Implementation of a Peer HIV Community Support Worker Program in Rural Ethiopia to Promote Retention in Care

Alan R. Lifson, MD, MPH1, Sale Workneh, MD2, Abera Haillemichael, MS2, Workneh Demisse, MPH2, Lucy Slater, MPH3, and Tibebe Shenie, MBA2

Abstract
Retention in care is a major challenge for HIV treatment programs, including in rural and in resource-limited settings. To help reduce loss to follow-up (LTFU) for HIV-infected patients new to care in rural Ethiopia, 142 patients were assigned 1 of 13 trained community health support workers (CHSWs) who were HIV positive and from the same neighborhood/village. The CHSWs provided HIV and health education, counseling/social support, and facilitated communication with the HIV clinics. With 7 deaths and 3 transfers, the 12-month retention rate was 94% (95% CI = 89%-97%), and no client was LTFU in the project. Between enrollment and 12 months, clients had significant (P < .001) improvements in HIV knowledge (17% increase), physical and mental quality of life (81% and 21% increase), internalized stigma (97% decrease), and perceived social support (24% increase). In rural and resource-limited settings, community-based CHSW programs can complement facility-based care in reducing LTFU and improving positive outcomes for HIV-infected people who enter care.

Keywords
HIV, community health workers, retention in care, rural health, social support

A major challenge in scaling up HIV treatment in sub-Saharan Africa (SSA) is failure to retain those who initially enroll in HIV care.1 2 In SSA, only 81% of those started on antiretroviral therapy (ART) are retained in care by 12 months, with loss to follow-up (LTFU) the most common cause of attrition, and significant losses occurring in the first 6 months after enrollment in care.1 2 Of 89 451 persons living with HIV (PLWH) who started ART at multiple sites throughout Ethiopia, only 79% were retained in care after the first 6 months.3 Many patients defaulting from HIV care die without treatment4 5 or return only after developing advanced immune suppression and HIV disease.6 Those failing to continue on ART and suppress viral replication have a greater risk of transmitting HIV to their sexual partners7 and increasing new infections in their communities.

Health facilities in resource-limited settings, including in SSA, face multiple resource challenges in providing care for HIV-infected patients, including lack of adequate numbers of trained health workers.8 9 Such challenges may be particularly acute in rural areas, where HIV clinics face growing numbers of PLWH needing care.10 11 In Ethiopia, where 82% of the population is rural, over 35% of PLWH live in rural areas, and prevalence of HIV is increasing in small market towns compared to larger cities, with such towns potentially serving as bridging sites for further spread of HIV to rural areas.12 13 The number of HIV-infected patients receiving care in rural health facilities is growing, as programs promote decentralization of HIV care to peripheral health facilities.14 15 In addition, many of those who become infected in urban settings (such as migrant workers) return to their rural homes after becoming ill, further increasing the demand of rural HIV health services.12 To help provide specific HIV health services in resource-limited settings, including in rural areas, programs have used community health support workers (CHSWs) to provide patient counseling and other assistance to extend health care delivery and complement facility-based care.16 17 18

From 2010 to 2012, we implemented in rural Ethiopia a program using trained peer CHSWs who were also PLWH to promote retention in care, through provision of patient education, social support, and facilitated communications with the...
patient’s HIV clinic. Because the risk of LTFU is greatest within the first 6 months after entering HIV care, we recruited for this project HIV-infected patients who had recently enrolled in their HIV clinic. This report describes how we implemented this CHSW program for PLWH, the impact of our community-based intervention on retention in HIV care, and changes that were seen over a 1-year period in client knowledge, perceived social support, self-reported quality of life (QOL), and feelings of internalized stigma.

Methods

Study Participants

This project was conducted in Arba Minch located in rural Ethiopia in the Southern Nations, Nationalities, and Peoples’ Region. In February 2010, data from Arba Minch Hospital, the main zonal referral hospital, revealed that of the 1849 patients who had ever started ART at that facility, only 1240 (67%) were still on treatment at that facility.

During 2010 to 2011, 142 participants were enrolled from HIV clinics in Arba Minch Hospital and 5 local health centers serving this area. Patients at these sites who were ≥18 years of age and newly enrolled in HIV clinical care within the previous 3 months were identified by the HIV clinic nurse and sequentially recruited for this project.

Intervention

From each neighborhood or village from which a participant was enrolled, a CHSW from the same geographic area was assigned to that client. Thirteen CHSWs provided services for 142 PLWH (maximum caseload = 1 CHSW/20 clients). The CHSWs visited clients 1 to 4 times/month to provide (1) education on HIV treatment, nutrition, and other health-promoting behaviors; (2) counseling and social support, including discussing with clients negative personal feelings about being HIV-infected and disclosure of HIV status to others; (3) facilitated communication with the nurse from the HIV clinic (typically by cell phone), including addressing with the clinic questions or concerns clients had about changes in their clinical status or ART side effects; and (4) referrals as needed to community organizations (including PLWH associations) for assistance with nutrition, clothing, housing, or income-generating activities.

