

**WOMEN LIVING  
WITH HIV  
SPEAK OUT  
AGAINST  
VIOLENCE**

A collection of essays and reflections of women living with and affected by HIV



# ESSAYS AND REFLECTIONS FROM WOMEN LIVING WITH AND AFFECTED BY HIV

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# OVERVIEW

Violence against women and girls is an unacceptable violation of basic human rights. It also is so widespread that ending it must be a global public health priority.

An estimated one in three women is beaten, coerced into sex or otherwise abused by an intimate partner during her lifetime. Intimate partner violence has been shown to increase the risk of HIV infection by around 50%, and violence (and the fear of violence) deters women and girls from seeking services for HIV prevention, treatment, care and support.

Achieving zero tolerance for violence against women and girls is one of the main priorities for UNAIDS, because until that happens, we will never see the end of the AIDS epidemic. Women living with HIV who themselves have experienced violence know better than most how essential it is to address both of these issues together.

The goals of seeing the end of the AIDS epidemic, realizing total gender equality and achieving zero tolerance for violence complement each other, and they all demand a place in the post-2015 development agenda. This is an opportunity to ensure that all women and girls reach their full potential, without the threat of violence, the risk of HIV or the violation of their sexual and reproductive rights.

Men play a key role in standing up against violence, as husbands and partners, brothers and sons. No one can tackle it alone—all must reach for shared dignity, mutual respect and a renewed commitment to end violence against women and girls.

UNAIDS would like to thank the women who have been willing to share their life stories. Their experiences and actions continue to be an inspiration and example to all. A picture emerges from the following contributions and personal experiences, one of women and girls who have not been defeated by abuse, violence or HIV. On the contrary, they have stood up, organized and moved to the forefront of the AIDS response, and now they are sharing their struggles with us, calling on the international community for increased support.

UNAIDS asks that when reading the articles that follow, you hear what is being said and take this opportunity to participate in a meaningful dialogue. By listening to these stories and thinking of how to better support the courageous and still tremendously undervalued work of women living with HIV; we must learn from their experiences and determine how we can better incorporate gender equality and women's rights into programmes, policies and budgets.

# INTRODUCTION

Women living with HIV have a unique perspective on the AIDS epidemic. Similarly, women who have personally experienced violence can inform the debate on how to stop violence against women in a way that no others can. Together, they can provide valuable insight and experiences to end the AIDS epidemic and violence against women.

This collection of essays by women living with and affected by HIV sheds light on the experiences of women living with HIV in overcoming and addressing violence against women.

Some of the contributors acquired HIV through the violence they experienced. Others have faced violence because they are living with HIV, violence that was perpetrated not only by their family members and intimate partners, but also by those with a duty of care towards them—groups such as the police and other agents of the state, including health-care professionals. While some of the contributions are personal testimony, all of them are informed in some way by personal experience.

What shines through in each of the following contributions is that wherever women are being left behind—including women living with HIV, young women, female sex workers, women who inject drugs, transgender women, mothers, and children—women themselves have stepped up and organized. They have built care and support networks, conducted research, campaigned and demanded their right to a life of dignity and respect. Their voices show us that for any effort to address HIV and violence to be successful, women in all of their diversities, including women living with HIV, must be at the forefront of the movement.



# 1 ESSAYS FROM EASTERN AND SOUTHERN AFRICA







# WHEN HEALTH CARE BECOMES AN ACT OF VIOLENCE

— **A.B.\***

*Namibia*

*\* The authors' identity has been protected*

I was born in 1980, gave birth to my son in 1999 and got married in 2008. My last pregnancy was in 2004, but I had a miscarriage. From that point on, I started feeling worse and worse, and I was diagnosed with tuberculosis and HIV in the same year. I started antiretroviral treatment.

In 2005, I was sterilized. The nurses had said that my uterus might be affected by cancer, and therefore needed to be “cleaned.” At first, I was unsure about going ahead with this procedure, but later I decided to follow the nurses’ instructions.

One day, when I went to the hospital to get my antiretroviral medicines as usual, I was told to come back the following day for the treatment to get rid of the cancer. I went back the next day, stayed overnight at the hospital and went into theatre the following afternoon. Only as I was being wheeled into surgery was I given consent forms to sign. I signed on the understanding that I was giving consent for the “cleaning” of my uterus.

It was during post-surgical recovery that I learned from the doctor that I had been sterilized. I asked him what sterilization was, and he explained to me that I could not have children anymore. When I asked him why I had been sterilized, he said that patients like me do not always understand the importance of sterilization. He went on to say that, as a doctor, he had to make decisions for us, as he was always on our side to protect our health and ensure that we did not pass on HIV in the womb. He finished by saying that he was doing me—and other HIV-positive women—a favor.

I was angry, but at the same time, I thought that being HIV-positive made me useless and unable even to get married. So I just left it at that and did not seek any justice.

Later, having put the sterilization incident behind me, I met the man who was to become my husband. I did not hide the fact that I

was living with HIV, because he was, too. As our relationship grew stronger, we fell deeply in love and married. Soon after marriage, I decided to tell my husband that I was sterilized and could not bear children any more.

One day, when I went to collect my antiretroviral medicine, I told a doctor that my husband and family were not happy about the fact that I had been sterilized, and I asked if it was possible to reverse the procedure. The doctor told me it could not be done, especially due to my condition, adding that my health records did not specify what type of sterilization I had undergone. He advised me to go to Katutura Hospital in Windhoek and ask if they could do a physical examination to check what type of sterilization had been done and if it was reversible. He also warned that it was a major operation that could cause death.

On hearing this, my husband became scared that he might lose me, and he said we must cancel all plans of following up in Windhoek.

