

# Social Factors in HIV/AIDS Response

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Abstract: There are significant social factors present in the transmission of HIV that are perceived differently by different groups. Furthermore, an understanding of these local social contexts and personal risk assessments can be useful in informing aid responses and disease control measures. Twentieth century upheavals, due first to colonialism and then to wars and workforce migration are generally regarded as contributing factors to the building up of the AIDS crisis in Uganda and in Africa as a whole. There are also significant socio-cultural factors that contribute to the spread of the virus that result in "a series of AIDS microepidemics that are localised in their precise patterns, causal factors, and meanings." There are several disease control measures put forth by both the local and international communities that have variable success rates in the control of the disease that are heavily dependent on public perception of both the disease and the control measures themselves.

This essay will examine differing responses to the AIDS pandemic in Tanzania and Uganda. In examining Tanzanian practices around HIV/AIDS, I will look mainly at Rugalema's study of the Buhaya (2004), Dilger's study of the Luo (2003; 2008), and Roura's study of the population of Kisesa (2010). In all three studies, the role of social and cultural pressures and preconceptions about HIV/AIDS and those who have it are sometimes in conflict with the western outlooks that shape many of the foreign-based aid programs targeting the disease. Some may point to this conflict as an example of factors contributing to unsuccessful disease prevention. For an analysis of the Ugandan response, I will be primarily referencing Epstein's more generalised study of the population of Kampala. In Uganda we have a telling example of some risk interventions that may have successfully decreased HIV infections rates. It is not surprising that many of these interventions were locally generated and take into account the many cultural and social aspects of transmission and infection. However, in Uganda as

in many other places, as public perception of the disease and control measures have changed, the rates of infection too have changed.

### **Tanzania**

From a western medical and disease control perspective; “The pandemic was and is still perceived as a medical problem and hence a domain of medical experts” (Rugalema 2004:191). However, it is clear after three decades of the pandemic, there are social and cultural factors at work in both the spread and control of the disease. A variety of cultural and historical factors makes the Buhaya in the Bukoba district in northern Tanzania exceptionally susceptible to AIDS (and other STDs). Rugalema (2004) highlights the historical frequency of commercial sex work in this area and that Buhaya women who engaged in such work frequently travelled to work in different parts of East Africa. There were few other options for single women to support themselves in starkly patriarchal Buhaya society. Buhaya men also found it necessary to migrate to different areas of East and North Africa for work after World War II and throughout much of the 20th century. Thus, the population flux of the Buhaya left multiple points of entry for viruses such as HIV. This along with the declining economic environment of the 1970s and 1980s and an accompanying lack of medical access left room for the virus to take a significant hold over the community. Similar migration patterns, patriarchal systems and medical issues are at work in other areas of Tanzania.

### ***Social Factors***

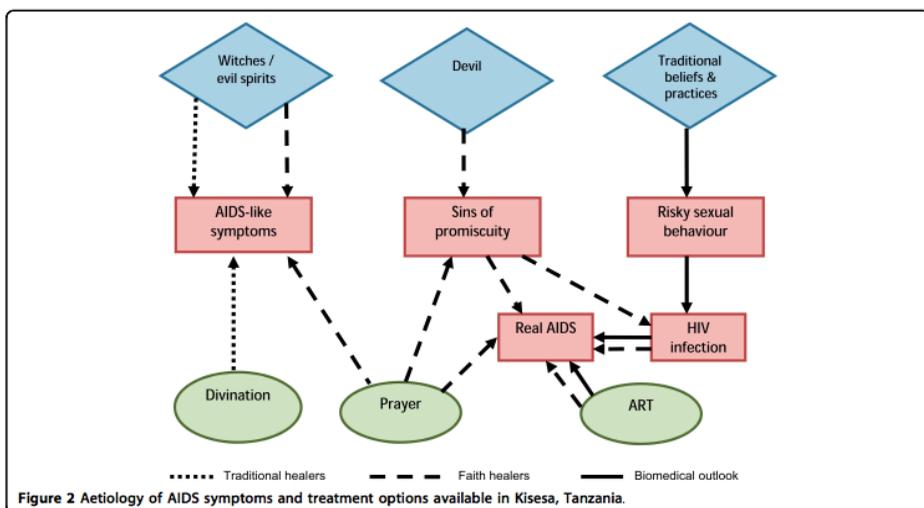
Among the Lua, AIDS is classified as a “bad disease” (ie: a bad person’s disease) and a “punishment by god” for societies ills and is perceived as a “metaphor for the moral breakdown of society” (Dilger 2008:209). The Lua are not alone in this perception. The faith healers of Kisesa, Tanzania, would understand HIV-positive status to be ‘a punishment from God.’ They cited “sinful behaviour (promiscuity)” and “instigations of Satan” as the cause of “punishment” (Roura 2010:9). In accordance with sinful behaviour cited as a possible cause, over 1/3 of Roura’s study participants also reported “belief in miraculous cures for HIV.” This included fifty percent of leaders of revivalist churches who saw faith healing as one appropriate response to the disease. Faith leaders “from all denominations referred to a cosmology based on a battle between Good and Evil. Misfortune, including disease, was interpreted as a (temporary) triumph of the Devil over God” (Roura 2010:6).

