



> This issue was produced in collaboration with the International Community of Women living with HIV/AIDS (ICW)

Women living with HIV

This issue of Exchange focuses on some pressing concerns of women living HIV and AIDS. An overview article written by guest editor Emma Bell of ICW (International Community of Women living with HIV/AIDS) together with her colleague Luisa Orza highlights some of these concerns. One of these is the balancing required by positive women to be able to manage the fears instilled by their positive status (of infecting one's loved ones, of being stigmatized and discriminated, of abandonment and violence, etc.) with the need for security and support and the desire for intimacy, love and children. Another concern is the lack of recognition of sexual and reproductive rights of women living HIV.

Some of the topics addressed in other articles in this issue are the much-discussed ABC approach to behaviour change and how that ignores complex issues like human needs and desires; the loss of property and land experienced by many women living with or affected by HIV and AIDS in India; and the approach of 'memory work' with mothers living with HIV and their children as developed by NACWOLA in Uganda some ten years ago.

We wish you pleasant reading and welcome your comments!

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Talking about love, sex and abstinence p.5



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Understanding positive women's realities

Despite growing recognition of the right of HIV-positive women to have healthy fulfilling sexual lives and reproductive choices, there remain myriad factors that make such rights only a dream for most of them. The reasons why women have sex and how they have it are influenced by various factors. It is widely known that violence, abandonment and blame on disclosure can be major problems for positive women, as are loss of land, livelihoods and children. The fear thus created can be an even more pervasive influence on how HIV-positive women live their sexual lives, including whether or not they will talk openly to their partners about their sexual health and needs.

Then there are the very human desires of love, trust and intimacy that make practising ABC (Abstinence, Being faithful, Condom use) not as easy or desirable as it sounds. These often go unrecognized in sexual health programmes, which tend to render sex sterile and pragmatic, rather than the expression of a complex mix of emotions, identity and intimacy which is what many people experience. *"Messages are abstract and sterile. We need to bring love back into the whole thing,"* an International Community of Women Living with HIV/AIDS (ICW) member from Namibia said at a session entitled Love, Sex and Abstinence at the International AIDS Conference (IAC) in Toronto held in August 2006.

For many women, an HIV diagnosis brings about significant changes in the way they enact their sexuality and how they feel

about sexual relationships. There are many reasons why HIV-positive women continue to have sex or not. Some choose abstinence while others feel that abstinence is thrust upon them. For many, a period of time is needed before they discover that sexual relationships can still be a necessary and healing part of their lives. At the session in Toronto an ICW member from Zimbabwe said: *"At the time of my diagnosis, I was in a good relationship with someone and although we had always had protected sex, I could no longer have sex with him. I felt dirty, disgusting, used, defiled and as far from sexy as humanly possible. The relationship ended and I spent the next four years celibate."* In some cases, HIV-positive women are able to use their status to negotiate safer sex. An ICW member from the United Kingdom, who was interviewed for the Silent Voices Project, said: *"I grew*



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to like condoms as there is no mess. And I felt as if I was in control and I wasn't prepared to let anybody have unsafe sex with me and throw it in my face So in some ways [HIV] has made me more assertive sexually."

Testing and rights

HIV and sexual and reproductive health programmes and policies generally fail to recognize the complexity of people's lives and the contexts in which their sexual and reproductive choices are situated. Take for example the drive to test as many people as possible for HIV. It is as though programmers equate knowing one's status with being able to act on that knowledge to improve one's well-being and that of one's partners and children. For many, this is not the case and services are not preparing people for the consequences of a positive result of an HIV test. In many cases, more women than men have access to voluntary counseling and testing (VCT) services, and though testing is usually framed as voluntary, the power imbalance existing between service providers and service users is often not taken into account, as the following testimony shows: *"When I was pregnant and went for antenatal care, I was told to have a blood test. They did not tell me what the test was for... I realized it was the AIDS test when I received the results."* (HIV-positive woman from Thailand)¹

Testing, along with other HIV services, has to be carried out and projected within a sexual rights framework which takes into account the context of women and men's daily realities. This should include their sexual realities and the appropriate support services to enable them to manage the

complexities of their post-diagnosis lives. Voluntary, informed, confidential testing is the cornerstone of ICW's work in protecting the rights of people living with HIV. An example of good practice in this arena is the Liverpool Voluntary Counselling and Testing Project in Kenya. This project addresses HIV from a perspective of gender-based violence and their training addresses gender inequalities within relationships. Counsellors

"Messages are abstract and sterile. We need to bring love back into the whole thing"

are trained to discuss women's experience of sexual power relations with clients, and to provide them with strategies for sexual negotiation and disclosure.

Understanding women's realities

Many HIV-positive women have sexual desires and sexual relationships, and services need to recognize this by providing them with contraceptive advice and services, sexual health check-ups and comprehensive advice on pre- and post-natal care for mother and child. There is need for service providers to understand that women's relationships impact on their ability to access treatment and other health services. Women's relationships also impact on their ability to act on advice given to them by service providers. Partner control can prevent women from accessing treatment and can also impede their ability to adhere to treatment regimes.