Since then, my husband and I have moved to live with my brother-in-law and sister-in-law. This move has traumatized me greatly. I have suffered physical and emotional abuse at the hands of my in-laws, including being beaten, stigmatized and discriminated against. My in-laws often complain that I am just enjoying the wealth of my husband while I cannot give him children. Whenever I cook food, my sister-in-law never eats it. Sometimes, she just feeds the food to the dog in front of me to further torment me emotionally. The situation is even worse when I visit my mother-in-law. She abuses me, shouts at me and tells me that I am a witch who has bewitched her son.

Throughout all of this, my husband has been supportive, but sometimes when he drinks, he says negative things to me. All these experiences have led to me being hospitalized a number of times due to depression and stress. Now I also suspect that my husband is cheating on me.

If I could speak to the doctor who performed the sterilization, I would tell him to reverse it, as my life is falling apart—so much so that I am even thinking of suicide. I am a woman who was told that my womb was going to be cleaned, and instead I was sterilized. This is causing me to struggle in my marriage and my life.

If I could speak to someone with the power to make a difference, I would ask them if there is a way they can help me. There are many women who are in the same situation as me. How can the government not take action to stop this happening?

## IN THE NAME OF TRADITION AND CULTURE

- **Annie Banda**  
*Coalition of Women Living with HIV and AIDS,  
Malawi*
  
- **Hajjarah Nagadya**  
*International Community of Women Living  
with HIV/AIDS (ICW) Eastern Africa,  
Uganda*
  
- **Martha Tholanah**  
*ICW Southern Africa,  
Zimbabwe*

Violence against women and girls, particularly those living with HIV, remains widespread in all eastern and southern African countries, cutting across class, tradition and culture. This violence is deeply present and ingrained in our daily lives, and it often is sustained by cultures that ignore, condone, justify or encourage it in the name of tradition.

The main challenge is that in patriarchal societies, the cultural norm of masculinity is one of the key drivers of violence against women, leading some men to believe that they can treat women as their personal property. Unequal and often violent treatment of women has gone on for so long that many women and girls just accept it as part of their culture. Many have not known any other way of being treated.

As women and girls living with HIV, we face violence in our homes, our churches and places of worship, our workplaces, our schools and our health-care facilities. These places, which should be safe havens where we can seek care and support, can become places of violence, hurt and judgement (1).

***“ Unequal and often violent treatment of women has gone on for so long that many women and girls often just accept this as part of their culture. ”***

Attacks on women and girls often result in emotional scarring, physical injury, disability and death (2). Women and girls face multiple forms of violence (including sexual violence), forced and early marriages, and emotional abuse. All of these increase our vulnerability to HIV (3–4).

While many gains have been made to improve and ensure access to prevention, treatment, care and support services for women and girls living with (and affected by) HIV, there still are significant barriers to women’s access to these services. This includes violence perpetrated against us within the health system—where the violations of our human rights include the negative attitudes of health-care workers—non-voluntary family planning methods, and sterilization that is forced and coerced because of our HIV status (5).

As women, we often lack bargaining power or economic independence. This, combined with the pervasive fear of ostracism, affects our ability to protect our sexual and reproductive health.

Many cultural practices—such as widow inheritance, child marriages and female genital mutilation—are common practices in Kenya, Uganda and the United Republic of Tanzania. All of these practices have severe physical and psychological consequences. For instance, female genital mutilation not only deprives women of sexual pleasure, but it can also cause disability and death (6). Furthermore, such practices can lead to widespread depression and stress-related illness for women, and they have a knock-on effect on women’s ability to take medications, including antiretroviral drugs (7). Studies also have shown that depression and stress caused by experiencing violence have severe negative consequences that affect the ability of women to protect and support their children, which has potential developmental consequences for the next generation (8–13).

Acknowledging the role that violence can play in increasing the vulnerability of women and girls to HIV, leaders in eastern and southern Africa have established laws and policies that protect them and offer redress for violence (9–12). These include national response frameworks to mitigate, prevent and end gender-based violence and HIV (14–15). Some countries in the region also have established victim support units within police stations and the court system, with officers who work in the units receiving conduct training (16).

## Women living with HIV take action

As women living with HIV, we know that violence against women cannot be excused in the name of tradition and culture; we know that our cultures are rich with love and solidarity, and that we must build upon these values to end violence against women and curb the HIV epidemic. Organizations of women living with HIV in the region are creating grass-roots campaigns for sexual and reproductive rights and access to quality HIV treatment and support (17). Our work includes organizing training that empowers women living with HIV by providing them with knowledge about sexual and reproductive health rights, enabling them to make better, more informed choices.

Women living with HIV in the region have designed and developed advocacy strategies and activities that address the sexual reproductive health issues and challenges affecting them. They hold governments accountable for implementing sexual and reproductive policies in their respective countries and for honouring international commitments. For example, the Coalition of Women Living with HIV/AIDS is implementing a project entitled *We Have Rights Too!*, where women claim respect for their sexual and reproductive rights from service providers (such as health care facilities and police units) (18). The Coalition also is engaging men to champion reduced gender-based violence and to promote gender equality using the *Stepping Stones* methodology, which promotes and encourages mutual communication among couples (19).

Another example of promising community actions can be found in Uganda, where the Men Engage Network was established to increase men's involvement in supporting women to access sexual and reproductive health services (including HIV services) and in preventing gender-based violence. However, pervading social norms, combined with a chronic lack of funding, means that our efforts so far have only had a limited effect. To build on these promising actions, we need to change social norms and secure sustainable funding. Only in this way will our efforts have impact.

