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A follow-up on follow-up: shifting to a community-based response to improve retention in care

Why we have returned to the subject of loss to follow-up

Earlier this year, HATIP wrote about growing concerns that although most people initiating antiretroviral therapy in resource limited settings are doing well on their first-line regimen, an unacceptably large and increasing proportion of patients are being lost to follow-up and care, even at model sites, as facilities reach the limits of the number of subjects they can easily manage (<http://www.aidsmap.com/cms1191180.asp>). These worries have been reinforced as some public sector facilities in South Africa have reported rather high rates of dropout (see below).

However, at the big conferences this June and July, (the Third South African AIDS Conference, the Fourth International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention in Sydney and the HIV Implementer's Meeting in Kigali, Rwanda), there were numerous examples of programmes improving patient retention by moving ART delivery and support closer to the patient. This was done either by decentralising to the most peripheral levels of the formal health sector through greater reliance on nurses and community health care workers — especially people with HIV empowered to act as members of a clinical care team — or by partnering with non-governmental organisations (NGOs), faith-based organisations (FBOs) (including Catholic Relief Services) and community-based organisations (CBOs) already providing community- and home-based care.

The Home Based AIDS Care project referred to in the last HATIP was just one example of the excellent results that can be achieved when existing community capacity, which in this case involved a home based care team delivering comprehensive preventive care, is expanded to deliver ART as well (<http://www.aidsmap.com/cms1234609.asp>). Yet, even though the outcomes are some of the best ever reported, they were not directly compared to those of any other model of ART care.

But a recent analysis of data from another enormous PEPFAR-supported programme operating in eight countries, provides clear evidence showing that **programmes that support people on antiretroviral therapy (ART) in resource-limited settings with home visits or home-based care appear to have a significantly lower percentage of loss to follow-up than when ART and adherence support are primarily facility-based.**

The study, which was presented in a poster at the IAS conference by Martine Etienne of the Institute of Human Virology at the University of Maryland, evaluated different models of care provision and adherence support being used by 16,641 patients attending 34 sites during the first year of AIDSRelief, a consortium of NGOs, FBOs and CBOs working in the developing world. Over the last three years, the consortium has placed over 70,000 people on ART at over 140 sites in Kenya, Tanzania, Uganda, Zambia, Haiti, Rwanda, Guyana and Nigeria.

“Reviewing and identifying the best models [of care] is critical to continued successful scale up in resource limited settings,” the study team wrote. So the programme has started to compare available outcome data from its many sites to determine what are the best models of care for ART delivery. For purposes of this analysis, models of care were defined by the type of adherence support offered at the different AIDS Relief ART sites.

- Tier 1: Facilities that provide adherence counselling only (n=11 sites)
- Tier 2: Facilities that provide adherence counselling with a structured treatment preparation plan — in which people designate friends or family to serve as adherence supporters and both go through an intensive HIV education and ART preparation; follow-up is facility-based (including defaulter tracing, if necessary) (n=4 sites)
- Tier 3: Includes Tier 1 and 2-type interventions, plus intensive home-based care and/or adherence follow-up provided by trained community-based health care workers (often other people living with HIV/AIDS) (n=10 sites)
- Tier 4: The same as Tier 3 but with the addition of a community-based nurse who provides supervision to the home-based care teams and can quickly respond to medical needs such as opportunistic infections and adverse events that the patient might experience (n=9 sites)

This particular study did not look at individual patient adherence as an outcome, but rather examined cumulative loss to follow-up (LTFU) data from each site which would generally be associated with very poor outcomes (see below). The data, abstracted from patient charts for patients who went onto ART between August 2004 to June 2005, were aggregated from the quarterly grant reports and bivariate and logistic regression analyses were performed.

The analysis found that people getting ART from a Tier 1 facility were twice as likely to be lost to follow-up compared to those receiving ART in other tiers. The cumulative LTFU was 18% in Tier 1, 13% in Tier 2, 8% in Tier 3 and 3% in Tier 4. The differences between Tier 2 (facility based) and Tier 3 (home based) were statistically significant. Although the best outcomes were observed in Tier 4, it was not significantly superior to Tier 3.

