



“When in the body, it makes you look fat and HIV negative”: The constitution of antiretroviral therapy in local discourse among youth in Kahe, Tanzania

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ABSTRACT

Antiretroviral therapy (ART) is becoming increasingly more accessible within the health care system in Tanzania. However, the impact of the increased availability of ART on local conceptions about medicines, health and physical wellbeing has not been fully explored. In this article we examine how ART is constituted within local discourses about treatment and healing. Based on 21 focus group discussions with young people aged 14–24 years in a rural area (Kahe), we examine how local terms and descriptions of antiretroviral therapy relate to wider definitions about the body, health, illness and drug efficacy. Findings illustrate how local understandings of ART draw on a wider discourse about the therapeutic functions of medicines and clinical dimensions of HIV/AIDS. Therapeutic efficacy of antiretroviral medication appeared to overlap and sometimes contradict locally shared understandings of the clinical functions of medicines in the body. Implications of ART on bodily appearance and HIV signs may influence conceptions about sick role, perpetuate stigma and affect local strategies for HIV prevention. Structural inequities in access, limited information on therapeutic efficacy of ART and perceived difficulties with status disclosure appear to inform local conceptions and possible implications of ART. Policy and programme interventions to foster public understanding and acceptability of ART should emphasize treatment education about the benefits and limitations of therapy and increased access to ART in rural areas, and should integrate voluntary status disclosure and HIV prevention.

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Introduction

Although current medical breakthroughs have not produced a cure or vaccine for HIV/AIDS, the availability of antiretroviral therapy (ART) has improved the health and wellbeing of people living with HIV and AIDS. ART has contributed to a reduction in hospitalization rates, morbidity and mortality by 80% in countries where treatment is available and turned the disease from being a death sentence to a controllable chronic condition (Detels et al., 1998; Paul et al., 2002). Sustained access to ART is envisaged to help strengthen patients' damaged immune systems, assist in managing opportunistic infections, lower the viral load and limit chances of transmission (Detels et al., 1998; UNAIDS, 2006).

Access to ART in resource poor settings like Tanzania is still limited. In response to such limitations, the “3 by 5” initiative has been implemented to increase access to antiretroviral medication (UNAIDS, 2006). In line with implementation of the initiative, Tanzania adopted a public health approach to ART programme in order to ensure universal access with an initial target of reaching 400,000 eligible persons by 2008. By the end of 2006, the programme had been able to set up 200 ART sites and reached 44,000 people (Tanzania Ministry of Health, 2006). Like many other sub-Saharan African countries, treatment coverage stood at 11% of those in need of therapy (Stoeckle et al., 2006; UNAIDS/WHO, 2006). Despite the recent increase in the number of people receiving treatment, antiretroviral drug coverage in eastern and southern Africa is still only 32% of those in need. Major obstacles to reaching universal coverage include weak health care systems, shortage of human resources, weak monitoring systems to track impact of HIV programmes and lack of sustainable funding (WHO/UNAIDS/UNICEF, 2008). At the community level, problems with maintaining drug adherence, nutritional requirements and transport costs pose

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challenges for individuals and families (Hardon et al., 2007; Mshana et al., 2006a, 2006b). The constraints highlighted above show that universal access has not been attained. This highlights the need to explore and understand factors that may support the realisation of national treatment programme goals at the local level.

Antiretroviral therapy is a relatively recent phenomenon in the management of HIV/AIDS in the Tanzanian public health system. Implementation of ART programmes requires combined efforts of health systems, policy environment, individuals on ART and other affected community members. However, community definitions and responses to antiretroviral therapy remain largely unknown. Social responses to the introduction of ART might prove crucial in supporting available policy and programmes aimed to achieve universal access. It is recognised that one way of reacting to disease and illness is to make sense of the problem in everyday social interactions using language. The role of language and communication becomes crucial in explaining a disease and finding appropriate responses to illness (Helman, 1990). The human body is often the most immediate and visible site of representation of illness and communicating about treatment. It is the visual changes in persons' bodies that are the basis of how others explain treatment outcomes. It has been suggested that there is an apparent link between therapeutic efficacy of drugs and its effect in modifying bodies (Whyte, Van der Geest, & Hardon, 2002). Local descriptions of HIV/AIDS have often taken the form of metaphors about signs, symptoms and the real and perceived implications of the disease to the welfare of community members (Farmer, 1990, 1994; Helman, 1990; Mshana et al., 2006a; Setel, 1999; Stillwagon, 2003). Previous studies underline the importance of signs and symptoms in people's reactions to HIV/AIDS. Borrowing from this the current study will further explore how ART may affect local understanding and social responses to bodily signs of HIV/AIDS.

