



# Perceived changes and challenges in the quality of life of HIV infected individuals on ART: a qualitative study in Uganda

Barbara Nyanzi Wakholi<sup>1</sup>, Antonieta Medina Lara<sup>2</sup>, Paula Munderi<sup>1</sup>, Charles Gilks<sup>3</sup>, and Heiner Grosskurth<sup>1</sup> on behalf of the DART trial team

<sup>1</sup>MRC/UVRI Uganda Research Unit on AIDS, <sup>2</sup>Liverpool School of Tropical Medicine, and <sup>3</sup>World Health Organization

## Issues

It is widely recognized that HIV/AIDS affects both life expectancy and the individual's quality of life. Research has shown that antiretroviral therapy (ART) can successfully improve the quality of life of recipients and increases their survival. These qualitative research findings emerge as part of a sub-study conducted in Entebbe that was set up to assess the changes in the quality of life of HIV infected individuals receiving ART in the Development of Antiretroviral Therapy in Africa (DART) trial. The DART trial was set up in 2003 to evaluate monitoring strategies and structured treatment interruptions in three African Sites (Entebbe (n = 1020) and Kampala (n= 1000), Uganda and Harare (n=1000); Zimbabwe).

## Description

Data were generated from six pre-determined Focus Group Discussions (three with men and three women). In addition a discussion was held with health-care providers administering ART to this population, to verify and validate the findings.

## Lessons learned

Study participants recognized counselling to foster positive living after testing for HIV and found that counselling was crucial for coping with thoughts of death, depression and stigma. They reported that counselling enhanced adherence to ART and helped them adopt safer sexual practices. Health care providers regretted that HIV infected individuals delay seeking health care until in the later stages of the illness making medical management and care difficult. Participants reported ART to have improved their physical health and appearance thus enabling them to return to their day-to-day activities. However, the positive effect of ART on participants' perceived quality of life was limited by stigma, pill burden, drug side effects and socio-economic constraints such as lack of employment and inability to meet basic needs including food, clothing and school fees for their families. Our findings confirm the multidimensional nature of quality of life as a composite outcome measure for HIV infected individuals in Africa.

**Table 1 General Focus Group Discussions Findings**

Positive changes	Perceived challenges
Improvement in physical health and appearance	Exposure to HIV status
Ability to embrace HIV status	Swallowing pills on empty tummy
Increased life expectancy	Coping with misconceptions about ART
Reliable treatment option	Uncertainty after DART trial ends

## Factors limiting good compliance

- Forgetfulness and constant efforts required to cope with pill burden
- Not willing to swallow pills particularly if healthier
- Frequent need for water to drink while taking tablets
- Difficulty in maintaining confidentiality for those who had not disclosed their status
- Concern that visible drug side effects would lead to stigma

**Female participant:** I struggle swallowing tablets...I put the tablet in a piece of banana then throw it in my mouth and drink water to wash it down. Does that spoil the medicine?

**Female Participant:** Would it be wrong to roll the tablet in a bit of maize meal then swallow it?

**Male participant:** How I wish they would combine all the tablets we have to swallow a day into one tablet. It gets even harder when we are given additional tablets for other illnesses

## Physical health and appearance

**Male participant:** I looked like a stray dog that lives in an ash heap. My hair was all sparse, each time I scratched myself, specks of ash would come off

**Male participant:** You were dying but you now look very fine

**Male participant:** Aha! You ought to have seen me that time

**Male participant:** In March 2003 I was very weak and I looked horrible. However, when I went to my village in December 2003, people came to check on me, they were amazed and started gossiping about how well I looked!

## Stigma

**Female participant:** I would not mind if people got to know that I am HIV positive but the trouble in that is that once they get to know, they start gossiping about me, they start sneering at me, they stop talking to me

**Female participant:** once they know that you are infected with HIV they stare at you; they stare and stare and stare. If you were in my shoes you would also feel very depressed

## Empty tummy!!!!

**Female participant:** The medicine has done us a lot of good. It has restored our appetites. We now love to eat... unfortunately we do not have money to buy food... There are times when we get only 500 Shs...so you buy a few fingers of bananas to feed you and the whole family. Surely, that cannot be enough!

**Female participant:** The medicine has done no harm to me, except for the hunger pangs that force me go to the kitchen every night to find something to eat. At one time, my brother in whose house I live found it difficult (expensive) to cope with the situation so an uncle offered to bring food on a weekly basis

## Recommendations

**Although participants recognised ART enhance their overall quality of life, it should not be assumed that ART provision alone is sufficient in itself to lead to a major improvement on the perceived quality of life among persons living with HIV/AIDS. Socio-economic constraints, issues around stigma and difficulties to maintain confidentiality and the challenges associated with a high pill burden lessen the positive medical effect of ART. Access to counseling and other additional support services may play a pivotal role in consolidating the positive effects of ART and in increasing the probabilities for long term success of ART programmes.**