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Sexual and Reproductive Health of HIV-Positive Women in Asia:

A Policy Framework for the Future

INTRODUCTION

At the 1994 International Conference on Population and Development (ICPD), 179 governments joined together to establish that equal rights for women and girls and universal access to sexual and reproductive health and rights are necessary factors for sustainable development and a priority to improve the quality of life for all people. These rights are defined as the ability of people to experience sexuality safely throughout their lifespan and to have the ability and freedom to make informed decisions on if, when, and how often to reproduce.[1]

> **"The healthcare worker won't sit on the same chair that I have sat on or use the same pen. When they look in my mouth they stand far away...We want to be treated the same as everybody else."**
>
> ***—Woman living with HIV,* Viet Nam**

The fact that HIV can be transmitted during sexual contact, pregnancy, or breastfeeding intrinsically links the HIV epidemic to sexual and reproductive health. Yet governments do not consistently integrate sexual and reproductive health services into their national HIV strategies, resulting in the fragmentation of care for women living with HIV (WLHIV). Furthermore, governments inconsistently adhere to international frameworks set forth to protect and promote reproductive health, weakening the quality of available care. The result is that 20 years after the International Conference on Population and Development, the agreed upon sexual and reproductive health rights of WLHIV in Asia are yet to be fully realized, and support for pregnant WLHIV remains inadequate.

In 2013, 58% of HIV-positive pregnant women in the World Health Organization's (WHO) Western Pacific Region received antiretroviral (ARV) medicines to prevent infection in their infants, and only 26% received the treatment in the Southeast Asia Region.[2] This compares to the 68% coverage seen in sub-Saharan Africa.[2] Inadequate ARV coverage among pregnant women has grave implications for women's health and increases risk of onward transmission to partners and children.[3]

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In addition, reports from Asia suggest that reproductive choices of WLHIV continue to be threatened and restricted, and they face a wide range of discriminatory treatment in healthcare settings when seeking services for their sexual and reproductive needs. This discrimination can be compounded by other sources of societal stigma if the woman participates in sex work, injects drugs, or is transgendered. In some countries, such as Thailand, as much as 30% of HIV-positive female study respondents reported being coerced into sterilization by their healthcare providers, despite evidence that successful methods of preventing mother-to-child transmission lead to rates of infant HIV infection as low as 5% or less.[4]

The inclusion of sexual and reproductive health rights in existing national health infrastructures, such as national HIV programs and healthcare provider networks, would help Asia advance HIV prevention and treatment goals. Without increased dedication to the commitments made to ensure access to sexual and reproductive health and rights for all women, the region as a whole will not achieve its goals on gender equality or be able to meet indicators on maternal mortality and child health.

NATIONAL COMMITMENTS TO EXISTING HUMAN RIGHTS FRAMEWORKS THAT PROTECT WLHIV

National governments in Asia have already signed on to international human rights frameworks that protect women, including the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)[5] and the International Conference on Population and Development.[6] These agreements hold Member States accountable for promoting the sexual and reproductive health of WLHIV and provide legal and policy foundations that are intended to help women exercise their reproductive health rights. They explicitly promote the right of all women to choose the number and spacing of their children and access healthcare that will support their decisions.

In addition, the countries that make up the Association of Southeast Asian Nations (ASEAN) have signed a regional Declaration of Commitment, which affirms comprehensive and effective national responses to HIV, including promoting the human rights of people living with HIV and the elimination of HIV-related discrimination.[7] These priorities were reaffirmed in the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) HIV resolutions (66/10 and 67/9), which call for legal and political action to achieve universal

Despite the fact that most Asian governments have signed on to international frameworks agreeing to protect and promote the sexual and reproductive rights of women, these basic human rights have not been fully realized for women living with HIV (WLHIV) in the region. This report seeks to inform policy makers, community advocates, and healthcare providers about the rights violations WLHIV face, the negative impact this has on HIV prevention and treatment, and how stakeholders can work together to protect the sexual and reproductive health rights of WLHIV.

