



Confronting Coercion:

A global scan of coercion, mistreatment and abuse experienced by women living with HIV in reproductive and sexual health services

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This report is dedicated to the memory of Veronika Kalambi, a fierce human rights defender and an ardent advocate for justice for women living with HIV and to all women living with HIV who are fighting for their rights around the world.

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- Charity T. Mkona: Chairperson, ICW Global and ICW Malawi.
- Lillian Mworeko: Executive Director, ICW Eastern Africa, Uganda.
- Ayu Oktariani: Indonesia Positive Women Network (IPPI), Indonesia.
- Immaculate Owomugisha: Attorney, Centre for Women Justice, Uganda.
- Arely Cano Meza: ICW Nicaragua, Nicaragua.
- Veronica Kalambi: ICW Namibia, Namibia.
- Sita Shahi: Regional Director, ICW Asia Pacific, Nepal.
- Diana Weekes: Regional Coordinator, ICW Caribbean, Trinidad and Tobago.
- Rosa Gonzalez: Director, Fundación Llaves, Honduras.
- Hilda Esquivel: Colectivo Sol and ICW Latina, Mexico.
- Mariana Iacono: National Coordinator, ICW Argentina, Argentina.
- Norlela Mokhtar: Chairperson, ICW Asia Pacific, Malaysia.
- Baby Rivona: Former Chairperson, IPPI, Indonesia.
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Executive Summary

Around the world, across geographies and political divides, women living with HIV have documented experiences of coercive practices and other forms of mistreatment and abuse, particularly while exercising their sexual and reproductive health and rights. These human rights violations occur in the context of prevalent and well-documented stigma and discrimination faced by women living with HIV within health-care settings more broadly and pose a significant obstacle to achieving global HIV targets. Yet, as the Confronting Coercion report reveals, these **experiences of coercion, mistreatment and abuse remain normalized, underreported and inadequately addressed.**

Confronting Coercion is global level research conducted by the International Community of Women Living with HIV (ICW) which seeks to understand women living with HIV's experiences of coercion, mistreatment and abuse in sexual and reproductive health-care settings. The report represents an important step towards filling a critical gap in research on coercive practices experienced by women living with HIV along the continuum of their reproductive lives and beyond.

Women living with HIV from over 60 countries came forward to share experiences of coercion while accessing sexual and reproductive health services, including women who are sex workers; who use drugs; those living with a disability; are incarcerated; are experiencing poverty; and those facing racism or faith-based discrimination, as well as indigenous women and trans and gender diverse people.

Our findings confirm that **reproductive coercion, mistreatment and abuse experienced by women living with HIV is a persistent and widespread problem** that occurs along the continuum of services as women and gender expansive people living with HIV seek to exercise their sexual and reproductive rights. A review of data collected from 26,502 women living with HIV from 23 countries, which recently completed the Stigma Index 2.0, revealed that in **every single country, women living with HIV have reported experiencing some form of coercion within the last 12 months.**

Across all Stigma Index 2.0 implementations included in this report:

- **4.4%** of women living with HIV reported experiences of coercive practices in the past 12 months,¹
- **4%** reported experiencing at least one form of mistreatment or abuse in the last 12 months.
- Nearly **20%** of women living with HIV who participated in a Stigma Index 2.0 study reported experiencing some form of coercive practice in their lifetime.
- Across regions coercive practices were concentrated around pregnancy and infant feeding.
- Women living with HIV who reported engagement in sex work, drug use, or had disabilities reported experiencing coercive practices at higher rates than other women living with HIV.
- Younger women living with HIV and women living with HIV who were migrants were also more likely to have experienced coercive practices than older women and women who were not migrants.

An ICW qualitative study conducted in parallel to the Stigma Index 2.0 analysis delved more deeply into the experiences of 205 women, trans and gender-diverse people living with HIV who shared their experiences of reproductive coercion or mistreatment within the last three years.²

¹It should be acknowledged/recognized that questions related to reproductive coercion in the Stigma Index 2.0 do not take into account if individuals sought relevant health services or not. Therefore, we are unable to distinguish between individuals who sought relevant health services and did not experience reproductive coercion with individuals who did not seek relevant health services.

²The survey was administered in Arabic, English, French, Russian and Spanish.

“After the doctor found out that I had HIV, she took me to a separate room and told me to undress. I asked why. She said since I was living with HIV, why should I give birth to a sick child? It is better to have an abortion and live as long as I have left. When I refused, she called me names and screamed. I left.”

–A woman living with HIV, Tajikistan

“I felt soiled, dirty. I am left with the after-effects of those feelings. I think they will stay with me forever. Every time people ask me about the birth, about the pregnancy, I can’t tell the whole real story. I am now getting psychiatric treatment and counselling.”

– A young woman living with HIV, Argentina

Women living with HIV who responded to the qualitative study reported experiences in every single category of coercive practice identified in this study and many women indicated that they had faced multiple experiences of coercion, mistreatment and abuse. Women described the variety of ways that coercion and mistreatment occurs, including pressure or incentives to accept treatment, care or support that women do not want or do not feel comfortable with, lack of informed consent, limited options, denials of care, stigmatizing comments or insults, paternalistic treatment and neglect, verbal and emotional abuse, physical and sexual abuse, lack of confidentiality and consensual care, and inappropriate use of medical intervention, such as episiotomies, inductions, unnecessary Caesarean sections and even forced or coerced sterilizations or abortions.

Many women shared that they had not reported these experiences through formal or informal channels as they felt their report would not amount to anything, or possibly result in retaliation from health-care workers who they relied on for essential care. Other reasons for underreporting may include a lack of human rights knowledge, lack of avenues to report, or having reports dismissed or met with disbelief, denial, and blame.

Methodology

The report methodology triangulates: (1) qualitative research methods, including an online survey in five languages, in-depth interviews with women around the world and key informant interviews with activists working on sexual and reproductive health and rights; (2) a scoping review of existing literature on coercive practices and reproductive coercion; and (3) a gender analysis of data from 23 countries which recently implemented the People Living with HIV Stigma Index 2.0 (Stigma Index 2.0) study. Using this information, it explores the experiences of thousands of women living with HIV who have accessed sexual and reproductive health services between 2020 and 2023 and analyzes in depth women’s experiences of coercion or other forms of mistreatment and abuse within these services. The research focuses on describing the types and prevalence of coercive practices, mistreatment and abuse experienced by women living with HIV. However, the available data are limited in their ability to quantify the scale of coercive practices, mistreatment and abuse in health-care settings.

“My nurse warned me that if I became pregnant when I have a high viral load, I will knowingly give birth to a child with HIV, and as such they will sue me.”

–A young woman living with HIV, Kenya

Our research found that coercion, mistreatment and abuse experienced by women living with HIV including women from key populations:

- ✓ **Are frequently not reported or underreported.**
- ✓ **Are persistent, widespread, normalized and routine.**
- ✓ **Are systematic and structural problems reinforced by harmful social norms, discriminatory and out-of-date policies and practices and a lack of meaningful efforts to confront these practices.**
- ✓ **Have immediate, medium and longer-term negative impacts on the well-being of women living with HIV, including fear of accessing services and disempowerment.**

Our work also identified the ways in which:

- ➔ **Sexual and reproductive health programmes, protocols and service providers often prioritize the best interests of others, including babies, partners, other health workers, other service users, etc., to the exclusion of the interests, rights and autonomy of women living with HIV.**
- ➔ **Medical and legal professionals who enforce prevention practices, particularly prevention of vertical transmission of HIV, prioritize these goals over women's bodily autonomy and consent and penalize and criminalize women living with HIV, subjecting them to increased surveillance, punishment and judgement.**
- ➔ **HIV related stigma and discrimination intersect with harmful gender norms and inequality and represent key drivers of coercion and abuse in reproductive care settings.**
- ➔ **Access to justice via official or informal complaints procedures or other reporting mechanisms is rare and vital, but rarely results in tangible or distributed justice or remedy.**

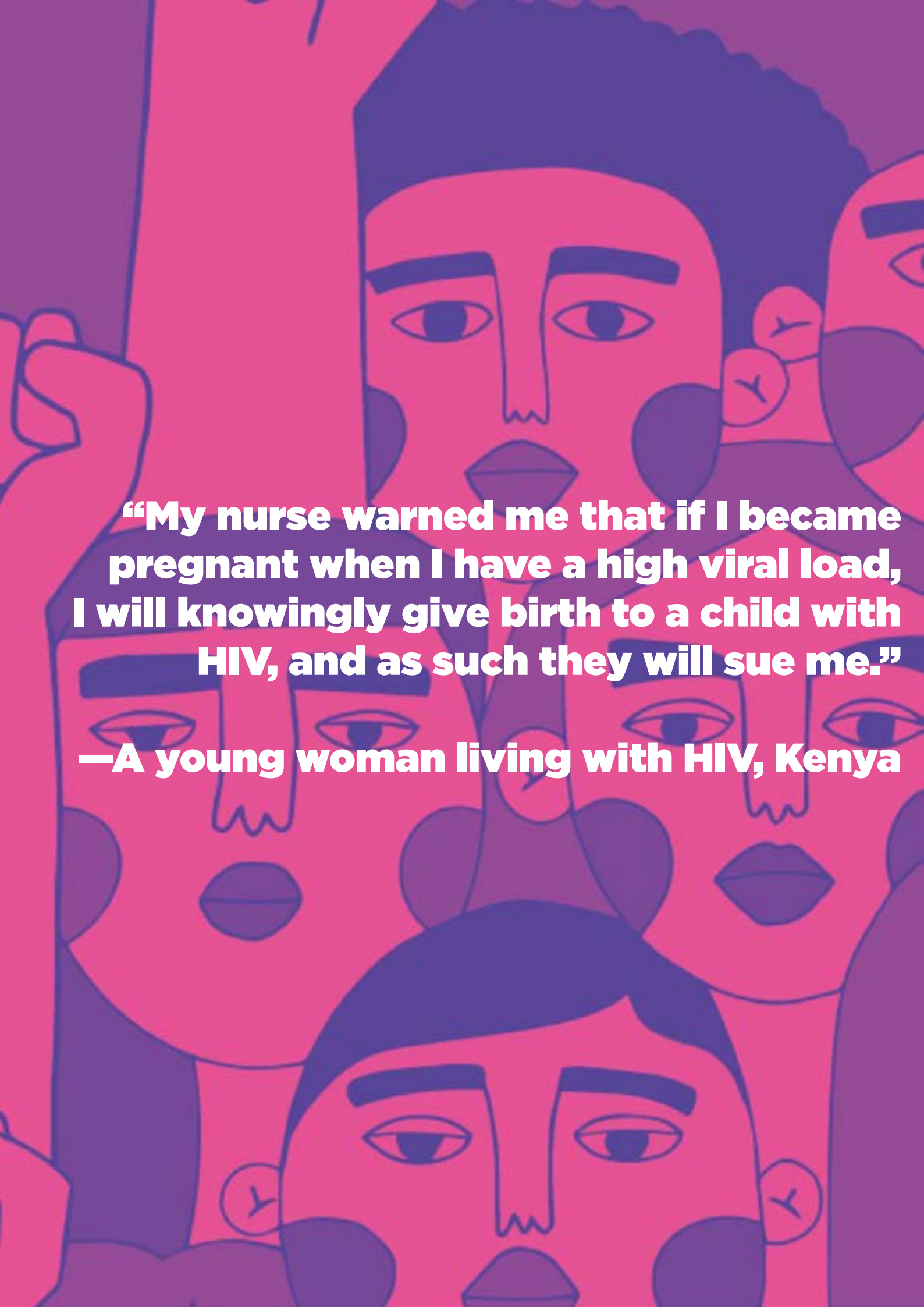
Power imbalances between health-care providers and women living with HIV seeking services, lack of rights awareness and other barriers to the fulfilment of rights create the conditions for these practices. The problems of coercion and mistreatment are systemic in health services. The existing data reveal that many women living with HIV describe experiencing multiple forms of coercion and abuse in different service settings. Harmful social and cultural norms, power imbalances, the lack of adequate provision for informed consent, women's bodily autonomy and the existence of discriminatory, out-of-date laws and policies can be at the root of women being coerced into services even when individual staff members are supportive.

ICW's Call to Action

A crucial finding of the report is that networks of women living with HIV are, against the odds, documenting, confronting and implementing innovative methods to address and transform coercive practices, mistreatment and abuse even though this work is under-recognized and underfunded. This collective body of work articulates a powerful call to action and a way forward to eliminate these harmful practices and ensure that health systems support women living with HIV in realizing their full right to health, including sexual and reproductive health and rights, bodily autonomy, and the right to informed consent. We call on governments, donors and ministries of health to recognize and fund this vital work and to take urgent action to implement the recommendations offered in the following areas:

- ➔ **Take urgent steps to achieve a culture shift and transform harmful dynamics in healthcare.**
- ➔ **Respect, protect and fulfil sexual and reproductive health rights in policy and practice.**
- ➔ **Increase rights knowledge amongst women living with HIV and women from key populations.**
- ➔ **Support additional research on coercive practices and documentation of rights abuses.**
- ➔ **Increase avenues for access to justice for all women.**
- ➔ **Invest in efforts led by women living with HIV and women from key populations.**

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“My nurse warned me that if I became pregnant when I have a high viral load, I will knowingly give birth to a child with HIV, and as such they will sue me.”

—A young woman living with HIV, Kenya

What reproductive coercion, mistreatment and abuse of women living with HIV look like

*“I was denied certain laboratory tests aimed at planning pregnancy:
‘You have HIV. Why do you need these problems and risks?’”*

—A woman living with HIV, Argentina

Experiences of coercive practices, mistreatment and abuse in health-care settings have been documented and reported by networks of women living with HIV for more than 20 years. Notably, although women living with HIV had identified the practice of forced and coerced sterilization, the issue first received global attention in 2008 at a younger women’s dialogue hosted by the International Community of Women Living with HIV (ICW) and led by the Namibian Women’s Health Network, an ICW affiliated network in Namibia. Women living with HIV who had been forcibly sterilized without their informed consent brought a landmark lawsuit in which the Supreme Court of Namibia ultimately “found that the Government of Namibia had breached its duty of care to three women living with HIV who had been forcibly sterilized in a public hospital.” (1) The Namibian Supreme Court ruling effectively brought the issue to global attention.

Since that time, women’s networks and allies have documented, raised awareness and worked to eliminate forced and coerced sterilization in over 40 countries around the world. ³ Litigation to confront forced and coerced sterilization has been brought in Kenya as well as effective complaints to national and international human rights bodies in South Africa and Honduras. This important advocacy and awareness brought about global condemnation of this egregious practice, including an important interagency statement from UNAIDS and WHO. (2)

The high public profile of some of the litigation, the awareness raised by advocacy and such statements from multilateral agencies have created an impression that rights violations of this nature were being adequately addressed or eliminated. However, obstetric violence and coercion continue to be systemic and systematic towards women living with HIV and significant obstacles to reporting and accessing justice remain. Indeed, a strong focus on experiences of forced or coerced sterilization in the public discourse has partially masked the broader spectrum of coercive practices and mistreatment experienced by women living with HIV along the continuum of sexual and reproductive and HIV care. These often-overlooked types of coercive practices, including coercion with regard to contraceptive choices, birth method options and infant feeding, also constitute violations of fundamental human rights, including the right to health and rights to autonomy, bodily integrity, reproductive choice, informed consent and rights to available, accessible, acceptable and quality services.

All people, regardless of gender, sexuality or HIV status, have the right to sexual and reproductive health services that are free of judgement and discrimination, to make autonomous decisions about whether and when to have a child, to bodily autonomy and the right to informed consent ^{6,7} This means that all individuals must be provided with accurate information in an understandable language about the risks and benefits of treatment, services, care and support options available to them. Furthermore, they must be given time to understand these options and their rights in order to make the decision that is best for them, free from coercion, pressure, or force. Unfortunately, as this report reveals, for many women living with HIV these basic requirements are not met.

³ Countries where experiences of forced or coercive sterilization have been documented or shared by women living with HIV include: Bangladesh, Belize, Brazil, Cambodia, Chile, China, Democratic Republic of the Congo, Dominican Republic, El Salvador, Fiji, Guatemala, Honduras, India, Indonesia, Jamaica, Kazakhstan, Kenya, Kyrgyzstan, Mexico, Republic of Moldova, Mozambique, Namibia, Nicaragua, Nepal, Pakistan, Papua New Guinea, Peru, Philippines, South Africa, Sierra Leone, Sri Lanka, Swaziland, Tajikistan, United Republic of Tanzania, Thailand, Uganda, Ukraine, Venezuela, Viet Nam, and Zambia.

What is Coercion?

Coercion is undue pressure to make a specific decision or accept a particular treatment or service option that people may not autonomously choose, want, or feel is in their best interest, or without access to accurate and unbiased information. (3,4)

Coercion can take the form of pressure to make a certain decision or accept certain treatments or services that an individual does not want, may be uncomfortable with, or does not have enough information. This pressure may arise from unequal power dynamics or paternalism in the health-care setting. Women might be told, persuaded, threatened, or tricked to do something or accept a treatment, practice or medication that they may not want, or that they may not have agreed to if they were advised of their options or were given accurate information. Such pressure can come in the form of negative or judgemental comments, persistent or repetitive attempts to persuade an individual, bullying or threatening, and withholding information about the risks and benefits of alternative options. This pressure can also come in the form of incentives such as offering specific benefits—nutrition, services or financial support—or in the form of withholding treatment or access to needed support or services until the woman agrees to the services or treatment. Mistreatment and abuse contribute to the power imbalance that creates the conditions for coercive practices and denials of autonomy.

What follows are the categories of coercive practices, mistreatment and abuse that are captured in this report.

Types of coercion

Coercive practices by health-care workers and staff, as experienced by women living with HIV, can be categorized as follows:

- **Advice not to have a child; told not to have children or not to have another child.**
- **Advice to terminate a pregnancy.**
- **Pressure or encouragement to undergo sterilization.**
- **Sterilized without knowledge or consent.**
- **Denied contraception.**
- **Pressured to use a specific type of contraceptive method.**
- **Told there was no alternative to using contraception in order to get HIV (antiretroviral) treatment and/or other forms of health care.**
- **Pressure to use a particular birth/delivery method (e.g. Caesarean section or vaginal delivery).**
- **Pressure to use a particular infant feeding practice (e.g. advised not to breastfeed).**
- **Pressure to have a pap smear test.**
- **Pressure to have a vaginal examination.**
- **Pressure to undergo female genital cutting/mutilation.**

These categories represent the most commonly reported types of coercive practices, and they are those captured in this research. However, this list of coercive practices is not exhaustive and there may be other experiences of coercion not discussed in this report.

Mistreatment and abuse experienced by women living with HIV are also prevalent and occur both independently of coercion and in ways that support coercion. Mistreatment and abuse reinforce gender inequalities, undermine bodily autonomy and represent violations of the sexual and reproductive health and rights of women and girls and gender non-conforming people.

What types of mistreatment and abuse are women living with HIV reporting?

Mistreatment and abuse include the following:

- Denials or delays of care, including sexual and reproductive health services.
- Being advised not to have sex.
- Being talked about badly or gossiped about.
- Verbal abuse (yelling, scolding, name calling, or being otherwise verbally abused).
- Physical abuse (pushing, hitting, or being otherwise physically abused).
- Avoidance of physical contact with you/taking extra precautions (e.g. wearing double gloves).
- Disclosing your HIV status without your consent (e.g. to family, friends, or the community).
- Notifying a partner about your status without your consent.
- Requiring that a partner or parents be present in order to access a service.
- Health-care workers ask partners or parents for their views or to make decisions instead of you.
- These manifestations of stigma and discrimination serve to further disempower women living with HIV and undermine their agency, autonomy and ability to receive treatment, care and support, further creating the conditions for coercive practices to flourish.

