



george house trust
still life with HIV



SEMINAR REPORT

WOMEN, HIV & MICROBICIDES

GEORGE HOUSE TRUST & UK AFRICAN MICROBICIDES WORKING GROUP

George House Trust, Manchester

12 March 2007

About the seminar

Some background information

HIV organisations in the North West of England are actively supporting people living with HIV. This support extends to updating members with information on HIV prevention, treatment, support and care.

In celebration of International Women's Day, George House Trust (GHT) invited the UK African Microbicides Working Group to jointly organise a seminar on women, HIV and microbicides. The aim of the seminar was to bring together African people and other interested parties to learn about microbicides and to explore possibilities of campaigning for microbicides in the Northwest England. The seminar would not only focus on the potential impact of microbicides as tools that would prevent HIV infection, but it would also highlight the potential level of protection for people who are living with HIV.

About GHT & UK African Microbicides Working Group

GHT is a leading HIV organisation in the Northwest of England. It provides voluntary support services for people with HIV in the North West, together with support to carers, partners and children directly affected by HIV; challenges discrimination against people with HIV; and campaigns for the best quality of life for all people with HIV.

The UK African Microbicides Working Group is one of the two working groups of the UK Campaign for Microbicides. The Working Group consists of African HIV activists, people living with HIV, health promotion specialists, researchers and policy analysts. It is coordinated by the African HIV Policy Network (AHPN), which advocates for fair policies for African people living with HIV in the UK. The group aims to ensure that the public interest of African people in relation to microbicides are protected and the rights and interests of trial participants, users and communities are fully represented and respected.

On the day...

The seminar was facilitated by Georgina Caswell (AHPN) and Lynda Shentall (GHT). The presenters were Angelina Namiba (Positively Women), Lydia Zigomo (Interact Worldwide) and Mary Lima (Terrence Higgins Trust). GHT provided a comfortable venue for participants, who were predominantly African women living with HIV. It was encouraging to see a number of African men also attended. Other participants included HIV activists, community workers and students from the University of Manchester.

Introducing microbicides – Angelina Namiba

Following the viewing of the DVD 'In Women's Hands', Angelina Namiba introduced key issues regarding microbicides. Microbicides are products that could prevent the transmission of HIV and some other STIs. They are being formulated as gels or creams designed to be applied vaginally or rectally to prevent infection with HIV and other STIs. They could also take the form of a sponge, suppository or a vaginal ring. Some could be contraceptive and others non-contraceptive. Angelina also discussed how they would work and emphasised that they would not replace existing HIV prevention efforts. Condoms must continue to be made widely available. There are some individuals for whom condoms are not a viable option because they are unable to insist on their use, they are uncomfortable or impractical. In these cases, they would have the option of microbicides. Microbicides do not currently exist. They are being researched and developed. Several are being tested for safety and there are three in the last stage of clinical development, known as Phase III. The first generation of microbicides are being designed for women. However, scientists are also exploring the development of rectal microbicides that could be used by homosexually active men, as well as heterosexual couples who practice anal sex.

Q&A

Would a microbicide achieve all aspects (kill pathogens, strengthen the body's normal defences, prevent viral entry and prevent viral replication) at the same time, will it carry out the functions separately or will it involve different combinations?

Different combinations are currently being explored.

Would a microbicide cover the entire surface area within the vagina or does the microbicide work according to the amount of penetration that occurs?

It would cover the entire area.

If a microbicide is placed in a vagina as well as on the penis, would that give people double protection?

No. The first generation of microbicides are being tested for women for use in the vagina. Men are encouraged to use condoms.

Are people tested before they enrol on trials to test the products?

Yes. If a woman tests negative, then she can enrol in the trial. The first generation of microbicides are designed for women who are not living with HIV to prevent them from getting infected. If a woman tests positive, she cannot enrol onto the trial. However, scientists are ensuring that any microbicide that is found to be effective for women who are not HIV positive will not do any harm to women who are HIV positive.

If the microbicides are currently primarily being tested in African countries, how will we know the effectiveness of using them in other settings?

The first generation of microbicides are being designed to protect women who are most affected by HIV. The geographical areas with the greatest numbers of affected women are in sub-Saharan Africa. However, they are being tested at various stages in other countries too, including India, the United Kingdom and the United States.

A 40-60% effective microbicide seems too low for anybody. Might this be a violation of someone's human rights?

For many women, using a less effective microbicide is better than having nothing. Microbicides would be marketed along with condoms.

Although this might be a political or economic question, could you please expand a bit more on the governments and pharmaceutical company's reluctance to put money into research because it is more profitable to treat people already infected?

The trend has recently started changing. Pharmaceutical companies are now seeing future potential in investing in the research and development of microbicides. The International Partnership for Microbicides (IPM) have been doing some advocacy with pharmaceutical companies. The Global Campaign for Microbicides (GCM) is calling for pharmaceutical companies to do more and also to have a greater ethical conscience. More pharmaceutical companies are releasing products for investigation, including Gilead, Bristol-Myers Squibb and Tibotec. Civil society need to continue advocating so that pharmaceutical companies release even more products.