Other respondents to Roura’s study explained HIV as an act of fate or a danger of living in a chaotic universe; “HIV is just like other diseases ...if the person’s fate is to die, however we pray for him/her ... prayers may or may not be answered” (2010:6). Even outside of a Christian context, AIDS is viewed as an uncontrollable force that may strike at random. For the young men of Kagera

“contracting AIDS is viewed as an ‘occupational hazard’” or simply as a dangerous side effect of life (Rugalema 2004:197).

In areas where AIDS is perceived as striking only particularly bad or sinful people, steps are taken by those who are HIV seropositive to prove their “innocence” or inherent goodness to the community. When AIDS strikes a particularly “good” person or household, individuals and family attempt to extend blame elsewhere, sometimes to external witchcraft or a failure to acknowledge ritual practices. Plummer (2006), Dilger (2008) and Roara (2010) all cite witchcraft as being blamed for HIV infection and AIDS deaths in different groups in Tanzania. Plummer examines the process of attempts at healing, which generally happen in a multi-step process that brings more serious conditions to a health facility as a last resort, after having exhausted first local traditional healers and then smaller, lesser trained or equipped health services before finally resorting to a hospital or large healthcare facility. This may point to a lack of trust put into the biomedical setting or a desire to be diagnosed with a less stigmatised disease such as “false AIDS” which is defined by healers as having the same symptoms as AIDS but is attributed to external causes such as curses or witchcraft (Plummer 2006; Roura 2010). Plummer uses the example of a 30-year-old woman who was rumoured to have AIDS:

She did not have the 5,000 Tanzanian Shillings [6 US Dollars] to have the blood tests done [to determine the problem] and thus just came back home...A week after the above interaction, the same woman optimistically reported that she had raised 5,500 Tanzanian Shillings (6.50 US Dollars) for treatment by a healer who had told her she was bewitched by her deceased husband’s relatives. (2006:464)



Roara (2010:10) includes the above diagram to show the complex relationships between Christian beliefs, traditional beliefs and western medical diagnosis and treatment (ART). In practice, an individual may consider all of the causes and any of the treatments available or rely on one treatment based on perceived effectiveness.

### ***Control Measures***

Prevention efforts in Tanzania have focused on “risky sexual behaviour.” This is especially the case in areas whose response and control measures are highly influenced by western HIV control models. Both foreign and domestic programs are generally reliant on the “Health Belief Model” in which an individual “will take responsibility or act rationally and desist from unsafe sexual behaviour once they have been informed and educated about the dangers” (Rugalema 2004:191).

However, many studies in Tanzania show that “almost everyone” is aware of HIV/AIDS and the infection rates are not decreasing by significant amounts (Kalipeni 2004:191). This may highlight differing concepts of risk based on different societal norms. For example, in Rugalema’s examination of “hierarchical, patrilocal” Bukaya society, the possibility of a woman losing her husband over an insistence on condom use may present a greater risk to her immediate livelihood than the possibility of HIV infection (2004:197). Similarly, a person who believes he has been entirely spiritually healed of an existing HIV infection, as in the case of Roara’s “Mr. X,” would see no risk to his partners and thus take no precautions during potential exposure (Roura 2010:7). As Rugalema states, “It is our institutionalization that tells us which risks to worry about and which to discount” (2004:192).

### ***Outcome***

“At present, medical professionals, the political elite, and other powerful groups have a more or less freehand to impose their own culturally constructed risk assessments on the general public” (Rugalema 2004:192). This creates a dangerous and hierarchal social judgement that turns HIV positive people into “victims” of their own “risky” behaviour. As Rugalema (2004), Plummer (2006), Dilger (2008) and Roara (2010) argue, an understanding of local concepts of risk and healing are imperative in controlling the spread and management of HIV/AIDS in Tanzania.

