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### Hunger, waiting time and transport costs: Time to confront challenges to ART adherence in Africa

A. P. Hardon<sup>a</sup>, D. Akurut<sup>b</sup>, C. Comoro<sup>c</sup>, C. Ekezie<sup>d</sup>, H. F. Irunde<sup>e</sup>, T. Gerrits<sup>a</sup>, J. Kglatwane<sup>f</sup>, J. Kinsman<sup>a</sup>, R. Kwasa<sup>g</sup>, J. Maridadi<sup>h</sup>, T. M. Moroka<sup>i</sup>, S. Moyo<sup>j</sup>, A. Nakiyemba<sup>k</sup>, S. Nsimba<sup>l</sup>, R. Ogenyi<sup>m</sup>, T. Oyabba<sup>k</sup>, F. Temu<sup>n</sup> & R. Laing<sup>o</sup>

<sup>a</sup> University of Amsterdam, Amsterdam School for Social Science Research, Amsterdam, Netherlands

<sup>b</sup> University of Amsterdam, Amsterdam School for Social Science Research, Kampala, Uganda

<sup>c</sup> University of Dar es Salaam, Dar es Salaam, United Republic of Tanzania

<sup>d</sup> Sekgoma Memorial Hospital, Sekgoma, Botswana

<sup>e</sup> Tanzania Food and Drug Authority, Dar es Salaam, United Republic of Tanzania

<sup>f</sup> Botswana Essential Drugs Action Program, Gaborone, Botswana

<sup>g</sup> Jinja Regional Referral Hospital, Jinja, Uganda

<sup>h</sup> National Institute of Medical Research, Dar es Salaam, United Republic of Tanzania

<sup>i</sup> Social Work Department, University of Botswana, Gaborone, Botswana

<sup>j</sup> Botswana-Harvard School of Public Health, Aids Initiative Partnership, Gaborone, Botswana

<sup>k</sup> Busoga University, Jinja, Uganda

<sup>l</sup> Muhimbili University, College of Health Sciences, Dar es Salaam, United Republic of Tanzania

<sup>m</sup> Mahalapye District Hospital, Mahalapye, Botswana

<sup>n</sup> AMREF, Dar es Salaam, United Republic of Tanzania

<sup>o</sup> World Health Organization, Department of Medicines policy and standards, Geneva, Switzerland

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## Hunger, waiting time and transport costs: Time to confront challenges to ART adherence in Africa

A. P. HARDON<sup>1</sup>, D. AKURUT<sup>2</sup>, C. COMORO<sup>3</sup>, C. EKEZIE<sup>4</sup>, H. F. IRUNDE<sup>5</sup>, T. GERRITS<sup>1</sup>, J. KGLATWANE<sup>6</sup>, J. KINSMAN<sup>1</sup>, R. KWASA<sup>7</sup>, J. MARIDADI<sup>8</sup>, T. M. MOROKA<sup>9</sup>, S. MOYO<sup>10</sup>, A. NAKIYEMBA<sup>11</sup>, S. NSIMBA<sup>12</sup>, R. OGENYI<sup>13</sup>, T. OYABBA<sup>14</sup>, F. TEMU<sup>15</sup>, & R. LAING<sup>16</sup>

<sup>1</sup>University of Amsterdam, Amsterdam School for Social Science Research, Amsterdam, Netherlands, <sup>2</sup>University of Amsterdam, Amsterdam School for Social Science Research, Kampala, Uganda, <sup>3</sup>University of Dar es Salaam, Dar es Salaam, United Republic of Tanzania, <sup>4</sup>Sekgoma Memorial Hospital, Sekgoma, Botswana, <sup>5</sup>Tanzania Food and Drug Authority, Dar es Salaam, United Republic of Tanzania, <sup>6</sup>Botswana Essential Drugs Action Program, Gaborone, Botswana, <sup>7</sup>Finja Regional Referral Hospital, Finja, Uganda, <sup>8</sup>National Institute of Medical Research, Dar es Salaam, United Republic of Tanzania, <sup>9</sup>University of Botswana, Social Work Department, Gaborone, Botswana, <sup>10</sup>Botswana-Harvard School of Public Health, Aids Initiative Partnership, Gaborone, Botswana, <sup>11</sup>Busoga University, Finja, Uganda, <sup>12</sup>Muhimbili University, College of Health Sciences, Dar es Salaam, United Republic of Tanzania, <sup>13</sup>Mahalapye District Hospital, Mahalapye, Botswana, <sup>14</sup>Busoga University, Finja, Uganda, <sup>15</sup>AMREF, Dar es Salaam, United Republic of Tanzania, and <sup>16</sup>World Health Organization, Department of Medicines policy and standards, Geneva, Switzerland