Coercion is persistent and widespread.

Experiences of Reproductive Coercion

An analysis of Stigma Index 2.0 data on reproductive coercion

A gendered analysis of recent Stigma Index data from 23 countries in three regions from 2020 to 2023 representing more than 26 000 women confirms that reproductive coercion is persistent, cumulative and impacts women living with HIV across all countries and regions where data were collected. Our analysis examined both lifetime reported experiences of coercion, or instances of coercion ever experienced, as well as more recent experiences that have occurred within the 12 months prior to the Stigma Index 2.0 study. These experiences were then organized into phases of sexual and reproductive health and rights care, including contraception and family planning, pregnancy, childbirth and feeding practices, and experiences of forced or coerced sterilization (Table 1).

Table 1.

Reported experiences of coercion at different phases of sexual and reproductive health and rights care

Contraception and family planning	Pregnancy, childbirth and infant feeding	Sterilization
<ul style="list-style-type: none"> • Advice or pressure not to have children. • Incentives to use contraception, including long lasting forms. 	<ul style="list-style-type: none"> • Pressure to terminate a pregnancy. • Pressure to have a Caesarean section. • Pressure to use infant formula. 	<ul style="list-style-type: none"> • Pressure to be permanently sterilized.

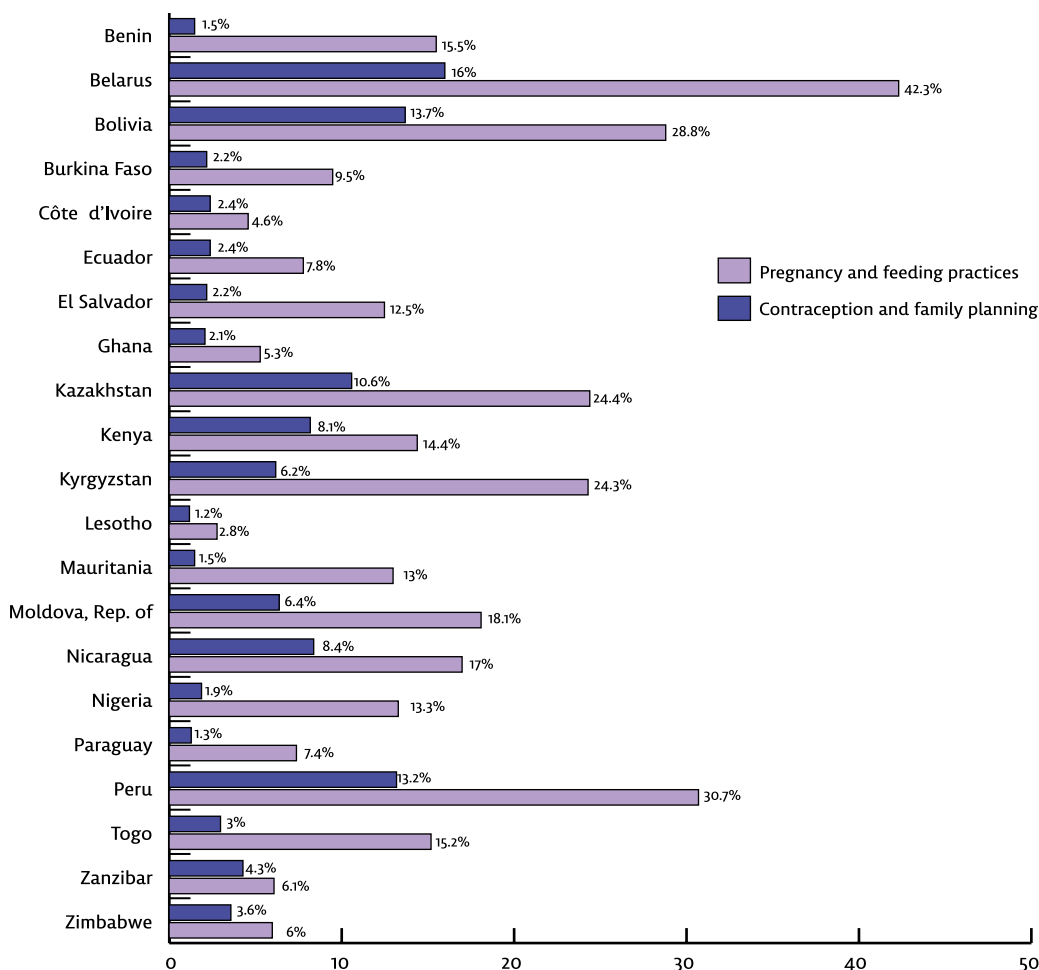
Lifetime Experiences of Reproductive Coercion by Country

Nearly 20% of all women living with HIV who participated in the selected Stigma Index 2.0 country implementations reported experiencing some form of coercive practice in their lifetime.⁴ Women living with HIV may have experienced coercion from the very start of their journey with HIV, while 85.3 % of women living with HIV reported that they chose to be tested for HIV, 14.7% of women living with HIV in recent Stigma Index 2.0 implementations indicated that they did not choose to be tested and a further 3.9% of women living with HIV indicated that they had been tested for HIV because the test was mandatory (e.g. for employment, visa/citizenship, incarceration, marriage, accessing antenatal care. (5)

In our analysis, lifetime experiences of coercion related to contraception and family planning reported by women living with HIV who participated in a national stigma index ranged from 1.1% in Lesotho to 8.1% in Kenya in the sub-Saharan region, from 6.2% in Kyrgyzstan to 16.6% in Belarus in the Eastern European region, and from 1.3% in Paraguay to 13.7% in Bolivia in Latin America. Reports of coercive practices over the lifetime of women living with HIV related to pregnancy and infant feeding practices were slightly higher, ranging from 2.8% in Lesotho to 15.5% in Benin in sub-Saharan Africa; from 7.4% in Paraguay to 30.7% in Peru in Latin America; and from 18.1% in the Republic of Moldova to a high of 42.3% of women reporting coercive practices in Belarus in Eastern Europe.

Figure 1.

Experiences of reproductive coercion among women living with HIV by country



⁴ The Stigma Index 2.0 does not have a question which asks for lifetime experiences of pressure to accept permanent sterilization.

Table 2.

Lifetime experiences of reproductive coercion among women living with HIV by phases of sexual and reproductive health and rights (SRHR) care by country

Country	Contraception and family planning		Pregnancy and feeding practices	
	%	n/N	%	n/N
Benin	1.5	7/481	15.5	87/560
Belarus	16.	50/302	42.3	121/286
Bolivia	13.7	31/227	28.8	65/226
Burkina Faso	2.2	33/1511	9.5	145/1528
Côte d'Ivoire	2.4	32/1329	4.6	60/1316
Ecuador	2.4	5/209	7.8	16/204
El Salvador	2.2	4/185	12.5	22/176
Ghana	2.1	25/1210	5.3	63/1197
Kazakhstan	10.6	44/414	24.4	89/365
Kenya	8.2	190/1105	14.4	158/1098
Kyrgyzstan	6.2	5/241	24.3	57/235
Lesotho	1.2	9/777	2.8	22/793
Mauritania	1.5	5/341	13.0	47/360
Moldova, Rep. of	6.4	22/345	18.1	54/299
Nicaragua	8.4	15/178	17.0	30/177
Nigeria	1.9	13/678	13.3	92/693
Paraguay	1.3	4/307	7.4	22/298
Peru	13.2	21/159	30.7	47/153
Togo	3.0	20/672	15.2	102/671
Zanzibar	4.3	20/462	6.1	28/462
Zimbabwe	3.6	23/644	6.0	39/647

Recent Experiences of Reproductive Coercion by region

Recent experiences of reproductive coercion of women living with HIV of reproductive age across the continuum of reproductive health care remain unacceptably high (see Table 2 and Figure 1). Reproductive coercion is seemingly more intense and concentrated around pregnancy and infant feeding practices, but persists across contraception and family planning and pressure to accept permanent and irreversible sterilization.

In Latin American Stigma Index studies, 14.1 % of women living with HIV of reproductive age reported experiencing coercion to accept sterilization and 13.2% of women reported coercive practices during pregnancy and infant feeding in the past 12 months. In Eastern Europe and Central Asia, 8% of women living with HIV of reproductive age reported coercive practices around pregnancy and infant feeding in the past 12 months. In sub-Saharan Africa 5.2% of women reported experiencing coercive practices during pregnancy and infant feeding practices in the past 12 months.

The highest level of both recent and lifetime experiences of reproductive coercion among women living with HIV who participated in the study was in Latin America followed by Eastern Europe and Central Asia and sub-Saharan Africa. Across regions, 4.4% of all women living with HIV participating experienced some form of coercive practice in the 12 months prior to the study. **In real terms, the data indicate that thousands of women living with HIV around the world continue to experience coercive practices while seeking reproductive health care annually (see Tables 3 and 4 and Figure 2).**

Figure 2.

Experiences of reproductive coercion in the past 12 months among women living with HIV Stigma Index 2.0 participants, across phases of SRHR care, by region.

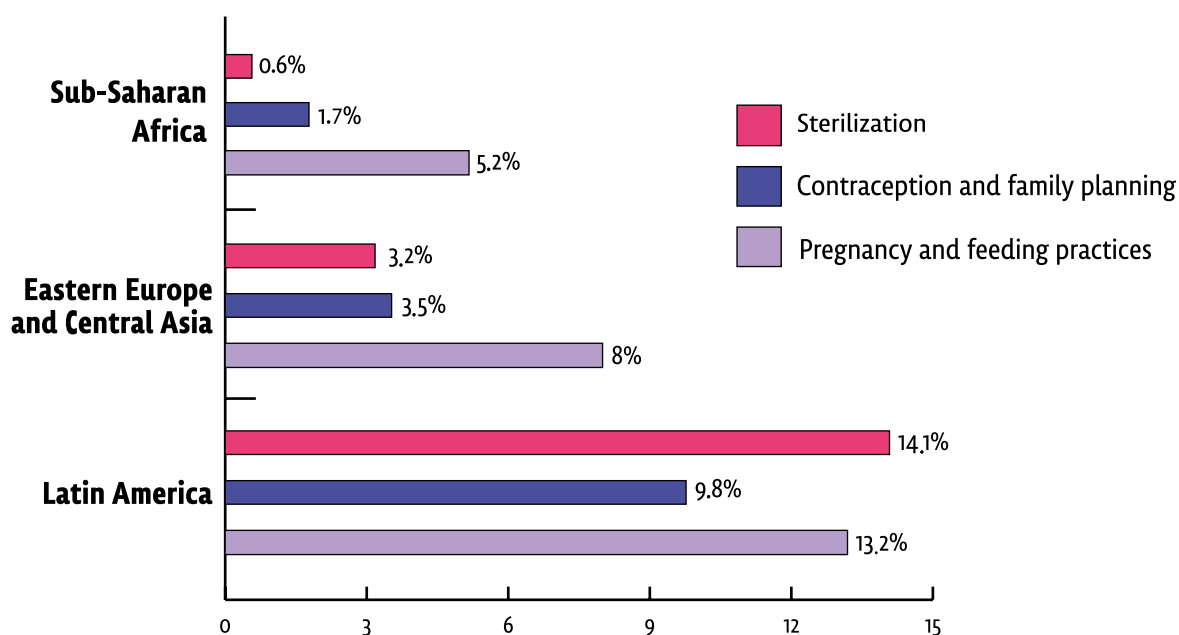


Table 3.

Experiences of reproductive coercion in the past 12 months among women living with HIV Stigma Index 2.0 participants, across phases of SRHR care, by region.

Reproductive coercion within the last 12 months	Sub-Saharan Africa		Eastern Europe and Central Asia		Latin America	
	%	n/N	%	n/N	%	n/N
Sterilization	0.6	48/8486	3.2	67/2105	14.1	153/1087
Contraception and family planning	1.7	155/8725	3.5	80/2265	9.8	112/1146
Pregnancy and feeding practices	5.2	452/8739	8.0	178/2224	13.2	152/1152

Table 4.

Experiences of reproductive coercion within the last 12 months among women living with HIV of reproductive age by phases of SRHR care, by country, from 2020 to 2023

Country	Sterilization		Contraception and family planning		Pregnancy and feeding practices	
	%	n/N	%	n/N	%	n/N
Angola	1.6	13/828	1.3	11/828	5	46/828
Benin	0.0	0/430	1.1	5/456	6.1	28/459
Belarus	7.1	20/282	4.3	13/300	12.6	37/294
Bolivia	24	53/2212	0.5	47/229	24.7	56/227
Burkina Faso	0.0	0/1171	0.7	8/1189	4.7	56/1202
Côte d'Ivoire	0.1	1/1222	1.0	12/1223	2.0	24/1223
Ecuador	13.7	22/161	7.3	12/165	15.4	26/169
El Salvador	11.6	18/155	4.4	7/158	6.1	10/165
Ghana	0.3	3/891	1.3	12/946	2.9	27/949
Kazakhstan	5.4	21/387	8.0	32/398	15.6	61/392
Kenya	1.1	11/967	4.6	46/1001	10.5	105/996
Kyrgyzstan	0.9	2/220	5.2	13/248	11.6	28/242
Lesotho	0.5	3/654	1.1	7/668	3.0	20/672
Mauritania	0.00	0/269	0.00	0/272	5.2	14/272
Moldova, Rep. of	3.1	9/294	0.9	3/319	5.5	17/308
Nicaragua	17.7	27/153	18.1	32/177	10.7	19/177
Nigeria	0.5	3/589	0.8	5/634	5.7	37/648
Paraguay	4.6	12/264	0.7	2/278	4.0	11/273
Peru	15.8	21/133	8.6	12/139	21.3	30/141
Russian Federation	1.1	2/184	2.1	4/188	4.3	8/185
Togo	0.7	4/546	3.2	18/557	9.9	55/556
Ukraine	1.8	13/738	1.9	15/812	3.4	27/803
Zanzibar	1.9	7/363	2.5	10/393	3.1	12/393
Zimbabwe	0.5	3/556	3.8	21/556	5.2	28/541

⁵ The individuals who responded to the survey spoke Arabic, English, French, Russian, or Spanish.

Findings on coercion from the ICW qualitative study

Asked to share experiences of coercion and mistreatment, 171 women, transmen and gender-diverse people living with HIV responded to our online survey tool. A further 34 women were interviewed and reported experiencing various forms of reproductive coercion within the last three years.⁵

Each category of coercive practice had at least one respondent reporting that they had experienced that type of coercive practice. **Almost all of the women living with HIV who responded to the qualitative survey (98% of respondents) reported that they had experienced multiple forms of coercion, mistreatment and abuse**, mainly in government-run sexual and reproductive health facilities. The women also described negative treatment in other health services, such as those run by private providers, or services that are not focused on sexual and reproductive health. Only a handful of respondents reported experiencing only one form of coercion. The multifaceted, ongoing nature of coercion in services, and its impacts, came out particularly strongly in the consultations.

Notably, respondents stated that they were advised:

- Not to have sex (22% of respondents).
- Not to have a child/not to have children, or not to have another child (40% of respondents).
- To terminate a pregnancy on the basis of their HIV status (13% of respondents).

The number of experiences that may in some cases be related to national clinical guidelines was also high. In these cases, health-care providers may simply have been following protocol. However, women often felt they were trying to impose their discriminatory attitudes, views and beliefs, using their position of power over the women seeking services to do. Examples include pressure to use:

- A particular infant feeding practice (e.g. advised not to breastfeed) (31% of respondents).
- A particular method of giving birth/delivery option (either Caesarean section or vaginal birth) (20% of respondents).

Experiences of coercion are underreported.

Among women living with HIV in particular, experiences of coercion are frequently underreported for a variety of reasons, including normalization of these practices, and fear of retaliation, or further denials of care if they speak out. Shame and lack of rights awareness and a sense from women living with HIV that reporting these violations is futile and will not result in meaningful change for themselves or at the policy level also accounts for underreporting. In our qualitative study, only an approximately 14% of qualitative survey respondents made any complaint about their experiences of coercion, mistreatment or abuse.

In a recent Stigma Index Report, a regional analysis of seven west African countries with recent Stigma Index 2.0 implementations, less than half 49.4% (n = 1995) of women living with HIV reported they were aware of their rights. (6) Women with less awareness of their rights face greater challenges asserting those rights and may be less empowered to speak out publicly and seek support to report rights abuses. In the same study 88.5% (n = 567) of women living with HIV who had experienced some form of rights violation did not file a complaint or speak out against these abuses.

It is important to note that the Stigma Index 2.0 methodology may underestimate the presence of recent reproductive coercion in sexual and reproductive health services because the research is conducted for women living with HIV aged 18–49 regardless of whether they accessed relevant services. It is unlikely that the majority of women who participated in the Stigma Index 2.0 research would have been pregnant in the last 12 months.

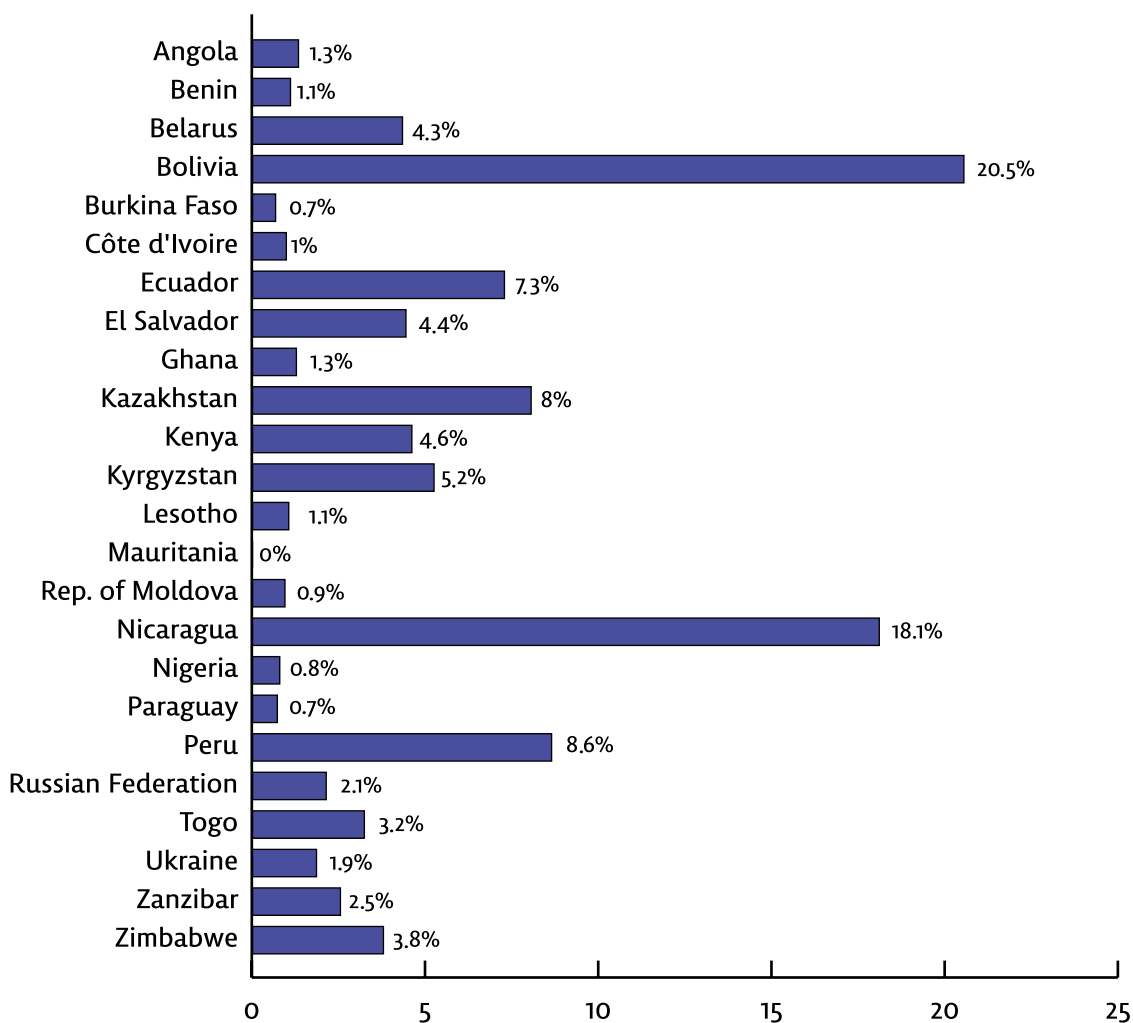
The understanding that these data represent a significant underreporting of the incidence of coercive practices is supported by other data sets which document high rates of obstetric violence experienced by pregnant women in the general population, (7) including estimates of disrespect and abuse in childbirth facilities between 15% and as high as 98% (8).⁶ These data illustrate the way that stigma, including gender-based stigma and HIV related stigma and discrimination, can intersect to further marginalize women living with HIV and undermine the ability of women to confront rights violations in health-care settings.