Previous studies on the interrelationship between ART and the body have dealt with issues related to medication adherence and side-effects (Schrimshaw, Siegel, & Lekas, 2005), body image (Huang et al., 2006; Sharma et al., 2007), changes in sexual behaviours and sexual dysfunctions (Colson et al., 2002). Psycho-social implications of bodily syndromes and changes in physiological composition resulting from medication have also been a subject of several studies (Mallon, Miller, Cooper, & Carr, 2003; Power, Tate, McGill, & Taylor, 2003; Santos et al., 2005). These studies have mainly focused on implications of therapy on self-perception of body image and physical functioning amongst persons living with HIV. Our study takes self-perceived body image and physiological changes resulting from ART as starting points in understanding how therapeutic function of ART is conceived and communicated through local descriptions of ART and the lived experiences of young people.

Most recent evidence from Tanzania has revealed that although antiretroviral therapy is a welcome development, structural constraints continue to limit access to treatment (Hardon et al., 2007; Mshana et al., 2006b; Stoeckle et al., 2006). There are concerns about costs of transportation to health facilities, supplementary food costs, difficulties in sustaining long-term treatment and fear of stigma and rejection following status disclosure (Mshana et al., 2006b). Although these studies have been successful in highlighting constraints to access and suggestions to improve ART programme, they fall short in identifying local interpretations of ART and how these might affect community responses to treatment programmes. As Van der Geest and Hardon (2006) assert, it is important to study how social and other meanings of medicines impinge on the quality of provision and medicine use in different communities.

Local understanding and social responses to ART may be critical to ensuring increased access and provision of quality services.

Responses to new treatments may take different forms for different social actors. Medicines are usually evaluated based on how they perform a core clinical function, namely, healing. Concepts of "labelling" and "managing" a particular illness (Kleinman, 1980) are useful tools employed in understanding the social and clinical aspects of ART. Labelling is done through assigning local terms to ART. Equally useful is analysing how young people manage this new medical breakthrough in their daily lives. Our study attempts to present how antiretroviral therapy is constituted within the local discourse about treatment and healing. Young people were selected to participate in this study as they continue to be among the most at risk population in Tanzania (Tanzania Ministry of Health, 2004). This is particularly true of the study area. Evidence shows that although HIV prevalence among people aged 15–24 years has been stable in recent years, HIV prevalence and sexual risk practices in the general population have been increasing (Mmbaga et al., 2006, 2007). Availability of ART should also be viewed in the context where 85% of people are unaware of their HIV status and those aware are faced with the dilemma of managing status disclosure (Tanzania Ministry of Health, 2007). ART requires community-based support; therefore understanding young people's perspectives could be one of the key steps in engaging specific population groups and affected communities in support of ART. The current study may inform treatment education efforts and make a contribution to improvement in strategies to integrate ART into other national HIV/AIDS programmes and ultimately achieving universal access.

The purpose of this study was to determine how antiretroviral therapy is understood and constituted in local discourses among young people. It presents how antiretroviral therapy is interpreted within the local conceptions about treatment and healing. Young people were selected to participate in this study as they continue to be among the most at risk population in Tanzania (Tanzania Ministry of Health, 2004).

The study is guided by the following research questions: What are the local terms used to describe and communicate antiretroviral therapy among young people? How are definitions of therapeutic efficacy of ART related to local ideas about the body, health and HIV/AIDS?

Methods

Study context

Kahe ward is a site of a reproductive health system project targeting young people. It is a rural area in Kilimanjaro region of Tanzania, located about 30 km south of Moshi town. It is comprised of 11 villages, most of which are remote except two found along the highway. A number of ethnic groups inhabit the area with an estimated total population of 23,700 inhabitants. Main ethnic groups include the Kahe, Pare and Chagga, and several others from within and beyond the country. A majority of inhabitants practice small-scale rice farming and animal husbandry. In addition to different tribal languages, Kiswahili is most widely spoken. A majority of inhabitants are Christians (predominantly Catholic and Protestant). The location of study area adjacent to a sugar factory has attracted in-migrants from different parts of Tanzania. As such, in-migration is among the risk factors of HIV-1 and high HIV prevalence in the area (Mmbaga et al., 2007, 2008). Two government run dispensaries serve the ward population. At the time of study, antiretroviral drugs were available at the regional hospital in Moshi town. Over-the-counter (non-prescription) drugs for treating common illnesses (malaria and fever) are available in drug shops in the villages. This proliferation of unregulated drug sales has implications on how study participants understand medicines,

as we shall point out later. More details about the study area have been presented elsewhere (Mmbaga et al., 2006).

