

This article was downloaded by: [2.128.255.213]

On: 27 July 2013, At: 00:12

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



African Journal of AIDS Research

Publication details, including instructions for authors and subscription information:
<http://www.tandfonline.com/loi/raar20>

Barriers and facilitators to antiretroviral therapy adherence among patients with HIV in Bissau, Guinea-Bissau: A qualitative study

Dlama N Rasmussen^{a e h}, David da Silva Té^g, Lotte Rodkjaer^c, Inés Oliveira^{a b}, Candida Medina^g, Toke Barfod^d, Alex L Laursen^c, Peter Aaby^{a f}, Morten Sodemann^{a e} & Christian Wejse^{a i}

^a Bandim Health Project, Indepth Network, Apartado 861, 1004, Bissau codex, Guinea-Bissau

^b Clinical Research Centre, Copenhagen University, Kettegård Allé 30, 2650, Hvidovre, Denmark

^c Department of Infectious Diseases, Aarhus University Hospital, Brendstrupgårdsvej 100, 8200, Aarhus N, Denmark

^d Department of Internal Medicine, Section for Infectious Diseases, Roskilde Hospital, Køgevej 7, 4000, Roskilde, Denmark

^e Department of Infectious Diseases, Odense University Hospital, Sdr. Boulevard 29, 5000, Odense C, Denmark

^f Statens Serum Institute, Artillerivej 5, 2300, Copenhagen S, Denmark

^g National HIV Programme, Ministry of Health (Ministerio da saude), Bissau, Guinea-Bissau

^h Center for Global Health, Faculty of Health Sciences, University of Southern Denmark, J.B. Winsløvs Vej 9B, 5000, Odense C, Denmark

ⁱ GloHAU, Center for Global Health, School of Public Health, Aarhus University, Bartholins Allé 2, 8000, Aarhus C, Denmark

Published online: 26 Jul 2013.

To cite this article: African Journal of AIDS Research (2013): Barriers and facilitators to antiretroviral therapy adherence among patients with HIV in Bissau, Guinea-Bissau: A qualitative study, African Journal of AIDS Research, DOI: 10.2989/16085906.2013.815405

To link to this article: <http://dx.doi.org/10.2989/16085906.2013.815405>

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the "Content") contained in the publications on our platform. However, Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Any opinions and views expressed in this publication are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor and Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages, and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Terms & Conditions of access and use can be found at <http://www.tandfonline.com/page/terms-and-conditions>

Barriers and facilitators to antiretroviral therapy adherence among patients with HIV in Bissau, Guinea-Bissau: A qualitative study

Dlama N Rasmussen^{1,5,8*}, David da Silva Té⁷, Lotte Rodkjaer³, Inés Oliveira^{1,2}, Candida Medina⁷, Toke Barfod⁴, Alex L Laursen³, Peter Aaby^{1,6}, Morten Sodemann^{1,5} and Christian Wejse^{1,9}

¹ Bandim Health Project, Indepth Network, Apartado 861, 1004 Bissau codex, Guinea-Bissau

² Clinical Research Centre, Copenhagen University, Kettegård Allé 30, 2650 Hvidovre, Denmark

³ Department of Infectious Diseases, Aarhus University Hospital, Brendstrupgårdsvej 100, 8200 Aarhus N, Denmark

⁴ Department of Internal Medicine, Section for Infectious Diseases, Roskilde Hospital, Køgevej 7, 4000 Roskilde, Denmark

⁵ Department of Infectious Diseases, Odense University Hospital, Sdr. Boulevard 29, 5000 Odense C, Denmark

⁶ Statens Serum Institute, Artillerivej 5, 2300 Copenhagen S, Denmark

⁷ National HIV Programme, Ministry of Health (Ministerio da saude), Bissau, Guinea-Bissau

⁸ Center for Global Health, Faculty of Health Sciences, University of Southern Denmark, J.B. Winsløvs Vej 9B, 5000, Odense C, Denmark

⁹ GloHAU, Center for Global Health, School of Public Health, Aarhus University, Bartholins Allé 2, 8000 Aarhus C, Denmark

*Corresponding author, email: drasmussen@health.sdu.dk

Adherence is a decisive factor in achieving a successful response to antiretroviral therapy (ART) for HIV infection. No previous studies have been conducted regarding HIV treatment adherence in Guinea-Bissau. In this study we assessed barriers and facilitators to patient ART adherence. Semi-structured interviews were conducted with 20 adult, HIV infected individuals receiving ART at a HIV treatment centre in Bissau, Guinea-Bissau. The grounded theory method was used to gather and analyse data. Results indicated that HIV-related knowledge was a determining factor for optimal adherence. The facilitators were experienced treatment benefits and complementing social networks. The barriers were treatment-related costs and competing livelihood needs; poor clinic infrastructure; perceived stigma; and traditional practices. Our findings indicate that good ART adherence, especially in resource-limited settings, requires that patients achieve adequate HIV-related knowledge. More studies on HIV-related knowledge and adherence among HIV infected individuals are currently needed.

Keywords: Africa, ART, compliance, grounded theory, HIV/AIDS, HIV-related knowledge, qualitative research

Introduction

Non-adherence is a significant barrier to using antiretroviral therapy (ART) in Africa (Harries et al. 2008). Side effects to treatment; complex drug therapy regimens; patient-related factors such as alcohol abuse and lack of social support; are common barriers to ART adherence in both developed and developing countries (Mills et al. 2006a, Oliveira et al. 2010). In sub-Saharan Africa, difficulties also include fear of stigmatisation; the need to travel long distances to receive treatment; poor documentation of treatment and lack of access to correct information (Unge et al. 2009; Kagee 2011). In addition, severe poverty and food insecurity aggravate cost-related barriers to adherence such as transport expenditure, registration and user fees at the private health facilities, and lost wages due to long waiting times (Hardon et al. 2007, Yu et al. 2007).