“Home visits markedly improved patients’ retention in care,” wrote Etienne et al. “These data support the utilisation of proactive adherence support programmes, beyond routine patient counselling and defaulter tracking to support the ‘public health approach’ to ART.”

The study has several limitations. One is that there could have been differences in record keeping (two sites’ records were deemed to have “less than accurate” follow-up data), however, even though one or two Tier 1 and 2 sites reported better patient retention, the patterns across the tiers were very consistent. Also, some of the sites had more experience offering treatment than others when the official programme started. In fact, Etienne and colleagues noted that “some sites already had active home-based care programmes and community links, providing ART became an addition to these programmes.” So, it may not be entirely fair to compare programmes that have already been caring for people via home-based care to new facility-based programmes just starting out.

There also are different ways of defining the models of care, or a different analysis may show that some models of care perform better in urban versus rural settings (53% of the 34 ART projects in this study were in rural areas).

Importantly, the study doesn't clearly explain whether most of the Tier 1 and 2 facilities were large centrally located hospitals or primary health clinics, although one might infer that Tier 4 was home-based care associated with a nurse-led primary health clinic (other studies suggest that patient retention is markedly better at the latter, see below). Also, home-based care generally entails much more than simply adherence support, usually offering a preventive care package and an array of other co-localised family-based services that could be difficult for vertical medical facility-based programmes to match, though it is conceivable that some facilities could effectively link together a similar package of comprehensive services.

In other words, this study doesn't tell us everything. That being said, the cohort is large enough to safely say that there is something to be gained by supporting people on ART as closely as possible to their homes.

Patient retention difficulties for South Africa's public sector

The findings are particularly interesting in light of the distressingly high loss-to-follow up rates reported by some large ART-dispensing facilities — most of which could be considered Tier 1 or 2 sites— at the 3rd South African AIDS Conference.

The public sector in South Africa is charged with providing healthcare equitably to all who need it (and, theoretically at least, this should include ART). Clinicians involved in the HIV programme have taken this to heart, but to some extent, enrolling people as quickly as possible may be somewhat at odds with making sure that they stay on care.

With the very rapid scale up of ART programmes underway, so many HIV-infected people to serve, and health systems already strained, it is not surprising that facilities — which were not designed to provide chronic care to so many and are only now beginning to learn how to reorient their activities to do so — may surpass their capacity to offer high quality individualised support, and that, as a result, some people are lost to follow-up. Some of the first efforts out of the gate seemed to have found this out the hard way.

For instance, 27% of the first tranche of patients enrolled at King Edward VIII Hospital in Durban starting after April 2004 were “non-persistent” (defined as having failed to return for prescription refills for 90 days or more) within 12 months of starting ART. According to the poster, there were no significant differences between baseline variables evaluated or drug readiness or adherence training for those who were and those who were not retained in care. “We do not understand the reasons for this early loss to follow-up,” wrote Magula et al.

This unusually high rate of loss to follow-up could be because the ART programme was just starting out, but several other reports demonstrated that losses to follow-up are a continuing challenge as the programme has matured.

Dr Helen Schneider of the Centre for Health Policy at the University of Witwatersrand gave a report on experience in what she called “the routine public sector institutional environment” where most of the scale up is now happening in the country.

“We have ample evidence that the public health sector can provide good quality ART to poor communities, but a lot of the evidence comes from ‘innovator’ sites and programmes,” which she said had been “led by motivated champions and often had external support from NGOs, academic institutions, and a lot of donor support.”

So her team reviewed the performance and capacity of four randomly selected “second generation” ART sites in Gauteng Province. There was a fairly brisk enrolment into the sites, some of which had grown to be quite large; for instance, the Regional Hospital in Ekurhuleni had enrolled more than two and a half thousand patients by the middle of this year. Nevertheless, the review found that outcomes among patients still on treatment were good, and that the sites’ performances were “on par with the innovator sites.”

