

Making a difference in HIV

POSITIVELY Women



Rights Here,
Right Now



The Pope, Sexuality and Vienna

A recent visit to the UK from Pope Benedict XVI led to two leading charities FPA (Family Planning Association) and NAT (National Aids Trust) submitting a press release to highlight the discriminatory nature of his statements and his dismissive approach toward modern day teachings on sexuality and sexual health and wellbeing.

In 2008, in an abhorrent expression of discrimination, the pope claimed the need to save “humanity from homosexual or transsexual behaviour as important as preserving the rainforests from destruction”. The Catholic Church teaches that homosexual orientation is not a sin but homosexual acts are. It opposes civil partnerships and gay marriages, the pope has said that “homosexual inclination was not a sin”, but it represented a “more or less strong tendency ordered toward an intrinsic moral evil”.

Such comments impact on the tireless work of the NGOs to try and overcome the high levels of stigma that perpetuate persecution of people because of their sexuality, and or gender identities. Here is a man who says, behaviour beyond traditional heterosexual relations is a “destruction of God’s work” and therein lies the church’s ‘control’ on how a person ‘should’ be in their eyes, to be an accepted member of society. Fundamentally this has a devastating impact on those who feel ‘unable’ to be true to themselves for fear of rejection from their families, peers and in this case also their church. People are forced not to disclose, to live a secret, to compromise their truth, to deny themselves their sexual and reproductive rights, and practice behaviours that leaves them at greater risk of exposure to HIV and sexually transmitted infections.

I have spent the last four years facilitating a group for lesbians living with HIV in London. However small our numbers we have effectively raised visibility and the need for support was officially recognised (we won funding for the group after two years). As a group we reached women who had lived in isolation for almost 20 years, with consequential mental ill health issues because they had felt unable to speak to health professionals for fear of discrimination. We reached women not only on a national level but also internationally; we (Positively UK) are the first HIV charity in the UK to provide specialist support for this community of women.

The lesbian community received some recognition at this year’s World AIDS conference which raised awareness that this is a group affected by the global pandemic; they just haven’t been recognised enough. There is a need to gather information around women’s sexual practices and support the LBT (lesbian, bisexual

and transgender) community to mobilise around the invisibility of woman’s sexual diversity. This invisibility will continue to deny the LBT female collective effective responses and HIV and STI services. As an HIV positive lesbian an acknowledgement of our needs and raised visibility planted a seed of hope in me. To meet and talk with many other positive lesbians and bisexual women was so significant, it was very apparent there is a large community of LBT women living with HIV globally who need recognition to overcome the isolation and silence that so many of us experience.

I was very fortunate to attend the 2010 World AIDS conference and also be invited to speak at a couple of conference sessions. Firstly, at the session: Is AIDS Activism Dead? About my experience as an HIV positive woman, diagnosed in prison, and Positively UK’s work with incarcerated women and then on the theme of LBT: Gender and Sexualities, discussing lesbian’s invisibility in the HIV world. I also submitted an ‘abstract’ titled ‘Claiming voice and visibility for HIV positive lesbians’ which was exhibited as a poster. There are many things I would like to see achieved, but close to my heart is the increased visibility and voice of the LBT community and the promotion of gender equality. For me the conference was a chance to develop my learning, share my skills and experiences and bring back a wealth of insight and information to pass on to others so their lives can change too.

Currently, I am working independently to compile a behavioural study which will hopefully provide a more truthful picture of just how much of a fundamental place the LBT voice has in the global HIV community. Although transmission is very low in numbers between WSW (women having sex with women), these are not reflective of transmission rates. Much research globally needs to take place, hopefully this will support us in our ongoing work at Positively UK with this group of women and I can take this back to the next AIDS 2012 in Washington DC. Studies are being carried out in Lesotho by UNAIDS and evidence of those studies are hoped to be shared at AIDS 2012 in Washington DC.

