

Challenges for antiretroviral provision in northern Uganda

Matthew Wilhelm-Solomon

Uganda faces major challenges to ensure the continuity and sustainability of treatment programmes for IDPs returning home.

Northern Uganda is in a phase of momentous transition. The end of hostilities between the Lord's Resistance Army and the Ugandan government in 2006 paved the way for the return of hundreds of thousands of IDPs. The challenges of treating HIV in the post-conflict phase are almost as formidable as during the conflict itself.

A 2004-05 study by Ugandan Ministry of Health suggested in 2006 that northern Uganda had an HIV seroprevalence rate of 8.2%. There are indications based on this sample that northern Uganda has the highest rates of recent HIV incidence in the country¹, though reliable data from rural areas and camps is scarce, and the validity of the evidence disputed. In 2007, St Mary's Hospital Lacor, a surveillance site, recorded an antenatal sero-prevalence figure of 9%. Recent data from other health facilities suggests that prevalence has been increasing over the last three years.

Antiretroviral therapy (ART) to conflict-affected communities is now being promoted and viewed as feasible by governmental and non-governmental institutions in northern Uganda and internationally, including Médecins Sans Frontières (MSF) and UNHCR. However, it is important to prepare for the post-conflict transition and the return of the displaced in order to ensure continuity and sustainability of treatment programmes.

Research in northern Uganda between 2006 and 2009 into ART programmes implemented by the AIDS Support Organisation (TASO)², St Mary's Hospital Lacor³ and the Ugandan Ministry of Health indicates that, for those who have been able to access it, ART is helping transform HIV infection from a terminal to a chronic illness. Antiretrovirals, and associated treatments for opportunistic infections, have brought about substantial improvements in the health of those with HIV. In addition, the frequency and intensity of stigmatisation, especially linked to fears of transmission, have declined. ART has saved thousands of lives and created new possibilities for friendship, family and productivity.

Provision of ART was started in 2002 in Gulu, the region's main urban centre, and from 2004 was extended to other towns, and from 2005, to some rural areas and IDP camps. By March 2010, there were over 22,000 HIV-positive people on ART – mostly free or at low cost – in previously conflict-affected districts.⁴ High adherence rates to treatment have been shown for the TASO and St Mary's Lacor programmes, using community-based strategies.

Over the period of return, data does not show a significant impact on treatment adherence for TASO and St Mary's, though field workers claim that food scarcity may be affecting the adherence of some

patients. However, there has been a definite impact on patient retention and missed appointments, which has strained resources. Adherence and patient retention data is mostly lacking for state health services in northern Uganda, though interviews suggest similar problems.

Uncertainties for patients and providers

Many of those living with HIV faced significant anxiety around the return period, often choosing to remain in camps or towns as long as possible. The burdens of return may be severe and include reconstructing homesteads, restarting agriculture, moving to areas where service provision is weak, and the withdrawal of food assistance. As Nighty Acheng, an HIV-positive woman in Pabo camp, explained in 2008, "when we go back to the village you don't have the strength to dig anymore. And there are cases where some of us have been neglected by our families."

ART requires rigorous life-long adherence. Unmanaged interruptions to treatment can lead to treatment failure, as well as the emergence of drug-resistant viral strains. Monitoring adherence was relatively simple in displacement camps. Many people could be reached easily and even during the conflict provision was rarely interrupted. Support groups were also created in the camp environment, providing networks of care.

Return movements, and the opening of trade routes, have made continuity

of treatment much more complicated. The scattering of the population and increased distances between patients and their nearest health centre have created difficulties for patients and providers. Some are so sick they cannot come to collect their medication and those who have lost all their relatives have nobody to collect their medication for them. All programmes have had to contend with patients who miss appointments or who give up attending.