Participants and data collection

We conducted focus group discussions (FGDs) in all villages between July and October 2006. FGDs targeted in-school and out-of-school youth. We conducted separate FGD sessions for in-school and out-of-school youth. To facilitate open discussion, groups composed of between 7 and 11 participants were further segregated by school, village and sex (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 min. A semi-structured FGD guide with options for probes guided moderators (see Table 1).

All group discussions were audio taped. We also recorded important issues that transpired during discussions in notebooks. At the end of each discussion, we held a debriefing session to double check recording quality, identify gaps and discuss new leads to be followed up on in consecutive sessions until no new information was forthcoming. This process allowed us to rephrase and constantly adapt words we used to introduce antiretroviral therapy in discussions. Each FGD session was code numbered to maintain anonymity.

Data collection adopted an inductive approach (Cresswell, 1998) to continually describe, compare and contrast young people's experiences of ART as data collection progressed. The inductive approach gave us the flexibility to explore all possible terms/descriptions throughout the data collection. The interdependence and relationship between local discourses surrounding ART and other social practices relevant to health and HIV/AIDS (Cameron, 2001) was the guiding principle in data collection and analysis. For instance, while available empirical evidence suggests that HIV/AIDS is a growing problem in the study area (Mmbaga et al., 2006), in exploring local terms and its implications, we were mindful of contextual factors (such as general constraints to accessing health care and sexual explanations of HIV/AIDS) that might influence local understanding of ART.

Analyses

Moderators transcribed, translated and double-checked collected data. We created free nodes classified according to specific words, statements and phrases that described ART. Coded narratives were grouped into categories representing major issues that emerged by comparing and contrasting them throughout the process. The analysis also involved reading the categories of text to determine consistency and establish underlying assumptions behind the local terms and conceptions about the body. We compared and contrasted the categories based on how they explained health and illness in the context of locally relevant

understanding of therapeutic function of medicines. In the "Results" section, we present key themes that emerged.

This work is part of the larger adolescent reproductive health project (targeting both in-school and out-of-school youth) conducted in Kahe ward. We obtained ethical approval from the Ethical Committee of the Ministry of Health in Tanzania and the Norwegian Committee for Medical Research Ethics.

Findings

We present findings from twenty-one (21) focus group sessions involving 100 (M = 50, F = 50) in-school and 93 out-of-school (M = 59, F = 34) participants. The mean age of study participants was 17.2 years, and the ages ranged from 14 to 16 years for in-school and 15 to 24 for out-of-school participants. Analysis revealed three main themes: accessibility and target group for antiretroviral therapy, explaining the efficacy of ART and descriptions of the body on ART and its implications on local HIV prevention dynamics. Throughout the "Results" section we also present local terms commonly used to describe ART.

Awareness of antiretroviral therapy

Nearly all participants had heard something about ART. Radio, hospital and peers/friends in the streets or neighbourhoods (known in Kiswahili as *mtaani*) were the most commonly mentioned sources of information. Family members, religious institutions and school were least mentioned sources. In all villages, participants were concerned about the impact of advertising (through radio and other media) that some people (specifically herbalists) had invented herbal medication that cured AIDS. Information delivered through radio appeared to have powerful influence on participants' knowledge and awareness about ART. Many participants mentioned that ART was available in hospitals. They also indicated that the drugs could be available in big hospitals, while others thought that the drugs were available in their local dispensaries and some health facilities located outside Kahe ward. Awareness about ART in the study area varied from village to village. Out-of-school youth appeared to be more informed about ART. This could be due to their relatively unrestricted freedom of movement to urban areas, contact with health facilities and involvement in village-wide and other social networks. Few participants admitted to have personal knowledge of someone who had tested positive and been using ARV as one of them revealed;