***“ We know that our cultures are rich with love and solidarity, and it is upon these values that we must build to end violence against women and curb the HIV epidemic. ”***

# 2 ESSAYS FROM WEST AND CENTRAL AFRICA







## I DID NOT WANT TO PASS ON HIV

— **N.D.S.\***

*Senegal*

*\* At the author's request, her identity has been protected*

I was married at 10 years old. When I lost my husband, he left a letter for me. On the envelope, he had written "confidential"; I thought it was a legacy. In the letter, he said he had been living with HIV but had been too ashamed to tell me. I had two children by him, and as I had not been informed, both were HIV-positive.

I came to Dakar to have the test. I stayed with my uncle, who is an important person, a high-ranking government official. The test indicated that I was positive. I showed the results to my uncle. He put me in the garage. I had my own cutlery that

**“ When women living with HIV seek family planning services, the unspoken judgment is that they shouldn't be having sex. ”**

was bleached every time I used it. As I had sores on my skin, he forbade his children to play with me. His wife did not speak to me. I left and settled down in Independence Square. I slept under the stars, and that's how I started to "get out," as they say (sex work). It allowed me to pay for my medication and food, and it let me send money to my children in the village.

Most women I work with today had similar experiences and entered the sex work profession because of poverty. What do you do when you have five kids, no job and no education? Their ages range from 14 to over 50. These women have been abandoned by their husbands: they are widowed, divorced, or were subjected to early or forced marriages at the age of 13 years or less. Some of the women have a master's degree but could not find work because of stigma and loss of self-confidence. When they say you have HIV, you're down.

Sex workers usually try to use condoms, but many customers do not want to use them; they offer to increase the price and beat you if you refuse. What do you do when you are HIV-positive? You go alone with a man, but when you arrive in his home, there are several other men who all want to have sex with you. If you refuse, they beat you up. Last week, a girl was thrown out of the third floor and she died. I was beaten because I refused to not use a condom, but I did not want to pass on HIV.

You cannot go to the hospital because it is too expensive. The police ask you to file a complaint, but you do not know the person who assaulted you. The police themselves are highly corrupt. We pay them to avoid trouble, so they release us during the raids, but some only let you go if you sleep with them, and they refuse to protect themselves.

Sex workers living with HIV have no guarantee of confidentiality. Some women refuse to talk to anyone about this and will go two or three days without treatment to ensure that no one knows. When someone knows, everyone whispers behind your back, and you lose all your customers. You cannot eat anymore.

HIV is likely to result in violence and poverty. Women tell me that before they got tested, they went from healer to healer because they thought someone had put a spell on them. They sold all their jewelry to get treated discreetly. It is only when they became too sick that they went to the hospital, and there they paid again for the scans and blood tests.

At the hospital, women living with HIV describe being discriminated against by service providers, especially new students (who shout at patients). If women are pregnant, the

staff put an HIV sign (a kind of cross) on their maternity book and tell everyone their status. It is the same problem with midwives and nurses: they insult us, despise us, say “this one is a prostitute.” Many women prefer to go elsewhere, which increases loss to follow-up.

There are many unwanted pregnancies. Some women will abort their pregnancy; others leave their babies in nurseries. Many do not have access to treatment for prevention of vertical transmission; we have HIV-positive children who we care for in our organization.

***“ People always speak for us, especially decision-makers, but I am the one concerned, and I must speak and be heard. ”***

I did not want to pass on HIV, which is why I got the inspiration to create my association. Karlene—which means “stop illiteracy and HIV” in Wolof—conducts talks in bars to educate girls about HIV and condom use. All of our members are sex workers living with HIV who want to support others to protect themselves. In our sessions, we demonstrate the use of condoms and support sex workers to negotiate the use of female and male condoms. We participate in activities to raise awareness with uniformed forces about sex work-related issues, and we participate in gender-based violence workshops and advocate for sex workers’ rights. We also provide psychosocial care to peers, orphans and vulnerable children, identify loss to follow-up, and support sex workers in treatment uptake and adherence.

We work to offer choices to sex workers living with HIV by providing them with training and income-generating activities. We also provide community meals, home visits, family and social mediation, and support for children. We encourage those who are sick to fight for their rights and for themselves.

People always speak for us, especially decision-makers, but I am the one concerned, and I must speak and be heard. If I speak for myself, people will understand me.

# WOMEN LIVING WITH HIV MUST BE AT THE HEART OF WORK ON VIOLENCE

— **Patricia Omowumi Ukoli**

*Pan African Positive Women's Coalition,  
Nigeria*

— **Calorine KenKem**

*Cameroonian Network of Associations of People Living  
with HIV*

Women living with HIV in both Nigeria and Cameroon face violence resulting from interwoven factors. These factors include harmful gender norms and traditions, a social acceptance of violence, and stigmatization. There also is eviction, denial of access to property, accusations of bringing HIV into the home or behaving immorally, and customs that allow violence to be perpetrated with impunity.

When a woman is diagnosed with HIV, she may be exposed to further violence (20). Research conducted by national networks of people living with HIV in Cameroon, Gabon and Nigeria using the People Living with HIV Stigma Index showed that women living with HIV are victims of violence at higher levels than men living with HIV because of their HIV status and gender.

Patriarchal systems render women more likely to be subjected to non-consensual sex or sexual exploitation, and less able to convince partners to agree to abstinence, monogamy or condom use. In many countries and settings in West and central Africa, women generally have limited autonomy, and they are at risk of experiencing violence within the family setting.

HIV also results in distress when it comes to inheritance issues. In our experience, too many women living with HIV still are blamed for their husband's death, evicted from their houses and barred from seeing their children. We have seen many cases of women living with HIV being denied their late husband's property or property rights by their birth family on the assumption that they soon will die. This is a form of physiological and emotional violence.

We have seen that women seek health care more than men do, so they tend to be the first in a couple to know their HIV status (21). They also are likely to face the consequences, even though it may have been the man who brought home the virus.

