

Barriers and facilitators to patients' adherence to antiretroviral treatment in Zambia: a qualitative study

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Abstract

Patients' adherence to antiretroviral therapy (ART) is important for effective medical treatment of HIV/AIDS. We conducted a qualitative interview study in the Copperbelt Province of Zambia in 2006. The aim of the study was to explore patients' and health care professionals' perceived barriers and facilitators to patients' adherence to ART. Based on data from individual interviews and focus group interviews with a total of 60 patients and 12 health care professionals, we identified barriers and facilitators related to patients' beliefs and behaviours, the health service, and socio-economic and cultural factors. Among the barriers we identified were lack of communication and information about ART, inadequate time during consultations, lack of follow-up and counselling, forgetfulness, stigma, discrimination and disclosure of HIV status, lack of confidentiality in the treatment centres, and lack of nutritional support. Feeling better, prospects of living longer, family support, information about ART, support for income-generating activities, disclosure of HIV status, prayers and transport support were among the facilitators. Our study suggests that several issues need to be considered when providing ART. Further research is needed to study interactions between patients and their health care providers. Our findings can inform interventions to improve adherence to ART.

Keywords: AIDS, HIV, antiretroviral therapy, adherence, patient compliance, delivery of health care.

Résumé

L'adhésion de malades à la thérapie antirétrovirale (TAR) est importante vis-à-vis l'efficacité du traitement médical du VIH/SIDA. Une étude d'entretien qualitatif a été menée dans la province Copperbelt de la Zambie en 2006. Cette étude a pour but d'examiner les obstacles et les facilitateurs perçus par des malades et des professionnels de santé par rapport à l'adhésion de malades à la TAR. D'après les données des entretiens individuels et de groupes de foyer, 60 malades et 12 professionnels de santé ont identifié les obstacles et les facilitateurs liés aux comportements et aux croyances de malades, aux services de santé et aux facteurs socio-économiques et culturels. Parmi les obstacles identifiés, il y a un manque de communication et d'information sur la TAR, le temps inadéquat pris durant les consultations, le manque de suivi et de consultation, l'oubli, la stigmatisation, la discrimination et la divulgation du VIH, le manque de confidentialité dans les centres de traitement et le manque de soutien nutritionnel. Parmi les facilitateurs étaient les suivants : se sentir mieux, la possibilité de longue vie, le soutien familial, l'information sur la TAR, le soutien financier, divulguer le VIH, les prières et le soutien en moyen de transport. Cette étude suggère qu'il y a plusieurs sujets à considérer lorsqu'on met à disposition la TAR. Il est nécessaire d'avancer cette recherche afin d'étudier les interactions entre les malades et leur fournisseurs de soins de santé. Nos résultats peuvent guider les interventions ayant pour but d'améliorer l'adhésion à la TAR.

Mots clés: SIDA, VIH, thérapie antirétrovirale hautement active, conformité de malades, distribution de soins de santé.

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Introduction

Antiretroviral therapy (ART) has significantly improved the morbidity and mortality of individuals infected with HIV (Palella, Delaney, Moorman, Loveless, Fuhrer, Satten *et al.*, 1998). However, lack of adherence to highly active antiretroviral therapy (HAART) remains a key challenge to successful management of patients with HIV/AIDS. It is estimated that adherence rates lower than 95% are associated with development of viral resistance to antiretroviral medications (Nachega, Hislop, Dowdy, Chaisson, Regensberg & Maartens, 2007; Oyugi, Byakika-Tusiime, Ragland, Laeyendecker, Mugerwa, Kityo *et al.*, 2007; Wahl & Nowak, 2000). Adherence has been defined as 'the extent to which a person's behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical advice' (Haynes, 1979). The findings from a recent systematic review indicated that adherence to ART among patients in sub-Saharan Africa compares favourably with adherence rates in North America: among the included African studies (totalling 12 116 patients), 77% of the patients achieved adequate adherence, while the corresponding proportion from North-America was 55 % (17 573 patients) (Mills, Nachega, Buchan, Orbinski, Attaran, Singh *et al.*, 2006). However, the authors of the review stressed that 'efforts to sustain adherence in Africa and elsewhere remain important goals to optimize outcomes for individuals and global HIV treatment.'

