

# Imagined Fu+ures III

## Posi+ive Fu+ures

25 -26 September 2008, Pretoria, South Africa



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Conference organisers: Johan Maritz and Palesa Mphuthing

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## Abbreviations and Acronyms

ART	Antiretroviral treatment
ARV	Antiretroviral
CSA	Centre for the Study of AIDS, University of Pretoria
HCW	Health care worker
HEAIDS	Higher Education HIV/AIDS Programme of South Africa
MCH	Mother and Child Health
MCP	Multiple Concurrent Partners
OVC	Orphans and Vulnerable Children
PMTCT	Prevention of Mother to child transmission
SADC	Southern Africa Development Community
SAIH	Students and Academics International Assistance Fund
SRC	Student Representative Council
STIs	Sexually transmitted infections
UCA	University of Zambia Standing Committee on HIV and AIDS
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNAM	University of Namibia
UNICEF	United Nations Children's Fund
UNZA	University of Zambia
UP	University of Pretoria
VCT	Voluntary counselling and testing

**Opening Session**

The Imagined Futures Conference III was opened by Mr Johan Maritz, Senior Manager, Centre for the Study of AIDS, University of Pretoria. Mr Maritz welcomed the delegates to the third in the series of Imagined Futures conferences, expressing pride in the growth and stature of the event, this year coinciding with the centenary of the University of Pretoria.

He thanked the Students and Academics Assistance Fund (SAIH) for their generous sponsorship to both the Imagined Futures Conference and the Future Leaders @ Work Programme, and passed on their regret for not being able to attend. SAIH was in the process of finalizing their proposal for funding for the next phase, to be submitted to the Norwegian government in the next week, and he praised their very critical role in these programmes, and the importance of this proposal for this group, at the receiving end of the proposed scope of work.

He welcomed delegates from across the Southern Africa region, including from Botswana, Malawi, Mozambique, Namibia, South Africa, Swaziland, Tanzania and Uganda, expressing the hope that opportunities for collaboration would only increase in the future. He thanked the speakers for making time to participate in the programme, and the Student Chair, Ms Prishani Moodley, whom all delegates would get to know over the two-day programme.

In keeping with the model employed by Future Leaders @ Work, it is their practice to always try to invite both staff and students, to ensure that they don't develop programmes without getting students' voices heard, but also to ensure sustainability and continuity.

Ms Mary Crewe, Director of the CSA, had hoped to be here, but was unable to attend due to speaking engagements in Australia. Mr Maritz also announced some changes to the programme, primarily involving the keynote speakers. Professor Jonathan Jansen was unable to attend and deliver the keynote address, and similarly Ms Maureen Mashele, who was due to deliver the third Keynote address, was unavoidably detained. He therefore introduced Mr Edwin Smith to deliver the keynote address of the conference.

**Keynote Address: Edwin T. Smith, Director, University of Pretoria, Mamelodi Campus**

### **The deadly silence**

A university colleague recently sent me an article published in a South African newspaper of Tuesday, 2 September 2008. (*The colleague, Professor Andy Ramaranka Mogotlane, Vice Principal: University of Pretoria, was in the audience and I pointed him out*) In traditionally dramatic style, the article is headlined, “1 000 000 voters ... Dead!”<sup>1</sup> The article reports how our young democracy is losing voters registered on the national voters’ roll and how graveyards are filling up, causing local government officials to ponder the idea of families reusing graves. Besides the idea of “mass graves” being completely untenable in the private spaces in public imagination, such is the crisis around HIV and Aids in our country that this has now become a serious matter in our urban centres. But tellingly, the government officials reportedly “do not know the causes for these deaths. ... According to the Independent Electoral Commission, the national voters’ roll is losing an average of 35 000 to 40 000 people EVERY MONTH!” the article reports. “Mr. Michael Hendricks, a commission spokesman” is reported to have “said on TV on Sunday night: ‘We don’t know the causes of why they are dying, but clearly we are putting our strategies in place to ensure that through continuous registration we give people an opportunity to register.’”

While some things have changed and progressed, others remain locked in the irrational bureaucratic tracks of simple-minded government. But the silence on the ravages of HIV and AIDS keeps killing our communities. In the silence, we miss opportunities to engage and save lives.

On the other hand, there have been numerous attempts to try to understand this “silence” among us. A recent Centre for the Study of Aids Forum presented Dr. Isak Niehaus’ take on this “silence” through his presentation titled “Death before dying: AIDS, lepers and zombies.” Dr. Niehaus utilizes “ethnographic fieldwork [he] conducted in Bushbuckridge and argues that the association of AIDS with sexual promiscuity has not been the major source of its stigma. Instead, he suggests that denial, silence, fear and fatalism have stemmed from the construction of persons living with AIDS as ‘dead before dying’, and from their symbolic location in the anomalous domain betwixt-and-between life and death. In this process the

notion that AIDS is a fatal terminal illness carries as much symbolic weight as the popular association of persons with AIDS with lepers and zombies.’<sup>ii</sup>

To me this was a curious take on “deconstructing and problematising” the “silence” around AIDS in our communities that I so much wanted to attend the August Forum where Dr. Niehaus was due to make his presentation. In the end I could not but hope to get a glimpse of his take on the matter through reading his work. If you know I fancy myself a writer, you might better understand why Dr. Niehaus’ other book, a biography titled, *Father of Misfortune: The life of a South African Teacher, 1964 to 2005*<sup>iii</sup> should have been, and was, of immediate interest to me. I tried to locate the book but learned he is still finalising the copy for printing. But you might be curious as to why his talk on HIV and AIDS and death before dying would be important to me as I am not a researcher in the area of AIDS.

While I have been aware and involved in one way or the other with HIV/Aids related issues and activities from my early visit to the Kilimanjaro Christian Medical Centre in Moshi, Tanzania in the late 1980s to my work with the American Foundation on AIDS Research's unit at the Graduate Hospital in Philadelphia in the 1990s, I find my own responses and reactions to the issue of HIV and AIDS often as pathetic as some of the reactions cited above.

Therefore Dr. Niehaus’ talk was important because I too am confronted with the danger of the silence in our communities and families around the issue of HIV and AIDS. More pressing is that the silence is more personal than many of us imagine or care to admit publicly. It is deadly and it must stop.

Perhaps you are now wondering what on earth I am talking about. Well, one Friday morning in July this year, I drove from Pretoria to East London for a quick visit to bury my baby sister, my mom and dad’s last-born child. She died of complications arising from HIV/AIDS and multi-drug resistant TB. This was a strange personal experience. Till that weekend, I had never buried one of my mother’s children. I had buried one of my father’s children, from his previous marriage, who died of a brain tumour a few years before but never one of my mother’s children. Consequently, this was un-chartered territory for me. Since returning home to Pretoria following the funeral, I have been reflecting on the experience. I expect I will be occupied with such reflections for a while as I try to distil the meaning of it all, if ever that is possible.

At one point when I heard about my sister’s death, all I really cared to do was to know how much I needed to pay for the funeral, transfer the money to my brother’s account, and let the

family in East London sort things out on their own. I just wanted to get on with my life. As far as I was concerned, I had my own demons to slay; I had my own personal challenges to mind and attend to. I knew the responsibilities I signed on to in the choices I made in my life and they demanded my attention as urgently as breathing. I could not be bothered with going to East London to sort out the mess over there. I was further bolstered in this as I had distanced myself from my baby sister a few years ago due to the life she elected to live and the choices she continued to make.

Though they troubled me from the time I got to know about them seven or eight years earlier, I suffered this drastic choice because I had come a long way with this particular sibling.

My baby sister was born in 1983. When she was born, my mother had heart complications during labour. Because my mother was retained at the hospital following her health complications, I received my baby sister when she was only three days old to be exact. I took care of her until I left for exile in the mid-1980s. When I speak of taking care of her, I mean doing everything I now know a parent does for a baby. I even learned to read with her in one arm in the middle of the night when she could not sleep, to taking her, strapped on my back, to political meetings and underground sessions in the height of our political activities in the 1980s.

When in 1989 it was clear I was to leave the continent having been in exile in southern African countries a few years by then and having completed my studies at Somafco, the ANC school in Morogoro, Tanzania, I organised to have my mother and her visit me in an underground hide-out in Harare, Zimbabwe. I arrived in Harare in 1990 for the visit the week New Zealand Anglican Priest Father Michael Lapsley received a parcel bomb from South Africa. According to media reports when he opened the magazines he was sent, “it detonated a bomb so powerful it took out the ceiling of three rooms of his house and left a hole in the floor”<sup>iv</sup>. Having lost both hands and injured his face, Fr. Lapsley survived the attack. Clearly it was dangerous to be in the ‘Frontline States’ in the eighties, hence my family’s visit was a serious risk. I could only justify having them visit me by claiming my sister was my daughter. When they returned home and I busied myself to go to the US after returning to Zambia, I arranged to have the Canon Collins Defence and Aid Fund in the UK provide her financial support to help with family needs in my absence. Again I justified this as I claimed her as my dependent.

As a result, many people who know me from my years in exile know my baby sister as my daughter. These lies were not “white lies”. They were necessary fabrications to keep life and



hope alive. I did this fully aware one day I would have to come clean as the lie kept haunting me in my own personal life and in the circles I kept as I plodded stubbornly along the journey to here and now.

Post 1994 I was able to visit home frequently while still in the US. Then my baby sister continued to enjoy certain privileges. She was enrolled at Sterling High School, a well-reputed, white high school in East London. I expect it was a “Model C” school if it was not a private school. My parents drained all their financial resources to make these opportunities available to her. On looking back, she was the most privileged sibling in my family as all the rest of us attended public coloured schools in coloured locations. Perhaps unaware, we all tried to give her the opportunities closed to us during our time. We wanted, wished, and hoped better for her. When I returned home in 1999 and settled in Pretoria, I ran home to collect my baby sister in December 2000 when I learned she had failed Standard 9 (Grade 11). I was shocked and angry because until then, no one in my family had ever failed a grade in school. I was cautioned against such impetuosity and impulsiveness, noting that paying for someone’s school fees was a different matter to taking on a teenager and subjecting them to your sensibilities, however noble. But I was her big brother and she could not fail me I reasoned.

Having brought her to Pretoria to live with me and my family, I kicked her out of my house only two weeks later. In the short span of two weeks, she had befriended a neighbour’s daughter in our complex who was attending the same school I intended enrolling her in. I was initially happy she was making friends until I learned they had visited Hatfield with this selfsame friend and that they were doing drugs.

I confronted her about this and told her that one of two things was going to happen to her: either I would kill her with my own bare hands or the things she was doing would kill her. Since I had no wish to stain my hands in this manner, I put her on a Greyhound bus and dispatched her back to East London. The next day my mother called, disappointed and angry at me for being such an obstinate, non-understanding, and strict person. She told me my baby sister was still a mere child and that children made mistakes. I told my mother that since she understood these things and tolerated them, she was welcome to live with her daughter. I would have nothing of the kind in my life. I also told her that if she understood and tolerated my sister’s behaviour, she should prepare herself to bury her daughter. With these charged statements, I severed contact with my baby sister. That was over seven years ago and I would occasionally run into her when visiting home and only the polite ‘hello’ would pass between

us. A few months after this incident, the girl she befriended in my complex was found dead one morning in her bedroom at home. She died from a drug overdose.

Shortly after my baby sister returned to East London, she got pregnant. I was not told about this until my sister in Cape Town called me to ask for my help because she could no longer financially carry the burden of hosting my mother and our baby sister with her newborn child at her house in Cape Town. She herself was a single working mother. That was the first I heard about my baby sister having had a child. Apparently my mother, baby sister and the rest of my family conspired to have the child born in Cape Town so I would not know about the pregnancy and the baby should I visit East London unannounced as I was want to do often. I also recently learned my baby sister had a second child because the baby who was only five months old at the time of the funeral was also very sick and is continuously hospitalized. The child was not in East London because he was in an intensive care unit in a hospital in Cape Town.

Before the strange private viewing for family only at the house and the church during the service, I last saw my baby sister during my last visit to East London about 18 months or so before the funeral. Then she looked well and fine from a distance. Things must have turned for the worst after I left, which included her second pregnancy. I then started receiving reports about her health from my sister in Cape Town, partly because they were requesting financial support from me as she had developed the multi-drug resistant tuberculosis which is wreaking havoc in South Africa right now, particularly among Aids patients.<sup>v</sup> While I was willing to support the children by sending money to my sister in Cape Town whenever I could afford to, I made it very clear that not only was I unhappy to be enlisted in this manner, I was not interested in getting involved in my baby sister's shenanigans. My baby sister called me a month before her death to tell me she was very sick. This was the first time she spoke to me directly about anything and particularly about her illness. I told her I already knew about her illness and that there was nothing I could do for her. But we did not speak about AIDS.

"Is that how you feel?" she asked.

"Yes...that's how I feel," I replied.

"Oh. I did not know," she said.

"You must be absolutely stupid not to know," I told her with steadfast determination. "Is there anything else?" I asked and when she said there was nothing else, I ended the call. The next time I received a call about her, it was from my baby brother telling me she had died in hospital.

With her passing, my youngest brother called me to ask me to help pay for the funeral. I transferred money into his account and paid for the funeral. He called us again to report on all manner of family complications and trouble.

Our mother was losing her composure over her loss and grief. Reportedly she ordered my baby sister's boyfriend, the father of her youngest child, and his mother to leave our house and not attend the funeral. She held the young man responsible for her daughter's death. While this was absurd, I understood her anger and need to hold someone responsible for her loss. I was angry too. I held my mother responsible for my baby sister's death. My wife counselled it would be best for us to go to East London to support my younger brother and the rest of the family to manage these issues. Somehow, my presence had a "calming" effect on my siblings and parents it seemed. Some think it is fear as I am an enigma to them. Besides my baby brother was in dire need of some support.

Upon our arrival everything proceeded without a glitch, such that on Saturday morning we as siblings led by our dad, carried my baby sister's casket to its final resting place. On the day of the funeral I stood with my oldest brother, the brother that comes after me, my sister from Cape Town and my baby brother, as we were led by our father as pall bearers for his last born child and our baby sister. We carried her into our house for the morning service at home, took her to the church for the service there, and were the pall bearers carrying her to her grave, her final resting place. My father shed a dignified tear as he watched his daughter's casket lowered into the grave and I scanned my siblings' faces, trying to comprehend their sorrow. Looking over the open grave, I looked at my parents and siblings. For a moment I was happy to be with them and to share in our grief and loss. I was proud of my family. Led by our parents, we carried our loss and sorrow with silent dignity.