Why only investigate microbicides for Sexually Transmitted Infections? Why not investigate those that can be used to address other modes of transmission?

Scientists need proof of concept for first generation microbicides, and then they can investigate others.

Is age an issue? Would they be effective for women of all ages?

Yes, scientists are researching microbicides for women of all ages. They are currently being tested on women ages 16+ years.

How much will they cost and can they be bought over the counter?

The GCM and IPM have begun negotiations to ensure that when microbicides are available, they would cost the same as the male condom. They are advocating for microbicides to be affordable and accessible especially to communities that they are being tested on.

Has any research been done to investigate the impact this would have on men's behaviour change? Condom migration?

Trials in Uganda included simultaneously looking at sero-discordant couples, the change in male partner behaviour, and the acceptability of microbicides, including how it feels, taste etc. Some research has shown that there was not much change or condom migration. Work is ongoing, although there is perhaps need for greater social research.

It is important to address the use of microbicides anally, given that many people engage in anal sex for various reasons (to remain virgins, as a sexual preference or choice, and as a contraceptive method). Sexual practices, particularly amongst young people, are constantly evolving so it is important to carry out this social research.

Yes, studies are happening simultaneously into the development of microbicides for rectal use.

Ethics of trials and community preparedness - Lydia Zigomo

Lydia presented on the ethics of trials taking place around the world, particularly on the African continent. Thousands of women enrol onto trials, where they are given either a microbicide or a placebo to use. Data is collected to examine the effectiveness of the products. The trials pose several ethical questions including, should women be offered a placebo when an effective microbicide may actually save their lives and are women in developing countries being used as guinea pigs by Western scientists and researchers? Lydia highlighted that the trials need to take place in areas of high incidence and high prevalence in order to be able to monitor the effectiveness of microbicides as an intervention. Lydia also stated that while some may consider being involved in a trial a risk, it would also be risky not to be involved since the trials are the only way that scientists can test the effectiveness of a lifesaving product. A crucial aspect in these trials is informed consent: participants must be informed about their contribution to the trials throughout the trial in order to be able to confirm their participation, to ask questions and to shape the process of the trials. Linked to this is the issue of community preparedness. Communities where the trials are taking place must be informed about the trials so that when microbicides do exist, they are able to demand and use them.

Q&A

How do researchers prove that it is the microbicide that is being effective and not other external factors such as the economic situation?

The researchers take into account external factors. They know that people are influenced by their environments and they also know that people will not use microbicides in all sex acts all the time.

If a microbicide is being used at the same time as a condom, how do we assess whether it is the condom or the gel that is doing the protection? What if the effectiveness is due to all who have started insisting on condom use?

Researchers also take this into consideration. Furthermore, we know that people are not using condoms all the time, which is why we need microbicides.

Mothers and their daughters may share microbicides. How is their practical use within the household being monitored?

Scientists are exploring imaginative ways of testing how microbicides are being used. For example, some scientists are able to test whether they have been used in the vagina. However, participants are educated about how the trials work and what needs to happen in order to monitor the effectiveness of products.

How does pregnancy of those enrolled on the trials impact on the trials?

A pregnant woman cannot participate in the trials. Some women do become pregnant after they have enrolled on the trials, in which case, they cannot continue to participate because it is unclear what effect the microbicides may have on pregnant mothers and their unborn babies.

If a trial participant becomes positive, can they access ARVs? What happened to the women who seroconverted in the trials that closed recently?

The researchers ensure that women who seroconvert during the trials are linked up to healthcare systems, such as PEPFAR programmes, so that they have access to necessary HIV treatment.

Is the gel obvious? If a husband discovers or believes there are extra fluids in his partner's vagina, she may be forced to explain why this is the case. This defeats the point of it being a user-controlled tool that women can use without men knowing.

There are different amounts of the gel currently being tested in trials. Some women have reported that their partners like the fact that they were lubricated.

Do you think microbicides would work more effectively in situations where both couples know about it and are involved or does it not matter?

As well as carrying out scientific research, researchers are conducting social research. This has involved speaking to men about their experiences and views of the microbicides. Some research has shown that the trial participants adhered more to the criteria when their partners were involved and aware. Women will have to gauge their situation and decide how they want to use to address it in their relationships.

We are assuming that it is always men that are infecting women. Let's not make that big assumption.

Yes. It is about both men and women taking responsibility for their own sexual health and using the tools available to protect themselves.

We often talk about high-risk groups that are affected by HIV, such as sex workers and injecting drug users. Are the trials especially targeting people from high-risk groups?

No, the trials involve ordinary women who are at high risk by virtue of where they are, the fact that they live in places with a high prevalence and a high incidence of HIV.

