

VIEWS & REVIEWS

PERSONAL VIEW

WHO's poor consultation with patients on HIV guidance has denied women choice in drug treatment

Criticisms abound among HIV activists about World Health Organization guidelines, which include antiretroviral treatment for all children aged under 5 with HIV. Why does WHO not consult properly with those affected by the disease, asks **Alice Welbourn**

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I write as someone who has spent 12 of the 22 years since my HIV diagnosis trying to uphold women's rights at a global level and on behalf of many international colleagues who sense a profound disquiet about recently launched treatment guidelines from WHO's HIV Department.¹ These guidelines promote lifelong treatment with antiretroviral drugs for all of us with HIV with a CD4 count below 500; all pregnant or breastfeeding women with HIV; and all children with HIV under 5 years. The guidelines promote integration with other services (including for antenatal care and tuberculosis), decentralisation, and task shifting (where prescriptions of antiretrovirals are initiated and maintained by trained non-physician health workers and dispensed by community health workers). All these have merits but also present huge challenges.¹

The concerns about promoting lifelong treatment for women (called "option B+") and children are echoed by some clinicians in Africa, Europe, and the United States.^{2 3 4} We all believe firmly in antiretrovirals. Without them we would be long dead, as many of our former sister activists are. Yet we also believe firmly that treatment is a choice not a compulsion.

Option B+ is a euphemism for choice when women have none. It is only an option for health ministers and not for the women supposed to be in their care. Countries adopting option B+ require all pregnant women to be tested for HIV and to start antiretrovirals for life straight away if they test positive, irrespective of their health.

The paediatric guidelines require that these women also ensure that all their children under 5 with HIV also start treatment for life. These two policies are part of UNAIDS' Global Plan towards the Elimination of New HIV Infections Among Children by 2015 and Keeping their Mothers Alive, a document that never mentions the words "voluntary," "confidential," or "informed consent," thus granting countries carte blanche to ignore fundamental human rights in pursuit of UN millennium development goals.^{5 6}

The UNAIDS strapline "Getting to zero" and its first priority, "Zero new HIV infections" is most easily translated into numbers by putting all pregnant and breastfeeding women on treatment, as Gottfried Hirnschall, director of the WHO HIV Department, explains, "through the benefit of reducing new infections."⁷ So this ramping up of treatment is clearly viewed primarily as a mechanism to prevent HIV rather than a means to keep women healthy in their own right. This is a slippery ethical slope. Meanwhile, 6.8 million people who currently need treatment cannot access it.³

As for children, no one is more committed to keeping children alive and well than their mothers.⁶ Unicef acknowledges the challenge in having to keep drugs refrigerated, their dreadful taste, and long term concerns about bone toxicity in teenagers.⁸ Yet this policy too is forging ahead, without consultation with the recognised networks of women who have HIV in the most affected regions.

Perhaps most disconcerting is WHO's apparent disregard for its own publications on the prevalence of violence against women and its role in increasing vulnerability to HIV, and how positive tests for HIV can cause or exacerbate violence against women, in healthcare settings and at home.⁹

WHO also recognises that pregnancy itself is already a time of heightened risk of violence for many women—before HIV detected during pregnancy is thrown into the equation.

In Namibia women with HIV have been coerced into sterilisation by doctors during labour. In Uganda women throw away their drugs on the way home for fear of the consequences of their being discovered.¹⁰ In Malawi women are abused by their partners for accessing antiretrovirals, and adherence to treatment is the first casualty of violence against women at home.¹¹ Many similar reports exist worldwide of the violence women with HIV experience, in health institutions and communities alike.¹²

Unless safety and dignity can be guaranteed in health institutions, women will avoid attending them, giving birth in them, or taking their children to them. Unless communities can

also be supported to become safe, adherence to treatment for women and their children will also be difficult, and drug resistance will develop.

WHO's guidelines were launched with minimal consultation with those most affected by these lifelong regimens: women with HIV. There is little recognition of the realities of poor rural settings, where food security, solar fridges, supply chains, and even HIV tests are distant dreams. The WHO HIV Department has acknowledged through correspondence that key ingredients are missing. Yet we maintain that there should be investment first in these criteria critical to sustainable development, to avoid wasting scarce resources and jeopardising people's chances to survive and thrive. History shows that healthcare staff often blame women with HIV for non-adherence, as if we intentionally seek to make their plans fail. Yet it is lack of infrastructure, lack of recognition of the challenges to successful implementation, and, perhaps most importantly, sustained disregard for our experiences and opinions that we find so questionable.

In sum, we remain dismayed that women with HIV were not widely consulted (especially considering our key role in safeguarding our children's health), that quantitative and qualitative analyses of the benefits and harms were not conducted, that piloting trials and realistic evaluations were not undertaken. Considerably more research was undertaken before "voluntary" medical male circumcision for HIV prevention was introduced—and the voluntary nature of this intervention continues to be emphasised.¹³ This situation is dangerous—and vulnerable to the criticism of a double standard.

Many clinicians in other disciplines are thankfully beginning to recognise that harnessing lived experience of a long term condition is just as valuable in its successful management as their own knowledge and can contribute greatly to psychosocial and economic cost efficiency. We hope and trust that the doctors in WHO's HIV Department will also soon develop this recognition.

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