

The effects of enhanced access to antiretroviral therapy: a qualitative study of community perceptions in Kampala city, Uganda

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Abstract

Introduction: Since 2001, Antiretroviral Therapy (ART) has been integrated as part of the Uganda National Program for Comprehensive HIV/AIDS Care and Support. If patients take Antiretroviral drugs (ARVs) as prescribed, quality of life is expected to improve and patients become healthier. It is, however, postulated that scale up of ARVs could erode the previous achievement in behaviour change interventions. This study examined community perceptions and beliefs on whether enhanced access to ARVs increases risk behaviour. It also examined people's fears regarding HIV/AIDS infection and the use of ARVs.

Methods: This was a qualitative study that utilized Focus Group Discussions (FGDs) and Key Informant (KI) interviews. Participants were purposefully sampled. Twenty FGDs comprising of 190 participants and 12 KI interviews were conducted. FGDs were conducted with adult men and women (above 25 years), and youth (male and female) while KI interviews were held with Kampala City Council officials, Kawempe Division Local Council officials, health workers and religious leaders. All data was tape recorded with consent from participants and transcribed thereafter. Typed data was analyzed manually using qualitative latent content analysis technique.

Results: Most participants felt that enhanced access to ART would increase risky sexual behaviour; namely promiscuity, lack of faithfulness among couples, multiple partners, prostitution, unprotected sexual practices, rape and lack of abstinence as the risky sexual behaviours. A few FGDs, however, indicated that increased ART access and counselling that HIV-positive people receive promoted positive health behaviour. Some of the participants expressed fears that the increased use of ARVs would promote HIV transmission because it would be difficult to differentiate between HIV-positive and HIV-negative persons since they all looked healthy. Furthermore, respondents expressed uncertainty about ARVs with regard to adherence, sustainable supply, and capacity to ensure quality of ARVs on the market.

Conclusions: There are fears and misconceptions that enhanced access to ART will increase risky sexual behaviour and HIV transmission. Information Education and Communication (IEC) on ART use and availability should be enhanced among all people. Prevention programs which are modified and specific to the needs of the people living with HIV should be developed and implemented, and should include information on the ability of individuals to transmit HIV even when they are on ART.

Key words: ART, 'enhanced access', perceptions, qualitative, Uganda

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Introduction

Since 2001, Antiretroviral Therapy (ART) has been integrated as part of the national program for comprehensive HIV/AIDS care and support in Uganda. If patients take Antiretroviral drugs (ARVs) as prescribed, quality of life is expected to improve as well as make patients healthier¹⁻⁴. Evidence from the industrialised countries indicates a possibility for the prevention benefits of ART to be beset by complacency about the threat of HIV/AIDS which may result in an increase in risky behaviour and new infections.⁵⁻⁷

There is, therefore, fear that a scale up of ARVs could erode previous achievements in behaviour change interventions, especially in poor resource settings. It is thus feared that there could be an increase in prostitution, promiscuity, unprotected sex and lack of faithfulness. This study established community perceptions and beliefs on whether enhanced access to ARVs increases risky behaviour as well as fears regarding HIV/AIDS infection and use of ARVs. Currently, the coverage of ART in Uganda is about 50% and the foregoing misconceptions may delay the extension of this coverage.

This study is part of the larger two year project study 'HIV Prevention Intervention in the Context of the Antiretroviral Therapy' funded by the Bill and Melinda Gates Grant through the Academic Alliance for AIDS Care and Prevention in Africa. The overall goal of this project was to understand how to successfully reduce

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and sustain reduction in HIV incidence and prevalence in the context of improved access to ARVs and treatment for opportunistic infections in an African setting.

Methods

This was a qualitative study that utilised focus group discussions (FGDs) and key informant (KI) interviews. FGDs refer to a qualitative method that gathers people of homogeneous background or experiences to discuss a specific topic of interest to the researcher.⁸⁻¹⁰

A moderator who introduced the topic and the aim of the study guided the discussions. Key informants on the other hand are people who, because of their position or experience, have greater knowledge of what is being investigated than the average person.¹¹ Purposeful sampling was done to select study participants. This study was carried out in Kawempe Division, one of the five divisions of Kampala, the capital city of Uganda. Kawempe division is divided into 22 parishes and 119 local council one (villages) with a projected population of 282,000 (52% females and 48% males).¹²

