

Full Length Research Paper

# Why do patients refuse antiretroviral therapy before they complete tuberculosis treatment? A qualitative enquiry

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In Sub Saharan Africa, human immunodeficiency virus (HIV) and tuberculosis (TB) co-infections are common, and patients often find out about their HIV positive status during consultation for pulmonary tuberculosis. Reports from the HIV and TB hospital unit in Swaziland indicate that many deaths are related to low uptake of antiretroviral therapy among patients co-infected with TB, and anecdotal evidence suggests reluctance and refusal by some TB/HIV co-infected patients to initiate antiretroviral therapy (ART) before completing TB treatment, and this phenomenon is not well understood. The aim of this study was to explore the reasons for refusing antiretroviral therapy among HIV co-infected tuberculosis patients, prior to the completion of tuberculosis treatment, at a regional hospital in Swaziland. A qualitative descriptive study was conducted to understand patients' views and concerns, which results in their refusing to initiate ART before completing tuberculosis treatment. A sample of convenience, consisting of nineteen HIV/TB co-infected patients was selected to answer the research question. Reasons given were the clients' un-readiness for ART, the perception that one was still in good health, the fear of adverse outcomes being precipitated by combining ART with TB medicines, preference for traditional medicines, and health systems-related problems.

**Key words:** Antiretroviral therapy, human immunodeficiency virus (HIV)/tuberculosis (TB) co-infections, tuberculosis, HIV.

## INTRODUCTION

The scourge of human immunodeficiency virus (HIV) continues to significantly contribute to morbidity and mortality in Sub-Saharan Africa, and it is estimated that 70% of the worldwide acquired immune deficiency syndrome (AIDS) mortality occurs in Sub-Saharan Africa (UNAIDS, 2009). *Mycobacterium tuberculosis*, which is one of the opportunistic infections for HIV infected people, has been identified as a major factor in these deaths. The HIV/TB co-infections therefore remain a major public

health challenge in Sub-Saharan Africa (Hesseling, 2009).

Tuberculosis is the most frequent opportunistic infection among HIV infected individuals, and also accounts for the majority of deaths in these patients in developing countries. Despite effective tuberculosis chemotherapy in HIV/TB co-infection, tuberculosis is associated with substantially increased case fatality rates. HIV is the strongest risk factor for TB infection in countries that have a high prevalence of HIV (Karim et al., 2010). Not only do

recurrent or persistent co-infections increase the risk of HIV transmission, and thus HIV incidence, but this may be reversed with treatment (Barnabas, 2011), thus confirming the need for concurrent treatment of HIV and TB.

In the developing world, many HIV-infected individuals only become aware of their HIV positive status after being initially diagnosed with tuberculosis in a healthcare facility (Akksilp et al., 2007), and this has resulted in the clinical protocol of testing people who present with tuberculosis for HIV. Treatment with highly active antiretroviral therapy (HAART) significantly improves the outcomes of HIV-infected people, and clinical trials have confirmed the benefits of initiating antiretroviral therapy during the course of tuberculosis treatment (Karim et al., 2010), with HIV co-infected tuberculosis patients who did not receive HAART while on TB treatment being reported to have a six times greater risk of death when compared with those co-infected patients who received HAART prior to completion of TB therapy (Sanguanwongse, 2008). Thus, the World Health Organisation's recommendation that TB patients who are on treatment, are co-infected with HIV and are eligible for antiretroviral therapy, should be initiated on HAART within two to eight weeks after beginning TB treatment (Sanguanwongse, 2008).