In a systematic review of patients' reported barriers and facilitators to adherence, the authors found that 'fear of disclosure, forgetfulness, a lack of understanding of treatment benefits, complicated regimens, and being away from their medications were consistent barriers to adherence across developed and developing nations.' (Mills, Nachega, Bangsberg, Singh, Rachlis, Wu *et al.*, 2006). Barriers that were more specific for developing countries were 'access, including financial constraints and a disruption in access to medications.' However, among the 37 qualitative studies included in the review, only two were from developing countries, thus the authors concluded that 'Research is urgently needed to determine patient-important factors for adherence in developing world settings.' Several reports have been published since then from qualitative studies exploring factors that may affect adherence to ART (Hardon, Akurut, Comoro, Ekezie, Irunde & Gerrits *et al.*, 2007; Kumarasamy, Safren, Raminani, Pickard, James, Krishnan *et al.*, 2005; Malta, Petersen, Clair, Freitas & Bastos, 2005; Nachega, Knowlton, Deluca, Schoeman, Waltkinson, Efron *et al.*, 2006).

Zambia is one of the countries with the highest prevalence of HIV in the world. According to the Zambia Demographic and Health Survey of 2002, 16% of the population aged 15 - 49 years is infected and 98 000 people die each year because

of AIDS (Central Statistical Office, Central Board of Health, ORC Macro, 2003). The number of people accessing ART in the last few years has increased more than eightfold from 3 000 in 2003 to over 47 771 by the end of 2005, out of the 200 000 eligible patients (Ministry of Health, 2006). Transmission of HIV is predominantly heterosexual, but mother-to-child transmission is also significant. The peak AIDS prevalence for women is in the 20 - 29-year age group and for men in the 30 - 39-year age group, suggesting transmission from older men to younger women (Central Statistical Office *et al.*, 2003). HIV prevalence is significantly higher among women (18%) than men (13%). Women account for 54% of all people living with HIV/AIDS in Zambia. HIV/AIDS treatment is given priority by the government (Ministry of Finance and National Planning, 2006; Ministry of Health 2005a; National HIV/AIDS/STI/TB Council, 2002). In July 2005, the Zambian Government began providing free treatment to people eligible for ART. This new policy includes free drugs and basic laboratory investigations (Ministry of Health, 2005b). Resistance to treatment may threaten the sustainability of the programme, and represents a major public health challenge. In an open cohort study of more than 16 000 adult patients that were started on ART in urban Zambia (Lusaka), poor adherence was among the factors found to be strongly correlated with mortality (Stringer, Zulu, Levy, Stinger, Mwangi, Chi *et al.*, 2006).

Adherence to ART in Zambian hospitals is assessed through patient self-reports and monthly reports from pharmacies. To our knowledge no research to identify barriers or facilitators for ART adherence has taken place in Zambia previously. A better understanding of factors that influence patients' adherence to ART can improve treatment programmes of patients with HIV/AIDS. We conducted a qualitative study with the aim to explore patients' and health care professionals' views on barriers and facilitators to patients' adherence to ART in Zambia.

