

## THEME ONE: HIV/AIDS, REPRODUCTIVE HEALTH AND RIGHTS

# EVOLUTION OF HIV/AIDS DISCOURSE AMONG THE HAYA ON TEN LANDING SITES ON THE WESTERN SHORES OF LAKE VICTORIA, TANZANIA: NEED FOR A SHIFT FROM A BIOMEDICAL TO A MEANINGFUL LIFE DISCOURSE

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### Abstract

*Kagera is one of the areas considered to be an epicentre of the HIV/AIDS epidemic in Tanzania. This has been due to linking HIV/AIDS and the cross-border trade between Uganda and Tanzania, an activity that was due to lack of essential commodities after the Uganda-Tanzania War of 1978-1981. In a survey in the landing sites of Lake Victoria, where one of the elements is to know the state of HIV/AIDS, it is found out that people are giving up in their struggle against HIV/AIDS, a situation that leads to the perception of contracting HIV/AIDS being an "occupational hazard". As the African sexual permissiveness theory has been at the back of the bio-medical discourse and the eventual behavioural change paradigms in guiding HIV/AIDS interventions, this article proposes change of discourse by having the meaningful life discourse in HIV/AIDS interventions.*

### Introduction

In Africa, HIV/AIDS was first observed in the Kagera Region of Tanzania and the bordering areas of Rakai District in Uganda. Despite multiple interventions over the years, the disease spread fast and has persisted due to a number of reasons, not least of which is the local perception of the disease. Studies, however, have shown how the HIV prevalence has drastically fallen in the years between 1984 and 1999. In the high prevalence area of Bukoba Urban, it has fallen from 24.2% to 13.3%; in the medium prevalence of Muleba, from 10% to 4.3%, and; in the low prevalence area of Karagwe, from 4.5% to 2.6% (Kwesigabo et al. 2005). The reasons for the decrease of the prevalence are linked to changes in sexual behaviours, norms, values and customs that are of high risk for HIV transmission. There has been increase in condom use, abstinence, "zero grazing" (sticking to one partner), and uptake of HIV testing, while traditional practices such as polygamy, widow inheritance, excessive alcohol consumption, and sexual networking are declining (Lugalla 2004).

This article is about an assessment of the HIV/AIDS situation in light of the dominant discourse on the

disease among the Haya people of Kagera Region. It is a reflection of the state of the HIV/AIDS pandemic in ten landing sites on the western shores of Lake Victoria. It is part of a baseline survey on the "Public-Private Partnership Pilot project of Eco-Labeling of Nile Perch at Bukoba", conducted between February and May 2008 with funding from the GTZ. The article begins with background information based on the results of the survey, giving a general overview of the HIV/AIDS situation in the landing sites. There follows a presentation of the changing perceptions of HIV/AIDS among the Haya people, with an aim of showing that the perception of the disease has changed over time, given the prevailing socio-cultural contexts. Analysis of the HIV/AIDS discourse follows with the aim of understanding the dominant discourse that has informed and influenced HIV/AIDS-related interventions. The article winds up with a call for change of discourse based on the Logotherapy discourse, based on the will to find meaning in life.

### Methodology

The study was conducted in ten landing sites on the western shores of Lake Victoria. The data were obtained by administration of 414 questionnaires, 10

Focus Group Discussions (FGDs) and more than 20 in-depth interviews. While the standardised questionnaire was analysed by use of the Statistical Program for Social Scientists (SPSS) to obtain the descriptive statistics, content analysis was used in interpreting the FGDs and interviews. The findings have been corroborated with those from a thorough literature review.

The respondents were largely (77%) people engaged in fishing and its related income-generating activities. They were mainly (79%) male and young adults (73%) and only 38% were single. The main issues raised concern the extent of the prevalence of HIV/AIDS; the presence of stigmatisation; the awareness and use of Voluntary Counselling and Treatment (VCT) services; and the most important actor in dealing with HIV/AIDS issues.