Having reconvened at the house, I met some old childhood friends, some I had not seen for as many as 23 years. Reminiscing about the past, many of them remembered being in my shoes burying a sibling or family member. Like the community mothers who conducted the service at the house that morning, they said I would get over it; I too would live and move on. After saying our goodbyes, my wife and I got back on the road for our long journey back to Pretoria to face our life's demands. I was pleased I attended the funeral and that I had been there with my family during this experience. The only nagging feeling which accompanied me as I've tracked on from that moment is my guilt over the missed opportunity to talk to my community and my late baby sister's peers about HIV and AIDS.

While I wanted to talk about this to the captive audience during the church service, I felt it

would not be appropriate to mar my family's grief on this occasion. Somehow it seemed inappropriate. My sister read the obituary during the service and you would swear my baby sister was an angel. I was asked to thank the community on behalf of our family. Referencing the preacher's remarks, I managed to say that we all would end up where my baby sister was, pointing at her casket. And that what would make a difference in when and how we ended up there largely depended on the choices we make in our lives. That was as close as I could get to the matter on that occasion.

On the way back to Pretoria and since, I now realise how I have been plagued by guilt because we did not talk about how getting tested and knowing one's status early can help prevent you from ending up like my baby sister. Save for the preacher leading the service at the church decrying the loss of so many young people to AIDS in our communities, no one talked about what killed my sister nor about the ravages AIDS is causing in our homes. No one even talked about what help is available to those who are infected or affected by AIDS. Like so many others, on that day of the burial, no one said a thing, and the worst thing about it is, neither did I.

## Discussion

### Discussion

Mr Smith noted that the opportunity to hear feedback on his own personal experience presented an opportunity for him to talk about HIV and AIDS that he did not have at his baby sister's funeral or since. The "avalanche" of appreciation represented a real sense of how close everyone is to the epidemic. His expression of who he is through his very personal story somehow made AIDS real to many in the audience. The realisation came to him that what he was trying to demonstrate was how inadequate our responses are, on a personal level, to the epidemic, and that, notwithstanding our learning and knowledge, we still suffer serious limitations when this issue confronts us up close. It is one thing to pass judgement on government policy, and individuals suffering, living with, and affected by HIV and AIDS, but it is a totally different ball game altogether when HIV and AIDS makes a direct demand in your own life.

Mr Smith's hope was that sharing and reflecting on these issues and experiences would enable enormous growth, discovery and learning, and a transformation of his own loss, if he

wished for any chance to move on with his life. But in order to do this, it was necessary to break the silence wreaking havoc in our lives.

Pierre Brouard, Deputy Director of the CSA, welcomed Professor Mogotlane, Vice Principal of the University of Pretoria, in the audience. He thanked Mr Smith for his highly personal and detailed account that could not have been easy, but brought home that, very often in the epidemic, it is easy to forget that these are real lives, real people and real families who are struggling amidst all the figures and statistics. His story showed that knowing and having the information about HIV is not enough. We are complex people, so we cannot assume that if we give young people the information, they will automatically become good citizens and responsible partners, which is not realistic. Our question should be, how can we support people as they make changes in their lives, and attempt to integrate this knowledge into their behaviour?

There were many positive responses from delegates to Edwin Smith's presentation, encapsulated in the following points:

- This highly personal and real life experience reinforced that, as student leaders, it is important to learn change and then seek to change others' behaviour.
- The story demonstrates how present HIV is in families, and that it is really important to talk about it. The problem is that there is often a tendency to have a judgemental attitude towards relatives who engage in risky behaviour. This is understandable, but it also emphasises that it is better to sit those people down, no matter how angry we are - even though Mr Smith was taking care of his sister, and she showed no appreciation, it would have been better to sit her down.
- The first part of the presentation hinged on political systems, and their inability to move fast and respond to the fact that HIV is ravaging our populations. This reinforces the fact that it is time for governments in the region to move more quickly.
- A key message in the presentation is that until we break the silence among us, we will make no headway in fighting HIV. "Silence is not golden" when it comes to HIV and AIDS.
- Some expressed the view that African cultures are lagging behind, as some things are considered taboo. We can't talk about sex in our homes, but we need to break the barriers in our homes.
- Our culture promotes silence about sexuality, and in the midst of this crisis, people like Mr Smith really make a difference - some reported that they had also had family members die, and that it is never discussed in the family, so the cycle continues.

- The story instilled anger about HIV, anger that it cuts young people's lives short, anger that we are imperfect as human beings, and that it is not enough to know that AIDS kills to make us change our behaviour.
- In summary, there was a feeling of pride in the group, that as young people, the same age as Mr Smith's sister, they had taken note of the need to empower each other, to be aware of their own sexual awakening, and to know that it could happen to them.

## Keynote Address

### Keynote Address: Pierre Brouard

Over the next two days we will be dealing with some complicated issues that impact on the epidemic in different ways. On day one, the focus is on stigma, discrimination and disclosure, while day two will concentrate on treatment and adherence strategies.

In the interests of painting a bigger picture, I would like to tell you about my own HIV journey. As far as I know, I am not HIV positive, and I add that as it depends so much on the last time you had a test, if one is sexually active. It leads to the question of how often we should have tests: every time you have sex where you're worried you might have done something risky? Should we be rolling out testing every time one visits a clinic or hospital, where of course there are challenges around human rights, but also is it doable?

I was a sexually active adult in the late 1970s, which makes me a dinosaur in the room. This epidemic has a long history. When it first came out, we thought it was a gay disease, characterised by gay-related immune deficiency, but then we began to see other manifestations beyond the gay community. Primarily, this was confined to those people who were marginal, for example sex workers and drug users, which is where the stigma and shame came about, that it was something horrible and dirty. There was no test until 1985, and I remember that when I started counselling in 1987, I would tell people not to test. We also encouraged secrecy, advising people not to tell anyone about their status, or about HIV, and we have been bedevilled by it ever since. We even have patients these days who say, I want you to tell X person, and the nurse or doctor says they cannot, but of course they can if the person gives consent.

When treatments became available in 1997, it changed the terrain, although it involved drugs that only rich people could afford, and so it split us again, as the battle for free access started. Now, in this country, ARVs are free, but access to them can be difficult. We do, however, have images of hope now that treatment is here and it has become an extraordinary time to be living through the epidemic. However, we still have stigma and discrimination, and we still have people not coming forward, we still have people dying. We could ask, why, in 2008, do we have this situation, and there are no simple answers to that.

Thinking about this conference, and the work you are doing in your universities, one is compelled to think about the bigger picture in the sub-region. We are severely affected by HIV, especially if one talks to someone in, for example, Australia, where they have 50 000 PLWHA, whereas in South Africa the figure is 5 million. This says something about the scale we are dealing with: our ARV rollout is the largest treatment programme of its kind in the world, which does not excuse some of the tardiness and denials experienced in our leadership here, but it does point to the challenge. It is also important to recognize that it is young people like you, discovering yourselves at university, and your sexuality, who are the ones who must also carry the burden of struggling with HIV and its impact on your lives.

It is also primarily a sexually transmitted disease, which brings up the whole discomfort about talking openly about sex. One of the dangers is that it has led to a kind of moralism, and a tendency to talk in the language of do or don't, the language of danger and of risk. This has resulted in a move away from the idea of sex being about joy, happiness, and intimacy, and so we have to find a way of balancing that.

It is also a social epidemic, dominated by doctors and epidemiologists and biomedical people, but the roots of HIV are about beliefs, and social practices, and inequality. If we only approach HIV from the perspective of rolling out VCT and ARVs, we are missing the root causes and consequences of HIV, which are in the social fabric of societies. It has the potential to disrupt social society, and while we need biomedical interventions, we also need to locate HIV in a social frame. Given that we are from universities, we need to look at HIV through different lenses - the lenses of sociology, anthropology, psychology, geography, history, law etc. Unless we take a holistic perspective, our interventions will be critical and narrow. We need to use those lenses to understand the epidemic.

There is also a language of despair around HIV, the idea of devastation, destroying societies and communities. We need to, instead, look at the language of hope, to start to envisage the societies that we want to live in. We need to examine what HIV is teaching us about our

societies that we want to challenge and change, issues around gender, race and class, for example.

We can also look at HIV from the perspective of leadership and not helplessness. Someone talked about leadership at the senior-most level, as if there isn't the political will to address HIV we will have challenges. We need to be inspired, and we need a leader who says "I want to do something about HIV, I want to work with you."

We have a number of Imbizos in this country, and yet, when has there ever been in South Africa an Imbizo about AIDS? This would involve going to communities, finding out how they are addressing AIDS, and stigma, treatment, access to social grants, care for orphans and so on. Going to communities - how are you addressing AIDS< stigma, treatment, are our social grants coming through, are your orphans being looked after.

Similarly, one could ask about the role of universities. They are a microcosm of society, where there is a complex array of people from different backgrounds working in different hierarchies. In many ways, what is going on out there in terms of attitudes, beliefs, social capital, sex etc, is what is happening in the universities as well. This makes it important to address the issue inside universities first, and then to look at ways to apply these lessons to external communities.

It is important to ask about the culture of my institution: Is there a culture of openness, is it a place of denial, is it one where women are not in positions of leadership, or a place where class divisions are rife? Universities are also about future leaders, as you are the ones who are going to go out and join government, be active in the workplace, live and work in communities, have families etc. We need to examine how we can work with this in a way that is practical, useful, and sustainable. There is the opportunity to do something about HIV for students that is more than just about information, more than the two weeks in your first year that touches on HIV.

Every first year student goes through an amazing two week course, so that the university can tick the numbers off, but so what? People come from communities that are complex and informed by different values and structures. We need to think about how to inspire and motivate students beyond the AIDS 101 approach.

This kind of conference is critical as it offers the opportunity for a horizontal engagement,



which is vital so that we don't work in our own individual bubble. Universities can conduct research through disciplines as diverse as economics, dietetics, law, all of which can help us to think innovatively about HIV.

Universities are also places to get young people to start thinking about what it means to be an engaged citizen. I would argue that this means that it is important to look around, and to feel that one has a responsibility to do something, that it is about participatory democracy, and not just about having services, but about me being actively involved, about voting, and looking for ways to contribute to better governance.

I would like to just touch on what enables changes to happen. We are here to try to change, to evolve and grow and do something different. My view is that we need to look at individual level factors, for example, am I motivated, do I feel inspired, have we addressed issues of self-esteem, do I feel like I am in control of my life? There are a whole lot of factors that need to be addressed as part of the component of change.

In terms of social factors, are we addressing people's attitudes, exploring issues of race, gender, class, sexual orientation, and are we trying to influence those, as well as looking at social institutions?

In summary, there are also the structural factors, or the things that enable change to happen such as processes, places, policies, buildings, e.g. making testing possible for students by having them available on campus. If we want people to make those changes, we need to make those services available to them. If we want to do something about stigma, treatment, and testing programmes, we need to locate them in connection with other factors.

My hope is that in the next few days you will feel inspired to make a difference, and that you will get ideas to inform your own lives and the lives of others. My wish is that you will go away with a sense of inspiration, determination, and motivation to make a difference. We value your presence here.

## **DISCUSSION**

Some key points were raised in response to the above address:

- **The Politics of Trials:** The point was raised that every drug is tested first in the poorest areas of the world, in particular, in Africa, where people are offered money to participate in the trials, but without any explanation or communication between the drug companies and those being tested. This echoes a long-held belief that people in poor countries are used as guinea pigs. It is a complex issue as often what is needed is a large sample of people, which is harder to find in developed countries. However, it does highlight the need for very ethical guidelines, as well as people to monitor and communicate to people about the trials. There have been some successful trials, however, for example, recently Brazil rejected a patent from a US company, as they did not believe that the drug had enough components to it. Brazil opted to make the drug themselves, refusing to conform to the norms, indicating that there are opportunities to address inadequacies in the drug trial process.
- **The location of universities within HIV/AIDS:** The group discussed the role of Student Representative Councils (SRCs) on campuses, which in some contexts are almost like mini or pseudo-governments. On one campus, the SRC is involved in the annual HIV/AIDS week, and then it ends there. The aim of a dedicated centre like the CSA on campus is that they don't engage in small vertical programmes, but look at the role-players across campus and examine ways to engage them on an ongoing basis. This approach looks at institutionalizing AIDS so that it is a part of the thinking, breathing life of the university. This requires constantly looking at building bridges and alliances within campuses. This acknowledges that no one is immune from the effects of HIV, not in communities or families, or campuses. Mr Smith expressed great disappointment in the role of SRCs on campus at present, where the focus is to acquire budget for parties and trips, but never for education programmes on campus. SRCs have enormous budgets at their disposals, and as such, they have a responsibility. However, they can only be held responsible or accountable when students hold them accountable. In the absence of student mobilization around issues, the SRCs will continue to lead on issues that have no bearing on students' lives. It is difficult to get to university, so for young people who make it there, it is important that they assume responsibility and take charge of their own lives, and that includes honesty in their reactions to HIV. If campuses continue to do more of the same, nothing will change.
- **Language of despair:** Delegates agreed that the language around HIV is all about despair, and about fear, which is associated with stigma and the fear of being ostracized. It is important to develop a new language of hope, which delegates felt

was an important message to take away with them.

- **How to integrate HIV into institutions?** At UP, apart from inclusion in the curriculum, and the fairly intensive training around HIV, institutions are encouraged to get involved in other projects, to go beyond their own areas of focus and people, which helps to build social capital. This produces a sense of cohesion and involvement in a shared endeavour, and access to support from others. The results are, of course, not perfect, as students are still testing positive, but it does make people aware that they are part of something bigger. One delegate made reference to a study some time back that revealed that those students more likely to carry condoms felt more affirmed and confident in their lives. The aim is to build social capital and to work towards affirming young people, and making them positive about the future. Each institution needs to grapple with those issues. After a recent workshop at UNZA, students said they were tired and bored with information. It becomes a challenge to think about how to disseminate information on HIV to make it constantly interesting and relevant. An example was given of the SMS campaign: Sex Manners for Students, which was devised as a way of integrating humour and provocation into the campaign, to address the issue of AIDS fatigue. There isn't a magic bullet around anything to do with HIV, but at UP, they remain committed to innovation in their approaches. The message that came out of this session was that, like Mahatma Gandhi said, if you want to see change, be the change in the world, so it is highly personal, and begins with individuals.

## Coping with stigma and disclosure

Session Chair: Patrick Eba - AIDS and Human Rights Research Unit

The following presentations will relate mainly to issues of stigma and disclosure, two very important aspects in response to HIV. Stigma is an impediment and hindrance to treating HIV, and disclosure is considered a key element in terms of accessing treatment.

**Speaker: Bernard Kampolombo: University of Zambia**

**Stigma on Campus: The case of the University of Zambia (UNZA): My experience**

I am a third year student in the School of Education. I am a Health Promoter for ZAMANAWE, and a student who is HIV positive and has gone public at UNZA. I have had first hand experience of stigma on campus. I went public on 1/12/06, in my first year.