All CHSWs were PLWH themselves. To select CHSWs, position announcements were posted in target communities and word-of-mouth recruitment through local PLWH associations. Applicants were interviewed, and final selection made only after observing applicant performance during the initial training. Selection criteria included demonstrated understanding of training content, maturity and good communication skills, and sensitivity and commitment toward working with PLWH.

The CHSWs were given initial and refresher training, which included didactic lectures about HIV and health-promoting behaviors (eg, nutrition) and role-playing and group exercises on counseling clients in supportive and empathic ways. The CHSWs received a monthly stipend of 700 Ethiopian birr (~US$37) and supportive supervision from a project coordinator. The CHSWs met as a group every month with this coordinator to discuss problems encountered, potential strategies, and lessons learned in working with clients. The CHSWs filled out encounter forms for each visit with clients, allowing the project coordinator to monitor work performance and provide constructive feedback.

Measurements

With consent, selected data were abstracted from the participant’s HIV clinic record. Abstraction of HIV clinic record was done at baseline and at 6 and 12 months after enrollment in the project. At 6- and 12-month abstractions, we collected dates of all HIV clinic visits within the previous 6 months. We also collected date of transfer for those transferring care to another clinic and date and (if known) cause of death for study participants who died. In addition, at each data abstraction, we recorded the date and results of the most recent CD4 count determination. Date of the last clinic encounter was based on either a documented clinic visit or a CD4 count specimen collection date, whichever was most recent. Patients were considered LTFU during the 12-month period if their last clinic encounter occurred more than 90 days before the scheduled 12-month follow-up date (365 days from initial enrollment in the project) and if they were not known to have died or transferred out during this period.

At entry into this project and 12 months after enrollment, participants completed a health survey verbally administered in Amharic, which included assessment of (1) demographic characteristics; (2) knowledge about HIV care and treatment; (3) physical and mental QOL using items drawn from the World Health Organization (WHO) Brief HIV Quality of Life Survey; (4) perceived social support and connectedness to others using items adapted from the Social Provisions Scale; and (5) feelings of internalized stigma, using items drawn from an HIV/AIDS Stigma Scale. A summary HIV knowledge score was calculated based on the number of knowledge questions (n = 6) answered correctly. Summary QOL scores were calculated based on responses to 7 physical QOL and 5 mental QOL questions, and for responses to each question, a score of 0 to 2 was assigned, 0 represented the worst self-perceived QOL and 2 the best. A summary social support score was calculated based on the number of statements (n = 24) respondents agreed with that indicating feelings of social support or connectedness. A summary internalized stigma score was calculated based on the number of statements (n = 5) respondents agreed with indicating negative personal feelings in the past 3 months about being HIV-positive. For those respondents who completed both the baseline and the 12-month follow-up survey, pre- and postintervention responses on specific scales were compared using repeated measures analysis of variance.
Consent

Informed consent was obtained from all participants. Ethical approval was obtained from the University of Minnesota Institutional Review Board and the Hawassa University College Medicine and Health Sciences Institutional Review Board.

Results

Client Characteristics

Of 142 HIV-positive patients, 93 (65%) were female and 49 (35%) male, and the mean age was 33.7 years (range = 19-70 years). In terms of current marital status, 47% were married, 20% single, 20% widowed, and 12% other (eg, separated, divorced). Seventy-three (51%) patients either never attended school (33%) or attended some primary school but did not complete it (18%). Religion was primarily Ethiopian Orthodox (58%) or Protestant (37%).

At the time of enrollment in this project, 41% were classified WHO clinical stage I, 24% stage II, 25% stage III, and 10% stage IV. When asked about symptoms of illness lasting more than 1 month, 60% reported chronic fatigue, 43% chronic pain, 27% chronic fever, 22% chronic cough, 14% chronic diarrhea, and 56% weight loss. The mean baseline CD4 count was 220 cells/mm$^3$; 50% had $\leq$200 CD4 cells/mm$^3$, 37% had 201 to 350 CD4 cells/mm$^3$, and only 13% had >350 cells/mm$^3$. The mean baseline body mass index (BMI) was 20.5 kg/m$^2$, and 33% of clients had a BMI $\leq$18.5 kg/m$^2$, considered underweight. One hundred six (75%) clients had started ART; however, since we recruited only patients newly enrolled in HIV care within the past 3 months, these clients had started ART very recently, typically within the previous 1 to 2 months.

