

Case Study: '*Stigma in your Pockets*'

Why is it that whenever we hear those words 'HIV and AIDS', our ears instinctively perk up? Why is it that after 20 years of experience and learning is this disease still raging around the planet? And why is it that despite years of public health education about the virus, does HIV-related stigma and resultant discrimination continue to be major barriers to the uptake of services – limiting the success of prevention, treatment and care programmes globally?

Nothing compares to you

Despite what some may say, HIV and AIDS just cannot be compared to any other disease. We're not talking mosquitoes and dirty water – No, we're talking sex, morality, shame, blame, fear, condoms and rights – it's a human disease, a social disease – a raw, personal, emotional disease that challenges our beliefs, attitudes and behaviour. Malaria, cholera and the rest of their buddies – well, they simply don't compare.

Stigma and disease have been common companions throughout human history. As Crandall and Moriarity (1995) suggest, 'stigma is most frequently associated with diseases that have severe, disfiguring, incurable and progressive outcomes, especially when modes of transmission are perceived to be under the control of individual behavior'. They go on to suggest that stigma is also common in diseases that are perceived to result from the transgression of social norms, such as socially unsanctioned sexual activity (1995). It is of little surprise then that stigma has played a leading role upon the HIV/AIDS stage. Right from the beginning, the HIV/AIDS epidemic has been accompanied by an epidemic of fear, ignorance, and denial, leading to stigmatisation of and discrimination against people with HIV/AIDS and their family members (International Center for Research on Women, 2002).

Go on – check your pockets!

But whose fear, ignorance and denial are we referring to? Is it only 'those' people or could *we* be included too? Stigma is *no* enigma; it *can* be pinned down and captured. It's right there in all our pockets whether we choose to see it or not. For some of us, it is stuffed deep inside, so we may not even realise it's there; for others it is clearly visible, poking out defiantly for the world to see. And for those living with the reality of HIV and AIDS, stigma weighs down their pockets in the form of shame, guilt, isolation and loneliness. So where does all this stigma and discrimination happen? Let me take you to the rural village of Nalwei in Mongu District, Western Province, Zambia.

Down the long dusty road

Zambia is battling a devastating HIV/AIDS crisis. There has been an explosion in prevalence of the epidemic and currently in Mongu District, adult prevalence rates are reported to be at 22% and rising (CSO, 2003). But Mongu's HIV/AIDS landscape is not a totally depressing one – in fact, within the district, a variety of initiatives have sprung up, including anti-AIDS clubs, awareness raising drama groups, anti-stigma steering committees, church-based stigma workshops and support groups for those living with HIV and AIDS. The ubiquitous NGO 4x4s are too an index of such activity.

And with the recent introduction of free ARVs in 2005, levels of stigma appear to be reducing. But unfortunately and worryingly, this hub of activity has been very much urban based. So what about Mongu's rural communities scattered along the long dusty Lusaka road? Well sadly, the picture isn't so positive.

Nalwei, listed as one of the HIV/AIDS high risk areas within Mongu District, with a population of approximately 5664, is a relatively short forty minute drive from Mongu town. Figures available from Nalwei Health Centre show that of the 366 people tested since the beginning of this year (2006), a total of 71 have tested positive for HIV.

The notion of blame and responsibility embedded in HIV-related stigma is strong in this community. Thus the challenge of tackling stigma is increasingly difficult. Findings from two focus group discussions show that the vast majority of people in this community still view HIV as a *'punishment from God for immoral behaviour'* and a *'shameful state to be in'*.

'It's a punishment because you never bothered to look after yourself properly – you never cared for yourself so that is what you deserve – that is why it's a punishment'
(Male Focus Group Participant, Nalwei)

Likewise, comments such as *'our daughters are busy selling their bodies – I don't know whether its because of hunger or what – but you should see the way they dress – they have long slits in the skirts and when they see us men, they get excited and they then infect us - so the ladies are definitely to blame'* merely highlight the reality of the situation. It is also clear that culture has a powerful influence on this traditional kingship community and the deep rooted cultural taboos and beliefs that exist here clearly inhibit people from discussing sex and thus creates obstacles for effective prevention strategies. The belief that HIV can be transmitted through witchcraft is alarmingly high, with the result that many people in Nalwei refuse to go for VCT until they are in the advanced stages of the disease.

'We think levels of stigma here are very high actually – we base that on the people we have tested and who are on ARVs. We find that they come to us at such a late stage, that by the time they come, when they are quite ill and tend to die very quickly then – some within a few weeks. So its takes them a long time to decide to come and start ARVs – they might have had a test but then don't want to be seen on ARVs – they would prefer to believe that they have been bewitched instead – you see there is no shame with witchcraft'.(Healthcare worker, Nalwei Health Centre)

What is most interesting is that although over 90% of the focus group participants said that they would personally care and support someone who was HIV+, they themselves would not disclose their own status to the general community for fear that they would be stigmatized. The point is this – it is the perceived fear and silence that is fuelling stigma, the lack of opportunities to discuss these issues openly, safely and freely.

'I never knew the views of anyone before today... I'm surprised... I thought they would say more bad things...' (Male Focus Group Participant)

'We wonder why everyone is just working in the urban areas – why not here too, because here I think the problem is very big and they don't want to deal with us'
(Healthcare worker, Nalwei Health Centre)

'We need more lessons about stigma so that we learn how to encourage each other to go for VCT – but no one ever comes here – no one is interested in rural areas...I mean we have never had anyone come here before to talk to us... NGOs just don't come here... no- one does...' (Female Focus Group Participant)

So, armed with some new group activity ideas, seven sheets of flip chart paper and one blue marker, the people of Nalwei haltingly begin this work alone.

Standing on my own

But what about those people who do brave it to the Nalwei Health Clinic and receive the 'dreaded news' – well, let me introduce you to Julie M., a 41 year old mother, grandmother, widow, soon to be remarried woman, who says that she *'gave up on my life dreams back in December'*. Having discovered she was HIV positive in December 2005, Judith now describes a life that is lonely and frightening.

'I feel so lonely since I found out that I am HIV+ ... I don't accept it at all... I am thinking of moving somewhere else to where my brother is...to be in town instead of in this area would be better... I might have more support there and levels of understanding is better there too...the comments from the community worry me, I hear it every day... yesterday I saw a man who just said to me, "do you see that lady, she has the virus" he just commented on her for no reason – after that I just sat on the chair and cried' She continues by saying that *'here in the rural areas, stigma is still high and it will stay like that until the proper information is given to us all here...I mean some people still think you can be infected by sharing the same cup as someone'*.

Julie's final comments are *'if a HIV support group came to visit us in Nalwei and talked to the community that would be the best thing in the world'*. I'll let her words be my final ones too, in the hope that some of those 4x4s will take a spin down her dusty road soon.

Case Study provided by:

Emma Connors, *Stigma – What Stigma?* – A Study of HIV-Related Stigma in Mongu District, Western Province, Zambia, (On behalf of Concern Zambia), 2006

(All quotations taken from focus group discussions conducted in Nalwei)

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