HHR
Health and Human Rights Journal

In Women's Eyes: Key Barriers to Women's Access to HIV Treatment and a Rights-Based Approach to their Sustained Well-Being

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Abstract

There is rightly a huge global effort to enable women living with HIV to have long productive lives, through treatment access. However, many women living with HIV experience violence against women (VAW), in both domestic and health care settings. The ways in which VAW might prevent treatment access and adherence for women has not to date been reviewed coherently at the global level, from

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Competing interests: Sophie Dilmitis, Liz Tremlett, Souhaila Bensaid, Calorine Kenkem, Gracia Violeta Ross, and Alice Welbourn are all women living with HIV.

Disclaimer: The views expressed here are of the authors and may not necessarily reflect those of UN Women.

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women's own perspectives. Meanwhile, funding for global health care, including HIV treatment, is shrinking. To optimize women's health and know how best to optimize facilitators and minimize barriers to access and adherence, especially in this shrinking funding context, we need to understand more about these issues from women's own perspectives. In response, we conducted a three-phase review: (1) a literature review (phase one); (2) focus group discussions and interviews with nearly 200 women living with HIV from 17 countries (phase two); and (3) three country case studies (phase three). The results presented here are based predominantly on women's own experiences and are coherent across all three phases. Recommendations are proposed regarding laws, policies, and programs which are rights-based, gendered, and embrace diversity, to maximize women's voluntary, informed, confidential, and safe access to and adherence to medication, and optimize their long-term sexual and reproductive health.

Introductory overview

Since 2016, the World Health Organization (WHO) has recommended life-long anti-retroviral therapy (ART) for all people with HIV, from their diagnosis date, regardless of CD4 count or clinical stage.[1] Efforts are needed for ensuring that all people living with HIV have access to life-saving medication that can turn HIV into a manageable chronic condition. ART is central to the Sustainable Development Goal (SDG) of ending AIDS by 2030 and to UNAIDS' "90-90-90" targets aimed at ensuring that, by 2020, 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV will access treatment; and 90% of all people receiving ART will achieve viral suppression.[2]

Meanwhile, women living with HIV continue to face widespread violence, both at home and in health care settings after their diagnosis.[3] Policy makers are increasingly aware that this violence may act as a barrier to treatment access and adherence.[4] To date, however, there has been scant formal evidence, from women's own perspectives, regarding if and how this violence affects women's ability to start and continue with treatment.[5]

Further, funding for HIV, and global health, is shrinking.[6] While there is continued focus on strategic investments in biomedical approaches, psychosocial programs and complementary community initiatives remain under-resourced.[7]

Thus, to maximize women's health in this highly constrained funding context, it would be beneficial for policy and program makers to understand more about facilitators and barriers to treatment access and adherence, for women living with HIV, *from women's own perspectives*. Indeed, as this review reveals, the very manner in which women are tested for HIV and start ART can be a barrier, if based on compulsion, instead of informed *choice* as a fundamental principle of human rights.[8]

We describe a global review of HIV treatment access which has explored facilitators and barriers, through the normative framework of the human right to health, as established by relevant United Nations treaties and commitments relating to women, the Committee on the Elimination of Discrimination Against Women (CEDAW Committee), the Global Commission on HIV and the Law, and the recent WHO woman-centered guideline on the sexual and reproductive health and human rights (SRHR) of women living with HIV.[9] ATHENA, AVAC, and Salamander Trust—three civil society organizations—undertook this review effort in three phases: a qualitative and quantitative literature review (phase one); focus group discussions and one to one interviews (phase two); and three country case studies (phase three). The review was commissioned and funded by UN Women.

This is the first peer-led global study to date that looks at HIV care and treatment access for women living with HIV.

Method

The review methodology was led and governed by women living with HIV, based on a relationship of trust between the review organizers and those women living with HIV who agreed to take part in the review.[10] Our approach recognizes that women living with HIV are best positioned to frame and prioritize the topics that need interrogation, to best understand facilitators and barriers to treatment access. Few HIV treatment access analyses exist where women living with HIV are central to design and implementation. A Global Reference Group (GRG) of 14 women living with HIV—representing 11 countries and a range of diverse identities and experiences—guided the project throughout all phases.