In this presentation I hope to illustrate how for a person like myself, stigma is a hindrance to both treatment and meaningful participation of people who are HIV positive in the fight against HIV/AIDS on campus, drawing on my own experience at UNZA.

*The 2006 Baseline Survey on Sexual Behaviour among UNZA students*, which posed a series of questions to a sample of 759 first year entrants, showed the following:

- I would feel uncomfortable hugging someone who has HIV/AIDS”

Response	Frequency	Percentage
Strongly agree	32	4.2%

- I would not feel comfortable using the same toilet with someone with HIV and AIDS

Response	Frequency	Percentage
Strongly agree	47	6.2%

- If my roommate or housemate has HIV and AIDS, I would care for and support him or her

Response	Frequency	Percentage
Disagree	21	2.8%

The results from that survey indicate the prevalence of stigma on campus.

### **Forms Of Stigma**

Stigma comes at two major levels:

#### **(i) External (Community)**

This could be at:

Home, Church, Work place, health centre, School (my area of emphasis)

Among the indicators of stigma are: avoidance, moral judgement, rejection, discrimination, abuse (both verbal and physical), perception of self (low self-esteem), over-compensation (working harder than usual to make up for being positive), fear of disclosure (which is an inverse measure of stigma: high levels of disclosure may mean low levels of stigma) - I have observed all of these phenomena at UNZA, which I believe is a product of internal stigma. However, most of them I have only come to know and experience from print and never in reality

#### **(ii) Internal (self) Stigma**

This seems to be the major form of stigma exhibited at higher institutions of learning, more so than the external form. It stems from two sources: shame and fear.

### **Shame**

All of us wants to be perceived in a good way, both by our peers and the community.

Disclosing ones status means that one's character is brought into question, especially given that humans are quite protective and secretive about their sexual lives. If positive, one feels ashamed that all one's friends will know that one has engaged in sexual activities, even if it is a well-known fact that not all cases of being positive come through sexual intercourse.

### **Fear**

- Fear of being tormented through name calling, finger pointing, teasing, ridicule, labelling, blaming, back biting, rumours, rejection, gossiping and isolation, both by course mates and lecturers
- One feels that this, in turn, will affect one's academic performance. One will lose self-esteem and the result will be poor performance.
- Fear of remaining unemployed upon completion of one's course. Because of stigma imposed by the community, as a university graduate one is afraid regarding job and future career prospects. For instance, one wonders: Who is going to employ me? What about

my future career prospects? Which institution is going to give me a scholarship when they already know that I am positive?

### **Impact Of Stigma On Meaningful Treatment & Participation Of Positive People On Campus**

While UNZA's ART Clinic is well stocked and within a convenient distance for all positive students to access their drugs, some students have opted to go to other clinics that are far away from the campus. This is as a result of the above stated factors. Because of stigma, there are low levels of disclosure at UNZA and hence low participation of positive people in HIV/AIDS activities on campus.

At UNZA, they have tried to establish the Post-Test Club, a support group that was created where positive students can meet and share various information on Positive Living, such as dealing with various side effects of ARVs, for those on treatment, and for those not yet on treatment, how nutrition and other supplements can be used to maintain their CD4 counts higher, and so delay the time when to begin taking the ARVs. Because of stigma, many students are not ready to join the group and hence miss out on such informative discussions.

In conclusion, it is clear that these areas that create stigma need to be reduced through deliberate programmes aimed at addressing them, and also that there is continuous sensitization on the dangers of stigma.

#### **Recommendations regarding Stigma:**

- Continuous advocacy and sensitization on the need for people who are positive to come on board and join the fight against HIV/AIDS
- Creation of strong and sustainable Post-Test Clubs within institutions
- There is a need for both financial and nutritional support to be given to the support groups.

“Someone asked me what my greatest fear was, and my answer was that I do not wish to see my friends become positive like me.”

### **ADHERENCE & TREATMENT**

#### **Introduction**

Adherence is a term used to describe how loyally an individual “sticks” to the prescribed

treatment. When one misses, forgets to take doses, takes too many tablets, or even stops treatment for a “holiday”, these are all instances of non-adherence. ARV treatment requires very high levels of adherence.

Due to its specificity in terms of taking the drugs at the prescribed time, adherence is complex in the academic setting and the university campus.

However adherence is the cornerstone of successful ART treatment, and a mainstay element to viral suppression. Even a slight non-adherence can lead to a drop in the levels of drugs in the blood and the development of drug-resistant HIV. The treatment will therefore cease to be effective. Resistance does not appear suddenly.

### **Barriers to Adherence**

There are different barriers to adherence; among them:

#### **Emotional/Psychological Factors:**

- Depression, emotional breakdown
- Guilt at having survived the death of a loved one (survivor’s syndrome)
- Level of self-esteem
- Denial: if a person wants to forget that they are infected by the virus, they may not want to take drugs as they remind them of their status

#### **Mental Factors**

- Inability to understand and remember prescriptions, dosage schedules
- Lack of belief in the effectiveness of the treatment, related to perceptions of drugs in general

#### **Behavioural Factors**

Possible difficulties in organising and managing personal time (for instance in relation to work schedule)

- Reactions to side effects and other related constraints of treatment
- Consumption of substances such as alcohol and drugs

#### **Physical Factors**

For someone who is HIV positive and asymptomatic, the treatment can be perceived as the start of the illness - the side effects of ARVs may be perceived as the first signs of AIDS

For a symptomatic HIV positive person, the disappearance of opportunistic infections and other pathologies can give the impression of being cured and no longer requiring ARVs.

### **Social Factors (Environment)**

Taking the drugs secretly (in the family, at the workplace, at school/university, with friends)

Stigma, discrimination, fear, rejection, social isolation

Level of support from the family in general, and when taking the treatment

Lack of financial resources and greater priorities for survival, for instance, I am a self-sponsored student, so do I spend money on books or food?

The failure of treatment for another family member can affect a person's belief in the effectiveness of his or her own treatment.

### **My experience at UNZA**

The University of Zambia has a well-stocked and comprehensive ART clinic. It has a resident doctor that manages the ART clinic supported by other paramedical staff. It also has qualified psychosocial counsellors at the clinic itself, and also the counselling centre, which is within the residential place of students. There are certain key areas that come to the fore regarding my own experience.

The rigidity of the academic timetable and the tuition payment system, for example, has created some difficulty. Regarding the timetable, the difficulty is that some lecture times may coincide with the time when one is supposed to take the medicine. This leaves one with a choice to make: go to the lecture late; abandon the entire lecture; take the medicine while in the lecture, or reschedule the time for taking medicine.

In terms of the tuition payment system, the enforcement of making one payment for all tuition, or before the end of the semester leaves one with little or no financial means to supplement the taking of drugs with a balanced diet, diet being a critical component of ART treatment, as some drugs cannot be taken on an empty stomach.

There are other factors that may interfere with adherence, for example: failure of understanding on the part of the lecturers in certain courses, forgetting due to pressure of school, the situation of accommodation on the campus and the secretiveness associated with taking the drugs, and lack of support groups on campus, as well as lack of nutritional and financial support.

In conclusion, adherence and treatment is a crucial factor in the improvement of the health of students on medication on campus. It is also clear that it is a great challenge that the central



administration of the institution needs to take note of, and considerations should be given in the planning of programmes on campus to accommodate students.

My final recommendations are for there to be regular, clinic-initiated appointments with students on medication, as a means of conducting follow-ups and monitoring progress and adherence. The creation of student support groups on campus is also recommended.

Dankie, Enkosi kakulu!

### **Stigma on Zimbabwean Campuses**

#### **Speaker: Tayson Mudarikiri**

Tayson is an Information and Advocacy Officer on the Students and Youth Working on Reproductive Health Action Team (SAYWHAT), a student movement that works with students across the region that works to address reproductive health.

I want to acknowledge my brother, Bernard's issues, and I confirm that issues of stigma are quite universal. The purpose of my presentation is to identify the forms of stigma that HIV positive students face on campus, to establish the extent of the stigma challenge in Zimbabwean tertiary institutions, and to propose a shift in approach of programmes focused on fighting stigma in Zimbabwean tertiary institutions.

My presentation is informed by baseline evidence drawn from SAYWHAT's engagement with students and ongoing research, as well as interviews and focus groups with students, both HIV positive and negative, and interviews with programmers and college authorities.

The causes feeding stigma include the following:

- Lack of knowledge on HIV and AIDS
- Conflicting messages on HIV and AIDS
- Myths and misconceptions
- Low self-risk perception
- An inadequate response, lacking components of treatment and support. (Regarding this point, there is often a piecemeal approach in terms of programming, and frequently there is not a whole range of treatment and care options)
- Policy Inadequacies

How does stigma manifest itself on campus? In the following ways:

1. Often there is a low uptake of HIV- related services, including VCT and treatment. Some student quotes follow:

“That’s what will kill me (Knowing one’s status)” - Bindura University of Science Education

“Does it make a difference (knowing own status)? I won’t get treatment so I will die anyway. Getting tested and knowing my status will only serve to stress me up and speed up my death” - student, Mazowe Vet College

2. Labelling: Programmes on HIV are for the HIV positive, that is the perception

“My peers think that I am HIV positive...just because I am involved in HIV programmes”

3. Isolation

4. Victimization

“I am studying towards a science oriented degree programme, and I have compulsory practicals in the laboratory four days a week. It is stressful and time consuming to obtain permission to be exempted from them (to go and access treatment which is usually distant). This can only be issued by my counsellor from the university staff, after a lot of explaining and answering some funny questions” - UZ student

5. Self-Stigma - we need to reinforce individuals, and that they are part of us, to reduce this sense of self-stigma.

6. Policy Inadequacy: HIV/AIDS Policies, in most tertiary institutions are not enforced, where they exist at all. Some reported that they did not know whether a policy even existed in their institution.

### **Fighting Stigma: Rethinking Our Strategy**

The SAYWHAT programmes seek to address stigma through its strategic objectives:

- Information dissemination - addresses lack of knowledge, myths and misconceptions that fuel stigma.
- Networking and Advocacy - that relevant stakeholders ensure that other components necessary for positive living are made available for students (complete package of treatment)
- Provision of support - In Zimbabwe, this is a challenge under the prevailing social, economic and political environment

In assessing the provision of support to eliminate stigma, although not adequate, the UZ leads the way in support provision that might be necessary to fight HIV-related stigma, as follows:

- HIV and AIDS Prevention And Support Centre (HAPS Centre) - University of Zimbabwe HIV/AIDS policy product. The centre provides the following services:
  - VCT and PICT
  - Supportive Counselling
  - Nutritional Guidance
  - Information
  - STIs and OI treatment

And yet there is the sense that this response falls short. Students feel that the response is not adequate and also has shortfalls in the following:

- No ARVs: those who can provide ARVs have said that there are not enough numbers to justify such programmes on campus. Students say the reason that few students go for testing is because of stigma
- Nutritional Guidance has no link with food served in the university kitchen

The effect of an inadequate response is that it might promote even more stigma. An individual who tests positive and discloses status is a likely candidate for stigma in the absence of adequate treatment, care and support services.

In conclusion, stigma is still rife on campuses because the needs of HIV positive people are not addressed. Information dissemination on stigma is necessary in the sense that it improves the knowledge levels of students on what it means to be HIV positive, but in the absence of full treatment, care, and support services, it only serves to conceal stigma, making it more lethal than when it is exercised openly.

There are no programmes for the treatment of students and young people in Zimbabwe. Being HIV positive equals wasting away and a painful death; as such an HIV positive status is a cause for stigma.

### **Recommendations**

There is a need to strengthen current programmes to fight stigma, and the University of Zimbabwe case provides valuable lessons for modelling programmes meant to address stigma in Zimbabwean tertiary institutions of learning.

Addressing stigma does not work with a piecemeal approach, but requires a complete package of programming. In addition, provision of services on campuses is an issue that still needs to be debated further, as there is the issue of convenience versus stigma against those seen

seeking these services. This provides one more reason to fight stigma, as if we bring those services on campus, we will need to really fight stigma, which is preferable to building white elephant projects.

THANK YOU!

### **Presentation by Gift Mangwende**

I have no PowerPoint presentation, but will draw from my own experience as a student living with HIV openly at UZ. I will focus on the challenges and problems of disclosure, and will explain how I have dealt with this.

I agree that as an individual that has experienced it, stigma exists, or I should say, HIV-related stigma. As we are all aware in today's world, HIV is at the pinnacle of all stigmatization. You can remember that twins, albinos, women, gays, blacks, Zimbabweans - all have been stigmatized. The way I look at it, someone living with HIV is at the pinnacle of stigma. In order to take down the ladder of stigma, it has to be a negotiated settlement, but it is not even a point of discussion, it is all over once people know you are positive. The issue needs to be addressed at a regional level, but I would not say - one size fits all. The aim is to move from HIV being a master status, to being a normal status.

An example I can give you: if someone enters the room and he is very tall, gay and a lawyer, what would people react to?

It is important to sign an MOU, to sign a deal with yourself, and a deal with society to accept you - that is a negotiated settlement. I have lived with HIV for 16 years, but was diagnosed in 2003, and started with ARVs in 2004, the year that I enrolled at UZ.

I want to relate my first year experience, pointing to a few things that Bernard has said. I would classify the main issue as self-stigma. For example, I could not eat before taking my medication, and could also not take my medication on time. Treatment for opportunistic infection was difficult, as I could not tell them at the UZ clinic that it was HIV.

I also missed days where I had to go for reviews, and would have to send letters to lecturers, written on Development of Anti-Retroviral Therapy (DART) letterheads. My health had deteriorated, psychologically I was low, and my relationships declined. I did not want to get into bonding with people in my class, as I did not want them to get into my affairs. I tried to

create relationships that were not that strong, which did me a disadvantage as well, as most things were done in groups. I had two options: either disclose and suffer the consequences, or continue, and miss treatment, and experience loss of self-esteem.

I made a choice. I disclosed first to the Dean of Students, then lecturers, and students in my class. As expected, the results were both negative and positive. I got the accommodation that I required in my first year, which eliminated the need to travel long distances, complicated by the timing of food and medication. When I went to the clinic I also needed to tell the nurses. My first experiences here were not good: health workers would just call their other colleagues and invite them to come and hear what I had to say.

I created a group of students in my class, which relates to Pierre's issue of building social capacity, and this has been the most powerful factor in enabling me to get support. I did receive support from the Dean of Student Advisory Services, who was very supportive, and they ran an experiment involving group disclosure. During orientation for 1<sup>st</sup> years in 2005, I did a public exposure and I also did TV presentations. When I thought I was helping the world to come out of stigma, I did not know I was starting a new and difficult process of being observed. Once I became a phenomenon that the university community could study and research and measure, it was a challenge, as people are busy looking at your grades, at your mental capacity and so on. Living openly with HIV means that you have to keep up appearances, and it could be challenging.