Experiences of coercive practices along the continuum of sexual and reproductive health and rights services

Reproductive coercion while seeking contraception and family planning services

Figure 3.

Experiences of reproductive coercion within the last 12 months among women living with HIV of reproductive age related to contraception and family planning services, by country, from 2020 to 2023



⁶ USAID cites quantitative studies putting the prevalence of disrespect and abuse of women and girls in childbirth facilities at between 15 and 98%, and the risk is higher for women of colour, women living with HIV, adolescent girls, young women and others who are marginalized.

Confronting Coercion:

A global scan of coercion, mistreatment and abuse experienced by women living with HIV in reproductive and sexual health services

In the 23 Stigma Index implementations analysed, the percentage of women living with HIV reporting an experience of coercion while seeking contraception and family planning services ranged from under 1% in countries such as Côte d'Ivoire, Mauritania and Burkina Faso, to between 4.6% in Kenya and 8% in Kazakhstan, to as high as 20.8% in Bolivia (Figure 3 and Table 4). In our qualitative study, respondents shared that they felt pressured to use a specific type of contraceptive method and were told they had to use contraception to access HIV treatment or other health-care services and were denied family planning services.

“There is certainly coercion or denial of choice in contraceptives. For women with HIV, it’s often just condoms. Last week we were in a symposium and women from the provinces talked about going to SRH or gynaecological services and being given one condom or two. If the woman doesn’t have money to buy condoms, you are basically saying she should be having very little sex. And if she’s a sex worker, what good is one or two condoms? So yes, this is a form of coercion, and of judgement—that women with HIV should not have multiple partners or a very active sex life. [...] SRH services usually have all the contraceptive options—pill, implant, IDU, etc.—and also abortion, but the problem is in the offer (as in the ideology of the health worker, and who is offered what) that’s the problem.”

—A woman living with HIV, Argentina

“My facility does not offer condoms or contraceptives. They tell us to abstain, so when I need condoms, I have to go to the nearby facilities to get condoms, but I have never found a female condom”.

—A young woman living with HIV, Kenya

“When I got pregnant, I went to the maternity clinic to register, but there, during the examination, I found out about my HIV diagnosis. After the doctor found out that I had HIV, she took me to a separate room and told me to undress. I asked why. She said since I was living with HIV, why should I give birth to a sick child? It is better to have an abortion and live as long as I have left. When I refused, she called me names and screamed. I left.”

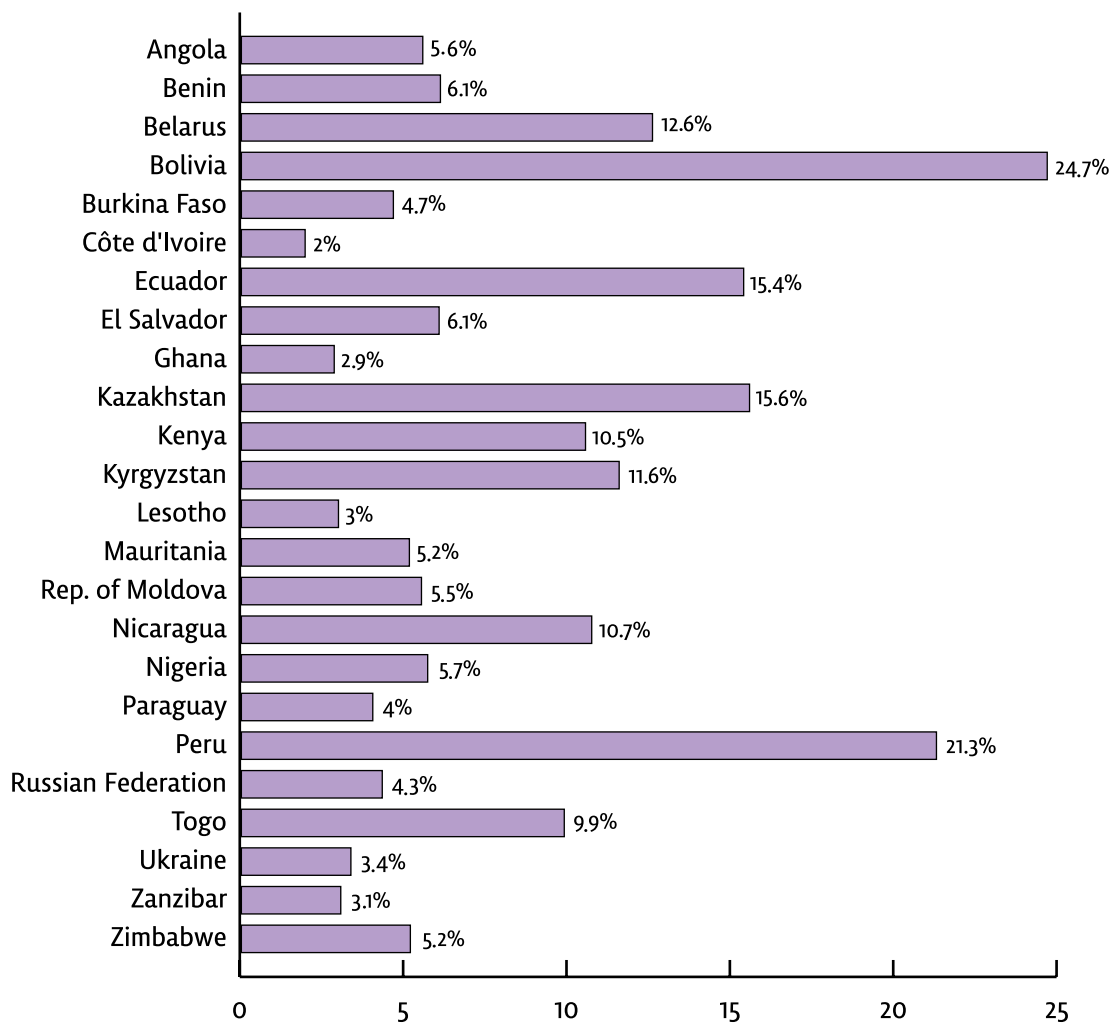
—A woman living with HIV, Tajikistan

Reproductive coercion during pregnancy and infant feeding practices

In Stigma Index 2.0, women living with HIV in sub-Saharan Africa reported experiencing reproductive coercion related to pregnancy and infant feeding practices in the last 12 months, ranging from 1.96% in Côte d'Ivoire to 10.54% in Kenya. In Eastern Europe, reports of these experiences ranged from 5.78% in Ukraine to 15.56% in Kazakhstan. In Latin America, the percentage of women living with HIV who participated in the study and who reported experiencing these forms of coercion ranged from 4.03% in Paraguay to 24.67% in Bolivia (see Figure 4 and Table 5).

Figure 4.

Experiences of reproductive coercion with the last 12 months among women living with HIV of reproductive age related to pregnancy and infant feeding practices, by country, from 2020 to 2023



Although the World Health Organization now recommends that elective Caesarean sections should not be routinely recommended to women living with HIV as an approach for the prevention of perinatal HIV transmission (9), 31% of women in our qualitative study reported being pressured into particular forms of giving birth/delivery. Whether or not this was in accordance with clinical guidelines, for the women it was an upsetting experience, which they linked to power imbalances between themselves and the service provider, as well as to the personal discriminatory attitudes of the health-care provider.

“I was abandoned in the hospital when I gave birth. When I arrived at the hospital in labour, the doctor wanted to give me a C-section rather than vaginal delivery. But then she left and was gone for a long time. While I was waiting, I felt like I was going to give birth. I was by myself in a room, left to my own devices, and I lost the baby. I gave birth in the room, there was nobody there. I was in danger and there was no one there to help.”

—A woman living with HIV, Democratic Republic of the Congo

“I was immediately told that I cannot breastfeed the child. I was given milk formula from the AIDS centre. For the first few days I fed my child with formula. But my husband left me because he was healthy and was given wrong information by the doctors of the AIDS centre. I did not have a job. I had to breastfeed the child in secret so that she would not die of hunger. Thank God now my child is healthy, despite the fact that I breastfed her.”

—A woman living with HIV, Tajikistan

The violence perpetrated against women living with HIV when pregnant highlights how the ways in which women's bodies are seen as public property and how prevention of vertical transmission goals are prioritized over their well-being when they become pregnant, subjecting them to discrimination and judgmental attitudes and behaviours regarding the health of their babies and intimate partners (10, 11).

Infant Feeding Practices: Criminalizing Breastfeeding

“I was told it was dangerous to have a baby and was pressured to be sterilized. She decided herself not to conceive again because of stigma. I experienced pressure not to breastfeed ‘because HIV can be transmitted through breastfeeding, but since I had no way to feed the child, I gave him the breast and today my child is healthy’.”

— A woman living with HIV, Cameroon

“When I gave birth to my son, I was told not to breastfeed him at all and formula was too expensive for me. My son was always hungry, so I decided to go against my doctor's instructions and, three years later, my little boy is still HIV negative. Why did they lie to me?”

— A young woman living with HIV from Kenya

“I was immediately told that I cannot feed the child. I was given milk formula from the AIDS centre. For the first days I fed my child with formula. But my husband left me because he was healthy and was given wrong information by the doctors of the AIDS centre. I did not have a job. I had to breastfeed the child in secret so that she would not die of hunger. Thank God now my child is healthy, despite the fact that I breastfed her.”

— A woman living with HIV from Tajikistan

In the qualitative survey, 31% of respondents felt pressured by health-care providers to use a particular infant feeding practice (e.g. advised not to breastfeed). In some settings, breastfeeding remains criminalized and health providers pressuring women to use formula feeding and enforcing this practice are simply following national protocol. (12) However, women again felt that the pressure was due to the discriminatory attitudes of the health providers.

Enforcement of prevention of vertical transmission practices by medical and legal professionals results in the punishment and criminalization of women living with HIV (13). Women are subjected to surveillance of their parenting and punishment and judgement for breastfeeding in many countries. For example, in our qualitative study, a woman from Argentina reported legal proceedings against her because of her plan to breastfeed, and a guard being positioned to oversee feeding (13). In the Asia-Pacific region, women living with HIV who had given birth reported being administered pills to suppress lactation without their informed consent as well as increased visitation from nurses to ensure they did not breastfeed and were ultimately taken off antiretroviral (ARV) medicines once the baby was born, after which the baby was taken away. Such enforcement can create a climate of fear for women living with HIV.

Women felt strongly that national guidelines that recommend avoiding breastfeeding should be updated to consider viral suppression and 'Undetectable=Untransmittable' (U=U). Furthermore, women reported being given pills to suppress lactation without their informed consent and were not supported to make an informed choice about their infant feeding options. A few women reported that they were told not to breastfeed but were not provided with infant formula, so they had no other choice.

Increasingly, there is a global consensus backed by empirical studies that confirms that criminalization runs counter to public health goals and does far more harm than good. Amid a worrying rise in prosecutions of women living with HIV who elect to breastfeed, there is strong evidence criminalization of breastfeeding by people living with HIV is unjustified. Fear of prosecution undermines the foundations of the HIV response, decreasing demand for testing, discourages prevention efforts and creates obstacles to adherence to treatment. To ensure an effective, sustainable response to HIV that is consistent with human rights obligations, it is necessary to decriminalize HIV and amend or repeal any law that explicitly or effectively criminalizes any aspects of the vertical transmission of HIV, syphilis and HBV, including through breastfeeding (12).

Experiences of forced or coerced sterilization

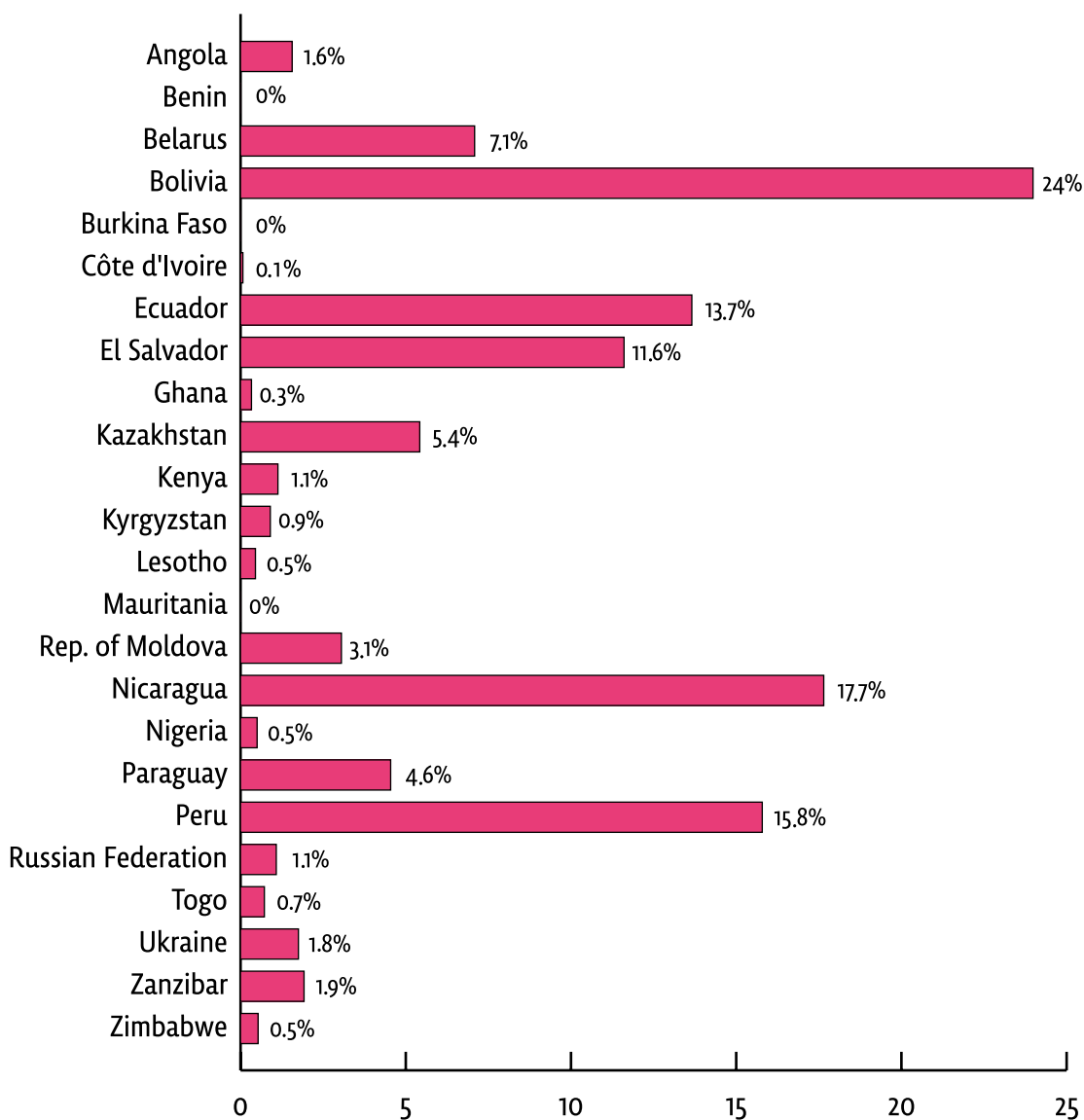
Sterilization is an effective, permanent and irreversible form of contraception. Sharing information about a woman's contraceptive options, including sterilization, is good practice. However, advising or recommending sterilization on the basis of HIV status is coercion (14). In our qualitative study, 15% of respondents reported that they were pressured to undergo sterilization because of their HIV status and 6% reported that their rights were violated when they were permanently sterilized without their knowledge or consent. This research corroborates previous research and legal filings by ICW and others documenting the practice of coerced sterilization of women living with HIV. (15)

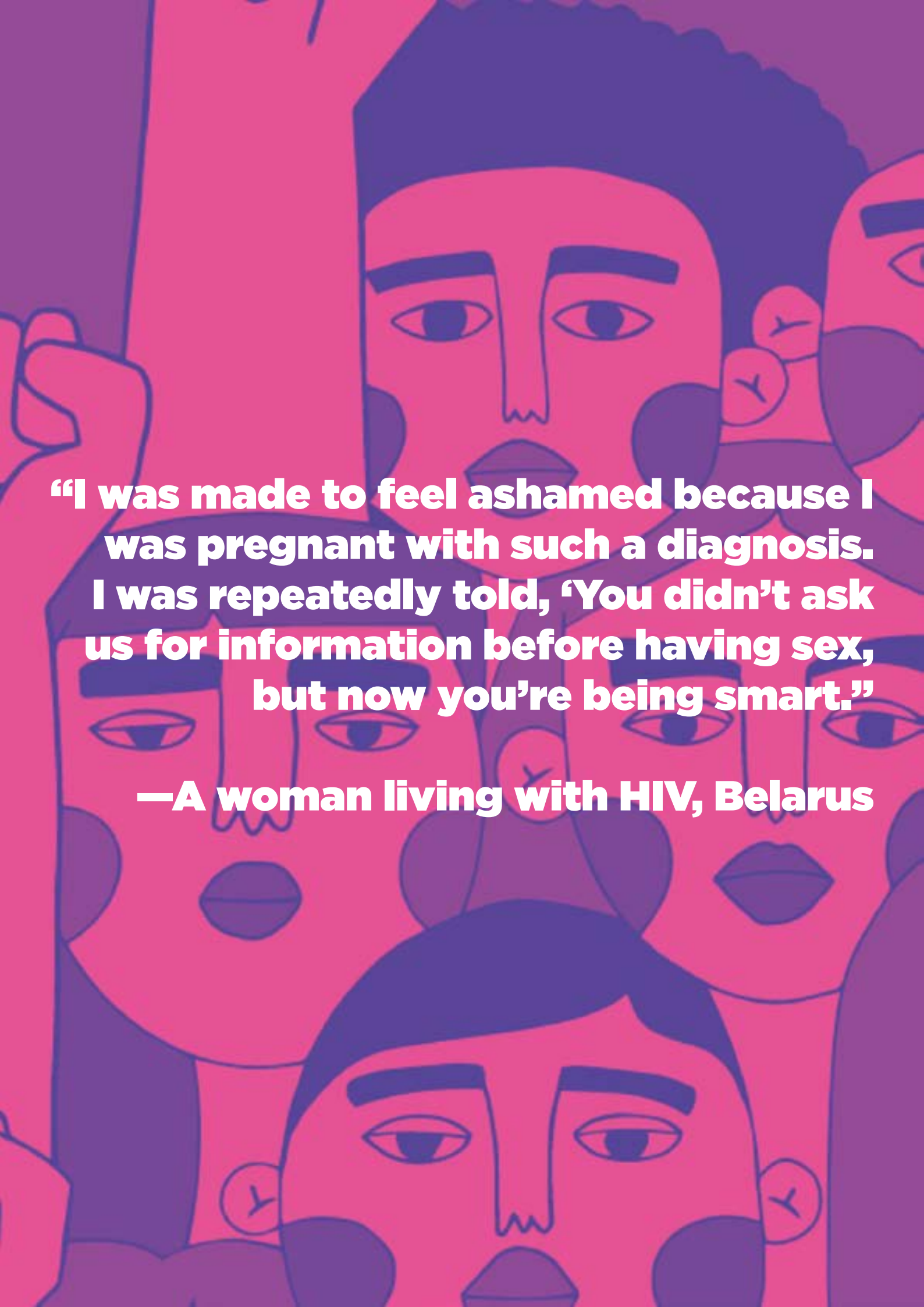
Despite high profile cases resulting in increased awareness of the practice, reports persist of forced or coerced sterilization or reproductive coercion related to sterilization. The Stigma Index 2.0 analysis indicates that over the last 12 months, 14.1% of women living with HIV who participated in the study in Latin America reported experiences of reproductive coercion in the form of pressure for sterilization. In Latin America, the percentage of women living with HIV of reproductive age who participated in the study and reported experiencing reproductive coercion related to sterilization ranged from 4.6% in Paraguay to 24.0% in Bolivia. In Eastern Europe and Central Asia, 3.2% of women living with HIV who participated in the study reported recent experiences of sterilization and experiences of coercion related to sterilization from 0.91% in Kyrgyzstan to 7.1% in Belarus. In sub-Saharan Africa, 0.6% of women living with HIV who participated in the study reported recent experiences of reproductive coercion to accept sterilization, ranging from 0.0% in Benin, Burkina Faso and Mauritania to 1.9% in Zanzibar.

