

Women's Realities... Testing rights for pregnant women?

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In 2007, the WHO published guidelines on provider initiated ('opt-out') testing in an effort to increase the number of people being tested for HIV. Gender and human rights advocates have raised concerns about 'opt-out' testing opening up potential for human rights to be compromised or violated. Policy-makers have dismissed these concerns as based on anecdote, and have asked for evidence to support these arguments.

Today in the Women's Networking Zone of the Global Village at AIDS2010, the results of a research project supported by the Open Society Institute's Public Health Watch were announced by three South African-based human rights organisations: AIDS Legal Network, Just Associates and Justice and Women (JAW). The results evidence how provider initiated HIV testing in the context of pregnancy has become another form of violence against women.

'Opt-out' testing assumes an equal relationship of power between client and service provider. Yet, women in the study were relatively young. Many of them had grown up in families disrupted at an early age by HIV. They had been absorbed into extended family systems, had often given up on education and were frequently unemployed. Sexual relationships with men were often a route to survival, making negotiation of condom use difficult. For many, pregnancy was their first point of entry to health services, and their life circumstances often combined to render them especially vulnerable to compromises, abuses or human rights violations in the healthcare setting.

Pregnancy was often an additional, unwanted burden to already complicated lives. Many women had conflicting feelings about the pregnancy, but there was no room

in clinics to discuss this. They were immediately pushed into having an HIV test, thereby facing yet another potential burden that they didn't feel ready to face – that of an HIV positive test result.

Women's rights in the areas of counselling, consent and confidentiality were regularly compromised or violated. In overstretched services, rural clinics are often staffed primarily by nurses (with infrequent visits from doctors), who themselves are overburdened both at home and in their communities, as well as in the workplace, and may indeed be facing many of the problems their clients encounter, including being HIV positive themselves. Confidentiality is often compromised. Nurses and counsellors have queues of women to see, and often announce test results in front of others, or through open doors with teeming waiting rooms behind them.

Pregnant women receiving an HIV positive diagnosis commonly experience judgemental attitudes at the hands of health providers, including in the delivery room, where women living with HIV may be attended to only after HIV-negative women have been assisted, due to lack of medical implements and fear of infection if these are used first to assist positive women. For women choosing not to test, punitive measures were reported, including refusal of care. Such is the dehumanisation of the health systems that women frequently choose not to go back to health service providers until they are really sick. Conversely, the smallest measure of kindness was received with incredible gratitude.

Provider initiated testing also needs to be seen in the context of power relationships the women experience in their households and

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families. After giving birth, women may not feel able to disclose their status to their partner and his extended family. To do so would compromise their personal security and livelihood. Lack of power to negotiate condom use continues after the birth of the first child. With a second pregnancy, women report being treated with increasing judgement and brutality by exasperated service providers sometimes resulting in unwanted sterilisations, while in the delivery room. Consent given under this kind of duress is a clear violation of rights and amounts to forced sterilisation, an issue which is gaining traction in international human rights advocacy in Southern Africa, and a form of institutional violence against women.

The President of South Africa has committed to huge scale-up of HIV testing, setting a target of having 15 million people tested for HIV in the coming year. Most of these will be women, many of them pregnant. Health services cannot hope to cope with such numbers while protecting the rights of counselling, consent and confidentiality of those most in need of it. Counselling is often replaced with information provision and pressure to test. There is little understanding of readiness to test, and research is needed on this.

There is a clear need to increase testing, but human rights must be protected. To ensure this, there is a need for further analysis of gender and power relations in health systems in the context of pregnancy and in the context of HIV testing, as well as a review of current testing models of practice to encourage both women and men to test outside of the context of pregnancy.

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