ADVOCACY BRIEF

Women, HIV and their Sexual and Reproductive Health Rights:

Are We Meeting WHO Guidelines?

A focus on contraceptive rights, inclusion, access, research in the context of HIV.

Some voices from the community.

APRIL 2020

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

BOX 1

A note on COVID-19

This brief is based on research carried out from December 2019 to February 2020 that complements a presentation to the 2020 Conference on Retroviruses and Opportunistic Infections (CROI). As the COVID-19 pandemic threatens to overwhelm all of us globally, the contents of this brief remain highly relevant.

We are yet to learn about the effects of COVID-19 on women living with HIV across the lifespan, including during pregnancy, as well as the effects on the baby in utero and postpartum. Each day, we learn of increased intimate partner violence facing women in communities in lockdown, of limited access to contraceptive goods and services, including condoms, and of reduced access to abortion. We anticipate concomitant increases in maternal morbidity and mortality. In addition, stock-outs of antiretrovirals and other medicines are likely to occur.

More than three decades of global community HIV activism – and growth of the women's rights movement – have taught us that there will be no ethical, effective, sustainable response to COVID-19 without women being at the centre of decision-making around their sexual and reproductive health and rights.

Introduction

Women's ability to decide when and if to have children is central to gender equality. Yet gender inequality and patriarchal norms underlie the challenges women face in accessing contraception. This and the importance of sexual and reproductive health and rights (SRHR) was illustrated in 2018, when a potential safety signal associating peri-conception use of the antiretroviral (ARV), dolutegravir (DTG), with neural tube defects was reported.

This cast a harsh spotlight on a chronic problem: access to and quality of SRHR and sexual and reproductive health (SRH) services, including contraceptives for women and girls vulnerable to or living with HIV. The resulting policy and access fallout, including national sex-based treatment restrictions for women and adolescent girls and the anxiety among women from exaggerated scare stories about how DTG would affect their infants, underscores the need for leadership by women living with HIV in the design, development, implementation, delivery and oversight of HIV research, policies and services.

This advocacy brief presents a snapshot of current views among women living with and vulnerable to HIV about their contraceptive priorities and experiences. A rapid review explored the extent to which these women felt that their SRHR are being upheld in relation to contraception and in the context of the WHO SRHR Guideline. The findings were presented at the Conference on Retroviruses and Opportunistic Infections (CROI) 2020 and are summarized here.

BOX 2

The World Health Organization (WHO) *Consolidated guideline on sexual and reproductive health and rights of women living with HIV* (2017[1]) recognizes that women living with HIV face unique challenges and human rights violations related to their sexuality and reproduction within their families and communities, as well as from the healthcare institutions where they seek care.

WHO calls for women-centred, accessible, acceptable and affordable services that are based on human rights and gender equality and for the meaningful involvement of women living with HIV in all programmes and policies that affect their lives. This guidance supports counselling on the full range of contraceptive options and healthy pregnancy planning for all women to support them in making voluntary choices. These services should be provided free from judgment, coercion or the need for parental or partner consent.

Methodology

From December 2019 to February 2020, the International Treatment Preparedness Coalition (ITPC), Salamander Trust, AfricAid and the International Community of Women Living with HIV/AIDS – East Africa (ICW-East Africa) consulted with 198 women in 28 countries through an online survey (ITPC), interviews (Salamander Trust) and focus group discussions (ICW East Africa and AfricAid). Salamander Trust also conducted a rapid literature review.

The interviews and focus groups included women from Kenya, Namibia, South Africa, South Sudan, Uganda, Zambia and Zimbabwe.

However, the survey was open to women in all countries, and responses were received from: Angola, Australia, Bangladesh, Brazil, Canada, Ecuador, Egypt, El Salvador, Germany, India, Indonesia, Kazakhstan, Kenya, Kyrgyzstan, Malawi, Namibia, Nepal, Netherlands, Nigeria, Rwanda, South Africa, South Sudan, Switzerland, Uganda, UK, USA, Zambia and Zimbabwe.

Participants in qualitative interviews in Uganda, April 2020.

Findings

The women who took part in the process had a diversity of experience, including living with HIV, sex work and drug use. They are women of different ages and marital status, with and without children, and from 28 countries. The women highlighted the following advocacy messages.

Rights

1 Women's rights to a full range of contraceptive options are limited by gender and cultural norms and practical considerations, such as the cost of transport to clinics, availability of different methods in clinics, whether nurses are trained to administer a particular method, restrictions based on age and marital status, a lack of support for women (and their organizations) who provide information and advice about SRHR to their peers, service provider views, and the priorities of donors and governments.

Women's contraceptive choices are also undermined by official agendas. These include deprioritization of contraceptive provision for reasons related to gender inequality, social norms or religious beliefs; emphasis on reducing onward transmission of HIV; rationing of limited contraceptive supplies by offering only a very reduced set of contraceptive options to women living with HIV; restrictions on abortion information and provision due to national legislation or global policies (such as the United States' Mexico City Policy); and targets for contraceptive distribution.