When it comes to the choice of whether to breastfeed or not, women tell us of the pressure and questioning they face from family and communities. Many women describe being compelled to breastfeed for fear of being stigmatized, verbally abused or sent out of the house.

The health centre is a place where—instead of feeling welcomed—women living with HIV can find themselves denied treatment and family planning services. When women living with HIV seek family planning services, the unspoken judgment is that they shouldn't be having sex. Many women that we know who sought out testing services or condoms were chastised by their communities, accused of being promiscuous and blamed for the spread of HIV.

Pregnant women living with HIV also struggle and continue to face human rights violations around access to treatment, in some cases being denied services until they bring their husbands. Health-service violence against women living with HIV also occurs in labour wards, and women with HIV have been left in labour to deliver on their own.

## Women living with HIV take action

Cameroonian women's associations, including of women living with HIV, focus on women's education, both on the subject of their rights and on health literacy. Activities include training and capacity building for women leaders, awareness-raising and education for communities, performing home visits, and researching cases of rights violations and building bodies of evidence to support advocacy efforts.

In 2013, networks of Cameroonian women living with HIV—with the support of the Joint United Nations Programme on HIV/AIDS (UNAIDS) Cameroon—worked with policy-makers, the Ministry of Health and a network of organizations working on human settlement in order to take stock of the specific challenges faced (and the violence experienced) by women living with HIV. This enabled us to educate women on their

rights and support them to regain some family inheritance that they had previously abandoned due to intimidation from the families of their spouses.

We also work hard to ensure that women understand that they should be able to enjoy their sexual and reproductive rights, despite their HIV status. This can help increase uptake of sexual and reproductive health services by women living with HIV.

# 3 ESSAYS FROM THE MIDDLE EAST AND NORTH AFRICA







# I HAD TO BECOME THE CHANGE I WANT TO SEE IN MY OWN COUNTRY

— **Eman\***  
Egypt

*\* At the author's request, her identity has been protected*

I have been living with HIV for almost 15 years. I have a family and enjoy my work, and I like to think that I have a good and successful life. Over the years, I have had a number of challenging experiences that have impacted my life, and I have had to be strong to deal with people's ignorance and become the change I want to see in my own country. While I continue to live with frustrations about how things are in my country, I also live with great hope that, one day, all women and girls will be treated as equals to men and live in a world where they are supported, nurtured and protected.

My country, Egypt, among other countries in the region, is well known for its high levels of violence against women, especially women living with HIV. Only recently did Egypt pass a law to punish sexual harassment and it has been approved by the Council of Ministers and legally revised by the Department of the State Council. This new development will encourage more women to report such violations.

Studies across the region have shown how women continue to experience gender-based violence, both at home and in public places. A 2011 study conducted using the People Living with HIV Stigma Index in Algeria, Egypt, Lebanon, Libya, Morocco, Saudi Arabia, Sudan, Tunisia and Yemen showed the inhumane treatment of women living with HIV (22–23). This includes being forced to have sex (or to have sex without condoms) and being beaten daily by their husbands. Girls from rural communities are at special risk of violence and sexual exploitation when they leave their homes to seek employment in towns.

Poverty, low levels of education and low literacy levels among women in the region give rise to violence against all women. Those who experience it, especially women living with HIV, still lack crucial knowledge about what they can do to prevent sexual rights violations by their spouses and partners and how to act accordingly.

Women need to understand their rights and be supported in claiming them; this will empower them to change their lives. The current low level of sex education provided to young people, combined with poor knowledge of HIV treatment and an overall lack of legal literacy, hinders our efforts to advocate for our rights and access to HIV quality treatment. Furthermore, economic insecurity makes women and girls more vulnerable to HIV and violence, and there are many social and cultural norms in the region that say women are not even supposed to know about (or enjoy) sex.

Medical care poses a huge issue for women living with HIV in most countries in the region, and we know how challenging it is for women living with HIV to access quality health care from health-care workers who do not discriminate against them. Furthermore, not all services are readily available or accessible. For example, although women in Lebanon do not pay for antiretroviral medication, they do have to pay for other related services, including CD4 count tests, medication for opportunistic infections and resistance tests.

Similarly, a lack of knowledge about health practices is a problem. For instance, medication for children is given in liquid form, but mothers often do not fully understand the correct dosage. This highlights the need for treatment literacy. In the Gulf States, there are general health facilities, but doctors who specialize in HIV are not always available.

Female genital mutilation is widespread in all parts of Djibouti, Egypt, Somalia, the Sudan and Yemen (24). Sadly, research carried out in the region shows that women as well as men are responsible for the continuation of these negative traditional practices. I feel this is an expression of the extent of the brutality, cruelty and violence that exists towards girls in some communities.

In Egypt and throughout the region, the media plays a significant role in adding to the stigma and discrimination faced by people living with HIV. It is always presented as a fatal disease, and the media do not clarify modes of transmission. Women living with HIV in my country are labelled as “prostitutes” or “drug addicts,”. We have seen good but very limited initiatives in utilizing the media such as the production of the movie “Asmaa”, but still much more needs to be done by the national actors to contradict these negative messages. Moreover, stigma and discrimination among health practitioners still persists as a major issue.

Information—not only about HIV but on sexual health and rights in general—must reach all women, especially sex workers and women who inject drugs. Even today—more than 30 years into the epidemic—most people are afraid to shake hands with you if they know you are living with HIV.

## Women living with HIV take action

MENA-Rosa is a regional network of women living with HIV that has been established in 2010. Its main objective is to help all women living with HIV in the region and especially those who had experienced violence and been mistreated by their spouses and medical staff. In 2013, MENA-Rosa initiated awareness raising campaigns targeting doctors and health workers, to provide quality services for women living with HIV in all the stages of their lives. We have ensured that psychologists and doctors are able to speak with women to educate and empower them. MENARosa network supports women to change their lives and solve their psychological problems, and it helps to bring to the concerned parties the human right violations they are subjected to.