In Zimbabwe, the current economic situation is so hard to describe, but we could not even open this year. I became so thin, and people began calling me by my old name, Mosquito, which was very apt.

In trying to reflect on a topical issue, it is complicated as one is also living openly with HIV. It is the sociology of the disease that makes it complex, as the actors matter in the equation; they are the ones who can negotiate a settlement for PLWHA and push for meaningful involvement. However, if I don't know the issues, what can I talk about? People want living proof, and it is not as simple as saying that I am proof that there is life after testing positive.

When you fight stigma you have to have substance: for example, if I am talking to young adults between 18 and 20, I need to know what the issues are that affect them, and to present them in a captivating manner, so that they can see it is really a reality.

In closing, I would say that dealing with stigma or disclosure requires that the individual

concerned negotiate a settlement. Disclosure opens up opportunities for access to support in different forms, but the challenge is that the individual becomes an experiment as to whether HIV is manageable.

### **Summary of presentations: Coping with stigma and disclosure**

Points summarised by Pierre Brouard:

- The three presentations remind us of the total institution approach to stigma, and stresses that there is no place for piecemeal work, but it has to be a wholly integrated approach.
- We are reminded of the challenges of disclosing, but also of living secretly.
- Bernard reminded us that in every country there is a national stigma strategy, a legal framework, although there isn't one in South Africa.
- It is clear that stigma that is internalised is quite high, as opposed to external stigma - emphasising the real perniciousness of stigma, which is the issue.
- It is helpful for institutions to think about programming around HIV and stigma in its entirety, and not just incorporated into bits of vertical programming, but in everything that the university does.
- These presentations show the power of stigma by association - even if you are not positive, you can be suspected as being so, if working in HIV.
- Stigma is built into the human condition - we are programmed to deal with differences with fear and suspicion.
- This session stresses how important it is to provide PLWHA with opportunities to process the impact of disclosure, the possible benefits and shortcomings, emphasising that it is a journey and a process. There is also the factor that one will constantly have to disclose to people who don't know, so every time is another painful experience.
- Living openly, while bringing a lot of power and relief, can also carry disadvantages; however, living secretly, too, has its disadvantages
- People want living proof, as Gift said, which is so true, as what we have had so far is Dying Proof.

Points raised by Allen Asire, from University in Uganda, Kampala:

- Involvement in the Positive Futures project for 6 to 7 months has shown the seriousness of stigma its effect on students in so many different ways. As Bernard told us, it affects adherence, as students are unable or unwilling to go to university hospitals, and are away from their usual clinic. Without HBC at university clinics, adherence becomes a key point in HIV management

- Disclosure is a process. People are unable to go public, as they fear the consequences. This relates to Gift's point about overcoming self-stigma, as it must begin with yourself, and the MOU that you sign with yourself and then the society around you. Those of us working in HIV should all take that path, and begin by telling the advantages of treatment. In Gift's case, once he had disclosed, he was able to get accommodation, and to do things openly.

## DISCUSSION

The following questions and points were raised in response:

Students asked for guidance about when and whether to disclose to someone one is dating: the advice was to review each situation individually, as they may leave, or they may stick around, so one has to be prepared.

Regarding the issue of stand-alone and integrated clinic programmes: when ARVs are available from campus clinics, it is often difficult for students to access them there, as a university is a community, and there is the fear that the word will get out. This applies when normal HIV services are separate from other clinic services, and yet, if the services are hidden, then one is colluding with stigma in a way. Gift made the point that there are different levels of disclosure, and the highest form of public disclosure is visiting a stand-alone clinic. When you have a programme where students go to a specific place for a specific need, it is stigmatized and he has even seen students laughing. The first level of disclosure encompasses, for instance, VCT - people often go for testing as partners, and one is not obliged to disclose to your partner, so there is some level of confidentiality.


Health is private matter and no-one else's business, and disclosure is a personal matter too. For some, the reason for disclosing is to get to a level of critical mass to improve the situation for others.

**Nationality and access to treatment:** When foreign nationals are studying in other countries, issues of access to treatment become key. If programmes are oversubscribed in home countries, what is the position, as a foreigner, in another country? This gets to be a political issue, and access to treatment can only be achieved if handled regionally, and not isolated to each individual country.

For example, South Africa should be able to offer treatment to foreign students as well.

There are no rules about disclosure. For some, disclosing to family first is the most important thing, but for others, the first port of call would be the Support Group, others living with HIV. The internal locus control is strengthened in the support group, so that if you disclose to your parents, and they don't accept it, one is still OK with that, with living positively.

As an individual, you need to be empowered. Disclosure is a process and it is not mandatory that you disclose, and if and when you do, there may perhaps be people in your family who are more understanding than others.





Pierre Brouard, Deputy Director

Centre for the Study of AIDS, University of Pretoria

As we consider the previous presentations, one comes to the realisation that stigma is very complex. This session began with a small experiential exercise requiring delegates at each table to do the following: think of a time when you have experienced something negative, a reaction towards you because of something about you that you couldn't easily change, e.g. your height, your age, your religion, your colour, the shape of your body, or a particular ability or impairment.

Delegates in attendance gave the following examples:

- People felt stigmatized often when they were in the minority, and powerless to do anything about it. However, some delegates spoke of accessing internal resources and making a decision to toughen up in order to deal with the feeling.
- Other delegates spoke about being singled out due to unusual physical characteristics, e.g. one student said he was told he had a “big head” and was, as a result, “re-parented”, and shipped off to his grandparents.

These stories illustrate that the desire to ostracise or alienate someone who seems “different” is fairly common, and that the consequences can be long-term for us. Often we carry the memory of those feelings and they arouse a lot of pain and hurt inside us. In addition, we have varying abilities to make sense of that stigma. Some of us are lucky enough to be resilient and strong, and can find within us resources to be strong and carry that pain.

Others may need to go for counselling and may need institutions in our societies to support them. Even in the very brief stories shared, one can see the complexities of stigma, which are embedded in social processes. As the epidemic evolves, so too does stigma evolve. We find sometimes now that people who have been on long-term treatment display certain long-term effects, e.g. there is a redistribution of body fat, so there is a certain look that someone gets. Often people are forced to disclose if they develop certain side effects.

The terrain of stigma is a shifting terrain. One area to focus on is to have a theoretical and practical understanding of what stigma is, as outlined on page 6 of the HIV/AIDS stigma resource pack, produced by Siyam'kela project, and distributed to all delegates.

This is not the last word on stigma, as if individuals want to address stigma in their institutions they may need to do some research themselves, delegates were told.

Stigma is primarily an attitude towards someone who is perceived as different, and when that attitude towards someone manifests itself against someone, even if it has never been experienced as active discrimination, one can still be carrying stigma inside.

Trying to tease out stigma as an attitude, and discrimination as an act, becomes difficult, when that attitude has been internalised or “taken-in” stigma. If we want to address stigma, maybe we need to develop indicators that can be measured over time. The Siyam’kela project has distilled some indicators which they consider observable and measurable acts, for example, your organisation not sending you for training if they suspect you are HIV positive, etc.

On the other hand, internalised stigma is not coming forward for services, seeing yourself as damaged goods or dirty, withdrawing from social occasions, or feeling that you may not deserve a relationship.

Some of our speakers spoke about people over-compensating for their positive status, but it can work the other way around, when you yourself over-compensate, which may lead to exhaustion and despair, especially if there is the fear of the consequences of disclosure.

In our projects at the CSA, we have developed an M&E tool that allows you to measure stigma, which is available on our website: [www.csa.za.org](http://www.csa.za.org)

We then need to look at how stigma develops, leading to the act of discrimination. An example is that people start to observe a difference - you have lost weight, you cough a lot, so you must be ill. Then they may say that the difference is due to negative behaviour, which relates to the notion that sickness is caused by sinful behaviour. The next step is to separate “us” from “them”, which reinforces the feeling that we are not like “them.” Following this often comes a loss of status, as well as discrimination, as people believe that they don’t deserve respect.

We need to look at why we want to try to exclude people, when we do this, as it starts to help us understand the dynamic, and the socio-economic factors. For many people, the idea of HIV is that it could be fatal, and that PLWHA may be a drain on families’ resources.

Instrumental stigma is based on resource concerns and ignorance of the risk involved.

Symbolic stigma is based on moral judgements, as a form of defence against fear and vulnerability, and fear associated with HIV enables us to distance ourselves from those seen as dangerous. It is a form of control that, by excluding people who are seen as morally undesirable, stigma controls behaviour. The issue of blame comes into play here, as by labelling people who have allegedly “chosen” to be “irresponsible”, stigma allows society to punish those who it believes could have avoided HIV infection.

It seems that stigma is somehow built into us, our desire for revenge, that we can put people away that have transgressed. One must examine why it is that we put all responsibility for stopping HIV onto people who now their status, when in fact we should all know our status, and all be doing what we can to combat HIV.

As referenced in page 7 of the stigma resource pack, one would argue that the psychological and social functions that are served by stigma are:

- A form of defence
- A form of control
- Blame
- Dealing with differences (non-conformity), as difference is threatening
- A form of power, which we like, as human beings to control others who are weaker than us

Over and above these understandings, it is also a good idea to understand how many phenomena interact with HIV, e.g. homophobia, sexism, xenophobia, gender discrimination, to name a few.

The one-page handout, Stigma mitigation in a tertiary setting - summary of key ideas, outlines some useful steps and principles when trying to address stigma.

It would also be useful, when addressing stigma in your institution, to look at what is going on at a national level and the CSA is working on a draft to address this factor.

The diagram on the reverse side of the handout illustrates a very simple model that deals, on a macro-level, with the following:

## Advocacy - Policies - Action - Research - Information

It would be helpful to address this model in relation to what is being done around stigma in our institutions.

Stigma mitigation in a tertiary setting - summary of key ideas:

1. Make sure you have a good theoretical understanding of stigma - what it is, how it develops, what impact it has, why it's important to address it.
2. Familiarise yourself with lobbying and advocacy techniques so that you are in a position to "sell" the importance of stigma mitigation.
3. Approach key role players in your institutions and try to win their support for a comprehensive approach to stigma mitigation - if possible develop a plan with aims, objectives, activities, budgets and indicators. It should be a total institution approach, and not just taking place at the level of the clinic, for example. The approach needs to address power relations and the culture of the institution.
4. Some ideas you can implement:
  - Focus on getting reliable, up to date information on HIV and AIDS to the whole institution, not only addressing myths, fears and beliefs, but also informing people about stigma and its effects
  - Keep lobbying key partners to keep stigma on the agenda - build alliances.
  - Other direct stigma mitigation interventions, for example:
    - Set up discussion forums and target opinion leaders
    - Establish support structures for PLWHA
    - Educate, inform and empower staff and students on HIV and AIDS, and stigma
    - Do an audit of tertiary media - how are HIV and AIDS represented and talked about?
    - Create opportunities for experiential learning where stigma is understood and challenged
    - Build social capital of PLWHA and attempt to get empowered PLWHA in key positions: look at the GIPA principle and find out if there is there anyone on any campus who is openly living with HIV and in a position of power
    - Review the possibility of offering testing and treatment programmes so that HIV is de-mystified
  - Conduct research: explore new forms of stigma, assess the impact of the work you are doing, document promising practices - let the results of this research inform other aspects of stigma mitigation

5. Ensure that you honour some key principles: involving PLWHA, use a rights-based approach, recognize the role of gender, develop multi-level, multi-sectoral and holistic strategies, and focus on sustainability.

In summing up, Pierre realised that he has spent six years thinking about stigma, and there is not enough time available here to fully address the topic. A total institution approach to stigma is needed and there should be a specific stigma plan to address the kinds of things that have been covered here today. The session also brought to light the need to take action against counsellors being indiscreet and disclosing one's status, and that the consequences of such actions should be incorporated into policy documents.

Delegates found the personal accounts by Bernard and Gift very powerful, and an encouragement to inform others about the impact of stigma. The experience of sharing ideas about stigma from other campuses was also empowering, creating a sense of making progress.

**New treatment developments: Anton Stoltz**

**Introduction: Prishani Moodley**

“Education is the most powerful weapon you can use to change the world”. This is a quote from Madiba, and I think Anton Stoltz best describes this, as he has taken education and used it to change the environment.

I will try to bring out some of the new developments in terms of drugs regarding HIV, and I will also look at what the public and private sector are doing.

The population of the earth stands at 6.7 billion at the moment, and it takes only 4 days to make one million babies, so there is an explosion of people.

**SLIDE 2: Graph: Industrial revolution**

There will be 9.2 billion people by 2050, which is too many people, as the earth cannot support this number of people. We need to consider global warming, for one, and although many people do not believe in it, there is definitely something in it. There is not enough water, not enough food. Poverty, famine, war, and the emerging and re-emerging diseases, one can see the impact of the climate change and population growth.

Referring to the Pulitzer prize-winning picture by Kevin Carter of a starving child, when asked what he did for the child that he photographed, he said nothing, as he didn't want to get infected, so he committed himself to that path.

There are a large number of re-emerging diseases in the world today, and the most important reason is resistance to antibiotics. The blue sections on the slide represent the diseases that are coming back. The red sections represent the newly emerging diseases, while the black areas are the ‘deliberately emerging’ diseases. A new disease or epidemic emerges every 8 months. Some pictures on the slide presentation show that ARV treatment does work, and that you can have a normal life of up to 35 years.

**The origin of HIV**

## HIV-1 and HIV-2

HIV-2 is mostly in West Africa

HIV-1 - the virulence and transmission rate is very high, and this type of HIV went global.

HIV is an example of an animal disease going over to man. HIV-1 originated from the chimpanzee, while in HIV-2, mostly in West Africa, the origin is a different type of animal, a monkey, and there is a low transmission rate.

HIV-1 actually started already in 1930, although it was only diagnosed in 1981, but in reality, the first infection was in 1930-32.

HIV-2 started in 1940. So this shows that there are two different types of HIV that started at different times, and originated from different species of primates.

The treatment of HIV-1 and HIV-2 is quite different. HIV-2 is quite difficult to diagnose. HIV-1 spread all over the world, and there are different sub-types around the world as a result. In Africa, it is mostly C, while in America it is mostly B, as well as in Europe. There are quite a lot of things involved in looking at either .....

To give an overview of the epidemiology of HIV, Asia has the second largest number of people living with HIV. Looking at the map, Sub-Saharan Africa is the burning point of this disease. This region has the highest number of people getting infected: at present there are 25 million infected people in Sub-Saharan Africa.

Needle prick injuries are a problem.

Mother-to-child transmission is a problem: a child gets infected one to two weeks before it is born.