### HIV/AIDS situation in the landing sites

The respondents were asked to estimate the extent of the prevalence of HIV/AIDS in the area on a scale of 1 to 10, whereby 1 was the lowest and 10 the highest. While the majority (44%) of the respondents perceived the prevalence of HIV/AIDS to be high, 34% perceived it to be average and 22% perceived it to be low. In stressing the perception of a high prevalence of HIV/AIDS, a respondent in a FGD said:

"when you see four people around, know that three of them are sick" (Resp., FGD 1 Igabiro)

In another landing site, a respondent in a FGD argued:

"If you came with a trailer and asked for AIDS patients to be transported free of charge to the hospital, you would fill it up, come back another round and have some more. You can never finish AIDS patients here" (Resp., FGD 2, Igabiro)

The respondents were also asked whether there was a problem of stigmatisation of HIV/AIDS patients on the landing sites. The majority (93%) of the respondents were of the opinion that there was no stigmatisation of HIV/AIDS patients in the landing sites. The explanation for the low level of stigmatisation is related to the people's view that since many people are sick, stigmatisation is useless. This can be seen from this respondent's view:

[As] you see all us of here, nobody knows who is sick and who is not. We all know that almost all of us are sick. When the signs of the sickness appear clearly, we shall disappear and go [back] to our villages. ... You normally hear that so and so is no longer here or you hear that so and so went back home and he died. ... Sometimes, you hear that they have come for one of us! So, at whom can you point a finger? If you did it you would be like

what the Swahili say Nyani haoni kundule (a monkey does not see its bum) - [meaning that nobody acknowledges his/her own ugly side] (Resp.1, Interview Nyabesiga)

The majority (94%) of the respondents said that they were aware about voluntary counselling and testing (VCT) services in the area and 71% had used them. However, these figures show that there are more people (29%) who are aware but have not made use of VCT services, compared to those (6%) who are not aware about them. Of the respondents who were aware of but have not made use of VCT services, 54% said they were afraid of knowing their HIV/AIDS status, 23% did not care whether they are HIV positive or not, 20% argued that the VCT services are far, 2% said that the HIV/AIDS test is not reliable, and 1% argued that the VCT services are expensive.

HIV/AIDS prevention interventions have declined in appeal. An observation made by one of the leaders in a landing site is revealing of this:

There is a new phenomenon in this island: there are many women who are pregnant and many little babies. In the past, there used to be a lot of condoms sold and consumed in the guest houses. Nowadays, we sell less condoms and I think that this is why we have many pregnant women. The danger is that there must be a lot of HIV/AIDS as well. (Resp.1, Interview Makibwa)

As a follow-up to the concern raised above, a resident who gave birth during the field research was interviewed and said:

I was brought in this island by my aunt, who used to own this hotel, which I now own. She is now dead. ... I have two children, both girls; they stay in the village. ... I am HIV positive. I was told by doctors, after they took my blood in Bukoba. I used to fear giving birth because I thought I would give my disease to the baby. But one day, I remember that I was told that it was possible to give birth to a baby who is not HIV positive even when you are positive. As I wanted to give birth, I decided to stop using condoms so that I could get pregnant. ... This is the baby. I did not fear HIV/AIDS because I have it already. I feared for the baby only. ... (Resp.2, Interview Makibwa)

Due to lack of appropriate equipment and facilities, fishing on Lake Victoria is a very dangerous activity. Many lives are lost due to boating accidents. This continuous risk of death on the waters seems, somewhat, to desensitise the residents from death. Combined with the presence of killer diseases like HIV/AIDS, the people feel exposed to danger from all sides of their lives and resolve not be scared of any cause. One resident said:

When I am on a boat, I am sitting on a grave. So when I come back, how do you tell me not to enjoy my life? Why not? I should sleep with as many women as possible. ... Some tell us to use condoms: the best way is to go live. Fearing death is not a solution to any problem. ... (Resp.1, FGD Makibwa)

This shows that some residents have despaired about the disease and no longer care to take any precautions to protect themselves or their partners. At most, they are only concerned about their offspring. Despair seems to be a kind of personal life crisis. The two responses above typify the current perceptions of the people on HIV/AIDS, which has had a rather long continuum of changing perceptions since its recognition in the early 1980s.