On average, fewer women are reporting this experience in sub-Saharan Africa than in Eastern Europe and Latin America, where the percentage of women reporting this practice in the past 12 months alone is worrying. It is essential that further research examine potential factors that may be contributing to the comparatively low reporting in sub-Saharan Africa as compared to the other regions in this study, including awareness of the issue or individual rights awareness (Figure 5, Table 3).

Figure 5.

Experiences of reproductive coercion within the last 12 months among women living with HIV of reproductive age related to sterilization, by country, from 2020 to 2023





“I was made to feel ashamed because I was pregnant with such a diagnosis. I was repeatedly told, ‘You didn’t ask us for information before having sex, but now you’re being smart.’”

—A woman living with HIV, Belarus

Under pressure: Experiences of women from marginalized and key populations

HIV is yet another axis of discrimination that intersects with other forms of discrimination, such as a person's gender, and influences how and whether sexual and reproductive health services are provided for women and girls living with HIV. In our qualitative survey, HIV was the reason women gave for the coercion and abuse they experienced, and their stories illustrate how HIV related stigma and discrimination is the driving factor shaping their experiences. However, our qualitative study as well as data from the Stigma Index 2.0 implementations suggest that across regions, young women living with HIV, sex workers, migrants, women who inject drugs, and women with disabilities experience higher levels of reproductive coercion compared to other women living with HIV.

“Early this year we were helping one woman who was jailed for non-adherence. She was struggling with drugs, she didn't go for her clinic appointment, and just had a baby. She was put in prison with her three-year-old child and three-month-old baby until her baby was 18 months so she could take her medicine and breastfeed her baby while being observed by law enforcement agents. It took us a long time to convince the authorities to let her go home and get psychosocial care at home instead of in prison. There is still a lot of stigma for sex workers and women who use drugs at the health facility.

—A young woman living with HIV, Kenya

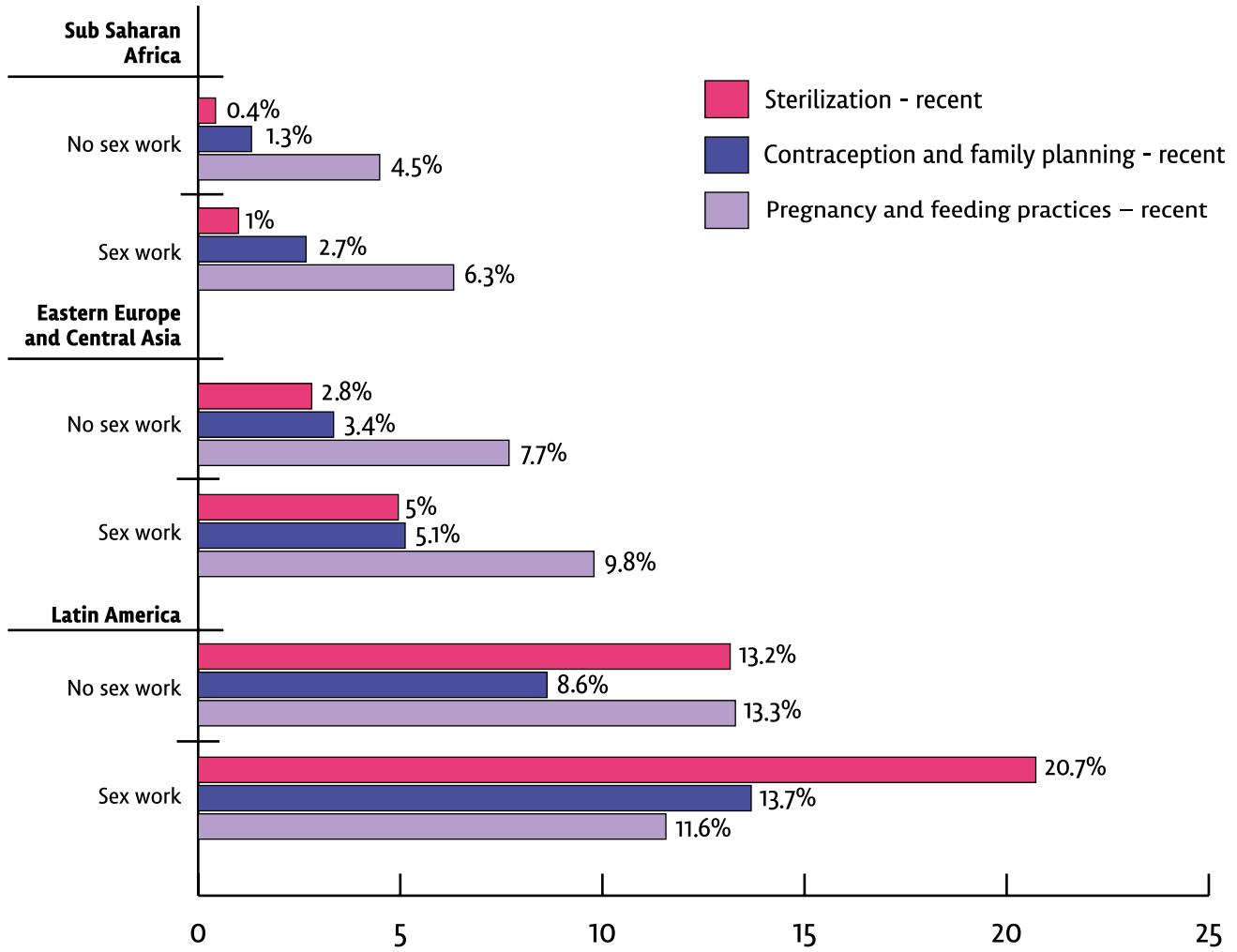
Stigma Index 2.0 Analysis: Reproductive Coercion Experienced by Sex Workers Living with HIV

Sex workers in Latin America who participated in the Stigma Index 2.0 reported higher levels of coercive practices in every category as compared to women living with HIV who engaged in sex work in Eastern Europe and Central Asia and sub-Saharan Africa. Other research utilizing Stigma Index 2.0 data also reflects this reality. In sub-Saharan Africa, women with a history of sex work were 1.91 times more likely to experience coercion related to family planning in the last 12 months than women without a history of sex work. In Eastern Europe and Central Asia, women with a history of sex work were 1.5 times more likely to experience coercion related to family planning than women without a history of sex work. (16)

Among women living with HIV of reproductive age who participated in a Stigma Index 2.0 and reported engagement in sex work, reproductive coercion related to contraception and family planning in the last 12 months was reported by 2.7% of women in sub-Saharan Africa, 5.1% of women in Eastern Europe and Central Asia, and 13.7% of women in Latin America. While reproductive coercion related to pregnancy and feeding practices in the last 12 months was also comparably high with 6.3% of women in sub-Saharan Africa, 9.8% of women in Eastern Europe and Central Asia, and 11.6% of women in Latin America reporting. Additionally, 1% of women in sub-Saharan Africa; 5% of women in Eastern Europe and Central Asia; and a concerning 20.7% of women who reported engagement in sex work in Latin America reported experiences of reproductive coercion related to sterilization in the last 12 months. (Figure 6).

Figure 6.

Experiences of reproductive coercion with the last 12 months among women sex workers living with HIV across phases of SRHR care, by region, from 2020 to 2023



Stigma Index 2.0 Analysis: Reproductive Coercion Experienced by Women with Disabilities Living with HIV

In all categories, the number of reports of coercive practices by women living with HIV who also have disabilities is consistently higher than from their counterparts without disabilities. Women living with HIV who also live with disabilities in Latin America report higher levels of coercive practices across the board than women in Eastern Europe and Central Asia and sub-Saharan Africa.

Reproductive coercion experienced by women with disabilities is higher around pregnancy and infant feeding: 11.2% of women in sub-Saharan Africa; 9.01% of women in Eastern Europe and Central Asia; and 24.6% of women in Latin America in the last 12 months (Figure 7 and Table 5). Experiences of reproductive coercion related to contraception and family planning within the past year included 3.6% of women in sub-Saharan Africa, 6.9% of women in Eastern Europe and Central Asia, and 19.4% of women in Latin America. Nearly 2% of women in sub-Saharan Africa, 2.8% of women in Eastern Europe and Central Asia, and a concerning 20.3% of women in Latin America reported experiences of reproductive coercion related to sterilization in the last 12 months.

Figure 7.

Experiences of reproductive coercion within the last 12 months among women with disabilities living with HIV, by region, from 2020 to 2023

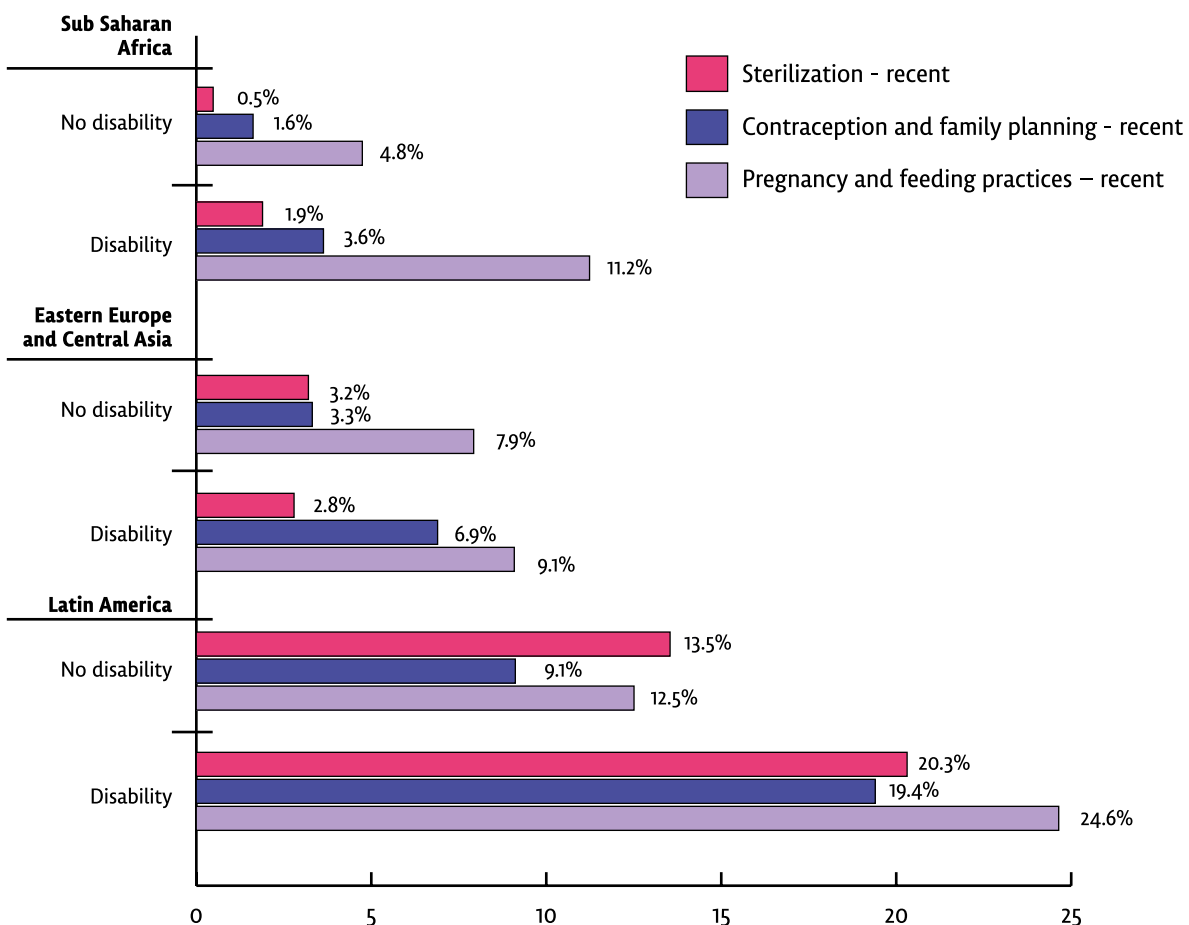


Table 5.

Experiences of reproductive coercion experienced by women living with HIV with disabilities, by region, from 2020 to 2023

	Sub Saharan Africa				Eastern Europe and Central Asia				Latin America			
	No disability		Disability		No disability		Disability		No disability		Disability	
Reproductive coercion	%	n/N	%	n/N	%	n/N	%	n/N	%	n/N	%	n/N
Sterilization: recent	0.5	39/7965	1.9	9/474	3.2	64/1991	2.8	3/107	13.5	138/1019	20.3	13/64
Contraception and family planning: recent	1.6	133/8177	3.6	18/495	3.3	71/2141	6.9	8/116	9.1	98/1075	19.4	13/67
Pregnancy and feeding practices: recent	4.8	389/8186	11.2	56/498	7.9	167/2107	9.1	10/110	12.5	35/1079	24.6	17/69

Stigma Index 2.0 Analysis: Reproductive Coercion Experienced by Women Who Use Drugs

Women living with HIV who have a history of drug use report higher levels of experiences of reproductive coercion than their non-drug using counterparts. Among women living with HIV of reproductive age who participated in a Stigma Index 2.0 and report illicit drug use, 4.4% of women in sub-Saharan Africa; 5.0% of women in Eastern Europe and Central Asia, and 11.4% of women in Latin America reported experiences of reproductive coercion related to contraception and family planning in the last year and 1.8% of women in sub-Saharan Africa, 3.8% of women in Eastern Europe and Central Asia, and 27.3% of women in Latin America reported experiences of reproductive coercion related to sterilization in the last 12 months. Among women living with HIV of reproductive age who participated in the study and report drugs, 10.5% of women in sub-Saharan Africa, 9.2% of women in Eastern Europe and Central Asia, and 22.9% of women in Latin America reported experiences of reproductive coercion related to pregnancy and feeding practices in the last 12 months (Figure 8 and Table 6).

Women in this group in sub-Saharan Africa are 3.16 times more likely to report forced sterilization in the last 12 months, 2.45 times more likely to report recent coercion related to family planning, and 2.08 times more likely to report recent coercion related to pregnancy than women living with HIV without a history of drug use. In Eastern Europe and Central Asia, women in this group are two times more likely to report forced sterilization in the last 12 months, 1.2 times more likely to report recent coercion related to family planning, and 1.77 times more likely to report recent coercion related to pregnancy than women living with HIV without a history of drug use. (16)

Figure 8.

Experiences of reproductive coercion within the last 12 months of women living with HIV who inject drugs by phases of SRHR care, by region, from 2020 to 2023.

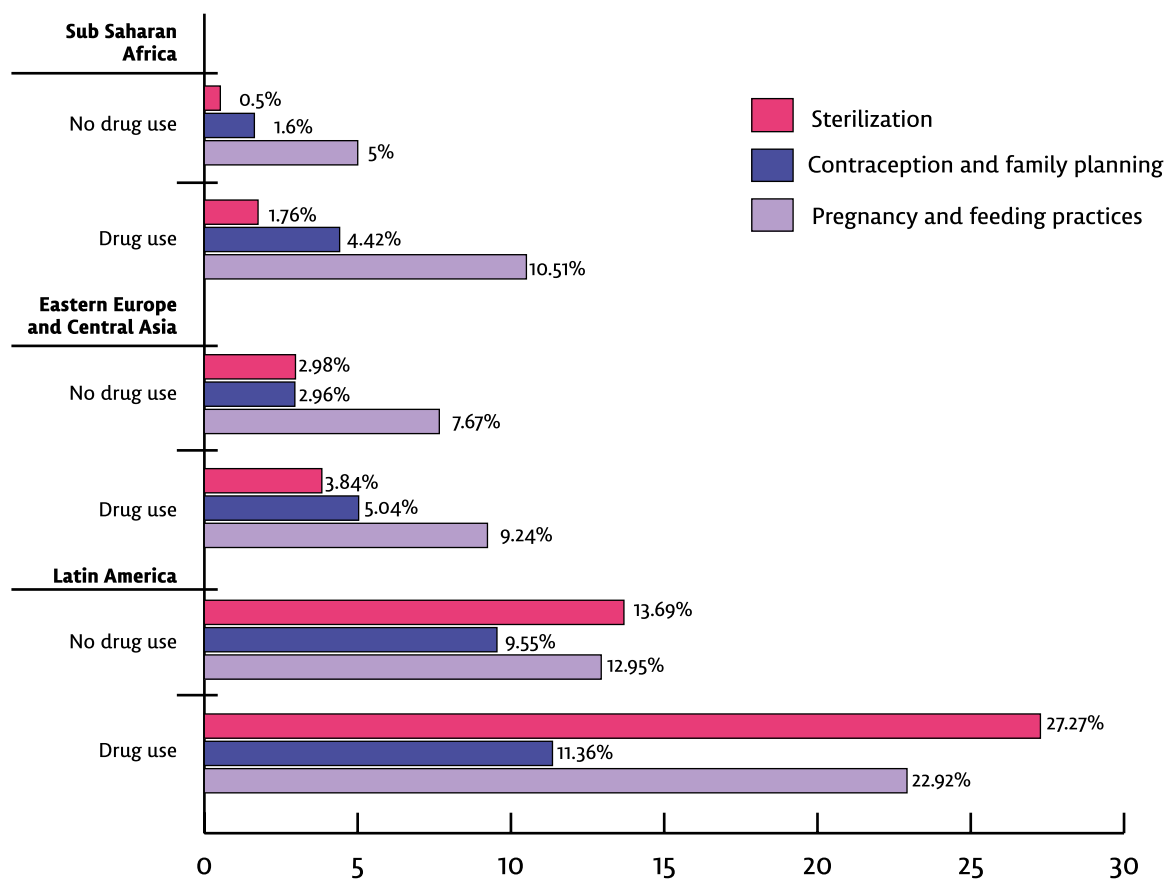


Table 6.