If microbicides are currently being designed for HIV negative people, it means that women need to know they are negative before they use the microbicides. Will the campaign for access to microbicides involve a campaign on HIV testing?

The microbicides that are being developed may not be effective for HIV positive people but they will not cause any harm. HIV testing is being promoted by HIV organisations as part of the broader HIV prevention strategy.

Positive people also need microbicides because we want to be able to have relationships with negative people without infecting them. A microbicide for positive people should be prioritised at the same time as one for negative people. There are millions of women living with HIV. They should not have to wait for generations of products to be tested. Plus, it only seems fair to develop a product, which can be used by anyone.

It is even more complicated developing a product for HIV positive people because scientists need to take into account the impact the products would have on the effectiveness of HIV treatment. Simultaneous studies are being undertaken to investigate microbicides for use by HIV positive people.

Advocating for microbicides – Mary Lima

Mary stated that as advocates, we are aiming to accelerate the ethical development and global delivery of microbicides and other HIV prevention options. Our key messages include:

- Women have human rights, including the rights to protect themselves and their families, to get pregnant without fear of disease, to more contraceptive options, and to sexual pleasure and enjoyment;
- Women want microbicides and this involves funding from governments;
- The interests of women in trials need to be protected and prioritized.

There are tools available to help pass on information about microbicides to HIV activists, colleagues and friends. These include fact sheets about microbicides, an easy-to-understand leaflet and a DVD 'In Women's Hands'. Advocates can also organise a speaker event by inviting a member of the UK Campaign for Microbicides to present and respond to questions.

Q&A

Why is there need for a *campaign*? It seems logical that we need microbicides so why a *campaign*?

We do not have microbicides so we have to call on governments to fund the research and development of microbicides. Once they exist, we also have to ensure that the women who need them will have access to them.

Why the focus on money? Can we not raise the money within the charity sector?

It involves millions of pounds. It would be difficult for us to raise that money ourselves. Plus, governments have a responsibility to ensure good public health.

Is the DVD 'In Women's Hands' available on the Global Campaign website?

No, please contact the UK African Microbicides Working Group to borrow a copy of the DVD.

How are advocates trying to reach other groups outside the HIV sector, such as students and other politically active groups?

We are hoping that participants at the seminar would be advocates who will pass on messages to their communities and will join in demanding for the existence of microbicides. The Working Group has been holding seminars or giving presentations to interested parties. If participants know of a group that might be interested in advocacy for microbicides, they can let the Working Group follow it up. If there are any individuals that would like to take the advocacy further, please contact the Working Group to learn how you could become more involved.

How are advocates and the campaigns involving men in what will initially be a woman's product?

We are pleased to see that there are several men at this seminar. The Global and UK Campaign both have men on their steering committees. As mentioned earlier, men are involved in research about the acceptability of microbicides.

What can we do in Manchester to advocate for microbicides?

Participants demonstrated an enthusiasm for advocating for microbicides. They felt that it is important to keep information simple, as it could become technical relatively quickly. In order to advocate for greater funding for microbicides, all HIV organisations in the UK, including George House Trust, the Black Health Agency and Body Positive North West need to be involved in demanding microbicides. Refugee organisations, university students, family planning clinics and GUM clinics can also call for

microbicides. Several participants emphasised the effectiveness of word of mouth in raising awareness about microbicides while others mentioned using innovative approaches to engage advocates, including the media, talk shows, youth forums and lobbying Members of Parliament. Others felt that it is important to engage profit making companies and the government at all levels in making microbicides a reality. Some participants believe microbicides should be integrated into current HIV prevention messages, which are disseminated by HIV organisations. The importance of including men, as well as women, in advocacy efforts was highlighted by several participants. When microbicides do become available, it is important that information is disseminated in educational settings, faith settings, in women's groups and gay men's groups. Many felt it was important to organise further seminars and campaigning events, and possibly an advocacy group, in order to raise the issue of women's vulnerability to HIV and to discuss new scientific initiatives.

Next steps for GHT & the UK African Microbicides Working Group

The UK African Microbicides Working Group will take forward the issues raised at the seminar to the European Advisory Group and the GCM. The UK African Microbicides Working Group will liaise with George House Trust to identify key advocates to engage in further discussions. Additionally, participants at the seminar will be updated regularly about microbicides and about activities in the UK through GHT and the UK African Microbicides Working Group.

Further information

Contact Lynda Shentall lynda@ght.org.uk at George House Trust or Georgina Caswell georgina.caswell@ahpn.org at African HIV Policy Network for further information about campaigning for microbicides in the UK.

This report was written by Angelina Namiba, Georgina Caswell, Lydia Zigomo, Lynda Shentall and Mary Lima.

We are grateful to the Global Campaign for Microbicides www.global-campaign.org for funding the event and to Arwa Meijer and Rebekah Webb at the European Secretariat for their technical support and assistance.