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How to deliver good adherence support: lessons from round the world

Individual barriers to good adherence

A systematic review of all the published studies looking at adherence in developed and developing countries found a striking universality of barriers to adherence – and facilitators of good adherence among individuals around the world (Mills 2006).

Barriers	Facilitators
<ul style="list-style-type: none"> ● Forgetting to take tablets or too busy ● Fear of disclosure ● Disruptive to everyday life or away from home ● Don't understand treatment ● Side effects – real and anticipated ● Depression / hopeless ● Concurrent substance abuse ● Suspicious of medicines 	<ul style="list-style-type: none"> ● Belief that the drugs work/seeing positive results ● Disclosure/social support ● Twice daily dosing or less, fewer pills ● Good relationship with health care provider

Katherine Semrau of Boston University reported at the 2007 HIV Implementers' meeting on reasons why women in Zambia refused or stopped HIV treatment. Her findings were strikingly consistent with findings from qualitative research among Africans living in the United Kingdom.

Reasons for not starting when treatment offered	Reasons for stopping treatment
<ul style="list-style-type: none"> ● "ARVs are bad" ● Stigma ● Fear of divorce ● "Not enough food" 	<ul style="list-style-type: none"> ● Fear of permanent lifestyle changes such as avoiding alcohol ● Taking medicines indefinitely when there is no cure ● Lack of accurate information about the drugs and HIV treatment aims

Her focus groups told her that people stopping or refusing treatment were repeatedly receiving inaccurate information from trusted figures such as pastors, traditional healers, teachers and respected elders which undermined the authority of information received from nurses, doctors and community-based organisations. A classic notion in circulation was the belief that ARVs must be taken with food to be effective.

It was clear, she said, that treatment information needs to be adjusted to the cultural context, and it was important to identify the information gatekeepers who are providing misleading information and work to re-educate them.

Community barriers and community empowerment

But stigma, and the inability to disclose one's HIV status, remain particularly important barriers to good adherence in most communities, and indicate the need to integrate treatment literacy within a community-based approach that seeks to address stigma.

The International HIV/AIDS Alliance carried out a two-year programme in Zambia from late 2004 at sites in Lusaka and Ndola to promote community preparedness for treatment.

The team's evaluation of lessons learned during the first six months of the project highlighted that "even in the hardest hit communities, stigma continues to be the most profound barrier to effective community-based responses."

The ACER treatment support programme aimed to reach 60,000 people in two low income urban areas, to provide community education on ART, voluntary counselling and testing, prevention messages and stigma reduction. It also set out to establish a two way referral system between the health system and the community, using community volunteers and treatment support workers living openly with HIV. The aim of the programme was to engage the whole community, to build on existing community structures, and break down barriers that might impede the success of ART roll-out – particularly stigma.

Full evaluation of the project isn't completed, but there has been a clear increase in the uptake of VCT in the community, recognition from the Ministry of Health of the key role that community organisations are playing in adherence support and linkage between clinics and communities, and a high degree of appreciation among patients for the support provided by peers within the clinic.

Further information on the project is available at:

http://www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=52&language=en

The experience in Zambia led to the funding by USAID of a larger and more ambitious community mobilisation programme managed by the Alliance in Uganda. The programme has recruited over 80 "network support agents" based in 43 health facilities across seven districts. The network support agents – people with HIV – have been chosen by their PWHIV support groups to act as links between the health facility and the group, and are trained to support delivery of prevention, treatment and care services, including VCT, disclosure, treatment education and adherence support. They carry out community follow-up of ART patients on bicycles provided by the project, and provide feedback to health facilities on community barriers to testing, treatment and adherence.

The project is also measuring success by measuring the number of PWHIV support groups which apply for project grants to expand their community services; 215 asked for money but only 45 could be funded.

In 2006-7 alone, the programme reached 94,500 people with education, including provision of adherence support to over 9,000 and ART literacy training to over 19,000.

The two projects show the difficulty of disentangling "adherence support" and "community engagement", and the value of integrating adherence support within a larger community mobilisation.

Structural barriers

Numerous studies have now shown that the most important structural barrier to adherence is the charging of fees for medical care or medicines. The second biggest barrier, as identified above, is transport to the clinic.