Participants and procedure

Study participants were recruited from Kawempe Division, Kampala city. We contacted the local community network (Local Council chairpersons and community guides) with whom we visited households identifying eligible participants. A total of 20 FGDs comprising of 190 participants (99 males and 91 females) and 12 KI interviews were conducted. Focus groups were conducted with adult men and women of 25 years and above. Two of the FGDs were with women and two with men in that age group. Other FGDs were with adolescents of between 15-18 years. Two of these FGDs were conducted with males who were still in school, two with males out of school, two with female in school and two with females out of school. FGDs were also conducted with young persons aged between 19-24 years of which two were with males still in school and two with males out of school. Also two of the FGDs were with females in school and two with females out of school. The average number of participants in the FGDs was ten¹³ and discussions were held at a venue identified by and convenient to the participants (tree sheds and classrooms were mostly chosen). Participants were served with a soft drink but were not paid to participate. Semi structured interviews (Box 2) were held with KIs who were considered to have greater knowledge of reproductive health issues including HIV/AIDS and treatment-seeking behaviour. The researchers also took advantage of the KI's position in society as well as their experience.¹¹ Key informant interviews were held with Kampala City Coun-

cil officials, Kawempe Division Local Council officials, health workers, and religious leaders.

Quality control

Back translation technique was used to ensure consistency of meaning in the FGD guide.¹⁴ The guide was translated from English into the local language (Luganda) by one group of bilingual research assistants (RAs). Another group of RAs translated the Luganda version back to English (Box 1) and it was compared with the original version. The FGD guide was pre-tested during one group discussion and thereafter adjusted for the main fieldwork. Results of the pre-test are not included in this article. Research assistants were recruited and trained to take field notes. All FGDs were tape recorded (with consent from participants) and transcribed into English. Participants were guaranteed anonymity and instructed not to share individual responses with others.

Data management and analysis

Typed text data was analyzed manually using qualitative latent content analysis technique.¹⁵ Open codes, categories and themes were developed. The major themes that emerged were: availability of ARVs and risky behaviour, positive health living for persons whose HIV status was known, beliefs about HIV as well as fears about ARVs.

Ethical consideration

The study was approved by the Makerere University School of Public Health Higher Degrees, Research and Ethics Committee, and Uganda National Council for Science and Technology (UNCST). Permission was sought from the management of Infectious Diseases Clinic, and Kawempe Division Community leaders to allow the study to be carried out in those settings. Informed consent was obtained from the study participants after explaining the goals and objectives of the study, confidentiality safeguards and potential risks and benefits of the study was fully explained. The informed consent document was translated into Luganda, the main local language of the area of study.

Results

Availability of ARVs and increase in risky sexual behaviour

Most of the FGD participants and KIs revealed that there was a strong belief that increased access to ARVs would enhance the spread of HIV. Over half of the FGD participants, irrespective of their education level, pointed out that ARVs increased the risk of unsafe sexual behaviour that would in turn increase HIV transmission. One key informant expressed this view in the quote below:

Box 1: Focus Group Discussion Guide

1. If someone is sick for a long time, (bed-ridden), what care is given? Where do they go for care and support? What care do they normally receive?
2. What type of treatment is usually given to AIDS patients? What type of treatment are people accessing for people living with HIV/AIDS?
3. There is increased talk of ARVs in the country. What do people in this community know about ARVs? What do you think of ARVs in terms of their role in the fight against HIV/AIDS?
4. The government is planning to increase access of ARVs to PLHA. What are some of the problems regarding use/availability of ARVs?
5. What are some of the beliefs or perceptions regarding HIV transmission and prevention now that there is increased access to ARVs?
6. Now that there is increased availability of ARVs on the market, do people perceive HIV/AIDS as a big threat in their midst?
7. Given the increased access to ARVs in the country, would you say this has influenced people's sexual behaviour? What in your opinion is the effect of ARVs' availability and use on sexual behaviour?
Probes:
 - a. People less concerned about becoming HIV-positive
 - b. People are less concerned about infecting others
 - c. People think a person on ARVs cannot infect a partner through unsafe sex
 - d. Because of availability of ARVs, there is no need of practicing safer sex (condom use etc)
8. What should be done to improve the availability and use of ARVs?
9. What should be done to make sure that the gains through prevention efforts are not lost due to complacency?

