KEY BARRIERS TO WOMEN'S ACCESS TO HIV TREATMENT: A GLOBAL REVIEW

BACKGROUND

AN OVERDUE EFFORT

In collaboration with UN Women, ATHENA Network, AVAC and Salamander Trust undertook a global multistage review of the status of access to antiretroviral therapy (ART) for women living with HIV.[1] Since the beginning of the HIV epidemic, this is the first ever peer-led global study of care and treatment access for women living with HIV of this scale. It is well overdue.

The global review comes at a critical juncture in the epidemic where there is an increased focus being placed on strategic investments in health guided by specific national and regional epidemiological contexts. In late 2015, the World Health Organization updated its guidelines on ART for prevention and treatment, recommending immediate offer of ART to all people living with HIV, regardless of CD4 count or clinical stage.[2] ART is positioned as central to the Sustainable Development Goal of ending AIDS by 2030. Pursuit of this goal is happening in the context of a constrained resource envelope for HIV and health overall.

To achieve current global goals, it is critical to understand and address key barriers to and facilitators of women's access to HIV treatment.

In this context, it is essential to understand the barriers to and facilitators of women's access to ART, so that individual choices about when and whether to start, and continue with, treatment translate into positive mental and physical health outcomes for the woman, as well as benefiting public health.

In this review, socio-structural factors[3] were explored at macro-, meso- and micro-levels in order to better understand the experiences women living with HIV have of treatment availability and their decision-making around uptake, and to assess how treatment programmes affect their lives. Removing barriers and changing policies and programmes to align with best practices will contribute substantially to efforts for the achievement of global goals such as the '90-90-90' UNAIDS 'Fast-Track' targets.[4]

Conventional measurements of national HIV care and treatment programmes include coverage and access. Coverage measures are used to quantify the reach of ART at population level, with measures of long-term viral suppression and retention providing proxy indicators of programmatic effectiveness. But there are levels of effectiveness and programme components that are not included in these measures, compounded by gaps in the development of sex/gender-disaggregated coverage data. Improving definitions and filling gaps are both critical to understanding effectiveness in reaching women with services that are delivered in a human rights framework and provide benefit on an individual and population level.[5]

Access to ART is defined in terms of **availability**, **affordability**, **acceptability** and **quality**, with measurement methods including; cost, income, geographic location, cultural and social acceptability, availability of technology, expected health gain, performance of provider and adherence. Current accessibility measures are limited by their focus on health system service delivery and are unable to address the critical points of intersection within the gendered experiences of women. Social, cultural, economic and environmental factors all influence access to treatment for women (i.e. access to economic resources, decision-making power, division of labour in the household, discrimination and stigma, etc.).

This review aims to broaden the conventional understanding of indicators of access to understand women's perspectives and the underlying causes of barriers to access, particularly at household and community levels. The full report proposes new dimensions and measures of access for consideration and suggests strategies to address structural factors. It is available online at: https://genderandaids.unwomen.org/en/resources/2017/09/key-barriers-to-womens-access-to-hiv-treatment

THE REVIEW

A UNIQUE METHODOLOGY: WOMEN LED AND GOVERNED

The global review took as its starting point the major gaps regarding information on women's access to HIV care and treatment across the lifecycle, and in particular for adolescent girls and women not currently pregnant.

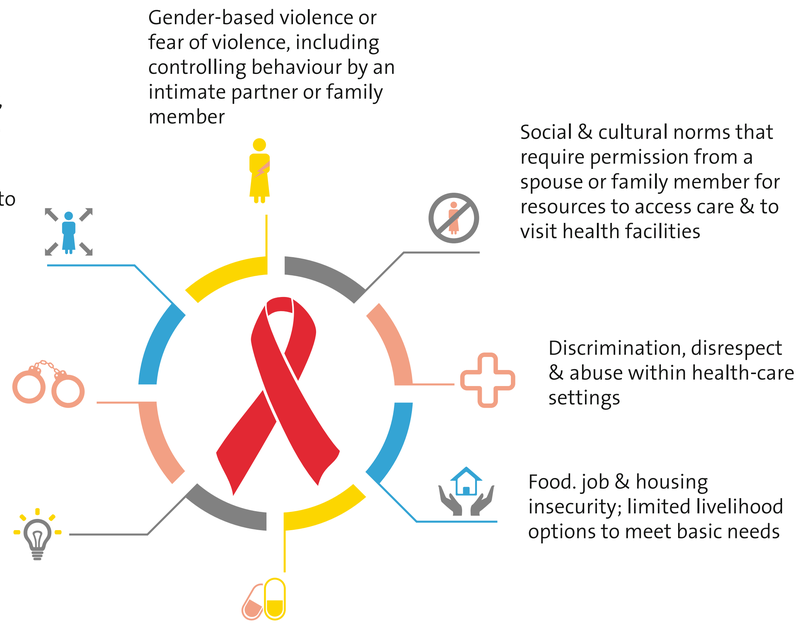
The three phases of the review included: 1) A literature review related to women's access to treatment and an unprecedented analysis of all available sex-disaggregated data from PEPFAR (United States President's Emergency Plan for AIDS Relief), Global Fund for AIDS, Tuberculosis and Malaria, UNAIDS and other sources; 2) Community dialogues via focus group discussions (FGDs) in Bolivia, Cameroon, Nepal and Tunisia of 175 women (175); consultations with all 14 Global Reference Group (GRG) members (14); one-to-one interviews with 8 of them and 1 additional woman (9); and an online discussion group with GRG members and 7 extra women (7). Thus, a total of 197 individual women were consulted in this phase; 3) Country case studies undertaken in Kenya, Uganda and Zimbabwe with in-depth focus groups (10, 10, 16), one-to-one interviews (0, 7, 10) and country-level policy scans to provide a fuller picture of women's access in specific contexts. Younger and older women were purposively sampled. Numbers of participants by country (women living with HIV, men living with HIV): Kenya (84, 20) Uganda (80, 19) Zimbabwe (118, 0). The International Community of Women Living with HIV East Africa led the case study work in Kenya and Uganda. Pangaea Zimbabwe AIDS Trust worked with members of the GRG to conduct case study work in Zimbabwe.