“What are the total out of pocket costs, not only of coming to the clinic, but of not staying at home to dig your cassava?” asked Alex Coutinho of TASO in Uganda during the HIV Implementers’ meeting.

An extensive qualitative study of barriers to adherence in Botswana, Uganda and Tanzania showed that transport costs, user fees for accessing health services and lost wages were all important financial barriers to good adherence. The researchers recommended that ART programmes provide transport and food support to patients who are too poor to pay, and that recurrent costs to users should be reduced by providing three-months, rather than the one-month supply of medication once optimal adherence levels have been achieved (Hardon 2007).

Loss to follow-up

Speaking at the 2007 HIV Implementers’ meeting Alex Coutinho of TASO, Uganda, highlighted the challenge that adherence support has posed for treatment programmes. In the early days of treatment roll out, programmes adopted either an enrollment or an adherence model of scale-up. While the enrollment model focused on starting the maximum possible number of people on treatment, the adherence model focused on preparing people thoroughly for the challenge of adherence to daily antiretroviral treatment.

Although the adherence model often proved slow to swell the number of patients of treatment, it has proved better at retaining patients on treatment. The enrollment model often saw 30% loss to follow-up rates, said Alex Coutinho.

As the 2007 HIV Implementers’ meeting heard, it is difficult to separate the issues of adherence and loss to follow-up. After all, if a patient is lost to follow-up, they are by definition non-adherent to treatment.

Spotting loss to follow-up starts with good systems for record-keeping, and reliable ways of finding patients who are lost to follow-up. As Colin Shephard of I-TECH Ethiopia explained, this can be pretty challenging.

I-TECH was working with the Felege Hiwat hospital in Bahir Dar, in the northern Amhara region, which had started over 3600 patients on ART by the end of 2006. However 22% of those patients were lost to follow-up, and in 41% of cases there was no contact information for the patient. In a further 47% of cases, the only information available was the name of a local landmark.

The clinic recruited and trained three patients already on ART to locate patients lost to follow-up, and to obtain accurate address information for all newly registered patients, together with consent for home visits if they missed a clinic appointment.

Home visits and other enquiries were able to locate just 6% of patients, with a further 44% of the LTFUs discovered to be dead, and the remainder still missing.

In South Africa, Klerksdorp Hospital in the North-West province has also employed default tracers since it became apparent that the loss to follow-up rate had reached 21%. The vast majority of those lost to follow-up defaulted during the first six months of treatment, but an audit of 300 patients lost to follow-up could only identify 126 deaths from local death records. The remainder were still out there somewhere, but, said Dr Ebrahim Variava, either their

address details weren’t complete, or they weren’t answering their mobile phones.

“We think cell phones are a blessing and a curse [from the adherence point of view]. People change numbers constantly because the cheapest way to run a phone is to buy a starter pack with a new number.”

Some programmes require that a home visit to verify residency in the district takes place before treatment can begin. In addition to phone and complete address, the International Center for AIDS Programmes’ Clinical Manual recommends attempting to obtain names, addresses and phone numbers for close family and/or friends, and places where the patient spends time (work or recreation — as well as permission to make home visits or to contact family and friends).

In Tanzania ICAP found significant differences in loss to follow-up rates between four clinics in the Pwani region south of Dar es Salaam. Although adherence support was delivered through a standard model of three sessions of adherence counselling prior to treatment, reinforced with counselling at each visit to the drug dispensing point, loss to follow-up ranged from 3 – 4% at two clinics up to 25% at another site.

ICAAP discovered that the higher loss to follow-up rates were associated with inadequate staff resources for defaulter tracing together with inadequate community sensitisation about the need for adherence. Stigma and lack of disclosure also played a part. The other big barrier was transport to the clinic.

In order to improve retention in care and adherence to treatment, ICAAP’s clinics took the following steps:

- They encouraged family-based counselling in order to promote HIV testing and disclosure
- They began to provide transport from rural health centres to ARV clinics with high loss to follow-up rates, and established satellite clinics at local health centres too.
- Patients with an excellent record of adherence were permitted to take three months supply of drugs rather than having to return each month.
- Local awareness campaigns about the importance of adherence to ART were mounted.