### Abstract

Adherence levels in Africa have been found to be better than those in the US. However around one out of four ART users fail to achieve optimal adherence, risking drug resistance and negative treatment outcomes. A high demand for 2nd line treatments (currently ten times more expensive than 1st line ART) undermines the sustainability of African ART programs. There is an urgent need to identify context-specific constraints to adherence and implement interventions to address them. We used rapid appraisals (involving mainly qualitative methods) to find out why and when people do not adhere to ART in Uganda, Tanzania and Botswana. Multidisciplinary teams of researchers and local health professionals conducted the studies, involving a total of 54 semi-structured interviews with health workers, 73 semi-structured interviews with ART users and other key informants, 34 focus group discussions, and 218 exit interviews with ART users. All the facilities studied in Botswana, Tanzania and Uganda provide ARVs free of charge, but ART users report other related costs (e.g. transport expenditures, registration and user fees at the private health facilities, and lost wages due to long waiting times) as main obstacles to optimal adherence. Side effects and hunger in the initial treatment phase are an added concern. We further found that ART users find it hard to take their drugs when they are among people to whom they have not disclosed their HIV status, such as co-workers and friends. The research teams recommend that (i) health care workers inform patients better about adverse effects; (ii) ART programmes provide transport and food support to patients who are too poor to pay; (iii) recurrent costs to users be reduced by providing three-months, rather than the one-month refills once optimal adherence levels have been achieved; and (iv) pharmacists play an important role in this follow-up care.

### Introduction

Since the launch of WHO's '3 by 5' initiative in 2003, many countries in sub-Saharan Africa have established national antiretroviral treatment (ART) programmes. Although the WHO target of providing access to ART for three million people by 2005 was not achieved, by the end of 2005 an estimated 1.3 million people in low- and middle-income countries had access to treatment, about 20% of those estimated to be in need (WHO & UNAIDS, 2006). By mid-2005, the WHO target had already been overtaken by an even more ambitious aim. In July 2005, the G8 group of industrialised countries

committed to the goal of achieving: 'As close as possible to universal access to treatment for all those who need it by 2010' (G8 Gleneagles Summit, 2005; UNAIDS, 2006).

Will these goals be reached and will they have positive health outcomes in Africa, where health systems are weak? Extremely high levels of adherence (at least 95%) are key to ensuring positive treatment outcomes and preventing the development of drug-resistance (Paterson et al., 2000). If drug resistances develop rapidly in Africa, large numbers of ART users will need to be switched to 2nd line treatments, which at present cost around 10 times

the first-line drugs. Will ART programmes be able to provide universal access to these more expensive drugs?

Previous studies on adherence to ART in Africa have provided quantitative estimates of adherence and data on clinical outcomes, mainly from experimental settings (Coetzee et al., 2004; Gill et al., 2005; Ivers et al. 2005; Koenig et al. 2004; Orrell et al., 2003). A pooled analysis of these adherence studies found an estimate of 77% of the African populations achieving adequate levels of adherence—for North America this percentage was only 55 (Mills et al., 2006). But are the adherence levels in Africa high enough, given that 23% of ART users in the populations included in the studies risk negative treatment outcomes and drug resistance? Indeed, Gill and colleagues (2005) stress that there is no room for complacency. With the move towards universal access, more relatively marginalised patients with adherence difficulties are likely to enter the programmes and their needs will have to be addressed.

