

High levels of psychosocial readiness for ART in an African population at the onset of treatment

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Abstract

Adherence at the earliest stages of treatment is likely to be influenced by prior illness trajectories and future expectations, best captured (and addressed) before treatment begins. We examined the influence of illness trajectories and treatment expectations on psychosocial readiness to start antiretroviral therapy (ART) in Jinja, Uganda. In-depth interviews were conducted between October 2005 and April 2006 with 41 members of an AIDS support organisation on their first day of treatment. Transcribed texts were translated, coded and analysed thematically using NVIVO-7 software. Results indicated that acute fear of death and progressive withdrawal from social, economic and sexual roles narrowed focus on survival, while efficacy-enhancing experiences with septrin prophylaxis and trust in counsellors reinforced belief in HIV diagnosis and importance of adherence. Most enjoyed supportive home environments after disclosing their serostatus. Lack of money for food and transport was anticipated as the main barriers to future adherence, particularly among women. Integrating strong counselling support with ART provision helped channel the power of shared illness experience into positive motivation to adhere at the onset of treatment.

Keywords: HIV, antiretroviral therapy, adherence, qualitative, Africa.

Résumé

L'adhésion aux premiers stades du traitement sera probablement influencée par des trajectoires de maladies et des attentes futures mieux saisies (et traitées) avant que le traitement ne commence. Nous avons examiné l'influence des trajectoires de maladie et les attentes du traitement sur l'attente psychosociale à commencer une thérapie antirétrovirale (ART) à Jinja, en Ouganda. Des entretiens approfondis ont été réalisés entre octobre 2005 et avril 2006 avec 41 membres d'une organisation de soutien sur le SIDA le premier jour de leur traitement. Les textes transcrits ont été traduits, codés et analysés par thème en utilisant le logiciel NVIVO-7. Une peur aiguë de la mort et un retrait progressif des rôles sociaux, économiques et sexuels ont rétréci l'attention sur la survie, tandis que l'expérience positive sur l'efficacité avec une prophylaxie à base de septrin et la confiance en les conseillers ont renforcé la croyance en le diagnostic du VIH et en l'importance d'adhérer au traitement. La majorité appréciait des environnements domestiques de soutien après avoir divulgué leur état sérologique. Le manque d'argent pour acheter de la nourriture et payer les transports était anticipé comme constituant la principale barrière à une adhésion future, en particulier chez les femmes. Intégrer un soutien psychosocial solide avec la fourniture de l'ART a contribué à canaliser le pouvoir de l'expérience de la maladie partagée en une motivation positive à adhérer au début du traitement.

Mots clés: VIH, thérapie antirétrovirale, adhésion, qualitatif, Afrique.

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Introduction

Patient adherence to HIV medications is critical for the success of antiretroviral therapy (ART) programmes in Africa. Depending on the type of drug regimen used, sustained moderate to very high adherence is required to prevent treatment failure and the rise of drug resistance (Bangsberg, 2006). Switching to second-line regimens is typically ten times or more expensive, adding to cost barriers for resource-poor settings (Global Price Reporting Mechanism on Antiretroviral Medicines, 2008). A pooled analysis of recent adherence studies in North America found only 55% of recipients reported acceptable levels of adherence (Mills, Nachega, Buchan *et al.*, 2006). Some have questioned how this record can be improved upon in resource-poor settings with weak health infrastructure and minimal patient support (Gill, Hamer, Simon, Thea, & Sabin, 2005; Harries, Nyangulu, Hargreaves, Kaluwa, & Salaniponi, 2001).

While preliminary evidence suggested African populations adhere to ART as well if not better than their Western counterparts (Mills, Nachega, Buchan *et al.*, 2006), serious concerns remain (Jaffar, Munderi, & Grosskurth, 2008). Most studies have been based on lifetime ART exposure of 6 months or less, often in the context of clinical trials where adherence tends to be better (Gill *et al.*, 2005; Osterberg & Blaschke, 2005), and have tended to ignore low retention rates observed in many programmes (Rosen, Fox, & Gill, 2007; Wakabi, 2008). Little is known about long-term adherence in Africa or the reasons for unexpectedly strong adherence reported in many African studies to date.