Methods

Data were collected during fieldwork in Kitwe and Masaiti districts in the Copperbelt Province of Zambia, from August to December 2006. Kitwe is an urban city, whereas Masaiti is a rural town. We conducted focus groups and individual in-depth interviews with patients using ART, and health care professionals. Patients were recruited at five different health facilities: three urban (Kitwe Central hospital, Chimwemwe and Ndeke clinics) and two rural (Fiwale and Mishikishi health centres). Recruitment was done by health care professionals working in the clinics, who were asked to identify men and women aged between 20 and 49 years, who were HIV positive and used ART, and who were not too ill to participate in the study. We recruited a sample of men and women on ART aged

Table 1. Characteristics of patients (N=60)

| Characteristic | No. |
|-----------------------------|-----|
| Age in years | |
| 20 - 29 | 17 |
| 30 - 39 | 33 |
| 40 - 49 | 10 |
| Gender | |
| Male | 33 |
| Female | 27 |
| Location | |
| Urban participants | 40 |
| Rural participants | 20 |
| Length of time on treatment | |
| Taking ART <12 months | 37 |
| Taking ART >12 months | 23 |
| Occupation | |
| Skilled professional | 2 |
| Self-employed | 30 |
| Unemployed | 28 |
| Marital status | |
| Married | 20 |
| Single | 12 |
| Widowed | 28 |
| Education | |
| Grade 0 - 7 | 30 |
| Grade 8 - 12 | 25 |
| College/university level | 5 |

20 years and older, with diverse social backgrounds (Table 1). We also recruited 12 health professionals who had experience with ART, including 3 doctors, 2 clinical officers, 3 nurses, 1 programme co-ordinator for a home-based care programme, and 3 pharmacists (Table 2). Their level of professional training varied between 3 and 7 years, representing the normal spectrum of Zambian health care providers who are actively involved in ART provision (nurses, clinical officers, physicians). Patients were informed that declining to participate in the study would not affect their access to treatment. All participants who were interviewed individually gave written consent, while participants in the focus groups gave explicit verbal consent. The study was approved by the Regional Committee for Research in Norway and the Tropical Diseases Research Centre Ethical Committee of Ndola in Zambia.

Interviews

We interviewed a total of 72 individuals, 60 patients and 12 health professionals. The final sample size of 72 participants was due to data saturation as consecutive interviews yielded diminishing returns of new information. The first author and a research assistant conducted individual in-depth interviews with 12 health care professionals (3 men and 9 women), and 10 patients (3 men and 7 women). The interviewers were independent of the provision

Table 2. Characteristics of health care professionals (N=12)

| | |
|--------------|---|
| Age in years | |
| 20 - 29 | 2 |
| 30 - 39 | 7 |
| 40 - 49 | 3 |
| Gender | |
| Male | 4 |
| Female | 8 |

of health care at the clinics. A total of 50 patients (27 men and 23 women) participated in 5 focus groups, with 10 participants each. Three focus groups were conducted by the first author and a research assistant in Kitwe, and 2 focus groups were conducted by research assistants in the Masaiti district. Individual interviews and focus groups were conducted either at the local clinic or at a local non-governmental organisation's training centre. We used interview guides that covered themes such as perceived factors that influence adherence and non-adherence to ART, how participants perceived HIV/AIDS and ART, experiences about ART, information on ART, and barriers and facilitating factors to ART adherence. The interviewees were given time to elaborate their answers and consistency of information was checked by paraphrasing what the interviewees said.

Analysis

Audiotapes of the interviews were transcribed verbatim by the first author and assistants. The interviews were translated from Bemba and Lamba, which are the local languages, into English. All authors read the transcripts from the 10 interviews independently and developed a coding frame for the analysis. The first author coded all the transcripts, and all the authors independently read the material and contributed in negotiating the final categories and their contents. Material about participants' perceived barriers and facilitators to ART adherence were identified and used for systematic text condensation, according to the principles of Giorgi's (1985) phenomenological analysis, as modified by Malterud (2001). The analysis followed four steps: (i) reading all the material to obtain an overall impression and bracketing previous conceptions; (ii) identifying units of meaning representing different aspects of participants' perceived barriers and facilitators to adherence, and coding for these units; (iii) condensing and summarising the contents of each of the coded groups; and (iv) generalising descriptions and concepts concerning barriers and facilitators to ART.

Results

We identified several perceived barriers and facilitators to patients' adherence to ART (Table 3). We classified our findings into three main themes: (i) factors related to patients' beliefs

and behaviours; (ii) factors related to the health service; and (iii) socio-economic and cultural factors.

