

Attitudes and perceived impact of antiretroviral therapy on sexual risk behaviour among young people in Kahe, Moshi Rural District, Tanzania

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Abstract: Free antiretroviral therapy (ART) has been provided through the public health system in Tanzania since 2004. The success of national ART roll out programme is premised upon collaborative efforts of health systems, communities and policy environment. However, community perceptions of ART and its implications on sexual behaviours and HIV/AIDS prevention remain largely unknown. Drawing on focus group discussions with young people, this paper examines perception about ART and the potential impact of antiretroviral therapy on risk sexual behaviour in rural Tanzania. Participants included a purposively selected sample of males and females aged 14-24 years. Results show that young people were both optimistic and concerned regarding availability of ART. Positive attitudes toward ART were associated with public health significance of therapy in managing opportunistic infections and extending lives of HIV infected persons. However, the positive outcomes of therapy were considered to be short lived, unsustainable and potentially threatening to the sexual health and wellbeing of HIV negative members in the community. ART was considered to empower infected persons to intentionally spread HIV to uninfected individuals in the community through deliberate unprotected sexual activities. The study highlights the significance of reinforcing HIV prevention while underscoring the need to provide appropriate information and increasing access to ART in rural areas of Tanzania. In conclusion, creating a therapy friendly atmosphere through information delivery is crucial in promoting social acceptability of antiretroviral therapy among youths. Efforts to improve access to antiretroviral drugs should re-emphasize prevention counselling to minimize sexual transmission of HIV

Key words: youths, antiretroviral drugs, HIV, AIDS, treatment, control, Tanzania

Introduction

Access to antiretroviral (ARV) drugs has been steadily improving in Tanzania. The number of people receiving antiretroviral therapy increased from 46,124 in October 2006 to 135,696 by December 2007 (WHO/UNAIDS/UNICEF, 2008). However in many parts of the country access is limited by socio-cultural, structural and health system factors (Mshana *et al.*, 2006, Stoeckle *et al.*, 2006). The availability of ARV has contributed to a reduction in morbidity and mortality, strengthened patients damaged immune systems and contributed to reducing stigma (Detels *et al.*, 1998; Pallela *et al.*, 1998;

Castro & Farmer, 2005). The fact that antiretroviral therapy (ART) sustains lives of HIV infected persons underscores its significance to public health. It also highlights the challenges that need to be addressed to manage therapeutic outcomes and achieve universal access.

Implementation of ART programmes have been facing challenges related to, among other things, treatment adherence, community attitudes to therapy, structural imbalances in different health systems and negative attitudes due to concerns with side-effects (Schrimshaw *et al.*, 2005). Furthermore, concerns regarding access, food costs, stigma, service provider related factors have been identified in some parts of Tanzania

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(Mshana *et al.*, 2006; Stoeckle *et al.*, 2006). Previous studies show that availability of ART has been associated with increased sexual risk behaviours due to "treatment optimism" as discussed by several authors (Bateganya *et al.*, 2005; Rice *et al.*, 2006; UNAIDS, 2006). Antiretroviral therapy is also reported to greatly prolong survival with the potential to increase time available for viral transmission of resistant strains (Cohen *et al.*, 2007). Contrary evidence shows that improvement in health status after antiretroviral treatment did not result in unsafe sexual behaviour (Luchter *et al.*, 2007).