Further discussion of approaches to dealing with loss to follow-up can be found in a previous edition of HIV & AIDS Treatment and Practice published in August 2007.

See <http://www.aidsmap.com/cms1234974.asp>

Preparing the patient for treatment

Treatment programmes take differing routes to determine which patients will start treatment, as Alex Coutinho noted, with some concentrating on quantity rather than quality in order to reach national and regional targets. Some also regard extensive adherence preparation as too demanding on sick patients, and see the priority to be getting them onto treatment.

On the other hand, adherence-focused programmes tend to take their lead from the pioneering model developed over the past five years by MSF in Khayelitsha, South Africa, and many other treatment sites around the world.

It’s a model that places the patient at the centre, and which eschews the frankly punitive attitudes of public health TB programmes, which assume that the patient will be irresponsible, in favour of an approach that assumes that, armed with sufficient knowledge and support, the patient is the one who is responsible for the long-term success of her treatment.

The model comprises thorough patient education on the benefits and side effects of ARV treatment prior to treatment initiation, and continuous support with participation in support groups, self-nomination of a treatment supporter and the availability of adherence counsellors for one-to-one sessions. Adherence to tablets is verified by regular pill counts on return dates at clinics. Pill boxes and printed material are provided as adherence aids.

ICAP stresses that “adherence is more than taking medications” but also must include (and generally begins with) “adherence to care.” Does the patient make all of her or his scheduled appointments, participate in education and counselling, and attend support groups? Are they receptive to the idea of home visits or other outreach? Have they come in and completed ordered tests, modified his or her lifestyle and made a commitment to keep from transmitting HIV to others?

In many clinics patients are judged to be ready for treatment only when they have been through a preparation process, and their cases are reviewed by a selection group. In Vietnam for example, the selection group at Family Health International-managed treatment projects consists of clinic and home-based care team staff, as well as an elected representative of local people with HIV.

Family Health International, which is running PEPFAR-funded treatment programmes in several countries, reported lessons from its early programmes in Ghana, Kenya and Rwanda in a detailed report in 2005 (Ritzenthaler).

All programmes mandated at least one, and preferably three sessions of treatment adherence counselling, conducted by nurses who had typically received two to three days of training on adherence. In Rwanda patients also received ART-related written material in the local language, including a card with a picture of each drug and the schedule for pill-taking.

Several of the FHI programmes mandated disclosure to a relative or friend who would act as a treatment supporter (see below). In Kenya counsellors said that while their training prepared them well for supporting disclosure, they were concerned about the growing numbers of patients, noting that counselling is time-consuming, should not be rushed and may be extensive when disclosure issues are involved. They agreed that more counsellors would be needed as the numbers on treatment expand.

Counsellors in the Kenyan programme highlighted the need for clear, precise information on side-effects and how to manage them. Quite apart from the need to educate about the risks associated with some drug side-effects, problems with drug side-effects are frequently cited as a reason for interrupting or stopping treatment, so educating about side-effects should be a core part of any patient's preparation for treatment.

FHI developed visual materials for use by counsellors to explain opportunistic infections, antiretroviral therapy and potential side effects. The Healthy Living counselling guide can be downloaded from

http://www.fhi.org/en/HIVAIDS/country/Kenya/res_healthy.htm

FHI also developed an extensive adherence support worker training manual with over fifteen modules. The training manual can be downloaded from

http://www.fhi.org/en/HIVAIDS/pub/res_ASW_CD.htm

The FHI materials were derived from a training programme developed in Zambia, which has now trained over 200 community volunteers. The programme is described in detail at

http://www.fhi.org/en/HIVAIDS/country/Zambia/res_ASWstory.htm

NAM has developed detailed training materials for health care workers and counsellors on each of the drug combinations commonly prescribed in resource-limited settings, with a description

of the key drug side-effects and how to manage them. They can be downloaded from

<http://www.aidsmap.com/en/docs/6B8B0557-7767-4AB5-95FF-4DA8D882DF1D.asp>

Africaid developed a nurse training programme which covers the background to antiretroviral therapy and the role of nurses in adherence support and patient monitoring. It can be downloaded from

<http://www.aidsmap.com/en/docs/3F5509B5-BC9C-4C63-9AFD-EA4EEA3B52E.asp>

Western Cape ART rollout patient materials

<http://web.uct.ac.za/depts/epi/artrollout/>

Great variations in models of treatment preparation and adherence support

Research by David Pienaar and colleagues at the University of Cape Town School of Public Health found a wide variety of models of treatment preparation and adherence support within the Western Cape province. Their findings are summarised in the table below, together with the practices of a large HIV clinic in Johannesburg.