Like all women, those living with HIV want access to the full range of contraceptives, non-judgmental information and advice, including that provided by their peers, and choice so that they can plan and space their families: they want their full SRHR to be upheld.

SRH and HIV services are a human right (see Box 2), as is informed choice around contraception methods.

"Family planning through eliminating unintended pregnancies reduces maternal and newborn mortality rates and improves the health and well-being of women and their existing children."

—UNFPA[2]

Inclusion

2 Women in the community are working tirelessly to support other women and community members with their SRHR and all areas of their lives that underpin SRHR, but they receive little help for that work. There is a chronic lack of meaningful involvement of women living with HIV, especially young women, in the development of policies and programmes that impact their lives. They explained that sometimes only one person from

"the community" is included in meetings and is expected to represent all community voices. As a result, there is a lack of understanding among policymakers and even programmers about the issues women face.

Most national strategies and the donors who fund them still do not consider, acknowledge or include the perspectives and rights of women living with HIV, despite the WHO Guideline emphasizing the importance of their meaningful involvement and leadership in promoting SRHR. Further, respondents reported that there was no national or global accountability mechanism to hold governments or donors to account for adhering to the WHO Guideline and monitoring its impact.

"Who supports you? Nobody supports us; we are supported by our passion."

—INTERVIEWEE FROM SOUTHERN/EAST AFRICA

Access

3 Women living with HIV reported that both women and men had concerns about contraceptives, which included interactions with ARVs, impact on HIV progression, fertility, weight gain, sex drive, fear of injections, and enjoyment and comfort during sex. Women who were not living with HIV were concerned about whether contraceptives increased vulnerability to HIV and how they might impact on their sexual and reproductive health. Women described additional concerns about onward HIV transmission and needing to have the ability to plan a family. Yet service providers rarely have or take time to discuss different options that would enable women to use mixed methods. Vital peer support provided by women and their organizations goes unrecognized and unsupported.

Restrictions on women's contraceptive options and failure to supply appropriate counselling make it difficult for them to navigate and influence the different SRH service scenarios and pressures they face. For example, service providers offer no support or referral for condom negotiation skills, even though many women may fear – or experience – intimate partner violence if they suggest condoms. Conversely, sometimes service providers provide long-acting reversible contraceptives because they assume that no women can discuss contraceptives with sexual partners.

Sex workers described experiencing high levels of violence and difficulties when negotiating condom use with clients. They also described how some forms of contraceptive are incompatible with their working lives. However, the stigma they experience from service providers prevents them from returning for contraceptives or HIV post-exposure prophylaxis.

The experiences that respondents described are in sharp contrast to non-judgmental advice and counselling about a range of family planning options, which they see as vital for all women, including women living with HIV. This includes, for example, counsellors listening to and understanding the

situations that women face when negotiating contraceptive use.

"Most service providers have the mentality that if you are living with HIV, why would you want to start a family?"

—INTERVIEWEE FROM SOUTHERN/EAST AFRICA

Agency

4 Long-held institutional norms among healthcare professionals – that they are the "experts" who always know what is best for women – deny women agency in their sexual and reproductive health or well-being. Service providers were often judgmental towards women about: a) having HIV; b) wanting children; and c) wanting to have sex without having children. These institutional social norms are a barrier, preventing women and girls from accessing SRH services, or leading women and girls living with HIV to not disclose their HIV status to SRH service providers for fear of censure.

As a result, they do not get tailored support. These attitudes may underpin violence in health settings. In particular, women who use drugs, sex workers, young, unmarried women and adolescent girls experienced hurtful comments and coercion regarding SRH services or, more commonly, denial of SRH services. Furthermore, coerced and/or forced sterilization – particularly brutal forms of institutionalized violence against women – are still taking place in service settings.

Women reported a gap between their experiences and the friendly, safe, supportive and non-judgmental services they seek. Such services would ensure that all women are able to access SRHR without experiencing institutional discrimination and violence. Peer support provided by women and their organizations is often the only avenue for such non-judgmental care.

Tailored Services

5 Good, specialized services for women are rare. Although some independent services exist, many are affected by donors' priorities, religious restrictions and/or organizational strategy change. Government services could have much greater reach, but must tackle structural violence by healthcare staff, instil understanding among the staff of SRHR for all people, and address understaffing and shortages of contraception supplies (among other areas).

An additional issue that can undermine the SRHR of women living with HIV is that services are largely siloed, rather than linked or integrated. Linked services for HIV, SRH and violence against women should be the norm, but this is rare.

Lastly, women described how friendly providers and peer supporters who specialize in SRH for young women, sex workers or women who use drugs (for example) – and good relationships between them and peer mentors and/or peer supporters, with smooth referral pathways – can make all the difference to the quality of women's SRHR.