Recent evidence shows that ART is of public health benefit when introduced earlier in an epidemic (Abbas *et al.*, 2006). Further evidence also shows that ART alone cannot control the HIV epidemic in mature epidemics unless combined with efforts to prevent behavioural disinhibition (Gray *et al.*, 2003). It has also been revealed that ART benefits both the infected and uninfected persons in the community since it acts as an effective prevention tool and could potentially eradicate the epidemic in the long run even with high levels of drug resistance and sexual risk behaviour (Velasco-Hernandez *et al.*, 2002). While enhanced access to ART is feared to increase risky sexual behaviours in the community, increased availability has also been associated with improved attitudes towards ART among users (Schrimshaw *et al.*, 2005; Atuyambe *et al.*, 2008)

Most of the studies on attitudes and impact of ART have mostly been conducted among ARV users (Velasco Hernandez *et al.*, 2002, Gray *et al.*, 2003, Bateganya *et al.*, 2005, Schrimshaw *et al.*, 2005; Luchters *et al.*, 2007). Previous studies underscore both the public health significance and potential public health consequences of ARV use on sexual conducts of HIV positive persons. However, perceptions about the social impact of ART among uninfected or people not aware of their HIV status in society remain largely unexplored. Furthermore these previous studies have largely been quantitative and concentrated on clinical aspects of ARV particularly those pertaining to individuals on medication. As has been suggested earlier, intervening at the individual level may not necessarily illuminate the wider societal-level processes that affect people's

relationships in the community (Crepaz & Marks, 2002). Individual patient factors and structural constraints to ART identified in previous studies may benefit from community perspectives of ARVs. An understanding of young people's attitudes and perceptions of ART may be crucial in supporting drug adherence and contribute to understanding of the changing dynamics of risk sexual behaviours in the context of ART. The current study is premised upon the notion that taking medication is a social action influenced by both individual ARV users and social conditions at the community level (Van der Geest & Hardon, 2006).

Since becoming freely available in the public health system, the potential impact of ART provision among different sections of population in Tanzania has not been well documented. Despite the recent increased availability of ART in the public health system, the sexual risk of getting infected with HIV remains high among some groups in society. Recent evidence of an increase in HIV prevalence and risk sexual behaviour among the general population in the study area (Mmbaga *et al.*, 2007) makes it imperative to explore the perceived impact ART may have on sexual transmission dynamics. The current study sets out to explore young people's perception about the potential impact of ART on HIV related risk sexual behaviours in a rural area in Tanzania. Since HIV/AIDS has been a growing problem in Kahe, it is important to examine how the ongoing ART roll out may impact on specific groups in a community.

Materials and methods

Study area

The study was conducted in Kahe ward, in Moshi Rural District (3°37'S, 37°27'E) in northern Tanzania. The study area is located about 30 km south of Moshi town. The ward is comprised of 11 villages with a total population of 23699, distributed in a relatively large area and is inhabited by a number of ethnic groups. At the time of study, there was no ART clinic in the ward. The nearest clinics were located in Moshi town. However there were non-governmental organisations that were providing home based care and support services for people living with HIV in

the area. The study area has been described in detail elsewhere (Mmbaga *et al.*, 2006)

Participants and data collection

Focus group discussions (FGDs) were conducted in all villages between July and October 2006. As this study was part of a project primarily targeting in-school and out-of-school youths, two FGDs targeting the two groups were conducted in each village. However, two of these villages did not have a primary school; therefore one FGD involving out-of school participants was conducted. Separate sessions were held for in-school and out of school youths. Groups were further segregated by school, village and sex to increase intra-group homogeneity and facilitate individual participation (Morgan, 1993). Moderators with backgrounds in social sciences, nursing and public health, conducted all sessions in Kiswahili. Each session lasted for an average of 110 minutes. The discussion guide covered topics related to general feelings about ART and people living with HIV, perception about health benefits of ART and potential impact of ART in the community. The flow of data collection responded to local realities in terms of participants' time and choice of location in order to facilitate attendance and participation. Thus, in each village the FGDs were conducted within village premises mainly under shaded trees or in school buildings.

All sessions were audio taped. Additional notes were recorded in field notebooks. At the end of each discussion, debriefing sessions were held to double check recording quality, identify gaps or unanswered questions, and discuss new leads to be followed up on in consecutive sessions.

Data analysis

Initial open coding was done for each FDG transcript. Coded narratives were grouped into categories representing themes. Findings are presented thematically as shown in results section below. Data was managed and analysed with QSR Nvivo 7 software.