Understanding the dynamic nature of adherence over time and treatment contexts, even for the same individuals, is critical to designing effective promotion efforts (Castro, 2005; Spire *et al.*, 2002). For example, adherence at the earliest stages of treatment is likely to be influenced by prior illness trajectories and future expectations, best captured (and addressed) before treatment begins. According to the health belief model which guided design and analysis of this study (Rosenstock, Strecher, & Becker, 1994), determination to adhere at the outset of treatment will depend more on how individuals *anticipate* benefits of adherence before drugs have had a chance to work, balanced against anticipated health consequences of AIDS without treatment. Qualitative approaches are ideally suited for exploring such contextual influences (Sankar, Golin, Simoni, Luborsky, & Pearson, 2006), but a general lack of studies employing longitudinal qualitative designs has been noted outside industrialised settings (Mills, Nachega, Bangsberg *et al.*, 2006). In this paper we present the design of a longitudinal qualitative study to document the experience of Ugandan trial participants over 3 years on ART. We further analyse qualitative data from baseline interviews conducted before treatment was

initiated, to assess the general state of psychosocial readiness to begin lifelong therapy.

Methods

All study subjects were members of the Jinja branch of the AIDS Support Organisation (TASO) enrolled in a cluster-randomised trial integrated into normal health service delivery (Amuron *et al.*, 2007). TASO is a large non-governmental organisation with 11 centres in Uganda offering counselling, outpatient medical care, and a range of social support services to HIV-infected clients. They also conduct counsellor training, AIDS advocacy and community outreach (Ssebhanja, 2007). It has been a pioneer in home-based AIDS care and the philosophy of 'living positively with AIDS'. This philosophy generally encourages optimism, acceptance, and openness with others about HIV status, especially within the household (Ssebhanja, 2007, p.11). Group cohesiveness is actively promoted by invoking images of TASO as a 'family' (Ssebhanja, 2007, p.9), and shared identity tends to be strong. A typical challenge of interviewing TASO respondents is a tendency to underreport attitudes or experiences at odds with a positive living approach (locally known as the 'TASO' effect). The Jinja TASO clinic serves a predominantly poor rural and semi-urban population drawn from a radius of about 100 km. Most TASO clients earn less than \$10 USD per month (about 30 cents per day), usually working as subsistence farmers. Few work in the formal sector for wages or salaries.

The primary aim of the larger trial is to compare the effectiveness of a home-based care strategy with health facility-based care in close-to-real-life conditions using quantitative methods. An independent qualitative study was nested inside the main trial. It was designed to chronicle life changes and evolving challenges of adherence among a subsample of 40 trial participants over the first 3 years on ART, using intensive qualitative methods. In-depth interviews were scheduled at the final enrolment visit before clients had started medication, and 3, 6, 18, and 36 months on ART. Home observation visits were conducted for all interviews after enrolment. The study is ongoing; in this paper we restricted analysis to baseline interview results alone.

The qualitative study sample was stratified to ensure equal numbers of participants by sex, trial arm, and clinical/immunological stage, contrasting early (CD4 counts above $150 \times 10^6/l$ or stage I and II-defining conditions) and advanced (CD4 counts below $100 \times 10^6/l$ or stage III- and IV defining conditions) categories. Those with CD4 counts between 100 and 149 and those living beyond 40 km from the main TASO clinic were deliberately excluded, in order to maximise the contrasts between early and advanced clinical stages and reduce transport costs of follow-up, respectively. Forty participants were recruited

in order of appearance between October 2005 and April 2006 until sample quotas for all categories were reached. One male participant died before the end of the enrolment period and was replaced, bringing the total sample size to 41. There were no refusals to participate.

Prior to enrolment on ART, TASO routinely assessed all clients on clinical and psychosocial readiness during three orientation visits over a 4 - 6-week period. Selection of a 'medicine companion' was mandatory, while disclosure to household members was strongly encouraged. For clients randomised to home-based care, visits took place at home where HIV testing and counselling could be offered to present household members. Facility-based clients were encouraged to invite household members to TASO for this service. The main objective of psychosocial screening was to educate and enable rather than exclude, and as failing eligibility criteria tended to delay ART initiation, psychosocial issues were addressed rather than denying treatment altogether. Outright exclusion on psychosocial grounds was rare.