Blood transfusions: if you were to receive infected blood, your chances of getting infected are 100%, but nowadays there is stringent screening.

## TRANSMISSION (2)

Factors that increase the risk of sexual transmission

In experience working with patients in 37 clinics, the viral count is very important. In South Africa treatment is being administered to patients with a 51 CD4 count, which is far too low.

An important aspect of HIV is the question of other infectious diseases, for example, bilharzias. This could be one of the reasons that Africa has such a high degree of infection, as a result of other infectious diseases that facilitate spreading of HIV.

### **Initiation of treatment**

Are there social instances for taking drugs?

Indications for treatment must be there. Counselling must have taken place three times before treatment begins, as well as HCW consultation, and the patient's viral load checked.

Treatment can encompass medical, traditional and nutritional interventions. In addition, opportunistic infections must be checked. It can take two to three weeks to accomplish all of this. It is possible, however, to start patients on treatment even when they are extremely ill, even in ICU.

Indications for therapy. If the patient is symptomatic, treatment must be started. When an asymptomatic patient has a CD4 count less than 200 it is important to start immediately.

Treatment is normally recommended for patients with a CD4 count between 200 and 500, although ARVs should be considered on an individual basis. There are conditions where patients start at the higher than recommended 200 CD4 count.

### **Indications For Therapy**

If a patient is pregnant, one must definitely start treatment.

If you look at opportunistic infections, South Africa has the highest HIV and the highest rate of TB - it is only Swaziland that has higher. One out of every 100 people are infected with TB, so in fact, it is more TB that you will see than HIV. TB is presenting not just in the lungs, but is now also presenting outside the lungs, in the spine, the bone and the skin. The warning is that if you want to start treatment you must make sure of opportunistic infections.

PMTCT -It is also important to defer the mother from breast-feeding, if she can - if she can't then no longer than 3 months. It is also preferable to conduct C-sections on women who are HIV-positive. The amount of women infected with HIV and in the last stages of pregnancy is high, and yet most hospitals are not doing C sections, and this is quite a problem to make sure that babies are negative. We can't afford to have babies testing positive.

He starts women on treatment quite early, no matter what the CD4 count is. His aim is to bring the viral load down below 1000 in week 28 of the pregnancy, and he prescribes a single



drug, AZT should be in the drug. The drug is quite important the drug - it was always Nevirapine and then AZT, but now he would rather go for the full HAART, which is Nevirapine and AZT.

### **Goals Of Treatment**

Clinical: Prolongation of life and improvement of quality of life.

Virological: Downplay is very important, as one is striving for the greatest possible reduction in viral load. The amount of virus in the body will affect the CD4 count. There can be as much as 20 billion viruses in the body, which is quite a lot!

### **Immunological: Immune reconstitution**

Therapeutic: It is quite important, if you want to treat people with ARV drugs, you must know what you are doing. There must be a rational sequencing of drugs, and limited drug toxicities. He has trained 3 to 4000 doctors so training is quite good.

The future is drug resistance to HIV

Epidemiological: Reduce HIV transmission

### **DOES HAART WORK?**

Of course it does. If we start at 1987 with a single drug, it was only when we introduced the third drug, including protease inhibitors, that we saw the deaths going down.

How and where does HAART work?

(Referring to slide): It looks very complicated. The HIV virus is not swimming around inside the cells but they are incorporating themselves into your genome: only when the cell dies down will you be free of HIV.

Co-receptors on the surface of cells. One of the new things that we do is to try to make sure that the virus does not get into the cell.

There is a new drug coming, called integrase inhibitors, but it is not on the market yet.

There are quite a lot of areas where we can intervene in terms of treatment.

We will look at reverse transcription: if you start failing your treatment, this is where we will go...

Department of Health (DOH) Guidelines:

Regime 1a:

Regime 1a:

Regime 2: It is important to mention that these guidelines were excellent for up until now. New data shows that we need to get rid of the old drugs, as there are too many side effects

Private

There are compounds under development to inhibit HIV fusion

Will talk about antiCXCR4

antiCCR5

These are important.

There are people living in Europe with an abnormality, who can't get HIV and they have worked out that it is something to do with CCR5 receptors.

Maraviroc: This is one of the important drugs coming out in the future. If you can bring something that brings down CCR5 T-cell count. There is a drug on the market at the moment, but this one is very expensive, at approximately R15 000 per month. However, this is the future of treatment.

Future of treatment is to make sure that HIV doesn't enter your cell - if you block it, you won't get AIDS.

What is needed is the right initiation therapy. We must move away from using Efavirenz.

This new regime does not induce resistance, and we need to switch over to?????

South Africa has not evolved with the new knowledge on HAART, but hopefully we will get some of new drugs.

95% adherence is required on this programme.

1 miss per week is less than 93%. It means that you have to be extremely careful about adherence with your regimen. A way around this is to look at using more injectable drugs, as we will maybe see one injectable drug per month.

What side effects are being commonly reported?

The hands and feet go dead

Lipoatrophy, which in South Africa is quite bad. This can lead to liver dysfunction.

There are side effects, but it is really only effecting a small percentage of people.

HIV Cure?

One important question is whether complete eradication is necessary for cure: do we need to remove the virus completely?

A cure could also mean that the body is able to control infection without the help of medication.

The disease is analogous to other infections such as herpes simplex or varicella zoster. There are elite controllers all over the world, where people stop the drugs and do not get AIDS. In some cases, they have been on treatment for 10 year, but have crippled the virus, and so can contain the virus. In this sense, they are actually cured in terms of not getting AIDS. So there are a lot of people who after a long time of treatment can control it.

### **The future of HIV treatment**

There is, in fact, a bright future, with a huge number of new drugs on the market. So in a sense, this is a form of cure for HIV. There is a lot of money being put into it and Anton does think we can control HIV, although it must be seen as a chronic disease.

## **DISCUSSION**

The following key points emerged from the questions and discussion:

**TB Treatment: How to treat HIV and TB simultaneously**

It is important to treat the TB first to make sure that the bacteria load is lower, either for 2 to 3 months, or for 6 months prior. Some people start at the same time, but he has seen patients become so ill that he has had to take them off both ARVs and TB medication. In general, he treats TB patients for 2 weeks, and then starts ARVs. By stopping TB he is bringing the CD4 load down.

**Types of HIV: HIV-1 and HIV-2 and sub-groups. How much research regarding drugs and treatment is being done on the type of HIV that is prevalent in Africa, and are treatment programmes being aimed accordingly?**

There is not much treatment or research being done on the type of HIV prevalent in Africa, which is C-clade. Most vaccines are produced to work against B-Clade, and most vaccines have failed. If you look at resistance, all of the tests being done are extremely expensive, and

they are being done on the B-clade, not the C-clade, which is a huge area of research. Treatment is so complex these days, and there are different combinations of mutations that can either bring your CD4 count up or down, so it doesn't help any more to just enter data into a computer.

#### Differences between B-Clade and C-Clade

Instances when CD4 count is very low and VCT tests are negative: Even if a patient has a low viral load and they are in the late stages of the disease, they should not test negative. It is important to make sure that the kits are not in the sun, and are not damaged in any way. With regard to SLE, there are cases where a patient has this and they test positive for HIV when they do not have HIV. It is important to test their viral load before treatment, as sometimes these patients are treated as HIV, but their viral loads are negative.

**Sero-discordant couples who continue to have unprotected sex:** There is not enough known about what makes people prone to infection, but eventually the other person will become positive, as there is no reason for them NOT to become positive.

**The future of treatment,** and the prevention of the virus entering the cells: How will this work?

The immune system is actively getting rid of the virus all the time, and this is effective if the virus can't get into the cell. Some people have very good immune systems and a lot of viruses are destroyed in the body, as the body will see the virus hanging around, will cover it with anti-bodies, and destroy it. However, the length of time required to block all viruses going into the body before someone is negative is approximately 73 years, which is too long.

#### **Can an elite controller pass on the virus to someone else?**

People controlling HIV don't have AIDS and it is presumed that the viral load is less than 1000, in which case they are unlikely to pass on the virus, but it does depend on the viral load.

#### **Q: When you test positive, do doctors test if it is HIV-1 or HIV-2?**

Most of the kits can detect HIV-1 and HIV-2 and some of the rapid testing can detect both. They do a Western blot and can look at sizes of HIV. However, I have never seen HIV-2 alone, it is mostly a combination. One cannot treat HIV-2 with certain drugs, and while HIV-2 is slower the end result is the same.

**Bilharzia:** What is being done to bring it under control?

This is a very recent finding, as if people have bilharzias, it is important to make sure that the eggs are dead, and to make sure there is no inflammation around the genitals. There is a lot of research being undertaken, but it is very new, and we are not precisely sure how infection works, but it seems as though it is easier for the virus to enter the cells. This could be why so many people in Africa are infected.

**Circumcision:**

Research shows that there is this area where you can hide the virus in uncircumcised men, but Anton is not yet convinced. It has been compared to the way the virus settles in the vagina, as the semen remains there with all those viruses, but to date, the research is not conclusive, and it has yet to convince him.

**Panel Session: Prevention and Support**

**Session Chair: Johan Maritz**

**Speakers: Lebo Ramofoko: Soul City Institute**

**Understanding Multiple And Concurrent Partnership To Inform The Soul City HIV Prevention Campaign**

By way of opening remarks, while it is necessary to put treatment on the agenda, it must be noted that only one third of people in South Africa are receiving treatment. If the disease grows at current levels, even given all the current investments in treatment, the current trends indicate that to every one person on treatment, three people will become infected. This makes it imperative to look at prevention.

I will present some of our Soul City research on multiple and concurrent partners, conducted in a number of countries, and comparing the situation here to the West, in an effort to understand why it is spreading so fast in this region. The practice of concurrent and multiple partners is scientifically proven to be a factor. This does not mean that Africans are having much more sex - in fact, maybe they are having less, and not as pleasurable -but the important factor is that people are having sex concurrently, and with more than one partner.

In South Africa, the system of migrant labour meant that men would leave neighbouring countries and rural areas to come to the cities and mining centres to find work. Many children were born nine months after Christmas or Easter in their home regions, after periods of leave.

The aim was not to question the practice, but to look at what its impact is, and what makes it quite risky. The issue of HIV is that in the first six weeks it multiplies a lot, and for the majority of people who go for testing in the window period will not pick it up. If one person is having sex with multiple people, and all are negative, the circle is closed. However, if, for example, he goes to Durban for business, has a bit of cash, and has sex with someone else, perhaps, also, his partner is unemployed and also engages in sex for cash, and then suddenly the circle is not closed.

These issues of mobility, transactional sex, and unequal power in terms of gender are all factors. What he is buying, perhaps she is selling while he is away. This explains why HIV is growing at such an alarming rate in Sub-Saharan Africa.

## **Background**

The overall rate of both men and women having concurrent partners is relatively high. Forty five percent of males and 28% of females aged 15-19 years, while 36% of males and 21% females aged 20-24 years reported concurrency. In May 2006 in Maseru a SADC Think Tank meeting identified multiple and concurrent partnerships (MCP) by men and women with low consistent condom use, and in the context of low levels of male circumcision as key drivers of HIV epidemic in Southern Africa. The practice of having multiple partners was reported throughout.

As part of this research process, Soul City is embarking on a five year HIV prevention campaign that will involve mass media, social mobilization and advocacy. One of the key aims of the campaign is to reduce multiple and concurrent partners. As part of a formative process to develop the HIV prevention campaign, Soul City reviewed literature, consulted stakeholders and conducted a qualitative research study on multiple and concurrent partners.

## **Objectives**

To explore audience views, opinions, attitudes, practices, risk perceptions about relationships, including multiple and concurrent partnerships.

## **Methodology**

The methodology, which was applied in every country, involved qualitative research with 30 focus groups nationally in South Africa, the breakdown chart of which is reflected in the attached presentation, by province.

## **Findings: themes**

People spoke about:

- The importance of sex
- Types of relationships
- Reasons for MCP
- HIV
- Reasons for staying in relationships: particularly when they know their partner has other partners

### **Importance of Sex**

Participants across all groups felt that sex is important in life and love, as follows:

Expression of love

Without it you will be stressed

Without it you will die (!!!)

We need to understand that people are enjoying it and doing it but we also need to make sure that they are safe. “Abstinence only” messages do not get through. People are saying that of all the things happening in my life, this thing is good.

### **Types Of Relationships: Women**

In most of the groups the women spoke about their primary partner, the husband of the “regte”, the “steady”, the “real one” or the “straight man”. These are the partners they love, even if they don’t provide, which often means that there are other partners to meet other needs, often financial but also sexual or physical. There is the fling, and whether he phones or comes or not is not important, they don’t care.

This throws out the window the notion of women as victims, as this kind of sexual agency that is happening with women shows quite the opposite, that they are going out there too. This is not to deny that women do NOT have power in some instances, but it also suggests that not all women are victims. Women are seeing sex as currency that they are trading.

### **Types of relationships: men**

In terms of men, most felt that men will have the one relationship that is primary, the long-term relationship with one person whom they love. Some spoke about how men care for their loved one by not wanting to abuse or overuse them sexually, which taps into the notion of the “real one”. The kind of sex that you have with the “real one” is not the same, as it should always be special, and she should not do the sexual things that they sometimes do with their lovers. Men even talked about protecting the woman from other men, by not taking her to parties because other men might make a move on her. They believe that she, too, is keeping herself for him because she loves him. They trust that such a woman is not sleeping with other men, and would not use a condom with her even though he is having unprotected sex with others sometimes.



### Young women (16 - 20)

Young girls talked more about friendship in relationships and were more cautious in relation to sex - being more upfront about the risks involved.

**Quote:** *Many people when they think of relationships, they think about sex, but it is no longer like that. Nowadays, we (my boyfriend and I) take the relationship as a friendship. This is when there is good communication in the relationship. We give each other advices about the relationship, if things are not going right or not. Many people think to be in a relationship is about having sex and children, but it is not like that.* [Western Cape Urban girl 16-20]

We are beginning to see that young people are beginning to look at relationships as not just about sex, therefore.

### Reasons for Multiple Concurrent Partners (MCP)

Women	Men
Lack of communication	Lack of communication
Fulfil different needs especially around money and possessions	Alcohol and drunkenness
Not sexually satisfied	Lust/sexual desire and greed
Status	Not sexually satisfied
Searching for Mr Right	Perform better with their wives
Culture	Peer pressure
	Culture

For both men and women there was a real lack of communication.

Women are saying he comes home, hops on top, and after three minutes it is over. Men say, that is how it should be, I am preserving her, but it is not that he is “BAD IN BED”. To be the good woman, she cannot talk about how she would like to be pleased and she is not able to express her sexual needs, is sometimes scared about being beaten etc. What it is to be a man or a woman informs the kind of sexual practices.