Early studies on adherence to HIV treatment in Africa have shown promising results with adherence levels equivalent to or exceeding those seen in Europe and the

United States (Weiser et al. 2003, Mills et al. 2006b). Yet, sub-optimal levels of adherence in Africa have also been reported (Rosen et al. 2007, Wakabi, 2008). Several studies have shown that adherence rates decrease significantly over time (Godin et al. 2005, Lima et al. 2009).

Low adherence levels in Africa could threaten current and future ART programme. It is therefore crucial to address the factors leading to non-adherence and target the available resources accordingly (Jaffar et al. 2008).

Guinea-Bissau is a West African country situated between Senegal, Guinea Conakry and the Atlantic Ocean. In 2010 the population was estimated at 1.6 million people; the nation is currently ranked among the 10 poorest countries in the world (UNDP 2011; US Department of State 2012). The HIV epidemic in Guinea-Bissau has changed drastically over the past 20 years. The country has had the highest prevalence of HIV-2 in West Africa for many years, while HIV-1 was absent only two decades ago (Poulsen et al. 1992, Poulsen et al. 1993, Wilkins et al. 1993, Larsen et al. 1998). In rural Guinea-Bissau, the HIV-1 prevalence

rose from 0.5% in 1990, to 3.6% in 2007; HIV-2 decreased from 8.3% to 4.7% in the same period (Tienen et al. 2010). The same trend has been observed repeatedly in studies conducted in urban Guinea-Bissau (Da Silva et al. 2008, Mansson et al. 2009). In 2009 UNAIDS estimated that 2.5% of the adult population was infected with HIV (UNAIDS/WHO 2009). Current data show that the estimated prevalence has reached a new peak of 5.8% (INASA 2011). This prevalence is worryingly high compared to that of neighbouring countries such as Senegal and Guinea-Conakry which both have HIV prevalence's estimated at 2% or lower (UNAIDS, 2010). Guinea-Bissau has a prevalence that may reach the levels of the most affected countries in sub-Saharan Africa. Research aiming to understand and address the HIV epidemic in Guinea-Bissau is therefore urgently warranted.

The National HIV Programme was first implemented by the Guinean Ministry of Health in 2005. ART has since been available in the country thanks to the sponsorship of the drugs by Global Fund and the Brazilian Government. At the end of 2009 the country had 26 ART centres with more than 7,000 patients on follow-up and 2,764 people receiving treatment (UNGASS 2010). All treatment is free of charge in the country, but drug supply has been inconsistent (Oliveira et al. 2010).

Despite numerous studies investigating and describing causes of non-adherence, few qualitative studies on ART adherence have been conducted in resource poor countries (Mills et al. 2006a). To the best of our knowledge, no reports of previous studies are available on ART adherence in Guinea-Bissau. The scope of this study was to examine and conceptualise barriers and facilitators to adherence among people undergoing ART.

Methods

This study was conducted from August to December 2009. For data collection and analysis, we chose a grounded theory design, aimed at generating theory rather than mere description (Glaser and Strauss 1967). Grounded theory encompasses a specific methodology on how to get from systematic data collection to producing a multivariate conceptual theory. It provides a series of systematic, exact methods that start with collecting data and guides the researcher through the analytical process. The theory considers cultural diversity, making it an appropriate method for this study. The aim of grounded theory is to generate concepts, a model or a substantive theory which is complete, coherent and sheds light on the area under study rather than testing hypotheses based on existing theory. The analysis generates codes, categories and concepts, in which the substantive code is the most concrete level and the core category the most abstract (Glaser and Strauss 1967, Glaser and Holton 2007).

Study participants and setting

We conducted 20 semi-structured interviews with HIV patients on ART. Patients were recruited by purposive sampling at the Simão Mendes HIV Treatment Center in Bissau, Guinea-Bissau. In December 2009 this study site had 1 313 HIV patients in follow-up, of whom 62%

(812 patients) were using ART. The health care providers (HCPs), at the centre, were asked to identify and recruit relevant adherent and non-adherent men and women, aged between 15 and 65 years, undergoing ART for more than one month. The degree of adherence was assessed during drug administration based on pill counts, self report and clinic attendance. Patients were given an exact number of pills for either one or two months with an extra of three pills in case clinical visits were delayed. Pill count adherence was calculated as the absolute value of the number of pills the patient took divided by the number of pills that should have been taken since the last prescription refill. Seven pills or below the correct amount to be taken was considered adherent. Clinical visits and scheduled visits were also recorded in patient journals. Patients who failed to visit the clinic before prescriptions ran out were categorised as non adherent. Patients agreeing to participate gave informed consent before being introduced to the researcher. The sample ($n = 20$) comprised 45% men and 55% women. Of the participants, 25% were single, 50% were married and 25% were divorced, separated or widowed. The median age was 44 years for men and 33 years for women. Period of time on ART ranged from 1 to 48 months with a median of 18 months for men and 22 months for women.

Data collection

Data were collected using open, semi-structured interviews with each patient. The intention was to uncover the interviewees' perspectives in-depth, with interviews lasting 1–1½ hours. The questions were open-ended, however, an interview guide was used to cover fixed themes such as: patient's perception and knowledge of HIV/AIDS; information received about ART; perceived barriers and facilitators to ART; and experiences before and after starting ART. In addition, notes and memos were written after each interview. Often, the patient's own words were used to confirm that the identified words or phrases were really grounded in the data, rather than being generated from an implicit hypothesis or from the researcher's preconceptions.