There is still little evidence as to *why* and *when* ART users do not achieve optimal adherence levels (Akileswaran et al., 2005; Bennet et al., 2006; Farmer et al., 2001; Gill et al., 2005; Jaffar et al., 2005; Kent et al., 2003; Koenig et al., 2004; Safren et al., 2005). Reports on sub-optimal adherence to ART in developed countries indicate that the key factors are patient- and treatment-related, including substance and alcohol abuse, complexity of dosing regimen and 'pill burden', dietary restrictions and side-effects (American Public Health Association, 2004; Chesney, 2000; DiMatteo, 2004; Vermeire, 2001; WHO, 2004). The few studies conducted in resource-poor settings suggest that economic factors predominate. Weiser et al., in a study in Botswana in 2003, identified financial constraints as the major obstacle to adherence. Similarly, in Chennai, India, Safren et al. (2005) found that cost of treatment was a major obstacle to adherence. Ivers and colleagues (2005) found, in their meta-analysis of ten studies conducted in resource-poor settings, that providing medication free of charge to patients was associated with a 30% higher probability of

having an undetectable viral load at months-six and -12.

In this article, we present the results of rapid appraisals conducted in Botswana, Tanzania and Uganda, aimed at identifying the main factors challenging optimal adherence to ART and at providing health ministries and other health agencies with context-specific recommendations on how to enhance adherence.

The countries differ in HIV prevalence, density of ART sites and in their level of ART coverage by December 2005 (see Table I).

The quantitative findings of these studies, published elsewhere (Hardon et al., 2006), point to relatively high average adherence levels in these African settings. Average percentage of doses taken at the right time in the study population was found to be 93% for Tanzania, 98% for Botswana (based on one-month pill counts) and 100% for Uganda (based on self-report). Although the adherence rates seem high when measured as an average percentage of doses taken at the correct time, the Botswana study suggests that a significant proportion of ART users (around one out of three) do not achieve the optimal adherence rate of at least 95% needed to minimise the risk of treatment failure and the development of drug-resistance. Adherence support and ART provision is well-established in Botswana—one of the first countries in sub-Saharan Africa to scale-up access to ART. Hence, levels of optimal adherence are likely to be even lower elsewhere (Hardon et al., 2006). What are the reasons for *not* achieving optimal adherence levels?

## Methods

The rapid appraisals used mainly qualitative methods to identify current and future challenges to optimal adherence from the perspectives of both antiretroviral (ARV) users and front-line health workers. Multi-disciplinary teams of local health professionals and researchers conducted the appraisals. The methods used were: (1) semi-structured interviews (SSIs) with ARV users, health workers and key informants; (2) focus group discussions (FGDs) with ARV users and key informants; and (3)

Table I. Overview of ART provision in Botswana, Tanzania and Uganda, 2005\*.

Country	Population size	Estimated adult HIV prevalence (%)	Number of treatment sites	Number of people in need of treatment	Estimated treated as of December 2005* (%)
Botswana	1.8 million	24	32	84,000	85
Tanzania	37 million	6.5	44	315,000	7
Uganda	25 million	6.7	175	148,000	51

\*For this table we refer to the WHO/UNAIDS '3 by 5' Report of 2006 and the UNAIDS 2006 Report on the Global AIDS Epidemic (see references), which have some discrepancies with the data for 2005 reported in the country studies.

Table II. Number of respondents by data collection instrument.

	Number of facilities	SSIs with health staff	SSIs in community	No. of focus group discussions	No. of exit interviews
Botswana (four regions)	4 public	16	23	16	128
Tanzania (Arusha and Dar es Salaam)	3 public 4 private	28	30	8	70
Uganda (Jinja only)	1 public 1 private	10	20	10	20

SSI = semi-structured interview.

exit interviews. Rapid appraisals tend to use a mix of methods to increase the validity of results. In this way, the evidence collected with different instruments can be compared and used to validate findings. The strongest evidence is that which emerges from different 'angles', i.e. through 'triangulation'. The SSIs and FGDs were used to find out *why* people do not adhere. The exit interviews allowed us to interview users about the information flows between health workers and users, as well as the quality of care provided (Hardon et al., 2004). Ethical approval for the national studies was provided by national authorities in each of the three countries. Sample sizes are shown in Table II.

Since the low budget for these studies did not allow for a representative sample of the countries' ART sites, the sampling frame used was multi-staged. Health facilities were selected purposively, with the aim of including a diversity of facilities as well as limiting travel costs and time. In Tanzania, seven health care facilities were chosen in two cities (Dar es Salaam and Arusha). They included both public facilities and private/faith-based facilities, which had been providing ARVs for at least three months. In Uganda, two study sites were selected in Busoga region, a sub-region of eastern Uganda, which has both a public health facility and a private facility providing ART, each site relatively research-naïve. In Botswana, the study sites were located in three of the country's nine districts: north west (Maun), central (Serowe and Mahalapye) and Kweneng (Molepolole). Serowe and Maun were among the pilot sites, while Mahalapye and Molepolole were second-generation facilities.