However, Dr Schneider said that “when we visited them, a couple of sites were showing visible signs of cracking at the seams. They were busy places that from a space and from a human resources point of view were struggling to see the patients... The tracing of drop-outs seemed to be the one thing that, as the sites got stressed, would get dropped.”

Her team found it very difficult to use the sites’ records to establish actual drop-out rates. “What we thought maybe was the most reliable way of establishing the drop-out rate was simply saying ‘What is the total number of patients that you’ve enrolled in the site, and how many do you have now? That figure suggests, that over variable periods of time from 19 to 24 months, a drop-out rate of 27-31% at these sites.”

Through triangulating various sources of data, they concluded about a third of these ‘drop-outs’ were deaths, some were transfers, and that the remainder, 15-20% would be true losses to follow-up.

Very similar figures were reported for three major ART sites, Tshepong Wellness Clinic, a semi-urban facility in the North West Province, Johannesburg Hospital, and Taung Hospital (a rural facility in the North West Province), which all receive technical assistance from the Reproductive Health and HIV Research Unit (RHRU) of the University of Witwatersrand. Together these facilities have enrolled around 14,000 people with HIV.

“With the increasing number of clients, management of data and loss of patients to the system had become an area of concern for the clinics,” said Dr Malebo Maponyane of RHRU. So the management of Tshepong Wellness Clinic, which with over 6500 patients was by far the largest ART site, asked RHRU for assistance to sort out what was happening. So they devised a one page data collection tool and mobilised over 70 people from DoH and RHRU to conduct an exhaustive review of 12,987 patient files from the facilities (all the files since the beginning of the rollout) to see how many people were currently on treatment, how many were lost to follow-up and so on.

They found high rates of loss to follow-up. At Taung Hospital, 17% had defaulted on treatment after initiating ART although a relatively higher percentage, 8%, were reported to have died there — which Dr Maponyane believes was because people in a small rural community are more likely to report such events back to the hospital staff. At Johannesburg Hospital, 22% had defaulted on treatment after initiating ART while (2%) were reported as having died. Finally, 20 % of those attending Tshepong clinic, defaulted post ART, while 2% were reported to be dead.

Reasons for defaulting

Dr Ebrahim Variava, head of the Klerksdorp Tshepong Hospital Complex wanted to find out the reasons for loss to follow up, as far as they could be ascertained. So the site’s social worker and the counsellor audited 300 patient files (about half of those lost to follow-up), and tried to contact the defaulters by telephone. If they couldn’t get a hold of them, they had local NGOs conduct home visits.

"What we found was that 42% had died and that's quite a significant number," said Dr Variava. In half of these, the death occurred before they were due to return to the clinic (in other words, death was the reason for loss to follow-up); 87% died within six months of starting ART.

Early death on ART could be due to an opportunistic infection that occurs before ART has a chance to work or pre-existing life-threatening conditions, or due to an immune reconstitution inflammatory syndrome (IRIS) related condition, but given the retrospective nature of the data collection, it is difficult to be certain whether the patients were actually taking ART at the time of death. The remaining deaths occurred after the person had defaulted for some other or unknown reason. Of note, about 31 patients who had achieved undetectable viral loads were subsequently lost to follow up.

In the majority (57%) of the defaulters, the team couldn't determine what was the cause for loss to follow-up. About a third couldn't be traced. Dr Variava said that cell phone numbers in South Africa proved to be both a blessing and a curse because while they make things much simpler when they work, they are constantly changing. It's important to point out that Tshepong serves a mining community with an unusually mobile population (of course, the population attending sites in and around Johannesburg may also be quite mobile, since it is a place South Africans go to find work).

But concrete reasons for dropping out were only identifiable in a minority. These included a lack of finances, which accounted for 5% of the defaulters, travel and relocation for 5%, "patient choice" in 4% and 7% for a variety of other excuses.

A number of other factors that could cause loss to follow-up were listed Dr Scott Worley, of the International Centre for AIDS Care and Treatment (ICAP), who has been working on a system to deal proactively with high loss to follow-up rates at some sites within the East London Medical Complex in the Eastern Cape (some of the facilities have rates as low as zero but ranging up to 22%).