For women, having MCPs fulfils different needs especially around money and possessions. There are expectations, particularly around alcohol and drunkenness, when the expectation is that she will sleep with you. What is very surprising is the relationship between the lack of communication, and not being sexually satisfied, which applies to both men and women, where the cultural norm is that you don’t talk about what you need to be satisfied.

Women are having sex for status, although they demonstrated having agency in terms of seeking sex, but they are using sex to get status. Some women also spoke about searching for Mr Right, for instance, the first one who pays lebola is the one you will marry.

In both groups, culture became quite a big discussion, and both men and women spoke about it being expected of them to have multiple concurrent partners. The comments around staying with a partner, even if that person has multiple partners, relates to the whole issue of leaving a relationship, which is stigmatized, particularly in a marriage. There was mention of forefathers having had multiple partner, as well as peer pressure.

### **Not Being Sexually Satisfied**

Many women discussed this and the fact that they could not talk about sex to their partners, which was one reason for having additional partners, as the following quote demonstrates:

**Quote:** *It's because now we are discerning - we know the difference between good sex and bad sex. Like you know if someone is boring in the bedroom and you know when you have met someone who hits the spot. You carry on with the other one if he gives you other things but you know that he just doesn't do it for you sexually.*

[Women Rural KwaZulu/Natal 25-35]

Men spoke about how women in the home fail to look good for the man, they get too relaxed and do not take care of their looks. This leads to men looking elsewhere for things that will please their eye.

Men also spoke about young women being “fresh” and not challenging them, but rejuvenating them.

### **In summary** *(additional points to be found in attached presentation)*

One could think that people are being silly in their responses to these questions, but it is important to reflect some of the effects of socialisation through these questions.

Women spoke about the pressure of raising small children and communication around roles in raising children. They felt that their men are not interested in them, and men spoke about women not taking care anymore.

When asked what they would like, women said for their men to help with raising children or caring for children. The point she is making is that one can understand the limitations of the ABC approach. While they are important messages, we need to be speaking about how

people relate to each other, how people communicate with each other, and what sex means to them.

Unless we address the gender inequalities in society we will not be able to address HIV in its entirety, and complexity. Soul City's 5-year campaign will at least get people to talk about sexual choices and what drives them, as until you investigate what drives people, you won't be able to address the challenges, and ABC will not work.

People interpreted being faithful as NOT telling the "regte" one about other partners. For women, the notion of being faithful is that she always cooks for him, keeps his children clean and cares for them. If we understand what people understand about being faithful, we will be in a better position to unpack this.

Session Chair: We have looked at the biology of the transmission for so long, but we have not looked at sexuality and sexualities enough. This is the right direction to be moving into, looking at sex as not something that is only bad, but, as reflected in some of the work that researchers have been conducting, taking the sex positive approach.

### **Panel Session: Prevention and Support**

#### **Speaker: Mkhonzeni Gumede, DramAide**

Mkhonzeni Gumede from DramAide introduced the Health Promoters Project and began by giving a short summary of DramAide, which was established in 1992, is based at the Universities of Zululand and UKZN, and implements HIV/AIDS prevention, research and OVC projects in schools, universities and communities.

The methodology used is very deliberate, and is informed by components of drama, using participatory communication techniques, getting those participating involved in the process. Theirs is a theory-based intervention, using a participatory approach based on Paulo Freire's principles of dialogue, interaction, problem-posing reflection and conscientization.

DramAide does not take a deliberate view that they are going to solve the problem and don't go in assuming that there is a problem. The aim is to facilitate learning and transformation.

The method uses drama workshops that are interactive and participatory, including games, role-plays and reflection, as well as educational theatre involving plays that are devised and

presented by young people. The use of forum theatre, linked to a big screen television, can be a powerful tool that can demobilize, often resulting in emotions that overcome participants, as in Oprah's "Aha" moment.

## **Methodology**

### **Games**

Games bond the group, are fun and wake up the body and mind, should link with the main activity and are important for reflection.

People come to workshops with preconceived ideas about the world, but when a very brilliant speaker comes on stage, he/she starts to help you to speak. Games are powerful in helping to break down barriers.

### **Group Work**

The skills learned through working in small groups include:

- Being able to listen actively and clarify points
- Sharing information, and allowing everyone an opportunity to speak
- Assertiveness, standing up for a point of view
- Analysing and processing information
- Making decisions

Group work also assists in shaping attitudes and values, as participants learn respect for themselves and others, as well as self-control. In keeping with the basic principles and views of what changes the world, in as much as we know, it is important that the learning experience must incorporate what is different and new, in order for it to be a learning experience for the learner.

### **Role-Play**

The use of role-play is important to enable young people to have fun, to participate using body, mind and emotions, to try things out, talk about sensitive issues, and to see and feel the consequences of their actions.

### **Songs**

Songs provide an important way of communicating, they are part of the oral tradition, and can be changed and used for AIDS messages, and allow for many learners to participate. It is an important component of the DramAide methodology, in that it incorporates other areas of

folklore, and encourages people to spontaneously come on stage and express their feelings. The tools we use are important to deepen the educational experience.

#### The Health Promoter Project

The thinking behind this project is that, if they provide information and then challenge people about various issues, whether stigma, prevention etc, they will get people talking and thinking. Our process also challenges participants to start to question their belonging to a collective, and how their status as a unique individual fits into that.

The Health Promoter project started in 1992 in nine historically black institutions (at the time, the historically white universities through there was no problem), and in 2006/7 was implemented on 23 campuses and over the years reached 762 000 students.

Essentially, the programme addresses stigma and discrimination, and is about a person living with HIV and AIDS coming to live on campus. Initially, we took PLWHA with guards as we didn't know what would happen, as previously one student was killed. However, the response was overwhelmingly positive, and we were able to provide information and support for students on campus, as well as to provide a public "face" to the epidemic.

The work of the health promoters allows students to live openly with HIV, providing basic HIV/AIDS information to students and staff as well as access to appropriate referral services.

The primary objectives of the programme are to:

- Personalise the risk of HIV infection
- Reduce the number of HIV infections
- Promote VCT
- Reduce HIV/AIDS stigma
- Support staff and students infected and affected
- Strengthen peer educators in providing leadership on HIV/AIDS
- Advocate for prioritisation of HIV in academic and social life on campus
- Assist with community outreach programmes

The matter of reducing the number of infections is very challenging, as the programme tries through a number of different activities to contribute through prevention strategies. However, some people ask whether prevention works, and our answer is that no-one has shown where we would be without prevention, although some people challenge that prevention efforts globally are not that important, and that one strategy is to adopt a bio-medical approach. Our preference is to use the approach of addressing how people live and interact as human beings, as this is important in relation to HIV.

The findings of the programme relate to areas of stigma reduction, HIV prevention, care and support, promoting VCT, and reach, scale and scope, and can be viewed in the attached presentation.

### **Conclusion**

The impact of the cultural, social and economic environment mitigates against behaviour changes: we say information is power, but if we don't understand or confront these issues, we will not progress. The backlash we are seeing in South Africa now has resulted in factors like an increase in domestic violence, for example.

There is also conflict between spiritual-religious beliefs and scientific beliefs that translate into a conflict between African traditional ways of understanding healing which is not scientific, but is based more in a belief in the balance of universal and natural forces. The DramAide intervention takes account of this, and is informed by cultural understanding of these practices.

Scientific language has been introduced into AIDS prevention and the sector and we aim to translate these into appropriate language, translating concepts and focusing on communicating the meaning.

The programme also seeks to normalise HIV with treatment and escape despair. And yet there is ongoing risk taking, often due to conditions of poverty and lack of opportunities, or to meet physiological and psychological needs. We have also begun to see some developments, for instance we have had three health promoters becoming pregnant, and are worried that this might mean they are not concerned about their health, and are having unprotected sex. Their response is that it is their reproductive and democratic right to have a child. This raises the question about whether are people claiming back their lives and their hope, and saying, I want to live a full life.

This brings up questions about modelling and whether these are good role models where they are based, questions that we ourselves are not answering, but can perhaps be better managed by Positive Living.

We also conclude that the structure of society is such that decision-making often does not rest with individuals in a patriarchal and hierarchical society, and that social context and social relations sometimes mean that gains in making new choices are easily lost again.

The theory around behaviour change is inadequate, as the dominant theories stress individual change, and assume individual agency.

It is also clear that the issue of disclosing your status is very challenging, and it is very brave for people to expose for others what would otherwise be a very private matter, in order that others can learn from their experience and not repeat it.

## Discussion

Below is a summary of topics and issues raised during the ensuing discussion around prevention and support:

### **Cultural responses and practices regarding multiple partnerships:**

An example was made of a male relative having passed away with HIV, and the cultural tradition is that his wife is now his brother's wife, and she, too, is infected. This becomes a challenge when addressing the issue of cultural tradition. In response, there is a level at which there is not sufficient questioning of cultural responses, a result of a significant breakdown of social cohesion. Some people are taking remnants of culture and not really understanding them in their entirety, especially where society is transforming so fast.

The session highlighted the fact that many of the messages are very individual, and that there are very few processes that are addressing the collective, or that are questioning traditional leaders. Now that it is clear that MCP is a major factor of infection, how do we address this matter with leadership, to ensure that all those in communities remain safe? Until we begin to ask and clarify the roles of the different tiers of leaders to address these issues, individuals such as the man above are going to find it very difficult. We look forward to the day when our leaders start to talk to their communities about how to keep each other safe, collectively. The whole issue of staying safe from HIV is such an individual choice and people are making such a big separation in their lives regarding what to do collectively.

This also raises issues such as virginity testing, which is illegal in terms of the constitution, but was supported by the King as part of our culture. Culture is deeply ingrained and will take a long time to address, as there are so many different social influences, and practices are different in urban and rural contexts.

As much as the dissemination of information is targeted at the youth, it is also important to make this available to older people to make them aware that certain cultural practices that are not acceptable, although for many of them, in their minds, HIV is about sexual cleansing.

This speaks to our identity and the development of methodologies that work within people's frame of reference, but also make them aware of the circumstances that oppress them, and provide some suggestions about how to address those areas. The head of UNICEF in South Africa once said that where cultural practices are regressive, it calls for important men and women to come forward and point out that this is not acceptable.

### **HIV and Spiritual healing**

People frequently take a spiritual approach to dealing with the virus. There are instances where people have gone to church and have stopped treatment, persuaded by one or another pastor, or who talk to the virus in their body, how it is connected, psychologically, to the viral loads in the body, and believe sincerely that it works, without a scientific explanation.

It is important that we attempt to match science with indigenous processes, that we negotiate a balance, as practitioners or facilitators, between traditional and indigenous knowledge and approaches, and scientific approaches.

### **Edutainment and HIV**

Some delegates pointed to the unintended outcomes or negative results of edutainment programmes. In Zimbabwe, for instance, some of the educators become celebrities, and the use of music often provides a place where people engage in risky behaviour.

In terms of lessons and best practices around edutainment, the key to these programmes is not to develop anything without adequate research, as not everything is edutainment. There will be negative responses if you don't test the messages. An example is a Soul City campaign about eight years ago that dealt with violence against women that looked at getting the balance right between emphasising this as a crime, but without demonising the perpetrator. Also, messages that are not carried over for a period of time do not take hold, another example being around xenophobia, which people perceived as being justified, and so the outcome was negative. The effects of activities around edutainment are a drop in the ocean, amounting to about 1% of what, say, Coca Cola does in terms of marketing budgets and messaging.



The important thing is to develop a brand and to continue to apply that. Regarding the use of celebrities, there are obvious problems around packaging concepts around, for example, World AIDS day, and jumping on the bandwagon using artists and music, assuming that young people cannot process information unless there is song and dance. The way we circumvent the celebrity status is to ensure that all artists go through media literacy training, and are positioned as nothing but human beings who may make mistakes. In the end, they also provide an opportunity to talk about the complexity of human behaviour.

### **People with disabilities and HIV**

Delegates expressed concern about the way very little emphasis is placed on people with disabilities, some of whom are sexually abused by police or individuals, or are subject to misguided beliefs that if someone sleeps with a visually impaired person, or an albino, they will be prevented from HIV. People with disabilities also need sex, and also need seminars focusing on their needs.

A lot more work needs to be done in this area. With Soul City, a decision was made to subtitle all programmes for people with hearing disabilities, and to ensure access to radio programmes for the visually impaired. These challenges brought up, however, highlight the need for more advocacy rather than programmes, to ensure that the work is much more inclusive. Now that there is progress on the universal access to treatment, there needs to be more focus on the area of people with disabilities.

**Speaker: Robin Hamilton, Aurum Institute for Health Research**  
**Enhancing Adherence To Antiretroviral Treatment**

Robin heads up an HIV training programme focusing on HIV and psychosocial support at the Aurum Institute for Health Research. There are 50 000 people on treatment and the organisation works in a whole range of different settings.

**Presentation**

**Own medication experience**

Think back to your own experience of taking medication over a longer period of time. It is a useful exercise to ask oneself the following questions, as it links to adherence.

- How well did you adhere?
- Did you finish the course of treatment?
- If you took all your medication, what helped you?
- If you failed to take all your medication, what got in the way?
- What strategies could you have used to help you?

In response, most people have a problem taking extensive medication over a period of time, and will probably take it when they are feeling ill, but will stop when they start feeling better.

It requires a lot of strategising and hard thinking when about to start treatment and patients about to begin treatment need to be counselled.

**Aurum ART Programme**

- Aurum Institute for Health Research is a non-profit health research organisation
- We conduct research in TB, HIV treatment and HIV vaccines
- Based in Johannesburg, active in 7 provinces
- Treatment programme: workplace and community (PEPFAR- funded)
- Treatment programme running since 2002
- Over 18 000 individuals in our treatment programme
- We provide training, drug supply, monitoring and evaluation

## **Evidence of research about adherence to ART**

What does NOT make a difference:

Age

Socio-economic status

Literacy - as long as education is provided, this is no barrier

Language

Gender

Disclosure of status

What does make a difference:

One of the major factors is the distance of the health facility from the individual's home, especially so in poorer communities who are without funding to make trips

Quality of health care

Commitment of health-care workers to programme

Simplicity of ART regimen: sometimes patients are also taking other drugs so sometimes the pill burden can be bigger than we imagine.

Starting the ART regimen early enough, for example with a 350 CD4

Acceptance of HIV status

Counselling, counselling, counselling: this must be good quality counselling that is focused on the individual, and counselling by lay counsellors. We have certainly seen research do great counselling, psychologists are OK, nurses are sometimes good, sometimes not, and doctors are by far the worst.

## **Compliance versus collaboration**

### **Old-style compliance**

The health-care worker is the expert

Has all the important knowledge

The patient is passive and ignorant

One-way form of communication

A lot of practitioners are stuck in this old style of communication.