The pope’s power as an individual is unparalleled, there are currently over a billion members of the Roman Catholic Church worldwide, he is one of the most influential men on the planet. With such influence and a growing ‘membership’ to his church, how damning are his ignorant messages when it comes to addressing the global pandemic towards HIV? Africa and Asia central and south east show the highest rate of HIV infection anywhere in the world, his ever-increasing followers reside within these countries and far beyond, how

do 'we' address such conflicting messages? Then there's his stance on 'modern day contraception' with far reaching consequences by denying women access to information on contraceptive methods and accessing advice on sexual health and reproductive rights.

I am a firm believer and advocate for people's human rights. Self-expression through sexuality is an individual's birth right, regardless of gender and sexual orientation, as is the freedom and right to sexual pleasure within any relationship whether that be heterosexual, MSM (men having sex with men) and WSW. Yet the Catholic church condemns those very rights through their teachings.

Sophie



Sophie

Vienna Voices

We interviewed a few of the thousands of women living with HIV from around the globe at the conference and here is what they had to say!

Would you like to introduce yourself?

Jessica from Nigeria, 30 years old. I'm a volunteer and was diagnosed in 2002 and started treatment immediately.

Why did you test for HIV?

I was sick on and off for six months, I was tested for other conditions such as malaria and eventually got tested for HIV.

How did you feel after your diagnosis?

I felt depressed and that everything was over for nearly a year.

Did you find it difficult to tell your family and friends?

It was extremely difficult to disclose my status to family and friends.

Why did you come to Vienna 2010? So far what are your impressions?

I came to Vienna to identify with other people and to be empowered, as back in Nigeria I can't live openly with HIV.

What are your views on criminal prosecution of HIV transmission?

I think this is going to undermine all the progress and efforts and achievements done so far and it's going to take us back ten years.

We Hear the Thunder But We See No Rain

Whilst the dollars roll big-time for medical male circumcision, we are forever at the wrong end of a deeply entrenched uneven male playing field of traditions when it comes to gender, HIV – and funding

Back in the UK after the International AIDS Conference. The drums are silent again, the bras have found new homes. Time to reflect and work out if and how our knowledge of the world in relation to HIV has changed or not.

From the main conference came the news of the microbicide breakthrough – a powerful scientific advance. Another highlight was a World Bank session highlighting research from Malawi and Tanzania, which clearly shows that giving girls and their parents small regular cash transfers of a few dollars monthly over two years significantly reduces their risk of acquiring HIV. This emphasises the poverty dimension to young women's vulnerability to HIV, since there is consequently less need for these impoverished young women to engage in transactional sex. In both these findings of course, it is important to continue to remember that neither medical nor financial interventions alone are the Holy Grail cure that so many keep looking for. Our lives are far more complex than that. Nonetheless, such breakthroughs are highly important in filling in another two pieces of the jigsaw and deserve celebration.