Patients' beliefs and behaviours

Barriers

Forgetfulness, experiencing better health, busy work schedules, living alone, excessive alcohol consumption, beliefs about ART and side-effects were mentioned as barriers to adherence. Both patients and health care professionals reported that certain beliefs about ART could act as barriers to adherence. There were patients who had experienced ART as a sexual stimulant and therefore had interrupted treatment, as illustrated by a quote from the interview with a 35-year-old female patient: *There is lady I know who stopped taking her drugs because she felt a strong desire to make love to someone each time she took the drugs. This is a very old lady and she is a widow. She started taking these drugs after the death of her husband. She told me all this after I disclosed to her that I was taking ARVs. She is currently quite ill and is refusing to go to the hospital.*

Side-effects from medication were mentioned by patients as a factor contributing to non-adherence. Health care professionals also emphasised the negative impact side-effects could have on patients' motivation for treatment, as illustrated by this statement from a 27-year-old female health care professional: *I have this patient who is on the second-line treatment who stopped her drugs as a result of side-effects. She had terrible diarrhoea. She actually confessed that for her she had just to stop taking the drugs because the side-effects were just unbearable, in the sense that she had this diarrhoea and she just didn't like it; but after so*

much counselling, I had to call in a doctor who talked to her, and we just had to stress to her that if she broke this rule now, it was very difficult for us to manage her. So she fortunately did continue and came back and said okay, the side-effects are still subsiding but for now I'm okay.

Feeling better and healthier after a period on treatment was reported by patients as a reason for not taking medication. A 37-year-old married and self-employed male patient said: *There is this patient in my neighbourhood. He has stopped taking his medication after becoming well. He says that the drugs are too many to be taken every day in the morning and evening as if it is a prayer.*

Some interviewees also knew of patients who had stopped taking their medication because they were overwhelmed by 'pride', as they were looking physically fit and had regained their health.

Facilitators

Experiencing better health, living longer, knowing health workers personally, and prayers were reported by both patients and health care professionals as factors that facilitated adherence. Patients generally appreciated the positive effects of ART and were encouraged to continue treatment. Health professionals also reported that better health was a motivation for patients, as conveyed by a 43-year-old female health care professional: *I can give an example of one patient who was brought on a stretcher the first day he was seen by the doctor. Two weeks later, from the stretcher to a wheelchair, and he could stand from the wheelchair to sit on a chair to be seen by the doctor. A month later, that patient comes walking on his own. So what motivates them is what they get after starting the drugs.*

Table 3. List of barriers and facilitators to adherence to antiretroviral treatment

| | Barrier | Facilitator |
|-------------------------------|---|---|
| Health service | Lack of information and communication about treatment Time constraints Language barriers Poor staff competences Lack of patient follow up Inadequate counselling Long distance to treatment centres Concerns about confidentiality | Nutritional support Knowing health care professionals personally Information about ART Government policy of free ART |
| Patient belief and behaviours | Side-effects of drugs Pill burden Beliefs about ART Forgetfulness Excessive alcohol consumption Feeling better | Feeling better Prospects of living longer Prayers |
| Socio-economic and cultural | Lack of emotional/psychological support Lack of food Lack of disclosure of status Stigma and discrimination Preference of alternative treatments | Family support Support programmes for income-generating activities Disclosure of status Free transportation |

Health care professionals and patients said that access to ART was an opportunity to prolong their lives, thus enabling them to continue with their caring responsibilities. Patients said that they were motivated to take their drugs as prescribed because of their good relationship with the health care professionals. Some said that God was the most superior physician of their illness, and reported that this conviction was a motivating factor. Patients mentioned prayers as facilitators to adherence, as illustrated in a statement by a 32-year-old unemployed female patient: *My good lord is my motivator on this treatment as he answers all my human needs.*