Data analysis

Digital audio recordings of the interviews were transcribed verbatim by a Kriol-English interpreter present during each interview. The interviews were entered into the NVIVO 2.1 computer program (NVivo2 2002), which helped structure and manage the data. The analytic process included open, selective, and theoretical coding. In the open coding process, the transcripts were inductively analysed line by line, and several codes were developed to assess the data. Subsequently, the open codes were clustered into categories. After an analysis of the first eight interviews, the core category 'HIV-related knowledge' emerged as a main concern, which was ethnographically faithful and enduring beyond the single participants. Once the core category was generated, the sampling became selective in line with this category. Sub-categories and their properties were developed using further data collection (12 interviews) and a constant comparison of the data as a whole. In the theoretical phase of the analysis, the relationships between the core category and its sub-categories were determined and described. The process continued until no new

properties emerged and theoretical saturation was reached. In accordance with the grounded theory method (Glaser and Strauss 1967), memos were written during the entire analytical process to record ideas about emerging categories and assumptions about their relationships. The main analysis was done by the primary investigator (PI) with continuous review from all co-authors.

Data credibility

Interviews were conducted in Guinea-Bissau's local language, *Kriol* (a Portuguese-based Creole, the lingua franca), by the PI, who is not a native *Kriol* speaker, with assistance from a native interpreter. The interpreter was present during all interviews, ensuring that questions were worded correctly and that any questions or answers not understood by the interviewee or interviewer could be clarified. To strengthen validation, the PI and the interpreter discussed and compared notes after each interview (Kvale and Brinkmann 2009). All interview recordings were transcribed into *Kriol* and subsequently translated into English by a professional interpreter. The PI and interpreter compared all transcripts with the MP3 audio recordings to ensure key points and vital data were not lost in translation. The process of data collection and analysis is illustrated in (Figure 1).

Ethical issues and approval

Potential participants were recruited by an adherence nurse during either prescription refill or consultations. After written consent was obtained, patient names and data were given to the researcher. Participants were informed that all data would remain confidential, and that declining to participate in the study would in no way affect their access to treatment. The study was approved by the Guinean Ethics Committee in November 2008.

Results

After an analysis of eight interviews the core category HIV-related knowledge emerged. Alongside this core category, five additional subcategories were uncovered. Data saturation was obtained after 16 interviews; the final 4 interviews did not present any new information, rather, they strengthened the core category of the theory. In the following sections we present the core category followed by the sub-categories.

HIV-related knowledge

The findings indicate that *HIV-related knowledge, a form of health literacy* was the most important factor influencing patient adherence. The term refers to having appropriate information and knowledge about HIV and understanding that ART is a lifelong treatment demanding good adherence. HIV-related knowledge can either be a barrier if knowledge is limited or a facilitator, depending on a patients' understanding of the favourable effects of HIV treatment and the harmful consequences of non-adherence. Even very basic HIV-related knowledge is sufficient to help patients adhere to treatment. One patient revealed:

'I don't know anything about this disease [HIV]. I only know how to take medicine as the Doctor says. If you don't take it as the Doctor tells you, after a while you will feel it [HIV] tires you. But if you take it as they told you, it [HIV] will not makes you sick. It's like they said, this disease is sleeping, it will not go away. It [the HIV virus] cannot die, but the medicine makes it sleep. The medicine can make you live for many years. I really feel good with this treatment. I am going to complete two years on treatment soon' (man, age 29).

HIV-related knowledge was a key product of patient-reported facilitators and provided an important instrument against barriers associated with poverty, stigma and

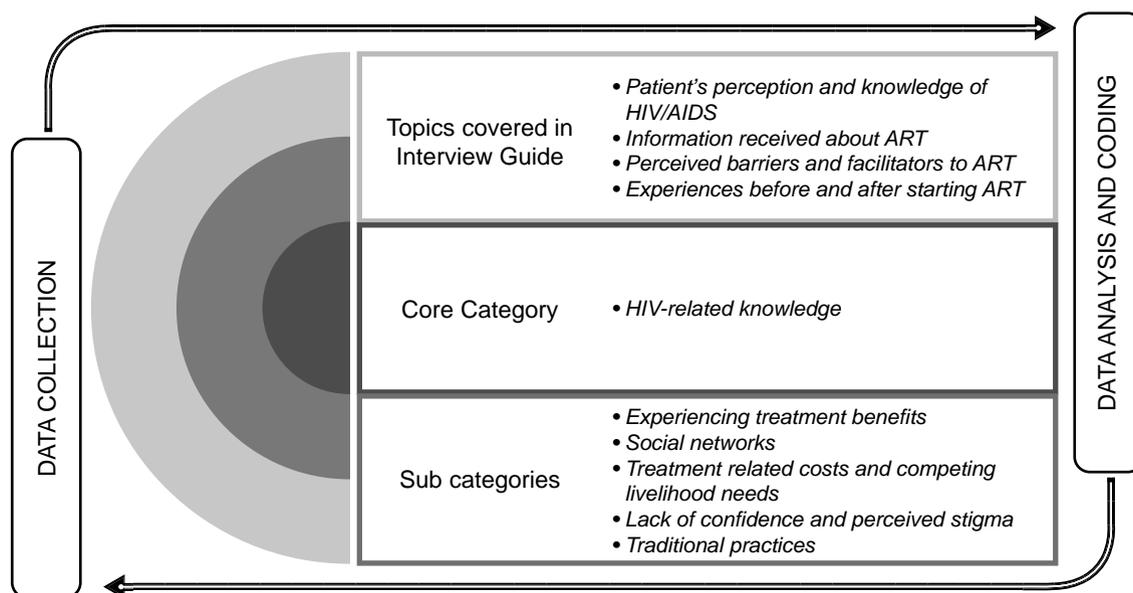


Figure 1. Data collection and analysis. A continuous process of data collection and analysis leads to the emergence of the core category and sub categories

culture. Patients who demonstrated appropriate HIV-related knowledge underlined the importance of taking medication at the designated hour as well as timely renewal of prescriptions. These patients were also better at obtaining and utilising social support. Some patients, who demonstrated insufficient HIV-related knowledge, were often affected by traditional beliefs, myths and fallacies about HIV. One patient was convinced that HIV was not contagious and that she had contracted the virus by walking past an evil spirit:

'No it [HIV] doesn't transmit. If it could transmit my aunt would have been transmitted, she sleeps beside me on the bed during the night. It doesn't transmit. They said that it comes from a spirit. They say that if you pass where he [the spirit] is or has been the same spirit will make you sick. Look, the children [patient's children], when they eat my food, it [HIV] doesn't catch them. I went for a walk in the forest where he [the spirit] had passed that is how the spirit got me' (woman, age 42).