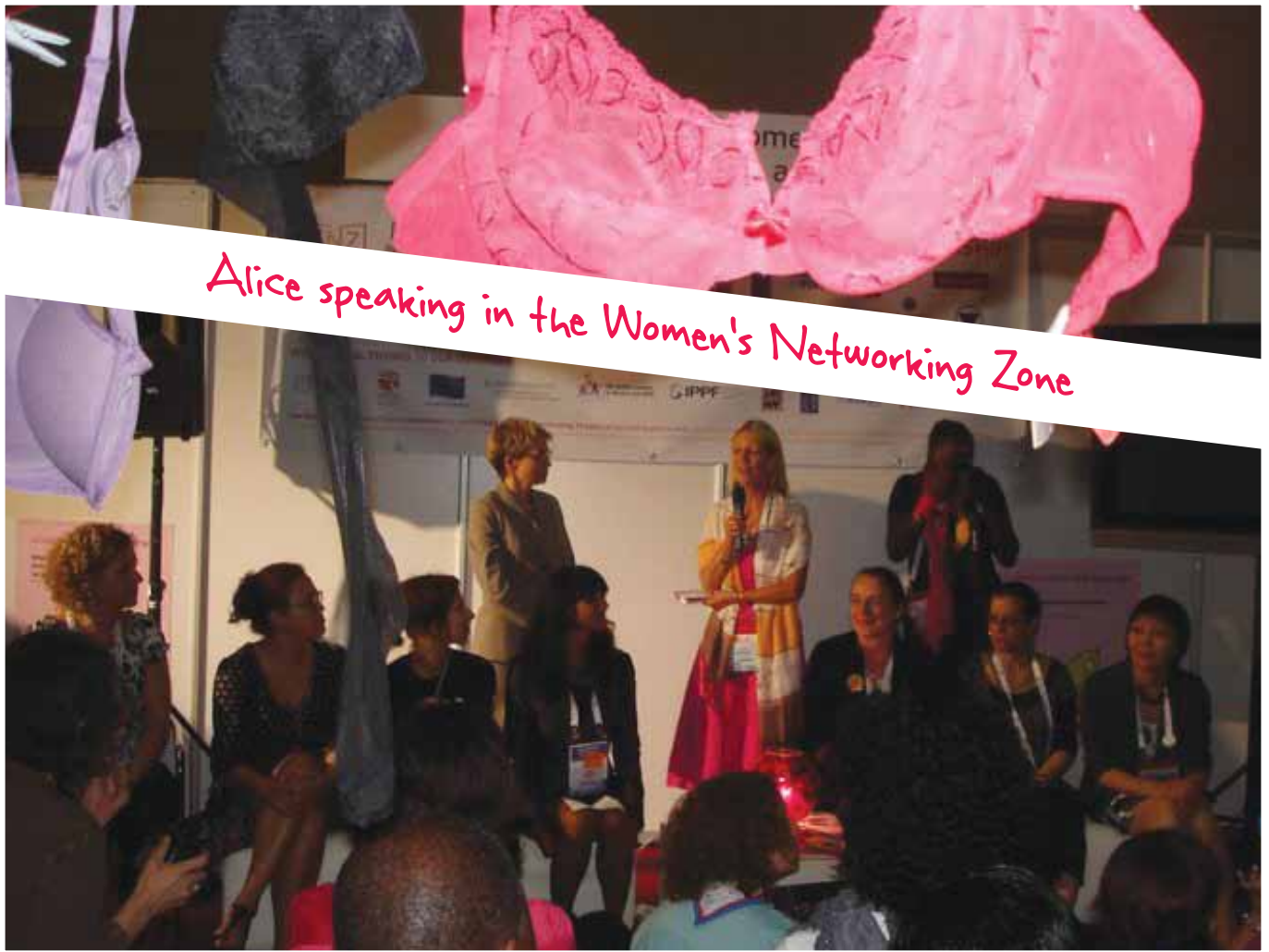
Which brings us to the thorny subject of funding for women's rights and HIV, an issue which is clearly so immense and central, and yet one for which there is – as yet – “no evidence base”. With the costs of medication to keep us alive spiralling, medical male circumcision has been hailed as a great breakthrough to stop HIV in its tracks by protecting men by 55%. It is being rolled out across Africa with huge surgical budgets by large donors. A colleague visiting Swaziland recently was amazed to see young men being bussed in from far and wide to have their foreskins surgically removed at the local clinic, with hardly any other health service available, as the circumcision campaign had literally taken grip. Strong concerns have been raised by many women in various countries about the wisdom of such a techno-fix campaign, with little educational follow-up, which men often interpret as akin to wearing a permanent “natural” condom. Negotiation of safer sexual practices is even further from women's reach. And, when the 45% likelihood of a man still getting HIV becomes a reality, blame on women will increase, in this kingdom where its head of state has so many wives, girlfriends and children that even he may have forgotten their numbers.

Yet whilst the dollars roll big-time for medical male circumcision, I bet my bottom dollar that similar funds will not roll for the scientific findings of this conference – the evidence that gender violence doubles HIV risk for women, the evidence that microbicides can protect women from HIV by 39% and from herpes by 50%, the evidence that cash transfers to girls can reduce their risk of acquiring HIV from 12 to 9%. Curiouser and curiouser, as Alice said down the rabbit hole...

“In Vienna, many of us were in a rare bubble, where to be open about one's status both feels normal and widely accepted.”

Something I learnt at the conference, with my heart for a change rather than just with my head, is the enormity of the HIV challenge just on our doorsteps, in Eastern Europe and Central Asia. I was particularly struck by a powerful film from Ukraine, entitled “Returning Home” about a young Ukrainian woman who has lost her husband, her brother and her best friend through injecting drug use and related health conditions. She considers herself and her friends fortunate because they are part of a highly supportive substitution therapy programme which has given them their lives back. She and her friends can now get on with being parents and workers, with this medical support which is still so highly criticised in many countries.