Health services-related factors

Barriers

Lack of communication about ART between health care professionals and patients, time constraints during consultations, lack of counselling skills and patient follow up, lack of infrastructure to conduct counselling, and long distances to health facilities were reported as barriers to adherence. One group of patients said that they had not been informed about how to take their medication when they started using ART. A 34-year-old female patient, a widow and teacher, explained her experiences: *The doctor just writes prescription for collecting drugs. He does not discuss or give information on ART. There is no one who has asked me whether I'm taking my drugs or not, not even at the pharmacy.*

One group mentioned the health facility as their most valuable source of information, while another group of patients said that the pharmacy was more important. Lack of communication about treatment was mentioned by health care professionals as a potential barrier, as illustrated by this quote from the interview with a 43-year-old female health care professional: *Medicines are usually part of the pharmacy. Because of these changes in the doctors' routine work in the ART clinics, information dissemination to patients has not been so good. We encourage them to ask for more information at the pharmacy when they go to collect their medications.*

Patients reported that health care professionals rushed through their consultations, and they felt that the information given under such time constraints could easily be misunderstood. Health care professionals, on the other hand, reported having not enough time to assess patients' concerns and needs that might affect ART adherence. They observed that the ever-increasing number of patients on ART overwhelmed the available personnel resources. Few health facilities had a procedure for tracing and managing patients who had defaulted from their treatments. A 32-year-old male health care professional shared his experiences: *Like at this hospital, we have about 700 patients*

who have missed their scheduled monthly collection of drugs in the last 3 months. I do not know whether to declare them lost or not, but we don't know what has happened to them.

Inadequate training of health care professionals and unsatisfactory conditions for patient counselling were perceived as barriers, as reported by a 31-year-old female health care professional: *We do not have a counselling room, so most of the time we use a small office we call an HIV/AIDS office, but that office is being shared with the accountant. So it means if I have to counsel a patient, that accountant has to leave her work.*

Patients and health care professionals from rural areas mentioned long distances from the treatment centres as a contributing factor to non-adherence. Health care professionals recognised that patients have trouble walking long distances when they were ill. A 46-year-old female health care professional working in a rural health facility shared her experiences: *I had two patients who could not collect their medicines as scheduled. Most of the time they used to come on wrong dates. When you ask them why they missed their appointments, they will tell me that 'sister I had no energy to walk and I had no one to send' and they would have not been taking their medicines even for a week.*

Facilitators

We found that nutritional support, information about ART and free treatment were perceived as facilitators to ART adherence. Nutritional support was mentioned by both patients and health care professionals as important for improving adherence. A 27-year-old female patient stated: *I'm motivated to continue taking my drugs because of the food stuffs the home-based care programme offers me. Since I'm not employed, I wouldn't be managing to feed myself.*

Patients said the information they received about ART motivated them to take the drugs. This could be information given either by health care professionals or from booklets and workshops. Provision of free treatment was another facilitator to adherence mentioned by patients. Knowing health workers personally was also reported as a motivating factor for patients to continue taking ART.

Socio-economic and cultural factors

Barriers

Stigma and discrimination, disclosure of one's status as HIV positive, concerns about confidentiality, use of alternative treatments and lack of food were reported as barriers to adherence. Patients and health care professionals mentioned that stigma and discrimination related to being HIV positive were still present in their communities and families, despite the positive benefits of ART. There were examples of patients

who had withdrawn from social life as a result of being infected, as expressed by a 29-year-old single and unemployed female patient: *In my case, I stay with my father and mother. We are not on good talking terms because of this disease I have. They have told me that your friends bring money, but you have only brought this disease. So, even when there is food, they do not give me. Most of the time, I feel like I am confused, due to thinking too much. As a result I feel it is better to die because there is no one to care for me. I am always alone since my sisters died.*