Phase one, the literature review, is an extensive and exhaustive review of all the qualitative evidence regarding facilitators and barriers in relation to ART access and adherence. A quantitative review then addressed women's access to HIV treatment, with an unprecedented analysis of all available sex-disaggregated data from PEPFAR (United States President's Emergency Plan for AIDS Relief), the Global Fund for AIDS, Tuberculosis and Malaria, UNAIDS, and other sources.[11] In phase two, community dialogues via focus group discussions (FGDs) were conducted with 175 women in Bolivia, Cameroon, Nepal, and Tunisia; together with consultations with all 14 GRG members; nine one-on-one interviews; and an online listserv discussion. In total, 197 individual women were consulted in this phase. In phase three, country case studies were undertaken in Kenya, Uganda, and Zimbabwe, and included in-depth focus groups, one-to-one interviews, country-level policy analyses, and an additional literature review to provide a fuller picture of women's access in specific contexts. Younger and older women were purposively sampled.

The whole process was guided by the Ethical Guidelines of the International Community of Women Living with HIV (ICW) for conducting research with women living with HIV, and WHO guidelines on research with women who have experienced violence.[12]

The participants described a wide range of barriers, including many, such as transport costs, child care issues, travel permissions and limited time, which are common to most women seeking health care. However, some of these key barriers were exacerbated by HIV and other barriers, specific to women living with HIV were also described. This paper addresses these barriers—and facilitators—that are specific to women living with HIV.

The dialogues, although relatively small in scope, explicitly report the perspectives of women living with HIV. The review's primary limitation was that it was designed as a snapshot with a modest budget: the findings could thus be limited in their generalizability. Nonetheless, there was marked similarity in the respondents' experiences across phases two and three. These also resonated with the studies led by women living with HIV, which were included in the literature review. This 'convergence of evidence' across continents and between the varied formats indicates widespread uniformity in the reported findings.[13]

In this paper, we analyze the phase two findings employing Gender at Work's change matrix, also used in the new ALIV[H]E Framework document (Figure 1).[14] This change matrix amplifies the normative framework offered by the socio-ecologic model, by providing a second analytical axis representing informal through formal life spheres.[15]

Findings

All three review phases reflected clear similarities in findings with uneven progress in women's HIV treatment access and adherence. There have been improvements in women's access to ART and treatment program scale-up, but women face complex experiences in both accessing and continuing to take treatment. In particular, violence from family, community members, and health care professionals act as barriers to accessing ART.

Findings from the treatment access literature

Our qualitative and quantitative literature review shows that HIV treatment is being scaled up as a global policy; that women's treatment access worldwide is higher than that of men, partially due to ARV provisions for pregnant women; and that women increasingly access treatment over much longer timeframes.[17] Formal research has primarily focused on the number of people receiving treatment rather than on the quality of their care or retention, and on treatment initiation alone, rather than on adherence.

