

Tracing clients on anti-retroviral therapy in northern Uganda

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Many TASO clients walk long distances to medicine distribution points. (Photo courtesy of TASO).

Northern Uganda has suffered armed conflicts and insecurity for the last two decades. According to the 2004/2005 Uganda HIV Sero Behavioural Survey, HIV prevalence in the region stands at 8.2 per cent, far above the national average rate of 6.4 per cent¹.

The Lord's Resistance Army (LRA), led by Joseph Kony, waged a 20-year-long campaign of violence in northern Uganda, before being driven out of the country in 2006. This civil war between the Uganda Peoples Defence Forces (UPDF) and the LRA left behind a trail of kidnappings, death and destruction.

Evidence shows that clinical outcomes of antiretroviral therapy (ART) in conflict and post-conflict settings, though limited in scale, compare favourably with those found in non-conflict settings and further indicates that with adaptation and resources, comprehensive HIV care can be effectively administered in both post-conflict and chronic conflict situations. The success of an ART programme in conflict and post-conflict settings hinges on the level of preparedness for complex emergency situations².

A survey carried out in Gulu District, northern Uganda, found that adherence rates were notable. Whereas 92 per cent of The AIDS Support Organization (TASO) patients achieved at least 95 per cent adherence, the reported adherence in the capital, Kampala, was 82 per cent. This was impressive compared with pooled adherence rates across sub-Saharan where 77 per cent of patients adhered to combination antiretroviral therapy. In 2008, TASO put 1,396 HIV patients on ART in two direct service delivery centres of Gulu and Masindi.

However, as access to HAART increases globally, and in Uganda in particular, there is growing concern about the numbers of drop-out and lost-to-follow-up patients, considering that HIV medicines have to be taken for life.

The drop-out and lost-to-follow-up patients on HAART are likely to be worse in conflict and post-conflict areas, particularly in northern Uganda which is affected by the long running civil war, including loss of lives, the breakdown of social, economic and other infrastructure, massive population displacement and populations in transit. Under such circumstances, many patients being enrolled onto HAART programmes may be difficult to trace.

This article reflects on some of the qualitative findings of a study on factors influencing lost-to-follow-up TASO clients on ART programme in the post-conflict areas of northern Uganda. The study was conducted in Gulu and Masindi districts and targeted 200 patients who had been assumed lost-to-follow-up for at least three months.

Difficult to trace

It was noted from a study carried out in Botswana, Tanzania and Uganda that patients

are more likely to continue adhering to treatment when their communities and family members can support them with transport, food and reminders to take medicine. Absence of this support can lead to drop-out². The TASO study, "lost-to-follow-up patients" targeted patients who are registered with TASO and have been initiated on ART, but who have not been in contact with any TASO programme for three months since the date of their last appointment. The study excludes those documented as having left the area or being reported as dead.

Failure to return for treatment

Clients who were registered as lost-to-follow-up but came in for service again were interviewed in the study. Six of those lost to follow-up were interviewed when they turned up in 2009, three in Gulu and three in Masindi

when honouring their appointments during clinic days. Two of the clients expressed concern that their files were missing; one from Gulu said staff at the centre kept mixing up his file.

A client was challenged by the distance he had to cover to the distribution point, as he lived far away. Another said he had missed taking his ARVs because the caregiver who was supposed to help him, was away; another stated he had too much work to do and so was unable to come for his medicines. Yet another client had forgotten his appointment date, while two others feared being rejected by their community if they disclosed that they were taking ARVs. A client in Gulu complained about the distance to the distribution point: "They put you in a place to pick your drugs which is not near your home."

All the clients stressed that bringing the distribution of the ARVs closer to their homes would be more effective in ensuring they remained on the ART programme.

The service providers said the challenge of tracking clients was aggravated by poor mapping of clients' homes and failure by the clients to inform the clinic when they relocated.

The study shows the need to strengthen systems in order to reduce the numbers of clients who end up classified as lost-to-follow-up. Distances from homes to drug distribution points should be short; and close monitoring of those collecting ARVs from the TASO facilities should be stepped up to avoid cases of clients forgetting to collect their drugs. Improvement of documentation, record-keeping and updating of systems should be emphasised so as to ensure proper reporting and monitoring of clients on ART. ■



A TASO field officer meets clients at a health facility. (Photo courtesy of TASO).



Proper keeping of clients' records is essential for effective delivery of health services. (Photo courtesy of TASO).

Lessons Learnt

- Meaningful involvement of clients' companions should be emphasised during home visits to improve adherence.
- Reallocating and resettling of clients makes client follow-up difficult.
- Communities should have trained focal persons to record the details of clients, including residential addresses.
- Information sharing and awareness-creation should be stepped up so that clients know the problems caused by poor adherence and also to demystify myths and beliefs about ARVs.
- The success of an ART programme in conflict and post-conflict settings hinges on the level of preparedness for complex emergency situations.

References

¹Access to adherence; challenges of ART adherence; studies from Botswana, Tanzania and Uganda, WHO 2006, p320

²Uganda HIV/AIDS Sero-behavioural Survey 2004-20

³UNICEF and UNHCR, 2006. HIV/AIDS, Conflict and Displacement-Conference Report. XVI International AIDS Conference, Toronto, Canada August 12, 2006

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TASO clients during a meeting in northern Uganda. (Photo courtesy of TASO).