Another great moment for me in the week was the launch of WECARE+, the first Europe – and central Asia-wide network of HIV positive women, together with a survey of 165 HIV positive women from across the region, conducted in four languages. As Angelina Namiba blogged, despite 70% of women in the UK with HIV having been born in Africa, and despite there being sizeable numbers of HIV positive women in other parts of Western Europe born in Africa, it seems curious that UNAIDS holds no statistics on this. Another odd quirk of UN statistics is the grouping of Western and Central European statistics with those of North America, rather than with those for the rest of the European and Central Asia landmass. In the WECARE+ survey, it came as no surprise to us that one third of the respondents had experienced gender-based violence. Yet – another odd quirk of institutional thinking – the recent European Commission Charter promoting gender equity



Alice speaking in the Women's Networking Zone

and speaking out forcibly against gender violence, makes no mention whatsoever of its widely known links to HIV.

In this survey, depression and fear of the consequences of disclosure of one's HIV status were very widespread. In Vienna, many of us were in a rare bubble, where to be open about one's status both feels normal and widely accepted. Yet I remind myself repeatedly of the conferences I went to before I felt safe to be open myself and remember that there were, no doubt, many others there who are still yet to disclose their status, even to their professional colleagues. There are, of course, many other issues which one feels nervous speaking out about. It was particularly moving to hear one woman from south east Asia talking publicly for the first time, in a session in the Women's Networking Zone, of her experiences as a sex worker. She received a warm round of applause. By contrast, one extraordinary young woman activist, who has been HIV positive since birth, had her cover blown back at home during the conference, after one well-meaning but misguided colleague posted a video of her speaking on her Facebook page. Speaking openly involves risk and stress. Thus many young HIV positive women activists whom I know go "back into hiding" once they decide to reclaim their lives and start a family of their own.

One piece of news which I am thrilled about is that one of the two young graduate volunteers we took with us to help

with Russian/English translation in the Zone has come back so inspired by the whole experience that she has decided to take a Masters' degree in Human Rights. Both these young women were amazed and rightly shocked that this whole HIV world was so new to them – and that comprehensive sexuality education is still not a compulsory part of the UK's National Curriculum.

To return to the money question: the WECARE+ network development and survey was conducted without any funding, like so many of the other women led projects represented at the conference. What is it about women's rights work that makes it so systematically unfundable, despite all the rhetoric that has been played out in Vienna about the fundamental centrality of gender issues to an effective AIDS response? We are forever at the wrong end of a deeply entrenched uneven male playing field of traditions when it comes to gender, HIV – and funding.

In the words of one session which highlighted the lack of access to funding for women's rights: "We hear the thunder but we see no rain". This, to me, is the outstanding challenge to move forward from the Vienna conference. Meanwhile I am off to write yet another funding proposal.

Alice

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“We were a little apprehensive about it at first – I felt a little embarrassed and clumsy inserting it, although, once it was in, it felt fine and we forgot about it, for the rest of what was, a highly pleasurable afternoon, thank you!”

“I like the female condom as I often have issues with negotiating safe sex with my partner. With the female condom I can take control and I feel more confident.”

“My experience has been a good one. Me and my husband can feel more sensation when we use the female condom. My husband is not positive and he feels more comfortable if I use a female condom...”

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Small Study, Big Impact -

The future belongs to microbicides!?

“Today we celebrate the evidence that microbicides can effectively protect against HIV”, announced Gita Ramjee, director of the Research Council of HIV in South Africa. In the last few years studies in microbicides have repeatedly disappointed, but tenofovir 1% gel was celebrated as a breakthrough at the World AIDS Conference in Vienna. DHIVA editor Christin Seifert was in Vienna with Rebekah Webb, the former European Co-ordinator of the Global Campaign for Microbicides (GCM), and they met for an interview.

DHIVA: The most important question right first: What are the results of the study?