Client Outcome

During twelve months of follow-up, 3 (2%) patients transferred to another clinical facility outside the study area, and 7 (5%) patients died. The 3 transfers left the study at 1.0 to 9.7 months after enrollment. Those who died tended to have advanced disease at enrollment, with a median CD4 count of 107 cells/mm$^3$ and a median BMI of 17.9 kg/m$^2$. The most common cause of death was tuberculosis (4 patients) followed by sepsis (2) and heart disease (1).

Of the remaining 132 clients, all 132 (100%) remained engaged in the project without LTFU as supported by their participation in the 12-month follow-up interviews and continued engagement with their CHSWs. Of these 132 clients, 131 (99%) had their last documented clinic encounter either at or after the 12-month follow-up date (102, 77%) or within 90 days prior to the 12-month follow-up date (29, 22%). The remaining client was last seen 102 days (3.3 months) before the 12-month follow-up date. Using our definition, the 12-month rate of LTFU by the clinic was 1% (95% confidence interval [CI] = 0%-4%). The 12-month rate of retention in care (reflecting both deaths and LTFU) was 94% (95% CI = 89%-97%), largely due to early deaths.

Changes in Response to Health Survey

The 132 participants taking both baseline and 12-month follow-up surveys were asked 6 questions about HIV treatment (eg, If someone with HIV gets started on ART, it is OK to stop taking it once you feel better). The mean number of questions answered correctly increased from 4.7 to 5.5 ($P < .001$; Table 1). For 5 mental health QOL questions, summary scores were calculated as 0 to 10. For example, at baseline when asked if “I feel my life to be meaningful,” 33% said very much or extremely (scored 2 points), 58% said a moderate amount (score = 1 point), and 9% said little or none (score = 0). Between baseline and 12 months, the mean mental health QOL score rose from 6.8 to 8.2 ($P < .001$). When asked 5 questions assessing internalized stigma, 33% reported at baseline feeling at least once in the past 3 months “ashamed of having this disease,” and 33% also said felt that “I did not deserve to live.” Between baseline and 12 months, the mean number of negative feelings reported by respondents decreased from 1.6 to 0.05 ($P < .001$). Finally, participants were asked 24 questions about perceived social support or connectedness (eg, “There are people I know will help me if I really need it”). The mean total social support score rose from 18.2 to 22.5 ($P < .001$) between baseline and 12 months.

Over 12 months of follow-up, patients reported a number of improvements in physical health. For 7 physical QOL

Table 1. Baseline and 12-Month Follow-up Summary Scores From Health Survey for HIV-Infected Patients Assigned to Community Health Support Workers: Arba Minch, Ethiopia.*

<table>
<thead>
<tr>
<th>Summary Scores</th>
<th>Possible Score</th>
<th>Baseline</th>
<th>12-Month</th>
<th>P Value$^b$</th>
<th>% Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV knowledge</td>
<td>0-6</td>
<td>4.7</td>
<td>5.5</td>
<td>$&lt;.001$</td>
<td>+17%</td>
</tr>
<tr>
<td>Physical health QOL</td>
<td>0-14</td>
<td>7.5</td>
<td>13.6</td>
<td>$&lt;.001$</td>
<td>+81%</td>
</tr>
<tr>
<td>Mental health QOL</td>
<td>0-10</td>
<td>6.8</td>
<td>8.2</td>
<td>$&lt;.001$</td>
<td>+21%</td>
</tr>
<tr>
<td>Internalized stigma</td>
<td>0-5</td>
<td>1.6</td>
<td>0.05</td>
<td>$&lt;.001$</td>
<td>-97%</td>
</tr>
<tr>
<td>Social support</td>
<td>0-24</td>
<td>18.2</td>
<td>22.5</td>
<td>$&lt;.001$</td>
<td>+24%</td>
</tr>
<tr>
<td>Symptoms of illness</td>
<td>0-7</td>
<td>2.3</td>
<td>0.1</td>
<td>$&lt;.001$</td>
<td>-96%</td>
</tr>
</tbody>
</table>

Abbreviation: QOL, quality of life.
$^aN = 132$.
$^b$Repeated measures analysis of variance.
questions (eg, “physical pain prevents me from doing what I need to do”), summary scores were calculated as 0 to 14. Between the baseline and the 12-month surveys, the mean physical QOL score rose from 7.5 to 13.6 ($P < .001$; Table 1). When asked about 7 symptoms of chronic illness such fatigue or chronic fever, the mean number of symptoms reported decreased from 2.3 to 0.1 ($P < .001$).

**Discussion**

Among 142 HIV-infected patients newly enrolled in care in rural Ethiopia, implementation of this pilot CHSW program was associated with minimal rates of LTFU. The overall 1-year rate of retention in care was 94%, with losses largely due to early deaths. Of patients who did not die or transfer to another clinic, 100% remained engaged with their assigned CHSWs in this project over a 12-month follow-up period, and 99% had a documented clinic encounter within 90 days of our 12-month follow-up date or thereafter. Clients also had documented increases in knowledge about HIV treatment and improvement in a number of mental health parameters including feelings of internalized stigma and perceived social support.