A woman from Tanzania said during a treatment mapping meeting organized by ICW: *"Most of us women living with HIV*



KIC



Royal Tropical Institute

Knowledge Infrastructure with and between Counterparts (KIC)

The KIC Project aims to boost dynamic knowledge sharing, collaborative learning and networking. It is an action-oriented, counterpart-driven pilot project, of which the first phase runs up to the end of 2006. Within the KIC Project Oxfam International and Exchange are collaborating to reinforce the learning on HIV/AIDS. Oxfam counterparts are invited to write articles about lessons learned related to these topics. The articles produced in the framework of

this collaboration are accompanied by an Oxfam logo in a green title box. The KIC Project also has an interactive website: www.oxfamkic.org, which enables Oxfam counterparts to share evidenced-based practices and documents, and to participate in online communities. For questions and comments about this edition or about the project, counterparts are encouraged to use the email address aids.kic@oxfamnovib.nl.

and who are using antiretrovirals (ARVs), we face a common problem that our husbands or partners tend to force us to give them our ARV dose while he has not tested for HIV and doesn't know his CD4 count. They do not want to go for testing while they show all HIV symptoms. Even if you refuse he will find out where you keep your medicine and steal them." Too often health care workers fail to recognize such pressures and label patients 'difficult to manage' or feel that their advice is ignored.

The right to have sex and children

More problematic is that health care workers, under pressure themselves, often make harsh judgments concerning HIV-positive women's rights to have sex and children and pressure them into taking certain courses of action. HIV-positive women with children are frequently considered deviant in some way – to have made a mistake. Health care workers, community members, the media, even HIV activists have labeled HIV-positive women who get pregnant as irresponsible. In fact ICW members have reported that access to ARVs can sometimes be offered only to those who are on contraceptives; women in Lesotho and Namibia have reported that access to ARVs has been tied to use of certain types of contraceptives – either

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hormonal injections or IUDs, in both cases doctor-controlled methods – because it is believed that as HIV-positive women they should not get pregnant.² This is not only a violation of their reproductive rights, but also places them in danger of re-infection and STIs as safer sex is often negotiated around contraceptive use.

Conversely, others have been denied contraceptives because it is believed that



ICW members coming together at the International AIDS Conference

they should not be having sex, as one HIV-positive woman from Thailand learnt: "I'd been to hospital and was told to have an IUD fitted. Then, when he checked my medical file and learned that I had HIV, they said 'Oh! This one was infected! The HIV-infected should not use it'."¹ Under such circumstances when HIV-positive women do fall pregnant, the emphasis is on saving the life of the child, neglecting the health of the 'undeserving' mother, which not only reverses the impact of prevention of mother to child transmission (PMTCT) but also denies women their right to health: "You are only important when you get pregnant, the baby becomes important; once you are separated you have to see to yourself."³

Balancing fear, security and desires

For many women, the balancing act requires them to manage the fear of abandonment from partners, fear of unwanted disclosure, fear of stigma, discrimination and violence, and fear of infecting infants and partners, with the need for security, support and the desire for intimacy, love and possibly

children. This can simply be too much to manage. "If you start using milk powder everyone will know you must be HIV positive. If you demand condom use, to stop repeated exposure, he will either hit you or just go off and have sex somewhere else and likely bring back other infections. So you just go on having unprotected sex and breast feeding even though you know you are doing exactly what they tell you you mustn't do..."³

Women are often left to research treatment options for themselves, and only those who have access to and confidence in the relevant information are successful in accessing the treatment they require, especially around reproductive choices. "[The Support group] is run by an NGO but if you get pregnant you have to go to the Federal AIDS Centre and they try to discourage you from having a child... It is very much frowned upon for a woman with HIV to have a child and a sex life... at the Federal AIDS Centre you are told to have an abortion. You can get information [about PMTCT] from the support group...

*but the doctors will convince you that it's not effective... If a woman does decide and insists on having a child they will help."*⁴

Towards more meaningful involvement

The complexities of the lives and circumstances of women living with HIV require their involvement in policy and programme design in order to effectively address these issues. More often than not, people living with HIV, and especially women, are still excluded from decision making fora, and when they are invited to participate, it is still someone else who has set the agenda. Such situations can be intimidating and overwhelming, and many ICW members report having felt sidelined once they have delivered a personal testimony on how they became infected. Yet these same policy makers claim to embrace the principle of Greater Involvement of People living with HIV and AIDS (GIPA). ICW actually prefers the term MIPA: Meaningful Involvement of People living with HIV and AIDS – including HIV-positive women – in all decision making that affects their lives. This means that policy makers need to ensure that such inclusiveness is developed. At present the onus still lies with the people who are living with HIV to push for their own inclusion.

Challenging stereotypes and inequalities

Examples of good practice in the areas described here do not abound, but they do exist. An example is the MTCT Plus Initiative

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in clinics in South Africa operated by MSF (Médecins Sans Frontières) in Cape Town. The programme involves HIV-positive women who have already been through the programme to support new mothers and families entering the scheme. The initiative provides long-term follow-up care for HIV-positive mothers, their children and their partners, fostering caring and healthy families in which the responsibility for childbearing and rearing is shared.

Programmes need to be non-stigmatizing and reflect the realities people living with HIV already face, rather than burdening them with a whole host of new ones. They need to challenge existing stereotypes and inequalities and if possible, be led by

women living with HIV. If not, then they need to involve HIV-positive women at every level – from planning and consultation to development of the budget, implementation, training, monitoring and evaluation.

ICW's vision is a world where women have the right to make choices concerning their reproductive and sexual lives. This cannot be achieved through top-down calls for abstinence or fidelity or tokenistic strategically placed boxes of condoms, but by changing the conditions of all women's lives. It also involves challenging the existing power relations between men and women and inequalities that influence these women's reproductive and sexual lives. Only then will HIV-positive women realize their sexual and reproductive rights. ■

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Meaningful involvement? Part of a poster developed by ICW to show the different types of involving women living with HIV: from manipulation and tokenism to real participation.
Download poster: www.icw.org/icw/files/icw_poster.jpg

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