Lack of general HIV-related knowledge made it difficult for patients to comprehend the implications of having a chronic illness. This strongly contributed to non-adherence. One patient who had stopped treatment explained:

'There was a time I stopped taking it [HIV medication]. It was the time of the junjun [Ramadan fast]. My body got weak during the time and it was hot' (man, age 44).

Our findings suggest that most patients knew that HIV was a serious disease, but had difficulty explaining why it made them sick or why it was a potentially fatal disease. Many patients had not known what HIV was until they had been diagnosed. One patient explained:

'Before, I never believed HIV existed. I used to say no, it is just people talking. But after that day, when I came to do the test, I was sure' (woman, age 27).

None of our study participants could name the pills they took. They had difficulty differentiating between pills because of illiteracy and because almost all the generic ART drug bottles looked similar. Some participants were unsure whether discontinuing treatment was harmful. A patient who had been in treatment for two years asked about stopping:

'This treatment that brings me here, can I never stop taking it?' (woman, age 56)

Despite being on treatment for a long period of time, some patients had not understood that HIV demanded lifelong treatment.

Facilitators to treatment adherence

Experienced treatment benefits

Experiencing improved health after starting treatment was reported as a strong motivator for patients to adhere to ART. Those experiencing health improvements reported that ART provided them with the strength to work, support their family and increased their overall quality of life:

'In my case, if I didn't take this medicine, I would be in a different world now. In the beginning when I started to come here, they had to carry me. I was unable to walk by myself, but now I walk, I play football, I feel well and I feel I'm gaining weight' (male, age 29).

Many patients reported gaining weight as an important motivator for taking ART because it lessened worries about being stigmatised. One female patient explained:

'After I started taking medicine I started feeling balanced [healthy], now all I want is to gain weight and get fat... you see in Bissau a person can have HIV but if he/she is fat people will say no it's not possible. But if you are skinny people will suspect you. Sometimes I am afraid of going out. People ask what's wrong with you. What's got you?' (woman, age 27)

Furthermore, patients explained that the fear of returning to a poor physical state or, even worse, death, strongly motivated them to adhere.

Complementing social networks

Patients reported a good and confidential relationship with HCPs as a motivator to adherence. Those who were followed closely by their physician or nurse also stated that HCPs acted as confidants and were their primary source of encouragement, comfort and counselling. Patients also reported support from family and friends as an essential component. Surprisingly, very few of the patients interviewed had disclosed their HIV status to their social network. Nevertheless, friends and family members indirectly provided support by helping patients overcome certain daily challenges such as getting food and money for transport. One patient explained his method of getting by:

'We go visit our friends. They might give us 1000 FCFA (2 USD), something small... If I come to visit you and we talk. When we finish talking, you might give me money to pay for transport home. I'll save that money and go on foot, because I know how the situation is at my house' (male, age 37).

Another patient said:

'I don't have a husband, my husband died. That's why I went back to my father's house. My mother gives us food, if she didn't give us we [patient and her children] would not eat. That's why I went back' (widow, 42).

Barriers to treatment adherence

Treatment related costs and competing livelihood needs

The impact of poverty (e.g. food insecurity, and limited funds for transportation and non-ART medications), emerged as an important barrier to adherence. Patients reported difficulties taking ART on empty stomachs; some would postpone medication until they succeeded in getting food, convinced that ART could not be taken otherwise. Others explained that they would skip doses if they were unable to find something to eat because they felt that antiretrovirals 'tired them' and lead to general discomfort and increased hunger:

'If I haven't had breakfast I don't take it [medication] in the morning. I only take it at lunch time when I am full. It's like that. If I don't eat I can't take it [medication]' (man, age 29).

Lack of money for transport also contributed to non-adherence. Patients described how they had to divert already limited funds to more pressing necessities, such as food and other non-ART medication, and how they often

had to delay renewal of prescriptions by several days. One patient explained:

'Today I gathered all my strength to come, because of this crutch, to come from my house to the street, it's far. We live close to Sao Paulo [suburb of Bissau], but I woke up at 5 o'clock in the morning. I spent an hour and ten minutes getting here. I walk step by step. When I got to the bus stop I told them that I only had 1.000 FCFA [2 USD]. I didn't have enough money because I used it to make juice yesterday evening. I had lost my appetite and could not eat anything. They let me on the bus. Now I'm thinking, how I will get back' (man, age 50).

Poor clinic infrastructure and perceived stigma

Many patients reported the lack of confidentiality during clinical visits as a barrier to adherence. This is because counselling and consultations often took place in open rooms in the presence of other frustrated patients. Many therefore found it difficult to speak openly, as they were worried that peers would judge or expose their current condition.

