

"Sometimes you feel like you have no choice but to bear with it all"

How much do we understand side-effects of ARVs on lives of women living with HIV?

A. Welbourn¹, L. Orza², S. Bewley³, E.T. Crone⁴, M. Vazquez⁵

¹Salamander Trust, London, United Kingdom, ²Salamander Trust / ATHENA Network, London, United Kingdom, ³Women's Health Academic Centre, Kings College London, United Kingdom, ⁴ATHENA Network, Seattle, United States, ⁵Salamander Trust, Barcelona, Spain



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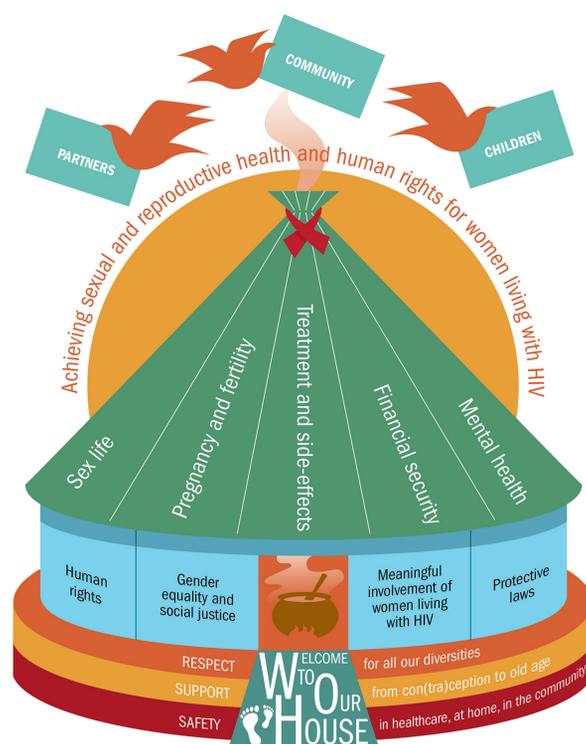
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Background

WHO promotes far-reaching ARV coverage for prevention and treatment of HIV¹. However, to date, little^{2,3} is known about long-term adherence to ARVs and their effects in relation to physical, sexual, psychological or other dimensions of women's lives. The aim of this study was to examine ARV side-effects in women living with HIV.

Methods

A global online values and preferences survey was commissioned by WHO⁴. It was informed and shaped by a Global Reference Group of 14 women living with HIV and included an optional section on HIV treatment and side-effects. The survey contained a mix of closed questions (quantitative analysis) and free text responses (qualitative analysis^{5,6}).



"Building a safe house on firm ground"
image from the original survey report for WHO Department of Reproductive Health and Research

Results

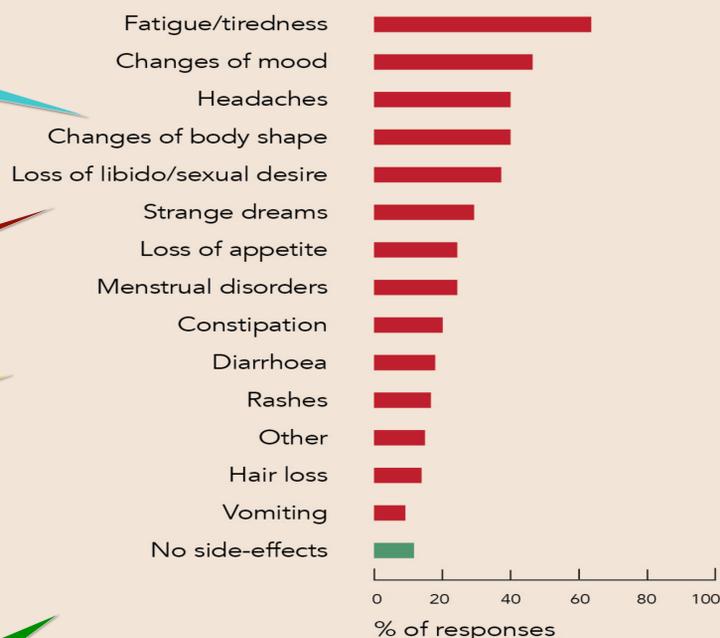
832 women aged 15-72 from 94 countries took part in the online survey, and 434 (52%) responded to the optional treatment section. Of the 381 (88%) who were on treatment, only 52 (11.9%) reported no side-effects.