Key Facts:

- In 2013, only 58% of HIV-positive pregnant women in the World Health Organization's (WHO) Western Pacific Region and 26% in its Southeast Asia Region received treatment to prevent transmission of HIV to their infants, compared to 68% coverage in sub-Saharan Africa.
- 11% of WLHIV surveyed in the Asia-Pacific reported having been denied health services because of their HIV status, and 42% reported experiencing difficulty finding an obstetrician who would care for them.
- 57% stated that they had been counseled not to have children by their healthcare professional, and 39% that they had not been informed of their reproductive options, despite the fact that proper treatment reduces the risk of mother-to-child transmission of HIV to 5% or less.
- 30% reported having been advised to have a sterilization procedure by their healthcare professional—and many stated that they did not feel they had the right to refuse the recommendation.
- 22% reported that they had been coerced into having an abortion.

Health providers, governments, civil society, and communities must work together to successfully guarantee the sexual and reproductive health rights of WLHIV.

Priority Recommendations:

- Government and health authorities need to incorporate international standards for women's sexual and reproductive rights into national HIV programs, integrate HIV services with reproductive and maternal healthcare services, and ensure WLHIV are engaged in the development of all programs that address their needs.
- Providers should be encouraged to create stigma- and discrimination-free healthcare environments and support efforts to educate WLHIV about their sexual and reproductive health options.
- Civil society can combat stigma by conducting widespread outreach to educate health workers and their communities about reproductive health, interventions to prevent mother-to-child HIV transmission, and the rights of WLHIV.

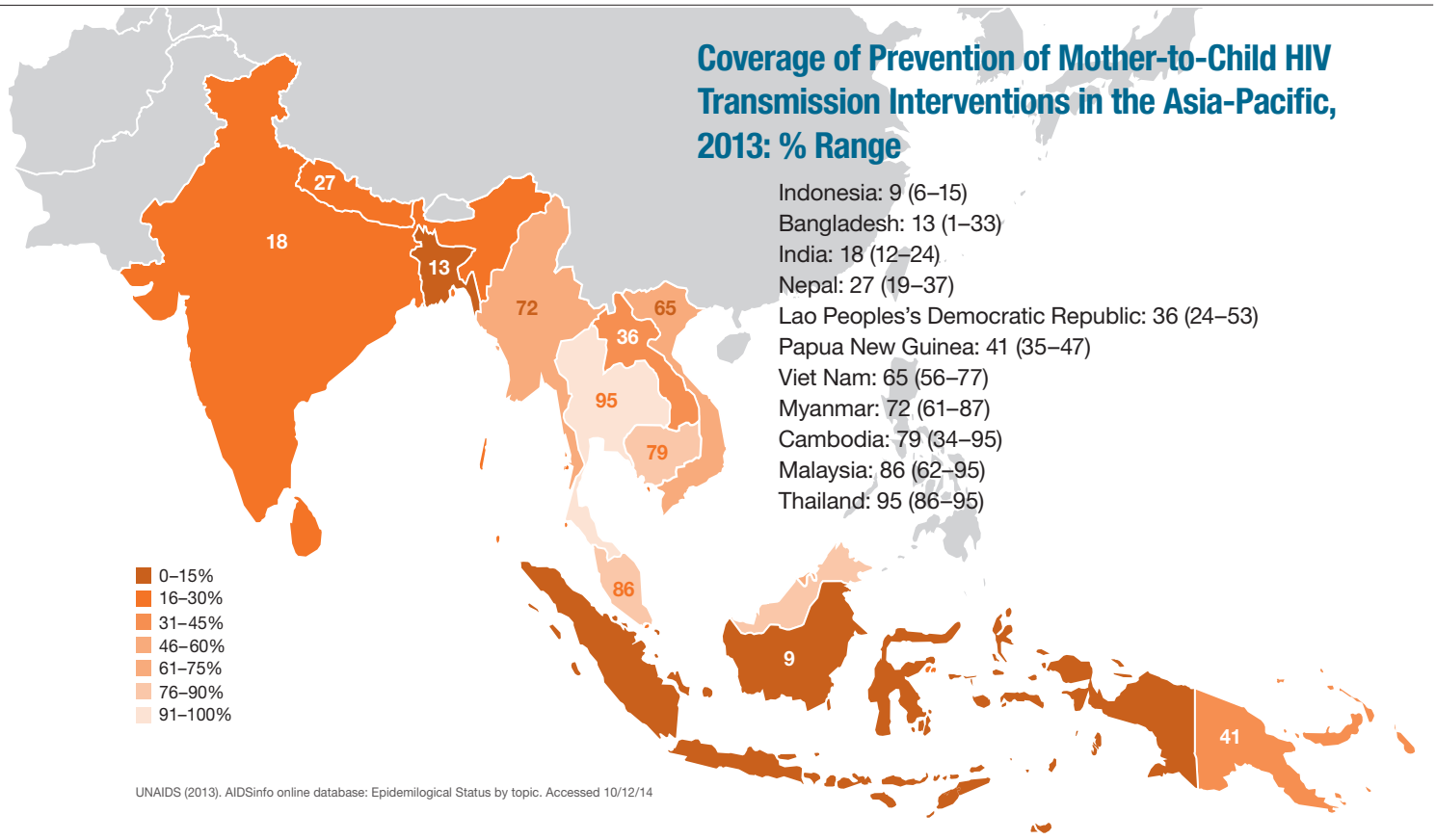
access to HIV prevention, treatment, and care, especially for sex workers, men who have sex with men, and people who inject drugs.[8,9]