Clinic	Pre-ARV education	Decision to initiate	ARV adherence support
GF Jooste	<ul style="list-style-type: none"> Three counsellor sessions on same day as medical work-up 	<ul style="list-style-type: none"> Meetings held end of each working day Consensus between medical and counselling staff 	<ul style="list-style-type: none"> Hospital-based only Identified adherence issues are referred to counsellors for ‘booster’ sessions
Guguletu	<ul style="list-style-type: none"> Three mandatory group sessions (15-20 people); each session covers 2 topics over same time period but not necessarily on same days as medical work-up Home visit 	<ul style="list-style-type: none"> Inter-disciplinary meetings on Tuesdays Consensus between medical, counselling and other staff 	<ul style="list-style-type: none"> PA visits, theoretically daily for a week, then bi-weekly, eventually monthly Focus of home visits changing to identified problems only, not everyone
Hout Bay	<ul style="list-style-type: none"> Two to four adherence sessions depending on the patient's understanding. Dietician and social worker available. Encouraged to attend group counselling and bring a treatment assistant to sessions. PA home assessment 	<ul style="list-style-type: none"> Once a week on Mondays Consensus between medical staff, counsellors, patient advocates and dietician and social worker 	<ul style="list-style-type: none"> PA home-visits variable Identified adherence issues are referred to counsellors for ‘booster’ sessions

Michael Mapongwana	<ul style="list-style-type: none"> Structured counselling sessions delivered individually. Mandatory nomination of a treatment assistant who must attend one counselling session 	<ul style="list-style-type: none"> Twice a month on Tuesdays Consensus decision between medical and counselling staff 	<ul style="list-style-type: none"> All new starters get a pillbox Only two week supply of ARVs initially Identified adherence issues receive targeted 'booster' sessions Counsellors occasionally visit clinic non-attendees
TC Newman	<ul style="list-style-type: none"> No standardised 'work-up.' Ideally, six individualised counselling sessions, more usually, sessions tailored to patient's comprehension and motivation. Counsellor attends 'outreach' clinics. PA's available 	<ul style="list-style-type: none"> Tuesday morning meeting Consensus decision 	<ul style="list-style-type: none"> Identified adherence issues receive targeted 'booster' sessions at clinic Network of PAs and home-based carers provide community outreach and problem identification
Themba Lethu Clinic, Johannesburg.	<ul style="list-style-type: none"> Three mandatory group sessions (15-30 people); each session covers a number of topics. Last session includes adherence counselling and CD4 measurement. Pregnant women and low CD4 fast tracked. 	<ul style="list-style-type: none"> Medical officer seeing the patient. (we start between 50 and 150 patients per week) 	<ul style="list-style-type: none"> Any patients with viral loads that are detectable are referred to one-on-one sessions with adherence counsellors. Two detectable viral loads and the patients are changed to second line.

Training adherence support workers

Family Health International has reported on a project to train adherence support workers in Zambia that is now being used as a template for work in other countries where FHI is managing PEPFAR-funded treatment programmes.

The Zambia Prevention, Care and Treatment Partnership, a project managed by Family Health International trained adherence support workers to become part of the multidisciplinary team at health care facilities, and make connections between the health care facility and the local community.

The training didn't just focus on adherence and antiretroviral treatment; it also helped adherence support workers participate in referral networks; work alongside nurses and doctors as part of a clinical team; and interact with patients in clinical, community, and home settings.

Adherence support workers were almost all people living with HIV who were already taking antiretroviral treatment. They worked as volunteers for at least 20 hours each week, receiving a transport grant of 100,000 kwacha (about US\$25) per month. (These payments are arranged through subagreements with district health authorities, not directly with the health facilities).

