



Published in final edited form as:

AIDS Behav. 2006 July ; 10(4): 437–442.

The Price of Adherence: Qualitative Findings From HIV Positive Individuals Purchasing Fixed-Dose Combination Generic HIV Antiretroviral Therapy in Kampala, Uganda

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Abstract

Contrary to early expectations, recent studies have shown near-perfect adherence to HIV antiretrovirals in sub-Saharan Africa. We conducted qualitative interviews with patients purchasing low-cost, generic antiretroviral therapy to better understand the social dynamics underlying these findings. We found that concerns for family well-being motivate adherence, yet, the financial sacrifices necessary to secure therapy may paradoxically undermine family welfare. We suggest that missed doses may be more due to a failure to *access* medication rather than a failure to *adhere* to medications, and that structural rather than behavioral interventions may be most useful to insure optimal treatment response.

Keywords

adherence; HIV; generic fixed-dose combination antiretroviral therapy; Africa; ethnography

INTRODUCTION

Early debates over public health responses to AIDS in sub-Saharan Africa assumed poor adherence to HIV antiretroviral (ARV) medications in impoverished countries (Stevens, Kaye, and Corrah, 2004). Recent studies, however, have measured antiretroviral adherence rates of over 90% in several southern African countries (Laurent *et al.*, 2004; Orrell, Bangsberg, Badri, and Wood, 2003; Oyugi *et al.*, 2004), including findings from our own group showing mean adherence rates of 91–94% in an urban Ugandan cohort purchasing self-administered, generic ARV therapy (Oyugi *et al.*, 2004). Given that adherence in the industrialized world—where treatment is often free—is only 70%, these findings were surprising (Bangsberg and Deeks, 2002).

Although sponsored programs providing free ARVs are slowly increasing, many individuals in Uganda directly purchase ARVs on a monthly or twice-monthly basis from local pharmacies

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and clinics. Patients may opt to purchase drugs because free treatment is not available locally or because they do not fit the eligibility criteria for free treatment programs, which often require that patients are treatment-naïve. Among the least expensive ARV therapies available in the country is a fixed-dose combination of stavudine, lamivudine, and nevirapine manufactured by Cipla (Mumbai, India) under the brand name Triomune[®]. Although inexpensive by Western standards (US\$27 a month in 2003), the cost of these medications approaches the median monthly income in Uganda (US\$30). In an effort to better understand the social dynamics of the incentives and barriers to adherence to self-pay antiretroviral therapy, we conducted in-depth qualitative interviews with a subset of Ugandan patients purchasing generic antiretroviral therapy followed in a prospective cohort (Oyugi *et al.*, 2004).

METHODS

Participants were recruited from a longitudinal study measuring Triomune[®] adherence through monthly electronic medication monitor and unannounced pill count adherence assessments conducted at patients' homes (Oyugi *et al.*, 2004). Individuals in the parent cohort were consecutively recruited from pharmacies upon receipt of their first antiretroviral medication. All patients were treatment-naïve upon initiating therapy and were purchasing their therapy themselves or with the assistance of an extended family network. In recruiting individuals for qualitative interview, an effort was made to select a subsample reflecting the sociodemographic and clinical characteristics of the larger cohort. Both English-speakers and non-English speakers were recruited. Interviews not conducted in English were conducted in Luganda, the local language common to the Kampala area.

Participants were recruited for qualitative interviews by the second author, who is also a home visitor for the longitudinal study and had established rapport and trust with participants. Interviews were conducted with informed consent at participants' homes by a pair of researchers, one Ugandan and one American. In all cases the Ugandan interviewer was one of two home visitors working with the longitudinal study, and therefore was known to the participant. Participants were asked to describe how they initiated antiretroviral medication and the impact of HIV therapy on their health, their household finances, and their family. Interviews were coded according to theme, and analyzed using an inductive method (Miles and Huberman, 1994). Results reported here on adherence and medication cost reflect "theoretical saturation," meaning these themes emerged consistently in the data and were redundant across interviews (Glaser and Strauss, 1967). These results are presented in narrative form in order to highlight the complex social dynamics of medication access and adherence described by participants.