Rebekah Webb (RW): The Caprisa 004 study looked at whether tenofovir gel could prevent HIV infection in women. Caprisa stands for Centre for the AIDS Programme of Research in South Africa. The study was conducted among a total of 889 women in South Africa, all with a high risk for HIV infection. 422 women received a gel containing tenofovir, the control group of 421 women received a placebo. After 30 months, the study showed that 38 women acquired HIV in the group using tenofovir, while in the control group 60 women acquired HIV. This means: In the group that tested the microbicide, the risk of HIV infection by 39% was lower than for women without the tenofovir gel.

DHIVA: Thirty-nine percent do not necessarily sound much. What do the numbers mean exactly?

RW: The number itself may not sound much but in a context where many women have nothing they can use to reduce their risk, 39% better protection represents a massive difference. Of course higher levels of protection are being aimed for but the critical thing about this trial was that it proved that microbicides can work.

DHIVA: When can we expect a marketable microbicide for HIV prevention?

RW: The Caprisa 004 trial was never designed for licensure. Two trials are planned to confirm the result. But so far there is insufficient funding to start them, meaning that women may never get to use this microbicide.

DHIVA: The active ingredient is tenofovir, which is now used in anti-retroviral therapy against HIV. Why is it now used as a microbicide to prevent HIV infection?

RW: Tenofovir has hitherto been used in therapy and scientists increasingly believe ARVs to be the future of HIV prevention. The application as tenofovir gel is ideal because it is easily absorbed by the mucous membranes in the vagina but not into



the bloodstream. Tenofovir is known to have few side effects and can also be used in pregnancy, which is especially relevant to women.

DHIVA: How exactly did the participants of the study use the microbicide?

RW: The microbicide is used as a vaginal gel. The women applied the gel at least twice within a 24 hour period – twelve hours before intercourse, and then again within twelve hours after intercourse. The next step will be to test a single dose.

DHIVA: Did the study also show protection against other sexually transmitted infections?

RW: The study showed a 50% protection against the pathogen herpes HSV-2. Worldwide, nearly 20% of all sexually active adults have this infection.

DHIVA: What does this result mean for you personally?

RW: It is a historic day for the people who are committed to sexual and reproductive health and rights. This research has been quietly going on for years and is not motivated by profit. In early 90s, scientists said that it was possible to create a microbicide, but not necessary. They were not interested. The Global Campaign for Microbicides has brought together over 300 NGOs working for the research on microbicides and HIV prevention in women. Now there has been a breakthrough we need the financial push to carry on. There must be further studies into efficacy. Women around the world need microbicides so they can take HIV prevention into their own hands. I am very proud of the men and women who have contributed to this success!

CD4. Know the score.

The British HIV Association¹ now recommend starting treatment when your CD4 count drops to

- or earlier, if you

- have a high viral load and your partner is HIV negative
- are at risk of cardiovascular disease
- have a co-infection like hepatitis B or C
- have an underlying AIDS diagnosis or
- have a low CD4 percentage (<14%) which may put you at risk of an opportunistic infection

350

Talk to your Healthcare Professional about your CD4.

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Date of preparation: April 2010
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Gender Gaps Stigma and Sex

Conference Diary Excerpt

It is 8:45 on a Sunday morning and I am sitting in a session room. The theme of the session is 'Gender Gaps Stigma and Sex'. Sunday mornings don't get much better than this, right?!

Sophie, Rebecca and I arrived yesterday, but we are wasting no time. The conference has not even started yet, but our Rebecca has her first presentation at an International AIDS Conference, so obviously Sophie and I want to be there to support her. It is a great session that highlights the progress of the Stigma Index around the world. In a nutshell the Stigma Index is a global participatory research by and for HIV positive people to measure levels of stigma. This session focuses on how stigma manifests itself in the lives of women in different countries.

It was clear from all the presentations that stigma affects women very heavily in the domestic domain and that it is strictly linked to gender violence. Now that I read my notes some of the statistics give me goose bumps. In Dominica Republic 34% of women have been shoved or pushed by their partners in the last 12 months and 11% has been attacked with a knife, a gun or another weapon.

