Through effective linkages and partnerships, the TUNAJALI program has registered many achievements that have contributed significant improvements to the lives of the people it serves

Tracking HIV lost to follow-up patients: Best practices and lessons learned from the TUNAJALI project

BACKGROUND
One of the goals of the Tanzania National HIV & AIDS Care and Treatment Plan (2003-2008) was to provide quality care and treatment services to as many eligible HIV+ people in the country as possible. The five-year plan was developed by a joint task force of Tanzanian government officials, Clinton Foundation representatives, and representatives of many other public and private groups, which have been active in Tanzania’s efforts of combating the HIV/AIDS pandemic. The plan envisaged making anti-retroviral (ARV) drugs available for treatment of about 400,000 People Living with HIV and AIDS (PLHIV) by the end of the program’s fifth year. The implementation of this plan was also guided by the Health Sector HIV Strategic Plan (HSHSP 2004 – 2009), which focused on strengthening and scaling comprehensive HIV care and treatment services in public and private facilities so as to reach an estimated 90 percent of all PLHIV in need of ART.

The TUNAJALI program is funded by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) through USAID and is implemented in four regions of Tanzania: Dodoma, Iringa, Morogoro, and Singida. TUNAJALI is implemented by a consortium of four core partners: Deloitte Tanzania Consulting as the prime partner and also lead for grants and finance management; Family Health International (FHI) as lead technical partner for the care and treatment component; Emerging Marketing Group (EMG) as the lead partner for Capacity Building; and Management Sciences for Health (MSH) as the lead technical partner for supporting the multi-donor funded Rapid Funding Envelope (RFE).

Treatment services started in January 2005 with the enrollment of patients for ART services in Care and Treatment Clinics (CTCs) initially only within major hospitals. Over the years, the ART service centers have increased rapidly and by December 2010, The National Aids Control Program (NACP) reported 825 health facilities providing and reporting HIV care and treatment services, with a cumulative number of 740,040 patients enrolled in CTCs of which 384,816 were on ART (NACP 2011). For the TUNAJALI program, by March 2011 a total of 72,636 patients were enrolled in care and treatment centers with 48,370 patients (15,376 male, 29,128 female, and 3,866 children) using ARVs, meeting an operational target of 81 percent this year.

With proper use of ARV drugs the life expectancy of PLHIV increases significantly. The ARVs are known to suppress the survival and replication of the virus in the bodies of infected individuals with optimal suppression of the virus achieved when treatment adherence is at 90 to 95 percent adherence (Patterson DL et al 2000). For Tanzania, The National Care and Treatment Plan targeted a patient adherence rate of 95 percent. The U.S. National Institute of Health indicates that poor adherence to HIV treatment can lead to the resumption of rapid viral replication, poorer survival rates, and the mutation to treatment-resistant strains of HIV (NIH 2006). The management of drug resistant HIV viral strains is significantly complex and expensive.
Thus, it is imperative that all efforts be made to ensure a high adherence to treatment among all PLHIV on ART in Tanzania. It is also to be noted that PLHIV on ART are healthy and sexually active. Thus, if their treatment adherence is poor, they are likely to transmit drug resistant viral strains to the general population.

After nearly three years providing treatment services, the TUNAJALI Care and Treatment Centers started experiencing a notable loss of patients on ART. Some facilities with over 5,000 patients were reporting a loss-to-follow-up (LTF) ratio of 30 to 40 percent of their enrolled patients. Within the USAID funded TUNAJALI Care and Treatment program sites, the regional hospitals of Iringa, Morogoro, and Dodoma were reporting a high rate of LTFs, and losses were also reported at a declining scale of 10 to 30 percent for all districts and church-based hospitals. This raised serious concerns about patient adherence to ART, efforts had to be made to identify the “lost” patients and ensure that such “losses” are minimal in the long run.

**BEST PRACTICES**

A patient is identified as LTF when he/she has missed three consecutive clinical appointments within three months. As an intervention to combat the rise in LTF, the TUNAJALI Care and Treatment (C&T) program sought the assistance of its sister TUNAJALI Home Base Care (HBC) program—both of which received support from USAID through PEPFAR to track “lost” patients and reduce the emerging trend of missing appointments.

The TUNAJALI program made a strategic decision to hire and deploy Patient Tracking Coordinators (PTCs) through the TUNAJALI HBC sub-grantees through which they could access an existing pool of community based volunteers. The coordinators were located within the treatment centers, and at the end of each clinic day, the triage nurse provided them with a list of patients who missed appointments. PTCs then started tracking these patients from their first missed appointment. They initially attempted to contact patients by phone. They were able to reach some patients this way who provided valid reasons for why they were unable to attend clinic that day. Common reasons for missing appointments included lack of transport, social problems, and travel out of station. PTCs then rescheduled appointments for these patients and removed them from the missed appointments list. A final list of all missed appointments and those previously noted as LTFs but not yet traced were then compiled, printed out, and handed over to the HBC community volunteers and focal persons who would be more likely to know where the lost patients live and/or work.

