



STIGMA: THE KEY CHALLENGE FOR HIV/AIDS COMMUNICATION

Thomas Tufte



“...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. It is by listening to the 'stories' that we can understand the context in which the pandemic is constructed, including factors that may promote or constrain behaviour change” Rugalema (2004: 192).

Two of the stories that Rugalema refers to are reported as follows: they are both voices of high school girls from Rhini Township, in Grahamstown, South Africa.

“Close by my house there is a little girl who is HIV positive. At her home it's only her sister who knows about the young girl's status. They are both scared that if they tell their parents, they will chase her away from home. Her sister told me, and asked if I could keep it a secret. In clinics people who are HIV positive are being treated badly. Even if you ask them to get you some water, they will shout at you for no reason. Even if you are still in bad condition to be discharged, they will tell you that you need to go home because there's no place for you here. You can just go home and die there. If your family knows your status they won't take you to the doctor or hospital, only when your situation is worsened they will take you to Temba Santa Hospital (TB Hospital) and say you had TB. Even at your funeral they will just say you died of TB. I think if we can learn to be more open about AIDS, we can defeat it” (Girl A).

“HIV/AIDS is the killer in our days, especially to our youth. People of Rhini are just making fun of people who are living with HIV/AIDS. That is why we have funerals every weekend. It's also one of the reasons why people who are HIV positive don't come forward. They end up turning to alcohol and drugs. Even in hospitals once you are told by the doctor that you are HIV positive, they told everyone that you are HIV positive, before you even tell your own family. (...) People always think that if they tell their families about their status, they would not be accepted. There is a girl that I know who is HIV positive. The first person she told was her school

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Principal. The principal told her teachers and the teachers told the students. No one wanted to be associated with this girl. They treated her so badly that she quit school. (...) They where talking to her as if she was not a human being” (Girl B).

Both of these testimonies are from Grahamstown, a town of 120.000 inhabitants in the Eastern Cape Province in South Africa. That is where in 2002 I conducted an audience ethnography, doing fieldwork amongst 14 to 19 years old youth from 5 different socio-economic strata.

The material and the quotes used in this article stem from essay written by students at 5 schools from different socio economic strate. At the five selected schools, in 11th grades, I collected 124 essays which were the young people's own account -a narrative about HIV/AIDS in their community. The essay writing was prompted by one statement: "HIV/AIDS affects each and every one of us, no matter how 'special' we think we are, and is rapidly becoming a part of everyone's reality. Drawing on own experience, to what degree do you think this statement is true, and why?". The task was framed in such way, and students were then given one class hour (45 minutes) to write an essay, in either English or Xhosa, and with anonymous response. 26 (all from the two poorest township schools) wrote in Xhosa, and these were later translated into English.

The objective was to seek a deeper understanding of how a local community handles the HIV/AIDS pandemic in everyday life, in order to use these insights to critically assess the relevance, quality and appropriateness of existing HIV/AIDS communication.

Considering the fact that donor agencies, governments, NGOs and Community Based Organizations (CBOs) are spending large and growing amounts of money on HIV/AIDS communication, the interest of this project was to see HIV/AIDS communication from the community's perspective. How is HIV/AIDS handled in the communities? What are the key problems? Where and how do the campaigns emerge as useful input? Ultimately, the aim of the project was to deliberately explore the complexities of everyday life in order to identify both research agendas and concrete communication challenges that future HIV/AIDS communication planners and strategists should deal with.

STIGMA

Both of the two girls' accounts reproduced above point towards one of the key challenges with HIV/AIDS today: the problem of stigma. Stigma is, according to the Collins English Dictionary, “a distinguishing mark of

social disgrace". Sadly, it is the myths and misunderstandings surrounding this mark of disgrace, the fear of meeting this mark and the denial of having the HIV virus that altogether create a very difficult to tackle situation. Stigma is resulting in the ill treatment at hospitals and in silence or gossip in the community, and leading to nobody really wanting to know their own HIV status. It's a situation that is locked, in which communication could possibly have a stronger role, facilitating an opening up in many communities.

What comes through strongly in my Grahamstown data is that young people feel their identities at risk. Young people are almost per definition the most energetic, optimistic, invincible generation, with their future ahead of them. But, as one young man wrote in his essay: "If you get the HIV virus, your future gets stuck" (M20) ^[1]. You become part of a real 'no future' generation. That's at least the perception many youngsters have due to the lack of a cure".

This again results in states of denial and situations of stress in which many young kids develop an attitude signalling that they don't care. Some of them deny that they should be at any risk, and most often they blame the spread of the virus on somebody else - certain groups of "others", be it the opposite sex, marginal groups such as prostitutes, those in the next neighbourhood, or simply "others". HIV/AIDS is in that respect dividing societies far more than it is promoting unity or any degree of the collective spirit required to face the actual problem.

Last but not least, HIV/AIDS is very obviously a problem of poverty and unequal power relations in society. It is a pandemic which blossoms in societies with gender inequity, which travels with human trafficking or migrant labour, and which strikes hardest against those that cannot afford any form of treatment. It is a symptom of social and economic injustice, and it should be combated accordingly. It's not just about changing individuals' behaviours, encouraging people to use condoms or abstaining from sex. That's merely treating the symptoms, and not dealing with the underlying causes.