The despair expressed by these people is connected to the economic situation in the landing sites. People work hard and long hours for little economic gain, mostly because of the exploitative contracts they make with the boat owners or money lenders who give them working capital. For example, one fisherman said:

All the fish I catch must be sold to him. He buys a kilo at 1,000/- shillings [about 1 USD]. I must buy all my essential commodities from his shop. They record everything and I pay after fishing. However, I buy fuel from his store at 2,000/- per litre. For every trip, I have to give him fish worth 5,000/- for his home consumption as "mukubi" [sauce]; and I also have to give him 5,000/- for renting the boat engine. At the end of the month, he deducts all my debts, and I am entitled to 30% while he is entitled to 70%. Nothing remains with me, and I am in perpetual debt to my boss (Resp.3, Interview Igabiro)

Regarding the most important actors involved in dealing with HIV/AIDS issues at the landing sites, the majority (49.1%) of the respondents mentioned NGOs dealing with health activities; followed by medical personnel (20.9%); radios (17.7%); family members, relatives and friends (9%), and village leaders (3.2%).

In this section, the paper shows the HIV/AIDS situation at the landing sites. The perception of the people is that the prevalence of HIV/AIDS is high; stigmatisation is low; there is high level of awareness of VCT services, even though their use is lower, and; the important actors dealing with HIV/AIDS are basically NGOs dealing with health issues and individual medical doctors. The next section deals with the changing perceptions of HIV/AIDS among the Haya people, lead to the current perception of HIV/AIDS.

### Changing perceptions of HIV/AIDS

Edisi, a local corruption of the word "AIDS", is widely

known among the Haya people of Kagera Region. However, the Kiswahili acronym, UKIMWI, (*Ukosefu wa Kinga Mwilini*) is also commonly used side by side with other names in the Haya language. The different names given to HIV/AIDS among the Haya people denote the different perceptions that people have had with HIV/AIDS over time. However, all the perceptions reflect psychological stress in the population.

The first people to die of HIV/AIDS were linked to cross-border trade between Uganda and Tanzania, which reached its peak from 1978 to 1984. At this time, both Uganda and Tanzania lacked most essential goods, a situation that had arisen due to the 1978-1979 war between the two countries. Cross-border smuggling (locally called *Magendo*) of mainly essential commodities was the order of the day (Malyamkono and Bagachwa, 1990; Kaijage 1993; Weiss 1993). One popular commodity, *Juliana*, a polyester-like cloth from which shirts and dresses were made (Rugalema 1999:90), symbolised the *Magendo* business. The majority of the earlier patients of HIV/AIDS were young men and women engaged in cross-border smuggling of *Juliana*. It was therefore thought that the disease came from across the border and so, HIV/AIDS was also called *Juliana* or a "disease or affliction of *Juliana* or *Magendo* traders" (Rugalema 1999:68).

Given the fact that the people who suffered from HIV/AIDS lost a lot of weight, HIV/AIDS was later named *Silimu*, a corruption of the English word "Slim". This name became more fashionable and replaced *Juliana* in the mid-1980s mainly because, after the war, trade liberalisation in both countries rendered smuggling of *Juliana* unnecessary and unprofitable since better clothing material was more available on the open market. While the name *Silimu* got widespread beyond the border areas, the preferred name for HIV/AIDS in Haya in the mid-to-late 1980's became *Ekiuka* ("pest"). *Ekiuka* is an expression of two basic issues. It ordinarily refers to the weevils and nematodes which destroy (usually young) banana crops. Kagera Region is a banana-growing area. Therefore, on one hand it is an analogy drawn between the infestation of bananas by pests and infection of the human population by the HIV virus (Rugalema 1999:68) and, on the other hand, it is an expression of the medical discourse explaining HIV/AIDS in terms of viral infection. As the destructive combination of weevils and nematodes kills immature banana plants (Walker *et al.* 1983), so does HIV/AIDS kill young adults.

Much as *UKIMWI*, *Edisi*, *Silimu*, *Ekiuka* still co-exist to date, other descriptive expressions have come along,



pointing out the known social effects of the disease e.g. increase in mortality, especially the among young adults. Such expressions include *Lumara Bantu* ("exterminator of humans"), *Lwaka Bazaire* ("depriver of parents" [of their children]), and *Kinaga mw'irungu*, ("desolator") (Rugalema 1998:68).