Another initiative used by some CTCs which has proven to work well was the introduction of “block appointments.” This system drastically reduced patient wait times, which increased their willingness to attend clinics, and CTCs noted a reduction of LTFs at their center and high patient attendance rates. Patients also felt more involved with their health choices since they were given an option to select a time block that best suited them, thereby making them feel recognized and appreciated. PTCs also went a step further by using clinic days to call out names of all LTFs during clinics times. This, too, was a success as they were able to get information on LTF patients’ whereabouts from others who were attending clinic the same day, as some of these people were the missing patients’ neighbors, friends, or fellow PLHIV support group members.

PLHIV support groups have played a part in identifying lost patients within their support group through actively checking each other’s CTC1 cards on their monthly meetings making sure that all members are attending clinics as required. Those seen to be going astray are referred to the group volunteer for more counseling and support so that they can continue with their clinic services, helping to reduce lost to follow-up in the process. PTCs have also used Regional hospital workers to track LTFs who might have been admitted in the regional hospitals with an illness or might be in the hospital deaths register list. PTCs also build and maintain key linkages between HBC program and the CTCs to ensure that timely follow-up is made to all PLHIVs registered at the CTCs in such a way that appointments are adhered to and retention rates meet the national standard of 95%.
Measurable Success: - Graph 1: Patients loss to follow up for first quarter (October –December 2010)

The figures above show an increase of more than 80 percent in the number of patients followed up between April to June 2011 (Quarter 3) compared to October to December 2010 (Quarter 1) in all the above listed health center facilities, with Mafinga District hospital having the highest number of patients followed up in the third quarter. The third quarter also had a higher number of recorded missed appointments compared to the first quarter. Most centers, except Dodoma Regional Hospital and Makole Health center, managed to track 60 percent of their patients within three months, reducing the number of LTFs among followed up patients by 50 percent and confirming the effectiveness of the tracking system employed by all PTCs and volunteers within the TUNAJALI program.
Challenges
There were many challenges that CTCs, PTCs, focal persons, and volunteers faced while tracking LTFs. For instance, a number of patients registered in more than one CTC under various false names and addresses making it nearly impossible to locate them unless a volunteer or focal person knew their face. Other patients stopped attending clinics once they felt physically better or their CD4 count increased. When tracked by volunteers, the patients would say they felt they no longer needed hospital services since they were feeling much better. Religious beliefs have also contributed to LTFs as some patients stopped attending clinics believing they would be healed by their faith. In some regions there was feedback that some religious leaders were advising patients not to take their ARV medication or go for further tests.

All these factors have led to some patients losing their lives and some going back to being bedridden. Stigma has also played a part in some regions where patients will not go back to the CTC clinic where they initially registered after diagnosis, fearing to be seen by someone who might know them since they had not yet disclosed their status. Poverty has also contributed to LTFs as during rainy seasons, farmers focused on their farms and stopped attending their clinic appointments. Transport fees and accessibility for those who have to travel out of the village have also been a deterrent to attending clinics. There have also been cases where volunteers or focal persons occasionally faced direct turndown from patients traced to their home asking them not to visit them at their homes again.

Lessons Learned
The introduction of block appointments in some CTCs has contributed to a large decline in LTFs. Patients have been more willingly to attend clinics as their waiting hours have immensely been reduced from almost a whole day to between two- to three hours. Overcrowding is also minimized, thereby helping fight opportunistic airborne infections such as TB, which can easily be transmitted in crowded spaces. This system has also helped PTCs be more coordinated when listing and identifying missed appointments and LTFs as the system as they are no longer overwhelmed with patients.

PTCs, with support from community volunteers, can also be used to effectively track patients who miss appointments and who are lost to follow-up.

Conclusion
The TUNAJALI program initiative has effectively shown that tracking lost to follow-up patients on HIV care and treatment through community home based care volunteers and patient tracking coordinators is feasible and cost-effective. A joint network relationship should be pushed for future strategies between the Care and Treatment program and Home Based Care program. It is an opportunity to link clinic-based interventions with community-based initiatives to enhance a continuum of care for PLHIV. Going forward all CTCs should be encouraged to introduce “blocked appointment” systems, as this has been seen to be very effective in reducing LTFs as patients feel more involved in making their own health choices and tend to pick appointment times that best suit them, thereby increasing the likelihood that they will not attend clinics. TUNAJALI will continue to collect data on patient follow-up by PTCs through community volunteers to further measure the impact of PTC intervention over time.
REFERENCE