RESULTS

Ten participants were recruited from the prospective cohort of 97 individuals. Participants in the qualitative sample were similar in age, sex, income, household size, employment, income, mean baseline log viral load, baseline CD4 cell count, and adherence compared to the remaining cohort (Table I).

The Financial Burden of Antiretroviral Treatment

Consistent with the findings of several groups indicating high levels of adherence (Laurent *et al.*, 2004; Orrell *et al.*, 2003; Oyugi *et al.*, 2004), participants rarely reported missing a dose of antiretroviral medication during qualitative interviews. However, they described this excellent adherence as the product of a constant battle to overcome the barrier of drug cost. Participants routinely named the price of medication (rather than side effects, stigma, or inconvenience) as the principal challenge to sustaining treatment, a finding consistent with

those reported by Byakika-Tusiime (Byakika-Tusiime *et al.*, in press), who found that financial sacrifice is the most important barrier to sustained adherence to treatment.

Participants described purchasing and adhering to their antiretroviral regimen as a major life priority. One single, working mother of two described Triomune as the first thing she bought after being paid each month. She described the medicine as “the most important thing in my life right now.” The strong desire to adhere despite medication cost led to rationing in the case of one participant who was unable to afford her next bottle of pills, and told a staff researcher that she was alternating between one dose a day and two doses daily in order to stretch a prescription because she did not want to go a whole day without taking any Triomune.

The financial sacrifices required to purchase antiretrovirals encouraged participants to postpone therapy until they experienced a rapid decline in their health or received a doctor’s warning that they would soon die without treatment. Their dramatic improvement, however, was often accompanied by new worries about the long-term sustainability of purchasing antiretrovirals. Three participants described being unable to cover the full cost of the medication themselves, and so relied on assistance from family members and extended kin networks to purchase ARV medications. One woman, a widow with five children, purchased her pills using money sent from an in-law working in Europe. Another woman was able to start therapy because her grandmother paid for her medications, but was forced to stop when her grandmother died.

A woman in her second month of treatment worried about the sustainability of her family’s financial assistance, who were also struggling to support the eight children orphaned by the sudden (non-AIDS) death of her sister a month earlier:

This time there are about three people or four people who contributed so that I may buy the medication, which means that it’s a problem, because by myself I can’t afford it. I don’t know whether in the coming months I will be able to buy it. Because if this is the second month, but three people contributed for that 50 thousand shillings, you never know how it will be the next month.

In addition, many families had several HIV-infected members in need of treatment, further compounding the financial strains of therapy and forcing families to choose whom they could afford to treat:

I face problems, because sometimes the Triomune gets finished when I do not have the money, yet I need it. For example what I have right now is about to get finished and I am already worried about where to get the money. I have no hope of where I will get it ... As you see, I have one pair of trousers and one shirt but I cannot buy any other because any money I get is used to buy Triomune It is only I who use it, though it would be good if my wife used it. I do not know what you doctors say, but we cannot manage. She does not take it because I cannot buy for both of us.

In addition to contributing cash resources toward the purchase of antiretrovirals, participants’ family members also suffered austerity measures in order to support antiretroviral treatment. Sometimes this involved cutting back on basic needs such as food:

What I know is that my people don’t get enough to make them satisfied. We are eight people and eat 1 kg of maize flour. That is what I can afford. We have one main meal daily. Yet a person is supposed to eat at least twice—that is, lunch and supper.