Box 2: Key Informant Interview Guide

1. In your view, do you think HIV/AIDS is still a big threat in this community?
2. Where do most HIV/AIDS patients seek care?
3. What type of care is available for HIV/AIDS patients in this community?
4. What sort of treatment is usually given to HIV/AIDS patients in this area?
5. Currently, there is increased access to ARVs for AIDS treatment in the country. Would you say this has influenced people's behaviour related to HIV infection and sexual behaviour?
6. In order to improve the livelihood of PLHA, what do you think should be provided?
7. What are some of the beliefs regarding risk to HIV infection with increased availability of ARVs?
8. What prevention measures against HIV/AIDS do people in this area use (probe for condom use, reducing sexual partners, abstinence, etc.)
9. What is the community's attitude towards HIV prevention with availability of ARVs for AIDS treatment?

"When people see that ARVs are now available, which makes the HIV dormant for sometime, they know they can now engage in sex knowing that at the end of the day, before they die, a cure will be available. It looks as if it has now made people more promiscuous. Before, people knew that there was no alternative but death. But now, we see risky sexual activities begin to increase." (KI, Local Council Official).

It was further reported that increased availability of ARVs had affected the traditional prevention approach such as condom use.

"I want to supplement what he has said, the drug (ARVs) has increased the AIDS transmission rate because in the

past people could protect themselves using condoms but now they no longer protect themselves since the drug is available." (FGD, Males in-school, 15-18 years).

Some participants felt that ARVs had led people to reduce on abstinence from sex and their faithfulness to their partners. ARVs have also led to an increase in multiple partner relations and reduced condom use, thus undermining the ABC strategy spearheaded by Uganda's Ministry of Health.

"HIV transmission will continue to increase as long as drugs are available. Even though it was me, I can't abstain because I know there are drugs (laugh) but if there were no drugs, I would have abstained from sex." (FGD, Males in-school, 19-24 years)

All FGDs felt that availability of ARVs was likely to reduce faithfulness between sexual partners. It was particularly pointed out that the married couples may stop being faithful especially if they were sure of their economic ability to purchase drugs for life. Most FGD participants expressed fear that availability or reduction in the cost of ARVs could lead people into having multiple sexual partners.

"If ARVs are more available at reduced cost, the rate of sexual promiscuity will also increase. If I know that I can get a drug at 10,000/= why can't I add on the number of ladies I have?"(FGD, Adult males, 30-50 years)

A few groups reported that because HIV-positive women can now give birth to HIV negative babies owing to the prevention of mother to child transmission (PMTCT) programmes that are in place, this had increased the number of HIV-positive mothers who want to have babies. It was argued that HIV-positive women would look-out for sexual partners to help then conceive, but in the long run would leave several men infected.

"When I come to the point of giving birth, the ARVs have increased the risky sexual behaviour of people both male and female because females continue conceiving and males continue making females pregnant because they know ARVs are available even if they get infected with HIV."(FGD, Females in-school, 19-24 years)

It was furthermore noted that the availability of ARVs could lead to false confidence of protection from infection as exhibited in the declined use of condoms as a protection measure.

"Automatically people's sexual behaviour has changed and people now go for unprotected sex (live) because they know that there are ARVs that can be used to weaken HIV/AIDS. Some people have hope now that there is medicine to use and keep them living hence having unprotected sexual intercourse."(FGD, Females out-of-school, 15-18 years)

Increased access to ARVs was also perceived to increase sexual crimes such as rape.

"There will be an increase in crimes related to sex that will be committed by some people such as rape or defilement of young children because people will now believe that there is a drug that cures HIV/AIDS. Such inhuman acts will increase."(FGD, Males out-of-school, 15-18 years)

FGD participants had a strong belief that prostitution was on the increase in the urban areas of Kampala. They also alluded to the possibility of prostitutes using their savings to buy ARVs.

"It will increase prostitution because people will know that

if I make money through 'playing sex, it will help me to buy the drug and even remain with some money to cater for me."
(FGD, Males in-school, 15-18 years)

Furthermore, study participants expressed concern over the increasing usage of ARVs, that it would undermine positive living. There were hence big chances that people living with HIV/AIDS (PLHA) would continue infecting unsuspecting people as illustrated below.

"Yeah! Because now people no longer notice. At least the other time you could see that someone has herpes zoster or a rash on the skin and you fear engaging with that person in sex. But now ARVs kill off the virus and someone gets refreshed ... the skin... everything changes to normal. You won't be able to notice an HIV-positive person. So, people will just go in for unprotected sex and in the end the disease will be transmitted."(FGD, Females in-school, 15-19 years)

In addition, participants argued that because ARVs prolonged people's lives, the duration of infection of the partners of PLHA engaged in unprotected sexual intercourse would be long. Previously HIV-positive people would die in a short period and therefore would have infected relatively fewer people.