Following the health belief model framework, respondents were asked about perceived susceptibility to AIDS death, perceived severity of non-adherence, and perceived barriers and benefits to adherence in the context of illness trajectories and treatment expectations. Baseline in-depth interview guides were developed based on two focus group discussions, each with TASO providers and ART clients enrolled before the trial began, respectively. Pre-tested guides were administered by experienced social science interviewers (two female and one male) trained to anticipate strong compliance bias by TASO study subjects grateful to be starting new medications. Sequential recruitment did not allow for matching interviewers and respondents by gender. Baseline interviews lasted about an hour, and covered illness and treatment histories, attitudes and understanding of ART, and expectations for the future. Tape-recorded interviews conducted in Luganda were later transcribed, translated and entered on computer by trained social science interviewers. Thematic coding was conducted by two analysts with the aid of NVIVO 7 software. To ensure inter-coder reliability, analysts coded the first several interviews independently and compared their results. Notes and interview attributes were also entered into spreadsheet overviews to allow systematic comparisons across sample categories. Final consensus on themes was reached by discussion and debate between independent analysts and the principal investigator. Dominant themes included: physical and emotional trajectories, social and economic trajectories, dependence and withdrawal, and attitudes and outcome expectations for ART. Baseline comparisons between sample categories were restricted to sex alone.

Written informed consent and baseline interviews for the qualitative study were conducted at the clinic site on the same day as enrolment into the main trial. Information sheets and protocols for both the larger trial and qualitative sub-study were approved by the Ugandan National Council of Science and Technology and the Institutional Review Boards of the Uganda Virus Research Institute, US Centers for Disease Control and Prevention, and London School of Hygiene and Tropical Medicine.

Results

Sample

Among 20 women and 21 men interviewed at baseline, ages ranged from 22 to 62 years, with a median of 35 years for women and 40 years for men. Almost all of the women (18/20) and about half of the men (11/21) were widowed or separated. Socio-economic status was poor, consistent with general levels of poverty in the surrounding population. More than half had never completed primary education. Only five men and one woman ever held a salaried job; the rest had worked as farmers, small-scale traders or manual labourers prior to falling ill.

Physical and emotional trajectories

By the time of enrolment on ART, self-reported physical health was predictably poor. Most complained of weight loss or general body weakness. Almost all could recount serious bouts of illness that interfered with their work or social lives in some way. Skin problems including herpes zoster (known as 'kisipi' or 'belt' for the tendency to form circular bands) and severe itching were the most common symptoms mentioned. Experience of pain was a unifying theme:

'It hurts! It hurts!'... I tell my friends, this disease is so painful!
(Woman, age 33, separated)

Living with the expectation of imminent death was another common theme. Half of respondents had watched spouses succumb to AIDS, and all had experienced the loss of family members or friends. Most had experienced intense and sometimes incapacitating fear of death, though more often in association with receiving HIV test results than subsequent illness. Belief in the inevitability of death from AIDS was reinforced by community perceptions:

When I learnt that I had HIV, I first worried so much. So, so much. I worried so much indeed knowing that my end had come. (Woman, age 22, separated)

They did not react very badly [when I disclosed to relatives in the village] but they thought I was going to die. Because

they think that whoever gets this infection dies, that is what they think. (Man, age 62, married)

Illness narratives suggested early acceptance of the biomedical understanding of HIV infection. Various healing strategies were tried to treat early symptoms, but most suspected HIV infection from the beginning. Men were more likely than women to admit delaying the decision to test and seek help, through active denial or suspicions of witchcraft. Almost all those interviewed described a period of active worrying and waiting before testing. In most cases the decision to test and seek care followed encouragement from a friend or family member.

