance for a number of locations, especially resource-limited and rural settings where formal mental health services and mental health professionals may be limited and difficult to access [57–59]. For example, in one Ethiopian district, rural residents with severe mental disorders, especially those who lived more than three hours from a health facility, were less likely to access care [57].

Our results support the valuable role that peer CSWs living with HIV can play in such resource limited settings to help improve the psychosocial health of PLWH. As HIV becomes increasingly managed as a chronic disease, by providing an understanding and informed peer supporter, especially one who is also living with HIV, CSWs can help ensure that PLWH not only live longer, but also live well.

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Author Contributions All authors were involved in design and implementation of the study, including development of data collection instruments, and provided intellectual feedback on interpretation of results included in this manuscript. ARL was lead investigator on all aspects of the project, and wrote the manuscript with assistance from co-authors. AH, SW, and TS had primary responsibility for local data collection and coordination with all local partners. AH, RH and RFM managed the study's data set. RFM was project statistician and lead on data analysis. KJH provided methodical guidance on psychosocial measures and their interpretation. AS, AH and TS provided administrative support for financial and other logistical requirements.

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Declarations

Competing Interests The authors have no competing financial or non-financial interests to disclose.

Ethical Approval Ethiopia's Ministry of Science and Technology National Research Ethics Committee and the University of Minnesota Institutional Review Board approved this study.

Informed Consent All participants provided signed informed consent after verbal explanation of consent provisions. De-identified dataset is not available as participants and the Ethiopian review agencies did not consent to the use of data by researchers outside the study team.

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