Disclosure of one's status as HIV positive and of taking ART was linked with negative consequences for many patients, and a majority of patients said that they did not disclose their status out of fear of being victimised, rejected or accused of infidelity. Because of the traumatic nature of such experiences, some patients had ended up not adhering to their medication, as explained by a 27-year-old female health care professional: *I have one client who is HIV positive and has disclosed to her husband. The husband has been negative about it and it has been affecting her. She has been non-compliant with her medication and she has been in and out of the hospital ward. We just have to keep on talking to her. Each time her relatives come in, they are pleading, can you please talk to our sister.*

Patients expressed concerns about confidentiality at the clinics or at the pharmacies where they collect their medication. A 35-year-old married businesswoman patient explained: *The current place they use to dispense ARVs is next to the main pharmacy and many people have come to know that. There is also a nutrition office on the other side. Some patients shun sitting on the bench and opt to go and stand somewhere else and wait for the people to finish before they can collect their drugs. I have seen this myself. This treatment has just come and people are not yet used to such.*

Patients mentioned having had difficulties explaining their symptoms and worries properly to doctors, because the facilities at the clinics did not ensure their confidentiality, as expressed by a 33-year-old female patient: *We are seen in the same room with other general cases. Most of the time we are found in situations where you are two patients in the same room and that becomes very difficult to explain properly about your illness when there is a stranger.*

The use of alternative treatments was perceived by patients and health care professionals as a barrier to adherence. They observed that patients stopped taking their ARV treatment and concentrated on traditional medicines or spiritual rituals. Another experience with alternative treatments from a patients' perspective is illustrated in this quote from a focus group where a 28-year-old patient stated: *There was a certain pastor who visited my aunt who had recently been commenced on ARVs. She*

was still taking the initial 2-week course of niverapine. The pastor told her to stop taking niverapine and instead she was given 'Holy Water.' He prayed for the water, about 50 litres which was to be taken in quantities of 10 litres per day for 5 days, and gave it to her. That is how she stopped taking ARVs. When I went to visit her, I found that her condition had deteriorated. When I inquired about her taking the drugs, she just produced the drugs that she had collected from the clinic. I counted them and found that they were almost equal to what she was supplied at the clinic.

Lack of food was perceived as a barrier to adherence. Many patients believed that ART could not be taken without food, as illustrated by a statement by a 40-year-old male patient: *I have this patient in our support group. The drugs give him a lot of hunger, that is why he was not taking the drugs properly. Most of the time he will tell me that he did not have food. Some doctors say that unless you have eaten that is when you can take the drugs. So if there is no food in the morning to eat, then you have to skip that dose until food is found.*

Facilitators

Self-disclosure, support groups and free transport were reported as facilitators to adherence. Despite being regarded by many as an important barrier to adherence, several patients and health care professionals mentioned self-disclosure as a critical facilitator, usually linked to the support they received from their families. A 47-year-old married and self-employed male patient shared his experience: *I have disclosed my status to my wife and children. They have accepted my situation and are very supportive. Even when I'm busy with work, they remind me to take the medicines.*

Patients and health care professionals stated that certain patients who belonged to support groups which had income-generating activities were motivated to continue with their medicines, because of the support they received from such groups. A 38-year-old married peasant farmer male patient said: *Our support group runs a grocery and a hammer mill. Part of the money we generate assists us to support ourselves. This has motivated many of us to continue with our treatments.*

Patients who were registered and supported by non-governmental organisations mentioned the transport support they received each time they went for their medical reviews as a facilitator for their adherence to treatment, as illustrated by the view of a 32-year-old single businesswoman patient: *Availability of free transport to take me to the hospital for review motivates me to continue taking my medicines. Otherwise if I had to use my own means of transport, I was not going to manage.*

Discussion

We recruited participants from ART clinics, who were all taking medication or were providing health services at a clinic. Our findings offer an understanding of the complexity and dynamics of the different factors that may influence patients' adherence to ART. We believe our results may be valid for other settings, although we cannot determine to what extent different factors are important barriers or facilitators in other contexts. A weakness of our study is that we were not able to interview people who did not seek help at a clinic.