Patients described difficulties disclosing their HIV status to their immediate circles. Most patients had only disclosed their condition to one or two people, and very few had disclosed their HIV status to their partners. None of the study participants had disclosed their status to their local communities. Patients explained that generally, people believed HIV was contracted from association with behaviours considered deviant or promiscuous. Nearly all patients anticipated negative outcomes associated with disclosure:

'It's like people don't treat patients like humans, as they should. If you are sick, you will realise that they run from you [abandon you] or avoid you. If you have a problem they will throw you out even if they have the same problem. So you worry about these things and that causes you to keep things secret' (man, age 44).

Almost all patients reported hiding their medication because they were afraid of losing their support network if their HIV status was discovered.

Traditional practices

According to patients, family elders and tradition played a large role in decision making regarding healthcare. One patient stated:

'In Guinea-Bissau, we have many tribes and each tribe has their traditions. [For] anything like this [HIV], the sick person first prefers to go do their traditions' (man, age 37).

This traditional conviction reportedly pressured some patients to stop biomedical treatment in exchange for traditional medicine. A newly diagnosed patient explained how a friend had encouraged use of traditional medicine as a cure for HIV:

'She [patient's friend] said her aunt had had it [HIV], she took traditional medicine, she re-did the test [HIV test] and it was negative' (woman, age 19).

Other patients reported that there were traditional explanations for HIV and HIV symptoms. One patient revealed:

'He [family elder] said; this illness, which is doing this to my body, is bajudesa [traditional belief that the careless behaviour during youth can cause certain diseases]. You see, we Balanta [ethnic group] have a saying: the washing of the virgins [a ceremony]. If you have sex with a virgin, she gets pregnant and gives birth without her having done this ceremony, that's how you get this disease [HIV]' (man, age 39).

According to the same patient some tribal elders advised traditional rituals as curative treatment for HIV:

'Many of them [patients], like me, have older family members, uncles. I have an uncle; he told me they [traditional healers] have a medicine which you put in water or if you're going to eat, you spread it over your food... He said I should go there [to the traditional healer] to take the medicine. He said I should stop the hospital treatment and go there. I said I would go, because he is an elder. To sit and talk to him and explain everything so that he would understand, that is difficult. I said I would go, but I never went' (man, age 39).

Nearly all participants were familiar with traditional medicine and many had earlier experiences with its use. Only one patient responded she had taken traditional medicine specifically to treat HIV. Nevertheless, patients disagreed about whether traditional medicine could cure HIV.

Discussion

Our results show that health literacy (Sorensen et al. 2012) in the form of HIV-related knowledge was a central concept regarding patient adherence. The results also underline the importance of gaining an increased understanding of the relationship between HIV-related knowledge and ART adherence.

In line with other studies, our findings emphasise the importance of ensuring appropriate HIV-related knowledge (Kumarasamy et al. 2005; Anuradha et al. 2013). Poor HIV-related knowledge is a structural barrier which, to a large extent, is a consequence of living in a resource-constrained environment (Kagee and Delpoit 2010). Guinea-Bissau is one of the poorest countries in the world. The adult literacy rate in the country is estimated to be 52% (World Bank 2012). Studies have demonstrated that low levels of literacy and poor information about ART negatively affect adherence (Mills et al. 2006a, Trzynka and Erlen 2004).

Knowledge of medication instructions is a precondition for adherence. Furthermore, HIV-related knowledge may also promote the development of adherence related skills and increase motivation (Weiss et al. 2003). Poor HIV-related knowledge is a potentially modifiable barrier to adherence. More focus on intensifying counselling services by HCPs could equip patients with the necessary knowledge to cope with the physical, financial and social barriers to adherence. Our findings support those from other studies that advocate for the design of ART adherence interventions tailored to lower-literacy populations (Kalichman et al. 2008). Simple, low cost counselling tools such as pictorials and the use of culturally modified metaphors may help to increase patient

HIV-related knowledge and thereby overall adherence.

Social relationships are principle mediators to sustaining adherence in sub-Saharan Africa (Edwards 2006, Ware et al. 2009). Our study found that some patients were able to access support from their family and friends, thereby obtaining better help, despite hiding their HIV-status. This is contrary to results from other studies that suggest disclosure is imperative for achieving social support (Coetzee et al. 2011). Despite this finding our study suggests increasing disclosure may help patients to access more social capital. Nevertheless, this may first be possible if stigma in the general population decreases.

Antiretrovirals are free of charge in many places in Africa, including Guinea-Bissau, but treatment-related expenses still hinder patients' access to treatment (Tuller et al. 2010, Badahdah and Pedersen 2011). Our findings are in concordance with those from other studies which have found that lack of food due to poverty is a common obstacle to patients taking their treatment (Nachega et al. 2006, Hardon et al. 2007, Sanjobo et al. 2008, Kagee and Delpont 2010, Weiser et al. 2010). In addition, our study showed patients would skip or delay medication if they had not eaten. Poor HIV-related knowledge coupled with financial constraints might complicate a patient's ability to access a steady ART supply because they risk prioritising erroneously, thereby opting against their lifesaving medication.

Informants in our study described poor clinical infrastructure, with insufficient facilities for conducting confidential consultations, prevented patients from communicating openly with HCPs. Insufficient counselling could facilitate misunderstandings about taking ART, leading to lower adherence. Studies from Botswana and Senegal have suggested that HIV patients tended to reduce clinical visits because of the risk of being seen by others and potentially having their HIV status exposed (Laniece et al. 2003, Weiser et al. 2003). Creating infrastructure that is more agreeable to patient confidentiality is imperative.

Perceived stigma, due to a general lack of knowledge in the public sphere about HIV, appeared to be considerable as it resulted in patients fearing disclosure. A national survey from Guinea-Bissau showed that approximately 30% would reportedly leave their partner and 59% would abandon a relative if he or she was infected with HIV (Bandim Health Project et al. 2009). In many African countries HIV-related stigma and discrimination is highly prevalent leading to lower rates of disclosure (Greeff et al. 2008). However, if discrimination is low, it appears disclosure will have more advantages, such as obtaining social support and increased empowerment (Sandelowski et al. 2004). Interventions targeting communities have been shown to increase acceptability of HIV-infected individuals and further reduce discriminatory attitudes (Brown et al. 2003, Babalola et al. 2009). Greater efforts to improve social awareness in the general public could lessen societal stigma, thereby reducing difficulties associated with disclosure and increasing adherence among HIV-infected people.