This MENARosa project ran for six months, in more than 14 Arab countries so far, with each country having its own two focal point of women living with HIV. The project was financially sponsored by the Ford Foundation and UNAIDS regional support team in Egypt provided all technical assistance. Through this support, we have been able to strengthen a wide network of women living with HIV who are fighting the violence they have experienced.

Women living with HIV have begun to talk openly, without shame or regret, about the violence they face. Civil society has started to play a role by supporting women living with HIV as they deal with these forms of abuse.

Women have mobilized, and they now understand and demand their right to fair treatment. Recently, we have even seen religious leaders in Egypt and the Middle East advocate for the rights of women living with HIV, especially those from poor backgrounds and those facing violence.

Using national TV shows, feminist activists have introduced education and public information programmes to eliminate prejudices that hinder gender equality, including for women living with HIV. In addition, there have been instances of women living with HIV starting to pursue their economic and social rights through custom tailored income generation projects.

***“ I also live with great hope that, one day, all women and girls will be treated as equals to men and live in a world where they are supported, nurtured and protected. ”***

# 4 ESSAYS FROM EASTERN EUROPE AND CENTRAL ASIA





# WE MUST CHANGE WHAT IS CONSIDERED NORMAL IN ORDER TO END VIOLENCE AGAINST WOMEN AND GIRLS

— **Svetlana Moroz**

*Positive Women*

*(the Union of Women affected by HIV in Ukraine)*

I live in a region where domestic violence is often the norm, where a drunken or angry lover, husband or partner may call a woman names or threaten, insult or persecute her, and his only punishment will be a 40 grivna (US\$ 3.80) fine. The police (often arriving 3 hours later) may detain him and take him over to the police department, but only if he beats her half to death or worse. Even pregnant women are at risk of experiencing abuse from their partner; this is particularly true if they have been beaten before, but, for a significant number of women, their first experience of domestic violence is during pregnancy (29).

I was lucky: despite the fact that he was an alcoholic, my father never beat my mother or his two daughters, even though I was a hyperactive child (especially as a teenager). After the age of 14, many of my friends started getting beaten by their boyfriends and later by their husbands. This was a normal part of their relationship. Before I got married, I didn't have many boyfriends, and they never beat me.

**“ Teach girls and boys alike not to tolerate violence, to break the vicious cycle of perpetration and victimizing. ”**



My first injection came when I was 16. Since then, there have been multiple attempts to rape me just because I use drugs or am around drug users. One day, I was stopped at our hangout by the owner's son (who did not use drugs). He said that he would not let me out of the courtyard unless I "gave it to him." I refused, and he and his pal beat me. When I told him that I had not yet had sex with anyone, he refused to believe me. "There are no women-junkies like this," he said.

Another time, I was walking with my friend after we had scored a dose. We were stopped by four guys who took our drugs and led us to a dark place. After the very first blow, my girlfriend agreed to have sex and left with one of them. I was beaten until I mentioned the name of my second cousin who lived nearby. I was lucky: they knew him and let me go.

The few female friends with whom I have injected have all been raped at least once. I didn't escape this fate.

Usually, it is girls and women who use drugs who are blamed for the situation. Women and girls face many challenges. Their children are taken away from them, and they can be beaten, raped and sent to do so-called work on the side of the road; their money and condoms are taken away, they are thrown out of their homes, they are treated for drug use without rehabilitation, and they are refused medical care, especially if they are HIV-positive.

This year, we opened a centre for women who use drugs who have children, many of whom have experienced domestic violence. Recently, a former assailant of these women broke our windows because his former partner had decided to stay with us. The police drew up a report and said that it would be considered disorderly conduct only if the attack to the centre happened during the daytime on a business day and directly interfered with the organization's operations.

Under these conditions, violence breeds violence. Women are forced to ask other men—their friends, new lovers, fathers or brothers—for protection. To solve it legally is too complicated and practically impossible.

There is another way, but it is time-consuming and requires a lot of patience and love. We call on all of you—whether you are in a position of leadership, a community member or a parent—to impart to children a new attitude towards violence. Teach girls and boys alike not to tolerate violence, to break the vicious cycle of perpetration and victimizing. Show them, through your own behaviour and values, how to change the consciousness of men and women.

## **TAKING ACTION AT THE CROSSROADS OF VIOLENCE AGAINST WOMEN, INJECTING DRUG USE AND HIV**

— **Alexandra Volgina**  
*Equity. Verity. Advocacy. (EVA),  
the Russian Federation*

— **Svetlana Moroz**  
*Positive Women  
(the Union of Women affected by HIV in Ukraine)*

Eastern Europe and central Asia is one of the only regions where new HIV infections remain on the rise (25). Since 2000, a rapid increase of HIV among people who inject drugs has caused the epidemic in this region to surge, and the number of people living with HIV in the region has doubled, reaching an estimated total of 1.1 million (1.1 million–1.5 million) in 2013 (25). Combined, Ukraine and the Russian Federation account for roughly 90% of new HIV infections in this region (25).

Women who use drugs often experience systematic and widespread violence, harassment and sexual abuse at the hands of law enforcement officers. This violence is facilitated by drug legislation, which results in twice as many women who use drugs being incarcerated in the Russian Federation as in all European Union (EU) countries combined (26). Women who use drugs often are denied their right to health care, and they also can be forced into drug treatment centres, where they can be subject to physical and psychological abuse. With nowhere to turn, they often find themselves without protection against violence from their sexual partners, parents and extended families.