In another example, one participant’s mother sold a goat in order to help pay for her daughter’s second month of medication. Paying for HIV therapy also impeded participants’ abilities to pay for their children to attend school. A father of six, unemployed due to illness, complained bitterly about his inability to finance his children’s education:

At times I find things not working out. I fail to get the money for school fees and they stay home without studying. Sometimes they miss a whole term without studying, or study for only 2 weeks during the beginning of the term. They are made to repeat classes but what can we do? Even if they repeat I still can't afford to pay for the whole year. They just continue in that way off and on.

The Benefits and Burdens of High Adherence

When asked why they did not miss doses, many participants responded simply, "I want to live." While all participants in industrialized and developing countries alike presumably take therapy to avoid succumbing to AIDS, most Ugandans begin therapy at extremely advanced stages of disease (median CD4 68 in those we interviewed). Thus, it is possible that Ugandan participants correctly perceive themselves as close to death, and this proximity to death may drive near-perfect adherence. One participant described seeking out ARVs after doctors told her that she needed to "look for ways of saving [her] life:"

Before I started taking Triomune I was not ok. I was very, very weak, I had diarrhea that had become almost permanent, and fever every evening. My skin was very, very bad and I was scratching myself the whole night at times not sleeping. I had loss of weight, no appetite, vomiting. But I was lucky; I never got TB or pneumonia. When I went to the clinic, they tested my CD4 and they told me that it was very low. They told me I had to look for ways for saving my life ... Since I started taking Triomune there is a lot of improvement, because now I feel very comfortable and safe, and I eat well, I sleep well, no more diarrhea, and the skin is clearing. I am now becoming like a normal person, and I feel like I can now go back and work and lead a normal life.

In addition, participants' desire to live was strongly motivated by their obligations to kin, specifically by their concerns about the welfare of surviving family members. One father told us, "I have to take Triomune because I still want to live so that I may take care of my children. This is only possible if I take this medicine." A mother of a young boy spoke more generally, saying, "Most people they have families to look after, they have dependents and they have to live to look after those people. You have to be healthy, you have to provide for children and the dependents ... So you have to keep strong and healthy."

Several participants hoped that ARV therapy could provide them with a few more years of life in which they might be able to see their children into adolescence or adulthood, and provide them with a degree of financial stability. A middle-aged man with several financially dependent children and grandchildren and an HIV-positive wife described his feelings:

When I look at the family, where I am going to leave them, hm? I am not sure of their future. So I believe if I can still live some few years, I can push them and see where they can go.

This man was the sole breadwinner for his family, and thus the possibility of his death implied broad repercussions. But even participants who were unemployed and depending on others for their support expressed a great desire to establish financial security for their children before they died. One young woman who had been without work for a year pleaded with the interviewers to let her know of any job possibilities so that she might earn some money to build a house to leave for her children:

If I can get a job and work so that I can get some money to look after me and my children, at least I could do for my children something in the future, you never know ... Because since now I am sick you never know when I might be down, when I might die. But at least if you have got something where you get some money, you can build for them a small house.

Providing for the welfare of their families, and especially children, was a major motivator for participants to continue therapy. Yet, at the same time, the financial sacrifices required to sustain treatment often precluded participants from adequately feeding their families, educating their children, saving money, or investing in the future. One woman told us, “Now I can’t save anything. That money which I would save I now use to pay for the medicine. I have to buy the medication because I want to be living.” Thus, tragically, the very thing that motivates participants to adhere to ARVs—providing for their families’ future through the purchase of land or a house to pass on—is subverted by the financial imperative of paying for the medicine. In the words of one mother of three:

I don’t have any other plan. I only think about the medicine. I cannot say that I may buy a plot of land and build a house. I cannot.

