

Use of Community Health Support Workers for Persons Living With Human Immunodeficiency Virus in Rural Ethiopia: Lessons Learned

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Abstract

Background: Health facilities in rural, resource limited settings face multiple challenges responding to a growing demand for HIV treatment, including lack of adequate numbers of trained health workers. Many programs have used community health support workers (CHSWs) to provide specific services related to HIV care, and to complement facility-based treatment.

Methods: In rural southern Ethiopia, 13 HIV-positive CHSWs were assigned to 142 newly diagnosed HIV patients from the same community to provide: education on HIV treatment and health promoting behaviors; counseling and social support; and linkage to the HIV Clinic.

Results: Lessons learned in planning and implementing CHSW programs for PLWH include the benefits of: involving local health bureaus, clinicians, and the community; careful recruitment processes and selection criteria for CHSWs; use of local PLWH as CHSWs to facilitate relationships with HIV-positive clients; initial and on-going training of CHSWs with didactic information and counseling skills; clearly defined responsibilities and regular, supportive supervision with constructive feedback; emphasizing importance of client confidentiality; and financial compensation for CHSWs.

Conclusion: Use of CHSWs can be an effective strategy to support the HIV health care system, and offers a strong complement to facility-based care in rural and other resource-limited settings. However, such programs may be most successful if they attend to the multiple issues described above in planning and implementation.

Keywords: Human immunodeficiency virus; Community support workers; Rural health; Sub-Saharan Africa

Abbreviations

ART: Antiretroviral Therapy; CHSW: Community Health Support Worker; HIV: Human Immunodeficiency Virus; PLWH: People Living With HIV; SSA: Sub-Saharan Africa; WHO: World Health Organization

Background: HIV in Rural Africa

Human immunodeficiency virus (HIV) is growing in rural areas, including in sub-Saharan Africa (SSA) [1-4]. In Ethiopia where 83% of the population is rural, over 37% of the estimated 1.2 million people living with HIV (PLWH) are in rural areas [5]. HIV prevalence in Ethiopia is increasing in small market towns compared to larger cities, with such towns potentially serving as bridging sites for urban to rural spread of HIV [6]. The number of HIV patients in rural facilities is also growing as programs promote decentralization of HIV care to peripheral health facilities [7-9]. In addition, many of those who become infected in urban settings return to their rural homes after they become ill, further increasing rural HIV health service demands [4].

Health facilities in rural settings face multiple challenges, including lack of adequate numbers of trained health workers [10-12]. To help address the shortage of trained health workers in resource-limited settings, many programs have used community health support workers (CHSWs) to provide specific health services related to HIV care, such as patient education, counseling, collection of clinical status data, and delivery of antiretroviral therapy (ART). Positive outcomes associated with CHSWs among HIV patients include ART adherence, viral suppression and overall survival [3,13-21]. Use of CHSWs also has beneficial results on loss to follow-up among HIV patients in care, including in rural settings [13,15,18-21].

CHSWs are recognized as integral to primary health care in resource limited settings, including in rural areas, extending health care delivery, and complementing facility-based care [22-24]. One task force estimated that one million CHSWs should be trained and deployed in sub-Saharan Africa by 2015 to help meet primary care needs and Millennium Development Goals [23]. We describe lessons learned from developing and implementing a CHSW program for PLWH in rural Ethiopia, including suggestions for others considering similar programs.

Description of a Community Support Worker Intervention for HIV Patients

In rural Ethiopia, we developed an intervention to support treatment adherence and prevent default among HIV patients, using lay community members who were also PLWH. This project was conducted in Arba Minch, a rural town in the foothills of the Rift Valley in the Southern Nations, Nationalities, and Peoples' Region of Ethiopia. In addition to the town, many persons live in the surrounding villages, supporting themselves through farming.