These human rights frameworks and commitments provide the foundation on which Asian governments should establish and promote policies and programs for gender equality and sexual and reproductive health rights. However, in spite of the region's commitment to these international conventions, integration of these ideals into national laws and implementation at the health service level have not been fully realized. Gaps in women's access to comprehensive reproductive healthcare persist, especially for WLHIV, who are faced with the additional barriers of HIV-related stigma and discrimination.[10]

For example, a legal scan conducted by the United Nations Development Programme (UNDP) and the Asia Pacific Network of People Living with HIV (APN+) in Bangladesh, India, Nepal, and Pakistan noted that while these countries had constitutional provisions and laws protecting women affected by HIV from such violations, few were enforced and implemented. Furthermore, while other studies have reported that WLHIV in these four South Asian countries face high levels of discrimination within healthcare settings, the researchers could not find a single legal case that had been filed by an HIV-affected woman against a medical institution or provider to include in the scan.[11] Asian countries are not being held accountable for assuring the enactment of these international agreements, and it is the health of women that suffers.

Coverage of Prevention of Mother-to-Child HIV Transmission Interventions in the Asia-Pacific, 2013: % Range

Indonesia: 9 (6–15)
Bangladesh: 13 (1–33)
India: 18 (12–24)
Nepal: 27 (19–37)
Lao Peoples's Democratic Republic: 36 (24–53)
Papua New Guinea: 41 (35–47)
Viet Nam: 65 (56–77)
Myanmar: 72 (61–87)
Cambodia: 79 (34–95)
Malaysia: 86 (62–95)
Thailand: 95 (86–95)



UNAIDS (2013). AIDSinfo online database: Epidemiological Status by topic. Accessed 10/12/14