Our study indicates that traditional treatment is a worrying antagonist to biomedical therapy. Traditional treatment is appealing because it is easily accessible, cheap, and often guarantees a cure in contrast to biomedical medicine. A study from South Africa found that traditional

healers occasionally advise patients to stop ART (Dahab et al. 2008). In addition, Coetzee et al. (2011) reported some charismatic churches encouraging the discontinuation of treatment (Coetzee et al. 2011). Our findings suggest that family and tribal elders also play a central role in decision making regarding treatment for HIV. If elders favour traditional practices their counselling might have a negative effect on patients adhering to biomedical treatment. Traditional, religious and social discouragers may be underexplored causes of non-adherence which must be investigated and addressed when commencing ART in countries such as Guinea-Bissau. HCPs must achieve a deeper understanding and clarification of ways to counsel patients on the use of traditional medicine and on how to tackle influence exerted by family, religious and tribal leaders.

The results of this study should be interpreted in the light of several important limitations. Firstly, these findings are context-specific and might not be generalisable to other settings, although the concepts may be able to shed light on problems in other African countries. Secondly, patients were recruited using purposive sampling from one outpatient clinic, primarily treating patients from an urban community in Bissau, Guinea-Bissau. The sample might not be representative of all HIV-patients in our study population. The presence and conducting of interviews by a foreign interviewer might have had an effect on participant openness.

Conclusion

This is the first study conducted regarding HIV and adherence in Guinea-Bissau. It shows that barriers to adherence in Guinea-Bissau are similar to those in other African countries. Nevertheless, this study also demonstrates that HIV-related knowledge is a determining factor for ART adherence which should not be forgotten in the race to achieve 'universal access'. Our findings indicate that greater efforts are needed to educate HIV patients sufficiently about HIV, ART and lifelong treatment. More targeted research on ART adherence and HIV-related knowledge in Guinea-Bissau is needed. We are therefore currently conducting a larger quantitative study which will shed further light on the barriers and facilitators to ART adherence.

Acknowledgements — This study was made possible through grants from the following: FI (the Danish Agency for Science, Technology and Innovation), ENRECA Health (the Danish Research Network for International Health), the Department of Infectious Diseases at Odense University Hospital and the Danish International Development Assistance (DANIDA).

We express our gratitude to all patients and research assistants at the Bandim Health Project for their invaluable contributions to this study. We also thank the Ministry of Health in Guinea-Bissau for supporting and facilitating our work.

The authors — Dlama Rasmussen, MD, is a research assistant at the Center for Global Health, University of Southern Denmark in Odense, Denmark.

David da Silva Té, MD, is a PhD student and the leading consultant for the national HIV programme in Guinea-Bissau.

Lotte Rodkjaer, MPH, PhD, is a research nurse at the University of Aarhus in Denmark.

Inés Oliveira, PhD, MSc, MD, is a senior associate in infectious diseases at the Hospital Clinic in Barcelona, Spain.

Candida Medina, MD, is the head of the outpatient ART Centre at the National Simão Mendes Hospital in Guinea-Bissau.

Toke Barfod, PhD, MD, is a senior consultant in infectious diseases at Roskilde Hospital, Denmark.

Alex Lund Laursen, PhD, DMSc, MD, is a senior consultant in infectious diseases at Aarhus University Hospital, Denmark.

Peter Aaby, Mag. scient, PhD, DMSc, is a professor and the founder and head of the Bandim Health Project research institution.

Morten Sodemann, PhD, MD, is a professor at the Department of Infectious Diseases, Odense University Hospital, and the Center for Global Health, University of Southern Denmark.

Christian Wejse, PhD, MD, is an associate professor at the Center for Global Health, Aarhus University, Denmark.