The decision to join TASO marked an important turning point in the experience of illness, both physically and emotionally, for most of those interviewed. Many reported improved health from septrin prophylaxis or TB treatment. Many more spoke movingly about the positive effect of counselling and the atmosphere of acceptance at TASO in loosening the grip of worry and fear on their lives. This was true for those who joined the organisation before ART became available in late 2004, roughly half of the sample, as well as those who joined after.

Social and economic trajectories

The path to ART for most was marked by dual themes of withdrawal from normal work and social roles, and progressive dependence on immediate family members. Most had stopped or cut back on work as health conditions worsened. Similar reductions in social activity were mostly attributed to restricted mobility due to illness or lack of energy. Others deliberately withdrew because of self-consciousness about visible symptoms. Aside from occasional finger pointing and labelling that most were quick to dismiss (at least in retrospect), no instances of enacted stigma from the outside community were reported:

I don't usually go to church... The rashes on my skin don't allow me to go there anymore. (Woman, age 36, widowed)

They didn't discriminate against me; it was me who feared them! (Woman, age 30, separated)

Withdrawal similarly affected family and conjugal roles. A number of clients described fostering out some or all of their children to relatives in anticipation of their own death. Others had ceded key adult responsibilities to their older children. Most women claimed to have lost interest in sex since testing HIV-positive, and planned to remain abstinent after starting ART. Men also reported less interest in sex and sometimes physical impotence, but included resumption of sexual lives among their hopes for the future:

Even if I see that I have recovered, is that any cause for desire? The time I have taken [without sex] is very long. That thing (HIV) is not going to cure. (Woman, age 49, separated)

As participants withdrew from active social and economic roles, their dependence on families for care and basic necessities grew. Most of the women had either moved in with another family member or relied on direct economic support from them. Even among ten married men in the sample, four had moved back to live with a sibling or parent. A sense of dependence created family strains, particularly among women, and added to the emotional burden of infection:

I asked my mother, 'Where should I stay now? I can no longer dig. I have been digging in order to survive, who will work for me if I stay [where I am]?' (Woman, age 35, married)

Even your very own do what? Get fed up with you! I had my money and every relative of mine used to come to me, but I have now turned into a beggar! (Woman, age 30, separated)

With a single exception, all had disclosed their HIV status to one or more household members. Reactions generally varied from neutral to supportive. In one of the few negative reactions, a co-resident brother forcibly evicted the participant after she disclosed, saying he could not live together with an infected person, but became more supportive after he tested HIV-positive himself. Participants were more circumspect about disclosing their serostatus outside the household. While a few were entirely open, most chose to disclose only if they perceived some immediate benefit in doing so. Idle gossip was more of a concern than active stigma.

Expectations about ART and adherence

Expectations for life on ART were characterised by cautious optimism at the outset of treatment. Counsellors had warned participants to anticipate serious side-effects from medications, but most expected these to last 2 - 3 months at most. All expected to be able to return to work (mostly expressed by men) or care for their children (mostly expressed by women) within a year of starting ART. Opinion was divided about how long improved health might last:

They tell us that these drugs do not cure but they just reduce on the effect of HIV so I don't expect full life. (Man, age 44, widowed)

Observing the effects of ART on fellow TASO members first hand was particularly important for building confidence in

new medications. Prior success with septrin prophylaxis or TB treatment had also provided a strong sense of self-efficacy about managing a long course of drugs. Both were important in overcoming surprisingly widespread rumours in the community about the safety of new medications:

I trust it [ART] 100% according to what septrin has done. Since septrin has helped me, then I am sure this one will work better. (Woman, age 50, separated)

Some people say that if they give it to you it kills you. But according to what we hear from those who are using it, they say it does not have any problem. (Man, age 43, married)

When asked what difficulties they anticipated, women clearly emphasised monetary concerns, underlining their uncomfortable sense of dependence. Worries about having to ask for help with transport costs or additional feeding requirements were most commonly mentioned:

I could, for instance, ask someone, 'My dear, give me some money to do this or that.' She tells you that we are not the ones who gave you the infection! (Woman, age 42, married)

By contrast, men worried most about side-effects that might interfere with their ability to work or identify them as HIV-positive to the outside world. A few raised concerns about maintaining adherence over a lifetime, but saw little choice in the matter:

It is like I am in prison. The virus imprisoned me, so now I have to follow what? Those rules! (Man, age 48, widowed)

Fresh from the final orientation session with counsellors, respondents were well-versed in the rules of good adherence. These were perceived to be quite strict, and consequences of even minor deviations potentially fatal:

Int: what happens if you miss for just one day?