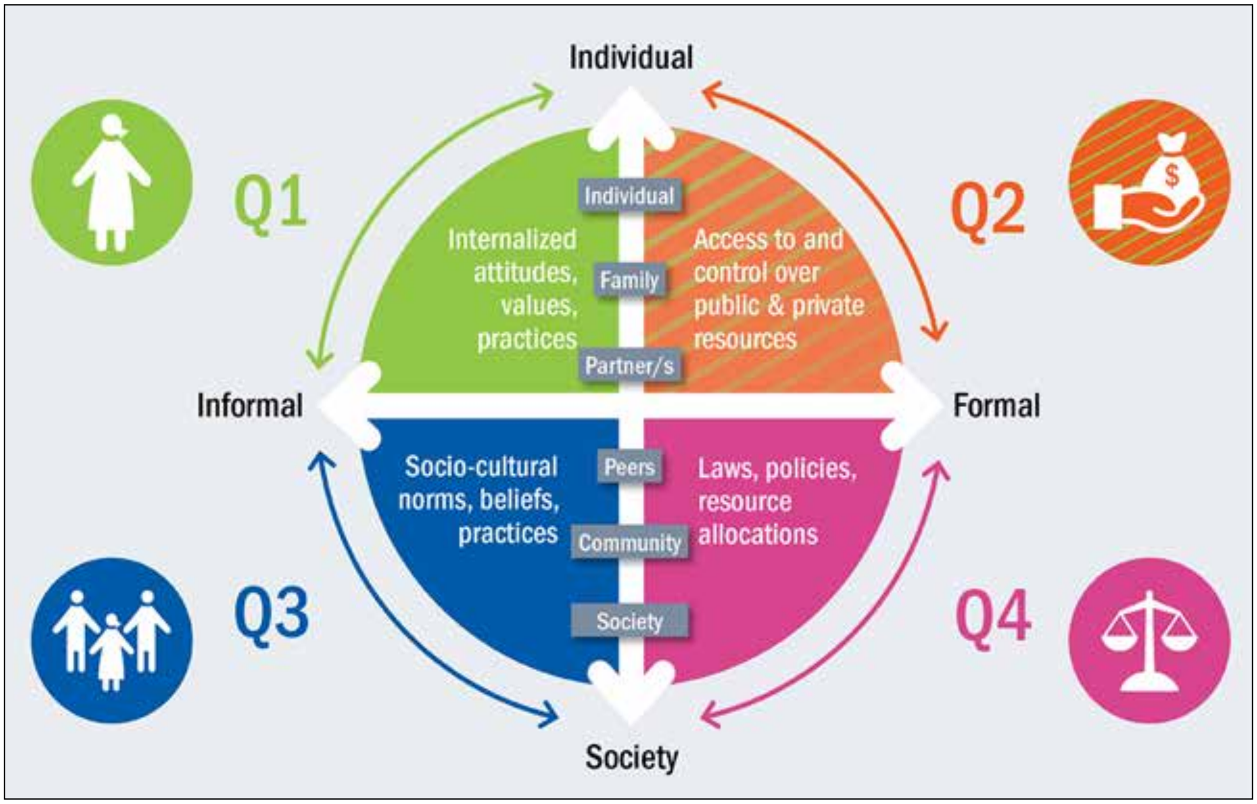
The precursor of the 2016 universal 'test and treat' guidelines was Option B+, which involved pregnant women living with HIV starting on treatment for life straight after diagnosis. Literature regarding Option B+ rollout in several countries is useful in ascertaining likely universal 'test and treat' treatment access patterns for women. While high numbers of women *initiating* Option B+ are reported, there have been high levels of 'loss to follow up' (retention in care), resulting in lower adherence rates.

Beyond pregnant women, treatment access and adherence research has limited sex-disaggregated data.

There is further confirmation that women from key populations continue to face particular barriers in accessing and benefiting from treatment. Meanwhile, the formal treatment literature lacks a focus on women living with HIV who are also members of key populations or at higher risk of acquiring HIV, such as women who inject drugs, women partners of men who have sex with men (MSM), displaced and migrant women, and girls and young women. Scant data exist from fragile and conflict-affected states.

Finally, formal quantitative evidence has, to date, placed limited focus on human rights violations, gender inequality, and discrimination in care: issues which may be acting as access barriers. Such major data gaps hamper current policy makers' awareness and understanding of, and ability to respond to, women's treatment access barriers.

Figure 1. Gender at Work's change matrix[16]



By contrast, some formal qualitative research and much grey literature strongly indicate that gender inequality, related to cultural, economic, and human rights issues, poses considerable barriers to women's choices regarding access and adherence to HIV care and treatment services. Women's decision-making on disclosure is shown to be significantly influenced by gender-based violence, including the fear of negative reactions, abandonment, and abuse. This can, in turn, limit their ability to access care and to both start and adhere to treatment. Many women may have lower retention rates over the long term than men.

The grey literature especially indicates that challenges to women of overcoming barriers at the household, family, and community levels are exacerbated by the discriminatory attitudes of health care staff and weak health systems, including poor treatment supplies, a lack of counseling, and long wait times. Negative health impacts such as side effects and having to take ART with food challenge women with HIV and inhibit the decision to access care and maintain treatment. Crucially, policy makers still lack understanding regarding women's own perspectives on what would help their sustained healthy prognosis.

Findings from community dialogues, consultations, and interviews with women

Barriers. Using the change matrix, we analyzed the phase two findings as follows, on the basis of four quadrants. Quadrant 1 is related to the individual and informal spheres; quadrant 2 refers to the individual and formal spheres; quadrant 3 addresses social-cultural norms, beliefs, and practices; and quadrant 4 relates to the formal, societal spheres.

