

Community HIV Support Worker Program in Rural Ethiopia: Client Attitudes and Outcomes after 1 Year

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Background: Challenges for HIV

Loss to Follow-up

- Despite starting > 7.5 million in sub-Saharan Africa on ART,
 failure to retain patients in care undermines this accomplishment
- LTFU → immune suppression/disease, death, HIV transmission
- One Ethiopian cohort of 89,451 patients on ART at 185 facilities:
 - 14.5% LTFU and 6.5% dead after only 6 months
 - 18.4% LTFU and 8.6% dead after only 12 months ¹

HIV in rural areas: Ethiopia

- ~760,000 HIV-positive Ethiopians, > 38% rural
- New HIV infections increasing in smaller market towns, which can serve as bridging sites for further spread to rural settings²
- Rural HIV patients may face number of access, service barriers

¹ Ethiopia HIV/AIDS Prevention and Control Office: ART Scale-up in Ethiopia, Jan. 2009

² Fed Dem Republic of Ethiopia: Country Progress Report on HIV/AIDS Response, 2012.

Background

- Ethiopian national HIV/AIDS Strategic Plan calls for at least 85% retention in care by 2015, with expanded HIV care access at primary care facilities, task shifting, and strengthened local community involvement in care and support of PLWH.
- To help address these needs, many HIV programs have used community support workers to provide specific services
- We implemented a pilot community intervention in rural southern Ethiopia using trained community adherence support workers (CASWs) to provide patient education, counseling, social support, needed referrals, and improved communication/ linkage to the HIV clinic
- Evaluated impact on client retention, clinical status, knowledge, attitudes (including internal stigma, feelings of social support)

Study Setting

- <u>Southern Nations Nationalities & Peoples</u> <u>Region</u>: 91% of the population is rural
- Study in <u>Arba Minch</u> (pop. ~95,000) and surrounding villages
- Arba Minch Sidama

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- Economy primarily agricultural
- <u>Kebeles</u>: Neighborhood or village Ethiopian administrative units to which every resident belongs; basic municipal services
- At Arba Minch Hospital in 2010, > 2,000 started on ART, but only about 2/3 still on treatment
- Project conducted 2011-2012



Community HIV Adherence Support Workers

- Overall Goal Work at community level to support persons living with HIV, improve retention in care and linkage to HIV care system (support efforts at hospital/health center)
- Support Workers Each HIV patient assigned a CASW from same, nearby kebele
- <u>Target population</u>: HIV-positive persons who enrolled for HIV medical care at the Arba Minch Hospital HIV Clinic, or one of the Health Centers in the Arba Minch area (in-town or rural)
- Inclusion criteria:
 - Adults ≥18 years
 - Because loss to follow-up greatest within first six months, focus on patients newly diagnosed within previous 3 months.

Community Support Worker Intervention

Community HIV Support Workers: All HIV-positive themselves

- Initial one-week training, refresher trainings (knowledge, skills)
- Supervised by Project Coordinator, with whom meet as a group on a monthly basis to discuss common concerns and challenges
- Received transportation/allowance stipend, cell phone
- Responsibilities:
 - Education: HIV prevention, ART (incl side effects), nutrition
 - Counseling/social support: Motivation, problem-solve barriers challenges
 - <u>Liaison with HIV Clinic</u>: Questions, change in medical status, follow-up
 - <u>Linkage to other resources:</u> (PLHA associations, NGOs) for referrals



Assessment Measures

Primary outcome: 12 month treatment retention rate

Hypothesis: Retention in care at 12 months will be <u>></u>90%.

Clinical status recorded at baseline, 12 month f/u

- Body Mass Index
- Clinical history: symptoms of chronic illness
- CD4+ count

Health survey at baseline, 12 months

- Knowledge about HIV, including care and follow-up
- Health status: Symptoms of chronic illness
- Quality of life: Physical; mental
- Social connectedness: social support, close relationships
- Perceived HIV stigma, including negative self-perception

Operational characteristics

Clients: Arba Minch ART Retention Project

13 CASWs assigned to 142 HIV-positive clients

Met clients at home 1-4 times/month; total 2-3 hours/month

Client Demographic characteristics

- Mean age = 33.7 years (range: 19-70)
- 35% male, 65% female
- 47% married, 20% single, 20% widow, 12% other
- Education: 51% had not attended/completed primary school

Client: Clinical Characteristics (baseline):

- 75% on ART at enrollment
- WHO Stage: I=41%, II=24%, III =25%, IV=10%
- Median CD4+ = 201 cells/mm³; 20%<100 cells; 87%< 350 cells
- Median BMI = 20.1 kg/m²; 33% < 18.5 kg/m² (underweight)

