MISSING THE MARGINS:

Recurring Gaps in AIDS Communication

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hemes and content of AIDS communication interventions are often predetermined by health experts with little consideration given to gaps and misunderstandings amongst intended audiences. Individual and cultural perspectives of disease vary, and the Western 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 18-14 and 25-49 in four African countries – South Africa, Uganda, Ethiopia and Nigeria - during 2006. Participants were recruited with the assistance of nongovernmental 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 over arching 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:

It will make us understand better. You know, if you understand the origin of something, you're going to understand better how to deal with this HIV/AIDS (Male, 18-24, South Africa).

If people ask you questions then you can't answer it then you keep on telling them something they find it hard to believe: 'Why can't she 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).²

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

It's because we don't abide by the words of the Lord... in the old days people used to respect their God but now there seem to be a lot of religions... People do not abide by the words of God. We just live the way we like to live and God looks at that... and he passes judgment (Male, 25-49, Ethiopia).³

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

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 wherever science stops superstition begins... (Male, 25-49, Nigeria).4

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.

So my question is... what is the level of possibility that one who is not HIV positive and has sexual intercourse with an HIV positive person and he doesn't contract the disease? (Female, 25-49, Nigeria).⁵

So at what level can one actually transmit to someone else. Does it have a particular level that okay, for example I am HIV positive, do I have to get to a certain level before it can be contracted by somebody else from me (Female, 25-49, Nigeria).6

There was also discussion of the relative risk male/female infection:

What I've heard is that chances are that if I've got HIV and then the guy doesn't have HIV, the chances of him getting infected are not as much as chances of him infecting me. So I need to know how is that? (Female, 18-24, South Africa).⁷

Below: Focus group in Kampala, Uganda

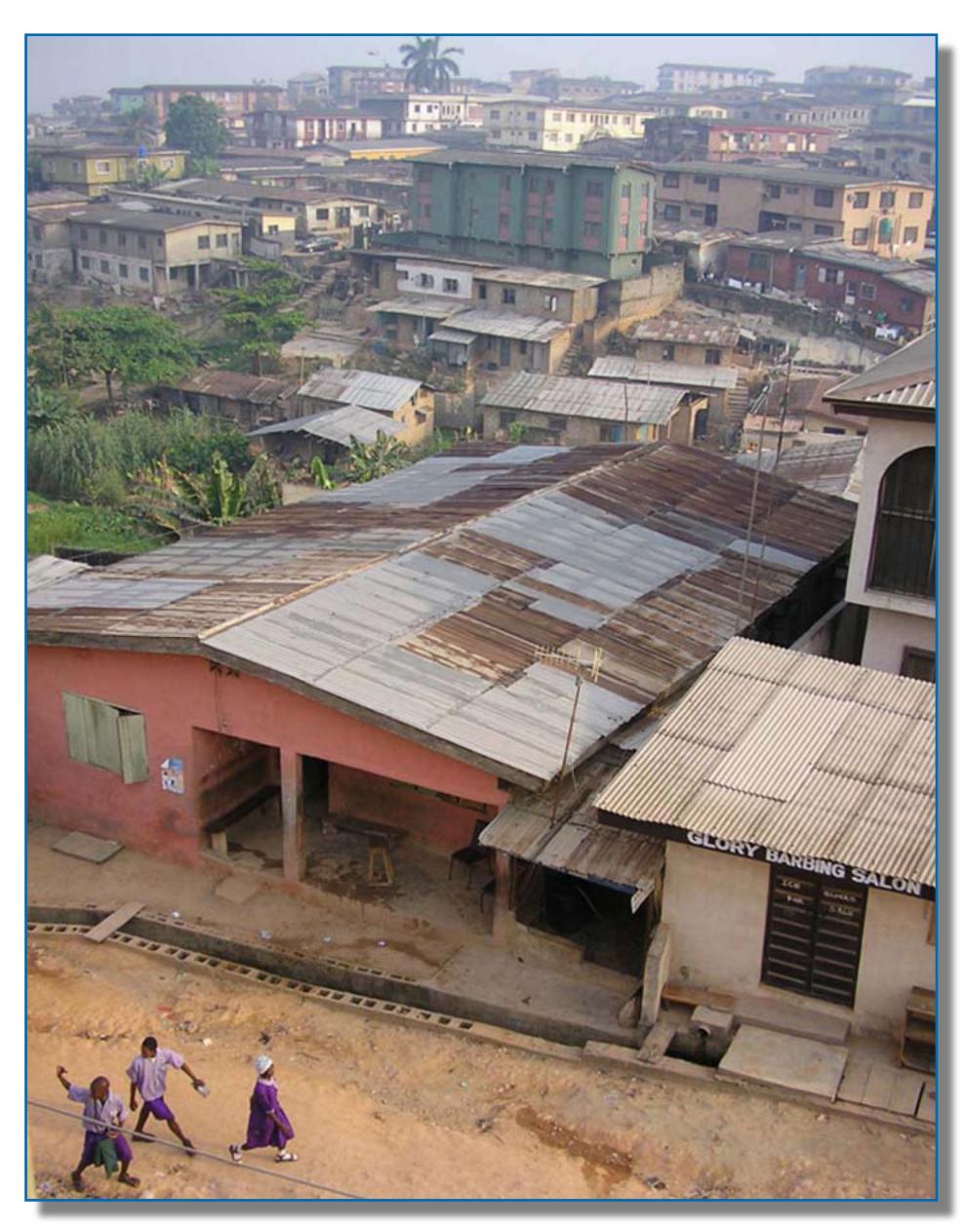


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Above: Street scene, Lagos, Nigeria.