Experiences of reproductive coercion of women living with HIV who inject drugs within the last 12 months

Reproductive coercion	Sub-Saharan Africa				Eastern Europe and Central Asia				Latin America			
	No drug use		Drug use		No drug use		Drug use		No drug use		Drug use	
	%	n/N	%	n/N	%	n/N	%	n/N	%	n/N	%	n/N
Sterilization	0.5	42/1883	1.8	5/284	3.0	43/1442	3.8	22/573	13.7	140/1023	27.3	12/44
Contraception and family planning	1.6	133/8104	4.4	13/294	3.0	46/1556	5.0	31/615	9.6	103/1079	11.4	5/44
Pregnancy and feeding practices	5.0	407/8121	10.5	31/295	7.7	117/1525	9.2	56/606	13.0	140/1081	22.9	11/48

Stigma Index 2.0 Analysis: Reproductive Coercion Experienced by Migrant Women in Sub-Saharan Africa, Eastern Europe and Central Asia

Migrant women living with HIV experience intersectional forms of discrimination and are often invisible. Among migrant women living with HIV in sub-Saharan Africa, 2.8% reported recent coercion to sterilize, 5.4% reported recent coercion related to family planning, and 15.5% reported coercion related to pregnancy. In sub-Saharan Africa, migrant women were 6.6 times more likely to experience forced sterilization than non-migrant women. In this same region, migrant women were 2.6 times more likely to experience coercion related to family planning, and 2.9 times more likely to experience coercion related to pregnancy. At the time of this study data on Latin America were not yet available.

Among migrant women living with HIV in Eastern Europe and Central Asia, 1.7% reported recent coercion to sterilize, 3.3% reported recent coercion related to family planning, and 6.2% reported coercion related to pregnancy. In Eastern Europe and Central Asia, migration status was not associated with an increased experience of reproductive coercion (16). At the time of this study, data on Latin America were not yet available.

Stigma Index 2.0 Analysis: Reproductive Coercion Experienced by Young Women in Sub-Saharan Africa, Eastern Europe and Central Asia

Among young women living with HIV aged 18–24 in sub-Saharan Africa, 0.9% reported recent coerced sterilization, 2.8% reported recent coercion related to family planning, and 6.2% reported coercion related to pregnancy. In sub-Saharan Africa, young women were 1.7 times more likely to experience coercion related to contraception and family planning compared to women 25 years and older.

Among young women living with HIV in Eastern Europe and Central Asia, 0.9% reported recent coerced sterilization, 3.3% reported recent coercion related to family planning, and 9.8% reported coercion related to pregnancy. In Eastern Europe and Central Asia young women were 1.7 times more likely to experience coercion related to pregnancy (16).

Stigma Index 2.0 Analysis: Reproductive Coercion Experienced by Transgender men

Living with HIV of reproductive age who participated in this study, 3.0% reported experiences of reproductive coercion related to sterilization in the last 12 months. Among these men, 4.1% reported experiences of reproductive coercion related to contraception and family planning and 3.0% reported experiencing reproductive coercion related to pregnancy and feeding practices in the last 12 months. Further research is needed on the experiences of transwomen facing reproductive coercion as neither the Stigma Index study nor the qualitative study adequately captured these experiences due to the limited sample size.

As illustrated by Stigma Index 2.0 data, women living with HIV in key populations, including sex workers, women who use drugs, transgender people and women with disabilities, intersectional experiences of stigma and discrimination have resulted in even higher reported rates of coercion. Forced and coerced sterilization remains a legal requirement to transition for many people seeking to realize their true gender. (17)

Experiences of Mistreatment and Abuse

Reproductive coercion is just one form of mistreatment and abuse that women living with HIV face in the context of sexual and reproductive health and wider health services. Like reproductive coercion, other forms of mistreatment, abuse and violence are grounded in gender inequality, women's lack of bodily autonomy and discrimination related to their HIV status. This is also the case for gender non-conforming people (though this report does not fully address them).

ICW's qualitative study explored in depth the nature of mistreatment and abuse in sexual and reproductive health services that women living with HIV had faced within the past three years from 2020 to 2023. This timeframe is important to capture a broader range of experiences, especially among a smaller cohort, as women may not be using these services on an annual basis if mainly connected with fertility/pregnancy/childbirth. These forms of mistreatment and abuse are not only violations in their own right but also undermine the ability of women living with HIV to make informed decisions regarding their sexual and reproductive health rights.

The number of respondents reporting mistreatment in the qualitative study was particularly high for the following:

- Being talked badly about or gossiped about (45% of respondents).
- Telling other people about your HIV status without your consent (e.g. family, friends or community) (37% of respondents).
- Avoidance of physical contact with you/taking extra precautions (e.g. wearing double gloves) (31% of respondents).
- Verbal abuse (yelling, scolding, name calling, or being otherwise verbally abused) (25% of respondents).

The qualitative study explored the following forms of mistreatment:

Denial of services. Women living with HIV reported that health-care workers withheld relevant testing, treatment and advice, contraceptives and procedures. It includes referring women living with HIV to private services where they would have to pay more (despite the service being available at the clinic visited).

"I had vaginal bleeding, and the gynaecologist told me that they couldn't treat me, because I was living with HIV."

—A young woman living with HIV, Guyana

"I was denied certain laboratory tests aimed at planning pregnancy:

You have HIV. Why do you need these problems and risks?"

— A young woman living with HIV, Argentina

In some countries, women living with HIV report being taken off ARV treatment after they have given birth as the focus is solely on the health of the baby. The prioritization of the health of babies and partners at the expense of women's health came up repeatedly in key informant interviews. The supporting desk review for the study also concluded that prevention of vertical transmission was prioritized over the reproductive health needs and rights of women living with HIV.

Rude and judgemental behaviour. Nearly half of the respondents to the qualitative research survey and interviews said that health-care workers talked badly about them and gossiped. Women faced rude and judgemental reactions from health-care workers for seeking services that would enable them to safely have sex and reproduce. This appears to be driven by an erroneous view that women were putting partners and children at risk of HIV infection. Health-care workers also treated women as though they were potentially dangerous to them.

“When registering for pregnancy, the nurse in the doctor’s office told me about the risks that can occur after childbirth. She insistently repeated many times about abortion, she repeated so often that the child would be born handicapped, that people like me do not live long and who will then raise my child?”

— A young woman living with HIV, Belarus

Careless, neglectful and humiliating behaviour Women living with HIV described being left for hours for sexual and reproductive services without attention and assistance even when they were in pain and distress. They also described health-care workers not taking sufficient care when addressing their needs. A few women reported being subjected to personal examinations in front of other health-care workers and even other patients.

“In the last three years, I have experienced abuse in the sexual reproductive health service because of my HIV status. During an external examination, the doctor constantly expressed disgust, wore gloves even when he measured my blood pressure, although he examined other women without gloves. During childbirth, proper care was not applied to me, I did almost everything myself—I remember how hard it was for me to get up and no one even brought me a step, and in response to my request they told me: ‘What do you want, with your diagnosis, a nurse is afraid to approach’.”

— A woman living with HIV, Anonymous

Violations of confidentiality Over a third of qualitative survey respondents said that health-care workers told other people about their HIV status without their consent (e.g. family, friends, or community). Health-care workers could be careless and/or seemingly vindictive regarding women’s confidentiality when it came to their HIV status, sharing information in front of colleagues, or in non-private spaces. There were a number of examples of relatives being informed by health-care workers of a woman’s HIV status without their consent. In one incident, the health-care worker called the woman’s home, telling the family member who picked up the phone that she was from the AIDS centre. Women respondents spoke and wrote about the fear of familial violence and the abuse they were vulnerable to if family members found out about their status. Sometimes services were set up in such a way that it was hard for women to utilize the services confidentially.

“I noticed that many doctors do not know what confidentiality is.

There are always a lot of people, and when the door to the office is open, you can hear the doctors scream “Why are you sick? How did you get sick? From what year?”

—A young woman living with HIV, Kazakhstan

Partner notification. In some countries, health-care workers are required to notify women’s partners if they test positive for HIV. Partner notification (particularly if not done sensitively) can cause distress to individuals and lead to possible abuse from partners.

Judgemental advice/misinformation. Many women reported being told by health-care workers not to have sex after their diagnosis, or being advised not to have a child/children, or not to have another child. Coercion and denial of services are also examples of judgemental advice and/or misinformation, whether on the part of the provider or driven by community norms, service, or country level protocols.

“It seemed to me that other women were treated kindlier and with a smile, but they treated me somehow differently, with condemnation. I felt guilty. It was clearly based on my HIV status and pregnancy.”

—A woman living with HIV, Anonymous

Use of unnecessary precautions. Nearly a third of the respondents who took part in the qualitative research survey and interviews said that health-care workers avoided physical contact with them or took extra precautions (e.g. wearing double gloves). Women were sometimes charged extra for services, drugs and equipment that health-care workers said were needed because of their HIV status.

“She has been denied services, advised not to have sex, gossiped about or spoken badly of, and verbally and physically abused. Health workers avoided physical contact: ‘Nurses wore double gloves and were very suspicious’.”

—A woman living with HIV, Cameroon

Requirement that a relative be present or give permission. Young women (aged 18–24 years), in particular faced requirements to have a partner or parents present in order to access sexual and reproductive health services and reported health-care workers asking their partner or parents to give their views or make decisions instead of them in the past three years. Parental consent laws for minors are increasingly recognized as counterproductive to public health goals and to the well-being of young people.

“I was told I absolutely must be accompanied to SRH services by a partner or parent, and health workers asked them for opinions and decisions on my behalf.”

—A young woman living with HIV, Cameroon

Stigma Index 2.0 Analysis: A Look at Mistreatment in HIV and Non-HIV Care

Recent experiences of violence from health-care providers are only measured in the Stigma Index as self-reported denial of health services, verbal abuse and physical violence by a health-care provider while seeking HIV-related care and/or non-HIV related care in the last 12 months. It was challenging to identify whether individuals were seeking sexual or reproductive care. Nonetheless, it was important to explore gendered experiences of violence in the forms identified in the Stigma Index. Furthermore, the Stigma Index does not specify if non-HIV care includes sexual and reproductive health care, which is a well-documented area of coercion, mistreatment and abuse for women living with HIV in all their diversities. Survey questions on experiences of mistreatment in the health-care setting are only asked of individuals who received HIV or non-HIV related care in the last 12 months. However, individuals may have experienced mistreatment by health-care providers at an earlier stage in life, which may have resulted in their avoidance of seeking health care. Additionally, these questions would not be asked of individuals who were unable to access HIV or non-HIV services due to systematic discrimination. These considerations should be taken into account when interpreting these findings.

Recent experiences of violence by health-care providers towards those seeking HIV care are measured as self-reported denial of health services, verbal abuse and physical violence by a health-care provider for those seeking HIV-related care in the last 12 months. Recent experiences of violence by health-care providers while seeking non-HIV care are measured separately as self-reported denial of health services, verbal abuse, and physical violence by a health-care provider while seeking non-HIV-related care in the last 12 months. Verbal abuse is defined as yelling, scolding, name calling, or being otherwise verbally abused because of one’s HIV status. Physical abuse is defined as pushing, hitting, or being otherwise physically abused because of one’s HIV status (Figure 9–11 and Tables 7–8).

Confronting Coercion:

A global scan of coercion, mistreatment and abuse experienced by women living with HIV in reproductive and sexual health services

Figure 9.

Recent experiences of violence from health-care providers experienced by women living with HIV while seeking non-HIV care, by country, from 2020 to 2023

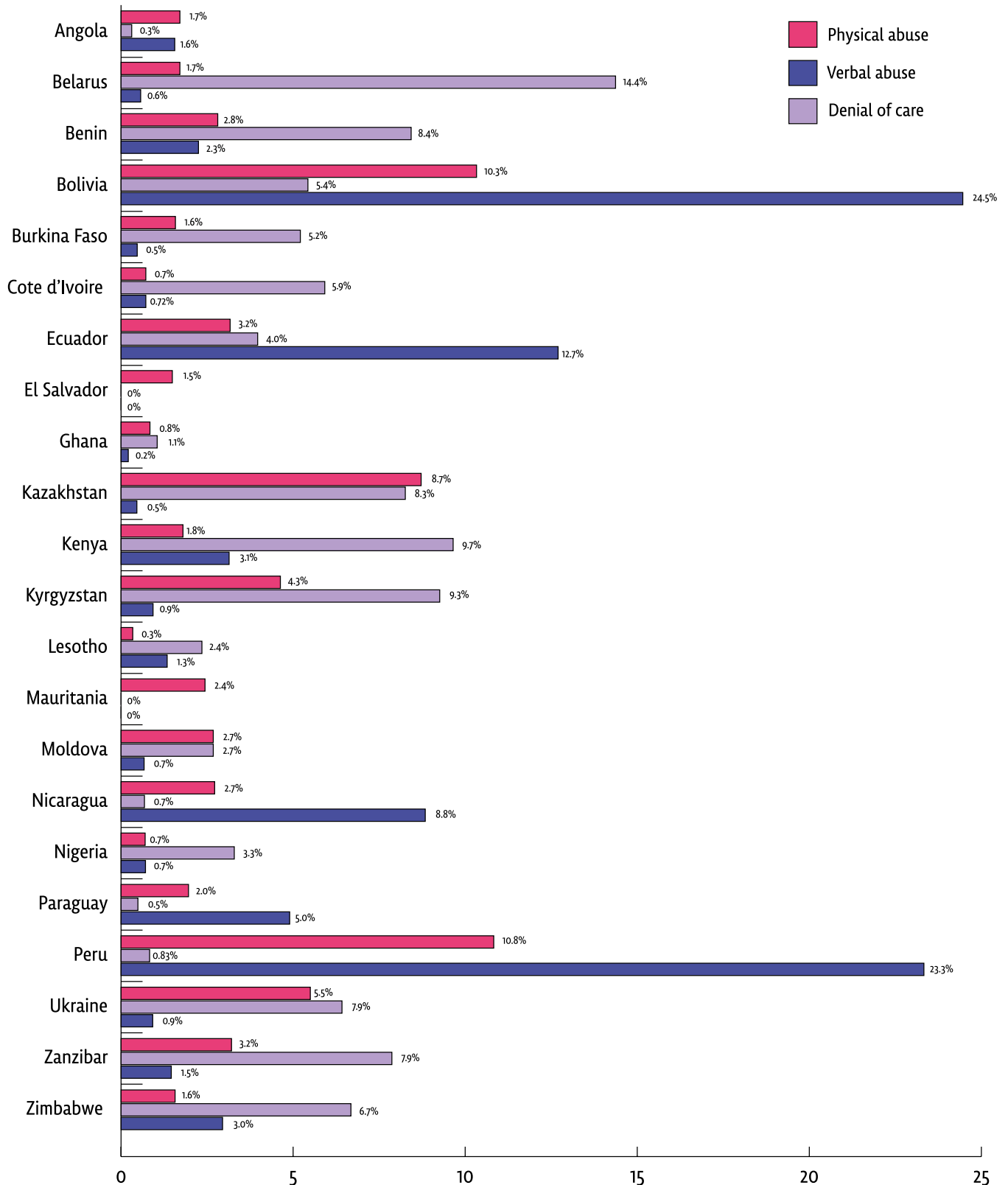


Figure 10.

Recent experiences of violence among women living with HIV by health-care providers while seeking HIV care, by region, from 2020 to 2023

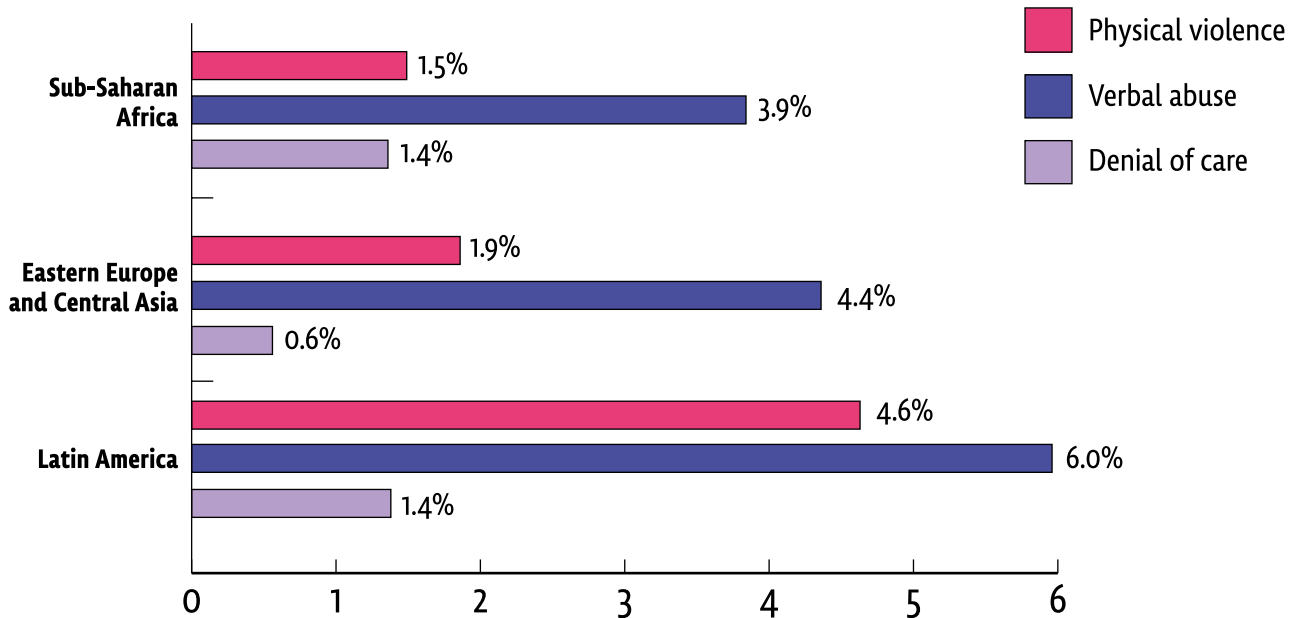


Table 7.

Recent experiences of violence by health-care providers towards those seeking HIV care

Violence in HIV care	Sub-Saharan Africa		Eastern Europe and Central Asia		Latin America	
	%	n/N	%	n/N	%	n/N
Denial of care	1.5	160/10 716	1.9	43/2316	4.6	77/1662
Verbal abuse	3.8	399/10 393	4.4	101/2316	6.0	99/1662
Physical violence	1.4	41/10 396	0.6	13/2316	1.4	23/1662

Figure 11.

Recent experiences of violence by health-care providers towards those seeking non-HIV care

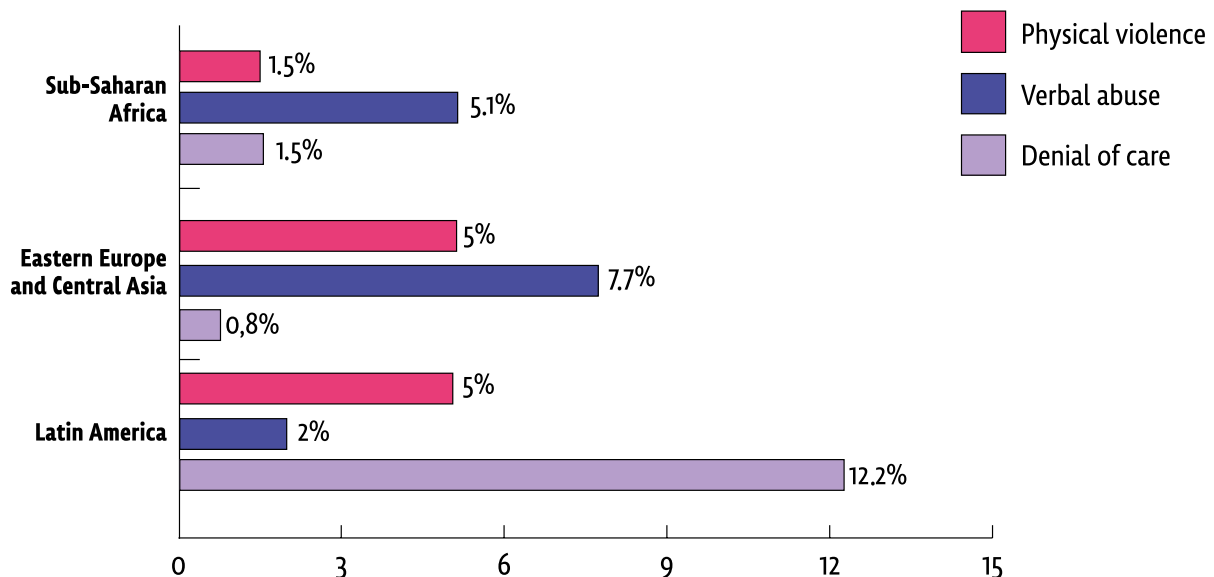


Table 8.