COMMUNITY CHALLENGES

A number of issues emerge as crucial community challenges from my Grahamstown fieldwork. To the best of my knowledge and understanding, these are challenges which many local South African communities are facing, and which may serve as communication challenges for future campaigns against HIV/AIDS. I will as follows illustrate those challenges with excerpts from the essays the youth wrote on HIV/AIDS in their

community:

1. *Stigma*: It cuts across most of the other challenges - making disclosure of your status, or simply revealing your uncertainties of possibly having the virus one of the most difficult decisions in life. As a boy from the township says: "They always think if they maybe tell a friend, family member or girl/boyfriend, that they will get into argument and get dumped. They think that their families will start to dislike them. Every thing their families are doing, they won't include them" (NB6-M). And as a girl from the township reports: "People with this disease are always ill treated and undermined their ability to life. You'll hear them saying 'instead of living this kind of life, I'll rather die'. Most parents chase their children away from their homes because they have the disease" (NB1-F).

2. *Fear*: Although most human beings are afraid of acquiring a serious illness, the widespread stigma throughout Grahamstown reinforced a feeling of fear to degrees that led to strong denial on the one hand and to careless behaviour and laissez-faire attitudes and blame of others on the other. In many reported cases, it also led to suicide. Thus, the need to tackle these profound feelings of fear lies at the heart of the problem.

3. *Lack of social support systems*: With this I refer to the social institutions present in any community -from hospitals, schools and churches to families, friends and neighbours. Gathered under the analytical concept of "institutional mediators" ^[2], the most common experience was a lack of social support encountered in these contexts. The two initial quotes tell the story of the hospitals. From their school experience, youngsters spoke of the risk of being thrown out if you were HIV positive, as well as the risk of being abused by teachers. As for the social networks in the community, the lack of support was expressed all the time: "What I don't like is when the community treats people who are living with HIV/Aids badly. Instead of welcoming them from your house you chase them away. Other families they start to dislike you when you are HIV positive. Even if you where drinking water with a jug, people who are not positive they won't use it. People who are living with HIV/AIDS, we need to support them so that they wont think about their status. When someone is HIV/AIDS I urge people not to make fun of people who are HIV positive" (M1-F).

4. *Superficial use of communication initiatives*: It was very striking how all the key messages from numerous campaigns came through in essays, everyday talk and in interviews, but on a slogan-like level, deeply contrasting the deep-felt problems of stigma, fear and lack of social support systems. Two handfults of excerpts provide an illustration: "the great thing is to talk about it" (M17); "And to the youth, they must stick to one partner and be protected, the condoms are there for safe sex..." (M17); "use a condom because HIV/AIDS is a killer disease" (M18); "I think the solution is to condomize" (M19); "The solution to this disease is to use condoms" (M20); "There is only one cure. Condom"; "In order to get help

about this you have to talk about it” (M22-Mtwisita Ayanda); “Young people must use condom -is the easy way to protect our life” (M24); “Message: Please, 'don't compromise, condomize, people' and 'AIDS kills our people so we must fight it” (N23-M? Loyi); “don't be shy, talk about it, eat good food, especially fruit and vegetables, and drink juice, not alcohol” (N25-Buwi); “Wrap it or Zip it” (K13-M). On the one hand the slogans illustrate the fact that the campaigns are reaching the target groups, being listened to, watched and even discussed in the community. The big problem arises when you start contrasting this apparent success with the other findings mentioned above. What appears seems to be parallel discourses -one of handling information in everyday discourse, the other revealing deep levels of ontological insecurity, fear and uncertainty.

5. *Lack of joint community efforts*: Seen from the perspective of the 14-19 years old youth, living in a community with a 10+ prevalence rate, with personal experiences of loss, illness and a stigmatized environment, what is needed is a coordinated community-based effort to tackle some of these challenges. This points towards the weaknesses of the systems of health and education and the need for improvement there. It also points towards the need for a more articulate civil society. In my field experience, civil society did not come through with any noteworthy visibility or strength. Such findings furthermore point towards the huge political challenge of replicating the current national process of seeking multisectoral and coordinated responses at the community level.

With these findings in mind, a broad range of communication challenges emerges. How do you communicate around stigma, around fear and denial, and around extreme situations such as suicide or abuse? How do you work with the reality of weak social support systems in a communication intervention? How do you find a form for a mass media borne campaign to deal with all these issues? The main insight generated by this research is the fact that stigma is the core challenge we -as communication planners, researchers and strategists- are facing. It must translate into joints efforts where media-borne and community-based initiatives are developed in a coordinated attempt to overcome the HIV/AIDS pandemic.

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[1] All quotes are followed by a letter and number to indicate school and student. Schools are referred to as K, G, MW, M and N. K is an elite boarding school gathering students from all over the country. G is a traditional 'white' school. MW is in the part of town where the coloured primarily live. M and N are in the black township areas, with M attracting the most marginalized segments of society.

[2] I have previously argued for a mediation model in audience analysis

where many simultaneous mediators -including HIV/AIDS campaigns- are taken into consideration (Tufte, 2004). The model is based on a typology of mediations developed by Mexican scholar Guillermo Orozco (1997).

Orozco, Guillermo (1997). *La Investigación de la Comunicación Dentro y Fuera de América Latina. Tendencias, Perspectivas y Desafíos del Estudio de los Medios*. Buenos Aires: Ediciones de Periodismo y Comunicación. Universidad Nacional de la Plata.

Rugalema, Gabriel (2004). *Understanding the African HIV Pandemic: An Appraisal of the Contexts and Lay Explanation of the HIV/AIDS Pandemic with Examples From Tanzania and Kenya*. In: E. Kalipeni et al (eds): *HIV/AIDS in Africa. Beyond Epidemiology*.

Tufte, Thomas (2004): *Soap Sense: Can Soap Operas Empower their Audiences?* In: Michael Cody, Everett Rogers and Arvind Singhal (eds): *Entertainment-Education in the 21st Century*. Lawrence Erlbaum Editors. New York.

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