Data collection took place between May and September 2005. Quantitative analysis of the exit interviews involved a standard data entry and analysis programme (Access). Qualitative data were analysed thematically with NUDIST software.

## Results

### *Reports from the frontlines: Challenges to optimal adherence*

The findings from these three country-studies reveal that although patients are highly motivated to take

ARVs as prescribed, constraints such as transport costs, user fees, long waiting times, hunger, stigma, side-effects, lack of appropriate counselling and workloads are a challenge to the optimal levels of adherence (>95%) required to ensure positive treatment outcomes and prevent drug resistance. In the section below we present these challenges as reported by ART users and local health workers.

### *Transport costs and user fees*

Although participants in all three studies received medicines free of charge, transport costs are an important reason why some ARV users fail to visit the health facility for follow-up and refill. These accounts illustrate the problems:

'I came from very far, over 50 kilometres from here. Before I come to the hospital I have to plan the money for a journey fare to the clinic. In fact my extra drugs got finished yesterday.' (Male ARV user, Uganda)

For others, the lack of a means of transport—especially from remote areas—can be an additional challenge:

'I once missed my appointment for refill because there were no vehicles coming here. I was at the stop from early morning and by noon I went back home. Fortunately I still had some medications.' (Male ARV user, Botswana)

An ARV user in Uganda suggested opening more treatment centres that were closer to home:

'I have very many people in the village, they are dying because they don't have money to transport themselves to the hospital. You need to have this money monthly. Like me, from the village where I come from, getting up to this place costs 15,000 Shillings (US\$8.50). To and fro is 30,000 Shillings (US\$17), which is a lot of money. And getting that money is a problem. So maybe, like people in Kyoga, if they can send that drug up to Kyoga, I think that could be good. Right now only Lira

Referral Hospital gives ARVs, and that is 130 kilometres from our place (Kyoga). Very far!

Health workers in all three countries were well aware that transport costs impede adherence. As one health worker in Uganda reported:

‘Some people have failed to report to the clinic on time because they failed to get transport to reach the clinic. Some people come from the islands, and they will tell you that they did not get money to cross the waters and that is why they did not come on time. And when you are told that, you cannot do much but to hope that when the next visit comes, he can afford to come on time.’

In addition to recurrent transport costs, patients have to pay registration and user fees in private facilities in Uganda and Tanzania. In Uganda, a fee of US\$3 was charged in the private facility at each visit. In Tanzania, the private facilities charge user fees with a range of US\$1.50 to US\$3 per visit and an additional US\$15 for laboratory investigations.

#### Waiting times

In all three studies, the problem of long waiting times was cited as a major challenge to adherence. In Tanzania, the mean time spent at the clinic was six hours. About half (12/28) of the health workers interviewed in Tanzania identified long waiting times as a problem. In Botswana, most (57%) of respondents reported that they spent four hours or more at the clinic, with the longest wait being 12 hours, as shown in Figure 1.

In Uganda, the average waiting time for ARV users was five hours in the public facility and one hour in the private facility.

ARV users may miss one working day per month in order to get ARV refills. This can be a problem for

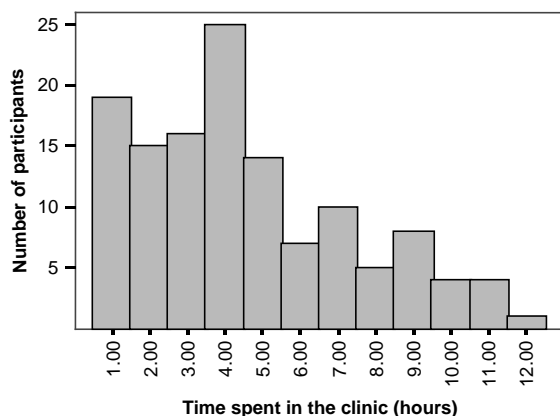


Figure 1. Distribution of the time spent by Botswana participants at the clinic ( $N=128$  exit interviews with ARV users).

some ARV users whose employers do not know that they are HIV-positive or do not support their need for care. One ARV user in Botswana said:

‘I resorted to asking my relative to pick up my medications, because my employer refuses to release me to go and pick up my medications.’