Ethical considerations

Ethical approval was provided by the Medical Research Co-ordination Committee, Tanzania and the Norwegian Committee for Medical

Research Ethics. Permission to conduct the study was obtained from district and village authorities, parents and school administration. Participants were informed, in writing and orally, that their participation was voluntary and that they had the liberty to withdraw from the study at any time. Participants were assured that individual data would be kept confidential and anonymity maintained. Verbal consents were obtained from all FGD participants before the discussions. All participants approved their voices to be audio recorded.

Results

Attitudes toward antiretroviral therapy

A total of 21 focus group sessions involving 100 (M=50, F=50) in-school and 93 out-of-school (M=59, F=34) participants were conducted. The mean age of study participants was 17.2 years (range: 14-16 years for in school; 16-24 for out-of-school).

Many participants were aware of ART. They reported to have heard about it from the radio, health facility and colleagues. Some appeared to be misinformed about availability of ART and thought the intervention could be available in dispensaries located within the ward. During visits of the dispensaries and local non governmental offices some written information (posters) about ART were noticed. Although many said ART did not cure HIV/AIDS, in most FGDs discussants feared that ART could be mis-understood by some people to be a cure for AIDS. Although many said ARV drugs were provided for free, some thought that they were sold at high prices.

Attitudes toward ARV comprised elements of both optimism and pessimism. Positive attitudes were associated with individual and public health benefits resulting from using medication. At the individual level, ART was perceived to be useful as it enabled HIV infected persons to get back to work and fulfil family and other social responsibilities like taking care of children. It was claimed that since AIDS has no cure, ARVs were the only option available to HIV positive persons. In some groups participants emphasized that as long as HIV positive persons were destined to die sooner; it was a reasonable

action to take the drugs, as suggested by one of the discussant: "...because someone knows that they are going to die, they would rather use ARV to prolong their lives. Sometimes ARV users will be thinking that should they die, their children would be left behind without someone to look after; so they are left with no other option but to take these drugs" (Female, out-of-school, 21 yrs).

In most cases attitudes about ART were described in relation to conducts of HIV positive persons. Those with favourable attitudes thought that ARVs extended lives and provided an opportunity for infected persons to engage in different activities for their own and family livelihoods. Positive attitudes to ART appeared to bear strong indications of family and community values. On the contrary, ARV use was considered by some participants as a waste of government and household resources. Some of them suggested that the money used for ARVs could alternatively be used to research on potential vaccines and for the provision of food for infected persons. One participant felt that making public announcements about availability of ARV through the media could mislead some people (particularly youth) into believing that AIDS can now be cured, and this could have negative consequences as some may resort to unprotected sex. "Let me say this...in fact these days we hear a lot in the media about these so called life prolonging drugs. But I think people who make announcements about these drugs simply want to kill us...because when they tell people that nowadays there some drugs for treating AIDS, some people might think that now AIDS can be cured. As a consequence some people may keep on having sex as they wish in the hope that even if they get infected they can survive on these drugs. But what happens if you don't get the drugs? You are dead!" (Female, in-school, 15 yrs).

In most focus groups participants tended to downplay the significance of ART. They claimed that ART was beneficial to persons with HIV and detrimental to uninfected members of community. A major concern was that ART could create an impression among young people that AIDS can be cured, and consequently lead to unprotected sexual practices.

Deliberate transmission of HIV

In most FGDs it was revealed that the availability of ART had made it more difficult to differentiate a "healthy" person from HIV positive person. To most participants this was considered a problem as people on ART were often regarded as "deliberate transmitters" of the virus owing to their return to good health. It was further pointed out that ARV use can make HIV positive persons appear healthy and sexually attractive and consequently endanger lives of uninfected persons who may be sexually attracted to them. In what appeared to represent the views of many in the groups, one participant offered this explanation: "I think that these drugs are beneficial to the sick person, but they also bring a lot of problems to those who have not tested (for HIV); let us face it, many people in this area normally assess (HIV) status by using their eyes ... You will hear someone say, this person looks beautiful, attractive, so she is not infected... These drugs are good to the sick person, but they will endanger the lives of those who are not aware of their HIV statuses" (Male, out-of-school, 20 yrs).