He noted that requiring the sickest people (those who are starting ART) to travel a longer way to get their antiretroviral drugs is a big part of the problem. But evidence from their site suggested other factors such as myths about ART, competition with traditional medicine, the lack of disclosure and home based support, fears of losing one's social grant; and at the facility level: staff shortages, high patient loads and poor counselling received upfront. He also noted that these factors were also leading to loss to follow-up in a lot of patients before starting ART.

"There is an urgent need for solutions to ease the process of ART initiation so we don't lose people in that process," he said.

This was noted in the RHRU study as well where a high percentage, around 75% at Tshepong Wellness, dropped out. Dr Maponyane said that she thought that this was due to the strict loss to follow-up criteria and that many of these people might have later come in for care, but Dr Variava pondered whether it had something to do with the ART preparation. "It brings in the question, the condescending way we prepare patients for ART: we treat people as children. They must come for four or five visits before ARV's and by the time you start them on ARV's, they're lost to follow up."

During the discussion a doctor from a clinic in George, Western Cape said "We did a small analysis of our patients that did default the ARV work up before they started on ARV's and about 80% of them were those that hadn't disclosed, and then the other amount was alcohol related. So we found disclosure was the biggest reason why they actually defaulted their ARV work-up."

But again, Dr Worley focused on the transport and time: "People having to be referred to the hospital to get their treatment and then

a lot of delays with that. We lose a lot of people because it's taking so long to get people initiated on ART."

A couple of posters at the conference stressed the importance of high travel costs and the long time spent travelling to get to the ART sites. For instance, Dr Gesine Meyer-Rath of the London School of Hygiene and Tropical Medicine and colleagues at RHRU performed a survey of several hundred patients at both Johannesburg and Tshepong Wellness Hospitals. People used a variety of methods of transport to get to their site, but for Johannesburg Hospital, the mean cost for transport to the clinic was R21.20 per visit, with a mean travel time of 2.18 hrs, and at Tshepong, the mean travel cost to the ART clinic was R16.82 and the mean travel time 1.46 hrs.

Before other sites became ART accredited, travel times (and costs) were much longer but as more peripheral ART sites are accredited, people can be sent to sites that are more convenient to them. As innovator sites, Johannesburg Hospital and Tshepong Hospital, working with RHRU and the Institute of Healthcare Improvement (IHI) [have done brilliant jobs mentoring many of the other facilities within their vicinity.](#)

Less loss to follow-up at primary health care sites

Making ART available at more convenient sites could address some of the loss to follow-up. Studies have suggested that retention on ART is better at primary healthcare sites within the heavily affected communities rather than at large centralised hospitals. For instance, Médecins sans Frontières (MSF) in a report on the scale-up in Lusikisiki, in the Eastern Cape, noted that, after 12 months, only 2% of people who started ART between January 2004 and July 2005, were lost to follow up compared to 19% at the hospital (see

http://www.msf.org.za/docs/lusikisiki_final_report_2006.pdf).

In Dr Worley's experience, this pattern is continuing in the Eastern Cape: "Those sites that are successful with low numbers of loss to follow-up - in general are primary healthcare facilities, as opposed to hospitals."

Likewise, in the Western Cape Province, which "has had a primary care approach from the outset," according to Dr Keith Cloete, from the Western Cape Department of Health, loss to follow-up rates are generally much lower than in other parts of the country. For the public sector as a whole there, the loss to follow-up among those who started after June 30, 2004, when the rollout began in earnest was about 7.2%, with 11.6% of all the enrolled people with HIV having died since starting ART (at 21 months) and at two years, the overall absolute adult retention in care was ~80%.

"We were very fortunate in the Western Cape to have innovator sites since May 2001, specifically in the Khayelitsha area with the MSF joint partnership with the provincial government," said Dr Cloete. In fact, by April 2006, close to 50% of the people on ART in the Western Cape were attending primary care clinics serving the poorer communities in Khayelitsha, Gugulethu/Nyanga, Mitchell's Plain, and Hout Bay.