Recent experiences of violence by health-care providers towards those seeking non-HIV care

Violence in non-HIV care	Sub-Saharan Africa		Eastern Europe and Central Asia		Latin America	
	%	n/N	%	n/N	%	n/N
Denial of care	1.5	74/4999	5.1	61/1195	5	46/915
Verbal abuse	5.1	256/4998	7.7	92/1194	2	18/915
Physical violence	1,5	77/4994	0.8	9/1194	12.2	112/915

Coercive Practices in Context: Understanding the ways in which coercion is a systematic and structural problem reinforced by harmful social norms, discrimination and out-of-date policies and practices

As described in the previous sections, data from Stigma Index 2.0 and our qualitative study, as well as the scoping review conducted to inform this report, illustrate that reproductive coercion and mistreatment of pregnant women living with HIV are prevalent, normalized and happen in a context of policy failure. In other words, such practices occur where: harmful norms, stigma and discrimination persist; policies and guidelines are outdated; service providers are not required to acquire appropriate training; comprehensive sexuality education is not offered; a culture of mistrust has developed within services and institutions; service provision is inadequate; and where follow-up is limited (e.g. lack of follow-up for pap smears, lack of alternative infant feeding options, etc.). Coercion, mistreatment and abuse also occurs against a backdrop of harmful social and gender norms that influence the behaviour and attitudes of health providers, as well as the structure of care, all of which can make it very difficult (and undesirable) for women to follow advice (e.g. regarding breastfeeding or fertility choices).

Violations of informed consent are manifestations of the power imbalance between women living with HIV and their health-care providers.

Seeking informed consent from patients for medical procedures or treatments is a legal and ethical requirement (18,19). Our scoping review revealed evidence of the ways that violations of consent are both a physical and behavioural manifestation of the power imbalance between a doctor and patient (20). The experiences of reproductive coercion and mistreatment of women living with HIV, in sexual and reproductive health services, are driven by judgemental and discriminatory views regarding both how they may have acquired HIV and their perceived priority to prevent vertical transmission of HIV. These discriminatory attitudes are further compounded by gender discrimination and harmful and unevolved views about women in key populations. As a result, the choices, agency and autonomy of women and girls living with HIV are often denied.

The qualitative study survey and interviews, women living with HIV reported that experiences of coercion regarding their sexual and reproductive health options in services illustrated how **their ability to maintain their sexual and reproductive health and have safer sex lives and reproductive choices were severely controlled by health service providers in terms of conditional care and coercive pressure to accept specific contraceptive measures, birth and infant feeding options who hold the power in their interactions with women using the services.**

Women also reported in our qualitative study that information tended to be provided, but it was not always correct, comprehensive, or up to date. Advice for women living with HIV on having children, having sex, breastfeeding, vertical

transmission and transmission to a partner were reported as areas where frequently the information provided by health services was not always correct or current. Furthermore, when information and advice are provided without due respect being shown, the delivery of information itself is not always reassuring or is trustworthy, nor does it meet the requirements for informed consent.

The scoping review confirmed patterns of misinformation—many women living with HIV participating in a range of studies were told by their health-care provider that they must get sterilized because of their HIV status. Some women were told that people living with HIV should not have children and others were even told that they or their baby would die if they did not accept sterilization (21). Misinformation and intimidation tactics were used to make women sign consent forms, often when they were unable to give informed consent (10,22). Examples of violations mentioned across peer-reviewed studies examined in the scoping review and legal cases in Namibia and Kenya included falsified paperwork, signatures obtained under duress or while in active labour or in pain, and missing consent forms (23). Women were given either insufficient or wrong information about sterilization (e.g. that the procedure is reversible) and were not informed of their right to refuse the procedure (24). The power imbalance meant that women were afraid to ask questions of their health-care providers and feared retaliation if they did not accept their recommendation, including in the context of fertility counselling and antenatal care (25). Consent was also violated in more subtle ways across the other domains of reproductive health, for example when injectable contraceptives or condoms were presented as the only option or the best option, disregarding others that may better suit the needs of individual women. Studies in South Africa and Mexico explored the ways that coercion related to contraceptive options impacted future family planning decisions and autonomy in sexual negotiations with intimate partners (26, 27).

All women interviewed as key informants spoke about the **general culture within services that largely failed to support the sexual and reproductive health rights of women living with HIV** that enable fully informed choice, including continued coercion and mistreatment.

Women living with HIV **face contradictory pressures** that can range from being forced to adopt a specific service related to their sexual and reproductive health, such as long-acting contraception, to being completely denied options. These contradictions extend to life outside the service setting. Young women in Kenya spoke about the social pressure to 'procreate' when young and as soon as their viral load was suppressed, while at the same time being threatened by health workers that they could be sued for violating the Sexual Offences Act if they knowingly decided to get pregnant when their viral load was not suppressed.

Our qualitative study revealed that women may not always be aware of their rights and may expect certain negative behaviour from health-care workers. Health-care workers may also not recognize that their behaviour and attitudes are problematic. If women are not aware of their rights, reporting of rights violations will be low. When they do realize the treatment is wrong, they may feel that they are unable to do anything about it, or may be concerned that they can be further mistreated if they complain. This is true for all women, but for women living with HIV the risks are exacerbated by the stigma and discrimination related to their status.

Our research has found that sexual and reproductive health programmes, protocols and service providers often prioritize the best interests of others, including babies, partners, other health workers, and other service users to the exclusion of the interests, rights and autonomy of women living with HIV. Women experience this as coercion and mistreatment. The scoping review highlights how the medical needs and autonomy of women living with HIV are often set aside in favour of medical decisions in service of the foetus or newborn, thus creating an environment ripe for human rights violations. Advice not to have sex or to have children is based on the erroneous view that in doing so, women inevitably put others at risk.

Coercion as a result of prioritizing prevention of vertical transmission over the reproductive health rights of women living with HIV

Our scoping review found that women's reproductive rights and needs can be undermined by the country's programmatic priority to prevent vertical transmission of HIV during pregnancy, childbirth and breastfeeding. As countries feel the pressure to meet global targets, this can result in pressure on pregnant and breastfeeding women—to be tested for HIV (28), to initiate early and lifelong treatment (29), and to follow a particular method of infant feeding (30, 31). Many are also pressured by health-care providers to accept medical procedures such as sterilization. In the reviewed studies, the main rationale for these sterilizations was often to prevent vertical transmission of HIV. However, this rationale is not based on the most current guidelines, which recognize that sterilization is an elective contraceptive option which requires informed consent, should not be a requirement of accessing services and that forced or coercive sterilization is a form of violence (14) and focus on antiretroviral therapy for HIV to reduce viral load and minimize the risk of vertical transmission (9). Also, the focus on preventing vertical transmission is often at the expense of attention to the needs and reproductive health of women living with HIV and other reproductive health challenges for women living with HIV, such as access to safe and legal abortion and safety from domestic violence (11).

Coercive and abusive behaviour, including in sexual and reproductive health settings, has immediate, medium and longer-term impacts on women living with HIV

Many women in the qualitative study expressed negative emotions and impacts as a result of the experience of coercion and mistreatment, including pain, resentment and anger, frustration, emptiness and powerlessness. Some have expressed a fear of accessing services and, as a result, an intention to avoid these services. A number of women have to deal with not being able to have (more) children. Women who experienced coercion and abuse more than three years ago are still feeling the impacts. However, a number of women said that they no longer felt the impacts, and a few described their actions to find better treatment; some felt that the experience spurred a commitment to their rights and a desire to promote the rights of other women.

The data collected in this study reinforced this reality as a number of women spoke or wrote about experiences of coercion that they had experienced more than three years ago and shared that they were still living with the consequences of these rights violations.

Consequences of coercion on women living with HIV—as individuals, as partners, as a community

Our scoping review highlighted the many harrowing consequences of reproductive coercion, especially coerced or forced sterilization, at the individual, interpersonal and societal levels. Several qualitative studies and one set of clinical case reports investigated the aftermath of surviving forced and coerced sterilization, and these levels emerged from all three sources (32, 33, 34). At an individual level, consequences of forced and coerced sterilization include psychological distress, such as anxiety, depression, feelings of worthlessness, change in sleep patterns and self-blame. Women also reported physical health issues like heavy menstrual bleeding and severe pain. This in turn requires women to seek further health services, which can lead to discrimination and have an impact on their income and livelihood.

At an interpersonal level, women reported emotional abuse from their husbands and in-laws for not being able to bear children. Study participants noted that women are not expected to make major decisions without their husbands and reported that some husbands were angry with their wives for being sterilized, even though it was without her consent. Abuse, violence and estrangement were all common consequences women had to deal with because of sterilization.

At a societal level, women who have been sterilized reported facing discrimination and receiving poor services from health-care workers. Women can become social outcasts after sterilization and therefore will avoid disclosing their sterilization to partners and families, further compounding the stigma of living with HIV.

What good sexual and reproductive health care for women living with HIV looks like.

An understanding of good sexual and reproductive health and rights care, including where rights have been upheld within sexual and reproductive health services and where services are delivered without coercion, is essential to the development and implementation of good policy and practice that is aligned with global guidance and that will have a meaningful impact on reducing coercion, mistreatment and abuse in these areas of care and within the broader health-care system.

Experiences of good care include being:

- ✓ **Treated with kindness and respect.**
- ✓ **Able to access clear and unbiased advice and information (up to date and accurate).**
- ✓ **Able to access emotional support throughout the women's experiences of health services.**
- ✓ **Able to access peer support.**

There are currently good tools, developed and informed by women themselves including women living with HIV, such as the WHO Consolidated Guideline on SRHR of Women Living with HIV (9), which provides a comprehensive framework to address sexual and reproductive health and rights, including addressing violence in all its forms. However, given the testimonies of the women featured in this report, it is clear these guidelines have yet to be implemented.

Some women identified positive attitudes and behaviours by health-care providers. Basic respect, kindness, ability to interact with women in trauma-informed ways, confidentiality, support for women's autonomy/self-determination, and professionalism make a big difference for women in their experiences of services.

Although some women who answered the question about positive experiences said there were none, there were a number who had good experiences of sexual and reproductive health services at some point in their lives:

- *“My gynaecologist is always professionally loyal to me. He always checks for compatibility of the drugs he prescribes with antiretroviral therapy. And he is ready to support my second pregnancy when I want it.”*
- *“The positive thing was that I myself found a gynaecologist to participate in childbirth and paid her for it.”*
- *“While I was pregnant the doctors and nurses at the antenatal clinics were very nice and explained everything well.”*
- *“In my prenatal check-up at a primary care centre, I saw their willingness to care for women with HIV. This was public assistance in La Paz, Bolivia.”*
- *“Going through prevention of vertical transmission and seeing my babies coming out HIV negative... [this measure] is working.”*
- *“The services at the antenatal clinic are very good, with a conducive environment because the clinicians are well sensitized with HIV information.”*

Respondents also highlighted how being part of a women's HIV support network can improve their experiences with sexual and reproductive health services:

- *“Joining MENA Rosa in 2021 was the best thing and has affected and helped with my experience accessing services.”*
- *“Because of the psychological support of the MENA Rosa Foundation and receiving some good workshops from them, my life changed into a positive woman who helps others.”*

Participants in the qualitative study emphasized the importance of choice for women living with HIV and respectful care:

First, it should offer multiple choices for contraceptives, childbirth/delivery, infant feeding, unless there is specific, scientific advice and evidence.

—A woman living with HIV, Argentina

Telling somebody about the experience can be a positive experience, but many women do not feel comfortable sharing their experiences of coercion, mistreatment or abuse. This relates to telling friends, family and sometimes a support group. Telling someone can be therapeutic even if it does not lead to a change in the service where the abuse took place.

“When one woman found out she was pregnant, she was newly diagnosed, and the doctor told her ‘You have a choice, and these are your options’, and reassured her that this was her choice. He didn’t give advice or pressure—that was one particular woman and it stood out a lot. I had to interview five or six and only one could give such a positive response from a health-care provider.

—A woman living with HIV, Trinidad and Tobago

In some cases, it just took one key health-care provider, such as a gynaecologist, who treated women with respect and friendliness to change the culture of the service and women’s experiences of it.

“Today, mentalities have evolved considerably; we no longer encounter too many differences in care and treatment.”

—A woman living with HIV, Anonymous.

Women helped each other to seek out ‘friendly’ services that offered non-judgemental services and were driven by an understanding of the needs and priorities of women living with HIV.

The support provided by networks of women living with HIV is vital. Such support is largely holistic, wrap-around and non-judgemental, and stretches from personal, immediate first response action to strategic, preventive and widespread change, both within a woman’s life and across a country’s response. The work of women-led responses is persistently underrecognized and underfunded.⁷

Voluntary accompaniment by peers, relatives, or friends can make a big difference. Women shared their view that simply having someone trusted in the room and the other person offering health advocacy improved their confidence in asserting their rights and needs—though not when the accompaniers were making decisions for the woman. Younger women described being told they had to have someone with them as a condition of service access, which undermined their own decision-making. The right to accompaniment can come under threat during emergencies, for example in humanitarian or pandemic settings.

⁷As defined by UNAIDS, in a series of community Fireplace Conversations to develop an Operational Definition on Organizations & Responses Led by Women in the Context of HIV, women-led organizations and networks are those created and directed by a majority of self-identified women in all their diversity that work for these groups of women and other groups. They are entities whose governance, leadership, staff, spokespersons, members and volunteers reflect and represent the experiences, perspectives and voices of women in all their diversities and spectrum of ages and are accountable to them. Their experience is anchored in the lived experiences of women and girls, which reflect conditions of inequity and inequality that determine the organizations’ priorities. They speak for themselves and are an intrinsic part of the global response to HIV.



Women living with HIV face contradictory pressures that can range from being forced to adopt a specific service related to their sexual and reproductive health.

Confronting Coercion: How Women's Networks and Allies are Confronting and Transforming Coercive Practices, Mistreatment and Abuse

Women living with HIV and their networks have been leading critical but often under-resourced efforts to confront and transform coercive practices, develop infrastructures of mutual support for women living with HIV, and advance the human rights, particularly sexual and reproductive rights, of women living with HIV and women from key populations. Key Informant interviews with activists working to achieve sexual and reproductive rights identified that networks of women living with HIV utilize a range of advocacy strategies, including:

Conducting research and documenting human rights violations.

- Building intersectional movements to raise awareness and effect change.
- Challenging harmful policies and laws through litigation and law reform efforts.
- Working with policymakers and donors to influence their policy and practice.
- Bringing complaints via mechanisms through human rights bodies, multilateral treaty bodies and litigation.

Networks also play a key role delivering critical direct services to women living with HIV and women from key populations:

- Providing emotional support, including peer support.
- Helping women understand their sexual and reproductive health rights.
- Supporting women to understand their bodies and their right to pleasurable sex.
- Accompanying women to services.
- Supporting them through complaint procedures.
- Communicating information about health and relevant 'friendly' services.
- Working with health-care providers to heighten rights awareness and the experiences of women living with HIV.
- Developing self-help guides.

Despite raising the issue of coercion and mistreatment of women living with HIV in health services for decades, women's expertise and experiences are often ignored or marginalized in relevant decision-making areas and their concerns are subsumed under targets focused on access to services, testing, treatment and viral load suppression. The lack of funding and recognition of the work of networks and organizations led by women and girls living with HIV hamper the vital work they do.

Efforts by women-led responses to confront and transform coercive practices, mistreatment and abuse

Research and Documentation of Human Rights Violations

The women interviewed for this report all spoke about research their organizations and networks had conducted on the issue of reproductive coercion and mistreatment over the years of women living with HIV, including documenting specific cases. However, the findings in these reports and their accompanying recommendations rarely get the recognition they deserve. The research conducted by networks often provides an important qualitative complementarity to the largely biomedical, non-participatory research conducted by research institutes looking into HIV. For example, ICW East Africa has conducted research on the violation of sexual and reproductive health rights of women living with HIV in clinical and community settings in Uganda and specifically of sexual and reproductive rights violations against women living with disabilities (36).

ICW Caribbean: A Multi-country Human Rights Documentation Project

In September 2023, ICW Caribbean, Trinidad and Tobago Community for Positive Women (TTCW) and ICW Global conducted a study in four English-speaking countries of the Caribbean—St. Vincent and the Grenadines, Trinidad and Tobago, Jamaica, and Guyana—to document the experiences of women living with HIV who had given birth in the last one–five years.

The study provided an important space for sharing knowledge and information about sexual and reproductive health and rights for women living with HIV. Overall, the participants had limited knowledge of their rights, and many had questions, especially on their choices for family planning, birth options and infant feeding, especially in the light of U=U.

While participants spoke about positive experiences in the context of sexual and reproductive health and rights and maternal health care, many women also listed numerous examples of mistreatment or abuse. Women shared experiences of breaches of confidentiality regarding their HIV status and being subjected to judgmental attitudes and verbal or physical abuse by health-care workers. Some participants also shared experiences of neglect after giving birth. One of the common themes that emerged from across the countries was the pressure women living with HIV experienced on family planning, birth method and infant feeding. Many felt that they were not able to choose the option that would suit them best—they were either not given the options to choose from, pressured to adopt a certain method, or denied the option they wanted. The priority recommendations for the region that emerged from this forthcoming study include:

- Educating families, communities and health-care providers on sexual and reproductive health and rights and HIV.
- Ensuring that health-care workers provide respectful care to women living with HIV.
- Ensuring that women receive accurate information, choice, dignity and care with regard to infant feeding.
- Investing in women’s groups to provide information, support and champion human rights (37).

Peer Support

In-person and virtual peer support groups for women living with HIV provide an essential space for women to understand their rights, identify and speak about their experiences of coercion and mistreatment in health-care services. These spaces are often where women first realize that they are not the only ones who may have had a negative experience in the health-care setting. Networks also sometimes refer their members who have experienced coercion and abuse to organizations that can provide psycho-social support, counselling or support to seek redress.

Peer support is also important to inform women about their sexual and reproductive health and rights, enabling them to discuss issues they face and their worries, improving their self-esteem and informing them about the services available that will treat them with respect and understanding.

“Before we go for health care or to the health setting, we need to talk to our peers who have the same background, so that when we go for health care, we have knowledge about what services they offer, what kind of things we can ask them.

—A woman living with HIV, Indonesia

Ikatan Perempuan Positif Indonesia (IPPI): Peer Support and Law Reform

IPPI is an association led by women living with HIV that has a powerful history of addressing issues of violence against women living with HIV, providing essential psychosocial support to parents with children living with HIV and mobilizing communities through strengthening feminist leadership.

Its work includes sensitizing women living with HIV on their sexual and reproductive health rights, including on safe abortion and post-natal contraception which are rarely offered by health-care workers. It also sensitizes organizations offering sexual and reproductive health services to the rights, priorities and needs of women living with HIV.