It is said that women are more easily infected than men because women are shaped like a bowl and men like spoons. So for women the virus can stay inside there but for a man it can sometimes not get into him. You see... that is how I understand it (Male, 25-49, South Africa).8

Casual contact

Participants clearly understood the concept that HIV was not transmitted by casual contact. In spite of this knowledge, many expressed reservations at knowingly touching a person with HIV. This fear was not directly related to stigma - rather it had to do with the difficulty in absolutely trusting the 'science' of HIV transmission.

I only found out at the funeral when they were talking about it, what killed him. Then that's when I found out that he had HIV... I was freaked to find out that I actually had to carry him to bed and holding him, and now that I know he's got AIDS I would have never done that... I am scared of the disease. I know you won't get it like that but I don't want to take my chances (Female, 18-24, South Africa).9

I think people are just scared because the virus scares everyone. AIDS scares everyone because it's a death sentence... you're still scared of touching someone specifically because you know it's a killer, it's like the same as touching a bomb, you're going to die. [You] feel scared of someone who has AIDS because you know it can kill you (Female, 18-24, Uganda).¹⁰

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.

When people know it leads to death, why do they put themselves in this kind of situation? This is what I cannot understand. Maybe there is another way of thinking linked to it that they should live for today and don't care about tomorrow. It really surprises me (Male, 25-49, Ethiopia). 11

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.

I don't understand why there has to be quite a large number of HIV infected people in our country when the culture and our religion constrains us from it. Ethiopian people... they follow their culture and are religious... How come when we are so religious and traditional, how come we seem to contract AIDS? (Male, 25-49, Ethiopia). 12

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

A careful person doesn't have AIDS (Male, 25-49, Ethiopia). 13

[If] you're not reckless and you're faithful, your partner could not be faithful. She can go somewhere else with another man and bring the AIDS to you. So you don't have to be reckless to get AIDS, anyone can get AIDS... Sometimes it's just luck (Male, 18-24, Uganda). 14

When you've taken enough [alcohol] you don't care what can happen. So you could go and have unprotected sex with someone who is HIV positive and that could end your life just like that, just alcohol (Female, 18-24 Uganda). 15

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.

Alternatives to 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/faith-healing intersect with concepts of a cure for AIDS. This is often linked to relating personal experience of such cures, or hearing about or seeing proof via media sources.

I think someone can pray for you. You have to pray. I've seen people who have gotten cured who have been prayed for (Male, 18-24, Uganda). 16

... the Born Again's can pray and you get healed. Those are the few cases we hear that they are there and they are healed. And they even test and were found that they no longer have it (Female, 25-49, Uganda).¹⁷

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

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, the liver and the joints were also mentioned. There was a good understanding of the concept 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 goes into you and when it is in it does not attack you right then. So if it sees that the immune system is strong in one side then it attacks it one by one. It starts in the level of the cell, and converts it into the virus until my whole body is converted, then it starts destroying the body cells (Male, 25-49, South Africa). 19

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 immunity is strong. And there will be a lot of battles in the body. Basically it's the white blood cells that's engaging with them. So at some mature time they'll find where to hide in parts of the body, that is depending on how strong the immune system is (Male, 25-49, Uganda).²⁰

Parallel frameworks of meaning

In all four countries there was considerable commonality in constructions, misperceptions and gaps in knowledge about AIDS. These included lack of understanding of the origins of AIDS – which clearly reflects an absence of attention by communication interventions in addressing this fundamental aspect of the disease.

Suspicion about AIDS origins has a fundamental impact on how other aspects of AIDS knowledge are constructed and how knowledge is weighed and legitimated. Other common emerging themes included a strong emphasis on links between religious beliefs and the acquisition and treatment of AIDS, as well as fears of contagion in spite of understanding that HIV is not casually transmitted. Whilst many aspects of 'what' AIDS is were well understood, misunderstandings centered around questions of 'why'.

Overall participants held many divergent views about HIV/AIDS, although it is important to note that Western biomedical concepts were understood alongside viewpoints that might be considered antithetical to scientific points of view. Partly, this was related to not being fully informed about scientific aspects of the disease, but there were also a complex of cultural, spiritual and psychological intersections that allowed for parallel meanings and interpretations to be held.

Psychological fears of contagion also intersected with fear of casual transmission – and it is clear that a great deal of trust needs to be placed in scientific explanations of infection to overcome fear of a remote possibility of infection.

In addressing the science of AIDS it is important to integrate a nonjudgmental approach to parallel frameworks of meaning. It is, for example, possible for someone to go to church and pray to be healed, and at the same time, to take ARVs. Both systems of meaning are real, true and acceptable to individuals, and non-scientific perceptions should not be treated dismissively. The findings provide important insights into communication intervention development and point to surprising longstanding gaps in communicating about AIDS.

Endnotes

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