SECURING SEXUAL AND REPRODUCTIVE HEALTH RIGHTS FOR WLHIV: A LONG WAY TO GO

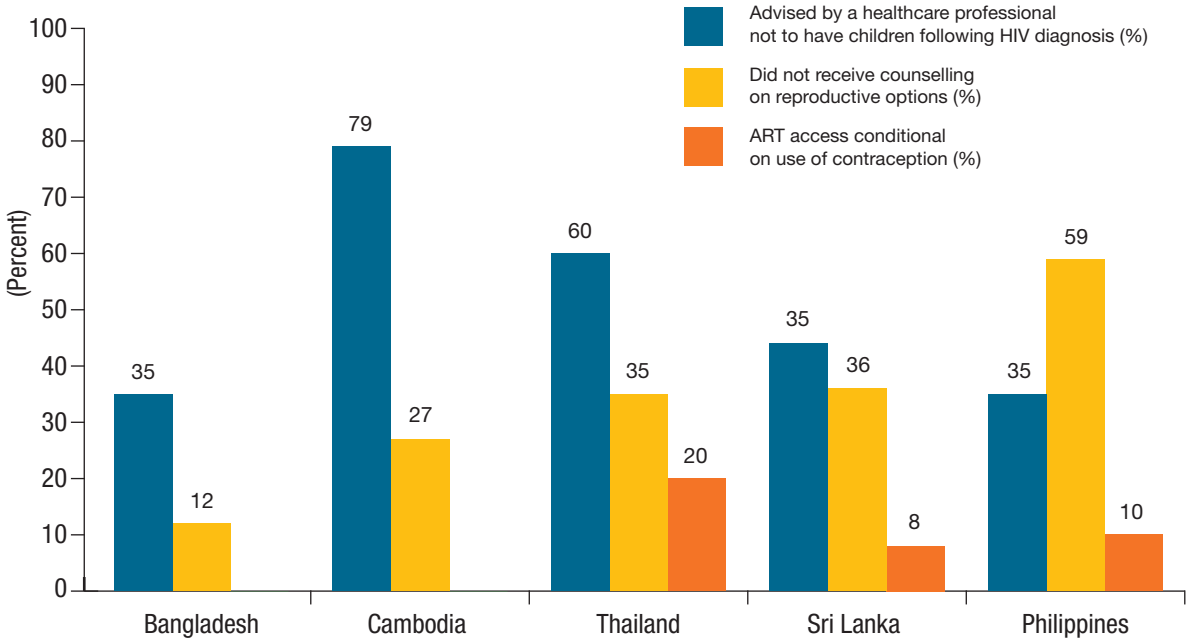
The commitments made to improve the sexual and reproductive health of women in Asia cannot be realized without the engagement of a supportive healthcare system. When WLHIV face discrimination during their interactions with the healthcare system or healthcare providers, it discourages them from accessing services and hampers the ability of health institutions to serve the population. Despite the establishment of internationally recognized patient-focused and rights-based principles for healthcare delivery to WLHIV,[5,6,8,9] they continue to report being criticized by healthcare providers for choosing to have children. Studies from the region reveal a landscape in which WLHIV do not have equal access to antenatal services, are provided with incorrect information related to their pregnancies, and lack support from a healthcare system that does not prioritize their needs or advocate for their rights. The injustices faced by WLHIV violate their human rights, degrade their health, and prevent them from fully accessing HIV care and treatment services in Asia.

> "One doctor asked me why I wanted to have the baby when I'm HIV positive. He said the baby will also be infected and advised that I should not have the baby. Then he discussed it with my husband and asked him if he wanted the baby, and he decided against it."
>
> —*Mina*, Nepal[7]

Discrimination in healthcare settings: stigma and denial of services

Discrimination against WLHIV in healthcare settings or denial of health services violates the universal right of women and girls to sexual and reproductive health established in 1994 by the International Conference on Population and Development. Multiple studies have shown that people with HIV on antiretroviral therapy are at minimal risk of infecting others,[12,13,14] but healthcare providers in the region do not consistently promote that message.[14]

Discrimination Against People Living With HIV in the Reproductive Healthcare Setting in the Asia-Pacific (2011)



**Data Source: UNAIDS (2011) People Living with HIV Stigma Index, Asia Pacific Regional Analysis 2011.

The 2011 Asia and Pacific People Living with HIV Stigma Index noted that over half (57%) of women living with HIV have reported being advised by a health professional not to have children, and 39% of respondents did not receive counseling about their reproductive options.[4]

Stigma in the healthcare setting was also found to be a powerful barrier to receiving care, with 21% of respondents avoiding clinics, 16% avoiding hospitals, and 11% reporting being denied health services because of their HIV status.[4] According to a study conducted by UNDP in 2011, over 30% of people living with HIV reported being discriminated against in a health facility, and 9% of WLHIV reported not seeking healthcare due to fear of stigma and discrimination.[15]

Similar reports of discrimination were published by APN+, which surveyed 757 pregnant women across Southeast Asia about their access to sexual and maternal health services. As much as 42% of women reported having difficulty finding an obstetrician to care for them during their pregnancy, which they believed was directly due to their HIV status.[7] HIV and antenatal care services are frequently separated and managed by different sectors of the public health system in Asia, and this fragmentation of healthcare for WLHIV further complicates their search for basic health services.[7]

The result is that WLHIV must navigate a complex system in order to meet their basic sexual and reproductive health needs. The addition of stigma and discrimination in the healthcare system exacerbates existing barriers to care by encouraging delayed testing, concealment of HIV status, or refusal to seek out services. The inadequacy of the healthcare system in meeting the needs of WLHIV reduces access and uptake of services, negatively impacts women's health, and increases the possibility of onward transmission.