"Access to ARVs has improved people's health status. HIV-positive persons on medication live a normal and prolonged life. However, they can go on transmitting the disease to others. So may be if these ARVs were not accessible to people, may be someone would notice the sick who would live for a shorter time. She/he wouldn't be going into an unprotected sexual affair with him or her."(FGD, Females in-school, 15-19 years)

HIV/AIDS not perceived as a big threat

Study participants felt that HIV/AIDS was no longer a big threat owing to the increasing availability of ARVs. It was noted that the process of administering ART would enhance positive change because of the provided counselling as emphasised below by a female adolescent during an FGD.

"I think ARVs have influenced people's sexual behaviour, now if a person takes these ARVs, that person will become more healthy, so he will know that, 'let me protect myself when I am going to have sex so that maybe I do not infect my partner'."(FGD, Females in-school, 15-18 years)

Results from FGD participants and KIs echoed views that HIV/AIDS was no longer a big problem. They also noted the fact that ARVs were making people live longer and healthier lives. Furthermore, they alluded to the fact that with ARVs in place, AIDS was a less painful

disease since AIDS patients no longer became too wasted or too sick with opportunistic infections such as herpes zoster.

"In reality, people no longer fear AIDS, because there are drugs that fight against HIV/AIDS, it makes people look good again and people no longer recognize an HIV/AIDS person unlike in the past when people would suffer and appear very sick. People no longer see it as a big threat because at first it was seen as a terrible disease. It could cut people's nails, remove people's hair but now with use of ARVs, it is difficult to see such signs." (FGD, Male youth out-of-school, 15-18 years)

Participants also reported that people had hope that a complete cure for HIV/AIDS would be discovered sometime.

The only problem with ARVs now, as earlier mentioned, is that people now have confidence in these drugs even when it does not cure and hope that later a drug that cures will eventually be discovered." (FGD, Male married adults, 25-67 years)

Misconceptions about ARVs

Results from the study showed widespread misperception, especially amongst the young people, that ARVs could cure HIV/AIDS. The virulence of HIV was underplayed:

"No, you see people are no longer afraid because as you catch the disease, you go and get ARVs, you take them and be somehow okay. Another thing is that some people believe that ARVs can cure the disease so they are no longer afraid." (FGD, Male youth in-school, 15-18 years)

Less than half of the groups equated HIV/AIDS to any other disease that can be treated and can cause death, just like cough, malaria or accidents.

"Now people take AIDS as a cough, which can be cured because now they know ARVs are available. Even if one is infected, he/she can swallow ARVs and live for a long time." (FGD, Males in-school, 19-24 years)

Fears about ARVs

Focus group discussion participants expressed fears about adherence to ART regimen, especially with low levels of formal education among the population. They noted that it would be difficult for patients on ARVs to take the drugs as required, which would lead the ART access program to fail.

"People may not take the drug as important especially following its prescriptions well. People can be told for instance to swallow two tablets a day and then the second swallowed in the evening at 8:00pm. But some people may

not follow these instructions accordingly. Like he/she can swallow today and tomorrow she/he doesn't take and then swallows it another day. They may not take ARVs following the given instructions well, a thing which can cause problems for them." (FGD, Males out-of-school)

Another important issue raised by the out of school adolescents was the low level of literacy among the patients. It was argued that because of this, the patients would not take clinicians' instructions seriously since they could not conceptualize clinical implications. This could result into complications including death as noted below:

"Most people are illiterate, and will not follow the recommended doctor's instructions on how to swallow ARVs. For instance, a person can be given a drug to be taken for a period of seven days but because of ignorance that person may decide to swallow all that medicine at once, believing that AIDS will get cured immediately, not knowing that he/she may in fact die." (FGD, Males out-of-school, 15-18 years)

Also raised were fears concerning the quality of ARVs on the market. It was noted that some of the ARVs were either counterfeit or expired.