But stigma doesn't just express itself as violence in intimate relationships. It is chilling, but it is reported that health providers, and especially family planning clinics, are the ones who proactively discriminate against HIV positive women. In the Dominica Republic 30% of women were advised to be sterilised after testing (but only 17% of men). What is more horrific is that one of the conditions of provision of ARV's for women was sterilisation. This was reported by 21% of the women interviewed. The picture portrayed by the speaker from Bangladesh wasn't much different. Shockingly 84% of those interviewed reported that they had taken the decision of not having children. We still do not have the results of Stigma Index research in high prevalence countries like Zimbabwe or South Africa, but they will probably add more lights on the links between HIV related stigma, gender violence and obstacles to access safe sexual health and reproductive services for women with HIV.

When we finished this session we jumped in a taxi to take part in a satellite session on 'Criminalisation of HIV exposure and transmission: global extent, impact and way forward'. How is that for a Sunday lunch?

Silvia

Laxmi is a hijra, they are men who dress and act like women in India. Hijras do not try to pass for females, as transsexuals might. They are neither male nor female, but a third gender, enshrined in Indian culture, and often defined as eunuchs.

Laxmi is very vocal with her comments and is continuously fighting to protect the rights of her community. She hopes this conference, emphasising and promoting human rights,

will also focus on protecting her community, which is being neglected by governments in their interventions.

According to an earlier survey, there is high prevalence of HIV in the Hijra community. Friends from her community are dying and the numbers are alarming. This needs to be acknowledged and strong and fast action must be taken by governments and UNAIDS to protect them.

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w: ahpn.org **t:** 020 7017 8910

w: tht.org.uk **t:** 0845 122 1200
w: positivelyuk.org **t:** 020 7713 0222

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POSITIVELY UK

A Microbicide Success:

Feminism is Essential to Good Science

Ida Susser

The International AIDS Conference, Vienna 2010, has represented a series of major successes for women. First and foremost, we had the announcement today of the first microbicide ever shown to convincingly prevent HIV in women. Tenofovir gel, applied by a woman anytime in the 12 hours before sex and then again anytime up till 12 hours after sex, reduces HIV transmission to women by at least 39%. In the International Conference at Durban in 2000, there was a plenary announcement of microbicide trials which did not work. Now, ten years later, it is very fitting that two of the scientific organizers of IAS Durban 2000, Quarraisha Abdool Karim and Salim Abdool Karim have announced the success of their research.

Microbicides were the dream of Zena Stein and promoted with Anke Ehrhardt by the Columbia University HIV Center which has focused on women since its inception in the 1980s. It was the product of feminist visions and carried through by many more feminists over the last 25 years. Advocates for women pushed for microbicides when scientists working on AIDS vaccines and treatment had not even envisioned the problem of “methods women can use.”

“A central aspect of good science is generating the questions that make sense in people's lives”

This example illustrates that scientific research is only as good as the concepts which drive it. No scientific method is the gold standard, no matter how much it is randomised and controlled, if there is no vision behind it that reflects the needs of the affected community. Feminists have struggled with AIDS research for a generation, trying to frame questions that address women's prevention, safe fertility and breastfeeding. A central aspect of good science is generating the questions that make sense in people's lives. As documented in my recent book, feminists have had to fight continuously to frame the right scientific questions for women in AIDS. Once we have the questions, we have to generate the best methods to answer them – whether that be a controlled, randomised trial or a qualitative ethnographic case study.

In this respect, as the Town Hall Meeting at the Women's Networking Zone amply demonstrated, “evidence-based” research has to reflect thoughtful concepts and a variety of appropriate methodologies, both quantitative and qualitative.

There have been many victories for women at this conference. The request for a gender breakdown in the abstracts has become routinised, and this request has also been added to the request for papers in the Journal of the International AIDS Society. The opening plenary on Monday morning featured two women who have long been active in AIDS advocacy, Vuyiseke Dubula, General Secretary of the Treatment Action Campaign in South Africa and Anya Sarang, President of the Andrey Rylkov Foundation for Health and Social Justice in Moscow, Russia. Such changes were the result of over twenty years of organising for the recognition of women's agency and women's collective rights in the treatment and prevention of AIDS.