## **Compliance versus collaboration**

### **Collaboration**

Paradigm shift in treatment

HCW and patient are both "experts" - patients are experts on their own lives and individual experiences

HCW and patient have different kinds of knowledge

Two-way communication

Alliance formed between HCW and patient - they work together

### **Stages of ART adherence counselling**

State 1: Pre-ART readiness (prepare patient for treatment)

Stage 2: ART initiation counselling (develop treatment plan)

Stage 3: Maintenance (keep adherence up)

Stage 4: Treatment changes/re-motivation (give ongoing support)

### **Stage 1: Pre-ART Initiation**

This is by far the most important stage, and involves the following:

- Encourage individual to be an active participant in treatment
- Give access to educational materials
- Provide ideas on social support
- Encourage disclosure of status - not obligatory
- Get individual to think of benefits of treatment
- Start counselling *at least* 2 weeks before initiating treatment, and have minimum of 3 counselling sessions
- Brainstorm about obstacles to treatment and possible solutions
- Assist individual to develop adherence tools

### **Challenges to Stage 1**

Building a strong collaborative relationship

Involving the whole health-care team; involving everyone in the adherence process

Motivating individual fully about ART, as people have a choice

Enabling individual to make an informed decision about ART

Ask individual: What are the pros and cons of taking ART?

#### **Pros**

Extended life span

Take away 'death sentence'

Delays or avoids opportunistic infections

Strengthens immune system

Opportunity to raise children

More productive years

Quality of life enhanced

Opportunity to pass on life experience  
Empowers individual and family

We have seen with mine-workers, working underground doing very hard physical work, some amazing recovery stories, as after being really ill, they have gone back to their jobs.

### **Cons**

Lifelong commitment  
Dosing complex, especially if other medications are taken too  
Danger of drug interactions  
Side-effects unpleasant and sometimes dangerous  
Risk of drug resistance and treatment failure  
Adherence a challenge  
Need to access social support (disclosure)

### **Stage 2: ART Initiation**

Once you are ready to start the patient on treatment, you need to look at the realities of people's lives:

- If the individual is not ready, continue with stage 1 counselling
- Talk about challenges of treatment. Address individual's concerns
- Ask individual to recall personal benefits of treatment
- Agree on a drug-taking routine that fits individual's lifestyle
- Make sure individual understands dosage and timing
- Mention side-effects and action to take
- Be strongly encouraging

### **Stage 2 challenges**

Some examples of challenges that a mineworker living in a hostel might consider are: How will I be able to take treatment living in a hostel with others? How can I prevent my status from becoming known? How can I stop my children from getting hold of the drugs? How do I fit treatment around shifts?

- Educate individual fully
- Help work out a routine for medication
- Empower individual about side-effects and their management
- Address any anxieties

### **Stage 3: Maintenance**

It is important to think of changing circumstances for this person, to think about the other contextual demands, as they have other things going on apart from HIV. Assist through the following activities:

- Reinforce individual's understanding of treatment
- Help individual learn more about HIV/AIDS
- Watch out for drug sharing or dosage change
- Monitor for drug side-effects
- Counsel about living positively
- Discuss disclosure of status
- Encourage individuals on treatment to support each other
- Counsel about risk reduction, e.g. condoms
- Look out for depression and anxiety, and treat

### **Stage 3 Challenges:**

Keep motivation levels high

Encourage social support

Avoid boring individual on treatment and yourself with monotonous counselling

### **Stage 4:**

#### **A Treatment change/B Remotivation**

When first line treatment doesn't work, you will have to try second-line treatment, and the patient may be concerned about the prospect of that not working.

At this stage, treatment may need to be changed, requiring re-counselling, OR

The individual may become discouraged, requiring re-motivation for taking treatment.

### **Stage 4**

#### **A. Treatment change**

Remember that the individual will need re-counselling, from stage 1 again. Feelings of failure, shame, guilt, anger or fear of failure may emerge, needing counselling. Don't judge the individual for failing.

## **Stage 4**

### **B. Remotivation**

- Adherence often starts to fall off between 3 and 12 months after initiation
- Be proactive. Warn individual about risks of non-adherence, and make a plan to avoid this
- Be aware of stressors living with HIV
- Look out for other life challenges in individual's life
- Remind individual of original reasons for taking ART
- Encourage individual to celebrate successful adherence anniversaries

### **Stage 4 Challenges**

Remotivate yourself and people on treatment; learn lessons from adherence successes and failures; take care of own stress levels and address burnout.

### **Adherence tips**

To succeed at taking treatment, individuals should:

- Accept their HIV status
- Attend clinic regularly
- Have a clear motivation for treatment
- Not be compelled to take medication
- Develop a sense of self-efficacy
- Have plans for the future

### **Adherence tools**

- Setting an alarm clock
- Setting a cell phone alarm or reminder
- Using a pillbox
- Using a diary card or chart
- Keeping a treatment diary
- Using cell phone SMS reminders
- Using a treatment supporter
- Having a buddy on treatment
- Using a support group
- Using a family member as a support
- Using daily TV or radio programmes as reminders
- Directly observed treatment using a HCW

Other useful tips:

Always carry at least one ARV dose when leaving home. Inform other medical personnel and traditional healers of ARV treatment (as sometimes other treatments interfere with ART).

## Discussion

### **Measurement of adherence**

This is quite a sticky topic, the issue of measuring adherence, although a bit of research has been done, looking at self-reported adherence and viral load.

### **Debriefing of health-care workers**

It is important to have measures for health-care workers who become depressed or tired. This needs to be addressed proactively: one must provide debriefing, get people into a group and allow them to express the difficulties they are having, and encourage them to ask for help.

This is seldom addressed in health-care issues as doctors, particularly, are so reluctant to ask for help.

### **Starting treatment when patients are ill**

The subject of starting treatment for symptomatic patients already in hospital setting was raised. In the early days, patients were started on treatment when they were really ill, so the approach was to start treatment and counsel later, as the thinking was that they would appreciate the benefits of treatment. However, that is a mistake, as there are very few cases where a person needs to go on treatment straight away. Those few days are important, as they will also ensure sustained adherence.

### **Age as a factor**

While the findings suggest that age is not a factor, essentially a lot of these points above apply to adults. There are particular challenges in dealing with children, often regarding family members, but these can be overcome and there have been great success with the treatment of children.

Where problems can manifest are with children who have been on ARVs for a long time, when they become teenagers and begin to go through many of the difficulties that their peers



are going through. At this point it is no longer possible for parents to insist on adherence to treatment. In this way, teenagers can be quite a challenge.

### **Approach to adherence in different contexts**

Delegates commented on the difference in tone regarding treatment, compared with the morning presentation, and the focus on working with the patient. The point was made that approaches are different in other country contexts, in terms of resources and so on. In some countries, they are unable to do a CD4 count, or a viral count, so treatment is provided based on symptoms alone. In fact, even in South Africa, it may be necessary to take a totally different approach in the future, as we may run out of doctors, and may even run out of nurses.

In summing up, there was an appreciation for the two divergent views expressed during the course of the day, one disease-centred, and the other patient-centred.

**Project presentation: Positive Futures Programme for HIV positive students**

**Speaker: Patricia Machawira**

**Session Chair: Mala Mnyamanda**

Patricia introduced the interns on the panel who had worked on the regional Positive Futures Project, funded by the Ford Foundation, the aim of which was to provide strong support for students and staff living with HIV and AIDS on university campuses. The project was based at the following universities: Makerere University (Uganda), University of Dar es Salaam (Tanzania), University of Nairobi (Kenya), University of Namibia, University of Zambia and the University of Zimbabwe.

By way of some general background of the project, the aim was to find creative ways in which universities can respond to the challenges posed by the epidemic, and create a non-discriminatory environment for staff and students living with HIV and AIDS.

The student interns who facilitated the day to day running of the project on each of the six universities will report on their experiences on the ground. This will tie into the sessions heard yesterday that dealt with stigma on campuses.

In terms of institutional arrangements, the location of the project varied from institution to institution, although the ideal had been to locate the project within the Dean of Students' office. In that way, the project would work in collaboration with other student activities running under the Dean of Students.

In all six universities, project volunteers were recruited who worked closely with the project interns. The number of volunteers varied from campus to campus, with some campuses having as many as 100 volunteers working on the project. The main function of the volunteers was to be able to reach out to the larger student community. Volunteers played a key role in the project and in a number of cases were translating their knowledge to help other students e.g. students from the faculty of law would provide free legal aid, while those from the medical faculty assisted in passing information on HIV infection and treatment.

The project did not try to set up new structures within these institutions, but took part in existing activities. These included: the project launch, incorporating activities into existing

structures such as Orientation Week, VCT campaigns etc, setting up campaigns such as the Shedding of Stigma Campaigns, Living Positively workshops, and outreach activities.

The project attempted to broaden the scope of messaging around HIV, to address how treatment is accessible, increase access to information, and create support groups for those living with HIV.

### **Highlights**

There were several highlights of the programme. The project was able to draw attention to the university HIV and AIDS policy, and to address what it was saying. There was also success in breaking the silence, and in broadening the scope of HIV interventions.

Some progress was made in bringing members of staff on board, and in networking and regional collaboration. There was an increase in access to information on HIV and AIDS on campus, as well as the creation of support groups.

A key motivation for the project was that there is always a lot of talk about prevention, almost as if there are no people living with HIV, so the project was focused on addressing the challenges and needs of people living with HIV and AIDS, also highlighting the need for the whole continuum on campuses, from prevention through to care and treatment.

### **Challenges**

The project had a short timeframe of implementation. This was compounded by delays in the signing of project documentation, with the result that project activities in some countries took off long after February 2008. At both the University of Nairobi and the University of Dar es Salaam, there were only about six months of project implementation, and it was not possible to implement all the planned activities

Some university administrations were reluctant to fully embrace the project, which also resulted in significant delays. This also delayed the process of getting the interns set up on campus to commence project activities. Some institutions did not approach this as a partnership, wanting to know what was in it for them. The need was there, but universities have their own ways of doing things, and did not necessarily buy into the approach.

### **Stigma**

Despite some advances towards eliminating stigma, this remained a key challenge to the project. In some universities, PFP volunteers faced stigma from fellow students who

associated them as people living with HIV and AIDS, reacting negatively. Secondly, in some cases students were unwilling to open up to their colleagues mainly due to lack of confidentiality and fear of stigma. Although they readily listened to and accepted the ideals of the programme, they were not willing to engage freely in discourse on sex and sexuality.

There was also a lack of IEC Materials for the project, which made it very difficult to promote project activities because there was limited publicity, and no means to publicise the activities for the Positive Futures Project.

### **Lessons learnt**

Clearly, the project formalities with partner universities need to be finalised before commencing project activities. Involving partner projects at the proposal stage can also help to avoid misunderstanding during implementation, and planning and requesting funding in advance would also work toward overcoming funding gaps.

### **Conclusion**

Despite the short time frame for implementation, the Positive Futures Project demonstrated massive potential in supporting the needs of positive students and staff in universities. It also encouraged a shift in focus from purely prevention to the need for the whole continuum in relation to HIV, from prevention to care. One of the project's major successes is that it managed to bring to the fore the plight of staff and students living with HIV and AIDS, and demonstrated the great need for support for PLWHA. Now that the programme has come to an end, the challenge is to continue to provide support to PLWHA on campuses.

### **Feedback from student interns**

Interns involved in the Positive Futures Project (PFP) shared their experiences in working with students on each of the six campuses, providing examples of the impact of the project on the lives of individuals coping with HIV.

#### **University of Zambia (UNZA)**

The Positive Futures Project on the UNZA campus reported on similar issues around stigma and discrimination at UNZA, highlighted by Bernard on the previous day, which prevented students coming forward in large numbers. Participants in the project also raised the question of nutrition and support, giving the example of one student who had accepted his status, was adhering to treatment, but needed financial support. In the absence of support from his family, with whom he could not address his HIV status, he had had to withdraw from university to seek work, and to raise money to be able to complete his studies. The support groups on campus do assist students in discussing and addressing challenges of this

nature, but they do not meet frequently enough and have insufficient resources to provide solutions.

### **University of Zimbabwe**

University of Zimbabwe PFP intern, Gift, focused on one of the key strategies of the project, Positive Living. Workshops were facilitated on positive living, in which attempts were made to incorporate students with HIV and also students living with disabilities. The project was able to address the very wide gap in the level of knowledge about living positively, and to make a difference. These workshops highlighted the need on campus for expansion of programmes around positive living.

### **University of Nairobi**

The success of the PFP project on campus, reported the intern, could best be seen through the example of one particular student, who had contracted HIV, and was living a life of vengeance, having unprotected sex as a form of revenge. Through counselling and involvement in the programme, this young man came to accept his status, and wrote a paper on stigma and discrimination, thereby assisting other students.

### **University of Namibia (UNAM)**

The success of the PFP project on the UNAM campus came largely through the experience of working together with student associations and unions, helping them with their programmes, and through counselling services. There are no openly HIV positive students on campus, which comes back to the issue of stigma, but they do have positive students approach them for counselling and information on access to services, where to have CD4 count tested, etc. Even though these students are not ready to go public, the project clearly represented a valuable resource of knowledge and support for them, and this points to its success. There was real pride in witnessing the first VCT centre set up at UNAM, and additionally in the strong HIV AIDS Policy, and the focus on implementation. The challenge was that, in the absence of openly positive students on campus, they felt a bit like throwing their voices in the desert, not really knowing which students to target, and how to enhance their lives. A disappointment was the reluctance of males to participate in HIV activities compared with about 80% female participation, and further research could help to understand why they withdraw and hand this responsibility to females, perhaps a result of socio-cultural factors. However, upon reflection, in spite of these limitations at UNAM, the PFP could be considered a success, thanks in large part to peer counsellors, without whom the quality and access to support would not be available to students.

### **Makerere University, Uganda**

The PFP managed to penetrate in various aspects at Makerere University, primarily through workshops, and outreach programmes.

The project created a sense of belonging for students living with HIV, even though many of them did not come out about their status. An example was given of one very beautiful student, who fell in love with one of her lecturers, and contracted HIV. Her situation deteriorated, and she decided to disclose to her family, after which her father refused to pay tuition for the next semester. The mother sympathized, but had no resources, so she was forced to leave, and attempts are being made to secure a scholarship for her.

In addition, a staff member was ill, and without financial support for staff to access medical treatment, this staff member had to get a loan to obtain treatment. Positive Futures was able to assist by looking for other available clinics for treatment. Now they are providing ARVs for free, and to address opportunistic infections, through funding that has been secured, and volunteers trained under the project are continuing with support. Even though the project has come to an end, they are continuing with the Positive Futures Club.