They spend two days in a health facility and the third day in a nearby community, where they visit patients to support their adherence to treatment and track down treatment defaulters and try to re-engage them.

http://www.fhi.org/en/HIVAIDS/country/Zambia/res_ASWstory.htm

Community follow-up

A review of adherence support in Uganda, carried out by the Ugandan Ministry of Health's AIDS programme, concluded that community follow-up after starting treatment, both to prevent default but also to maintain adherence, was an essential element of care.

The survey sampled 30 health facilities across the country in 2005, representing a cross-section of the types of health facilities providing ART in Uganda. While all the facilities required a treatment supporter before initiating patients on ART, just under half had some kind of organised community follow-up, and eleven of these 14 sites was receiving money from PEPFAR to do so.

The activities included:

- Follow-up of missed visits by home-health workers, treatment supporters or peers, and by telephone reminders
- Referral and linkage to community-based support groups
- Unannounced pill counts by treatment supporter or home/community health worker
- Post-test clubs and peer education
- Home-based care
- Disclosure support and family-based counselling

Adherence was higher in the facilities that had community follow-up: over 80% of patients reported >95% adherence. In comparison facilities without community follow-up reported a lower level of adherence (although not drastically lower). Health facilities were not providing community follow-up, the survey found, because they could not afford to do so. Eleven of the 14 sites providing follow-up were receiving money from PEPFAR to do so (Mutya).

However, some express concern that community follow-up, using HIV-positive volunteers, is not properly funded. David Barr of the HIV Collaborative Fund, which gives small grants worldwide to community organisations carrying out treatment support, literacy and advocacy work, said: "In most instances, people with HIV - clearly performing essential services - are not paid or are given small stipends for their work. Community organisations are receiving little to no funding in these partnerships. The PEPFAR structure seems to reinforce this problem, since the medical centers get PEPFAR money, but the community organisations would need to seek out USAID funding streams."

Directly observed therapy

Some treatment programmes have attempted to reinforce adherence by using facility-based directly observed therapy. FHI's treatment programme in Rwanda required patients to attend the clinic every morning for the first week of treatment to take their pills

under observation. In Vietnam, HIV-positive patients receiving methadone treatment through FHI's local programme are beginning to receive once-daily directly-observed ART.

Generally however, directly observed therapy within the clinic setting has played little part in promoting or maintaining good adherence in Africa.

"As a result of the numbers of patients that we see and the fact that most do very well we cannot use DOT as a strategy. It would not be cost effective. However in first line failures there may be a place for it," said Dr Francesca Conradie of the Thembaletu Clinic in Johannesburg.

Treatment supporters

Instead, many treatment programmes have adopted a variant of directly-observed therapy, the use of community-based treatment supporters.

The use of individuals in the community to monitor and support good adherence to treatment was relatively untested when MSF and Partners in Health first began to adopt the practice in South Africa and Haiti in early projects that demonstrated the feasibility of ART in resource-limited settings.

Today the use of treatment supporters is quite widespread in resource-limited settings, and indeed, is a compulsory requirement for obtaining treatment in some programmes.

Dr Jean Nachega carried out in-depth research in the Western Cape province, South Africa, with focus groups of HIV-positive people and health care staff experienced in providing HIV care. He found that treatment supporters could provide short-term assistance for very sick people starting treatment. These people were often sick, weak, confused and intimidated by the idea of taking medication. "The support helped me to not give up and keep taking my tablet when I was so weak that I thought I am going to die," said one HIV-positive woman.

But the treatment supporters also had a longer term role: maintaining long-term adherence and shifting the mind-set of the patient towards living with HIV, rather than struggling to survive serious illness. Treatment supporters were also well placed to talk about prevention issues, mother to child transmission and social welfare.

Who are the treatment supporters? "First it's the mother; second the sisters; third, the brothers, father comes maybe the last one, then it goes to the partner, the sexual partner," one medical professional observed. Having a degree of authority made a person a better treatment supporter, medical professionals thought, but people with HIV tended to see an accepting attitude towards their condition as the primary qualification.