Quadrant 1. This quadrant relates to the individual and informal spheres. It concerns individual women's values, attitudes, and practices. Women described experiencing internalized stigma due to their HIV status, resulting in depression, low self-esteem, and other mental health problems. These issues can also have an impact on their health-seeking behaviors, including HIV treatment access and adherence.[18]

Fear and experiences of violence led to HIV status non-disclosure, which respondents linked to higher anxiety rates, missing services, and lower adherence. Lack of privacy was also cited, with no safe space at home or work to take medications.

> *In this case, the woman goes to hospital secretly, if not she will miss the appointment if she can't justify the reason to go out the day that she is supposed to collect medicine.* (FGD, Cameroon)

HIV treatment side effects were also consistently cited as a barrier to long-term adherence. Side effects take various forms.[19] Some, especially body shape changes, had psychological repercussions, particularly around gendered norms regarding women's perceptions of their bodies and sexuality. One participant described how she no longer feels sexually attractive to her husband due to the ART side effects:

> *What affected me most is that I do not feel attractive to my husband. He does not say anything, but that is how I feel and that is why I get depressed.* (FGD, Bolivia)

Quadrant 2. This quadrant relates to the individual and formal spheres. It concerns access and control over public and private resources. Respondents referred to many financial and structural challenges in private and at institutional levels. First, we look at basic resource needs.

All FGD participants struggled to meet their basic needs due to poverty, including food security, nutrition, housing, school fees, and transport. While these are problems for many women, each served as a treatment access and adherence barrier for the respondents when coupled with their HIV status.

Regarding food security and nutrition, women reported prioritizing feeding children over themselves, making it difficult for women to access the healthy diets they need to take treatment effectively.

Some women lost their housing, post-diagnosis:

> *After the death of my husband started my journey with the suffering when his family repudiated me and my children, and they attacked and beat us then we were fired from the house. We are now living in*

> *the street homeless, depending on the righteousness and charity of some people and sometimes we lodge in the open without food or clothing.* (FGD, Tunisia)

Women's unequal power relationship is also reflected in lack of authority, affecting access to and control of resources, that would allow them to move freely. Participants also raised challenges in getting to the clinic due to high transport costs and distances. While ART is normally free, the associated services such as blood tests or transport are often not. This was another barrier, both to initial access and to continued adherence for many women, particularly those living in rural areas.

Once at the clinic, violence in health care settings, coupled with fear of violence, were also frequently cited as barriers for treatment access and adherence. We describe the institutional level violence here as "structural violence."[20] General human rights abuses, including violations of rights to privacy, confidentiality, and bodily integrity, were frequently cited, especially by Tunisian and Bolivian participants. These included health care providers disclosing female clients' HIV status to family members, other staff, and other clients; and refusing them and their children treatment. Additionally, violations of the rights to health and to protection from gender-based discrimination were experienced during and after labor and delivery, as well as through forced and coerced sterilization.

> *When I was pregnant, I went from hospital to hospital for fear of talking about my diagnosis. When my waters broke in the Dutch Hospital, I wet everything, I was 21 years old (cries), the nurse scolded me, they did not want to clean it up, they told me to clean it up, how could I clean it if I was sick? I was trembling with cold. They did not take care of my son. "You have to clean it," they said. I was in pain, but they didn't even give me a bed.* (FGD, Bolivia)

> *I feel bad for the pregnant women, they are young but already they have had their tubes tied, the doctors insist on tubal ligation sterilization when they do their caesareans, really they tell you "do not have children." It shouldn't be like that. Their duty is serving us.* (FGD, Bolivia)

Women also reported poor health care communications. This included limited time with, or effort by, health care providers to address women's concerns, or to deliver full information. They cited lack of or insufficient information regarding benefits and complications of treatment, what to take and when, or any information about drug interactions. These were reported as frequently ignored or dismissed by health care staff. Women cited lack of counseling, being unable to ask questions, side effects not being discussed, and being pressured to make quick decisions without adequate information. One woman living with HIV stated about her health care providers:

> *They ignore counseling about treatment.* (FGD, Nepal)

Women from marginalized groups especially (including women engaged in sex work, transgender women, women who inject drugs) or women partners of men who are at increased HIV risk, reported high levels of stigma and discrimination in health care settings and the community, that violated their rights to health and to protection from gender-based discrimination, and impeded their treatment access.

