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

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 settings
- Rural HIV patients may face number of access, service barriers

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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

- **Southern Nations Nationalities & Peoples Region**: 91% of the population is rural

- Study in **Arba Minch** (pop. ~95,000) and surrounding villages

- Economy primarily agricultural

- **Kebeles**: 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

- **Target population**: 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 $\geq 18$ 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
  - Liaison with HIV Clinic: Questions, change in medical status, follow-up
  - Linkage to other resources: (PLHA associations, NGOs) for referrals
Assessment Measures

Primary outcome: 12 month treatment retention rate
  • Hypothesis: Retention in care at 12 months will be ≥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
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

Enrollment

• 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
<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>12-months</th>
<th>p-value*</th>
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<td>Symptoms of Illness (0-7)</td>
<td>2.3</td>
<td>0.1</td>
<td>(p&lt;0.001)</td>
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<tr>
<td>Physical Quality of Life (0-14)</td>
<td>7.5</td>
<td>13.6</td>
<td>(p&lt;0.001)</td>
</tr>
<tr>
<td>HIV knowledge (0-6)</td>
<td>4.7</td>
<td>5.5</td>
<td>(p&lt;0.001)</td>
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<tr>
<td>Social Support (0-24)</td>
<td>18.2</td>
<td>21.6</td>
<td>(p&lt;0.001)</td>
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<tr>
<td>Internalized Stigma (0-6)</td>
<td>1.6</td>
<td>0.05</td>
<td>(p&lt;0.001)</td>
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<tr>
<td>CD4+ count (cells/mm³)</td>
<td>226</td>
<td>396</td>
<td>(p&lt;0.001)</td>
</tr>
</tbody>
</table>

* 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 accepting and comfortable with their own HIV status.
- Stipends helped provide financial support for CASWs and their families; allowed them to fully participate in the project.
- Close personal relationships and very positive social interactions with clients personally rewarding.
- Personal satisfaction of making a difference in the lives of other PLWH in the community.
- Enhanced their own feelings of self-esteem 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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- National Alliance for State and Territorial AIDS Directors, including Gezie Aba and Randy May
- Community support workers
- People living with HIV in Arba Minch and surrounding villages