Resp: That one day, the virus regains the strength that minute you have left it and it starts reproducing again. (Woman, age 42, married)

Determination to adhere was a deeply resonant theme. Expressions like 'becoming firm' (*okuguma*) or 'managing' anticipated difficulties (*okuyiyya*), whatever the cost, appeared in virtually all interviews. ART was openly recognised as the last chance for survival. While a degree of optimism and a desire to impress would both have been natural at the time of interview, there was an emotional intensity behind these passages that suggested more than simple posturing:

I told you that I already became firm, I am ready for what will come whether terrible sicknesses, I will tolerate them! (Man, age 44, separated)

I am really working hard now to see that I survive, my wife survives, in order to take care of our daughter. I am focusing on fighting for my health. (Man, age 31, married)

Discussion

Despite severe poverty, low levels of education, and limited access to health services (Amuron, 2007), Ugandan study participants about to begin antiretroviral therapy expressed a high degree of psychosocial readiness to face the challenges of adherence that lay ahead. We believe this readiness was essentially authentic, reporting biases notwithstanding, when disaggregated into its component parts according to the Health Belief Model, which provided the theoretical framework for this study (Rosenstock *et al.*, 1994). In terms of perceived susceptibility, clients had accepted the clinical narrative of HIV infection as the cause of their illness, some after trying and rejecting alternative diagnoses and treatments. 'Incompatibilities' between personal and medical definitions of illness that hampered adherence from the outset in an American sample were nowhere in evidence here (Wilson, Hutchinson, & Holzemer, 2002). Regarding perceived severity, most still considered HIV invariably fatal, as reflected by their intense fears of death when infection was first diagnosed. Rules and reasons for strict adherence were generally well understood, while perceived benefits of adherence were powerfully reinforced by first-hand observation of the positive effects of ART among those who started treatment earlier. The bond of trust with the organisation integrating counselling with medical care was sufficiently strong to override apparently widespread negative rumours in the community about safety of ART. Sense of self-efficacy with long-term medication had been boosted by successful experience with daily septrin prophylaxis or TB treatment. Each of these key elements of psychosocial readiness has been associated with significantly improved adherence in varied settings (Mills, Nachega, Bangsberg *et al.*, 2006; Vervoort, Borleffs, Hoepelman, & Mieke, 2007). With the possible exception of specific knowledge about ART and adherence, all of these factors would have been impressed on participants over the long course of illness trajectories, rather than acquired through didactic learning days or weeks before starting treatment.

Readiness to manage the social and physical costs of adherence in particular set this study population apart. All expressed realistic expectations of side-effects. Almost all enjoyed supportive home environments after disclosure of their serostatus, another important predictor of good adherence

in review studies cited above. Yet most had reached the end point of progressive withdrawal from social, economic and sexual roles, and progressive dependence on immediate family members over personal illness trajectories. While declining ability to work and the central role of families in care and support have been widely documented in Africa and other resource-poor setting (Bharat & Aggleton, 1999; Chimwaza & Watkins, 2004; Kipp, 2007; Seeley *et al.*, 1993; Robson, 2000; Thomas, 2006), their potential influence on adherence has never been addressed. Our findings suggest both may have actually enhanced psychosocial readiness for ART, by allowing participants to focus narrowly on survival with little to distract them from taking their medications. These findings highlight one of the recognised weaknesses of the Health Belief Model of ignoring the influence of social context on health behaviour. (Bajos, 1997; Van Campenhout, Cohen, Guizzardi, & Hausser, 1997). Later generations of health behaviour models, most notably Bandura's social cognitive theory, have acknowledged that it is not only individual conviction but active social reinforcement that is most likely to yield sustainable behaviour change (Bandura, 1994; DiClemente & Peterson, 1994). Such theories would predict that adherence reinforced by supportive social interaction would be higher and more sustainable than individually motivated mechanisms achieved in isolation.