Lastly, workplace-based structural violence was also discussed. Participants frequently raised work termination, or being refused employment because of their HIV status, as a key barrier to treatment access and adherence. There are two distinct but closely connected issues here. Firstly, respondents described labor rights abuses (termination due to HIV status, being refused employment due to HIV status); secondly, because women are frequently employed in informal or unregulated sectors, including sex work, they lack employment rights and protections, including health insurance, often linked to employment.

Seeking treatment can also result in workplace colleagues finding out about one's status, and being sacked, which can damage economic security and the capacity to care for one's health.

More, this can lead to women experiencing discrimination and harassment (also described as "psychological violence") in the workplace without recourse, reflected by this Uganda sex worker experience: "When a client comes, they will shout out 'she is HIV positive! Don't take her, take me.'"[21] Such experiences create a barrier for sex workers who prefer not to risk being seen accessing HIV services, or carrying ART, for fear of raising suspicion among their colleagues regarding their HIV status.

Quadrant 3. This quadrant relates to the societal and informal spheres. It concerns socio-cultural norms, beliefs, and practices. Respondents throughout repeatedly described their experiences with violence. This included physical, sexual, and psychological/emotional violence at the intimate partner, family/community, and institutional levels.[22] Violence, both in the home and at work, coupled with fear of violence, were the most commonly cited barrier for women. While some violence was no doubt already present for women before their HIV diagnosis, it is clear from here as well as from other research that intimate partner violence (IPV) can both start and worsen upon diagnosis.[23]

> *I am living with HIV AIDS since 2005 and I have knew (sic) about my infection when I gave birth to my daughter and from that date began my journey with agony, pain, and oppression of my husband, who started threatening me to reveal the story of my infection to the neighbors.*
>
> *I am living with HIV/AIDS since 2004 and I was infected by my husband, he made my life with him a living hell every day I live in a state of terror and fear because of beatings and various kinds of insults and verbal abuse.* (FGD, Tunisia)

Women living with HIV from key affected populations reported additional marginalization and violence in the community.

> *Stigma is on 2 levels in the family. Often we do not take care of you for what you are, sex workers. Worse yet, you are HIV positive…* (FGD, Cameroon)

A US-based transgender woman described how fear of violence acts as a strong and immediate disincentive to accessing care and treatment:

> *If just simply leaving the house increases the chance of being assaulted or being killed vs. not taking medication and starting later, which one do you think they would choose?*

Through HIV-related violence at home or in the community, it is either physically or psychologically difficult for women to care for themselves by accessing treatment.

Conventional gender roles and responsibilities and resultant power inequalities also include women having to ask partners/husbands' or other relatives permission to do many things. Fear of rousing suspicion or disclosure of HIV status is also a related treatment access barrier and a manifestation of violence. Women reported how fear of home-based violence can lead to missing appointments or treatment:

> *I have to ask permission from my mother in law… She always used to say that I am going to die because of my status so no need to go. So most of time it was really hard to go [to the] hospital.* (FGD, Nepal)

Respondents cited gender-based caregiving responsibilities as another treatment barrier.

Quadrant 4. This quadrant relates to the formal, societal spheres. It concerns laws, policies, and resource allocations. Participants also raised many issues relating to this quadrant.

> *The legal environment in Uganda has created lots of fears. Already, people who were strong and accessing medication, they are now hiding away because of the fear of being seen and known to be HIV positive now that you can be criminalized for HIV transmission.* (Interview, Uganda)

Punitive laws, including criminalization of HIV non-disclosure, of exposure, or of transmission, exacerbate structural and community violence against women living with HIV and/or from key affected populations.[24] This then acts as a barrier to accessing or staying on treatment, as described in Uganda.

Legal status can also be a barrier to access and adherence for women who are migrant workers, seeking asylum, or who have moved to a country for other reasons, since migrants may be charged for services or incarcerated.[25]

Concerns were also raised about patient rights in the context of the implementation of national treatment policies. For example, Option B+ was not in fact offering an informed choice to women. Instead it was designed for health ministries to choose between Options A, B, or B+. There have also been concerns from physicians about the ethics of the Option B+ policy and, more recently, ART policy for pregnant women.[26]

> *I was really in favour of early treatment and to have this Option B+. But now my worry is: are we being given this as an option or is this being pushed on us with no option?* (Interview, Zimbabwe)

Resilience, agency, and positive strategies

Despite the treatment barriers, women also shared positive strategies, highlighting areas of resilience and agency.