### **Uganda**

In Uganda, like Tanzania, there are similar histories of migration, patriarchy and inadequate medical facilities contributing to the spread of the disease. However, the unique Ugandan response and control measures during the early years of the disease produced unexpectedly improved outcomes.

Both Epstein and Barnett cite the common practice of concurrent relationships as a major factor in the quick spread of HIV in the late 1980s and

early 1990s. A 1993 study by Martina Morris catalogued a significant number (40% in men and 30% in women) of respondents stating that their most recent relationships overlapped by several months or years (Epstein 2008:54). While the number of sexual partners was not significantly different than those found in other areas of the world, Epstein hypothesises that it was Ugandan's frequently concurrent relationships that "gave rise to a stable interlocking sexual network that served as a 'superhighway' for HIV" Two years earlier, Barnett also alluded to Epstein's concurrence theory but stressed that there was very little information to go on.

The immediate causes of the rapid spread of the disease are directly related to the pattern of sexual contact. These can be established only very approximately through epidemiological modelling but since empirical studies on sexual networks in Africa are even more inadequate than those for Europe and the United States we had no data to go on. (Barnett and Whiteside 2006:241)

This is a situation that no doubt is still true today. Epstein, too, acknowledges the difficulties in gathering such data "Generalizing about sexual culture is always difficult; social life everywhere is complicated and constantly changing." (2008:73)

### ***Social Factors***

While clinical studies on sexuality are lacking it is clear that the ability to talk about a problem such as HIV is fundamental in trying to control it, and this appears to be a key triumph of Ugandan culture and policy in the early years of the AIDS pandemic. In comparing the Ugandan response with that of Botswana, a country with more infrastructure and less turmoil, Epstein finds a key difference lies in the public conversations around AIDS. In 2003, Botswana's infection rate was nearly six times that of Uganda's (Epstein 2008:169). In the same year, a Financial Times report stated that Botswana's health care workers were trained to not notify patients about the virus and that the virus was never mentioned by churches at funerals (Low-Beer 2003). While there is a major AIDS awareness campaign in Botswana at that time, many still saw it as a "disease of the poor, marginalized and immoral" (Epstein 2008:169). The many national awareness campaigns did not stress that HIV was something that could infect anyone and there was no groundwork by healthcare or community workers to explain the nature of the virus.

Epstein goes on to show that gender roles, transactional sexual relationships and a more general lack of women's rights also contribute to the spread of HIV (2008:75). In southern Uganda and the bordering Kagera area in northern Tanzania, Epstein cites more equal gender roles and a history of a strong women's rights movement as a significant influence in the control of the disease from 1996-2003 (an 80% reduction) while other comparable areas were still being inundated by new infections. (2008:159,163) "We told women, if your

husband is unfaithful and is going to kill you with AIDS, you divorce him.” said Mazine Ankrah of Action for Women in Development, a Ugandan Women’s rights organisation. (Epstein 2008:163) The very fact that it was possible for women to follow this advice is a testament to how powerful the women’s rights movement was in Uganda and highlights the important personal risk assessment options of Ugandan women. As Rugalema states, “To understand the HIV pandemic in Africa is to understand how people who live with it explain it or rather how they construct schemes of risk assessment in the face of it” (2004:192). It is only in a risk assessment situation in which contracting HIV is the worst of several outcomes that measures will be taken to moderate the risk of infection.

### ***Control Measures***

Epstein defines the true power of Uganda’s early response in terms of Felton Earl’s idea of “collective efficacy” or “the ability of people to join together and help one another” (2008:xii). What she may also be describing as a secondary characteristic is the ability for those embedded inside a population to understand and mitigate the risk factors present within that population. Only with that understanding can a move toward collective efficacy and behaviour change take root. One important element of Uganda’s collective efficacy in response to AIDS was the ability and willingness of the larger community to care for its AIDS-affected individuals. “Throughout the region, home-based care counselors taught millions of people that it was safe to touch and care for AIDS patients, and that the affliction was neither a curse from God nor a punishment for sin, but a terrible disease that no one deserved” (Epstein 2008:166). A 2005 study at the University of KwaZulu-Natal showed that home based care facilitates open discussion and changes in sexual behaviour on the parts of not only the person being cared for but for the caregiver and the friends, relatives and co-workers of the patient (Ncama 2005). This ability to address the problems of the epidemic in an open and honest fashion proved to be one of the most important and effective responses, as it influences all other risk assessment choices at the individual level.