...Yeah... I am aware of a woman who had been using the drugs...but she died recently. She was diagnosed at KIWAKUKKI (a non-governmental organisation supporting HIV infected people in Kilimanjaro region) clinic, and tested positive for the disease (AIDS). She had been on drugs until she died. But you could see how she became healthy again after being on medication. (Female, out-of-school, 22 yrs)

Accessibility and target group of ART

Some participants thought pregnant women were the targeted beneficiaries of ART (to prevent HIV infection in unborn babies). Furthermore, it was perceived to be available in villages considered more "wealthy, modern and developed" than their own. This appears to be in line with earlier discourses which often described HIV/AIDS as a "disease of development" (Setel, 1999). Nevertheless, the concept of antiretroviral therapy appeared to be new to some participants. In trying to make sense, others asked if the drugs had a name (brand) so that they could go and ask for them at local drug shops/kiosks. It is important to note that some non-prescription

Table 1

Focus group discussion guide.

- Are you aware of any medication used to treat people with HIV/AIDS? (*Probe*: sources of information on ART, accessibility, eligibility criteria, knowledge of someone on ART).
- Can you describe to us what you know about the antiretroviral medication (*Probe*: what ART does in the body)
- What are the terms used to describe ART in your daily interaction? (*Probe*: meanings and local context of the terms)
- What do you feel is the potential impact of ART on HIV prevention in your village? (*Probe*: beliefs about medicines, potential impact on HIV related preventive behaviours, feelings about people on ART)

drugs for treating other common illnesses are usually available for sale in local shops/kiosks. Normally people would identify drugs for treating common illnesses by their brand names. As most had long exposure to brand names of drugs used to treat other illnesses (and actually drugs can be bought without doctors prescription), it seemed logical for some participants to ask for the brand name;

This (ART) is a new thing to me, first of all, what do these drugs mean, we don't know how they are administered, and we don't have them in our village...we are not sure because we have never asked for the drugs at the kiosks, by the way what are they called? I guess no one knows its (brand) name... if we knew the name we could go and ask to check if they were available. (Male, in-school, 15 yrs)

In some villages, participants mentioned that ART was accessible to the rich, urban residents, and famous people. In local context, famous people were normally associated with financial power, political and social influence. Furthermore, the introduction and availability of antiretroviral drugs were understood to be intended to benefit people owning drug shops who were often perceived to make a profit (through drug sales) from other people's health problems.

Furthermore, while describing what they knew about ART, it was common to constantly invoke rural–urban inequities in access as is evidenced from one of the participants below;

I think there are no drugs to treat AIDS, but I heard in the radio they were saying that there were some kind of drugs used by people with HIV... but definitely these drugs is not something you can have in places this (village)... they must available somewhere in town (Male, in-school, 16 yrs)

The introduction of ART highlights difficulties regarding status disclosure. In many group discussions participants said that even if drugs were available at the local pharmacy, it would be difficult for most people to access them for fear of inadvertently disclosing their HIV status. Many said they would be comfortable to getting medication from hospitals away from their village. In many instances, participants insisted that it was difficult to know ART users as the drugs were taken in great secrecy.

Kubadilisha damu

This term refers to “exchange blood transfusion”. Although it was the least mentioned, participants stated that the procedure was expensive and only affordable to rich people residing in urban areas. In the local context of HIV/AIDS, exchange blood transfusion is a procedure to replace “dirty” (HIV infected) blood with “clean” (uninfected) blood. It appears that the availability of ART might have contributed to the decreasing popularity of this concept. Although this concept is relatively older than the rest identified here, it suggests that current discourses have remnants of previous ones. This concept highlights the centrality of blood as a vital fluid for life. It also highlights the fact that HIV/AIDS related treatments were, until recently, relatively very expensive and accessible only to affluent people.