Some participants felt that because ART did not kill the virus, it would extend the time for HIV positive individuals to "deliberately" infect others. As a consequence of deliberate actions of some HIV infected people, some people were said to be getting infected "accidentally" or "unintentionally". However, other participants explained that decisions to engage in what was described as the "deliberate spread of HIV" rested on individual intentions and state of mind of ARV users. This assertion often raised disagreements as to whether it was individual choice or a characteristic common to most HIV positive persons in their own localities. Generally, male participants tended to address deliberate HIV transmission as an individual failure to control sexual desires among some people on ART as described by a 16-years in-school boy: *You see... persons on ART are advised against having sex, but many can't control their (sexual) desires... and others don't want to die alone. But if the person on medication engages in sex, she can hardly survive even for two years before dying*".

ARV drug users were thought to engage in what was described as the "business of selling" or supplying the virus to the uninfected members of

population as one participant reveals: *"These (HIV infected) men go around and ask women to have sex with them in exchange for money. They make it their business to exchange AIDS for money"* (Male, in-school, 16 yrs). In several group discussions it was stated that people living with HIV "tended to care less for the lives of others". Consequently, they would deliberately want to infect others with the virus and "die with them". As one participant put it: *"People (on ART) end up becoming healthy and energetic again... and as a result of this they spread the virus to others. Some of them feel that as long as they are already infected they are not going to live longer. Therefore, instead of dying alone they want to die with others. They feel good that they have someone to escort them... They want to be sure that when they die others will follow"* (Male, out-of-school, 23 yrs).

Nonetheless, not all participants shared this view. Some participants felt that ART had no impact on promoting harmful sexual behaviour particularly for people in rural areas. ART was perceived to be difficult to access in the villages because it was meant for rich people in urban areas. It was claimed that since HIV positive persons were "known to almost everybody" in the villages, avoiding sexual intercourse with such persons was a feasible option. Some said that people with HIV would normally exhibit symptoms such as frequent illnesses, body weakness and wasting; thus it was unlikely for HIV negative people to be sexually attracted to them. However, not all shared this view. It was claimed that "sexual temptations" employed by HIV positive persons to spread HIV were sometimes hard to resist". It was stated that temptations usually involves monetary and material incentives in exchange for sex. They said that in most cases sexual intercourse and relationships in the area were premised upon some form of exchange. When asked how the availability of ARVs relates to wilful spread of the disease, one out-of-school 19 years old female participant said: *"These drugs are dangerous to our lives. If an infected person has the money to spend; they will keep cheating girls into having sex. I know that some infected people are doing this in our villages... but we can not mention them here..."*

Economic hardships were mentioned as one of the major factors that could potentially increase

the risk of HIV infection when ARVs are abundant. In most group discussions recounted stories of (older) HIV positive persons reportedly buying sex from young girls and women. Both in-school and out-of-school male participants pointed out that school girls were particularly vulnerable because they were believed to be "HIV free and easy to cheat". Female participants also shared similar views and added that due to socio-economic hardships at home some girls often end up engaging in transactional sex. However, they emphasised that not all girls succumbed to such temptations. Participants recounted incidences where some people allegedly compiled (long) lists of people they had sex with and made it public before they died. It was pointed out that the nature of sexual networks in their area extended from two sexual partners to several people within a village and beyond. Participants tended to hypothesize that in absence of ART, uninfected people would abstain from sex.