The potential challenges of the return period for HIV treatment were generally under-estimated during the conflict. For instance, Ministry of Health ART was expanded to some rural health centres in 2005 with no contingency plan for return and often little capacity for treatment monitoring. Coordination between programmes and sharing of experience were also problematic. The Health, Nutrition and HIV/AIDS cluster meetings chaired by the World Health Organisation focused on the more immediate challenges of transition, such as the hepatitis E and malaria outbreaks, and were not appropriate forums to develop longer-term approaches or monitoring capacity for patient retention in HIV as well as TB programmes. State health services have suffered from severe shortages of staff and drugs as returns have placed more strain on services.⁵

Selected rural health centres with ART provision were supported by different branches of MSF, which included community support, although these faced staff and supply-line challenges once MSF withdrew. In late 2006, the five-year Northern Uganda Malaria AIDS/HIV and Tuberculosis Program (NUMAT) was established to assist state health services with supply lines, community support and the decentralisation of treatment. This was a welcome development though in places community support started after the return movements. Treatment is still unavailable in a number of rural health centres, though coverage has improved significantly since the cessation of hostilities.

Even relatively well-resourced NGOs have come under severe strain. TASO's strategy of home-based

provision and monitoring using motor cycles was very effective when populations were static – but came under strain when patients moved further away. In the first two quarters of 2008, over 10% of patients were lost in each quarter. However, a strategic shift to using community members to monitor and track patients, as well as

follow patients as rigorously as in the camps. One of them, Simon Omara of Comboni Samaritan, reported, "the major difficulties I face are that the distances are far, most people take their medication at eight o'clock when it is already dark, and you may find it has started to rain. You may encounter drunkards on the



A newly formed HIV support group in a return area of Oyam district, Uganda.

decentralised treatment distribution points in rural areas, allowed TASO to radically reduce lost patients to under 1% in the second half of 2008.

St Mary's Hospital Lacor shifted to a community-based monitoring strategy from the outset of their programme, with the help of the community organisation Comboni Samaritan – a strategy which has proven very effective in ensuring continuity of treatment. Extensive networks of community-based treatment monitors were chosen from different geographic areas and few patients were lost during the return period, never exceeding 2% in a quarter. The success of St Mary's shows that extensive community networks can be as effective as decentralising treatment provision in ensuring ART continuity.

Community-based adherence monitors employed by most HIV programmes are themselves mostly HIV-positive and are also battling with the difficulties of transition. The small stipends provided are often inadequate to cover even their time, and community monitors across programmes said they were unable to

way who disturb you, and another problem is if you have to cover a long distance that makes you weak."

While some organisations like TASO are shifting to livelihoods programmes, there were few programmes supporting those with HIV in the transition from displacement to return. All the programmes also have HIV prevention components to them, although the St Mary's programme do not provide condoms, thereby limiting patients' reproductive health options particularly in rural areas where other services were not easily available.

Recommendations

Experience in northern Uganda is of relevance to other situations in which large numbers of people have been displaced for long periods. Among the lessons to be learned is the importance of working with national health ministries and NGOs to:

- acknowledge that post-conflict return processes can pose significant challenges to HIV treatment programmes as a result of increased distances between

service providers and often mobile HIV-positive populations

- acknowledge the reality that state-provided ART programmes are under-resourced
- decentralise treatment and fund community-based support to help ensure continuity of treatment
- recognise the burdens placed on community-based ART adherence monitors, especially those who are themselves HIV-positive
- target support to HIV-positive patients so that while they are struggling with transition they are also helped with treatment adherence
- use community workers to help patients overcome anxiety over the return period through providing information about treatment options

- ensure that data collection in post-conflict situations focuses not just on adherence but also on patient attrition.

In addition, data from well-resourced non-governmental programmes cannot be viewed as representative of all programmes; there is a need in northern Uganda, and elsewhere, for an assessment of more poorly resourced state antiretroviral programmes. While treatment provision can be successful to conflict-affected communities, the transitional phase poses a new set of challenges which have affected patients and may have increased the chances of drug resistance developing.

Those living with HIV in northern Uganda – as in other post-conflict contexts – show a remarkable capacity to adapt to the difficulties of return by forming new support groups. However, they remain vulnerable and live in fragile

circumstances. The long-term sustainability of ART relies on the fostering of strong communication and support between donors, civil society, national health authorities, patients and local providers.

Matthew Wilhelm-Solomon (matthew.wilhelm-solomon@qeh.ox.ac.uk) is a doctoral candidate in the Department of International Development, University of Oxford. He is the author of 'Stigmatisation, Disclosure and the Social Space of the Camp', *AIDS and Society Research Unit, Working Paper 267*. <http://www.cssr.uct.ac.za/publications/working-paper/2010/267>

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3. <http://www.lacorhospital.org/>
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