#### Hunger

ARV users in all three countries complained about hunger during the initial stages of treatment, when the body needs extra nutrition as it regains strength and weight. They said they could not afford the amount of food needed to satisfy their increased appetites. The following quotes illustrate this:

‘The problem I have with ARV is related to food. I have no money and ARVs increase appetite. I am not capable of buying food.’ (Male ARV user, Tanzania)

‘I want to eat all the time and fear the hunger will eat into my stomach, since I have ulcers already. Sometimes I wake up in the night to eat food. This is a difficult situation for me.’ (Male ARV user, Uganda)

‘Majority of people say the ARV treatment makes them to eat a lot. They go to an extent of begging for old age pension from their grandparents. Others quit the treatment because they complain about the lack of food.’ (FGD participant, Botswana)

‘Some patients have expressed lack of food as a reason for not wanting to swallow the life-saving drugs. In fact we have one woman who has declined her life-saving drugs because she does not have enough food to feed herself.’ (Doctor, Uganda)

In Tanzania, a female participant of a FGD reported that, because some ARVs have to be taken with food, some patients take their medicines only once a day in the evening (instead of twice daily), because that is the only time they have food.

In Uganda, some patients receive food support (soya flour, cooking oil, rice, sugar and maize flour) from TASO, a non-governmental AIDS support Organisation. In Botswana, the government provides a food basket for ARV users who have been assessed by social workers and found to meet certain criteria.

In all three countries, children were found to be important sources of support for ARV users, as illustrated here:

'My children after seeing the state I was in and after getting ARVs, I called them and told them about my state. They got encouraged and as a result they buy me passion fruits and sugar because they know the drugs I am taking are so strong. I even wrote my file number in TASO on the wall and told them that just in case I am badly off they can go to TASO and get me help. My children know very well that because of my drugs I have to drink enough and to eat on time.' (Female ARV users, Uganda)

### *Stigma*

All three country-studies reported on ARV users' experiences of stigmatisation and discrimination and lack of social support. Some ARV users reported that after disclosing their HIV-positive status they had lost their job (Tanzania); were abandoned or badly treated by their partners (Botswana); or were isolated by community members (Uganda). Fearing such stigmatisation, ARV users often decide to hide their HIV status from colleagues, friends and others. If ARV users do not disclose their HIV-positive status it may affect adherence in different ways. Firstly, non-disclosure may lead to patients taking their ARV medicines secretly and irregularly, as illustrated by quotes from ARV users in Uganda and Botswana:

'I cannot take my drugs when people are seeing. I always go and hide when I take them. Otherwise, people start whispering about you all the time.' (ARV user, female FGD, Uganda)

'I usually miss my medications when I visit friends because I have not told them about my HIV and so I do not want them to see my medications.' (Male ARV user, Botswana)

Moreover, when ARV users do not disclose their HIV-positive status to others they will not receive adequate social support and encouragement to take their drugs regularly and on time. The Tanzania study found that most of the ARV users interviewed had disclosed their HIV-positive status and received various forms of help from family and friends on the use of drugs (e.g. transport support, food, reminding them to take drugs).

### *Side-effects*

The side-effects most frequently mentioned by ARV users were: body rash, swollen legs, nausea, headache, increased heart rate, diarrhoea and vomiting. In Tanzania and Uganda, the occurrence of

side-effects was mentioned as an important reason for skipping doses:

'I had side-effects and decided to take medication only once per day.' (Male FGD, Tanzania)

'Feeling a lot of heat in the body, especially after taking the drug and excess sweating makes one embarrassed in public. So, you feel like postponing the drug to a later time when you are not relating with people.' (Male ARV user, Uganda)

In most cases, side-effects disappear over time. However, ARV users in Tanzania and Uganda have not always been given this important information. By contrast, in Botswana, where side-effects are discussed extensively in pre-treatment counselling, most ARV users reported that they had experienced side-effects, but only very few cited them as one of the reasons for missing their medication. This suggests that effective counselling increases patients' tolerance of side-effects.