IPPI and allies successfully advocated to include forced sterilization in the revisions of the draft law on sexual violence which was passed in April 2022. Their success was aided by their report to the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) on the issue and the recommendation from the CEDAW committee that forced sterilization should stop. IPPI subsequently developed guidelines on the issue. It is working to develop precedents and support the National Women's Commission to raise awareness of relevant laws among health service providers, since health services are where forced sterilization happens. IPPI also promotes legal literacy among women in their meetings.

The association runs the Amatler programme to support women during and after pregnancy to address the gap in information about their sexual and reproductive health rights:

“Our focus is not only to make sure the baby is born negative and the mother adheres to treatment, our objective and achievement is to make sure people know about forced sterilization, that they can access contraception after the pregnancy, etc.”

—Indonesia

However, there are no funds to support this type of work. In Indonesia, the Global Fund declined to support this work and the few resources provided to the Indonesian Ministry of Health never reached IPPI or its programmes for women living with HIV who are pregnant or with post-natal care. To date, no funding has been made available for IPPI's work through the Ministry of Health.

Self-Help Tools and Training

Networks of women living with HIV have also provided training and produced important guides and toolkits on the sexual and reproductive health and rights of women living with HIV, including the aforementioned WHO Guidelines on the Sexual and Reproductive Health of Women Living with HIV. In addition, many of the networks are working with health-care providers to establish dialogues and provide training on the sexual and reproductive health and rights of women and girls living with HIV. Such training and guidance can transform attitudes and practices of health-care workers:

“I have had a good experience when doctors have studied or trained, and during the meeting we had someone from women living with HIV groups to talk personally with them and have the opportunity to ask questions of women, to explain personal information. It helps them to better understand what these women feel when there is reproductive coercion. Sharing first-hand information is important.”

—A woman living with HIV, Ukraine

“In facilities where we regularly have dialogues, we’ve seen quite some change of attitudes. When health-care workers engage with the community, we see the difference. We see health-care workers who are passionate about supporting young mothers to be comfortable with services and have good outcomes.”

—A woman living with HIV, Kenya

Building intersectional movements and leading advocacy

Networks of women living with HIV have been at the forefront of building a movement for change at every level of the response to HIV and women’s rights, bringing wide-ranging policy and legal change as well as challenging discriminatory health-care environments and providing much needed peer support.

Yet within the HIV response, women living with HIV and women from key populations often find themselves ignored or under-supported and, as a result, it can be challenging to build effective movements for change. Women with intersectional identities, including women living with HIV, women who use drugs and sex workers, have also sometimes found themselves at odds with mainstream feminist movements which can be abolitionist in their views on sex work, and can have little to offer women persecuted and criminalized for drug use or indeed may not be inclusive of trans women.

Increasingly, networks of women living with HIV are rejecting ‘divide and conquer’ tactics to build solidarity and advance shared feminist advocacy. For example, in Ukraine (and in Honduras—see box below), networks of women living with HIV and networks of women in key populations have built strong intersectional movements to confront and transform the stigma, discrimination and rights violations experienced by women living with HIV and women who use drugs and sex workers seeking to realize their sexual and reproductive health and rights. These women have faced attacks on their rights to parent in Ukraine. Over a period of five years, Eurasian Women’s Network on AIDS and their allies formed an intersectional coalition in Ukraine that brought critical concerns about access to justice and to health to the

Committee on the Elimination of Discrimination against Women (CEDAW Committee). In 2022, this work paid off and the group was able to secure an important recommendation from the CEDAW Committee requesting that Ukraine: “Provide support to mothers with disabilities and mothers who use drugs and refrain from automatically depriving them of custody of their children (38).”

Fundación Llaves in San Pedro Sula, Honduras: Women Leaders Fighting for Justice

Fundacion Llaves (Key Foundation) has devised innovative ways to help women living with HIV understand their sexual and reproductive health and rights and ways they can help protect themselves from rape. The foundation has trained 30 leaders as facilitators of 20 self-help and peer education groups that are held in 6 of 18 Honduran administrative divisions. The Llaves team has designed outreach and self-help educational materials that support healing and well-being for women living with HIV who have also survived gender-based violence. In addition, they engage in mass media campaigns to promote sexual and reproductive health and rights for women living with HIV and, in particular, the right of motherhood.

Llaves also started a legal accompaniment process through which volunteers support women to realize their sexual and reproductive health rights and to confront stigma, discrimination and violence. The legal accompaniment programme has had the effect of recognizing and supporting women’s leadership in the community:

“Yesterday we had a new woman, and she is young, about 33 years old, and wants to be a mother, but her doctors have told her not to have kids because of her status, so we’ve been reading the materials with her, and told her U=U. Her face lit up when she heard us tell her that she CAN be a mum.”

- Honduras

Fundación Llaves has worked with allied organizations to stress the need for issues of coercion and mistreatment experienced by women, including women living with HIV, in health-care settings to be accurately understood as forms of violence, torture and cruel and inhumane treatment—and recognized as rights violations that must be stopped under international law. Advocacy by the network has also led to legislative reform, including decriminalizing HIV transmission and integrating reproductive health and gender-based violence in the Adult and Adolescent Patient Care Manual.

The efforts of Llaves to demand justice for women in Honduras who have suffered forced sterilization and who are experiencing other forms of coercion also reached beyond Honduras borders to the Inter-American Commission on Human Rights (IACtHR).

Maria’s Case

Maria, an Afro-descendant Honduran Garifuna woman living with HIV, was forcibly sterilized in 2005 in a public health institution when she was just 21 years old and giving birth to her first child (39). Health personnel told her that “women like you should not bring children into the world to die,” demonstrating the link between intersectional HIV-related stigma and being pregnant. Maria’s case is not isolated; six other cases of forced sterilization of young women living with HIV have been reported in Honduras between 2006 and 2020 (40,41). The network is currently preparing a study to document recent sexual and reproductive health rights violations.

Llaves and allies, supported by IPPF ACRO, submitted Maria’s case to the Inter-American Commission on Human Rights (IACtHR) for admissibility to the Inter-American Court of Human Rights (IACHR). As of this writing, the IACHR is expected to release a report about the issue of the sexual and reproductive health rights of women with HIV in Honduras.

Facing Retaliation for Speaking Out

Our qualitative research revealed the ways in which grassroots networks of women living with HIV often have valuable information and insights on individual experiences of rights violations and patterns of reproductive coercion, mistreatment and abuse. Our interviews revealed experiences of women who documented human rights abuses and sought to raise these issues via existing processes but who experienced retaliation for speaking out or feared such retaliation. There was general concurrence among the women we interviewed, that even if women did recognize coercion, mistreatment or abuse they did not feel they were able to challenge and this was particularly true if they were concerned about how they would be treated when they next accessed the services.

Some do, some don’t. Some realize they were treated unfairly but may not have the power to challenge back, or have anywhere to report or challenge the health-care workers, and maybe next time they will need the same health-care workers to work on them. Until they find an organization who can reach out to them.

—A woman living with HIV from Uganda

Our study revealed the harmful effect of preventing women and health-care providers from coming forward to report abuses.

WOMEN HUMAN RIGHTS DEFENDERS ON THE FRONTLINE: DENIALISM AND RETALIATION

Women living with HIV leaders and activists are not always engaged in important national or global policy processes. Even when women leaders are invited to these spaces their perspectives are not valued and worse they are sometimes reprimanded or silenced. One survey respondent described how she and a network of people living with HIV she represented had been silenced during a country process:

“I was the token woman with HIV. I was told I needed to be there but warned that I couldn’t speak and that I couldn’t raise concerns from my network. I tried to speak, to raise concerns about discrimination experienced by women, even to ask a question about breastfeeding, which is not allowed where I live, even though women may have undetectable viral load. I spoke up, saying we are not allowed to breastfeed, and the Ministry of Health leadership replied, ‘That is not true, we advise them not to’.”

“But it’s the same thing—women are given pills for the milk to stop; they check us in the home to make sure we don’t breastfeed our babies, so it’s totally not allowed. She couldn’t answer when we challenged her or asked her about the percentage of HCP who still tell women not to have babies, be sterilized, not breastfeed. They try to deny, saying we have our own way of doing things. I am now the enemy of the MoH.”

I am still facing retaliation, but I want to make sure that other women who want to raise concerns can strongly engage in dialogue with their health systems. Now I am trying to work with other countries on how we make sure that our voices are being heard and these things do not happen.”

Access to justice is vital, but reporting rarely provides justice or remedy.

Human rights principles provide a foundational right of access to justice for individuals who have experienced a rights violation and for those individuals to receive a remedy or redress. However, while human rights work often focuses on eliminating rights violations and changing policy and practice, access to justice falls short of realizing in practice the fundamental right of impacted individuals to a remedy (42). However, access to remedy and redress is an important aspect of healing and can create opportunities for trust building between individuals who have experienced coercion, mistreatment, or abuse and the health systems they rely on.

Data collected through the qualitative study indicate that it is very rare for a woman to agree to take forward a complaint and seek redress.⁸ Women living with HIV do not bring complaints for many reasons: complaints procedures can be lengthy; costly; and many women believe that ultimately filing a report would be futile as nothing would come of it. Reporting at any level—including service level, community level, or through legal channels—does not necessarily mean healing and recovery even if some form of redress is achieved. Reporting and response mechanisms are rarely

⁸Currently, the Stigma Index 2.0 does not include data on women’s access to justice for violations of SRHR.

survivor-centred: women do not tend to believe that reporting coercion and abuse will lead to anything and do not trust the system or feel it is safe for them. Some stated that because of their previous experiences, they were expecting 'the same or worse' treatment and approached future interactions with health-care workers with that fear.

No response was made but the staff treated us worse after they heard of the complaint.

—A woman living with HIV, Egypt

The staff cover each other and in the end I was harmed and looked bad and it was worse for me that the attention I received was in a bad way.

—A woman living with HIV, Bolivia

Women living with HIV expressed fears of having their HIV status exposed, or facing repercussions such as backlash from service providers on whom they depend. As a result of these beliefs and experiences, the majority of women in the ICW study did not report experiences of coercion, or other abuse and mistreatment they experienced from the service or to any other institution. Of the small group of women who did (7.32%, 28 respondents) report, less than half (3.9%, 11 respondents) received a satisfactory response and of these responses the satisfactory ones were supported by peer networks.

Women who received support from a peer network to file a complaint overwhelmingly appreciated this support. Women who make complaints can face repercussions at the service level by being labelled as difficult or just find that their complaints are ignored. Pursuing a complaint can be lengthy and costly, with the possibility of exposing the HIV status of those involved. Many advocates acknowledge the difficulties of long-term legal processes and suggest that the women they support may not be ready to take on legal cases:

“If they are ready to protect their rights in a court, we do not have this yet in Ukraine, but I think we could get this in the region—maybe in some countries there could be court cases protecting the rights of women with HIV. But not all women are ready to do this in a court.”

—A woman living with HIV activist, Ukraine.

Litigation is often considered as the primary strategy to achieve justice, but high barriers to entry for legal cases, in particular, has meant that relatively few cases have been brought to the courts. Those that have been brought through the courts can take many years before there is a judgement and/or remedy, and then relatively few women may directly benefit. As a result, for the vast majority of women living with HIV who have experienced coercive practices, mistreatment or abuse, access to justice remains elusive (43). Recent successful litigations in Kenya in which the ICW was an interested party, established a critical connection between discrimination and the forced sterilization of women living with HIV (). However, after this eight-year effort, it remains to be seen how other women living with HIV across Kenya who may have experienced coercive practices will ever receive meaningful access to justice.

Governments and international actors should also consider supporting communities and health-care systems in creating alternative avenues to justice for women living with HIV who have experienced rights abuses in these systems recently and historically. Networks are already assisting women through complaints processes at the health clinic level where these processes are available.

ADVANCING ALTERNATIVE ROUTES TO JUSTICE

In March 2015, ICW and allies filed a strategic complaint with the South African Commission of Gender Equality (SA-CGE) on behalf of women living with HIV who were sterilized without their informed consent. The complaint documented the experiences of women living with HIV whose rights were violated when they were subjected to forced and/or coerced sterilization in public hospitals and requested general and specific relief to achieve justice for these women as defined and identified by the women themselves.

The complaint was the result of many women reporting to ICW that they were coerced and forced at State hospitals. The strategy behind the complaint was that these women faced high financial and other barriers to litigation through the courts.

ICW and allies requested that the SA-CGE undertake an investigation into the prevalence of forced and coerced sterilization in public hospitals. The SA-CGE investigative report, released on 24 February 2020, found that women living with HIV were not provided with adequate knowledge of the sterilization procedure before being asked to consent, which violated their right to information. Furthermore, the report stated that: the women were not advised on other methods of contraception; medical staff breached their duty of care to the women; and the women could not reasonably be said to have consented to the procedure and therefore were forced and coerced into being sterilized.

Among other demands, the SA-CGE called upon the South African National Department of Health to facilitate dialogue between themselves and the women who brought the complaint to find ways of providing redress to the complainants. ICW legal counsel supported these initial negotiations with the South African National Department of Health and engaged the women directly in these negotiations to ensure the remedy and outcomes met the needs of women and that the process was accountable and provided justice for women living with HIV in South Africa.

Although the entire process took eight years, women whose rights were violated finally had the possibility of receiving tailored remedies through an alternative process that would respond to their individual definitions of remedy. For example, some women living with HIV wanted children and requested clinical interventions, which included medical examinations, assisted reproduction, medical consultations, surrogacy, and medical treatment required as a result of the sterilization. Many are also seeking compensation.

This case shows that collaborative and strategic advocacy by networks of women living with HIV can produce dramatic shifts in the government's willingness to make needed policy changes and provide remedy and redress. Efforts to confront and transform stigma and severe forms of intersectional discrimination experienced by women living with HIV in health-care settings can benefit from utilizing entities, such as national human rights institutions and gender equity commissions to support demands for dialogue and processes for justice.

As an alternative to traditional litigation, health systems can engage in processes to respond to reports of rights violations and develop a process with individuals who have experienced rights violations to provide rapid access to justice, including to remedy and redress (49).

Recommendations

The findings light the path for a series of critical recommendations aimed at donors, governments, including Ministries of Health, health-care providers and organizations working in HIV, sexual and reproductive health rights and violence against women and girls in order to eliminate coercive practices, mistreatment and abuse in HIV care, including in sexual and reproductive health and reproductive, maternal, newborn and child health settings.

1. Take urgent steps to achieve a culture shift and transform harmful dynamics in health-care.

- Recognize the impacts of harmful power dynamics and take steps to effect policy and culture shifts to transform these power dynamics in health-care settings, through awareness raising, establishing zero tolerance for misogynistic, sexist comments and paternalistic practices and review policy and practice with a view to prioritizing the agency and bodily autonomy of women living with HIV through policy improvements, training and accountability practices.
- Confront denialism in health-care settings, by recognizing that these practices continue to occur on a consistent basis and that such experiences are the result of systemic failures and not just the work of one or two 'bad apples' or health-care providers with outdated viewpoints.
- Support health-care providers and staff in better understanding gendered and intersectional power dynamics in the health-care worker/patient relationship and delivering woman centred and trauma-aware care, including by integrating intersectional gender and human rights modules into pre- and in-service training curricula and creating effective and accessible accountability mechanisms.

2. Respect, protect and fulfil sexual and reproductive health rights in policy and practice.

Take urgent steps to respect, protect and fulfil the rights of women living with HIV to make informed and uncoerced decisions about their sexual health, reproductive health, contraception, pregnancy and medical care, and the care of their children.

- Ensure that there are clear, written policies requiring that informed consent that meet with international standards on informed consent; ensure that women are provided with accurate and unbiased information about their options, including the risks and benefits; ensure that they have time to consider these options; and ensure that they are able to make informed and autonomous choices.
- Update policies regarding infant feeding and birth options; ensure that all staff are aware of the updated guidelines.
- Eliminate punitive policies and practices, including coercive monitoring and surveillance of infant feeding, and work with departments of justice to reform laws that punish or criminalize women living with HIV who are exercising their sexual and reproductive health rights, including making informed infant feeding choices.
- Take a public position as a Ministry of Health that criminalization of HIV status is counterproductive to public health goals.
- Support sexual and reproductive health services to implement the WHO consolidated guideline on SRHR of women living with HIV, and the use of the related Checklist (48) for community engagement to implement the WHO Consolidated guideline on sexual and reproductive health and rights of women living with HIV.

3. Increase rights knowledge amongst women living with HIV and women from key populations.

- Invest in ensuring that women living with HIV and health providers know and are supported in realizing their human rights to informed consent, bodily autonomy, and stigma free care at all levels of sexual and reproductive health care.

4. Support additional research on coercive practices and documentation of rights abuses.

- Expand, standardize and consistently invest in data collection on experiences of stigma and discrimination, mistreatment and abuse, including in sexual and reproductive health services among women living with HIV, particularly reproductive, maternal, newborn and child health and prevention of vertical transmission services

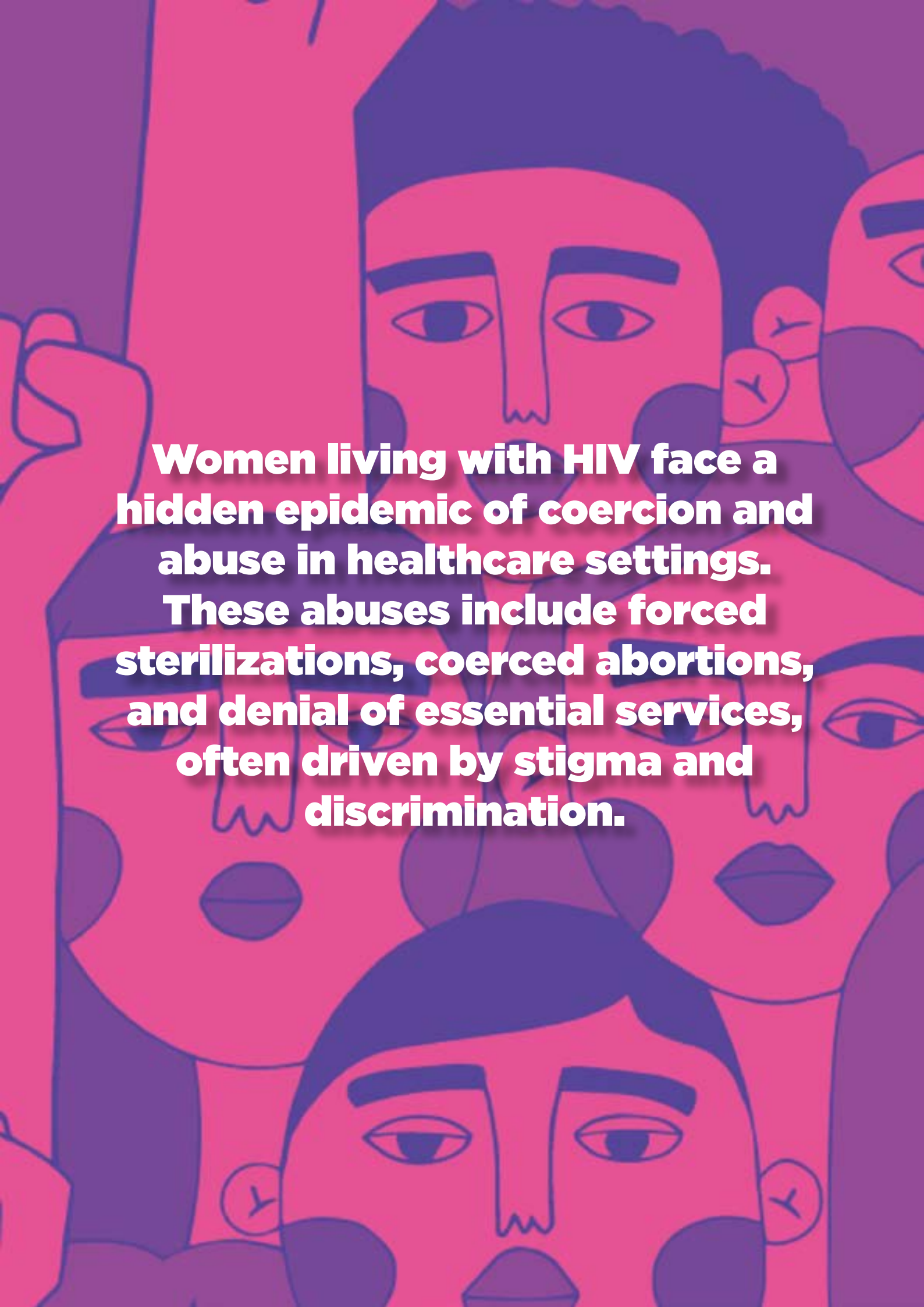
- Ensure that the research includes women who have had experience with relevant services.
- Establish women-led community monitoring practices to provide critical feedback and insight into the health-care system and service provision.