References

- Anuradha S, Joshi A, Negi M, Nischal N, Rajeshwari K, Dewan R. 2013. Factors influencing adherence to ART: New insights from a center providing free ART under the national program in Delhi, India. *Journal of the International Association of Providers of AIDS Care* 12: 195–201.
- Babalola S, Fatusi A, Anyanti J. 2009. Media saturation, communication exposure and HIV stigma in Nigeria. *Social Science & Medicine* 68: 1513–1520.
- Badahdah AM, Pedersen DE. 2011. I want to stand on my own legs: A qualitative study of antiretroviral therapy adherence among HIV-positive women in Egypt. *AIDS Care* 23: 700–704.
- Bandim Health Project, Secretriado Nacional de Luta Contra a SIDA, UNFPA (United Nations Population Fund). 2009. Inquérito sobre Cohecimentos, Atitudes e Prática em Matéria de Saúde Reprodutiva, IST e VIH/SIDA. Bissau, Guinea-Bissau, SNLS.
- Brown L, Macintyre K, Trujillo L. 2003. Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention* 15: 49–69.
- Coetzee B, Kagee A, Vermeulen N. 2011. Structural barriers to adherence to antiretroviral therapy in a resource-constrained setting: the perspectives of health care providers. *AIDS Care* 23: 146–151.
- Da Silva ZJ, Oliveira I, Andersen A, Dias F, Rodrigues A, Holmgren B, Andersson S, Aaby P. 2008. Changes in prevalence and incidence of HIV-1, HIV-2 and dual infections in urban areas of Bissau, Guinea-Bissau: Is HIV-2 disappearing? *AIDS* 22: 1195–1202.
- Dahab M, Charalambous S, Hamilton R, Fielding K, Kielmann K, Churchyard GJ, Grant AD. 2008. That is why I stopped the ART: Patients' & providers' perspectives on barriers to and enablers of HIV treatment adherence in a South African workplace programme. *BMC Public Health* 8: 63.
- Edwards LV. 2006. Perceived social support and HIV/AIDS medication adherence among African American women. *Qualitative Health Research* 16: 679–691.
- Glaser BG, Holton J. 2007. Remodeling grounded theory. *Historical Social Research/Historische Sozialforschung* 19: S47–S68.
- Glaser BG, Strauss AL. 1967. *The discovery of grounded theory: strategies for qualitative research*. New York, New York: Aldine Publishing Company.
- Godin G, Cote J, Naccache H, Lambert LD, Trottier S. 2005. Prediction of adherence to antiretroviral therapy: a one-year longitudinal study. *AIDS Care* 17: 493–504.
- Greeff M, Phetlhu R, Makoae LN, Dlamini PS, Holzemer WL, Naidoo JR, Kohi TW, Uys LR, Chirwa ML. 2008. Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative Health Research* 18: 311–324.
- Hardon AP, Akurut D, Comoro C, Ekezie C, Irunde HF, Gerrits T, Kglatwane J, Kinsman J, Kwasa R, Maridadi J, Moroka TM, Moyo S, Nakiyemba A, Nsimba S, Ogenyi R, Oyabba T, Temu F, Laing R. 2007. Hunger, waiting time and transport costs: time to confront challenges to ART adherence in Africa. *AIDS Care* 19: 658–665.
- Harries AD, Makombe SD, Schouten EJ, Ben-Smith A, Jahn A. 2008. Different delivery models for antiretroviral therapy in sub-Saharan Africa in the context of 'universal access'. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 102: 310–311.
- INASA (Instituto Nacional de Saude). 2011. *Prevalência de VIH na comunidade na Guiné-Bissau—Relatório final do inquerito Nacional 2010*. Bissau, Guinea-Bissau: Instituto Nacional de Saude Pública de Guiné-Bissau.
- Jaffar S, Munderi P, Grosskurth H. 2008. Adherence to antiretroviral therapy in Africa: how high is it really? *Tropical Medicine & International Health* 13: 1096–1097.
- Kagee A, Delport T. 2010. Barriers to adherence to antiretroviral treatment: the perspectives of patient advocates. *Journal of Health Psychology* 15: 1001–1011.
- Kagee A, Remien RH, Berkman A, Hoffman S, Campos L, Swartz L. 2011. Structural barriers to ART adherence in Southern Africa: Challenges and potential ways forward. *Global Public Health* 6: 83–97.
- Kalichman SC, Pope H, White D, Cherry C, Amaral CM, Swetzes C, Flanagan J, Kalichman MO. 2008. Association between health literacy and HIV treatment adherence: further evidence from objectively measured medication adherence. *Journal of the International Association of Providers of AIDS Care* 7: 317–323.
- Kumarasamy N, Safren SA, Raminani SR, Pickard R, James R, Krishnan AK, Solomon S, Mayer KH. 2005. Barriers and facilitators to antiretroviral medication adherence among patients with HIV in Chennai, India: A qualitative study. *AIDS Patient Care and STDs* 19: 526–537.
- Kvale S, Brinkmann S. 2009. *Interviews: Learning the craft of qualitative research interviewing* (2nd edn). Los Angeles, California: Sage.
- Laniece I, Ciss M, Desclaux A, Diop K, Mbodj F, Ndiaye B, Sylla O, Delaporte E, Ndoye I. 2003. Adherence to HAART and its principal determinants in a cohort of Senegalese adults. *AIDS* 17: S103–S108.
- Larsen O, da, SZ, Sandstrom A, Andersen PK, Andersson S, Poulsen AG, Melbye M, Dias F, Naucler A, Aaby P. 1998. Declining HIV-2 prevalence and incidence among men in a community study from Guinea-Bissau. *AIDS* 12: 1707–1714.
- Lima VD, Harrigan R, Bangsberg DR, Hogg RS, Gross R, Yip B, Montaner JS. 2009. The combined effect of modern highly active antiretroviral therapy regimens and adherence on mortality over time. *Journal of Acquired Immune Deficiency Syndromes* 50: 529–536.
- Mansson F, Biague A, Da Silva ZJ, Dias F, Nilsson LA, Andersson S, Fenyo EM, Norrgren H. 2009. Prevalence and incidence of HIV-1 and HIV-2 before, during and after a civil war in an occupational cohort in Guinea-Bissau, West Africa. *AIDS* 23: 1575–1582.
- Mills EJ, Nachega JB, Buchan I, Orbinski J, Attaran A, Singh S, Rachlis B, Wu P, Cooper C. 2006a. Adherence to HAART: A systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Medicine* 3: e438.
- Mills EJ, Nachega JB, Buchan I, Orbinski J, Attaran A, Singh S, Rachlis B, Wu P, Cooper C, Thabane L, Wilson K, Guyatt GH, Bangsberg DR. 2006b. Adherence to antiretroviral therapy in sub-Saharan Africa and North America: A meta-analysis. *Journal of the American Medical Association* 296: 679–690.
- Nachega JB, Knowlton AR, Deluca A, Schoeman JH, Watkinson L, Efron A, Chaisson RE, Maartens G. 2006. Treatment supporter to improve adherence to antiretroviral therapy in HIV-infected