### *Poor quality counselling*

Good counselling is a key requirement for successful ARV adherence. However, the frequency and quality of counselling was found to differ greatly both between the different countries and among the different facilities within each country. In Botswana, well-trained counsellors (nurses, social workers and lay counsellors) are available in all health facilities providing ARVs. In the public facility in Uganda, the counselling was done by nurses, who were not well trained because the public health facility could not afford to pay for good quality training courses for counsellors. Antiretroviral users in Uganda valued support from the community-based volunteers of TASO, many of whom are HIV-positive themselves. In Tanzania, the quality of counselling was found to be different in Dar es Salaam and Arusha. While patients in Dar es Salaam appreciated the quality of the counselling received, several ARV users in Arusha complained about the quality of their counselling due to the lack of trained counsellors. The exit interviews confirm that only a small proportion of ARV users see a counsellor at each visit (21%), while, in contrast, almost all (97%) see a doctor (see Table III). As one FGD participant commented:

'You find 25 patients and only one person attending all these patients and he just tells you to go and collect your medication.' (Male FGD participant, Tanzania)

Table III. Categories of health staff seen by patients in Tanzania ( $N=70$  exit interviews with ARV users).

Cadre of staff	Number of patients who consulted with this category of health worker	Percentage
Counsellor	15	21
General nurse	20	29
Pharmacist	54	77
Doctor	68	97

### Heavy workloads

At the public facilities in both Uganda and Tanzania, the scaling up of ART had occurred without any increase in personnel to cater for the increasing numbers. As a result, health workers were visibly overworked as they struggled to cope with the large number of patients on clinic days. One health worker in Uganda said:

‘You overwork like this without even a break because there are too many people all coming one day and yet you are very few.’ (Health care worker FGD, Uganda)

Table IV shows the main challenges reported by 28 health workers in Tanzania. Commenting on the large number of clients attending ART clinics, a female participant of a FGD in Tanzania said:

‘If the situation remains like this, doctors will be tired and the last patient will not be attended (to) properly.’

It is remarkable that, despite these heavy workloads, patients in all three countries expressed satisfaction with the quality of care at the facilities. In Botswana, 99% of ARV users interviewed in exit interviews at the facilities said that they felt listened to. In Tanzania, 80% of the ARV users at the facilities reported that they had been asked about their experiences in taking ARVs. In Uganda, two thirds of clients in the public facility

Table IV. Challenges most frequently mentioned by health workers in Tanzania ( $N=28$ ).

Challenges	Number of respondents	Percentage
Low motivation	26	92.9
Heavy workload	23	82.1
Inadequate training	20	71.0
Long waiting hours for patients	12	42.9
Too few staff	11	39.3
Work fatigue	5	17.9
Being faced with difficult or non-compliant ARV users	3	10.7

said the services offered were good, while all participants interviewed at the private facility said the services were good. They trusted the health workers.

### Discussion

Our study involved a rapid appraisal of adherence problems confronting ARV users and front-line health workers in resource-poor health facilities in three sub-Saharan countries. The findings suggest that patients are experiencing problems in their efforts to attain optimal adherence rates.

All the facilities studied in Botswana, Tanzania and Uganda provide ARVs free of charge but other related costs (e.g. transport expenditure, registration and user fees at the private health facilities and lost wages due to frequent clinic visits and long waiting times) are reported as obstacles to optimal adherence. It is significant that these same financial concerns were expressed in all three country-studies and at all the sites involved. Hunger in the initial treatment phase (when the patient is recovering) is an added concern for poor patients not covered by food support in the three countries. Antiretroviral treatment programmes in resource poor settings need to find ways to confront these constraints in order to ensure optimal levels of adherence at present and in the future. Clearly it is not enough to provide treatment free of charge.

The studies showed that health workers have heavy workloads and that waiting times are long. Treatment programmes also urgently need to find ways to reduce waiting times for ARV patients coming for refills and take into consideration the work schedules of ARV users. Evening and early morning clinics may be a good option, though these would be an additional burden for health workers. Patients could also be given appointments to reduce waiting times. In addition, workplace policies should include provisions for patients to take time off work to attend to their treatment needs.