Quadrant 1. Some women described three factors that provided strength, value and motivation to maintain their health post-diagnosis. These were: the ability to plan for or have children (especially in a supportive environment); their positions within families as mothers, partners and caregivers; and their roles as leaders within their communities.

Quadrant 2. Women named building trusting relationships with health care providers as important to treatment adherence.

Relating to quadrants one, two and three above, women in all discussions perceived that treatment access has improved over the last decade, for themselves and others around them, including access for women in marginalized contexts. They identified tailored women-specific treatment literacy as key to: becoming an informed advocate for one's own health; overcoming power dynamics and gender roles between patients and providers; and mobilizing communities for expanded treatment access.

Quadrant 3. Key among these was the reported importance of contact with other women living with HIV, through peer-led treatment literacy and support groups, networks, or other peer support services. Women described how their involvement in these groups was directly linked to accessing and remaining on ART over time. Supportive friends and family were also cited as important facilitators.

Quadrant 4. Participants did not identify any facilitators specifically related to this quadrant (laws, policies and resource allocations.) This perhaps unsurprising observation echoes a systematic review which observed: "the language of rights is used most often to describe their apparent neglect or violation rather than their promotion or inclusion in programming or services".[27]

Discussion of key findings

Given the existing literature on why patients in general decide whether or not to adhere to medication, and the importance of provider/client interactions to successful adherence, there is surprisingly little formal research exploring women's own perspectives of their voluntary choices around medical therapy initiation, continuation and adherence/retention, and the related barriers they face.[28]

By contrast, the women's discussions presented here dispel the dominant premise in the biomedical HIV treatment literature that women's treatment access is a straightforward process. This assumption describes women who do not access treatment immediately, and adhere to it, as 'lost to follow-up,' itself a loaded phrase. At best, there are calls for renewed efforts at community linkages to get women onto treatment, with no discussion about women's voluntary choices around if, why, or how women might be avoiding treatment.[29] At worst, women are subject to veiled or more open criticism for 'failing' to take up or adhere to treatment, with no exploration of why this may be so.

Thus, there is an unspoken—and often unrecognized—dissonance between what most of the formal HIV literature is assuming, with global promotion of '90-90-90' and 'fast-track,' and what barriers women actually face. This is of particular concern, not only regarding women's rights but also in light of increasing concern about potential development of drug-resistant HIV strains, through limited adherence.[30] If violence is affecting treatment, which in turn increases drug resistance, it is additionally critical to address women's experiences of violence.

It is thus vital to interrogate rigorously the socio-cultural and economic barriers to all women—both pregnant and non-pregnant—and especially to marginalized women. Then we may develop global policies that enable long-term, positive physical, psychological, and sexual health outcomes.

Treatment access barriers facing women in fragile and conflict situations are also severely under-researched. Ending AIDS involves listening to all women's experiences and translating this knowledge into solutions that leave no woman behind.

The nature of what constitutes the 'evidence base' also needs to change. Updating measures for treatment access and adherence to fill the data gaps are one key part of assessing effectiveness in reaching women with services and the impact of service provision at an individual and population level.[31] Recent research on evaluations of violence against women also confirms the importance of community-based participatory research to understand community perspectives, to build strong sustainable, rights-based policies and programs.[32] The new ALIV[H]E Framework (see Figure 1), also describes how the evidence base can be expanded, through holistic approaches to formal and participatory, quantitative, and qualitative research. This will ensure rights-based, peer-reviewed literature focused on women's expertise through their lived experiences. Harnessing the power and leadership of peer-led and -governed analyses of treatment access, such as this review, as part of a participatory research, implementation, and evaluation framework, can reveal invaluable new insights into what works for women.

The review further shows that while the 2016 Guidelines mean that women should increasingly take treatment over much longer timeframes, treatment access literature to date has focused on the numbers of people with HIV initiating treatment rather than on the quality of their care or length of retention in care.

We have seen how funding is shrinking, and yet HIV acquisition continues in many settings to outpace treatment availability or retention. To make best use of available funds, we need to maximize understanding of how to support women living with HIV, in all their diversities, in their voluntary choices regarding whether or not to initiate, continue, and adhere to treatment. This review has moved beyond the current bio-medical paradigm, to address this challenge through women's eyes.