Few examples exist of HIV treatment access analyses in which women with HIV are placed at the center of design and implementation.

Women living with HIV led the design and implementation of the review as they are best positioned to frame and prioritize the issues and areas that should be interrogated as part of an effort to fill these gaps. A Global Reference Group (GRG) of women living with HIV was constituted to guide the project throughout all phases. The 14 GRG members represent 11 countries and a range of diverse identities and experiences. The GRG was included in the development and revision of parameters for the extensive literature review, framing of priority topics and questions for a discussion guide used for FGDs and one-to-one interviews led by GRG members and other women living with HIV. Some GRG members are also involved in the final phase of the project, in-depth country case studies that probe issues and concerns raised in the previous phases. This project is one of a limited set of investigations of women's perspectives of why they choose to initiate and remain on or discontinue treatment. The project did not engage women who had never accessed ART, one of several areas for additional investigation.

HIV/AIDS
BARRIERS FOR WOMEN TO CARE & TREATMENT

Global data shows that through the scale-up of HIV care and treatment, services now reach more women than ever before. HIV treatment is central to the global discourse on how to end the AIDS epidemic, yet it can only be effectively delivered in a rights-based context. A myriad of gender-related and structural barriers make staying on treatment a challenge. Below are illustrations of such barriers.



RECOMMENDATIONS:
A SIX POINT PLAN FOR ACTION

1. **HUMAN-RIGHTS:** Define, implement and evaluate access in a rights-based framework that encompasses availability, affordability, acceptability and quality of care, to address gender-related social and structural barriers. This must include rights-based, voluntary and informed choice, with real options for women, so they can decide if and when to start, and how long to stay on treatment.

2. **GENDER:** Engage in more analysis of treatment access barriers with gender at the centre, recognizing the intersectionality with other structural factors.

3. **DIVERSITY:** Fill the data gaps that exist across the treatment cascade for women in all their diversities. Investigate, innovate and implement the findings of research to fill the existing gaps related to barriers and facilitators of women's access to ART, including:

4. **MULTIPLE LEVELS:** Ensure that care and treatment packages include basic needs and account for gender-specific barriers at individual, household and community levels.

5. **GENDER-BASED COMMUNITY ENGAGEMENT:** Incorporate a gender analysis into expansion of support for community-based service delivery – a core component of UNAIDS' Fast Track goals.

6. **PEER-LED INVOLVEMENT:** Harness the power and leadership of peer-led and -governed analyses of treatment access as part of a participatory research, implementation and evaluation framework.

THE WAY FORWARD

It is our hope that this extensive review will catalyze change and dialogue at international and national levels in the rooms, clinics and communities where new and existing forms of ART are being offered. Women's voices are clear, consistent and urgent in their articulation of what must be done to create a woman-centered, rights-based approach to holistic health and wellbeing. It is also our hope that the methodology used to produce it will be adapted and expanded as a basis for continuing to monitor progress and map gaps in the global AIDS response.

1. Tenofovir-based pre-exposure prophylaxis (PrEP) using daily dosing of one or two antiretrovirals (ARVs) is being introduced as HIV prevention for HIV-negative men and women. This use is not considered in this review. Here, we only review access to ART by women who know they are living with HIV, in the context of treatment for their HIV.
2. http://who.int/hiv/pub/arv/arv-2016/en/
3. HIV-related structural factors are defined as barriers to, or facilitators of, an individual's HIV treatment behaviours; they may relate to economic, social, policy, organizational or other aspects of the environment. Sumartojo E., AIDS. 2000 Jun;14 Suppl 1:S3-10.
4. The UNAIDS Fast Track goals include the following targets: By 2020: 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy; 90% of all people receiving antiretroviral therapy will have viral suppression.
5. Leigh F. Johnson and Andrew Boulle. "How should access to antiretroviral treatment be measured?" Bulletin of the World Health Organization 2011;89:157-160.

20TH ICASA INTERNATIONAL CONFERENCE ON AIDS AND STIs IN AFRICA KIGALI 2019
AVAC Global Advocacy for HIV Prevention
ATHENA INITIATIVE
Salamander Trust ON THE RIGHT(S) TRACK
UN WOMEN