

Our Sexuality, Our Stories: experiences of HIV-positive women in Kenya

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In July 2006, a group of HIV-positive Kenyan women from Women Fighting AIDS in Kenya (WOFAK), Society for Orphans Against AIDS (SOAN), and Kibera Community Self-Help Programme (KICOSHEP) began meeting at the Trust for Indigenous Culture and Health (TICAH) in Nairobi, Kenya to talk about their needs.¹ Soon, they realized that the issue of sexuality was central to their lives and that they yearned to learn more about it and discuss it with other women. This initiative has now evolved into the establishment of collectives of women and men who are meeting regularly to talk about sex. Two women involved in these collectives share their experiences in this article.

We come from all walks of life. Some of us work in the HIV and AIDS field. We began by listing all our needs, everything we need to be healthy and happy. Then we talked about which of the needs were the most difficult to meet and which ones we had already met. Again and again, our conversation focused on our intimate lives – the ways in which our sexual health, beliefs and behaviours were central not only to our health, but also other spheres of our lives. We talked about how our HIV-positive status has affected our feelings about our own sexuality. We also shared stories about disclosure. From these early meetings, we decided to put together our experiences and our questions concerning sex and sexuality. We realized that the process of safe sharing we were engaged in was not common among most Kenyan women. Much of what we talked about was not directly linked to our HIV-positive status; we believe that all women have a desire to know more about sex and find ways to talk about it safely with their partners.

We enjoyed our meetings and learned from sharing our experiences. We felt less alone and afraid, and we learned that our feelings about pleasure and desire were not unusual. We could see patterns and we could also find ways in which our stories differed. We began to unravel things we needed to know about our health. This made us realize that other women and men could also benefit from the opportunity to talk about their sexual lives in a safe and

supportive environment. We have now set up ten women's collectives and three men's collectives, most of them building on existing positive support groups. Groups range from 12 to 17 members and they meet once or twice a month. We are discovering that both women and men feel vulnerable and uninformed concerning their sexual lives. While men tend to see sex as a right,² they very much yearn for better communication with their partners about their intimate lives, and feel they have inadequate knowledge about sexual health.

'Ask A Doctor'

Our meetings always begin by making a promise to one another that everything discussed in our meetings will be confidential. We write our stories and share them, we craft lists of questions and answers, we read about sex and the ways in which culture and family shape our behaviours and attitudes. We laugh. Sometimes we cry. We support one another.

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Every week, we ask ourselves questions we wish we could ask our doctors or counsellors. We call this 'Ask A Doctor'. Some of the questions we have asked include:

- My lover wants me to put things inside my vagina to make me drier for sex. Will this hurt me?
- My boyfriend does not like using condoms. He believes that if he withdraws before he ejaculates, he cannot infect me with HIV or any other infection because the virus and germs are only in the semen. Is this really true? Is this safer sex?
- What causes my genitals to change their smell? Does it mean I am sick?



Being bold about sex

- My boyfriend likes anal sex. Sometimes it is painful. What do I do about this? How do I make sure we stay clean? Can I get pregnant? Can I get infected with HIV? Am I still a virgin if I have only had anal sex? Will anal sex cause difficulties in childbirth?

We have put together a panel of physicians, psychologists, and sexual health experts to help us find the best answers to these questions. We bring their answers back to the groups so that we can learn from what the experts recommend or advise. After the meetings in which we discussed our best sexual experiences, one of our groups started to describe characteristics of a 'good lover' on a flipchart. It took us some time to focus on sexual behaviours rather than personality traits (because for many of us, both are important if we are to have satisfying sex). After completing the list, we wondered if it might have been different had it been written by men. And now that we have men's groups, we are able to see how our sexual experiences do differ. Women's groups submit questions to men and men's groups present questions to women, which are then discussed and shared back. Through this process, we see the ways in which we each feel vulnerable, misunderstood, or unsure. We also see the ways in which our upbringing has shaped a different set of expectations around our sexuality.

Honest and informed discussions

But, aren't these women and men just having fun, you might ask? Is this really good programme work – writing about sexual experiences, talking about sex, putting questions to an imaginary doctor? What does this have to do with HIV, health and important social issues? We believe sex and sexuality have a lot to do with health and HIV. The fact that HIV is largely a sexually-transmitted infection has been known almost since the virus was identified. Nevertheless, because of the shame and silence preventing honest and informed discussions of sexual life – issues related to intimacy, gender power and relations, sexual pleasure and behaviours – sex has not featured as centrally as it should in our efforts to prevent new infections or cater for the needs of the infected.