Deliberate transmission of HIV was also blamed on people from both within and beyond the Ward. For instance, some participants thought that people from urban areas like Moshi who frequently came to do business and farming in Kahe were responsible for spreading HIV. They were thought to have money to buy both sex and ART.

Managing risk sexual behaviour in the context of ART

Participants indicated that counselling provided prior to using ART was a means to control risky sexual behaviours. Several participants recounted what they heard over radio that people on ART could survive on medication for as long as they strictly adhere to instructions attached to the medication. Many said that abstaining from sex was an important component of counselling. Apart from emphasising the role of counselling, they also felt that not all people on ART observed what they were told by health workers. Speaking about the importance of counselling one 14 years old female observed: *"I have the feeling that some of the people on medication do not follow conditions attached to drug use. I heard that some people have survived (with HIV) since 1994 to date. This means that a person could survive on medication for long time if he/she observed advice and conditions given*

by doctors. If he/she did not, this person would definitely have died already”

Discussion

The results of this study indicate that the availability of antiretroviral therapy may have both the desired and unexpected outcomes in the community. Young people's opinions highlight both a sense of optimism and pessimism about the availability of ARVs. Positive attitudes were associated with individual and public health benefits resulting from ARV use. Perceived benefits were mainly described in terms of enabling HIV infected persons to prolong lives and resume social roles. However ARVs were thought to have the potential to increase HIV spread due to reported reckless sexual behaviours among some ARV users. Nevertheless, the study has revealed that the potential impact of ART on risk sexual behaviour can be controlled through counselling. Generally, descriptions of ART contained three elements: a sense of optimism about short-term recovery and resumption of normal social roles; a concern over potential implications of therapy on risk behaviours of uninfected community members; and a concern that ART may lead to deliberate spread of HIV among some ARV users.

ART is basically intended to manage HIV related infections and improve quality of life of people living with HIV. Our findings suggest that improved quality of life of individual patient was perceived to have a wider positive impact on ability of HIV positive persons to care for immediate members of family (such as children and dependants). However, the findings show that improved quality of life was considered to be of limited value to other community members as this was perceived to potentially enable some ARV users to initiate risk sexual activity. This is contrary to previous evidence showing that receipt of ARV therapy was not associated with resumption of risk sexual behaviour (Batenganya *et al.*, 2005). Abstinence and reduced sexual risk behaviours have been reported to be preventive strategies adopted by the majority of HIV infected persons aware of their serostatus (Batenganya *et al.*, 2005; Keegan *et al.*, 2005; Schrooten *et al.*, 2001; Siegel *et al.*, 2006;

Luchters *et al.*, 2007).

Our study also suggests that health systems have an important role to play in managing risk sexual behaviour by emphasizing HIV prevention counselling and drug adherence. Participants believed that pre-ART counselling could exert social control over risk sexual behaviours and consequently manage the spread HIV/AIDS. This appears to be in agreement with evidence showing that effectively implemented ART programmes may achieve behaviour change through preventive messages (Crepaz *et al.*, 2004).

Findings show that positive attitudes towards ART were related to improved chances of survival and resumption of social roles among ARV users. This is in contrast with previous evidence showing that positive feelings were mainly attributed to the belief that ART reduced infectivity (Van de Ven *et al.*, 2000). On the contrary, unfavourable attitudes towards ART were attributed to the potential that antiretroviral therapy would have short term benefits to individual ARV users and negatively affect preventive sexual behaviours in the long run. Similar concerns about long term impact of ART on prevention fatigue have been reported elsewhere (Boily *et al.*, 2005).