Swaziland is reported to have the world's highest HIV prevalence (Mah et al., 2010), and cases of TB co-infections are common. Karim et al., (2010), concluded that the initiation of antiretroviral therapy during tuberculosis therapy in patients with confirmed HIV/TB co-infection reduced mortality by 56% and that a delay in initiating ARV therapy increased the death rate from 5.4 per 100 person-years to 12.1 per 100 person-years when the initiation of HAART was delayed until the completion of tuberculosis therapy. The interval between completion of TB treatment and the initiation of HAART is important because a considerable number of deaths in the sequential therapy group occurred during this period. Furthermore, tuberculosis accounts for more than 20% of all hospital admissions and is responsible for an estimated 50% of deaths among HIV infected persons. These statistics confirm that the mortality and morbidity of the current TB epidemic is being fuelled by the high prevalence of HIV infection in the general population, and that efforts to control the TB epidemic is not likely to be successful if equally serious attention is not given to HIV infection control.

Although WHO recommends that all HIV co-infected TB patients should be commenced on antiretroviral therapy within two to eight weeks of initiating TB therapy, when the patient is clinically stable (Sanguanwongse, 2008), quarterly hospital statistics in Swaziland indicate that there is a significant proportion of TB/HIV co-infected patients who are not on antiretroviral therapy. Anecdotal evidence from health care workers has identified reluctance and refusal by some TB/HIV co-infected patients to take concurrent TB and ARV therapy, preferring rather to commence ART after completing TB treatment. However, this phenomenon was not confirmed or fully understood,

hence this study.

## **The purpose of the study**

The purpose of this study was to explore reasons why HIV and TB co-infected patients who are on tuberculosis treatment refuse antiretroviral therapy before they complete tuberculosis treatment.

## **METHODOLOGY**

### **Study design**

This was a qualitative descriptive study, using in-depth interviews.

### **Study setting**

The study was conducted at the TB Clinic of a regional hospital in Swaziland. The hospital is the sub-region's referral facility and offers integrated TB/HIV management services at its TB Clinic. The TB Clinic offers TB screening services to an average of ten TB suspects per day, and an average of thirty new TB cases are detected per month. The clinic has fully integrated HIV management services so that TB/HIV co-infected clients access all services under one roof. Thus, HIV counseling and testing is offered to all TB suspects during the process of screening for TB and to all TB patients at the time of diagnosis.

### **Study population and sampling**

The study population consisted of patients who have been diagnosed with TB, are HIV positive and have refused ART until the completion of TB treatment offered to them. Purposive sampling was used to recruit patients who met the inclusion. Eligible patients were identified by clinic records because when a patient states that he/she is not prepared to initiate ARVs when they are offered by a healthcare worker, this is recorded in red ink as refusal of ART on the patient's outpatient records, and against the patient's name in the facility's TB register. This serves as an alert for healthcare workers that the patient needs further counseling and health education on the importance of HAART, until he/she accepts ART initiation. Potential participants were contacted by telephone and/or face to face contacts through the facility's mobile treatment adherence officers. They were then informed about the study and given an appointment for an interview on the day that coincides with their regular visit to the clinic.

### **Ethical considerations**

The study was approved by both the Medunsa Research Ethics Committee and the Ministry of Health's Research Ethics Committee in Swaziland. Permission to conduct the study was obtained from the management of the hospital. The purpose of the study was explained to recruited participants who were given an opportunity to ask questions, and those that agreed to participate in the study were requested to provide written informed consent.

### **Data collection**

After obtaining informed consent from each patient, data was collected by using a self-developed in-depth interview guide and the interview was conducted in a private room in the clinic, using ISiswati, which is the local language. A digital voice recorder was used to capture the interview discussion. Interviews were

conducted until the researcher reached a point of data saturation, which is when the data collection process no longer gathered any new information. The point of saturation was reached after conducting nineteen (19) interviews.

### Data analysis

The audio recordings from the digital voice recorder were transcribed verbatim and written as transcripts, translated into English, typed into word and uploaded into Nvivo 9 program for analysis. A codebook of codes or themes and corresponding definitions was developed, and the codes were applied to all the transcripts using Nvivo 9 software.