Coerced or forced sterilization and abortions

Coercive or forced sterilization or abortion occurs when a woman is compelled to undergo one or both of these procedures with incentives, misinformation, or intimidation, or when the procedure occurs without her knowledge or free and informed consent.[16] For example, coercive sterilization can occur when a woman is asked to consent to the procedure when she is already in labor or is told that she will only receive HIV treatment or prenatal care if she agrees to be sterilized.[17]

> **"When I went to the obstetrics department, the staff was afraid of me and said, 'How dare you have a baby. Aren't you afraid to die?' The doctor said, 'You are already positive so your health is not good so you should have an abortion.' He gave me many reasons why I should not continue with the pregnancy. I said to the doctor that I have a right to have a baby under the law."**
>
> **—*Kieu*, Viet Nam[7]**

These experiences clearly violate a woman's right to decide if, when, and how often to reproduce. The Committee on the Elimination of Discrimination Against Women goes as far as to specifically recommend a waiting period of at least seven days between when the patient is first informed about the risks and permanency of sterilization and when she is considered able to provide informed consent.[18]

The APN+ report revealed a history of coerced and forced sterilizations and abortions experienced by WLHIV in multiple Asian countries. The study found that 30% of the women surveyed had been encouraged by their healthcare provider to undergo sterilization. The majority (61%) of

Violation of Human Dignity

The Committee on the Elimination of Discrimination Against Women (CEDAW) considers forced sterilization a violation of a woman's right to informed consent and an infringement on her rights to human dignity and physical and mental integrity.[19] The United Nations Human Rights Committee recognizes forced sterilization as a violation of the right to be free from torture and cruel, inhuman, or degrading treatment. This position is echoed by the United Nations Special Rapporteur on violence against women, who has asserted that "forced sterilization is a method of medical control… essentially involving the battery of a woman—violating her physical integrity and security." Violating a woman's right to be free from torture is a serious offense, and the United Nations has requested that countries report on specific measures they have taken to combat this practice.[20] ■

> **"I wanted a C-section but the doctor said, 'Just let it go. Wait for a natural delivery.' After two days of pain, in the end they had to give me a C-section because my baby was two weeks overdue. But I had to sign a paper agreeing to a tubal ligation as well. I wanted to have another child, but I had no choice. It is not reversible for women."**
>
> **—*Mai*, Viet Nam[7]**

these recommendations came from gynecologists and HIV clinicians, and more than 80% of survey respondents believed that the recommendation was made on the basis of their HIV-positive status.[7]