Baseline Results on Health Survey

Number of chronic symptoms (0-7): Mean= 2.4

• Chronic fatigue (60%), pain (43%), fever (27%); 56% wt. loss

Physical Quality of Life (summary score=0-14): Mean= 7.3

Activity limited by physical pain: 37% very much, 30% some

HIV Knowledge (summary score=0-6): Mean= 4.7

Holy water can cure AIDS: 23% agree, 42% DK/uncertain

Social Support (summary score=0-24): Mean = 18.1

People I know will help me if I need it: 54% disagree, 6% DK

Internal stigma (summary score=0-5): Mean = 1.6

One or more times last 3 mos: felt I didn't deserve to live (30%);
 ashamed of having this disease (33%)

Loss to Follow-up Arba Minch Retention Project

Of 142 clients followed for 12 months

- 3 transferred out
- 7 deaths
 - Causes included: TB, other bacterial infections, cardiac
 - Median baseline CD4+ = 107 cells/mm³; BMI= 17.9 kg/m²
 - Median time from enrollment to death = 3.5 months

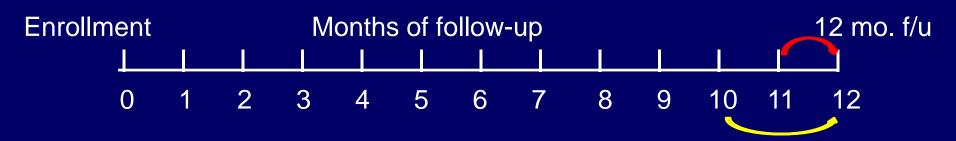
132 clients completed 12 month survey and remained engaged in project

Validation Study: Loss to Follow-up Arba Minch Retention Project

Reviewed data from HIV Clinic records

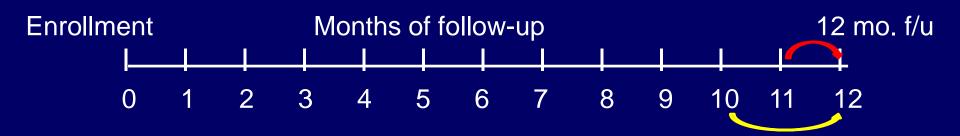
Primary Outcome: Engagement in HIV care through 12 months

Evaluated time from enrollment in project to last documented HIV Clinic encounter (documented clinician visit and/or evaluation for CD4+ count)



 Was there a documented HIV clinic encounter within 30 days of 12 month follow-up date? Within 60 days?

Validation Study: Loss to Follow-up Arba Minch Retention Project



- Was there a documented HIV clinic encounter within 30 days of 12 month follow-up date? Within 60 days?
- Of 132 participants not known to have died or transferred:
 - 89% had documented HIV visit encounters within 30 days of 12 month f/u date
 - 94% within 45 days of 12 month f/u date
 - 97% within 60 days of 12 month f/u date

Changes Over Time: Arba Minch CASW Project

Mean values:	Baseline	12-months	p-value*
Symptoms of Illness (0-7)	2.3	0.1	(p<0.001)
Physical Quality of Life (0-14)	7.5	13.6	(p<0.001)
HIV knowledge (0-6)	4.7	5.5	(p<0.001)
Social Support (0-24)	18.2	21.6	(p<0.001)
Internalized Stigma (0-6)	1.6	0.05	(p<0.001)
CD4+ count (cells/mm³)	226	396	(p<0.001)

^{*} Paired t-test

Impact of Project on CASWs

- Learning more about HIV treatment and the importance of adherence benefited their own health status.
- Participating in the project helped them feel more <u>accepting</u> and comfortable with their own HIV status.
- Stipends helped provide <u>financial support</u> for CASWs and their families; allowed them to fully participate in the project.
- Close personal relationships and very <u>positive social</u> <u>interactions</u> with clients personally rewarding.
- Personal satisfaction of <u>making a difference</u> in the lives of other PLWH in the community.
- Enhanced their own <u>feelings of self-esteem</u> and that they had valuable skills for their community.

Discussion

- Factors contributing to success included:
 - Selected motivated CASWs
 - Training and close supervision
 - CASWs were also HIV-positive
 - Stipends
 - Involvement of multiple stakeholders
- This was a pilot study with no comparison group
 - Proposing randomized community trial
- Early mortality--patients enrolled with advanced disease;
 need for earlier diagnosis and linkage to care
- Key to long-term success of such programs is sustainability

Conclusions

- A community support worker program was successfully implemented for people living with HIV in rural Ethiopia
- This program was associated with:
 - low rates of loss to follow-up after one year
 - improvements in clinical status and perceived quality of life
 - improved knowledge about HIV treatment
 - improved attitudes (less internal stigma) about HIV status
 - increased feelings of social support
- Support workers, who were also HIV positive, reported benefits for their own health and feelings of self-esteem

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- Community support workers
- People living with HIV in Arba Minch and surrounding villages