## RESULTS

### The demographic profile of the participants

A total of 19 patients, 10 males and 9 females participated in the study, with ages ranging from 22 to 63, and 68% (n = 13) being in the 30 to 49 year age groups. The majority (89.5%, n = 17) live in a rural area, and 63%, (n = 12) had attained secondary education. The majority (63%, n = 12) were monogamously married, and the number of children ranged between 0 and 8, with an average of 3 children per participant. Fifty three percent (n = 10) were self-employed, 16% (n = 3) were smokers and about a third drank alcohol. The majority (84.2%, n = 16) had been on TB treatment for a period exceeding two months,

### Qualitative results

The qualitative results are presented as themes that emerged from the coding of the data using Nvivo. Themes 1 to 8 are majority voices, which mean that each of these themes emerged from transcripts of at least 9 participants. The remaining themes are categorized as minority voices, because each of these were coded from scripts of at least 4 participants. The differences between the majority and minority do not refer to the importance or significance of the theme, but rather to the number of scripts that the theme emerged from.

#### Theme 1

**Relationship between TB and HIV:** This theme refers to the respondent's views on the relationship between tuberculosis and HIV infections. The respondents stated that HIV predisposes one to TB.

"Through health education I now know that there is a relationship between these two diseases. If you are infected with HIV you are more vulnerable to TB, especially if you are not on antiretroviral therapy because your

immunity is progressively declining thus increasing susceptibility to TB." 32-year-old female respondent.

"Yes, there is an association. If you have TB, you may also be HIV infected. If you have TB you must also test for HIV and if you are infected with HIV you must be screened for TB," male respondent.

"I think if you are diagnosed with TB, it is also very likely that HIV infection may be present in association with the TB. These two diseases are so inter-related that if you are diagnosed with one of them chances are very high that you also have the other one." 29-year-old male respondent.

#### Theme 2

**Comparison between health challenges of TB and HIV:** This theme refers to respondents' opinions about whether HIV or TB poses more health challenges than the other. There is a general opinion that TB poses more health challenges than HIV.

"In the absence of treatment, TB progresses fast and may result in a person being bedridden in a short period of time while HIV may slowly progress over years, especially if a person takes good care of herself, such as eating a healthy diet," 40-year-old male.

The finding suggests that patients delay ART initiation during TB treatment because they view TB to be posing immediate health threat, and thus is not seen as urgent. However, some were of the opinion that in the long term, HIV poses more psychological challenges than TB because it is known to be fatal.

"I think the one living with HIV will face more challenges because of the fear of death, and the stress of knowing that you are HIV positive for life because there is no cure for this disease," 36-year-old male.

Additionally, here is a view that the two conditions pose equal threats.

"In my opinion there is no better disease between the two. I mean TB is curable and HIV is manageable despite being non-curable when one takes ARVs," 26-year-old female respondent

"Both diseases have equal health challenges because both diseases result in death if an individual does not take care of one's self," 33-year-old male

This indicates that despite the views that in the long term HIV poses a threat to life and that both diseases pose

equal health challenges, the respondents still give TB treatment first preference over ART by delaying the initiation of HIV treatment until they complete their TB treatment.

### **Theme 3**

**Views on the complications of TB medication:** This relates to the side-effects of TB medicines that were experienced by the respondents, which resulted in them being reluctant to initiate additional HIV medication because they anticipate that complications will increase. Examples of such complications include skin rashes and itchiness, as well as increased appetite.

### **Theme 4**

**Preparation of participants for TB treatment:** This theme refers to the preparation of respondents for TB treatment before they actually start with the treatment. The preparation for TB treatment included health education on the TB medicines, their side-effects, and the importance of adhering to the full course of treatment until being discharged by the doctor, as well as the role and importance of a TB treatment supporter.

"I received health education. The healthcare workers informed me about TB medicines. They stressed the importance of taking them on time daily and taking the full course of treatment until discharged by a doctor," 31-year-old female respondent.

"The nurses offered me health education concerning TB therapy. They told me about the various side effects of the medications, they encouraged me to take all my medications," 32-year-old female.

"I received health education on the duration of TB treatment and the fact that TB is curable. I was educated about the TB medicines and the importance of protecting people around me from contracting the disease, including children," 31-year-old male respondent.