The main barrier to adherence anticipated by study subjects was poverty itself, expressed primarily by women over lack of money to buy food or transport for monthly refills. It is worth noting that few if any of these participants would have afforded even the least expensive first-line regimens on their own. Similar concerns have been expressed by participants in the early stages of treatment in resource-poor settings (Au *et al.*, 2006; Hardon *et al.*, 2007; Kim & Farmer, 2006), although the extent to which they interfere with long-term adherence after free drug provision remains to be seen.

This study had several important limitations. Recruiting study subjects from a self-help organisation advocating openness about HIV status may have biased selection towards those more likely to adhere well. Secondly, situating baseline interviews *before* clients started ART, at the clinic site on the final day of orientation, may have encouraged the appearance of conformity to provider expectations, whatever the truth may have been. Despite deliberate efforts by interviewers to distinguish themselves from providers, it is possible study subjects may have perceived interviews as another stage of ART screening and exaggerated their degree of psychosocial adjustment just to 'pass the audition'.

While the combination of interview timing and institutional loyalty may have amplified the natural desire of all respondents to say the 'right thing', most of the key features of psychosocial readiness would have been difficult to exaggerate. These were the ones shaped over the long course of illness and care-seeking trajectories such as fear of death, hope for improvement after treatment, trust in the voluntary organisation providing long-term counselling and care, and the dual processes of withdrawal and dependence among others. Some have been independently documented in similar African settings. For example, strong determination to adhere, perhaps the easiest to exaggerate, was similarly reported in a qualitative study of early ART recipients in Uganda (Crane *et al.*, 2006) who went on to achieve over 80% adherence after 24 weeks on ART, despite drug supply interruptions and having to pay for their own medications (Oyugi *et al.*, 2004).

Given the history and resources an organisation like TASO has to offer its members, the level of psychosocial readiness observed here should not be generalised too broadly beyond this population. Nevertheless, predisposing factors such as exposure to AIDS deaths among family members or close friends, deference to medical authority, and the slow process of withdrawal and dependence are likely to be common features of HIV illness trajectories across other high-prevalence, low-resource settings. To the extent that these contribute to psychosocial readiness, they may help explain better-than-expected early adherence rates documented in African populations with early access to ART. More attention towards the various and changing forms of social selection that influence access to new medications, for example Nguyen's study of West African confessional traditions akin to TASO's emphasis on status disclosure, would be useful for understanding adherence behaviour (Nguyen, Ako, Niamba, Sylla, & Tiendrébéogo, 2007).

Only time and experience over the course of the trial will tell how psychosocial readiness expressed by these participants translates into actual adherence behaviour. Overall, these results would predict strong adherence in the initial stages of ART, but increasing challenges as time goes on, health improves and lives return to normal. Expanding roles and responsibilities might be expected to raise the effective cost of adherence, but also the capacity to meet those costs. Our results also highlight potential advantages of integrating ART provision with strong counselling and support services from the onset of treatment. The thoroughness of psychosocial preparation for ART in this sample contrasts sharply with the comparative shortage of clinical support services and information typically available to such resource-poor populations (Van Damme, Kober, & Kegels, 2008; World Health Organization, 2008). Experience of

trial participants in later stages of this study will tell how well strength in one dimension may compensate for weakness in another.

Acknowledgements

The study is supported by Cooperative Agreement Number IU01-PS000065-01 from the US Centers for Disease Control and Prevention and the UK Medical Research Council. The contents of this paper are solely the responsibility of the authors and do not reflect the official views of the Centers for Disease Control and Prevention or the UK Medical Research Council. We would like to acknowledge study participants for their time and patience, Rebecca Bunnell from CDC for support and advice on the design of the qualitative study, Janet Seeley for helpful comments on early drafts, TASO-Jinja and MRC-Jinja staff for general support, and interviewers Sarah Nakamanya, Kennedy Bwanika, Fatuma Sembajja, and Betty Nalusiba for their hard work.

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