The mean number of ARV side-effects was four including fatigue (64.8%), mood changes (47.1%), headaches (40.6%), body dysmorphia (40.2%), loss of libido (37.5%), strange dreams (29.9%), and menstrual disorders (24.1%). These affected women's ability to enjoy a healthy and satisfying sex life, to work, and to enjoy social activities. Singly or collectively, side-effects strained relationships⁷, led to financial insecurity or poverty, and contributed to mental ill-health⁸, including loneliness, isolation, stress, anxiety, and depression.

Respondents reported limited information about side-effects, especially at treatment initiation, and felt that health providers did not take side-effects seriously.

Regarding an undetectable viral load, some women expressed potential or actual reduced ability to negotiate condom use, to protect against STIs or pregnancy.

Figure 14: HIV treatment side-effects



Global Reference Group, Core Team, WHO staff & others involved in the WHO-commissioned survey which gave these results : Jan 2015, Geneva

Conclusions

These findings have implications for treatment roll-out, warranting attention from policy makers and providers alike. Urgent research is required to understand: to what extent is it possible to adhere to medication which reduces quality of life, especially if women start ARVs when feeling well; how women's concerns about STIs and unplanned pregnancy can be addressed in the context of 'treatment as prevention'; whether and how coercion and potential gender-based violence can be avoided in relation to ARV uptake; and the risks, benefits and safety of long-term medication use.

References

- 1 WHO, (2016). Consolidated Guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: 2nd edition. WHO. <http://who.int/hiv/pub/arv/arv-2016/en/>
- 2 Athena, AVAC, Salamander Trust, UN Women (2014). Key barriers to women's access to HIV treatment: Making 'Fast-Track' a reality http://salamandertrust.net/wp-content/uploads/2016/04/web_UNWomenetal_IAS-treatment_access-4pp.pdf
- 3 Athena, AVAC, Salamander Trust, UN Women (2015). UN Women et al Satellite Slides. <http://salamandertrust.net/wp-content/uploads/2016/04/UNWomenetalSatelliteSlidesFinal19July2015.pptx.pdf>
- 4 Orza, L., Welbourn, A., Bewley, S., Crone, E. and Vazquez, M. (2015). Building a safe house on firm ground: key findings from a global values and preferences survey regarding the sexual and reproductive health and human rights of women living with HIV. Salamander Trust. <http://salamandertrust.net/wp-content/uploads/2014/05/BuildingASafeHouseOnFirmGroundFINALreport190115.pdf>
- 5 Narasimhan, M., Orza, L., Welbourn, A., Bewley, S., Crone, T. and Vazquez, M. (2016). Sexual and reproductive health and human rights of women living with HIV: a global community survey. *Bulletin of the World Health Organization*, 94(4), pp.243-249. <http://www.who.int/bulletin/volumes/94/4/14-150912.pdf>
- 6 Namiba, A., Orza, L., Bewley, S., Crone, E., Vazquez, M. and Welbourn, A. (2016). Ethical, strategic and meaningful involvement of women living with HIV starts at the beginning. *Journal of Virus Eradication*, 2, pp.110-111. http://viruseradication.com/journal-details/Ethical_strategic_and_meaningful_involvement_of_women_living_with_HIV_starts_at_the_beginning/
- 7 Orza, L., Bewley, S., Chung, C., Crone, E., Nagadya, H., Vazquez, M. and Welbourn, A. (2015). "Violence. Enough already": findings from a global participatory survey among women living with HIV. *Journal of the International AIDS Society*, 18(Suppl 5). <http://www.jiasociety.org/index.php/jias/article/view/20285>
- 8 Orza, L., Bewley, S., Logie, C., Crone, E., Moroz, S., Strachan, S., Vazquez, M. and Welbourn, A. (2015). How does living with HIV impact on women's mental health? Voices from a global survey. *Journal of the International AIDS Society*, 18(Suppl 5). <http://www.jiasociety.org/index.php/jias/article/view/20289>