Now, we cannot rest on our laurels – we have to do better than 39% protection!! However, from now on, no woman should get less! The next challenge will be to ensure that the results of the microbicide trials are transformed into practical benefit for women, both in South Africa and beyond. If tenofovir gel does reduce HIV transmission in women, it needs to be produced and distributed as soon as possible. As we all know, feminists and health advocates have the next struggle ahead and we need to educate ourselves and prepare to mobilise to implement the findings, imperfect as they may be.

The South African government, not Gilead, owns this patent – will they begin to plan to use this first microbicide that works? Perhaps they will protect only 40% of women or maybe 50% of those who use the gel – but women should be given the choice to use it – and that is the challenge – will it be available by the next international AIDS Conference in Washington DC in 2012? – will it save lives now?

Ida Susser is Professor of Anthropology at CUNY Graduate Center and Hunter College, and adjunct Professor of Socio-Medical Sciences at the HIV Center, Columbia University. Her latest book: “AIDS, Sex and Culture: Global Politics and Survival in Southern Africa” Excerpts are available at: www.onlinelibrary.com

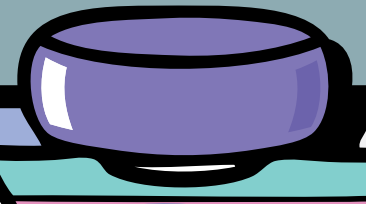
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CAN'T LET MY MEDS MESS UP MY NIGHT. THEY CAN WAIT

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Hot date or not, side effects shouldn't come between you and your anti-HIV medication. Your doctor or nurse can help you deal with problems or make changes to your prescription. Find out more at www.yourstoryyourscrip.co.uk



Faith and Spirituality in the Lives of Women Living with HIV



Winnie Ssanyu-Sseruma on behalf of Women for Positive Action

Women living with HIV have physical and emotional needs that are best addressed through a blend of medical, psychological and community support. A great deal of progress has been made in the medical arena, and the importance of psychological support to address a woman's wellbeing is recognised. However, the complex role that spirituality and faith play is less well understood. Many people involved in the care of women with HIV shy away from discussing religion and faith, as they feel uncomfortable engaging in such discussions, and may feel poorly equipped to deal with a patient who believes that 'God will cure them'. However, spirituality may be a source of considerable support for some people and, following diagnosis, many women with HIV turn to a variety of coping mechanisms, be it religious faith, community groups, faith-based organisations or individual spiritual practices.

The good and the not so helpful

Spirituality and prayer can provide a considerable source of wellbeing and solace, acting as an internal counsellor to overcome the shock and fear associated with diagnosis. Prayer can also act as a coping mechanism for stress and can help with the challenging decisions that women have to make during their HIV journey, such as disclosure and treatment choices.¹ Studies examining the effects of prayer and meditation have reported reductions in emotional distress, improved quality of life², lower rates of depression³ and greater optimism.⁴

However, in spite of the potential positive influence of faiths and beliefs for some women living with HIV, in certain circumstances there can be unhelpful conflict with the provision of appropriate medicines. While many faith-based organisations have been active in providing care and support for people with HIV, some have blocked measures that are regarded as 'best practice' in treating and reducing the transmission of HIV. For example, the Catholic Church has made clear statements against the use of condoms, instead promoting abstinence and faithfulness as the key route to halting the spread of HIV. Furthermore, women may sometimes be encouraged, inadvertently or otherwise, to hold the belief

that God and prayer alone can protect them, leading to them stopping therapy.⁵ The teaching that God can cure HIV is not necessarily meant to mean 'without medicines', but it can sometimes be interpreted this way by the individual or the faith leader. If someone with an undetectable viral load stops their antiretroviral treatment their viral load can remain undetectable for some time, which is subsequently interpreted as a cure. However, many people have gone on to die from the disease after misguidedly stopping their medication. The Mildmay Hospital's leaflet *Prayer or medicines for HIV – must there be a choice?* explains: "It doesn't show a lack of faith when we use medicines. Medicines are not different from everything else in creation. God gave them to us to use."