Currently, due to the failure of medical efforts to eliminate the virus that is responsible for AIDS and the seeming inevitability of the disease, people have come to see HIV/AIDS as an "occupational hazard" (Rugalema 1999:69). They have started rationalising about the inevitability of contracting HIV/AIDS with two similar sayings i.e. *enfuka egwa omundimilo* (literally, "a hoe only breaks in the garden") and *ekihosho kigwa omukikonya* (an *ekihosho* is a spear-like garden tool used for digging holes and uprooting plants such as banana stems - the proverb literally means that such a tool can only break inside the banana stump). The two proverbs basically mean that only those who are involved in activities where they may contract HIV/AIDS will be affected, hence the sense of the disease being an occupational hazard. However, from the tone of the proverbs, one reads a sense of resignation to the presumed inevitable.

This section has presented the different perceptions of HIV/AIDS among the Haya people over time, beginning from the early 1980s when HIV/AIDS was first recognised, linked with the trans-border trade between Tanzania and Uganda, to the present day when it has come to be considered as an occupational hazard. However, ever since HIV/AIDS was recognised in Africa to the present day, there have been numerous interventions to alleviate its impact on the different societies. Such interventions were informed by a certain discourse, which is discussed in the following section.

### HIV/AIDS discourse in Africa

The slowness of other disciplines in responding to the initial impact of HIV/AIDS gave room to medical and behavioural perspectives to become the predominant discourses on AIDS in Africa (van Eerdewijk 2007:36) and, consequently, on research on sexuality (Parker 2001). About 22 million people currently live with HIV/AIDS in sub-Saharan Africa, which is about 67% of the worldwide 32.9 million people living with the disease (UNAIDS 2008). Given that medical perspectives dominated the initial enthusiasm in dealing with HIV/AIDS and its effects (Packard and Epstein 1991; Parker 1995:260; Schoepf 1995:41). According to Vance (1999:47), "AIDS encourages biomedical approaches to sexuality through the repeated association of sexuality with

disease. And this is the basis of the hegemonic medical discourse, which is, basically,

concerned with symptoms, with depersonalised 'seropositives'. ... Medical discourse has shaped the cultural agenda of AIDS in which the person with AIDS, as a full human person, is absent. ... To think in terms of exclusive, fixed categories, of a fixed relationship between sex and gender, and to advance monocausal explanations for extremely complex social phenomena, is to be blind to the flexibility of sexual behaviours and to the interrelatedness of risk. ... The hegemonic medical paradigm has been deaf to women's voices, and altogether reductionist (Seidel 1993:176).

With the categorisations of HIV infection in terms of Patterns (Seidel 1993; Patton 1997), Pattern One referring to Europe and North America where most infections occur through drug injection and homosexual contacts, and Pattern Two referring to Africa where HIV is mainly transmitted through heterosexual sex, there was "invention of African AIDS" (Patton 1997), and the eventual struggle to explain the phenomenon.

With the limited knowledge of African cultures and societies based on colonial literature which was ethnocentric and evolutionist (Packard and Epstein 1991; Stillwaggon 2003; Lyons and Lyons 2004), higher levels of sexual promiscuity were put as an explanation for the African AIDS. Caldwell, Caldwell and Quiggin (1989), with the "African permissive sexuality thesis", became an important point of reference to explain Africa's high HIV rates from a distinct African sexuality that is characterised by high rates of partner change and sexual networking. In brief, their argument is: "there is a distinct and internally coherent African system embracing sexuality, marriage and much else" (Caldwell et al 1989:187), whereby Western Europe developed into a system with "a proper and stable marriage to a person of the same social class, and its ensuring by controlling female pre-marital and extra-marital sexuality. Sexual behaviour, especially the female sexual behaviour, moved to centre stage in morality and theology" (Ibid.: 192). All this was geared towards controlling property. In Africa, the situation was different: instead of controlling property, it was about control of people, a system named "wealth in people" (Bledsoe and Cohen 1993:70-71), whereby fertility and reproduction become important, with weaker marriage bonds than lineage links. Since non-marital births or marriage dissolution are not greatly feared, there is little need to control sexuality and the sexual act. From the African permissive sexuality thesis, it is therefore implied that

Sexual promiscuity, particularly among women, is the norm in Africa, and that the lack of "control" of women's sexuality is the key to the AIDS epidemic in that region (Le Blanc, Meintel and Piché 1991:501).

And Van Eerdewijk (2007:38) argues that

The conclusions of the Caldwells is that the high degree of permissiveness and little morality on sexuality in Africa allow for multiple partnership and high rates of partner change, and that this level of sexual networking makes it easy for HIV to spread.