## Women living with HIV take action

In recent years, the activism of national networks of women living with (or affected by) HIV has substantially increased in Georgia, Kazakhstan, the Russian Federation, Tajikistan, Ukraine and Uzbekistan under the umbrella of the Eurasian Women's Network on AIDS. The Network is now building its organizational structure and forming its advocacy agenda.

Specifically, more and more women's networks and groups in the region are mobilizing to promote non-violent societies. For example, the Georgian Harm Reduction Network's (GHRN) campaign against violence against women involved Georgian rugby players and other sports representatives. It's effective because rugby has brought international success for Georgia, and the players are symbols of victory. As such, their opinion is considered to be valuable and masculine among men. In 2013, the GHRN launched a national Find the Exit campaign that coincided with World Human Rights Day to attract social attention to the structural barriers faced by women who use drugs. Recently, the GHRN also engaged with formerly imprisoned women and communities of female sex workers to help them reorganize harm reduction services to make them more women-friendly.

EVA, the all-Russian network of women living with HIV, has—through federal-level advocacy—been working for several years to protect the rights of women who inject drugs. It has done this by trying to overcome structural forms of violence and by pushing for the development of appropriate drug and

HIV treatment programmes in the Russian Federation. EVA also has conducted HIV-related research in several Russian cities (such as Tomsk) that now have specific protocols—including protection against violence—to support women who inject drugs.

In many countries in the region, civil society organizations—in response to violence against women and girls—have established strong collaborations with community-based HIV organizations. Those working in service delivery and advocacy at national level also are trying to unite their efforts. For example, EVA is involved in lobbying for a law against violence in the Russian Federation.

In 2009, HealthRight International in St Petersburg—supported by the Social Policy Committee in the Russian Federation—developed a multisectoral referral and service provision system to identify and provide services to survivors of violence. As a result, an intersectoral response protocol and guidelines for its implementation were adopted.

In October 2012, representatives of various state institutions, non-governmental organizations, UN agencies, international funds, Positive Women—the Union of Women affected by HIV in Ukraine—and other key players in the HIV response in Ukraine discussed how to integrate gender into HIV policy. The goal of the policy is the integration of gender into all programmes in Ukraine's national AIDS response in order to ensure gender equality and equity. It also provides an opening to include violence in the conception of a new national AIDS programme for 2014–2018.

In October 2012, the Eurasian Harm Reduction Network issued a call for immediate action to stop violence against women who use drugs (27). This is a collective appeal to the Special Rapporteur on Violence against Women on behalf of harm reduction service providers, human rights activists and women who use drugs in Georgia, the Russian Federation and Ukraine. This was done to prevent further violence against women who use drugs and to establish mechanisms to investigate and bring to justice people perpetrating acts of violence against them.

The GHRN also conducted a study on violence against women who use drugs and their access to health-care services. It revealed multiple reasons for violence against women,

including cultural norms about femininity and motherhood, under-reporting of violence within the family, taboos around sexual violence, and a lack of support systems for women who have experienced violence. For women who use drugs, these factors are amplified because they fear being arrested for drug use if they report experiencing violence.

Additional research was undertaken by the All-Ukrainian Network of People Living with HIV from September 2011 to January 2012 under the international campaign Women Will not Wait: Stop the Violence Now! Representatives of local women's groups and members of the All-Ukrainian Union of Women Infected and Affected by HIV actively participated in the research (28). The research covered HIV, and violence against women, with a focus on better understanding the national epidemic, scale-up of programmes and services, and women's empowerment and leadership (in the context of the epidemic).

# 5 ESSAYS FROM ASIA AND THE PACIFIC





## HEALTH-SECTOR VIOLENCE AND WOMEN LIVING WITH HIV

— **Susan Paxton**

*Asia Pacific Network of People living with HIV (APN+),  
Australia*

All women deserve respect during pregnancy. Women living with HIV in Asia, however, are frequently denied their right to decide freely on the number and spacing of their children, to attend pre-test counselling, to determine which contraceptives to use and to obtain information about pregnancy outcomes and the implications of sterilization.

Furthermore, many pregnant women living with HIV in the region are denied their right to health care. Instead, they are subject to extreme discrimination from health professionals, including refusal of antenatal care and delivery services, and coerced abortion and sterilization. This amounts to state-sanctioned violence, and as a result, many women living with HIV avoid health-care services, and this compromises the health of both the women and their children.

These issues were revealed in a study comprising 757 women living with HIV who had been pregnant within the past 18 months in six Asian countries (Bangladesh, Cambodia, India, Indonesia, Nepal and Viet Nam) (30). The voices of the women interviewed are a powerful testament to the neglect and abuse they experienced, including rights violations and violence perpetrated by health-care workers.

**“ Women living with HIV need to be involved in the response in a meaningful way, from peer support to pregnant women at the point of diagnosis to participation in policy design. ”**



## **Contraception**

Male condoms are the only contraception promoted among women living with HIV, but they are not used consistently, often because partners object to them. Women who insist on condom use sometimes face violence from their sexual partners. Rates of unwanted pregnancy were high (37%), and women said they need contraceptives they can control, such as intrauterine devices, and oral or injectable hormones.

## **HIV counselling**

Pre- and post-test counselling for HIV is widely accepted as necessary because of HIV-related stigma. However, in India, where most women were diagnosed during pregnancy, only 50% received pre-test counselling, and results were often given to family members, not the woman herself. This kind of unwanted disclosure is in itself a form of institutionalized violence.

Some women, after being diagnosed with HIV, face violence from in-laws or partners who blame the woman for bringing HIV into the family.

## **Pregnancy and childbirth**

After their diagnosis, many women face judgmental attitudes from health-care workers, including discouragement from continuing their pregnancy. Of the women in the study who had an abortion, 29% said their pregnancy had been wanted. Furthermore, many women who are coerced into an abortion face discrimination when they go for the procedure. For instance, some pay higher fees than HIV-negative women, while others are made to wait until all procedures among HIV-negative women are completed.