Fear of disclosure to family members was frequently cited as a barrier, both because of fear of rejection in relationships, but also because of the frequently cited fear that family members would disclose their HIV status to the neighbourhood when drunk. Some treatment supporters came and observed pill taking themselves, while others checked up on pill taking by looking at pill containers each day, or calling up by mobile phone with a reminder. David Pienaar's research in five Western Cape clinics revealed that, where they were part of the support package, treatment supporters were the form of treatment support most valued by patients (n=749) and most often utilised. Eighty-one per cent of patients across the five sites had a treatment supporter, and 83% of them rated a treatment supporter as a 'very important' form of adherence support. In comparison clinic and community-based support groups,

although highly rated, were used by 38% and 14% of patients respectively, due to differing treatment support arrangements at the clinics surveyed.

In Haiti, Partners in Health has made accompagnateurs responsible for administering HIV and TB drugs each day, visiting the homes of local people. "Daily visits and observation of patients taking their medicines not only ensures that patients adhere to their treatment, but also affords an opportunity for the community health worker to provide support, monitor for symptoms of adverse reactions to ART and/or HIV-related complications, answer questions about medications and their side effects, and stress secondary prevention messages," Partners in Health reports.

Dr Nachega and colleagues suggest that the treatment supporter model ought to be tested in a randomised clinical trial against the standard of care, but since the model has already been adopted so widely, it is arguable that it is already the standard of care.

Support groups

As last month's HATIP review of community-based care and patient retention shows, community-based support has the potential to provide a powerful aid to adherence. Support groups, run either by the clinic or by community-based organisations, provide a peer support mechanism that not only helps to spot when people are failing, but also provides a forum for problem-solving and learning among people who are encountering the same barriers to adherence in everyday life. It may also offer the only opportunity for a person to openly discuss living with HIV.

Support group attendance is mandatory in some treatment programmes before starting treatment, as a means of preparing people for the road ahead and bonding with a peer group.

Pillboxes

In the clinics reviewed by David Pienaar and colleagues in the Western Cape, patients gave a very high value to pill boxes as a very important adherence aid if they were made available. At one clinic all patients were issued with a pre-filled pillbox (which stores each day's doses in separate compartments) for the first week of treatment, and this continues for two to three weeks.

A study in San Francisco found that use of pillbox organisers was associated with better adherence and a higher rate of viral load suppression among an urban population that were often homeless, prone to substance abuse and living on very low incomes. The study compared viral load and adherence changes in patients who used pill boxes and those who did not between 1996 and 2000, but was unrandomised (Petersen).

Checking adherence levels: pill counts and patient recall

Many clinics monitor adherence by pill counts; patients are asked to bring their pill bottles back to the clinic each month and the number of remaining pills is counted to show how many doses have been missed.

A study carried out in Uganda by Jessica Oyugi and colleagues showed that unannounced pill counts carried out during home visits correlated well with the results provided by an electronic pill bottle cap that recorded each time the pill bottle was opened, and that both correlated well with a three day recall test, in which patients were asked to report whether they had missed any doses in the preceding three days, and if so, how many (Oyugi).

However, a study carried out in Malawi appeared to suggest that pill counts may over-estimate adherence. The study compared three

methods of adherence assessment: pill counts, three day recall and electronic pill bottle caps in 80 patients who had been taking twice daily *Triomune* for a median of thirteen months (Bell).

The study found that the mean adherence level by pill count was 96.8%, while the electronic tracking devices that measured each time a pill bottle was opened recorded mean adherence of 88.1%. In four cases, adherence was below 20%, yet the monthly pill count suggested adherence of 100% for each of them. What was going on?

The electronic pill bottle caps could not determine whether pills were actually taken, but the researchers did ask whether any participants removed pills from the bottle, for storage in another container, and four patients who did so were excluded from the study.

"Patients who missed doses may discard their excess tablets at the end of the month so as to seem more compliant," the researchers suggested.

Participants were also asked to recall their adherence over the previous day, week and month. According to this measure, only four out of 80 had missed any doses in the previous month, which did not tally with either the pill counts or the electronic tracking device.