This paper would not like to get into a discussion on the criticisms about this thesis. It suffices to point out two big criticisms: The first criticism surrounds issues of interpretation of sources and findings. The thesis that claims the existence of African sexual permissiveness cannot be supported by empirical evidence (Stillwaggon 2003; Van Eerdewijk 2007); much as their selection of literature is not clear (Ahlberg 1994:223), their choice of studies seems to be biased towards those indicating lack of moral value for sexuality (van Eerdewijk 2007:38) because they ignore the historical context and changes by referring to studies from 1920 to the 1970s (Le Blanc et al. 1991: 498-499); they have adapted, distorted and rejected data that do not support their hypothesis (Stillwaggon 2003:819-820). Such issues indicate their zeal to interpret sources and findings in order to verify their theory, regardless of the countervailing issues.

The second criticism demands going beyond the issues of interpretation of sources and findings to pointing out an issue of the thesis' expression of profound Eurocentricism and racism (Stillwaggon 2003). According to Arnfred (2004b:67), the thesis

was more a re-vitalisation of these age-old images fed by sexual anxieties and fears than an introduction of something new. It is all there: the unbridled black female sexuality, excessive, threatening and contagious, carrying a deadly disease.

This is an expression of the Africans as the "social Other" in a form of a myth of hyper-sexualised Africans as opposed to idealised European sexuality (Lyons and Lyons 2004).

Regardless of the criticisms of the weaknesses identified with the African sexual permissiveness theory, it has been very influential and has dominated and still dominates interventions on HIV/AIDS in Africa. Basically, the theory has resulted into behavioural paradigms to deal with HIV/AIDS. The

paradigm has focused on identifying cultural aspects of sexuality that could contribute to the spread of HIV/AIDS. Gausset (2001) mentions some of them as polygamy, adultery, premarital sex, wife-sharing, widow inheritance, circumcision and scarification rituals, dry sex and witchcraft beliefs. The problem is that a good number of these practices were taken out of their contexts, exaggerated, distorted or invented (Treichler 1992:390) and, in so doing, lost their meanings, importance and embedment in cultural, social, economic and political contexts (Van Eerdewijk 2007:41).

This section has presented the dominant HIV/AIDS discourse as based on the African sexual permissiveness theory, expressed in the biomedical- and behavioural-oriented interventions. Some important conclusions may be drawn from the preceding, in light of the assessment of the dominant HIV/AIDS discourse among the Haya people of Kagera Region.

## Conclusion

Among the people studied, HIV/AIDS is perceived to be highly prevalent, stigmatisation is low, there is a high level of awareness of VCT services and their use is relatively quite high. HIV/AIDS has compounded the poor economic situation of the people on the landing sites and added stress to them, making them despondent. Current efforts to deal with HIV/AIDS are still informed by the biomedical discourse of interventions in treatment and change of behaviour to avoid more HIV infections. However, this discourse is deeply linked to the flawed premise of sexual permissiveness among Africans. It does not go as far as addressing livelihood issues in totality. As Munyonyo (2007:1) points out,

people and communities perceive and deal with HIV/AIDS as one of the many problems and tensions they experience as affecting their well being rather than perceiving and dealing with it as their single most significant problem

This implies that there is need to get an alternative or complementary discourse in order to address HIV/AIDS within the totality of people's lives. This paper opposes the idea of counteracting the biomedical discourse by putting the blame on the western lifestyles and practices as responsible for the breakdowns of the social and moral control and consequently for the spread of HIV/AIDS (Patton 1997) and to throwing away western lifestyles and practices as an alternative to African ones. As Gausset (2001:512) points out,

to think that restoring cultural traditions or, on the contrary, fighting traditions, will solve the problem of AIDS is ... naïve. Both discourses focus on the wrong targets. ... Traditional or western behaviour and ways of thinking are not what prevents the spread of AIDS....

This paper proposes an alternative discourse i.e. a meaningful life discourse. In this discourse, the livelihood aspirations of the people should be a central focus of an integrated approach that addresses the vulnerability contexts of the lives of the people. The livelihood aspirations should be what define the meaningfulness of people's lives. Each effort to address the vulnerability context should be construed as a means to achieve the meaningful life.

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