- South African adults. A qualitative study. *Journal of Acquired Immune Deficiency Syndromes* 43: S127–S133.
- NVivo2. 2002. NVivo qualitative data analysis program. Version 2. Doncaster, Victoria, QSR International Pty Ltd.
- Oliveira I, Jensen-Fangel S, da, SD, Ndumba A, Medina C, Nanadje A, Rasmussen DN, Rudolf F, Wejse C, da Silva ZJ, Sodemann M, Laursen AL. 2010. Epidemic Stevens-Johnson syndrome in HIV patients in Guinea-Bissau: A side effect of the drug-supply policy?. *AIDS* 24: 783–785.
- Poulsen AG, Kvinesdal BB, Aaby P, Lisse IM, Gottschau A, Molbak K, Dias F, Lauritzen E. 1992. Lack of evidence of vertical transmission of human immunodeficiency virus type 2 in a sample of the general population in Bissau. *Journal of Acquired Immune Deficiency Syndromes* 5: 25–30.
- Poulsen AG, Aaby P, Gottschau A, Kvinesdal BB, Dias F, Molbak K, Lauritzen E. 1993. HIV-2 infection in Bissau, West Africa, 1987–1989: Incidence, prevalences, and routes of transmission. *Journal of Acquired Immune Deficiency Syndromes* 6: 941–948.
- Rosen S, Fox MP, Gill CJ. 2007. Patient retention in antiretroviral therapy programs in sub-Saharan Africa: A systematic review. *PLoS Medicine* 4: e298.
- Sandelowski M, Lambe C, Barroso J. 2004. Stigma in HIV-positive women. *Journal of Nursing Scholarship* 36: 122–128.
- Sanjoko N, Frich JC, Fretheim A. 2008. Barriers and facilitators to patients' adherence to antiretroviral treatment in Zambia: A qualitative study. *SAHARA-J: Journal of Social Aspects of HIV/AIDS* 5: 136–143.
- Sorensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, Brand H. 2012. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health* 12: 80.
- Tienen Cv, van der Loeff MS, Zaman SM, Vincent T, Sarge-Njie R, Peterson I, Leligdowicz A, Jaye A, Rowland-Jones S, Aaby P, Whittle H. 2010. Two distinct epidemics: The rise of HIV-1 and decline of HIV-2 infection between 1990 and 2007 in rural Guinea-Bissau. *Journal of Acquired Immune Deficiency Syndromes* 53: 640–647.
- Trzynka SL, Erlen JA. 2004. HIV disease susceptibility in women and the barriers to adherence. *MEDSURG Nursing* 13: 97–104.
- Tuller DM, Bangsberg DR, Senkungu J, Ware NC, Emeryonu N, Weiser SD. 2010. Transportation costs impede sustained adherence and access to HAART in a clinic population in southwestern Uganda: A qualitative study. *AIDS and Behavior* 14: 778–784.
- UNAIDS (the Joint United Nations Programme on HIV/AIDS). 2010. *2010 Report on the global AIDS epidemic*. Geneva: UNAIDS.
- UNAIDS/WHO (the Joint United Nations Programme on HIV/AIDS/World Health Organization). 2009. Epidemiological fact sheet on HIV/AIDS and sexually transmitted infections, 2009 Update. Guinea-Bissau. UNAIDS, Geneva.
- UNDP (United Nations Development Programme) 2011. Guinea-Bissau country profile: Human development indicators. Available at <http://hdrstats.undp.org/en/countries/profiles/GNB.html> [accessed 20 March 2012].
- UNGASS (United Nations General Assembly Special Session). 2010. *Suivi de la Déclaration d'engagement sur le VIH/sida. Session extraordinaire de l'Assemblée générale des Nations Unies sur le VIH/sida. Rapport sur la période 2008–2009*. Geneva: UNGASS.
- Unge C, Sodergard B, Ekstrom AM, Carter J, Waweru M, Ilako F, Ragnarsson A, Thorson A. 2009. Challenges for scaling up ART in a resource-limited setting: a retrospective study in Kibera, Kenya. *Journal of Acquired Immune Deficiency Syndromes* 50: 397–402.
- US Department of State. 2012. Background note: Guinea-Bissau. Available at <http://www.state.gov/r/pa/ei/bgn/5454.htm> [accessed 20 March 2012].
- Wakabi W. 2008. Low ART adherence in Africa. *The Lancet Infectious Diseases* 8: 94.
- Ware NC, Idoko J, Kaaya S, Biraro IA, Wyatt MA, Agbaji O, Chalamilla G, Bangsberg DR. 2009. Explaining adherence success in sub-Saharan Africa: An ethnographic study. *PLoS Medicine* 6: e11.
- Weiser S, Wolfe W, Bangsberg D, Thior I, Gilbert P, Makhema J, Kebaabetswe P, Dickenson D, Mompati K, Essex M, Marlink R. 2003. Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *Journal of Acquired Immune Deficiency Syndromes* 34: 281–288.
- Weiser SD, Tuller DM, Frongillo EA, Senkungu J, Mukiibi N, Bangsberg DR. 2010. Food insecurity as a barrier to sustained antiretroviral therapy adherence in Uganda. *PLoS One* 5: e10340.
- Weiss L, French T, Finkelstein R, Waters M, Mukherjee R, Agins B. 2003. HIV-related knowledge and adherence to HAART. *AIDS Care* 15: 673–679.
- Wilkins A, Ricard D, Todd J, Whittle H, Dias F, Paulo Da SA. 1993. The epidemiology of HIV infection in a rural area of Guinea-Bissau. *AIDS* 7: 1119–1122.
- World Bank. 2012. Education—Literacy rate, adult total (% of people ages 15 and above). Available at data.worldbank.org/indicators/ [accessed 22 May 2012].
- Yu JK, Chen SC, Wang KY, Chang CS, Makombe SD, Schouten EJ, Harries AD. 2007. True outcomes for patients on antiretroviral therapy who are “lost to follow-up” in Malawi. *Bulletin of the World Health Organization* 85: 550–554.