Finally, stigma associated with a diagnosis of HIV remains a very real issue and has been linked with depression⁶, post-traumatic stress disorder⁷, reduced medication taking and access to healthcare.⁸ It can lead women with HIV to withdraw from their community and can prevent disclosure, creating a barrier to the social and medical support which is essential for coping and health. Religious organisations are influential social networks that have the power to support or stigmatise women living with HIV. This perceived stigma can occur at all levels, from faith leaders to congregation members, and many of the stigmatising attitudes arise from people's beliefs that women with HIV have behaved immorally, and from fears of acquiring HIV through casual contact with people living with HIV.⁹ Informed and knowledgeable faith leaders are therefore crucial in removing this stigma from their congregations and providing correct information about HIV.

The role of faith leaders in supporting women with HIV

Faith leaders can be powerful advocates in their community for the support of women with HIV, acting both as role models and educators. Faith leaders can help shape community attitudes and, therefore, can impact upon feelings of stigma and isolation among women with HIV. Isolation is a huge problem facing all individuals with an HIV diagnosis, and belonging to an accepting faith community may lessen this. "Pastoral responsibility also involves looking at how we can support the



Winnie

physical and mental wellbeing of our congregations. This is not an easy task, but we should do all that we can to support people and help them address the different issues that confront them. This means taking additional time to equip ourselves and learn about the challenges that affect our people. HIV is one of those challenges.” Reverend Ijeoma Ajibade, St Philip’s Church, Earls Court, London.

Most faith leaders are willing to help with HIV-related issues, but often require additional support. Recently, a number of faith-based organisations across all major religions have developed programmes offering education and resources to faith leaders to help them in discussing HIV-related issues, as well as offering support to women living with the disease. For example, the African Health Policy Network has developed resources for Christian and Muslim faith leaders and African community-based organisations and Tearfund, a UK Christian relief and development agency, is supporting a global network of churches to provide services to affected communities and tackle the stigma associated with the disease.

Integrating faith into HIV management

Healthcare professionals who care for women with HIV need to understand and acknowledge that faith and spirituality may be very important to the individuals they treat and should not be avoided in consultations. Furthermore, women should not feel uncomfortable about starting a conversation about spirituality or faith in a healthcare setting. Detailed discussions may reveal the dilemmas a woman faces regarding church attendance and related concerns about stigma and disclosure, and any beliefs she may hold that are preventing her from receiving or accepting the best possible medical care. Wherever possible it is more effective for people involved in the care of women with HIV to understand the importance of their patients’

religious beliefs and try to identify areas where a consensus approach may be possible. For example, a woman who rejects medical treatment because she believes that ‘God will cure her’ can be supported both by her clinical and religious advisors to find ways to incorporate appropriate biomedical care into her belief systems. In addition, certain religious observances, such as fasting, may mean that the woman stops taking her medication during that time – it is important that healthcare professionals, potentially with the involvement of faith leaders, discuss the importance of regular treatment to the woman’s health and wellbeing. Professor Jane Anderson, HIV Physician at Homerton University Hospital, London commented: “I know how important the support of a strong faith can be for some people, however, I am clear that faith alone is in no way a replacement for antiretroviral therapy. For many of the women I see, their faith and their cultural and social beliefs and values are inextricably linked, and only by unravelling and appreciating these beliefs are we truly able to care for the woman in a holistic manner and provide her with the best possible care.”

Ideally, healthcare professionals should discuss spirituality and religion routinely with women, providing they are happy to discuss it. An integrated relationship between women living with HIV, healthcare professionals and faith leaders, or faith-based organisations, can help provide appropriate holistic and individualised care. This type of supportive network can facilitate open discussion of religious and spiritual issues in relation both to living with HIV and its treatment. Ultimately, this will help ensure that women with HIV have the best possible quality of life and the infection is managed effectively.

About Women for Positive Action

Women for Positive Action is a global initiative established in response to the need to address specific concerns of women living and working with HIV. The group is made up of healthcare professionals, women living with HIV, and community group representatives from across Canada, Europe and Latin America.

Educational resources in relation to faith and beliefs and other issues affecting women living with HIV are provided at www.womenforpositiveaction.org.

Women for Positive Action is supported by a grant from Abbott.

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YOU WANT
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BODY CHANGES

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