But primary healthcare sites can come in a range of shapes and sizes and have limits (staff, space etc) to their capacity as well. "Over time, the increase in access to care has resulted improved in early outcomes, offset in part by increased loss to follow-up," said Dr. Cloete. Indeed, earlier this year, Dr. Gilles Van Cutsem of the MSF, noted that this has become a problem as the primary care ART sites in Khayelitsha have become "monster sites." Relying on just a few large primary care sites could conceivably become just as bad as using larger hospitals.

Clearly, there is a need to engage a wider range of partners and other strategies to improve follow-up.

Making better use of smaller primary care clinics, general practitioners and nurses

Most health districts have dozens of primary care clinics feeding into the large secondary and tertiary facilities. There's widespread agreement that greater efforts have to be made to integrate the HIV programmes into these other sites. But different models have been proposed on how to decentralise HIV care including ART (or at least ART follow-up) to more "peripheral levels."

Recognising that they needed to continue enrolling high numbers of people with HIV, but could only manage so many on site, the team at the Klerksdorp/Tshepong Wellness Clinic has been performing an amazing juggling act by setting up a system of down-referrals to local clinics and general practitioners (GPs), starting in November 2005 (Mlambo).

After being initiated on ART, people who were stable with an undetectable viral load were given the choice of being down referred to either a GP (working with BroadReach Healthcare) or to their nearest primary healthcare clinic. A centralised pharmacy then provides medication on a named patient basis to the clinic or GP practice so that people don't have to travel all the way back to the hospital to refill their script.

The retention rate after referral to a GP was 99%. However, in his presentation, Dr Variava noted that the majority of loss to follow-up occurs within the first six months on ART, usually before people become "stable" so this system of down-referral does not address most cases of loss to follow-up. Even so, these programmes have helped the Klerksdorp/Tshepong Wellness Clinic continue initiating new people on ART while maintaining a consistent number of clients at the clinic.

Dr Cathy Green of IHI described the process of integrating nurse-based primary health clinics into the ART programme in the Mhlontlo District in the Eastern Cape. The district contains roughly 200,000 people, 25,000 of whom are estimated to be HIV-infected. According to Green, that would mean that about 1700 people should be initiated on ART each year. When IHI started their work there, only one facility in the district was actually accredited to prescribe ART, however, a doctor and a pharmacist would go out regularly to three other clinics to make treatment more accessible.

But the district, which serves a large area with a widely dispersed poor population, contains 22 other clinics. These clinics were providing HIV testing, but sending people who tested positive to the other four sites. As a result, when Dr Green started providing technical assistance to the district, there were only 75 people on ART, and only 9 people were being initiated onto treatment each month.

"But the opportunity that these clinics presented was huge in sharing some of the burden of care for people living with HIV/AIDS and ensuring that the care was accessible to all," she said.

So they launched a "learning network" in March 2005 to begin to address this gap. This involved monthly meetings with representatives from all the clinics to look at needs and challenges and to try and solve them through learning from each other's experiences. And clinics were challenged to try out new ideas, initially on a small scale and then to implement those that had improved performance.

"One of the other things we did was to help people learn to love their data," she said. They encouraged clinics "to start looking at their data, to look at trends over time and try and work out what is

going on — particularly to look at those trends when they were making changes, to see whether they could improve the performance. We also started doing some analysis across the clinics so that we could identify who our poorer performers were and help support them and also learn from the better performers."

As a result, the district is now enrolling over 60 people on ART each month. Thirteen of the clinics are now able to provide all HIV services — with the exception of prescribing ART —including CD4 cell counts and preparation for ART, and then support for ongoing chronic care on ART.

"On the issue about defaulters, clearly having the focus of care down to a local facility, we would anticipate that the defaulters are far lower than they would have been [if we were] having to request that patients return to clinics some distance away on a monthly basis to collect their ARV treatment, which was the previous model of service," said Dr. Green.

"We have been issuing ARV's on a named-patient basis down to the primary healthcare clinic. So when the patient fails to collect that medication, it's very clear to the clinic staff that that has occurred, so they are then in a better position to send community health care workers to follow up on that patient — who is obviously a part of their immediate community — as opposed to some distance from the large facility providers."