Although caesarian sections are invasive and potentially dangerous procedures, in some countries, it is still government policy for women living with HIV to undergo caesarean delivery at the primary care level, despite WHO recommendations to the contrary (31). In fact, most women are given no choice about delivery method. Among the countries surveyed, the proportion of caesarean section deliveries among women living with HIV was as follows: Cambodia 7%, Nepal 33%, India 36%, Viet Nam 41%, Bangladesh 57% and Indonesia 67%.

Overall, 42% of women had difficulty finding a gynaecologist to care for them during pregnancy. Furthermore, some women were verbally abused during labour; others were abandoned during labour, and staff refused to touch them or their infant after delivery.

### **Sterilization**

Overall, 30% of the women living with HIV who participated in the study were encouraged to undergo sterilization, usually by gynaecologists or HIV clinicians, and 38% (11% of all women participating in the study) said they had no option to decline. Women who underwent sterilization also were significantly more likely to have a caesarean delivery. Some women do not know if they were sterilized; others were sterilized without their consent. Some women who were encouraged to be sterilized did not have any previous children.

### **Women living with HIV take action**

Unless discrimination by health-care workers towards women with HIV is addressed, women will avoid using maternal health services. This will result in poor health outcomes for mothers and their children, rendering ineffective government efforts to reduce HIV transmission to children. Women living with HIV need to be involved in the response in a meaningful way, from peer support to pregnant women at the point of diagnosis to participation in policy design.

Women living with HIV in the Asia Pacific region have begun to take action. The Indonesian Positive Women's Network contributed to the NGO shadow report as part of the country's reporting to the Committee on the Elimination of Discrimination against Women (CEDAW), resulting in a government policy change to stop coerced sterilization. APN+ also is rolling out sexual and reproductive health rights training for women living with HIV in eleven countries in the region.

## PUNISHED FOR WHO WE ARE

- ***Khartini Slamah***  
*Asia Pacific Transgender Network,  
Malaysia*
- ***Thilaga Socky Pillai,***  
*Justice for Sisters,  
Malaysia*

The Malaysian government has repeatedly indicated that transgender people are not protected under the laws and constitution of Malaysia. Since March 2011, the Department of Islamic Development Malaysia has created camps for transgender people. Ostensibly established to provide economic and employment opportunities, these camps include religious sessions—such as praying as men—and largely target economically marginalized Muslim transgender people to “lead them to the right path” (34). In the state of Negeri Sembilan, an individual can be fined US\$ 325 or imprisoned for six months (or both) if found guilty of posing as a woman (35).

Efforts to demonize lesbian, gay, bisexual and transgender people have further intensified since an annual sexuality rights festival (Seksualiti Merdeka) was banned in Kuala Lumpur in November 2011. Transgender people, especially transgender women (or *mak nyah* in Malay) remain closely watched by the police, state religious departments and the state-controlled media. This unwarranted attention shapes public opinion, perpetuating intolerance and violence towards transgender people.

This hostility and violence is fairly recent in Malaysia. Prior to the political Islamization in the late 1980s, four local doctors used to perform sex reassignment surgeries in a semi-government hospital. Then, after a 1983 fatwa (religious edict) banned sex reassignment surgery for Muslims, these sex reassignment surgeries and related services were arbitrarily shut down. The fatwa triggered a domino effect, eroding the rights of transgender people, including those who were not Muslims. As a result, post-operative transgender people struggle to change their name, gender and other details in identification cards. In fact, many state and government departments actively promote and support efforts to “correct” transgender people, and their inaction towards human rights abuses adds to an already hostile environment.

In March 2012, the Deputy Minister of Prime Minister's Department at that time announced a list of measures to curb the so-called spread of the lesbian, gay, bisexual and transgender (LGBT) lifestyle. This was intended as a response to social problems, such as sex work, drug use, risk of HIV, and psychological or mental disorders (32). When subsequently questioned in Parliament in June 2012 about the government's religious approach to the LGBT community, the Deputy Minister stressed that Article 8 of the Federal Constitution (which protects people against discrimination, including gender-based discrimination) is limited to men and women (33).

In May 2012, two new sharia-based laws were introduced in the state of Pahang to criminalize transgender or gender non-conforming people for posing as the opposite sex or for cross-dressing. This made Pahang the last state in Malaysia to enact such a law, and the fourth state to have sharia laws that criminalize both male and female transgender persons or gender non-conforming persons (36). Sharia-based law also empowers state religious departments to conduct raids and persecute transgender people. These raids make transgender women vulnerable to physical, emotional, verbal and sexual violence.

Without any legal protection, transgender persons suffer further violence in detention and therefore many opt not to report abuses. Transgender women often agree to provide sexual favours to get out of an arrest, as they do not want their family members to be notified or for the news to be featured in the media.

In 2011, following a series of violent and arbitrary persecutions by the state religious department, four transgender women from Negeri Sembilan filed a judicial review to review the rights of male persons posing as women. In the affidavits submitted by the applicants, they chronologically detailed the physical and verbal violence that they had been subjected to under the law. However, Justice Datuk Siti Mariah Ahmad ruled that as the four applicants were Muslims and male, the law was applied to them correctly (36).

There are an estimated 40 000 transgender sex workers in Malaysia, and because they are more visible and tend to frequent areas that are prone to raids, they are particularly vulnerable to the so-called cross dressing laws. The lack of job opportunities, coupled with the vilification of transgender persons in the media, further reinforces the stereotype that all transgender women are sex workers, and that sex work is immoral.