Explaining the efficacy of antiretroviral therapy: the problem with treating without cure/healing

In most discussion sessions, when asked if they were aware of any drugs for treating people (*dawa za kutibu UKIMWI*) living with HIV, most claimed to be unaware. It appeared that our reference to antiretroviral “drugs” or “medications” suggested to some participants that there was a cure for HIV/AIDS. The concept of “*dawa*”

(drugs/medicines) appeared problematic in view of what participants thought was common knowledge that HIV/AIDS was incurable. Generally, there was a sense of lack of familiarity with the new drugs as some participants said they did not have a brand name they could refer. This response was common amongst participants from remote villages. Sometimes participants quickly pointed out that we were wrong to suggest that HIV/AIDS had some kind of medication or cure as one participant suggests below;

Wait a minute, do they treat or prolong lives? Since when has AIDS had a cure? (Female, out-of-school, 19 yrs)

Indeed, our use of the concepts “drugs” and “treatment” linked to HIV/AIDS led some to question and revisit their understanding of ART. This explained why some participants initially admitted not having heard about any medication used to treat AIDS. Responses changed after other participants within groups clarified that we were talking about what many participants described as “life prolonging drugs/medication”. Our aim was to minimize bias and be as exploratory as possible by refraining from using “official” word/s used to describe ART. This approach proved useful as it allowed participants to come up with different terms as shall be shown in this article.

It became clear to us that we had to adopt a more explanatory and locally appropriate style of talking about ART to avoid suggesting that there was a cure. Participants claimed that a primary criterion of drug efficacy lied in its effectiveness at “curing” (by killing or removing) disease causing organisms from a human body. They claimed that ART was unable to achieve this function because it does not kill the virus (HIV). Consequently, some participants thought ART was of little significance because it only made the virus temporarily “dormant”.

I find these (drugs) completely useless... now, tell me, what is the use in having someone use drugs, or anything that does not cure? What it (ART) does is simply make the virus drunk...yes you may prolong your life a little bit... and that's all! (Male, out-of-school, 21yrs)

Dawa za kurefusha maisha

This term literally means “life prolonging drugs”. This was the most commonly mentioned term. Until recently the term featured in most official literature on ART. The popularity of this term could be due to the fact that it has been widely used by the mass media and in health care settings. As Foucault (1981) asserts, in every society, discourse production is controlled, organised and distributed by a number of procedures especially by the powerful forces. The powerful influence of mass media and government health institutions is a case in point. It may also be useful to study further the factors behind shifts in the official discourse about HIV/AIDS in general and ART in particular. Currently, the official term (known as *dawa za kupunguza makali ya UKIMWI*) is used. However none of the study participants mentioned this term.

A further analysis of how youth presented this term (“life prolonging drugs”) revealed some negative connotations on the logic behind this concept. Prolonging life was less useful than a cure. Long established diagnostic label describing AIDS as an incurable life threatening disease (death sentence) may provide a possible explanation. It suggests that persons on ART were merely prolonging life, hence a claim that as long as they were destined to die (because the drugs do not cure), they were likely to have sex and spread HIV. One participant remarked:

Mind you, this (ART) does not cure... but people (with HIV) continue to survive and at the same time, they keep spreading the virus (Female, out-of-school, 16 yrs).

As a result, this could make ART clients targets of discrimination and stigma. In the context where majority of people do not know their HIV status, this may also discourage people to test and disclose status. Efforts to address stigma against infected persons, ART adherence, and HIV testing and status disclosure are vital in this context.

Dawa za kuongeza nguvu

Literally means “energy enhancing drugs”. Participants mentioned that antiretroviral drugs have the ultimate effect of making HIV positive persons energetic and strong. They equated being energetic to physical health and wellbeing. In contrast, people with HIV who were not on ART were often thought to be sick (*wagonjwa*) and weak (*kuchoka/amechoka*). By using energy enhancing drugs, a person became healthy/well again.

Dawa za kusogeza siku

Literally translates as “drugs to push or extend days”. Participants described the drugs as capable of enabling someone to survive for more days as opposed to the concept of “life-prolonging” described earlier. Some participants chose to give an indication of the duration of life that ART could prolong. Responses varied from a few months to 10 years. Generally, most of them did not attempt to specify a definite length of time and preferred to give shorter estimates while underlying the sense of physical suffering associated with prolonged illness.