Government-sponsored messaging also played a part in the decline of HIV transmission levels. In 1986, at the very beginning of the pandemic, the leader of the newly in power National Resistance Army, Yoweri Museveni, assembled a team on Ugandan health experts to launch a campaign against the disease that had killed so many of his troops. “Warnings about AIDS were broadcast on the radio each day at lunchtime, accompanied by the beating of a drum in the traditional rhythm of warning.” The government slogans of “Love Responsibly” and “No Grazing” were ubiquitous, found on billboards, buildings, and official government speeches. “Newspapers, theaters, singing groups and ordinary people” spread the same message as given to them by government trained AIDS educators (Epstein 2008:162). A key component of this message

may have been its open acknowledgement of the possibility of outside-of-relationship and concurrent relationship sexual encounters without issuing a hard moral stance on either, the delicate contour of which could only have originated from within the society at which it was aimed.

The intimate, personalized nature of Uganda's early AIDS campaigns—the open discussions led by government field workers and in small group of women and churchgoers, the compassionate work of the home-based care volunteers, the courage and strength of women's-rights activists—helped people see AIDS not as a disease spread by disreputable high-risk groups or “others” but as a shared calamity affecting everyone. This made discussion of sexual behavior possible without seeming preachy or prurient. Behavior change then became a matter of common sense... It is not something that can be packaged and paid for and then shipped around the world. (Epstein 2008:167)

### ***Outcome***

In the early spread of HIV in Uganda, there do not appear to be as many social factors or stigmatising cultural elements at play, perhaps due to the larger pattern of collective efficacy. However, in recent years, as public perception of the disease and control measures have changed, the rates of infection have also changed. More recently, international funding parameters, morality judgements, and messaging originating from outside of the targeted culture have negatively affected the originally optimistic turn of transmission rates in Uganda.

In the first ten years of the 2000s much of the funding for Uganda's HIV education and drug therapy came from the United States. During the evangelical-backed Bush administration, its associated programs such as PEPFAR attached monetary aid to religious beliefs that are sometimes at odds with disease control. Aid organisations applied the same messages in every community, regardless of local cultural norms and stressed only premarital abstinence as a disease control measure. While abstinence is certainly a valid option for control of the epidemic, disregarding all other sexual realities including sexual activities within marriage, or concurrent stable relationships is a recipe for elevated transmission rates in any community (Epstein 2008:177).

With Christian evangelical organisations interest in Africa and easy funding from government agencies, an evangelical view of disease prevention spread with the expansion of evangelical Christianity itself. Like messaging around condom use, negative morality judgments became attached to the ideas of marital infidelity or concurrent relationships, the result of which was commonly non-acknowledgement or denial of possibly risky sexual behaviours. Denial creates a dangerous environment of secrecy and allows risky behaviour to remain unchecked by partners or the greater community. From the evangelical Christian perspective, promoting the use of condoms would promote premarital or extramarital sexual encounters by association, thus evangelical communities and

faith leaders frown upon condom promotion. Unfortunately, as Barnett states, “A prerequisite for managing a crisis is that it must be socially recognized” (Barnett 1994:234) and in the case of evangelical Christian control measures, the risks must be socially recognized in all of their many forms, not just the forms that evangelical leaders deem acceptable. The outcome of these response changes has been devastating. As of 2009, the number of new HIV infections in Uganda is higher than the number of annual death rates, prompting worries that transmission rates are once again on the rise (AVERT 2011). Hopefully, the disease prevention landscape will change again, as government funding agencies and faith leaders are forced to acknowledge the successes and failures of past transmission control measures.

## Conclusions

In examining disease control in Tanzania and Uganda it is clear that social components play a large role in HIV/AIDS prevention and management. Rugalema argues “the pandemic is contextualized differently by different groups of people depending on location, occupation, gender, age, etc. HIV/AIDS in Africa is as much ‘socio-economic’ as biological and requires to be addresses through socio-economic negotiation and reform in which those ‘at risk’ are thoroughly engaged” (2004:192). In a less formal way, Epstein agrees by quoting Nkululeko Nxesi, “We will realize that development is not only about how good your infrastructure in; it’s also about the heart” (2008:171). As subsequent generations of Tanzanians, Ugandans and the international aid community come to face the challenges of the AIDS pandemic, it is likely that “the heart”—localized understandings of illness, risk, and culture—will become more important to successful disease control.

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