However, other groups have argued against a system of up and down referrals, and have called for decentralisation from day one of the roll-out.

"Mseleni Hospital [in KZN] began providing antiretroviral drugs in July 2004, using all clinics with the roll-out. All work-up, initiation of drugs and ongoing follow-up are done through the clinics," wrote Dr Jennifer Nash in a poster presentation at the South African AIDS Conference. The primary healthcare clinics served by the hospital are visited once or twice weekly by doctors, make heavy use of PWHIV support groups who meet at the clinics and have integrated a range of HIV/TB related services for clients.

"We believed that the provision of antiretroviral drugs involved the building of relationships, which would continue for many years. For that reason the client needed to remain at their primary health care site for the provision of all health care needs, including antiretroviral drugs, and not be later 'down referred'. Thirdly, there were equity factors. All people within the subdistrict needed *equal* access to medication," she wrote.

Similar programmes in Zimbabwe and Rwanda were described at the HIV Implementers Meetings (Thistle, van Pad Bosch). For example, in Rwanda, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) has trained nurses who were already providing VCT and PMTCT services to provide some components of clinical support for people with HIV until they need ART (including CD4 cell monitoring). This required a number of changes to the existing tools and training, for instance registers had to be altered to contain pre-ART components, existing training was modified to include HIV care components and ART training, and new tools were developed to assist a nurse practicing with distant physician oversight (by phone and regularly scheduled visits).

"In terms of expanding nursing practice, it required us to build upon the relationship between the physician coming from the district hospital and providing very specific concrete tools for nurses to practice. In Rwanda nurses are not at this time legally or clinically able to prescribe ARVs independently, but as doctors get to know nurses, they have more confidence in their capacity, they can support their practice more effectively over the phone," said Dr Nancy Fitch.

Nurse prescribers!

In settings without a mobile clinical support team, until doctors start growing on trees or governments start allowing nurses to prescribe and dispense antiretrovirals, up and down-referrals may be the only option available.

But why shouldn't trained nurses with adequate supervision be able to prescribe ART? MSF has pioneered this quite successfully in rural Lesotho.

Lesotho has only 89 doctors for the country's entire population with a population of 2 million people. Duties done elsewhere by doctors simply must be done by nurses, and with an HIV prevalence of 23.2%, that has to include ART.

So MSF established a nurse-based care model in a district about 40 kilometres from Maseru, working with Scott Hospital Health Service which consists of one District Hospital and 14 rural primary Health Care Clinics serving a population of about 220,000 people dispersed in 941 villages, many in remote, mountainous areas. 35,000 people are estimated to have HIV/AIDS and 5,000 people are estimated to be in immediate clinical need of ART.

The programme consists of integrating ART into the existing nurse-run primary healthcare clinics. Nurses are given intensive theoretical and on-site training on management of HIV and ART and supplied with nurse-oriented guidelines and tools.

"Each clinic receives at least one visit weekly from our medical team," said MSF's Dr Pheello Lethola, which currently consists of two doctors and two nurses though they plan on going down to one doctor as the nurses gain more experience. The team provides in-service training, and support with complicated cases. Acutely ill patients are transferred to the hospital.

As of April this year, the clinics have tested over 10,000 people, close to 4,000 of whom were HIV-positive, and started ART in 1393. Uptake of PMTCT has increased to 86%, and they've introduced HIV DNA PCR testing for early diagnosis of HIV in infants. They've also integrated TB/HIV services, with the introduction of an MDR component this year.

In the first six-month cohort analysis of the programme, median CD4 cell counts have increased from a baseline of 74 to 258 and the median weight gain was 5.4 kg. 85.4% of the patients are still in care, 8.5% have died and only 6.1% have been lost to follow-up. This is particularly good considering the setting.

"One of the problems that we are facing is patients have to travel very far distances to get to the clinics as well as the fact that the clinics are in very rural, mountainous places where it's often very difficult to get hold of transport and there are often bad weather conditions," said Dr Lethola. Still, "decentralising ART provision to the primary care level, as opposed to referring patients down from hospital to clinic, provides many more access points to treatment and reduces bottlenecks to enrolment. Empowering nurses is essential for maximising efficiency at the primary care level."