I heard there are drugs for extending the lives of these people (living with HIV)... so that instead of dying today they can survive, may be, until next month or so. (Male, in-school, 16 yrs) They (drugs) are useful because they help to prolong life. If you were to die this year you may survive for a little bit longer, but with prolonged illness. (Female, out-of-school, 18 yrs)

The description of the terms above suggests that availability of ART did not rule out death as an important and predictable consequence of HIV and AIDS. Despite acknowledging that ART could prolong lives, participants’ descriptions still suggest that HIV/AIDS is associated with death. It was common to suggest that it was better to die quickly than endure long-term suffering with prolonged illness. “Six by six” was a metaphor often used by some participants to describe what HIV/AIDS meant. It symbolically represented a grave, which normally measures six feet in length and depth. In what appeared to be in agreement with the views of other group members, one participant described what he considered as “medication” for HIV infected persons:

The only medication for AIDS is six by six. I feel that people with HIV should be left to die, that’s all. (Male, out-of-school, 22 yrs)

Descriptions of the body on ART and implications for local HIV prevention dynamics

Descriptions of the therapeutic efficacy of ART mainly revolved around how bodily changes affected sexual relations and HIV prevention dynamics. Participants mentioned that ARV users had to adhere to certain conditions to realize the benefits of treatment. A frequently mentioned conditionality was abstaining from sex. They argued that sexual intercourse during ART use would make a person on treatment “very weak”. Persons on ART were described as sick, patients, and sometimes as spreading the virus.

ART appeared to interfere and introduce new dynamics in what participants already knew about signs and possible consequences

of HIV/AIDS. Participants described an ideal type of an HIV positive person as always sick, appearing weak, eventually dying. On the contrary, ART made infected persons experience brief recovery from illness and look fat/healthy. They claimed that it was difficult to avoid having sex with HIV infected persons who looked fat, energetic and handsome/gorgeous, appearances that were considered characteristic of healthy (probably uninfected) persons. Most of them said that a healthy body was always sexually demanding. Therapeutic consequences of ART in the body were often evaluated as symbolic of personal wellbeing and sexual activity. A claim that kept resurfacing in discussions was that since almost everyone knew one another in the villages, it was possible to suspect a person’s HIV status with a good degree of certainty. They often hypothesized that in absence of ART it was possible to tell a healthy body from HIV infected one through naked eyes. Skin rashes, wasting, frequent coughs and fever were frequently mentioned as vital signs to suspect someone was HIV positive. Since these signs “disappeared” with ART use, chances of sexual interactions with infected persons were higher. In a statement that resembled most of her colleagues, one participant summed it up as follows:

I heard that the drugs can prolong lives, make the body appear like someone is not HIV infected. The drugs make someone fat with an enlarged stomach (*kitambi*)...as a result of this other people may never know that this person was HIV positive and may end up having sex with them (Female, in-school, 14yrs)

Dawa/sindano za nguruwe

This term literally means “pigs’ drugs/injections”. It is a symbolic metaphor representing certain kinds of medication meant for fattening pigs. One participant described it as follows:

Yes, I have heard that some people are self-injecting with these pigs’ medications... When someone learns that he/she has the (HIV) virus... he/she injects oneself with the medication, that’s why they are called pigs drugs... yes, after using drugs someone becomes fat like a pig... you know how fat pigs can be! (Male, in-school, 15 yrs)

The term connotes the bodily changes seen to result from ART. It is crucial to note that a majority of residents in the study area were Christians. Pig farming is also common practice in the area. Participants claimed that swine farmers often inject pigs with a certain kind of medication to make them put on weight and consequently fetch a higher price in the market. Furthermore, participants believed that eating pork helped HIV positive persons put on weight.

Sindano za kunepesha

The term means, “fattening injections”. The term reflects accounts that ARVs injected into the body make HIV positive persons look fat. A dominant view among participants suggested that after learning of their serostatus they injected medication with the intent to put on weight. It was common to describe the outcomes of ART in terms of putting on weight and enlarged stomach (locally known as *kitambi*). In the local setting, the enlarged stomach is a sign of good health, wealth and high social status. Furthermore, many believed that injections were stronger, painful and in effect more efficacious than tablets because they went straight into the blood stream. However, views suggesting that ART was orally administered (mainly in the form of tablets) were dominant.