The message of this study is not that patients will lie, but that physicians and nurses shouldn't engage in wishful thinking. "Pill counting and self-report serve [a] useful function in this setting by ensuring that the issue of adherence is raised at each consultation," say the investigators, and clearly, as this study shows, the issue does need to be raised with patients each time they visit the clinic or come into contact with health care workers. Good results on a clinic's chosen method of monitoring adherence should not engender complacency.

But physicians should not assume that they are better placed to monitor adherence than patients, according to the results of a large retrospective study of ART patients in Zambia, Uganda and Kenya, carried out by the Institute of Human Virology, University of Maryland. This study reviewed medical records from 863 patients on ART for whom self-reports and physician reports of adherence were available together with viral load data.

The study found that patients were 2.6 times more likely to report non-adherence by one of three measures (past week, past month, missed appointment or refill) when compared with physicians. In Uganda for example, physicians reported an average adherence rate of 91.4% among their patients, but patients reported an adherence rate of 84%. The gap was less pronounced in Zambia and did not occur in Kenya, but the findings suggest that using medical records to spot and target less adherent patients may not be reliable (Etienne).

A high standard of clinic record-keeping also contributes to monitoring adherence. A system that can easily identify missed appointments at the end of the day is essential, but this can be done successfully with a paper-based system, as ICAP has found in Rwanda. Dr Miriam Rabkin of ICAP says that collecting data on adherence levels, missed appointments and missed pharmacy visits across facilities can help improve performance in district programmes by identifying which centres are having problems and which centres can serve as models to others.

Maintaining long-term adherence

Several studies suggest that well-functioning clinic and community follow-up systems, together with meticulous record-keeping, are necessary to maintain the high levels of adherence seen after short-term follow-up.

In the Eastern Cape Management Sciences for Health has been working with pharmacists and clinics to track adherence and develop tools to improve adherence when it is found to be wavering.

Gavin Steel of MSH told HATIP: "For those patients who required greater support we offer a pharmacist-led adherence support clinic run once a week that offers motivational interviewing and other adherence improvement interventions on a referral basis. All patients who have failed regimen one undergo an adherence assessment prior to introducing the second line treatment. Most of our referrals are from this group of patients. The health care professional with greater adherence support skills focus on the difficult cases. In the Eastern Cape pharmacists are a scarce resource and hence it is vital to optimise their time."

They also developed a computerised tool to shift medicines dispensing from Cecilia Makiwane Hospital in Mdantsane out to local health care facilities. Prescriptions are organised centrally by referral clinic, sent out to the local pharmacy with an adherence checklist and then dispensed by local nurses, who feed back results to the hospital. The system cuts travel costs for patients and allows consistent follow-up of patients in the community in the long-term. It has now been adopted for 1000 patients in the district receiving long-term mental health treatment.

"Our philosophy is essentially one whereby we assist the client in exploring options that will allow them to adopt the regimen into their daily routine. Consequently we find that motivational interviewing is extremely useful and is superior to throwing gadgets at the problem."

In clinics where viral load is available, it has proved a useful means of highlighting which patients need intensive adherence support. At the Desmond Tutu HIV clinic in Guguletu near Cape Town, Catherine Orrell and colleagues reported that among 929 patients who began treatment between 2002 and 2005, 67 patients experienced viral breakthrough (defined as one viral load measurement above 1,000 copies/ml). These patients were immediately assigned an adherence counsellor for intensive follow-up and tested again eight weeks later. Only 20 out of 67 (2.2% of all patients) eventually switched to second-line therapy due to continuing viral breakthrough; the rest achieved undetectable viral load once more. Using Kaplan-Meier analysis, the Cape Town researchers estimated a viral failure rate of 5.6% after three years of treatment using this approach.

Since that study was completed, procedures have tightened further, Dr Catherine Orrell told HATIP. "We target those who are struggling with adherence. Whenever a person is noted to have dropped their pill count to <85% or blipped a viral load above 50 copies/ml, this person is placed on "alert" and their counsellor sent out to visit them at home. They also redo the initial treatment education sessions and go back to having to visit the clinic monthly for meds." Red alert status stops only when a patient has shown adherence above 85% for two consecutive months.