### **Theme 5**

**Preparation of participants for ART:** This theme refers to the preparation of respondents for antiretroviral therapy by healthcare workers before they actually start with the treatment. The preparation was through health education, counseling and the provision of information on the ART regimen.

"I received relevant health education. The nurse informed me that I needed ART initiation regardless of my CD4 count because I have TB/HIV co-infection. She also explained about ART and the fact that I needed the ARVs to improve my immunity because TB worsens the decrease in the CD4 count in the absence of ART," 32-year-old female.

There were some, however, that stated that they did not receive any preparation for ART although it is not clear how this occurred, given the specific process that aims to ensure that all patients access all components of the treatment regime.

### **Theme 6**

**The complications of taking TB and HIV medicines:** This refers to the participants' opinions on perceived or anticipated complications of simultaneously taking TB and HIV medicines. Among the anticipated complications are overlapping side effects which may make it difficult to tell which of the two medications is actually responsible for any given side-effects, fear of confusing TB medicines with the antiretroviral medications, increased or compounded side-effects, deteriorating health status and increased pill burden.

"I thought that rushing to take ARVs could lead to deterioration in my physical well-being. When I was commenced on TB treatment my condition was critical hence I was afraid that being put on ART early would result in both medications being too strong for my incapacitated body with negative consequences," 42-year-old male.

### **Theme 7**

**Satisfaction with preparations:** This theme refers to reported satisfaction of respondents who had already been prepared for ART with the manner in which they were prepared for the HIV medicines by the healthcare workers. Mostly, the respondents stated satisfaction with the way they were prepared for ART.

"I am content with the health education that is being offered. I am content with the way that I was prepared for ART," 32-year-old female respondent.

"I am satisfied with the way in which we are being prepared for ART," 29-year-old male.

### **Theme 8**

**Barriers to taking HIV medicines:** This theme refers to minority voices on a range of reasons perceived as barriers

to initiating ART while on TB treatment.

a. HIV treatment has to be taken for life: "In the case of HIV, what de-moralises me is being on medication forever," 63-year-old male.

b. Lack of readiness to start ART: "I was still not psychologically ready for ART," 26-year-old female.

c. Self-perception of still being in good health despite being HIV positive: "I was undecided because I perceived myself to be still in a good state of health," 26-year-old female.

d. Preference for traditional medicines: "The Swazi belief that traditional medicine is better than medical one is also another barrier," 36-year-old male.

e. Anticipated side-effects of antiretroviral medicines: "I saw one patient who was initiated on ART yet he was not fully willing to be put on the treatment. He developed severe side-effects which resulted in his death," 35-year-old male.

f. Long distance between home and health facility: "This place is too far from home and I can't afford the transport costs," 63-year-old male.

g. Non-disclosure of HIV-positive status to partner: "I have been reluctant to open up," 33-year-old male respondent.

"The nurses asked if I had disclosed my HIV-positive status to my wife. After I told them that I had not yet done so, they explained the importance of disclosure in marriage," 42-year-old male respondent.

i. Lack of food: "My main problem is the lack of food," 43-year-old male study participant.

j. Stigmatization and the increased pill burden: "The barriers to taking HIV medicines include the fear of being stigmatized by friends and relatives, the lack of food, and the increased pill burden," 51-year-old female.

k. Health systems-related issues: "I was ill-treated by healthcare workers in this hospital's ART clinic. The way they treat patients in that building, you feel like you have already died. If I have to receive my ART from there I would rather stay at home," 32-year-old female.

"I am still not ready to start taking ARVs and this has been reinforced by the poor relationship with the Pre-ART counselor at my local clinic," 34-year-old male.

"I was also unable to do my CD4 test when I came for the baseline tests for ART initiation because the machine

was out of order," 40-year-old male.