Discussion

The study has revealed that participants hold mixed views and responses about the therapeutic value of ART. Participants tended to view treatments and cures differently and thus respond to medicine by their ability to perform both functions. Local terms identified had elements of lay, biomedical and official discourse about ART. All terms seem to acknowledge the role of ART in enduring survival while emphasizing different aspects of health and individual wellbeing. The study shows that local discourses may contain some remnants of the previous official or dominant discourses and at the same time embracing new ones. While some terms emanated from official/public discourse (such as life prolonging drugs), others appeared to come from participants' own local experiences (such as fattening injections, pigs' medication). Use of ART was understood as primarily intended to make persons on treatment recover (temporarily) from illness, get fat and look healthy. ART appeared to be at odds with a socially established body of knowledge about physical symptoms of HIV/AIDS. Assessment of physical symptoms was considered an important determinant of HIV status, participants' interactions with HIV positive people and consequent sexual decisions. Consequently healthy appearances among ART users were thought to compromise local ways of avoiding HIV infection and fuel deliberate HIV transmission. Structural inequities in access, limited information on therapeutic efficacy, difficulties with status disclosure, and limited access to counseling and testing services appear to inform conceptions about and sociomedical implications of antiretroviral therapy.

Findings suggest local descriptions of ART appeared to conflict with young people's explanatory model of HIV/AIDS and responses to treatment. The line between "treating" or "curing" a disease on the one hand and "prolonging life" on the other seemed blurred. For instance, participants challenged the notion of "AIDS treatment" in the context of what they regarded as common sense knowledge that HIV had no known treatment and cure. Hence the tendency to question the possibility that some medications could actually treat HIV/AIDS. However, their doubts appeared to confirm their awareness that antiretroviral treatment was not capable of transforming a sick body into a healed (*kupona*) one. Therapeutic functions of ART appeared to be in contrast to what has been described as the habitual form of therapeutic practice (Whyte et al., 2002) commonly experienced with other locally known drugs in the study area. This obsession with cure seems to have something to do with traditional healing procedures, where healers often 'remove' diseases by removing substances from the body. It is reported that HIV positive people often bring home what the healer has removed in bottles or glasses (Talle, personal communication, February 21, 2008). Further research should investigate how other forms of healing (traditional, folk and spiritual) conceptualize ART and how this shapes the local discourses.

Our assumption was that sources of information might influence local understanding of ART. Most participants relied on information from the radio and tended to emphasize the biomedical aspects of care. It is interesting to note that teachers, parents and religious organisations, which have been identified as important sources of HIV/AIDS related information elsewhere (Masatu, Kvåle, & Klepp, 2003; Ndeki, Klepp, Seha, & Leshabari, 1994), appeared to play less of a role as sources of information on ART. Practical implications of this observation warrant further exploration. As observed in this study, incomplete knowledge or misinformation about ART may cause confusion about the health status of persons defined based on bodily symptoms. Available evidence indicates that people with symptoms of opportunistic infections are often assumed to have HIV and consequently isolated and stigmatized (Nyblade et al., 2003). Such assumptions might explain why young people in our

study thought it was easy to identify people with HIV in absence of ART. This belief suggests that ART roll out should be well placed to address the role of physical appearances in explaining stigma.

It appears that availability of ART may contribute to fighting stigma if appropriate strategies (at community level and health systems) to promote voluntary testing and status disclosure are in place. The fact that ARV drugs were reportedly taken in secrecy suggests that participants were aware of the possible consequences (such as stigma and discrimination) of HIV status disclosure in their respective communities. Since HIV/AIDS appears to maintain the diagnostic label of a "deadly and incurable" disease, the practical implications of increased ART availability on stigma and status disclosure warrant further inquiry. This also highlights the key role of health workers and communities in addressing forms of stigma that may result from or disappear with increased availability of ART.

It has been argued that particular groups within society will tend to adopt approaches to the body which correspond to their social location in the social structure (Cregan, 2006). Consistent with the foregoing argument, ART related discourses reported in this study appear to define and represent structural inequalities shaped by geographic location, access to socio-economic resources and social position of youth. Youth concerns about ART highlight a sense of collective vulnerability to HIV/AIDS reported elsewhere (Herdt, 2001). In the context of this study, vulnerability may be expressed at two levels. First, by placing blame on ART users accused of bringing and intentionally spreading HIV and, second, consequently; vulnerabilities associated with perceived barriers to accessing ART in rural areas. Similar concerns about urban bias in ART accessibility have been documented elsewhere in Tanzania (Mshana et al., 2006a, 2006b; Stoeckle et al., 2006).