And lest one should think that this is the sort of achievement that only MSF can pull off, a few posters at the HIV Implementer's Meeting described similar nurse-led projects elsewhere in Lesotho. One is being operated by the Sisters at St Leonard Health Center in Semonkong, Lesotho a rural mountain town 120km and four hours by bus from Maseru. Nurses from the clinic were sent to a government-sponsored WHO IMAI training; then the Clinton HIV/AIDS Initiative provided volunteer clinical mentors until the nurses felt comfortable prescribing.

"This program shows that nurses can implement an HIV treatment program with no increase in staff and no physician

supervision, when short-term clinical mentoring is available during implementation. This resulted in a sustainable growing HIV treatment programme in a very difficult to access area. In nine months 1200 people were tested, 395 enrolled in care, and 120 people were on ART," wrote Wennsberg et al.

Several other countries, including Malawi and Ethiopia, are now allowing nurse practitioners to prescribe ART. MSF, in the meantime, has called on the South African government to remove restrictions that prohibit nurses from prescribing ART, arguing that without prescribing nurses, South Africa will never reach the National Strategic Plan goals of near universal coverage.

Systems for defaulter tracing

Regardless of what type of site ART is being delivered by, a proactive standardised system to quickly detect loss to follow-up needs to be put in place. "ART programmes in low resource settings with significant loss to follow-up problems can be improved with innovative and simple and well defined techniques," said Dr Worley, noting that in six months, the system implemented in East London had led to a decrease in loss to follow-up (down to 2%) despite increased numbers of patients, while loss to follow-up has been increasing at other sites in the Eastern Cape without the system.

One of the first steps, he said, is to develop standardised tools. Pre-ART and ART registers are used in order to identify who's lost to follow up, as well as appointment books, but they've also created a tracking register, to monitor tracking and re-entry to care.

This may be a part of the plan in many programmes, however, Dr Schneider noted that the record systems they encountered in their survey at the clinics in Gauteng were virtually useless and often redundant. Clearly some thought needs to go into better organisation of these systems.

In addition, the site coordinator in East London oversees the tracking process, while the site's data officers overseeing the data capture identify patients that have missed appointments and generate that list on a regular basis, and there are monthly team meetings to discuss the progress of the programme.

After a system has been put in place to detect and track missed appointments, of course, someone needs to perform follow-up. Some programmes are employing dedicated people to track down defaulters.

"Most of the cases of loss to follow up occurred within six months of ARV initiation and death," said Dr Variava, "which makes it important to consider home visits in trying to track those sick patients to come in and what we've done with the RHRU, actually we've employed a default tracer who prospectively picks up lost to follow up and then we will do home visits *immediately* to try to get these patients to come in sooner to access care."

The outcomes using this default tracer at Johannesburg Hospital were described by Tellie et al. Between July and December 2006, the tracer made calls to 745 patients who had missed their appointment. Of these, 48% returned to the clinic within 30 days of contact. Another 13% of patients eventually returned to the clinic but after a longer period of time. A large number could not be found by their contact information, and the authors concluded that it was important to "emphasise training of clinic staff to watch for certain patient tendencies or situations which may signal a potential defaulter."

Integrating people with HIV and the community into the clinical team

Indeed, although 'default tracing' is a start, it could perhaps be combined with a more proactive strategy. Dr Worley said that the system they have set up at East London, is using peer educators, who are themselves patients in the programme, to do the counselling and prepare the person for ART.

"Ideally we like to try to have a home visit, either before initiation of ART or at least very soon after initiation to see how it's going," he said. These peers, who will have already developed a relationship with the patient, and one hopes their families as well, are the ones who try to get the person back in for care in East London.

"Strong support groups," said Dr Worley, "are a well-noted mechanism to really help retain patients in care and to help find missing members. Task shifting definitely needs to be considered and the community-based mechanisms are absolutely essential."