A dynamic approach to adherence support is needed (Spire et al., 2002). As reported by Carrieri et al. in 2003, optimal adherence appears to be most critically important in the initial treatment phase if a patient is to achieve undetectable viral loads. In the initiation stage, many patients also suffer side-effects, some of which disappear over time. Treatment programmes need to emphasize adherence support in this stage. Health care workers should properly inform patients about the adverse effects they can expect and how to confront these. The treatment programmes should consider providing or subsidising both transport and food support to patients who are too poor to pay.

Once the health status of ARV users has improved and optimal adherence levels are being achieved, these must be maintained. To this end, recurrent costs for ARV users can be reduced by providing patients with two- or three-month refills, rather than the one-month refills that are current practice in the facilities studied. It is ironic that the system of one-monthly refills, intended to help monitor adherence, in practice creates a constraint to adherence because of the transport costs incurred. Transport costs can also be reduced by setting up a more extensive network of facilities where ARV users can go for refills, adherence monitoring and counselling. In addition, treatment programmes need to set up transfer mechanisms for ARV users to allow them to attend newly established facilities closer to home.

Pharmacists and nurses can play an important role in this follow-up care. Their involvement can also reduce the workload of doctors. To provide good quality care, all auxiliary health workers should be trained to recognise clinical signs of treatment failure, such as emergent opportunistic infections, and to provide adequate adherence support. When treatment failure occurs, intensified adherence monitoring by means of electronic monitoring devices or self-report could be used more systematically to investigate whether sub-optimal adherence is causing the treatment failure. This would help prevent unnecessary recourse to second-line ARVs.

Adequate counselling services are needed at health facilities or in communities in both the initiation and continuation phases of ART to help patients cope with the side-effects of ART, identify and confront the social constraints to adherence and address the financial problems that ARV users face.

In Botswana, all the facilities appraised had well-trained counsellors. The Tanzanian and Ugandan teams found that the quality of the counselling varied greatly. In the public facility studied in Uganda, nurses were given the task without adequate training. Yet training programmes for ARV counselling exist in sub-Saharan Africa and could be used more fully. Ministries of health and the agencies funding and providing technical support for ART programmes need to acknowledge that the provision of ARVs will not lead to positive treatment outcomes unless accompanied by the necessary adherence support in all health facilities. The Ugandan ARV users were very positive about the treatment support provided by TASO's community-based volunteers, many of whom are HIV-positive and can therefore better relate to the problems of people living with HIV (PLWHIV). Health facilities need to strengthen their ties with PLWHIV groups and other community organisations in order to strengthen community support mechanisms for ARV users. When such strong community-level adherence mechanisms are

in place, health facilities may be more inclined to provide ART users with two- or three-months refills, as we suggested above.

More specifically, adherence support programmes need to find ways to help ARV users remember to take their pills on time, for example through alarms on mobile phones or through using popular radio programmes as a prompt. Our studies suggest that, in all three countries, children play a role in reminding their parents to take their pills. Adherence support could recognise the potential role of children in adherence support and provide them with adequate information on ART, for example through school education programmes, to empower them in their role as treatment supporters.

Stigma was found to be a key constraining factor in all three countries. Most treatment programmes try to reduce stigma by encouraging disclosure to at least one person, who then becomes a treatment supporter. Our findings show that ARV users value such treatment support but still find it hard to take their drugs when they are among people to whom they have *not* disclosed their HIV status, such as co-workers or friends. Antiretroviral users are likely to have to take their medicines in social contexts where they have not disclosed their HIV status, especially if their work shifts vary or if they lead irregular social lives. Public and workplace education on ART is needed in high prevalence areas to help reduce the stigma attached to AIDS.

The researchers involved in our studies are now working with staff from the health facilities to help improve adherence support mechanisms along the lines of these recommendations. However, many of our recommendations cannot be implemented without external support. In addition to providing funds for free ART provision, donors should consider subsidising food and transport costs to ART users, especially in the initial phases of treatment.

We have shown that small-scale studies using a combination of qualitative and quantitative rapid assessment tools, conducted by local researchers in collaboration with front-line health workers, can be used to identify factors that facilitate or constrain adherence and indicate possible solutions. Antiretroviral planners locally and globally need to encourage such studies and acknowledge their findings in order to improve the effectiveness of ART programmes.

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