MISSING THE MARGINS: Recurring Gaps in AIDS Communication

Themes and content of AIDS communication interventions are often predetermined by health experts with little consideration given to gaps and misunderstandings amongst intended audiences. Indeed, the biomedical model is only one of a range of cultural interpretations of disease. With a view to developing a docudrama on the science of AIDS for the Discovery Channel Global Education Partnership (DCGEP), qualitative research was conducted to explore understanding of the disease.

Approach
We conducted focus groups with participants aged 18-49 in four African countries – South Africa, Uganda, Ethiopia and Nigeria – during 2006. Participants were recruited with the assistance of non-governmental organisations in each country and included participants of both sexes, participants who were employed and unemployed and who came from rural and urban locales.

Participants were asked to identify aspects of AIDS that they did not understand. Emerging questions included issues to do with the origins of AIDS, relative risks of HIV transmission, myths about transmission, and lack of clarity about a cure.

Understanding of HIV/AIDS
The origin of AIDS was raised by participants in all countries with an overarching concern being raised that it was impossible to understand or address AIDS without being clear on its origins. Two examples from South Africa illustrate this point:

[Quote] It will make us understand better. You know, if you understand the origin of something, you'll understand better how to deal with the HIV/AIDS. (Male, 24-29, South Africa).

[Quote] It's because we don't know the word of the Lord... in the old days people used to respect that God but now there seem to be a lot of religions... People do not abide by the words of God. We just live along the way we like and God looks at that... and he passes judgment. (Male, 24-29, Ethiopia).

One participant included an explanation of the concept of superstition in relation to science:

[Quote] What I mean by that is that we are all Africans and we have this culture of superstition. In fact most of our people even the learned ones amongst us, even our professors will tell you, that when science stops superstition begins... (Male, 24-29, South Africa).

Participants themselves did not necessarily believe these various interpretations – rather the concepts were related as beliefs that they had heard. Curiosity about the origins of the disease remained however, and were linked to the fact that HIV/AIDS was new and that therefore it was necessary to understand how it emerged.

HIV transmission
HIV transmission was generally well understood by participants, including the primary means of infection being unprotected sexual intercourse between serodiscordant couples. Other modes of transmission including contact with blood or other fluids, from mother to child, and through infected needles were also all mentioned and described in detail. There was however some uncertainty about the level of infectivity of the virus as well as the specific mechanics of transmission.

[Quote] If people ask you questions then you can't answer it then you keep on telling them something they feel it's hard to believe. Why can't the answer that question but she keeps on telling me that AIDS kills and AIDS does this, but then she doesn't even know herself where it comes from! (Female, 18-24, South Africa).

Understanding of the origins of AIDS focused on four main areas – transmission from animals including monkeys, dogs and lice; punishment from God; a product of bewitchment; or a virus that was developed in a laboratory – usually by American scientists.

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HIV prevention and risk
There was a heightened fear of the possibility of non-sexual transmission through cuts, kissing (with sores in the mouth), and other low risk and unlikely modes of transmission. In general, however, concepts of prevention of HIV through sexual transmission were well understood. There was some perplexity regarding why people put themselves at risk of HIV infection in spite of high levels of knowledge.

[Quote] When people know it leads to death, why do they just themselves in the kind of situation? This is what I cannot understand. Maybe there is another way of thinking but it is that they live for fairly and don't care about tomorrow. I really surprised me (Male, 24-29, Ethiopia).

Participants noted the importance of culture and religion as social mechanisms that should ideally constrain HIV risk, and were therefore surprised that HIV was prevalent.

[Quote] I don't understand why there are so many large numbers of HIV infected people in our country when the culture and our religion constrains us to that. Ethopian people... they follow that culture and are religious... How come we are so many as religious and traditional; how come we seem to contract AIDS? (Male, 24-29, Ethiopia).

HIV transmission was noted to be directly related to risk practices, but other factors also needed to be taken into account including an unfaultless partner, deliberation, illegal transaction, alcohol consumption, economic dependence, love and self esteem.

HIV treatment and cure
Treatment of HIV was understood in relation to preventing HIV from compromising the body’s immune system. Participants were also aware of antiretroviral drugs, and understanding of HIV/AIDS included the concept that the virus advanced slowly, that people with HIV looked healthy, and that people on ARVs could be healthy.

Acknowledging ARVs were however, not disregarded, and traditional herbal cures were seen as potentially viable. Whilst alternative perspectives on treatment and cure of HIV in Africa have often been associated with concepts of traditional medicine, it is clear that there is an emerging trend across contexts where concepts of faith/heath-healing intersect with concepts of a cure for AIDS. This is often related to particular experiences of such cures, or hearing about or seeing proof via media sources.

[Quote] I know as a girl when your younger brother is changing, you have self esteem problems. When a guy says I have you believe him. It doesn't matter how ugly he looks or whatever you believe him... He touches you and she's like, you know, I love you, if you do this for me this is what I’ll do for you (Female, 18-24, South Africa).

Understanding of immunity and HIV
Participants were uncertain about where the virus lived, although most agreed it lived in the blood. The brain, the heart, the lungs and the liver were also mentioned. Participants noted a complicated understanding of immunity and how infections compromised the body. This included particular conceptions of how HIV affected the body. This virus is very clever because it gets into you and when it is in it does not attack right then. So if you are with a person for a while it then attacks you if one by one. It starts in the liver of the cell, and convert it into the virus and when bodily cell is converted, then it destroys the bodily cell (Male, 24-29, South Africa).

Once you have HIV it gets distributed in parts of the body it looks like it happens at different times and there are areas where they can hide for a while. This depends on how the body immune system is strong and there will be a lot of bandages in the body. Basically it’s the white blood cells that’s engaging with that. So at some time maybe they feel where it hides in parts of the body, that is depending on how strong the immune system is (Male, 24-29, South Africa).

Parallel frameworks of meaning
In all four countries there was considerable commonality in misconceptions, misperceptions and gaps in knowledge about AIDS. These misperceptions were a lack of understanding of the origins of AIDS – which clearly reflects an absence of discussion on how the virus affects the body. There was some surprise about this and the prevalence of myths. Some participants noted that HIV/AIDS was new and that therefore it was necessary to understand how it emerged.

Endnotes
10 FGD Uganda, 18-24 21Nov06, ln 40, p 14
11 FGD South Africa, 18-24 16 Nov06, ln 24, p 12
4 FGD Nigeria, 25-49 01Dec06, ln 13, p 5
13 FGD Nigeria, 25-49 01Dec06, ln 16, p 13
7 FGD South Africa, 18-24 16 Nov06, ln 24, p 12
14 FGD South Africa, 18-24 16 Nov06, ln 24, p 12
15 FGD Nigeria, 25-49 01Dec06, ln 16, p 13
16 FGD Uganda, 18-24 21Nov06, ln 37, p 10
17 FGD South Africa, 25-49 16 Dec06, ln 8, p 5
18 FGD Nigeria, 25-49 01Dec06, ln 16, p 13
19 FGD Nigeria, 25-49 01Dec06, ln 16, p 13
20 FGD Nigeria, 25-49 01Dec06, ln 16, p 13
21 FGD Nigeria, 25-49 01Dec06, ln 16, p 13
22 FGD Nigeria, 25-49 01Dec06, ln 16, p 13
23 FGD Nigeria, 25-49 01Dec06, ln 16, p 13