Similarly MSF has been shifting more tasks to peer healthcare workers. "We're optimising use of existing community-member resources and creating new capacity," said Dr Lethola. "So, just as duties that are otherwise done by doctors are passed on to nurses, some of the duties of nurses are passed on to lay counsellors who are PLWHA." These include adherence support.

In Namibia, Lironga Eparu (a PLWHA CBO) has set up a 'buddy' programme to provide psychosocial support for clients on ART and also address issues of adherence. The buddy is given transport money to visit his or her clients at least twice a month and during the visit, the buddy might even perform pill counts.

"The support groups have proved vital in reducing stigma and discrimination, providing treatment literacy and tracking defaulting clients," wrote Zenagan Chirwa and Erich Africander of the Mapilelo Project, which provides HIV treatment and care programme in the Caprivi Region and which has partnered with the CBO.

ICAP is also providing programme support activities within three states in Nigeria to expand HIV/AIDS care and treatment. It is making the most of community-based resources there.

"When ICAP Nigeria began programme support activities, uptake of services was limited... and facility-level and community-level services were not well coordinated. But community-level resources did exist creating opportunities to partner with organisations and individuals with a deep understanding of the epidemic's local context," said ICAP's Bolanie Oyeledun at the Implementers' Meeting.

"This in turn provided an opportunity to decentralise services, reducing the burden on health care facilities and bringing care closer to the clients and to empower communities and involve them, including people living with HIV/AIDS in service delivery and decreasing stigma."

According to a poster highlighting the programme's work in the community with people living with HIV, "ICAP, NGO, and facility staff provide care, support and training (on adherence, support group facilitation, public speaking, home-based care, HIV prevention, etc) to PLWHA to equip them to play key roles in service delivery;" (in both paid and unpaid positions) and PLWHA are trained and enrolled as Peer Health Educators (PHE) to facilitate linkages in care, support and treatment (Ashie).

The project provides services to over 10,000 people with HIV and their families and has established 20 community-based support groups with a membership of approximately 5,800 PLWHA. Among other things, the support groups spearhead defaulter tracking

activities; and support peer educators to mentor patients and accompany them to appointments.

Hosea's story illustrates that defaulter tracing means more than getting someone back on treatment, it is also clinical monitoring and case detection:

"Hosea is one of the patients on ART at GH Saminanka. He missed his appointment on the 24/04/07. The records officer who volunteers to track defaulters went to look for him that same day. He met him at home very weak and sick with no one to take him to the hospital. The volunteer quickly made arrangements for him to get to the hospital where he received medical attention and his ARV refill. He is improving and is grateful for the timely arrival of the volunteer."

ICAP's programme in Nigeria goes beyond just employing peer adherence supporters.

"What we did was we came up with a package of door-step delivered services for clients," said Oyeledun.

After identifying and mapping out local CBO's, NGO's and FBO's which were strategically located within the health facility network, they created partnerships to weave a net of supportive services, holistic and family-centred care (including nutrition support and day-care) delivered to people with HIV and their families.

With so much to offer, and such an integrated approach, it's little wonder that these programmes have a low drop-out rate. It's quite similar to what TASO has developed in Uganda, and it's important to note that in the HBAC study, this led to one of the highest rates of retention in care ever reported in an ART programme (only one out of 987 adults was lost to follow-up) (Weidle).

The gulf between the formal medical establishment and the "community"

Getting the larger facilities to make better use of community organisations might be a challenge however, especially as the traditional medical establishment sometimes has a tendency to "go it alone" and does not always communicate well with the world of CBOs.

"We found that these health facilities were not talking with the community-based organisations who were also doing things in the communities, so you'd find that when you get the health facilities, they don't know what's happening within the communities, and the communities don't know what services are available within the facilities," said Oyeledun.

But engaging the community and developing community capacity to support and follow-up on patients isn't just politically correct, or some form of extracurricular activity – it is an evidence-based life-saving intervention. It may take time and require using a slightly different skill set, but for large programmes with high drop-out rates offering care to hundreds of thousands of patients, developing a home-based community-engaged system of follow-up could prevent tens of thousands of unnecessary deaths.

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about HATiP

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