Patients in this project had a number of positive changes in physical health with increase in CD4 count, BMI, and physical QOL scores and a decrease in symptoms of chronic illness, and this likely reflects the benefits of ART and other clinical health interventions. However, benefits of such clinical treatments are not fully realized if clients do not remain engaged in and participatory in their health care, a primary goal of this project. Improvements in physical health may have also contributed to improved mental health and client attitudes.

A primary reason why CHSWs had a positive outcome with their clients is likely through their provision of social support. Potential stresses faced by PLWH include insufficient information to make informed decisions, internalized stigma, social isolation, and poor communication with the HIV clinic with inadequate resolution of medical concerns. Social support can act as a “buffer” against these stressors by providing informational support (facts or advice to help individuals better understand and manage their situation), emotional support (empathy and acceptance to let clients know that they are cared about and valued), companionship support (reducing feelings of isolation and fulfilling needs for social contact), and instrumental support (including provision of specific services to reduce client needs). Our CHSWs helped patients to address each of these areas, resulting in increased HIV treatment knowledge, decreased internalized stigma, greater perceived social support, and improved access/communication with the HIV clinic.

The fact that CHSWs were PLWH and members of the same communities as their clients was especially valuable in facilitating client relationships and acceptance. Social support as coping assistance may be strengthened when it comes from those who have effectively managed similar stressors and life circumstances. Many clients expressed feelings that as another PLWH, their CHSW understood their personal experiences and challenges. As another benefit, many CHSWs reported that through participation in this project they became more knowledgeable about and comfortable with their own HIV status, allowing them to better manage their HIV infection and in turn reflect back to their clients a more confident model of a PLWH making a positive contribution to the health of others.

We cannot say with certainty whether the positive results we observed among clients were due to this CHSW intervention or to other aspects of their HIV care, including counseling and support received at the HIV clinic. However, the very low rates of LTFU in this study are in contrast to observational Ethiopian cohorts which report much higher LTFU rates, especially within the first 6 months after enrollment in care. Our results are also consistent with other SSA studies indicating a positive impact of CHSWs on retention in care.

Studies on use of CHSWs have identified a number of factors contributing to successful client outcomes, and our intervention utilized many of these. First, our program was developed only after discussions with key stakeholders, including local public health officials, HIV clinicians, community leaders, and PLWH associations. Second, we had specific recruitment processes and selection criteria for CHSWs. Third, training and supportive supervision were provided to CHSWs on a regular basis. Because of training, CHSWs were seen by their clients as knowledgeable sources of information about HIV. Meeting monthly as a group with the project coordinator helped to foster a sense of group identity and mutual support among CHSWs, contributing to their dedication to the project. Finally, CHSWs received financial remuneration for their time and effort. Lack of payment and reliance on voluntarism has been reported as a cause of attrition among CHSWs and a disincentive to spending significant time on program activities. The monetary support provided by the project not only helped CHSWs to meet their own financial needs but also acknowledged their role as trained professionals providing an important service to their community.

This study has several limitations. As a pilot study, we do not have a comparison group, although our LTFU rates are lower than data reported from other cohorts in Ethiopia. Based on our favorable initial results, we are currently initiating a randomized community trial at multiple sites in Ethiopia to further evaluate the impact of this CHSW program on retention in care and other outcomes for PLWH. Second, it is possible that HIV-infected patients who agreed to participate in this project were more highly motivated to work with CHSWs, reflecting a potential selection bias. Participants meeting inclusion criteria were sequentially recruited, and although we were not able to collect specific data on participation rates, the HIV clinic nurse recruiting for this study informed us that refusal rates were very low. In addition, demographic characteristics of our study sample are similar to other reported cohorts of HIV-infected patients from Arba Minch. Finally, this was a study of a specific population and geographic area, and results are not necessarily generalizable to all other PLWH. However, our findings are consistent with other reports demonstrating the
beneficial effects of CHSWs in extending HIV health care delivery to PLWH by providing education, counseling, and other support.\textsuperscript{17–27}

In summary, we describe successful implementation of a CHSW program for Ethiopian HIV-infected patients newly enrolled in care, a group for which support needs and the risk of treatment default are especially great. Favorable outcomes in our clients included very low LTFU rates and positive improvements in client knowledge and attitudes. Although measures to promote retention in care are a critical part of the HIV continuum of care, in SSA, it is estimated that more than half of PLWH are not aware of their HIV status.\textsuperscript{41} Those patients who died in this study after enrolling with advanced disease highlight the need for earlier diagnosis and linkage to care. We believe that programs using trained community-based support workers for HIV-infected patients can provide a valuable contribution to a country’s overall strategic plan to optimize the health of PLWH, including in rural, resource-limited settings such as this one.

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