The target population for this intervention was adult PLWH who were newly enrolled in HIV care within the past three months. Patients were recruited from the zonal referral hospital plus smaller health centers serving this area; those meeting inclusion criteria were sequentially offered enrollment. Of 142 participants in this project, 65% were female; the mean age was 34 years and the median CD4+ count at enrollment was 201 cells/mm³. Thirty-five percent were classified as WHO Stage III or IV, and 75% had started on ART.

In Ethiopia, kebeles are small units of administration, representing neighborhoods (in cities or towns) or villages (in rural areas). Every resident of Ethiopia belongs to a kebele, which provides many basic municipal services. From each kebele where an HIV patient was enrolled, a CHSW from the same area of residence was selected to work with that client. Thirteen CHSWs provided services for up to 20 clients each. CHSWs visited clients 1-4 times/month; the average total time spent with each client was 2-3 hours per month.

CHSW responsibilities were as follows: (1) education on HIV treatment (including ART side effects) and health promoting behaviors (including nutrition); (2) counseling and social support (including helping clients address negative personal feelings about being HIV-positive and disclosure of HIV status to others); and (3) facilitating linkage and engagement with the HIV Clinic. CHSWs were given cell phones to call a designated HIV Clinic nurse, including for questions about new medical symptoms or changes in clinical status in clients. CHSWs also provided referrals to local PLWH associations and other organizations that could help meet client needs such as nutrition, clothing, and development of income-generating activities.

Results and Discussion: Lessons Learned

Consultation with multiple stakeholders

This program was developed after discussions with and advice from health bureau staff at the local and regional levels, HIV clinicians, kebele and other community leaders, and PLWH associations. We believe that prior involvement of these various important stakeholders and partners contributed to the positive collaboration and support that CHSWs received from multiple sectors. In planning CHSW programs, we emphasize the importance of community participation and engagement of key stakeholders, including public health bureaus and clinical care providers [22,25-28].

Selection of CHSWs

Careful recruitment processes and selection criteria for CHSWs are important; belonging to the community they will be working in and motivation to serve that community are important considerations [22,25-29]. In this project, position announcements were posted in the kebeles included in our program area, as well as on Arba Minch Hospital notice boards. As part of the interview, applicants were

presented with case situations potentially affecting PLWH, and asked how they might address them. Evaluation criteria included previous training and work experience (paid or volunteer), plus demonstrated maturity, good communication skills, sensitivity and expressed commitment towards working with PLWH. Strong preference was given to applicants who were PLWH themselves.

Out of 27 interviewees, 20 were selected for participation in an initial one-week training (detailed below). During this training, participants were observed for personal skills described above. Based upon this observation, plus performance on a post-training knowledge test, a final group of 13 CHSWs (8 women and five men) were chosen; this final group included persons from both Arba Minch town and local villages, representing all of the kebeles in our project area.

Use of PLWH as CHSWs

In this support program for HIV patients, the fact that CHSWs were PLWH and members of the same communities as their clients was valuable in facilitating client relationships and acceptance. Social support as coping assistance may be strengthened when it comes from those who have faced similar stressors and life circumstances, and have been able to effectively manage these challenges [30]. A number of clients expressed feelings that their CHSW was a supportive and accepting partner, who as another PLWH could understand a client's personal experiences and challenges. Many CHSWs reported the personal satisfaction of knowing that through this project they were benefiting others in their community, in particular PLWH. Several CHSWs reported that through participation in this project they became more comfortable with their own HIV status, allowing them to reflect back to their clients a positive and confident model of someone living with HIV. Other programs also describe positive aspects of using PLWH to provide care and support services to other HIV-positive persons [13,31,32].

Training

We emphasize, as others have done, the importance of CHSWs receiving initial and on-going training [22,25-29,32]. The schedule for the initial one-week training is detailed in the Appendix, and contained both didactic information and counseling skills. This initial training included talks on: HIV transmission, clinical outcome, and monitoring; ART regimens, side effects, and adherence; nutrition and other health promoting behaviors; and counseling skills, using approaches that were supportive, accepting and empathic. Group exercises included practice counseling sessions and role-playing. Training was primarily conducted by the coauthors on this manuscript, with additional participation from HIV clinicians at Arba Minch Hospital and a nutrition specialist at Arba Minch University.