The Ugandan Home Based AIDS Care (HBAC) study described by Dr Jonathan Mermin at the HIV Implementers Meeting this year is another example of both the high adherence rates that can be achieved from community-based adherence support including weekly home visits (conducted by lay workers who deliver medications and use a standard symptom and adherence questionnaire) and the benefits of intensified support when monitoring indicates that there could be adherence problems.

The study compared three methods of monitoring patients, with routine CD4 cell counts, CD4 and viral load, or clinical (symptom) monitoring alone. While those in the clinical monitoring alone arm had significantly poorer responses than subjects in either of the

laboratory monitoring arms, the majority of participants in the study did quite well:

“90% of the patients had complete viral suppression at one year (less than 50 copies/ml). This is the highest viral suppression rate recorded in the literature and it attests to the excellent level of adherence achieved by participants probably because of weekly delivery of medication and a strong programmatic effort towards adherence counselling,” said Dr Mermin.

In fact, in each arm of the study, the first response to an indication of treatment failure was adherence counselling and support — which led to a very low rate of switching to the second-line regimen, particularly in the arms with laboratory monitoring.

However, in each arm, the routine adherence monitoring also likely improved response rates. At each weekly clinic visit, the lay healthcare workers, adherence was evaluated using the following questionnaire:

Are you having difficulty taking your medication? [] 1=Y, 2=N

Pill delivery	ARVs	TB medicines	Other medicines
Patient signature/print for receipt of pills X _____ _____			
Number of pills delivered			
Pill return			
If the pills being returned are different than those being delivered, please record the names of them in the boxes			
Number of pills returned			
If any pill(s) are returned what was the reason for not taking the pill(s). Tick as many reasons for each pill missed as patient provides.			
Forgetfulness Patient forgot to take pills, too busy.			
Toxicity or side-effects. Patient feels pills are causing side-effects.			
Pill(s) not working. Patient feels pills are not helping or are no longer working			
Pills not available. Lost pills, didn't have pills, could not find pills, away from home at time/did not have pills with him/her, pills were stolen.			

Other condition made patient not take pills. Too sick to take meds, sore throat, nausea or vomiting .			
Instructions from health care provider HBAC Medical Officer, Counsellor, or Field Officer told patient not to take pills. If other health care provider or traditional healer, specify _____			
Medication fatigue Client is tired of taking pills			
Change of schedule/delivery day or overfill			
Other, specify _____			
Notes regarding pill taking: Medical or counselling interventions, describe:			

In general, the lay counsellors provided the intensified adherence support, but according to Dr Mermin, when more complicated cases are encountered (such as in children on ART), adherence counsellors occasionally go along on the home visit.

However, conducting weekly home visits to thousands of homes is a significant human resources burden. In fact, Dr Mermin says that the HBAC programme is now modifying its protocol for visits to occur every two weeks.

Summary

- There are a wide variety of models of adherence support and they have not been compared in randomised trials.
- Adherence support systems that involve intensive preparation, a problem-solving approach to adherence problems and careful follow-up of defaulters and non-adherent patients produce strong results in terms of viral suppression.
- Preparation for treatment must address disclosure, problem-solving around potential barriers to adherence, and arrangements for follow-up and ongoing treatment support.
- The human resources needed for successful adherence support can be substantial. People with HIV have an important role to play in this process, but should not be treated as a source of free labour. Community support needs to be costed into treatment programmes at national level.
- Every clinic or health care worker contact should be treated as an opportunity to check and reinforce adherence. Pill counts and appointment keeping are important methods of tracking adherence, but cannot be considered infallible.
- Treatment supporters within the patient's own household or community are a powerful form of support, but this model needs to be pursued alongside community education to reduce stigma.

- Long-term maintenance of high levels of adherence needs to be studied more widely, but preliminary results from Uganda and South Africa suggest that it will continue to require quite high levels of human resources and careful monitoring.

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News headlines

Due to the length of the feature article in this HATIP, we have not included new headlines for key news stories relevant to resource-limited settings. These will be published next week.

about HATIP

A regular electronic newsletter for health care workers and community-based organisations on HIV treatment in resource-limited settings.

The newsletter is edited by Theo Smart (Cape Town) and Keith Alcorn, NAM's Senior Editor (London).

For further information please visit the HATIP section of aidsmap.com