### **Theme 9**

**Enablers for concurrent taking of HIV and TB medicines:** This theme refers to a group of factors that are perceived to make it easier for the TB/HIV co-infected participants to start taking HIV medicines while they were still on TB treatment.

a. A regular source of income and food security: "I think getting adequate food and having a job are essential. The health education that I received made me understand that even recovery from TB is faster when you take both medications together," 26-year-old female respondent.

b. Involvement of HIV/TB co-infected expert clients during pre-ART counseling of HIV/TB co-infected patients: "The involvement of people who are already on both TB and HIV medicines, co-infected expert clients, in the health education sessions will make it easier for fellow HIV co-infected TB patients to take ARVs," 33-year-old male participant.

c. Acceptance of HIV-positive status by the patient and good interpersonal skills among the healthcare workers: "The fact that some of healthcare workers are good at communicating with clients, and acceptance of one's positive HIV status are also strong factors to encourage people to start with HIV medicines," 32-year-old male.

d. Deterioration of one's physical condition: "A sudden deterioration of my general state of health, will push me to take HIV medication" 29-year-old male respondent.

e. Involvement of spouse or partner: "The availability of my husband for us to undergo couple counseling so that he can be counseled appropriately about our discordance," 48-year-old female.

f. Health education on the importance of initiating ART on time: "We need to be educated that these medicines are life-saving," 32-year-old female.

### **DISCUSSION**

The dearth of literature on the reluctance and refusal of patients to take ARTs before completion of TB treatment makes it difficult to assess how widespread this phenomenon is. However, the results of this study highlights the importance of further studies of this attitude and behavior, as it may explain the reason for some deaths among HIV infected persons who practice this behavior. It is not known how widespread this reluctance and refusal is, but it deserves further investigations and

address. The findings of this study suggest that although knowledge about the relationship between HIV and TB exists, it does not necessarily translate to acceptance of ART initiation during their TB treatment by HIV/TB co-infected patients. Despite stating satisfaction with the preparation for ART, the results show that this preparation was not adequate to influence the respondents to take TB and ART medications concurrently.

Although the participants acknowledge that both HIV and TB infections pose health problems, the participants view HIV as posing a lesser health threat than TB; hence their prioritization of TB medication and a decision to first complete this course of treatment before they can start with the perceived less threatening HIV infection. Interestingly, the fear of deterioration in state of health was identified both as a reason for not initiating HIV treatment before completing TB treatment, as well as a factor that will compel patients to initiate HIV treatment. The low socio-economic status, as reflected by inadequate resources for transport to the health facility, is similar to other studies in low income countries (Zachariah et al., 2007).

Of concern are reports that some patients reported that they did not receive preparation for ART, which is standard for all patients prior to initiating treatment. Failure to prepare patients by health professionals often results in them seeking and receiving information from other non-professionals, and may thus be contributing to failure to initiate treatment or failure to fully adhere for those who initiated treatment. Clinics that manage HIV disease need to take the results of this study to account, and address specific fears of patients, which goes beyond just imparting knowledge on ART. Considering that for immune compromised HIV infected patients, the deterioration in health often occurs within a short period, the findings of this study highlight the importance of an intervention to address this delay of ART by some patients, because the completion of TB treatment takes a minimum of six months, which may be too late to save lives.

#### LIMITATIONS OF THE STUDY

This was an exploratory study which did not seek to investigate the prevalence of the reluctance or refusal to complete TB treatment before initiating HIV treatment. The study therefore did not identify the extent to which this reluctance prevails among HIV positive patients, nor whether this is within a localized geographical area of Swaziland.

#### Conclusion

This study has identified a challenge that frustrates

effective treatment of HIV/TB co-infections, which are common in Sub Saharan Africa. The findings may explain some of the reasons why patients continue to die despite availability of drugs and treatment regimen. A responsive health system is one that understands the specific challenges in its operations, and this study may assist health care systems to focus on an area not previously given adequate attention. It is possible that the reluctance and refusal of ART is not limited to the community studied and that this practice is responsible for delaying initiation of ART and thus resulting in a number of deaths. The recommendation emanating from this study is that it be extended to other facilities and countries in Sub Saharan Africa.

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