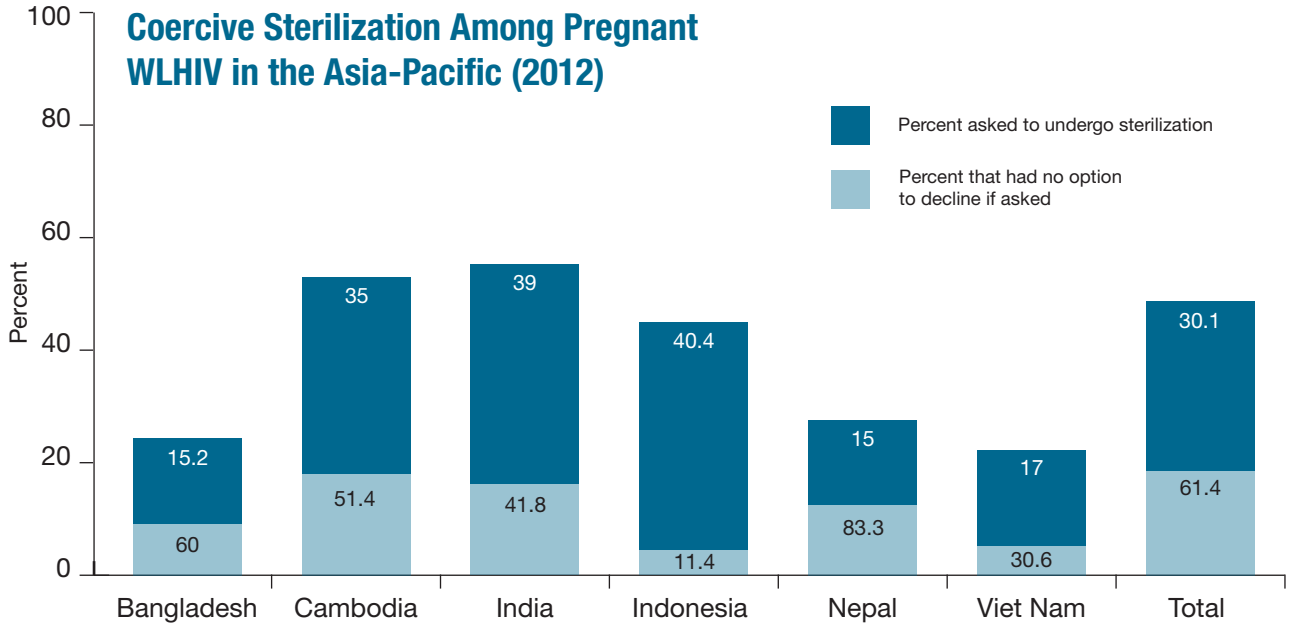
Additionally, not all of the women who were advised to be sterilized felt that they had the option to refuse. In Indonesia, 88% of the women reported having the option to decline sterilization, while in Cambodia only 48% reported being given a choice to consent or not.[7] Some women stated that they did not understand what the term sterilization meant when they agreed to it, while others were sterilized without their prior knowledge during a Cesarean section delivery.

The APN+ study further reported that 22% of all survey participants had had an abortion, and of that number the majority (60%) said it was specifically because of their HIV status.[7] The qualitative component of the APN+ study, which included 17 key informant interviews and 10 focus groups across six Southeast Asian countries, found that common reasons women had an abortion were that they assumed or were told that the baby would be HIV positive or that their health was too weak.[7] These discriminatory practices violate the basic right of WLHIV to make informed decisions about their sexual and reproductive healthcare.

A WAY FORWARD – RECOMMENDATIONS FOR ACTION

The United Nations joint statement on eliminating forced or coercive sterilization emphasizes the need for increased "procedural safeguards" for women who are at high risk of being medically exploited, such as WLHIV.[17] In order to close the existing gaps in the delivery of HIV prevention and care in Asia, providers, governments, and the community must come together to ensure that discriminatory policies and practices are ended and guarantee the sexual and reproductive health rights of WLHIV.

Coercive Sterilization Among Pregnant WLHIV in the Asia-Pacific (2012)



**Data Source: Women of the Asia Pacific Network of People Living with HIV (2012); Positive and Pregnant: How Dare You, A study on access to reproductive and maternal health care for women living with HIV in Asia.

Role of national governments and public health authorities

- Set standards for how principles of existing human rights-based frameworks (e.g., CEDAW, ICPD) should be incorporated into national HIV programs and establish support systems that ensure justice for WLHIV who experience rights violations.

Although commitments exist in writing, implementation of these frameworks is inconsistent across the region.[11] By setting common standards for non-discriminatory care, ministries of health can shift the policies of their healthcare systems and impact care at the patient level. National governments must also strengthen the local response to rights violations by enacting protective laws, supporting HIV-related legal services, and training judges to adequately respond to rights violations experienced by WLHIV.

- Integrate HIV services, sexual and reproductive health services, and the maternal healthcare infrastructure to enhance the quality of healthcare WLHIV receive and promote their retention in care.

In the Asia-Pacific region, a traditional separation between general medicine, obstetrics, and pediatrics makes it even more difficult for WLHIV to access comprehensive care. To achieve the elimination of mother-to-child HIV transmission, HIV, family planning, and maternal-newborn-child health programs cannot remain in silos. Greater alignment between healthcare management and patient care services across these programs will create an improved and more efficient continuum of care,[21] reducing the threat of HIV-specific discrimination and poorer quality antenatal care.

- Create mechanisms to facilitate community input into improvement efforts that address gaps in healthcare services for WLHIV, and seek to address and prevent rights violations through a functioning accountability system that documents and addresses patient complaints.