Our study identified barriers and facilitators which were diverse in nature, with a wide spectrum of factors related to patients' beliefs and behaviours, to the health services, and to socio-economic and cultural issues. These included barriers such as lack of communication and information about ART at health care facilities, inadequate time during consultations, follow-up and counselling, forgetfulness, stigma, discrimination and disclosure of HIV status, lack of confidentiality in the treatment centres, and lack of nutritional support. Facilitators included feeling better, prospects of living longer, family support, information about ART, support for income-generating activities, prayers, disclosure of HIV status and transport support. Besides long distance to the clinic as a barrier in rural areas, we did not find consistent differences between participants from urban and rural areas with regards to their perceived barriers and facilitators to ART adherence.

Improvement of health as an ambiguous factor

A striking finding in our study was that patients' feeling of improved health could be a barrier as well as a facilitator to adherence. Patients were said not to continue taking their medication when they felt better. However, patients and health care professionals also mentioned that patients were motivated to continue taking their medications when they began to feel better after being started on ART. Improvement of subjective health has to be understood in the context of patients' beliefs about the treatment and how well informed they were. Some patients believed they were healed and therefore did not understand why they should continue taking their medication. Earlier studies also reported that feeling better could act as a barrier or as a facilitator to adherence (Mills, Nachega, Bangsberg *et al.*, 2006). Adherence counselling is commonly offered to patients at the start of ART. However, these findings indicate that the stage of treatment when patients are starting to feel better could be a critical turning point with regards to adherence. Thus, counselling activities that specifically target patients during this treatment phase may be worth considering.

Communication about medication

Lack of communication and information about ART emerged as a barrier to adherence in our study. Most patients and some health care professionals mentioned that patients received little or no information about their medication from their health care providers. Other studies have also found that poor or lack of communication was a barrier to adherence to ART (Malta *et al.*, 2005).

Confidentiality

Confidentiality at treatment centres, especially at pharmacies, was another issue that emerged from our study. While the pharmacies were used as information dissemination centres for ART adherence, most patients did not favour such an approach. In some health facilities, the pharmacy for dispensing ART was different from the general pharmacy, which made patients feel labelled by their health institutions. This illustrates the importance of taking confidentiality and stigma issues into consideration when the provision of ART is being scaled up.

Stigma

We found that some patients and health care professionals experienced that stigma was still widespread in their local communities. Stigma and social exclusion has also been highlighted in other studies as a barrier to adherence to ART (Kumarasamy *et al.*, 2005). Fear of disclosure of HIV/AIDS status or being seen taking medication was identified as a barrier to adherence in previous studies (Mills, Nachega, Bangsberg *et al.*, 2006; Nachega *et al.*, 2006), and this was also mentioned by one group of patients in our study. For others, however, disclosure was reported as a facilitator to adherence. Disclosure can mobilise support from spouses, families and communities, and can motivate patients to take their medication (Mills, Nachega, Bangsberg *et al.*, 2006).

Nutritional support

Nutritional support emerged as an important factor for ART adherence. Lack of food was mentioned by both patients and health care professionals as a cause of non-adherence, and nutritional support was mentioned as a facilitator. However, most health facilities did not provide nutritional support to their patients on ART. Lack of food has been identified before in some studies as a factor responsible for patients defaulting from their treatments (Hardon *et al.*, 2007; Nachega *et al.*, 2006).

Conclusion

Patients' adherence to ART is influenced by a wide variety of factors related to patients' beliefs and behaviour, the health system, and social and cultural issues. Further research is

needed, including participant observations, to capture the actual interactions between patients and their health care providers. Also, future studies should assess the magnitude of non-adherence to ART in Zambia using quantitative measures. Our findings can inform the design of interventions to promote adherence to ART. However, the complexity of factors acting as barriers and/or facilitators to treatment adherence imply that the effectiveness of such interventions are unpredictable and need to be evaluated rigorously, preferably in randomised controlled trials.

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