There used to be a joke in reproductive health circles that the world seemed able to take on contraception as long as we did not talk

directly about sex! Unfortunately, the same could almost be said for the ways in which leaders, policymakers, and even activists have avoided sexual issues as they relate to HIV and AIDS. Anyone who has witnessed a condom demonstration in Kenya, where the wooden phallus is embarrassingly fetched from a drawer, the condom is solemnly opened, scrolled down the wooden replica, and quickly stuck back in a hidden place, does not have to be told how rare frank conversations about the links between our sexual lives and our efforts to respond to the epidemic are. They are rare, and as the epidemic in Africa becomes more of a woman's burden, this silence can be life-threatening.

Our stories of disclosure are a case in point. Women in particular have experienced rejection and violence when they have told their lovers they are HIV positive. Our groups are now starting to discuss their principles around disclosure. Some women think that if they try to negotiate condom use with a casual lover and he refuses, they feel it is fine to have unprotected sex. It is his responsibility to protect himself, not theirs. Others feel that this is never ethical – condoms must be used every time no matter what. These discussions compelled us to design posters which we intend to place at Kenya's VCT centres, where messages of abstinence now prevail. The posters have beautiful photographs and the following messages: *"Sex can be sweet and safe, it's not the person, it's the behaviour. Pendo or Baraka [Swahili names] did not give you AIDS; unsafe sex did. It takes two to play safe."* At the bottom of each poster, we will have tips for talking about sex and ensuring safety. In Kenya's climate, where HIV transmission has just been criminalized, we feel these messages are important. They recognize difficulties some women and men face if they feel unsupported as they try to negotiate safer sex.

Becoming more positively aware

Women are actors, we are not simply passive recipients of care or of knowledge about HIV and AIDS. Not only does the silence surrounding our sexuality affect our ability to protect our health, learn what we need to know, and claim our rights to safety, to pleasure, and to health, but so does the lack of thorough

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recognition of our responsibilities as care providers, our aspirations for our own care, and our wide experience with many modalities of treatment. This silence hinders us from contributing towards the development of policies and programmes that meet our comprehensive care needs. The experience women have gained about treatment, care for the affected, and burying our dead has tremendous practical value. It should be honoured, shared, and utilized. There are all too few opportunities for us women to share our care and treatment experiences, talk about our sexuality, let alone to use these discussions as a springboard to action.

For us, starting by talking *is* action. From this work, we intend to publish a book near the end of 2008. In it, we will include our experiences of losing our virginity, about our earliest sexual memories, about our best and worst sexual experiences, about our attempts – successful and not – to talk to our partners about our intimate lives, whether it be to tell them about our HIV status, our past, our fears, or our desires. We hope many women and men will want to read it, compare it with their own experiences, maybe set up groups themselves, and hopefully become more positively aware. We are now finalizing a facilitator's guide that would enable others to run these kinds of groups. So far, most of

our group members are HIV positive, but we believe that any group of women or men who trust one another and want to explore their sexuality through honest sharing, questioning and learning can do so. ■

1. This project is part of TICAH's 'Listening To Those Who Live It' project, which also includes the collection and publication of treatment experiences of HIV-positive people; the compilation of a herbal and nutritional guide for AIDS-affected families; the collection of death stories of those who die from AIDS-related illnesses, and artistic renderings of personal and collective experiences with the virus which recognize the therapeutic and policy power of creative arts.
2. Most of the men in both groups say they have raped a woman.

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Resources on sexuality education



Responding to what young people really want to know: Developing question-answer booklets on sexuality, HIV and AIDS with young people
GTZ HIV Practice Collection, 2006 (32 p.)

In this report, an experience is presented of developing sex education material that meets the needs of young people. The approach to develop question and answer booklets together with young people was developed in Tanzania and replicated in 17 countries in Africa and Asia. In each country, booklets have been developed based on their questions, written in their language and illustrated with images that appeal to them. This report presents the concept, method, results and lessons of this participative approach.

<http://www2.gtz.de/Dokumente/social-development/HIV-AIDS/en-question-answer-longversion-2006.pdf>

Sexuality, development and human rights

Expert Group on Development Issues, Department for International Development Cooperation, Ministry of Foreign Affairs, Sweden, 2006 (23 p.)

This paper from the Swedish Ministry of Foreign Affairs Expert Group on Development Issues calls for a new approach to sexuality and development. It argues that development policy has mainly concentrated on reproductive issues, or on the negative aspects of sexuality such as HIV infection and sexual violence. While these remain as significant challenges, it is also important to promote the right to sexual pleasure and fulfilment. There has been a tendency to ignore the connection between sexuality and poverty, and the paper argues that analysing this connection should be included in all policy and programmes tackling poverty. The paper recommends that policymakers build on the existing positive sexual rights framework and support people's right to sexual fulfilment, pleasure and well-being. As well as being an important right in itself, a sexual rights approach can also play an important role in promoting safer sex and reducing HIV transmission.

http://www.siyanda.org/docs/Correa_Jolly_EGDI.doc