This review maintains that the foundation of an enabling environment and the pursuit of solutions are found in women's insights and resilience. Women living with HIV know what has helped to improve or maintain their physical and/or mental health and wellbeing. The review has identified both gaps and sources of resilience, depth of knowledge, concrete, actionable recommendations, and a clear vision of what a rights-based, women-centered approach to the offer of ART provision must look like, moving forward.

Below are some key recommendations to donors, policy makers, and health care providers, for a human-rights-based treatment paradigm for long-term access for women living with HIV to care and treatment. These are offered as wayfinders for a wholescale revision of current policy and practice, to remove the structural, community-level, and intimate partner violence barriers that current policies have overlooked. This will lead to more effective treatment outcomes for women, and thus their dependents.

Human rights, gender equality, respect for diversity, multi-sectoral approaches, and relevant holistic research form the key concepts behind these recommendations. Once states, service providers (and employers) ensure that these key concepts are promoted, implemented, upheld, and that they can be held accountable to observing these—through laws, policies and programs—then there is more likelihood that women living with HIV will benefit. A process based on these concepts will enable treatment access—and adherence—to flourish, based on informed choice, safety, and a wider enabling environment.

Conclusions and recommendations

This extensive review reflects the lived realities and rights of women living with HIV globally. It confirms, through in-depth, qualitative analysis, what epidemiological figures and treatment program data suggest: that the AIDS response has improved over the past two decades but that much more needs to be done. Finally, evidence from this review demonstrates that while there has been immense, and often poorly conceived, focus on treatment access for pregnant women, there remains scant attention to, and significant treatment access barriers facing, women from key populations. Here, we offer recommendations for each quadrant in turn.

Quadrant 4 (laws, policies, resource allocations)

At this level, punitive laws which violate the rights of women living with HIV should be reformed and replaced with laws which are gender transformative, and which recognize and respect the rights of women living with HIV in all their diversities. Key normative frameworks, such as the UN conventions highlighted above, have been adopted in most countries. What is missing is how to hold states to account on these. Ensuring that all WHO and other global guidelines observe these international human rights protocols would be invaluable. Whilst further discussion of this is beyond the scope of this paper, there is urgent need for this. How laws and policies can most benefit women living with HIV appeared least well known to respondents. Literacy and advocacy initiatives around international laws, policies and guidelines and support for other accountability initiatives could help here.

Quadrant 2 (access to resources)

At this level, action is critical since this is where most women first learn of their HIV status and how this happens can determine their long-term prognosis.[33] Funders, policy makers, and practitioners should define, implement, and evaluate women's access to health services in a rights-based framework that encompasses availability, accessibility (including affordability), acceptability, and quality of care, to address gender-related social and structural barriers. This must include voluntary and informed choice, with real options for women in all their diversity, whether pregnant or not, so they can exercise their right to voluntary choices around medical therapy initiation, continuation and adherence/retention, which is primarily for their own intrinsic health. The use of treatment as prevention, while this can be an additional benefit, should not be considered the primary driver for women's treatment.[34]

How women living with HIV are treated by health care providers also has consequences for how they are treated by intimate partners, family members, in the community, and at work.[35] If health care providers do not treat women living with HIV with respect and violate women's rights to privacy, information about their HIV can quickly spread, with negative consequences for the women's overall health, safety, and psychosocial well-being.

Furthermore, many health staff seeing patients are women who are themselves living with HIV or are caring for family members with HIV. They fear that sharing this information would negatively affect their own employment. They too can often experience workplace-based treatment access barriers.[36]

Generally, negative attitudes and practices toward other people are usually based on lack of information and fear of the unknown.[37] It is therefore strategic to consider sector-wide HIV and gender-awareness training. This could ensure workplace care, treatment, and support for all health care staff affected by these issues, and could promote similar care and support by health workers for those seeking their services. This training, such as WHO's new Innov8 approach, should be career-long and health sector-wide, including for ancillary staff, embedded in continuing professional development.[38]

Further, health care providers should:

- implement a minimum package of services, with "know your rights" and treatment literacy programs available to all women on treatment in the community, and in health and other related settings (for example, with employers, police, and prison staff);[39]
- implement health center-based VAW prevention and reduction programs as core to all services;
- ensure that IPV mitigation programs are in place, such as the WHO clinical guidance for counselling and referral
- train service providers to deliver safe services for women, to:
- ensure the right to confidential, voluntary services at all times (to remove forced disclosure, which can lead to violence and/or clinic avoidance);
- understand gender and diversity issues and rights of all people in their care;
- improve providers' ability to address and minimize gender-specific HIV-related vulnerabilities in health care settings;
- ensure that providers are trained and resourced to offer ART non-judgmentally, supporting women's decision-making while providing adequate information and support on treatment uptake, adherence, and side-effects management;
- ensure that safe mechanisms exist for women to provide feedback on the quality and effectiveness of services, including on confidentiality, treatment literacy, respect, and safety;
- provide quality life-long, life-stage appropriate sexual and reproductive health care for all women living with HIV, including informed choice in the context of pregnancy and fertility desires; and
- provide clinic spaces, hours, and structures that are accessible to women in all their diversities (women with childcare and other family responsibilities during the day, those engaged in sex work, school age girls, etc.); and
- provide peer-support/counseling and mentoring schemes within health services.

Workplace policies related to Quadrant 2 that take place outside health care settings and promote care, respect, and support for women living with HIV, and ensure labor rights irrespective of HIV status, are also key. However, respondents discussed these issues less. This suggests the need for greater awareness around gender, HIV, and livelihood rights, across both formal and informal labor sectors.

L2 Quadrant 3 (community)

At this level, a rights-based gendered and diversity-based analysis should be incorporated into expansion of support for community-based service delivery, which is a core component of UNAIDS' Fast-Track goals. Community-level programs that transform gender norms, including gendered power inequalities, are also needed. These can reduce violence against women, promote grassroots understanding of HIV treatment access challenges and facilitators, and thereby create a respectful, supportive environment for people with HIV to look after themselves safely. Such support should:

- promote respect, support for, and inclusion of women in all their diversities in community-level responses through community-based programs;
- define gender-specific elements of community-based service delivery, while ensuring that, where possible, existing peer groups and individuals with relevant lived experience design, implement, and evaluate them;
- track all resources allocated to community-based groups to ensure that funding includes women-led organizations at grassroots level; and
- increase funding for networks of women living with HIV and peer support groups to provide

supportive services along the treatment and care continuum.

Quadrant 1 (internalized)

So much of women's experiences at this level depends on what happens in the other three quadrants. If women are surrounded by an enabling environment at home, in the community, the workplace, at health centers, and have their legal rights upheld, then they are likely to feel respected, cared for, safe and valued, able to deal with their HIV diagnosis, and supported to take their medication. This is essentially what is needed to uphold women's sexual and reproductive health and human rights. If women's own SRHR are upheld, which is their intrinsic right, they are then also far better placed to support their dependents.[40] Further, research reform is needed. Two practical steps are recommended in this regard to improve quantitative data collection rapidly. First, we recommend a rapid scan of types of data that are and are not routinely reported by treatment programs intended for women, such as 'test and treat' and sero-different couples' programs. Then we propose a coordinated plan to fill gaps in information, with attention to issues of choice, coercion, supportive services, and clinical and psychosocial outcomes for women. Second, we recommend a system for improved data collection at the national level that addresses the above issues, developed and implemented with coordination and cooperation from PEPFAR, the Global Fund to Fight AIDS, Tuberculosis and Malaria, UNAIDS, and other relevant entities. This system must ensure age- and sex-disaggregation of treatment data relating to women living with HIV in all their diversity, including information on access for pregnant and non-pregnant women.

It is our hope that this extensive review will catalyze change and dialogue at the international and national levels in board rooms, clinics, and communities in the context of expanded access to ART. Women's voices are clear, consistent, and urgent in their articulation of what must be done to create a women-centered, rights-based approach to maximize their holistic health and well-being, especially in the constrained funding climate. It is also our hope that the methodology described in this study will be adapted and expanded as a basis for continuing to monitor progress and map gaps in the global AIDS response.

Acknowledgments

UN Women commissioned and funded the review. Definate Nhamo of Pangea Zimbabwe AIDS Trust, Lillian Mworeko and Dorothy Namutamba of ICW East Africa contributed to the three country case studies. The review was shaped by a Global Reference Group of women living with HIV: Souhaila Bensaid, Cecilia Chung, Sophie Dilmitis, Pooja Kumwar, Rebecca Matheson, Svetlana Moroz, Suzette Moses-Burton, Hajjarah Nagadya, Daisy Nakato, Silvia Petretti, Violeta Ross, Sophie Strachan, Martha Tholanah, and L'Orangelis Thomas.

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