The broader community involved in supporting WLHIV can alert national programs on how programs are succeeding or failing to promote human rights frameworks for sexual and reproductive health. This may include creating programs to improve women's knowledge of their reproductive rights, or mechanisms to record violations and link women to HIV-related legal services. By establishing a feedback system among stakeholders, problems can be identified and addressed more rapidly and in collaboration, rather than in opposition.

- Involve civil society representing WLHIV in organizing provider trainings on optimal HIV prevention and care practices for pregnant and non-pregnant WLHIV, and on the need for stigma reduction, confidentiality, and informed consent for medical procedures.

Individual providers need to better understand the reproductive health needs and rights of WLHIV, so that they can provide effective HIV prevention and treatment interventions. As local HIV guidelines change, providers are trained on how those guidelines should be implemented. These trainings can include modules on patients' rights and on how providers can be more sensitive to the needs of WLHIV.

Role of individual providers

- Create a stigma-free environment and reduce discrimination to increase uptake of healthcare services by WLHIV.

A positive patient-provider relationship is essential for WLHIV in Asia to receive non-discriminatory medical care. The fear of HIV-related stigma (including the multiple layers of stigma experienced by women who are at higher risk of HIV, such as sex workers, women who use drugs, transgender women, and the partners of men who engage in high-risk practices) prevents too many women from coming forward for diagnosis and treatment, risking future health complications. Medical evidence should be prioritized over personal opinion when caring for WLHIV.

- Support patient empowerment efforts to help WLHIV understand risks of mother-to-child transmission and their prevention and care options.

Clinical providers are the experts that WLHIV rely on to give them the most up-to-date information on how to care for themselves and their families. Increasing awareness among WLHIV regarding their sexual and reproductive rights and health needs would help them to seek out and use available healthcare services. Providers can also be allies and mentors of community-based organizations contributing to this process.

- Hold colleagues and institutions accountable for adhering to national and international standards for non-discriminatory healthcare provision.

Providers have firsthand insights into how their institutions are delivering services and can be advocates for WLHIV. Training and capacity-building activities are needed to encourage awareness of and respect for patient rights. When rights violations occur, providers can work with their colleagues to

find solutions by reforming existing clinical care policies and developing oversight mechanisms that encourage dialogue to understand and address the basis for negative attitudes.

Role of civil society

- Conduct widespread community outreach to disseminate accurate information, combat stigma against WLHIV, and empower women to access HIV services.

Misinformation and discriminatory attitudes towards WLHIV are pervasive among many Asian communities. These attitudes can cause women to live in shame or fear and prevent them from accessing the services they need. Community-based organizations can improve the health and safety of WLHIV by combating stigma at the family and community levels, and addressing misconceptions about HIV transmission and treatment. These organizations could facilitate a peer-education system that trains WLHIV to provide education and support for women in their community regarding their right to appropriate reproductive and maternal care. To undertake this crucial work, the capacity and resources of civil society would need to be bolstered by local governments, international organizations, and other global health partners.

- Engage with community health workers and health systems to build up advocacy networks supporting WLHIV that can also link women to necessary health services.

Community health workers are on the frontlines of the health system and represent critical agents in health promotion. Community-based organizations can partner with public health programs and community health workers to improve the quality of service delivery, facilitate outreach efforts to marginalized groups, and connect WLHIV to non-stigmatizing health services.

- Link community-based organizations serving WLHIV to a broader range of community organizations addressing maternal and child health and reproductive health and rights and other women's advocacy groups.

The needs of WLHIV extend well beyond HIV care and should be situated within a larger system. Encouraging collaboration between networks of community organizations will strengthen their ability to serve all women and facilitate the development of social support networks for WLHIV.

CONCLUSION

Existing international human rights frameworks already prescribe a set of principles that should inform healthcare delivery for WLHIV. They represent a legal obligation to ensure that these fundamental rights are guaranteed at the national and provider levels. These frameworks need to be integrated into national healthcare programs in order for them to be properly enforced. By doing so, governments across Asia can make progress towards assuring that non-discriminatory treatment and care for WLHIV is the standard for the region, rather than the exception.

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