Local terms suggest that some physically observable (side) effects of antiretroviral drugs may acquire social and sexual meanings at the personal and societal level. In participants' descriptions, such morphologic changes (for instance weight gain and enlarged stomach) were a sign of "return to good health". Physical changes have been reported to have negative impact on drug adherence and body image among people with HIV (Guaraldi et al., 2003; Huang et al., 2006). In contrast, the current study suggests that bodily changes were both socially approved and perceived to have implications beyond individuals on ART. In structural functional terms, the bodily manifestations may represent a functional role of ART in restoration of health and social order following disequilibrium brought about by HIV/AIDS in the body. Furthermore, as Kleinman (1980) asserts, the restoration of order reflects the notion that disease affects single individuals while illness most often affects others besides the patient, and at times entire communities. In this regard, while ART is intended to manage individual illnesses, the potential public health effects (both positive and harmful) are likely to impact on entire communities. In the context of HIV/AIDS, a major concern among young people was that "regained health" could fuel unprotected sexual activities. Sexual constructions of the healthy body (Cregan, 2006) might explain concerns that restoration of good health could potentially result into unprotected sexual activity among ART users after restoring their "health". Availability of ART therefore reinforces the need for HIV prevention efforts with strong emphasis on safer sexual behaviours.

People on antiretroviral medication were often described as "sick" or "patients" even when there is evidence that not all people with HIV are in a clinical setting (UNESCO, 2006). Youth descriptions located them between the passive state of "patients" in need of care and active "agents" of HIV transmission. Participants' ambivalent positions appear to be influenced by the biomedical interpretations and diagnostic labelling of HIV/AIDS as a life long illness requiring continuous medication and care (Helman, 1990). It

is fair to say that despite the life prolonging properties of ART, the diagnostic labelling established in the medical and dominant discourse makes HIV/AIDS continue to be potentially deadly. The shifts in conceptions of people on ART described above may represent the paradoxes and dilemmas of defining a “patient” and assigning sick role in the context of ART. Such shifts may also affect how uninfected members of community interact with HIV positive persons, care-seeking behaviour, and the support (material, emotional) that uninfected persons can offer.

Findings from this study suggest that more efforts may be needed to conduct treatment preparedness education. Treatment education, among other things, emphasizes de-medicalising of ART related terminology by making information and messages on drug regimens gender-responsive, culturally appropriate, age-specific and available in local languages (UNAIDS, 2006). The need for treatment education at the initial stages of treatment roll out is vital in order to support adherence. Treatment education underlines the fact that taking medication is both an individual and a social undertaking. While individual agency may influence ART use, social arrangements may exert control in how medications are defined with regard to expected social function. The effect of medication onto the body may send numerous public health messages to different members of the community, as young people appear to suggest here. Perhaps one of the most startling messages in this work is that the introduction of antiretroviral therapy should serve as a reminder that, with ART, it is even more difficult to judge HIV status by physical appearance. Public health messages need to respond and accommodate changes brought about by ART.

Our study 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). Due to logistical problems, our study had fewer out-of-school female participants. However, those who participated were sufficient to allow for lively discussions and a wealth of information that may inform ART programmes and future research. Furthermore, during the conduct of this study ARV drugs were available in health facilities outside the ward. This might have limited ability of some participants to connect responses to existing realities and thus a potential for interpretive bias. The explorative nature of this study warrants further inquiry of social aspects of ART in other settings and social groups.

Conclusions

The functional and symbolic meaning of drugs shapes local understandings of ART. ART has introduced a paradigm shift in locally relevant therapeutic definitions of drugs and conceptions about the HIV positive body. While ART might be empowering to HIV positive persons it has the potential to perpetuate existing structural inequalities in access and affect local patterns of risk, transmission dynamics and prevention of HIV/AIDS. The combined influence of biomedical and official discourse and culturally relevant understanding of health, disease, and response to illness on local conceptions was also evident. Indeed, findings have shown how descriptions of ART at the micro level may paint a larger picture of the state of health and social organisation of illness and treatment. Further research on impact of ART on self-perception of body changes and medication adherence amongst persons may broaden understanding of the individual experiences of treatment in rural Tanzania. It might be interesting to investigate local discourses surrounding ART in different geographical settings concurrently with on-going national treatment scale up programme.

ART roll out in new settings should include treatment preparedness campaigns to engage communities to take positive steps to promote, understand and normalize ART. Information about ART should carry culturally appropriate messages addressing stigma, voluntary status disclosure and drug adherence support. Setting up ART clinics and hiring more health workers in rural areas may contribute to addressing the logistic barriers to access. Promoting HIV counseling and testing might prove useful in making ART fit well in the local context of treatment, care and support.

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