5. Increase avenues for access to justice for all women.

- Take reports of rights violations by women seriously and urgently, including by women living with HIV and women from key populations, on negative experiences in health-care settings, including coercive practices, stigma, discrimination, mistreatment and abuse, and recognize that such experiences are often underreported.
- Co-create alternative resolution mechanisms working with communities of women living with HIV and women from key populations to ensure that women who have experienced rights violations can access tangible remedy and redress without resorting to costly and time consuming litigation.
- Scale up or establish functioning, independently monitored complaint mechanisms with a patient advocate component for those reporting rights violations that include pathways to remedy and redress. Complaint mechanisms and processes should include psychosocial and rights training components and should work collaboratively with local support organizations for women living with HIV and networks of women living with HIV. Complaint mechanisms should also include consequences for health-care providers who violate the rights of patients including women living with HIV.
- Ensure that complaint mechanisms collect and publish data on the number and type of complaints received as well as their dispositions, for evaluation and other purposes.
- Recognize past abuses and the history and impact of coercive practices on the rights and well-being of women living with HIV and women from key populations and create opportunities for healing and reconciliation with women harmed by these practices.

6. Invest in efforts led by women living with HIV and women from key populations

- Establish advisory groups of women living with HIV to support stronger community engagement and feedback directly from service users.
- Protect women living with HIV human rights defenders by establishing whistleblower policies that incorporate a policy of zero tolerance for retaliation against those reporting concerns and violations.
- Recognize and fund the work of networks of women living with HIV; offer peer support; conduct community monitoring; and sustain demands for justice and remedy. In alignment with UNAIDS Global Strategy Goal to ensure that 80% of services for women are women-led, ensure that women living with HIV have the knowledge and skills to develop and implement programmes that address women's sexual and reproductive rights and their mental health needs.



Women living with HIV face a hidden epidemic of coercion and abuse in healthcare settings. These abuses include forced sterilizations, coerced abortions, and denial of essential services, often driven by stigma and discrimination.

Annex 1: Methodology

This report was developed using a mix of methodologies, including qualitative and quantitative research methodologies, and combines insights gleaned from the ongoing People Living with HIV Stigma Index 2.0 (Stigma Index 2.0) peer-led research as well as qualitative elements and a scoping desk review of existing literature and data on these topics. ICW also carried out qualitative work to capture the experiences of women living with HIV and ensure that women's voices are well represented in the research. This annex provides additional information on participants' backgrounds and methodology.

The process was guided by a global steering committee of 16 women living with HIV who are part of networks and organizations working to support the sexual and reproductive health and rights of women living with HIV in their diversity.

The study is composed of three concurrently designed elements:

1. A gendered analysis of recent data from the Stigma Index. ICW is a founding member of the International Stigma Index Partnership (ISIP), which manages the People Living with HIV Stigma Index 2.0. The ISIP is led by GNP+, ICW and UNAIDS, with technical support from Johns Hopkins University (JHU). For this report, a team from JHU led by Carrie Lyons and Gnilane Turpin conducted a focused gendered analysis of recent Stigma Index 2.0 data from 23 available implementations completed within the past three years, from 2020 to 2022, representing three regions: sub-Saharan Africa, Latin America and Eastern Europe and Central Asia and over 26 500 women who participated in these implementations.

2. A scoping review of existing literature and data on these topics. The scoping review was led by Althea Wolfe along with the JHU team (Carrie Lyons, Gnilane Turpin, Uma Bhatt and Danielle Lonbong Njiometio). It consisted of the development of search terms designed to capture literature on individual subtypes of reproductive coercion, as well as coercion more broadly. The literature search included articles published between 2011 and 2022.

3. The qualitative component included multiple elements:

a. Key informant interviews: We interviewed 11 women who are part of networks and organizations of women living with, HIV to explore the wider context of reproduction coercion and abuse in the countries and regions within which they work.

b. Online survey: ICW developed and conducted an online survey to enable women, trans and gender non-binary people living with HIV who have experiences of coercion and mistreatment in sexual and reproductive health services within the last three years (2020–2022) to share information about their experiences. The research team, led by Emma Bell, analysed responses in the survey to understand the current nature and scope of such mistreatment and its impacts. The survey was administered in five languages: Arabic, English, French, Russian and Spanish. It was circulated among networks of women living with HIV, resulting in 167 responses that were utilized in the analysis.

c. In-depth interviews and consultations: Twenty-six in-depth interviews and local consultations in five countries were conducted using an adapted version of the online survey as a guide, to permit a deeper study into the experiences of women living with HIV. Two of the interviews were conducted prior to the commencement of the project and served as a catalyst for the project itself.

d. Case study development: Key informant interviews were conducted with women living with HIV activists and advocates to explore current responses to coercion by grassroots networks and to develop some short case studies on existing responses.

Study Limitations

Despite the utilization of diverse research methodologies to explore and triangulate experiences of coercive practices, mistreatment and abuse, several limitations to this study must be acknowledged.

While the research provides important insights into the ubiquity of coercive practices mistreatment and abuse, it is important to note that the data is limited in its ability to give a precise measurement or estimate of occurrence frequency, or rather the extent of coercive practices, mistreatment or abuse in health-care settings due to sample size limitations. A key example is that while the Stigma Index 2.0 collects reports of experiences of coercive practices in sexual and reproductive health-care settings and particularly maternal health settings, the Stigma Index 2.0 does not capture utilization of such services which means that this data point underestimates the percentage of individuals utilizing these services and having an experience of coercion, mistreatment and/or abuse.

While measures were taken to ensure confidentiality and encourage honest responses, the sensitivity of the subject matter may have led to incomplete or non-disclosure of information by participants resulting in a further underestimation of certain findings. Across Stigma Index 2.0 implementations and the qualitative survey efforts were made to recruit a diverse sample, yet there is underrepresentation of certain groups which may impact the generalizability of the results. The available data does provide some insights regarding the lived experiences of transgender people who responded to the Stigma Index 2.0, the relatively small sample size means data interpretation is limited. These limitations should be considered when interpreting the results of this study. Future research should aim to address these gaps.

Ethical considerations across methodologies:

Stigma Index: For each Stigma Index study, approval for each implementation was obtained through the national ethical review board or equivalent body in its respective country. Everyone involved in the research, were required to sign a confidentiality agreement. All participants provided informed consent before taking part in the study. In some cases, if the implementation was funded by an international organization, the protocol would also have been reviewed by the organization's review board.

Qualitative study: Ethical considerations underpinned all aspects of the work, including 1. the anonymous, online survey, 2. zoom interviews conducted by the project team, and 3. in-person interviews and focus groups conducted by ICW women (mini-consultations).

Steps to ensure ethical considerations:

- Procedures to ensure anonymity, confidentiality and privacy of participants, informed consent and reduction of direct and indirect risks were adhered to in all countries and in the online survey.
- The online survey was anonymous and provided a contact email for ICW for any questions or concerns. It was made clear that questions were not compulsory. A section on rights in respect to reproductive coercion was included.
- Interviews were with key informants who were all ICW country contacts with significant experience of SRHR advocacy, peer support, and work on reproductive rights and coercion. Interviewees were not asked about their own experiences of reproductive coercion, but about their knowledge and understanding gained from their work as ICW focal points.

- Particular attention was paid to the safety and well-being of participants in focus group discussions and one to one interviews (that were part of the mini-consultations). These focus groups and interviews were run by women who are part of ICW, and also linked to local and national support networks. They all have experience of supporting women living with HIV and linking them to other relevant support. The women they spoke to are also already embedded in and linked to these support networks.
- The right of respondents to stop the interview or their participation in the focus group at any time and not to answer any question was emphasized.
- Women were provided with information about the study and its implications through various means (verbal and written) and at various times, including at meetings with organizations of people/women living with HIV.
- Measures to minimize unintentional harm included maintaining an open dialogue environment with open questions, thus avoiding re-victimization, stress, distress or discomfort to participants. Interviewers and focus group facilitators were guided to provide referrals to ICW for anyone needing further support and advice and onward referral.

The project team provided technical support to the ICW women who carried out focus groups, including: Technical aspects of development of focus group sessions and interviews. Supervision and technical assistance to focus group and interview facilitators, including self-care strategies for interviewers and focus group facilitators, and having in place crisis intervention plans and referrals to ICW for further support.

Each research element is described in more detail below:

The People Living with HIV Stigma Index 2.0 (Stigma Index)

The Stigma Index is a standardized tool to gather evidence on experiences of stigma and discrimination, and how stigma and discrimination impacts the lives of people living with HIV. As of 2022, more than 100 countries have completed the study and over 100,000 people living with HIV have been interviewed. Importantly, the PLHIV Stigma Index implementation puts people living with HIV at the centre of the study design, data collection, analysis, interpretation, and advocacy process.

The people living with HIV Stigma Index 2.0 sampling approach combined limited chain referral sampling alongside venue-based sampling in order to reach people living with HIV both connected and not connected to existing networks. Broadly, the sampling plan included proportional sampling at geographic sites and leveraging social networks for limited chain-referral sampling. Venue-based sampling was conducted through time-location sampling and a two-stage sampling design. To complement the venue-based sampling, limited chain-referral sampling was used to support generating additional diversity of the sample.

Survey data for this analysis was collected between 2020 and 2023 depending on each country specific timeline. Data were collected through interviewer-administered socio-behavioural questionnaires conducted by trained members of people living with HIV networks. Inclusion criteria for participation were: ≥ 18 years of age; aware of HIV positive status for >12 months; mentally sound and capable of providing consent; spoke the dominant language; and provided informed consent.

	Year	Total
Angola	2024	828
Belarus	2022	754
Benin	2021	1230
Bolivia	2023	945
Burkina Faso	2021	2338

Cote D'Ivoire	2022	2244
Ecuador	2023	751
El Salvador	2023	766
Ghana	2020	2066
Kazakhstan	2020	1172
Kenya	2021	2125
Kyrgyzstan	2020	708
Lesotho	2020	1481
Mauritania	2021	664
Moldova, Rep. of	2023	868
Nicaragua	2023	738
Nigeria	2021	1249
Paraguay	2023	958
Peru	2023	812
Russian Federation	2022	482
Togo	2020	1119
Zanzibar	2022	800
Zimbabwe	2022	1404
Total		26 502

Gender Analysis Measures

Two modules in the survey were used to assess experiences of reproductive coercion and one module was used to assess experiences of violence from health-care providers while seeking HIV care. The survey was designed so that individuals reporting female sex at birth were asked to respond to questions in both modules relating to experiences of reproductive coercion and violence from health-care providers while seeking HIV care. Therefore, cisgender women and transgender men were asked to complete both modules. Individuals who reported male sex at birth were only asked questions in one of the models, and therefore cisgender men and transgender women received a subset of questions on reproductive coercion.

For individuals who received both modules (cisgender women and trans men), reproductive coercion in this analysis is categorized based on experiences relating to 1. sterilization; 2. contraception and family planning; and 3. pregnancy and feeding practices. Recent experiences of sterilization describes experiences of being sterilized without knowledge or consent; or pressured or incentivized to get sterilized within the last 12 months. Recent experiences of reproductive coercion relating to contraception and family planning describes experiences in the of being denied contraception or family planning services; being pressured to use a specific type of contraceptive method to get HIV medication; or being pressured to use a specific type of contraceptive method in the last 12 months. Lifetime experiences of reproductive coercion relating to contraception and family planning are described as ever being pressured to use a specific type of contraceptive method. Recent experiences of reproductive coercion relating to pregnancy and feeding practices described experiences of being advised to mother/father a child; being advised to terminate a pregnancy; being pressured to use a particular method of giving birth/delivery option; being pressured to use a particular infant feeding practice; or being pressured to take HIV (antiretroviral) treatment during pregnancy in the last 12 months.

Lifetime experiences of reproductive coercion relating to pregnancy and feeding practices describes experiences of being ever being advised to terminate a pregnancy; pressured to use a particular method of giving birth/delivery option; pressured to use a particular infant feeding practice; or pressured to take HIV (antiretroviral) treatment during pregnancy.

Recent experiences of violence from healthcare providers while seeking HIV care is measured as self-reporting experiencing denial of health services, verbal abuse, and physical violence by a healthcare provider while seeking HIV-related care in the last 12 months. Recent experiences of violence from healthcare providers while seeking non-HIV care is measured separately, as self-reporting experiencing denial of health services, verbal abuse, and physical violence by a healthcare provider while seeking non-HIV-related care in the last 12 months. Verbal abuse is defined as yelling, scolding, name calling, or being otherwise verbally abused because of one's HIV status. Physical abuse is defined as pushing, hitting, or being otherwise physically abused because of one's HIV status.

Scoping Review

Reproductive Coercion Subtypes and Explanation of Search Objective

Reproductive coercion perpetuated by health-care professionals against women living with HIV can take many forms. Generally, the most common and distinct domains are abortion, contraception, Caesarean sections, obstetric violence, and sterilization. These domains stretch across the family planning field and cover multiple points in pregnancy and reproductive experiences. While not every form of coercion will look the same (withholding abortions because of fear of HIV transmission is very different from pressuring abortions to prevent women living with HIV from having children), they are all derived from HIV stigma, gendered ideas of family planning, and histories of human rights violations against women living with HIV. We conducted a scoping review of the existing literature which assesses, quantifies, and describes evidence of reproductive coercion affecting women living with HIV. This literature search was performed in order to better understand the state of available literature exploring, highlighting, and measuring reproductive coercion globally.

Search Strategy

The search strategy was developed in accordance with scoping review protocol, with search terms designed to capture literature on individual subtypes of reproductive coercion, as well as coercion more broadly. The literature search included articles published between 2011 and 2022. Three different health and medical literature databases were searched, including Pubmed, EMBASE, and LILACS. Articles were determined to be eligible for inclusion if they presented new evidence including novel data, analyses, case studies, or commentaries. Therefore, summaries of existing research or systematic reviews were excluded.

Overview of the Literature

Through this review,, 23 articles specific to reproductive coercion among women living with HIV were selected for final inclusion, consisting of qualitative and quantitative studies, legal and human rights commentaries, and case-studies. Three main themes emerged from the existing evidence: 1. The consequences of reproductive coercion on women living with HIV, as individuals, as partners, and as members of the community; 2. The prioritization of vertical transmission prevention over reproductive health needs and rights of women living with HIV; and 3. Consent violations that occur as a manifestation of power imbalances between women living with HIV and their medical providers.

The literature covered the range of reproductive coercion domains and spanned across regions, but the most commonly covered domain was sterilization. Latin America and sub-Saharan Africa were the most represented regions, and the legal commentaries highlighted the interplay between legal action, awareness, and research. Several related and adjacent topics to reproductive coercion were identified during this review, including fertility desire, method mix and unmet need, safe conception, and dual contraceptive use.

Qualitative Study Methodology

The qualitative study was comprised of an online survey distributed in five languages (Arabic, English, French, Russian and Spanish), as well as consultations and one-on-one interviews with women who had experienced reproductive coercion, mistreatment or abuse in the last three years. One-hundred and seventy-one, trans and gender non-binary people living with HIV who responded to the survey and had experienced reproductive coercion or mistreatment in the last three years. An additional 34 women were consulted in one-to-one interviews (consultations), including a focus group of five younger women in Kenya and two interviews with women in Malaysia that were conducted prior to the start of this project and provided some inspiration for the need for this survey. A total of 205 people participated in the survey and consultations. Additionally, women living with HIV activists were interviewed from around the world to explore the work of networks of women living with HIV who are responding to these challenges.

The report is informed by the information provided by 205 people from all the world regions. However, the aim of this survey was not to capture quantitative data or a globally representative sample. The aim of the survey was to capture the complexity of different experiences of coercion, mistreatment and abuse and describe respondents' views about their experiences, the impacts the experiences had on the individuals and how individuals responded to them. The survey tool encouraged women to describe their experiences and provide information regarding those experiences. The survey obtained responses from all age groups: 18–24, 25–30, 31–49, 50–55 and 55+. However, numbers were concentrated among the 31–49 age group

Gender: All but four of the people included in the analysis identified as women. Three persons identified as non-binary and one as a transgender man.

Country: We had responses from more than 56 countries (listed below). Unfortunately, we did not get country details from: ten people who answered the Spanish survey, ten the English survey, two the Arabic survey, six the Russian survey and three the French survey.

	ASIA	EUROPE & CENTRAL ASIA	LATIN AMERICA & THE CARIBBEAN	MIDDLE EAST & NORTH AFRICA	WEST AFRICA	SOUTHERN AFRICA	EAST AFRICA	
Survey respondents: 171	10	18	63	13	6	14	18	31
Mini-Consultation/ Interviews: 34	5 Malaysia Nepal	5 Belarus Kazakhstan Kyrgyzstan Tajikistan Ukraine	11 Mexico Honduras Trinidad & Tobago Argentina Guyana	3 Egypt Yemen	0	5 Cameroun Central African Republic Gabon Republic of the Congo	5 Kenya	N/A

Confronting Coercion:

A global scan of coercion, mistreatment and abuse experienced by women living with HIV in reproductive and sexual health services

Total Countries Represented	Australia	Kyrgyzstan	Argentina	Algeria	Malawi	Burkina Faso	Kenya
	Malaysia	Moldova	Barbados	Egypt	Namibia	Rwanda	
	Nepal	Tajikistan	Bolivia	Jordan	South Africa	Burundi	Uganda
	Papua New Guinea	Ukraine	Chile	Lebanon	Swaziland	Cameroun	
		UK	Columbia	Morocco			
		Uzbekistan	Costa Rica	Oman		Mali	
			Dominican Republic	Tunisia		Nigeria	
			Ecuador	Yemen			
			Guyana				
			Honduras				
			Mexico				
			Nicaragua				
			Paraguay				
			Peru				
			Trinidad and Tobago				
		Uruguay					
		Santa Cruz					
		USA					

Where the respondents live: Women who responded to the survey mainly live in urban areas. There is some representation from rural and semi-urban areas, though very little representation of women from rural areas in the French, Russian and Arabic surveys.

Other experiences: the analysis in this survey is not disaggregated by these experiences but they give an indication of the experiences of the people who have answered the survey and are experiencing SRH rights violations within services. We had respondents who identified that they:

- Engaged in sex work.
- Used drugs.
- Were recently incarcerated.
- Were married.
- Were unmarried/single.
- Were in a relationship.
- Have been pregnant.
- Have a disability.
- Have given birth.
- Have sex with women—queer, lesbian, bi-sexual.
- Were indigenous.
- Were migrant.
- Were affected by racism and/or faith-based discrimination.
- Were in a sero-diverse intimate relationship.

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