Specialized SRH services and independent organizations that offer tailored services, including peer support, could be really important, but they are still all too rare, particularly for women who experience institutional violence within public facilities, including young women living with HIV, sex workers and women who use drugs.

Research

6 The available contraceptive options reflect a top-down, biomedical-dominated space. Women living with HIV are rarely consulted about the contraceptive options they would like to see researched and developed. Generally, there is far too little research into women's priorities and far too little involvement of women in framing and participating in research.

Through their peer support work and community mobilizing, women explained the key role they play in ensuring that information on the latest research into HIV and family planning methods is provided to other women, and that women can discuss their concerns. Many of these concerns arise from previous research, policy and programming, which have not included women.

Respondents described how peer advice and support work is vital to improve rights-based contraceptive uptake. Yet the women who fill this role are rarely supported in doing so by funders or research institutions after their "field" research is complete, despite the possible wide-ranging implications of their results.

Women living with and vulnerable to HIV are yet to be recognized as essential stakeholders in the development and design of clinical trials and other relevant research, including as peer researchers, presenters and co-authors of research, as well as their role in ensuring that women are informed and can ask questions about research findings.

Limitations

This review was very rapid and conducted over a short period of time. Only women from East and Southern Africa were interviewed and included in focus groups. However, the survey was open to women worldwide. The focus groups included women aged 16-43 (South Africa), 17-24 (Zimbabwe) and 18-45 (Uganda). Girls younger than this were not included in the consultation, although women who work with girls were.

Numerous other identity groups of women (such as women with disabilities, migrant women, Indigenous women) were not consulted due to time constraints, and this should be addressed in the future.

Participants in the qualitative interview process in South Africa, April 2020.

Conclusion

What women reported in this rapid review process underscores the gap between the realities of their lived experiences and the WHO Consolidated guideline on sexual and reproductive health and rights of women living with HIV. The women who were consulted pointed out that they have repeatedly made all of the recommendations listed below, over decades, in many successive documents produced by women living with HIV. Women commented that if these recommendations had been taken into account in the first place, the problems created by the blanket ban on dolutegravir in many countries could have been averted.

Now that these recommendations are also stated clearly in the WHO Guideline, as well as the WHO/UNFPA 2018 A renewed Call to Action on SRHR-HIV linkages Advancing towards universal health coverage[3], respondents see this as the time for change. They trusted that their response to the survey, focus group discussions and in-depth interviews on this latest occasion might finally start to shift global research, policy, programmes and funding towards their much-stated priorities.

Rights

Support ethical, effective and sustainable contraceptive policies and programmes that uphold the SRHR of all women, including those living with and vulnerable to HIV. This involves ensuring that women have full access to non-judgmental information on contraception, choice over the full range of options – protection and care, respect and support for the choice a woman makes. It also requires instituting accountability mechanisms across funding, research, policy and programmatic streams in line with the WHO Guideline and Checklist, universal healthcare coverage and #LeaveNoOneBehind[4] to ensure that rights are respected.

Inclusion

Support the leadership and meaningful involvement of women living with and vulnerable to HIV in policy development and programme design, implement ation, monitoring, and evaluation to develop and support national strategies that include and reflect their own priorities and rights around HIV and SRHR. This includes funding women living with or vulnerable to HIV to maintain and increase the vital work they are already doing to support SRHR.

Access

Ensure that SRH and HIV services are integrated or linked, are fully stocked with a range of family planning methods and have well-trained staff and peer supporters with the time to explain the full range of options for women. Consider one-stop SRH centres, especially for young people, that provide safe and non-judgmental environments where information, advice and services are tailored to their needs and priorities.

Research

Meaningfully involve women and the organizations they lead in research from the beginning. Examples include – involvement in research steering committees and as researchers; consulting with women regarding their priorities for family planning; linking with women's organizations that can provide SRH services, support and advice to community members; and analysing, validating and disseminating research results. Research results must be shared promptly with women living with and vulnerable to HIV to support individual, community, local-, national-, regional- and global-level advocacy for their integration into policy and practice.

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Endnotes

1 The WHO Consolidated guideline on sexual and reproductive health and rights of women living with HIV (2017) https://apps.who.int/iris/bitstream/handle/10665/254885/9789241549998-eng.pdf?sequence=1

2 UNFPA website – https://www.unfpa.org/resources/contraceptives-save-lives

3 Call to Action: https://www.unfpa.org/press/renewed-call-action-srhr-hiv-linkages-advancing-towards-universal-health-coverage

4 https://leavenoonebehind2020.org/

Participants in the qualitative interview process in South Africa, April 2020.

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Salamander Trust
ON THE RIGHT(S) TRACK

Zvandiri
AFRICAID

Young
Positives
South Sudan

Phakama
Africa

International Community
of Women Living with HIV
Eastern Africa (ICWEA)

KESWA

SALVAGE