### **University of Dar es Salaam, Tanzania**

The PFP intern reported on some of the key issues experienced, around students' not accessing treatment, and lack of confidentiality. Although there are centres providing treatment, many students don't access them as a result of breaches of confidentiality. The Positive Futures Project organised a workshop to sensitize health workers on issues of confidentiality and are expecting that the turnout of students and staff accessing treatment care and support will improve, as a result.

Another issue identified through the PF project was the lack of involvement of PLWHA who had no knowledge of issues or activities relating to HIV on campus. Through workshops and discussion groups with students and staff they saw an increased involvement of PLWHA, and more opportunities to assist people living with infection. The project also mobilised PLHWA, students and staff alike, even though they are not yet willing or ready to openly disclose their status. They also highlighted the need to maximize the HIV policy on campus. Stigmatization is clearly a hindering factor, as until now no student or staff member has openly disclosed their status, even though it is clear that many people are living with HIV. However, the Positive Futures project has provided a forum for students to come and discuss their challenges, and lobby on their behalf around issues of HIV/AIDS to management.

## Discussion

Key points of discussion around the Positive Futures Project centred on the way forward, now that the project has ended.

In terms of the sustainability and future of the project, always a sensitive subject, it is largely a donor decision whether to continue to fund an initiative. Donors frequently point out that the aim is to institutionalise programmes and projects, and yet, within the context of higher institutions in Africa, there are always so many challenging and competing priorities, that HIV programmes are often not prioritised.

Two of the institutions have established Positive Futures Clubs, registered as student associations under the SRC, and there are plans to look at each institution to begin fundraising for their own programmes.

**Session Chair: Bowani Mutshewa**

**Speaker: Millica Mwela, UNZA HIV and AIDS Response Programme, University of Zambia**

Millica Mwela provided a brief overview of ART options being offered at the University of Zambia (UNZA). She began by providing a short background of UNZA that, along with the Copper Belt University, is the highest learning and research institution in Zambia, established in 1965 by GRZ. It is highly relied upon in terms of by resource and research.

The university's mission is:

*“To serve as a centre of excellence in higher education for individuals, industry, and society through the provision of quality education, research, and scholarly programmes for strategic human resource development, in order to promote national and regional development, through relevant and appropriate partnerships.” (UNZA SP)*

UNZA serves more than 10 000 students and employs nearly 2000 members of staff. UNZA is comprised of 9 schools on 2 campuses, namely: the Great East Road/Main Campus, with a population of approximately 9000 students; and the Ridgeway Campus, School of Medicine, with a population of 600 (students here seek medical attention at the University Teaching Hospital).

As an institution and in line with its mission, UNZA strives to engage and be responsible to the university community in mitigating the impact of HIV and AIDS, both on its internal constituency of students, staff, staff dependents and students, as well as on society as a whole.

The need to streamline various efforts by the University in addressing the AIDS pandemic necessitated the formation of the University of Zambia Standing Committee on HIV and AIDS (UCA) in 2003 (including the Medical School and the University Health Services). The UNZA HIV and AIDS Response Programme was formed in 2005 as the implementing body of the UCA.

Notable milestones of the Response Programme include:

- Workplace HIV and AIDS Policy



- Establishment of an antiretroviral therapy (ART) clinic in February 2005
- Development of a five-year Strategic Plan (2006-2010)
- Commissioning of the 2006 Baseline Sexual Behaviour and Sexual Harassment reports
- Setting up of the HIV and AIDS Resource Centre

Staff and students stay on the UNZA campus, and it is a priority that student and staff issues around HIV come to the fore. To inform the activities of the programme, a Baseline Sexual Behaviour Survey and a Sexual Harassment Report were commissioned in 2006.

The activities of the Response Programme have been mostly externally funded from a variety of funders, SAIH among them.

### **UNZA Clinic**

The main objective of the University Health Services is to provide primary health care and health promotion services to students, staff and their families, as well as the general community in the catchment area. The UNZA clinic is located adjacent to the HIV and AIDS Response Programme.

The UNZA clinic operates on a 24-hour basis and is registered with The Medical Council of Zambia, offering general outpatient consultations, with a twelve-bed facility for short stay admissions.

Services include: Mother and Child Health (MCH) Services, PMTCT; Specialist clinics for Psychiatry, Tuberculosis and Ophthalmology; a Laboratory to support the clinical services; and VCT and ART Services.

### **The UNZA VCT/ART Unit**

When someone is accessing treatment, they have to go to a separate wing to access these services, which is housed in the clinic, but in a separate unit, which may have an impact on the number of people being seen to access these services.

Counselling and testing for HIV has been available since the 1990s, but the ART clinic, and VCT was established in 2005. They first recorded a total of 52 clients, of whom 49 volunteered to test. In As of February 2008, 2500 patients had enrolled on its register, with 1201 receiving ART. To date, over 3500 clients have passed through the unit.

The ART clinic started with an initial staff of two (one nurse and one clinical officer trained in general counselling) and no support staff. Staffing currently stands at 15, which includes support staff. Healthcare staff includes a medical doctor who consults on any concern regarding treatment and patient management, 1 permanent and 2 alternate clinical officers, 2 nurses, and 3 counsellors.

In terms of treatment options, there are also health centres surrounding the university that have ART units in addition to the unit on campus.

When a patient comes in for treatment, there is no distinction made regarding where they come from, whether the university or the external community, as the service is open to all, and drugs are provided freely.

Several key issues in the UNZA ART service provision have arisen:

- Stigma still stands out as an issue, and a key barrier to accessing treatment in a closed community (confidentiality). Clients will access treatment in areas where they are not known
- Flow of information (community knowledge) to increase to demystify ART, and the programme is looking at creating more appropriate materials around treatment
- Students' low utilization of VCT/ART is an issue that needs to be handled; since 2006, the clinic's VCT unit has seen a total of 500 people; 300 staff and only 50 students have been registered at the clinic since the launch of the ART programme (UNZA clinic records)
- The set up of the VCT/ART unit separate from the general waiting area is also an issue, in that people don't want to be seen to be accessing those specific services
- The VCT/ART programme is externally supported, employing volunteer counsellors, which raised the issue of sustainability.

In conclusion, the UNZA ART clinic has been highly successful, making a significantly contributing to the nationwide roll out of treatment for people in need. Recent statistics indicate that there are over 160,000 Zambians on ART (over half of the estimated number of clients in need).

The success of this project has been dependent on the commitment by UNZA through the Response Programme to addressing all the facets of the AIDS pandemic by actively working towards prevention, care, treatment and support for people living with HIV/AIDS.

## Day 2: 26 September 2008

### Treatment Options at Universities

**Session Chair: Bowani Mutshewa**

**Speaker: Johan Maritz, Centre for the Study of AIDS, University of Pretoria**

A brief overview was provided in order to review the establishment of treatment options on the University of Pretoria campus. In terms of the national context, prior to April 2004, there was no public sector programme, and only one South African university provided ART prior to that. The university was one of the lobby groups that took the government to task in order to force them to provide PMTCT drugs to women infected with HIV.

In terms of the institutional context, the University of Pretoria (UP) is the largest residential university, with in excess of 50 000 students, and has students from all over South Africa, and more than 2000 international students. On the UP campus, there was no VCT programme prior to 2005. The system used at that point was pre and post testing on campus, with referrals to a laboratory, but that service was not free, although there was half price testing for students. The university examined the ethical considerations of providing ART. The approach was to examine their responsibility to students not only on campus but once they have graduated, as the debate centred around the fact that once students have graduated, they move into jobs and can afford medical aid. This is not, in fact, true, as some graduates are unemployed, so the result was an attempt to secure other funding.

The national treatment rollout began in 2004, and through a partnership with the Foundation for Professional Development (FDP), a health development organisation, of which Anton Stoltz is a part, the university was able to provide an onsite service.

The onsite VCT facility was linked to a treatment programme, and established a multidisciplinary AIDS management team. The team is comprised of:

- CSA Befriender
- Nurse
- HIV clinician: Professor Stoltz
- Dietician

- Social Worker
- Psychologist

There are other ad hoc members involved in the initiative, and stakeholders participating in the model include:

CSA - quality control but also counselling

Dean of Students

Student Support

Student Health Services

Metro Dept of Health - as an official VCT site, they are provided with all the kits

Provincial and National Health

FPD - also assisted with accreditation of the site

The VCT Service was established in 2005, which was an interesting process. As already mentioned, they had provided counselling but off-site referral prior to 2005, and 247 students came for testing at the outset, without the need for any advertising. The CSA negotiated with the institution to take ownership, and the result was that it became integrated into the campus health service.

The CSA Befriender provides counselling within the VCT service, the nurse performs the test, and the Befriender gives the result. This is the primary entry point on campus to treatment services, although students can also be assisted through the clinic to get onto a treatment programme.

There have been some national debates about the notion of students counselling other students, which also touch on issues of confidentiality. Concerns have been raised about whether VCT counsellors can be taken seriously, whether they can handle this situation, and whether they can be trusted with confidential information of this nature. However, in 8 years of counselling provision, there has never been a single incidence of a breach of confidentiality, and at any given time there are 20 counsellors providing this service. They are expected to attend a group supervision session every two weeks, in which they look at issues of in service training, debriefing, issues around suicide and couples counselling, so the support is there for them. There have been other institutions that have scrapped this approach due to low uptake, but this is not the experience at UP.

One of the biggest challenges was how to introduce the service onto campus, to encourage students to access the service. They tried to conceptualise ideas in an avant-garde manner, which disassociated the process of being tested from sex, risk and infection, so they came up with the idea of “Quick and Easy”. Previously, the process of being tested was difficult, and also the term quick and easy was tied to the risk, and the idea that infection can be quick and easy. They turned that around to apply to taking charge of knowing one’s status.

The Quick and Easy campaign was very well received by students, although not so well received by staff.

### **Entry into services**

The way the process works is as follows:

Student test positive:

Immediate confirmatory test (rapid test)

Blood is drawn and sent to the National Health Laboratory Service (NHLS) where the following is assessed:

- ELISA
- CD4 count
- Viral load
- Liver function

An appointment is made with Professor Stoltz, after which he will have an immediate idea of the progression of infection, and whether initiation of treatment is necessary.

### **Treatment initiation**

Treatment preparation

Befriender

Dr Stoltz

Rest of team

All the services are done at the campus health service

Drugs are accessed from:

Pretoria Academic Hospital

FPD Clinics (37 clinics)

Private sector

Some students haven’t disclosed to parents, and don’t want it appearing on medical aid.

FPD Clinics - are open until 7pm, and are donor funded, so options in terms of treatment.

### **Ongoing Support**

Limited sessions are arranged with the Befriender, as they don't want to create a dependency, and also there are limitations as they are lay counsellors. If necessary, referrals are made to psychologists at Student Support, or to a social worker. CSA psychologists are also available to provide support, as well as UP support groups, and community support groups.

The successes of the programme can be summarized as follows:

The programme has some of the highest testing numbers at a university in South Africa, although numbers are not a priority, as the aim is to normalise testing, but not trivialise it into a numbers game. If the numbers become the primary focus, it could jeopardize the quality of the programme, and descend into what could become a Test Fest. The use of student counsellors and the partnerships involved in the initiative are also strengths, as well as the fact that it is a free service. The fact that the programme links to the national programme lessens the obligation to take care of students once they graduate.

There are, however, challenges that do persist in terms of accessing the service. There are issues around questions of race, and sexual preference, for instance, and there are more black students accessing the service than whites, and more women than men. Stigma is prevalent, resulting in fear in accessing the service, and a reluctance to be seen to do so on campus. There is also the fear of knowing one's status, for in some students' minds, "knowing might kill me."

Another issue is that some of the health care workers and staff at the clinics are generally older from a previous generation, and HIV is a new issue for them, so the sensitization of these nurses is a challenge.

Students also don't always understand the need for pre-test counselling, and there are also sometimes difficulties in handling student numbers, when large numbers come in wanting to be counselled at the same time.

## **Discussion**

Key areas for discussion:

### **Comprehensive services on campus**

The presentations raised the possibilities of students having access to services on campus, but also to community services and treatment outside, which some students prefer, as they can access services without fear of being recognized.

### **Students as counsellors**

In spite of some opposition at first, the model of students counselling students has been a success factor, as long as student counsellors receive the necessary support. Other institutions hoped to learn from the experiences related here, and to formulate activities that are student-driven on their own campuses.

### **Diet and Nutrition**

Institutions could approach their respective governments around supporting not just HIV programmes, but also programmes that deal with diet and nutrition. It is often assumed that if students can access higher education, they can afford balanced meals, but this is not the case. There are some indigent students who have access to bursaries, but often it does not cover living expenses. At UP, the Office of the Dean of Students offers a feeding scheme to address these sorts of difficulties.

### **Monitoring uptake of services**

It can be an issue to collect accurate data in terms of monitoring uptake of services, and students' status when they come to access services. It is an issue being addressed, for example at UNZA.

### **Stigma**

Once again, the question of seeking treatment is also determined by stigma, as students are afraid to access services, and afraid to know their status. At UNZA, they have tried to address the fear of accessing services through the use of theatre and drama, in a more light-hearted way that brings home that it is not a death sentence, and that going for VCT is a good thing.

“If someone knows that the house is burning, they can take the necessary steps, but if they don't know, the house will still burn down.”

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<sup>ii</sup> The article was written by Metholo Moema, Kamogelo Sebola, Matseko Ramotekoa, and SAPA, the South African Press Association news services and published in a newspaper on Tuesday, 2 September 2008. The article deals with the crisis of the high number of deaths in the country as presented by the loss on the national voters' roll and the overflowing graveyards in the country and suggests that the HIV/ Aids epidemic is cutting more and more South Africans in the prime of their lives notwithstanding officials' silence on the matter.

<sup>ii</sup> The Centre for the Study of Aids at the University of Pretoria hosts a monthly AIDS FORUM where noted researchers and others present their thoughts and work on the issue of HIV and Aids.

<sup>iii</sup> Isak Niehaus' biography sent by the Centre for the Study of Aids with the invitation to the Forum included a list of publications Dr. Niehaus had published.

<sup>iv</sup> Article by Patricia Lefevere titled "Injured priest helps wounded South Africans heal - Fr. Michael Lapsley", published in the National Catholic Reporter, August 10, 2001 on-line [http://findarticles.com/p/articles/mi\\_m1141/is\\_36\\_37/ai\\_77556904](http://findarticles.com/p/articles/mi_m1141/is_36_37/ai_77556904) and accessed on 20 September 2008.

<sup>v</sup> Robert Koenig, Africa correspondent for *Science*, reported in his article titled "In South Africa, XDR TB and HIV Prove a Deadly Combination" on the rampage and challenge this new manifestation in the experience with HIV and Aids in South Africa. The article was published in *Science* on 14 February 2008.