Training updates for CHSWs were provided several ways. During their monthly group meetings (described below), CHSWs received from the HIV Clinic Nurse short talks on various topics related to HIV health, such as sanitation or proper food preparation. In addition, during his quarterly monitoring visits, the Project Director (Dr. Lifson) would present a lecture on some topic of interest requested by the CHSW group, such as tuberculosis or other co-infections. One year after the initial training, a one-day refresher training was also held for CHSWs, to provide updated information on many topics covered in the initial course.

Increasing their HIV disease knowledge and counseling skills helped CHSWs to most effectively support their clients, and ongoing

training helped to reinforce initially presented information and skills. As an additional benefit, some CHSWs reported that by learning more about HIV and its treatment, they were able to better manage their own HIV infection.

Supervision

We emphasize the importance of CHSWs having clearly defined responsibilities, regular and reliable supportive supervision, and constructive feedback [22,25-29]. A project coordinator was hired for this study to supervise CHSWs. CHSWs were required to fill out encounter forms for each visit with each client; CHSWs recorded on these forms the date and time spent for each contact and a brief description of what was discussed or decided. Forms were turned in each month, allowing the project coordinator to monitor work performance and to address any problems in a timely fashion. In addition, the project coordinator met monthly with CHSWs as a group, where they shared experiences, strategies and lessons learned in working with clients; this allowed CHSWs to advise each other and to provide recommendations to improve the project. Meeting as a group fostered a sense of group identity and mutual support among CHSWs, contributing to their dedication to this project.

Importantly, although CHSWs in this program had clear accountability, they also had a certain flexibility to use their experience and best judgment in responding to individual client needs and circumstances. We believe that not only did this contribute to CHSW motivation, but also provided the best model for collaborative care.

Confidentiality

Breach of confidentiality could occur if a CHSW revealed to someone outside the project information reported by a client, or even that the client was HIV-positive. Training and supervision for CHSWs stressed the importance of participant confidentiality, especially given the stigma that many PLWH face in their communities [33,34]. Maintenance of confidentiality is critical to the client-CHSW trust relationship; CHSWs were told that breach of confidentiality is an offense for which there would be minimal tolerance, with likely removal from the project. No such offenses were reported.

Financial compensation

We emphasize, as others have done, that CHSWs should receive adequate remuneration [22,25-29]. Lack of payment and reliance on voluntarism is a cause of attrition among CHSWs, and a disincentive to spending significant amounts of time on program activities [25-27,29,35]. CHSWs in this project received modest but very important financial support for their time and effort, with a monthly allowance of 700 Ethiopian birr (~\$37 U.S.). CHSWs expressed pride that they were able to financially support themselves and contribute to their families, and felt that this financial support allowed them to fully participate in this project.

Conclusion

If CHSW programs are to be successfully integrated into the HIV care system, sustainability will be critical. Ethiopia has implemented a nationwide program of health extension workers recruited from their prospective villages to provide basic health services [36], and we believe that training and implementation of a program using "specialist community health workers" [26] can be integrated into this

system to address specific health issues for PLWH. Education and social support needs for PLWH are likely to be greatest for those who are newly diagnosed; treatment default for ART patients tends to be greatest within the first year after enrollment in care [37]. As patients become more informed and accepting of their status, the frequency and intensity of CHSW support needs would be expected to decline.

Our experience suggests that CHSWs programs may be most successful if they include involvement and support from multiple stakeholders (including the community, clinical providers, and public health officials), plus specific procedures for CHSW selection, training, supervision and financial support. For HIV patients, CHSWs who are also PLWH can be particularly effective. If adequately designed and implemented, with careful attention to the issues described in this manuscript, deployment of CHSWs can be an effective strategy to support the health care system for PLWH, offering a strong complement to facility-based care in rural resource-limited and other settings.

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