COMMUNITY SUPPORT FOR THE HIV AND AIDS CONTINUUM OF RESPONSE IN UGANDA

Background

As part of its support to the Ministry of Health and US Government (USG) implementing partners in Uganda to improve the quality of HIV and AIDS care, the USAID ASSIST Project is working to improve care across the continuum of response, from HIV diagnosis to retention in HIV care to ensure the wellbeing of persons living with HIV (PLHIV) and prevent its spread. The community element of the continuum provides support to communities and HIV patients as a means to accelerate improvement across the spectrum.

USAID ASSIST is supporting a community support demonstration activity to improve retention of HIV patients on ART in 20 villages within the catchment of three health facilities: Bugiri and Kamuli hospitals in East Central (EC) region and Mitooma Health Centre IV in South Western (SW) region. These facilities were selected because they were high-volume sites with high loss-to-follow-up rates (above 10%) among ART clients.

Problem Statement

Retention on ART is required for optimal health outcomes in patients with HIV infection but remains a challenge in Uganda. Health system, policy, individual, and community factors all affect retention of HIV patients in care, including stigma, lack of HIV and AIDS awareness, and psychosocial and socio-economic factors. While interventions to address health system barriers have been emphasized, those aiming at addressing community-based barriers are limited in scope. Even where interventions exist, they are often conducted in a fragmented manner. Hence, USAID ASSIST’s efforts are aimed at achieving the following objectives:

1) Build capacity of district-based USG partners to integrate quality improvement in community activities to enhance community-facility linkages and long-term ART retention.

2) Strengthen existing community resources to develop a sustainable support system that can detect and address barriers to retention.

Community-led Quality Selection of intervention villages

A total of 20 villages with the highest concentration of missed HIV appointments were selected for the intervention: 14 villages in the EC Region and 6 villages in the SW Region. Other criteria for selecting villages included: proximity to health facility and existence...
of community support personnel such as Village Health Team (VHT) members, expert patients, and HIV community support agents (CSAs), who are the lowest level cadre in the national PLHIV network.

**Identifying barriers to retention**
In June 2013 and March 2014, we conducted interviews with patients and reviewed community-level tracking records for patients to identify barriers to retention at the three health facilities. A total of 41 patients were interviewed, and 26 patient tracking tools reviewed. Figure 1 shows that the three main reasons cited for missed HIV visits were: forgotten HIV appointment, long distance to health facilities, and conflicting work schedules.

**Forming QI teams**
At each of the three health facilities, a team comprised of expert patients (EPs) and community support agents (who serve as linkage facilitators) was formed. Their role is to link HIV patients on ART and HIV+ mothers on Option B+ to resources in the community and track patients to ensure they return for scheduled HIV appointments. In addition, they identify gaps in the above processes, test changes to address gaps, and track progress using a documentation journal. The team’s leaders participate in the health facility’s improvement team to give feedback and lobby for support for their work.

At the community level, 20 teams have been formed: 14 in EC Region and six in SW Region. Teams include representatives of VHTs (Village Health Teams), expert patients, local council leaders, religious leaders, families and PLHIV groups, with each playing a specific role. Teams received training from ASSIST and the implementing partner in basic improvement concepts and HIV care, job aids, and communication materials. On a monthly basis, teams meet with a coaching team from ASSIST, the USG partner, and district staff to receive on-site technical support, track progress, set aims, and plan activities. Once a quarter, the teams meet together for peer-to-peer learning sessions.

**Strengthen community-level support processes**
During a learning session held in May 2014, a standard linkage and follow-up process for PLHIV in the community was designed to guide teams in addressing patients’ needs, reduce stigma, and expand support by involving other community-based personnel.

Figure 2 illustrates the facility and community-based processes related to linking and following up PLHIV in the community. At the health facility, the process begins with a PLHIV visit to the health facility, identifying PLHIV by location, consent counselling for linkage, and developing PLHIV lists for linkage to the community and feedback. At the community level, the process involves collecting lists of PLHIV from the health facility, physical follow-up, and feedback.
Results

Figure 3 shows how these efforts to link PLHIV with community-level resources for follow-up has reached a high level of coverage at 95%. Changes made to achieve this result include: asking clients to identify who in the community improvement team they would prefer for their follow-up; coding patient files to facilitate identification; involving mentor mothers to link HIV-positive pregnant women to the community; assigning expert clients to counsel patients for consent for follow-up and identifying PLHIV from targeted villages and informing them about community activities and personnel.

Figure 4 shows improvement in the proportion of HIV patients on ART who have consented to follow-up and been linked with community resources who have been contacted in the community for appointment reminders. As of May 2014, 86% of all patients linked have been followed up at the community level, compared to 29% at baseline. Follow-up is conducted by expert patients, VHTs, HIV community support agents, and local and religious leaders.

Table 1 summarizes the main barriers identified by community teams and facility linkage facilitators to following up HIV patients in the community and the changes tested by these teams to overcome the barriers.

Table 1. Barriers to Follow-up and Changes Tested

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<th>Barriers to follow-up</th>
<th>Changes Tested</th>
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| No connection between health facilities and community | • An expert client/VHT in the community improvement team is assigned to pick lists of PLHIV for community follow-up from health facilities.  
• VHTs participate in health facility HIV activities to learn basic HIV skills, e.g., counselling, health education. |
| False identification of patients | • Names of PLHIVs linked to the community but not located are returned to the health facility to obtain correct addresses upon their return for HIV appointments.  
• Trace names PLHIV linked to the community in the village registers to identify patient locations.  
• Indicate patient locations on a village map to ease tracing. |
| Stigma and fear | • Community-based expert patients conduct initial visits to patients with no exposure to community follow-up.  
• Ask clients to choose members in community teams who they would prefer for their follow-up in the community.  
• VHTs participate in health facility HIV activities to learn basic HIV skills, e.g., counselling, health education. |
| Long distance to patients’ homes | • Patients linked to the community are assigned to community team members for follow-up based on proximity to the patient. |
Figure 5 shows how appointment keeping among HIV patients in the 20 villages has improved. A 20% increase from 50% in the baseline period (April – September 2013) to 70% in the period (October 2013-May 2014) after the community intervention was started in September 2013.

Similar improvements in appointment keeping were seen at both health facilities participating in the EC Region (Figure 6).

Challenges

- One main challenge has been patients giving wrong contact details in their health facility records, inhibiting their identification in the community. For this reason, among 51 ART patients of Kamuli Hospital who were considered lost to follow-up in January 2014, fewer than half (43%) could be located in the community and returned to care. To address this, local council leaders and VHTs plan to update village registers to identify residents, and health facility workers will ask patients basic information about their locations in a bid to confirm addresses given at the health facility.

- Another challenge is the difficulty of meeting logistical demands from community improvement teams, such as identification materials like T-shirts or badges, gumboots, rain coats, and stationery. To address identification, local council leaders are encouraged to introduce team members to the community during gatherings. For other logistics, USAID ASSIST liaises with partners to address demands within their ability.

Lessons Learned

- Involving VHTs and expert patients in facility-based HIV activities helps relieve patients’ fear, mistrust, and stigma for community activities.

- Assigning roles and responsibilities to individual participants in community quality improvement teams motivates participation in improvement activities.

- Seeking patients’ consent prior to community linkage and introducing community support personnel to patients helps allay community stigma.