"In the process of increasing ARVs use and availability in the country, some people will start manufacturing and selling fake and duplicated ARVs. This is because they will be interested to meet the people's increased demand for the drug." (FGD, Males out-of-school, 15-18 years)

The study also revealed that some community members held negative views about ARVs, arguing that ARVs were made to exploit the poor or reduce the African population. Other participants wondered why drugs that would cure HIV/AIDS completely could not be made:

"There is also a belief that, manufacturers make ARVs just to exploit the population. They say they want to make money out of them. ... if these people are capable of making ARVs why not make the ones that cure the disease completely? (FGD, Males in-school, 15-18 years) "Some people think that these ARVs are not good and that it is one way of eliminating people or reducing on the population, so the drugs don't prevent the disease but are just killing people." (FGD, Males in-school, 15-18 years)

Some of the questions raised by out-of-school adolescents showed a lot of mistrust and inaccurate information based on rumours. An out-of-school FGD participant remarked:

"We hear that ARVs brought here are made from European countries. That when you use that drug you have low chances of producing and some become completely infertile. They

want to make sure that this population is reduced and people should not be interested in sex.”(FGD, Males out-of school, 15-18 years, Kafeero Zone)

Discussion

Although ARVs do not cure HIV/AIDS, using them consistently tremendously improves the quality of life of most HIV-positive patients and helps them to live longer. This study revealed a big worry in the urban/peri-urban areas of Kampala city that increased availability and access to ARVs would increase risky sexual behaviour. Some of the risky sexual behaviours pointed out included promiscuity, lack of faithfulness, multiple partners, prostitution, and rape.

These findings show that high risk groups could relapse in behaviour as they become healthier. This confirms the evidence from industrialized countries which showed that the prevention benefits of ART were beset by complacency about the threat of HIV/AIDS and resulted in increased risky behaviour and new infections.⁵ ⁶ This implies that the relapse in behaviour would undermine the current HIV/AIDS prevention achievements as HIV infection rates increase. Although it is difficult to distinguish people's personal opinions from their reports of what others think, it is an indicator of what behaviours may occur. The national AIDS control programs ought to step up HIV campaigns targeting this new phenomenon of prevention among those who are HIV-positive.¹⁶ Past interventions focused on risky behaviours with emphasis on ABC strategy without the ARV phenomenon. So the fears and perceptions raised by participants in this study imply that prevention interventions ought to factor in the ART with emphasis on prevention among those who are HIV-positive as well as those persons whose HIV status is not known.

On the other hand, it should be noted that positive health behaviour among HIV-positive people was perceived as a benefit that has 'spill-over effect' to the community. In some cases, HIV-positive people, owing to intensified counselling and treatment realized that they had become healthier and productive again to society. These findings are in line with Bunnell et al (2006a-b) in rural setting in Uganda.^{17, 18} This positive attitude ought to be promoted and maintained.

HIV/AIDS was no longer perceived as a threat due to increased access to treatment. HIV positive patients have renewed hope to live and therefore should cease chance to live more productively and implement 'succession planning' for their families. Some youth on the other hand have misconceptions that ARVs are a cure to HIV/AIDS. This is a dangerous misconception and ought to be seriously targeted since it can promote HIV

spread. HIV/AIDS is still a threat despite improvement in treatment and yet there is no known cure. Tremendous efforts, however, have been directed to developing HIV vaccines, and persistent health education for everyone, regardless of their HIV status is critical.¹⁹

Concern over adherence to ART regimen was expressed mainly because patients may not be well educated. Furthermore, literacy on ART is still limited. In the event that adherence and compliance to medication is compromised, then the country would have a big crisis of drug resistance which would compound the problem. Nonetheless, good adherence can be achieved in resource-limited settings as observed by Weidle et al 2007. In their study, they concluded that good adherence and response to antiretroviral therapy could be achieved in a home-based AIDS care programme in a resource-limited rural African setting.²⁰ It is therefore recommended that health-care systems ought to continue to implement, evaluate, and modify interventions to overcome barriers to comprehensive AIDS care programmes, especially the barriers to adherence to ART.

Urban dwellers also expressed fear about the steady supply of ARVs. There was worry that if donor funding is withdrawn, the patients would be at a big disadvantage since there would be drug supply disruption. The known existence of fake drugs such as Paracetamol, Aspirin, etc on the market for other diseases was viewed as an indicator that the same could occur for ARVs. Control measures to curb fake drugs should be reinforced. The National Drug Authority in Uganda, the police and other law enforcement organs need to be on the alert.

Conclusions

There are still fears and misconceptions about the effect of enhanced access to ART, fears that it would increase risky sexual behaviour and increase HIV transmission. Information Education and Communication on ART availability and use should be enhanced targeting persons of unknown HIV status, HIV-positives on ARVs, and those not on ARVs. New prevention programs modified and specific to the needs of PLHA should be developed and implemented. They should include information that emphasizes the fact that HIV-positive people on ART can still transmit HIV.

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