Young people's concerns that ART could fuel risk sexual behaviours should be viewed against the contextual factors explaining HIV risk and transmission dynamics in the region as a whole and the study area in particular. While condom use among youth aged 20-24 years old is reportedly among the lowest in Tanzania (MoH, 2004), reproductive tract infections, sexual risk behaviours and HIV prevalence have significantly increased (Mmbaga *et al.*, 2006; 2007). It is against this background that our findings highlight concerns that public health benefits of ART identified by participants may be offset by what has been described as “behavioural disinhibition” among ARV users (Gray *et al.*, 2003). Further evidence indicating that the impact of ART on reducing sexual transmission of HIV-1 is likely to be small in areas with high HIV prevalence (Avert *et al.*, 2004). Furthermore, perceived impact of ART on sexual risk of HIV/AIDS should also be viewed in the context of power and gender relationships obtaining at the community. Participants reported that socio-economic hardships often exert pressure for some

girls to engage in sexual relationships with adults. As reported elsewhere (Haram, 1995; Nko & Pool, 1997; Luke, 2005), some form of transactional sexual relationships appear to inform young peoples' fears about availability of ART.

It appears that what was described by some participants as "unintentional or accidental" HIV infection highlights the constraints young people may face when negotiating safe sex in the face of economically powerful (older) people alleged to deliberately spread HIV. However, like in our study, empirical evidence shows that young people have not always yielded to sexual temptations of adults (Nkosana & Rosenthal, 2007). The existence of such relationships should also be viewed in light of reports of increasing HIV infection rates among adult population in the study area (Mmbaga *et al.*, 2007).

Participants' appeared to emphasise the role of individual motivation with regard to wilful transmission of HIV. However, at the structural level, deliberate acts of HIV transmission reported here suggests a lack of social control mechanisms (from family, community and health systems) to support positive sexual behaviour. Previous evidence shows that enhanced care and support, post-test counselling and positive family situation had an impact on risk reduction among seropositive population (Macneil *et al.*, 1999, Bunnell *et al.*, 2006). This highlights the combined roles of health systems, non-governmental organisations, affected communities and government policy in managing sexual transmission of HIV/AIDS. Recently the government of Tanzania passed a bill which among other things seeks to use legal mechanisms to manage and control HIV/AIDS (URT, 2006). It appears that widespread concern about deliberate transmission of HIV may have prompted the government to take this move. However, the public health implications of such legislation on HIV prevention and care are a subject for further inquiry and beyond the scope of this study.

Our findings suggest that public information about the benefits and shortcomings of ART need to be re-emphasised in line with objectives of the national ART care and treatment plan (MoH, 2006). The fact that some study participants reported that ART could be

misunderstood as cure for HIV/AIDS is an indication of a lack of appropriate information about ART. Appropriate information about ART may be vital in addressing negative attitudes and misconceptions about ART. Similar misconceptions have been reported elsewhere (Atuyambe *et al.*, 2008). Furthermore, empirical evidence reports that negative attitudes about ART during initial phases of treatment scale up can be changed (Schrimshaw *et al.*, 2005). Since ART roll out is currently going on in several parts of Tanzania, it is fair to say that public health education and information may promote attitude change and achieve social acceptability of antiretroviral drug therapy.

Our study had some limitations. The findings should be interpreted in light of the strengths and weaknesses of using group-based data collection techniques. While the method is useful in researching shared group experiences and opinions there are limitations on what people could openly express in presence of others (Morgan, 1993). In few instances some participants were not as outspoken as it was in others. Furthermore, more out-of school males than females participated due to difficulties (some reported to be married within and outside study area, others joined secondary school or were working as housemaids in urban areas) encountered in locating female out of school participants.

In conclusion, our findings show that ART has the potential to produce both positive and negative consequences to public health. While ART may sustain the lives of people on medication, it may potentially lead to risk sexual behaviours and stigmatise people blamed for fuelling deliberate HIV transmission. Creating a therapy friendly atmosphere through information delivery might prove crucial in promoting social acceptability of ART among youths. The study highlight both the need for antiretroviral therapy roll out in the study area while recognising the social and sexual behaviour challenges that need to be addressed to manage the social and sexual impact of increased availability of ART. Efforts to improve access to ARV drugs should re-emphasize prevention counselling to minimize sexual transmission of HIV.

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