DISCUSSION

Our qualitative inquiry suggests two observations. First, participants described the duty to continue caring and providing for their families as one of the major motivators for their high rates of adherence. Yet, at the same time, the cost of medication exacted a serious toll on family welfare and basic needs. Thus, self-paid ARV treatment may force participants to undermine the very thing that motivates them to take the medication. This dilemma exemplifies what Whyte and colleagues have described as the social (as opposed to pharmacological) activity of HIV medications in Uganda (Whyte, Whyte, Meinert, and Kyaddondo, 2004). Although the advent of programs offering free ARVs has significantly increased the availability of these drugs in Uganda over the last 6 months, many such programs have eligibility criteria, which either exclude or deprioritize participants who are not treatment-naïve. This means that participants who began buying medication before free treatment became available, such as those described here, may face barriers in attempting to switch over to subsidized medication. Better access to free ARV treatment for both treatment-naïve and treatment-experienced family members would avoid putting participants and their families in such a catch-22 situation.

Secondly, in the rare instances when participants did miss doses, it was most often due to an inability to afford the pills. This suggests that missed doses in impoverished settings may be understood best as an issue of access, versus adherence to medication. The distinction is more than semantic, because a problem with adherence suggests the need for intervention, whereas a problem of access suggests that efforts would be best targeted toward providing a reliable supply of free treatment. Some have suggested that the roll-out of antiretroviral treatment in sub-Saharan Africa should be modeled on the directly observed therapy (DOT) programs that have been widely used to ensure adherence to tuberculosis medication (Harries, Nyangulu, Hargreaves, Kaluwa, and Salaniponi, 2001). One component of these programs is witnessed dosing (Farmer, Mukherjee, Gupta, Tarter, and Kim, 2001). We argue that this type of intervention is helpful in securing stable supply and distribution of medications, but the daily witnessed dosing component may be unnecessary in populations that are already highly motivated to adhere (Liechty and Bangsberg, 2003). More appropriately, resources should be allocated toward reliable drug supply, the distribution of free therapy, the training of medical providers to prescribe optimal therapy, and the clinical and laboratory infrastructure needed to support the increasing numbers of participants on ARVs.

There are a number of limitations to this study. The small sample size, absence of formal random selection from the parent study, and urban location of the cohort limits the generalizability of our findings. Participation in the larger longitudinal study may have had a positive effect on participants’ adherence to medication, and possibly biased their responses during the qualitative interview. However, the longitudinal study found a very high correlation between self-reported and objectively measured adherence rates in this cohort, and for this reason we feel that participants’ descriptions of their adherence patterns are likely to be

accurate. Participation in the longitudinal study also may have had a favorable impact on the qualitative study, as the rapport and trust previously established with the Ugandan interviewers during monthly home visits is considered beneficial to the collection of accurate qualitative data. Lastly, the willingness of participants to be visited at home by a pair of interviewers may have influenced participation and responses to questions.

In summary, Ugandans who purchase antiretroviral medications appear to be highly motivated to adhere in order to sustain their health and enable them to rear their children. However, the high cost of therapy relative to their family incomes both periodically interrupts access to medications and competes with financing of necessary food, housing, and education. Therefore, missed doses may be more due to a failure to *access* medication rather than a failure to *adhere* to medications and that structural rather than behavioral interventions may be most useful in insuring optimal treatment response.

Acknowledgements

The authors would like to thank Mary Kasango for her assistance in data collection. This study was supported by the NIMH, NIAAA, NIDA, University of California San Francisco—Gladstone Institute of Virology and Immunology Center for AIDS Research, University of California, Berkeley Fogarty International AIDS Training Program, Doris Duke Charitable Foundation, and University of California, Berkeley Human Rights Center.

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Table I
 Characteristics of the Qualitative Subsample and Remaining Cohort

	Subsample N = 10	Cohort N = 87
Mean age	35.6	35.4
Female gender	60.0%	64.4%
Unemployed	30.0%	23.0%
income ≤ US\$50/month	60.0	56.3%
Household size		
1–4 persons	40.0	41.5
5–7	30.0	34.2
>7	30.0	24.4
Baseline CD4 (median)	68	56
Baseline viral log viral load (median)	5.3	5.6
Electronic medication monitor adherence (median)	97%	93%
Unannounced pill count adherence (median)	96%	96%