## Transgender women living with HIV take action

We continue to advocate for legal change in the face of danger and great adversity. The Asia Pacific Transgender Network advocates for change through UN agencies, and in 2010 and 2011, transgender women have filed judicial reviews in their states to review the state sharia laws that criminalize gender identity.

On the 20 November of each year, the Pink Triangle Foundation's Mak Nyah programme organizes a Transgender Day of Remembrance to commemorate the lives of mak nyah who have died, both locally and globally, due to intolerance, hate crimes and violence. In 2010, the Malaysian Network of Transsexuals (MyNetra) was established to support, build and mobilize the transgender community, and to address the lack of information within it. MyNetra's creation has triggered the birth of other smaller support and online groups for transgender people.

In May 2013, the transgender community launched the I AM YOU: Be a Trans\* Ally campaign to engage the public and encourage support for the human rights of transgender people. This campaign complements legal efforts and aims to win the hearts and minds of people to facilitate policy change.

In two states—Penang and Pahang—our transgender movement is vibrant. As part of the movement, the Penang Family Health Development Association works in collaboration with State Assembly official YB Teh Yee Cheu to promote and protect the rights of transgender people. Teh's political secretary, Hezreen Sheikh Dud, also has tabled a proposal at the State Assembly to establish a committee to study and oversee the welfare of the transgender community in Penang (37).

In Pahang, Drug Intervention Community Malaysia Pahang (DIC Pahang), the local organization working on transgender issues and rights, adopts strategies that aim to integrate mak nyah into the mainstream society. In August 2013, 12 mak nyahs participated in the National Day parade as members of DIC Pahang (38).

# 6 ESSAYS FROM NORTH AMERICA AND WESTERN EUROPE





## TURNING LEGAL BARRIERS INTO LEGAL PROTECTION FOR ALL WOMEN

— **Cecilia Chung**

*Global Network of People Living with HIV  
North America and the Transgender Law Center,  
the United States of America*

— **María José Vázquez**

*WECARe+ Network,  
Spain*

As women living with HIV, we celebrate the advances, though limited, in legal protections for gender equality that have occurred in both North America and western Europe. Yet violence continues to exist. The frequency of violence from an intimate partner in the United States remains high: it is around 55% for women living with HIV, compared to a national prevalence of 36% (39–40). We know that violence and HIV also are particularly prevalent among transgender women, with 58% reporting domestic violence and 28% estimated to have HIV (41). In Europe, one in three women experience physical and/or sexual violence in their lifetime (42).

Violence is woven into the lives of women living with HIV, and it creates barriers for those who most need support and health services in both North America and western Europe. Unaddressed trauma is a key reason why women fail to adhere to HIV medication and have rates of adherence failure that are four times higher than those who have not been abused (43). However, there are still huge gaps in data around violence against women in all its forms, especially how transgender women experience violence because of their identity. Given how women in all our diversity experience violence differently, we need policy-makers to explore the visible and hidden epidemics of gender-based violence in order to shape and implement protective laws, policies and practices.

Many economically disenfranchised women experience more drug use, increased mental health issues and incarceration, expanded participation in the street economy, and higher



rates of HIV (44–45). By not adopting necessary protective and anti-discrimination legislation, legal and political environments continue to expose the most marginalized among us to gender inequality, inequity and violence that is both gender-based and hate-motivated (46).

In North America, the war on human and sex trafficking has contributed to increased criminalization of sex workers, with proponents and law enforcement inaccurately conflating commercialized sex work with sex trafficking. In contrast, while some western European countries have now decriminalized or legalized sex work, law enforcement often fails to take seriously the violence caused by human and sex trafficking. Although a new EU directive was adopted in 2011 to impose greater penalties on traffickers and better protect victims, only six EU countries had completed transposition of the anti-trafficking directive into their national legislation by April 2013 (47).

Women and transgender women engaged in sex work are at risk of being exposed to physical violence from relationships, clients and law enforcement officers (48). Sex workers, transgender women and undocumented migrants often see no incentive to access HIV prevention and testing services for fear of arrest, police harassment and abuse by intimate partners (49–55). In the United States, transgender asylum seekers in immigration detention facilities often are housed by their birth sex, and as a result, they face high rates of harassment and sexual violence (56).

Fortunately, legal environments are showing signs of change. For example, the Canadian High Court has ruled that with effective viral suppression, it is not always a crime for a person living with HIV not to disclose their HIV status (57–58).

**“ Given how women in all our diversity experience violence differently, we need policy-makers to explore the visible and hidden epidemics of gender-based violence in order to shape and implement protective laws, policies and practices. ”**

In both North America and western Europe, our experience is that certain grass-roots advocates (including networks of women living with HIV) have shown their influence in increasing awareness about the interaction of health needs and social determinants in women's lives. The SHE (Strong, HIV-positive, Empowered Women) programme in western Europe seeks to unite women living with HIV, medical providers and researchers in dialogue in order to highlight the challenges and layers of vulnerabilities that women face (59). In the United States, the White House has released a report with recommendations on the intersection of HIV, violence against women and girls, and gender-related health disparities that is inclusive of transgender women (60). More research evidence can significantly improve these dialogues, as can anecdotal reports, which often are ahead of the evidence (61–62).

## **NOW I HAVE TAKEN A STAND TO BE THAT PERSON WHO WAS NOT THERE FOR ME**

— ***Ethel Winston***  
*USA*

I was diagnosed with HIV when I was five months pregnant and married. If you'd asked me back then, I would have said I was happily married. I already had two children from my previous relationship, and after nine years of being single, this new love felt so right.

Using protection was not even an issue, because I had kept my promise not to be with anyone until I got married, believing that with marriage would come trust and safety. My new love told me he was not seeing anyone either. I never questioned his faithfulness or his love, so we got married. We were a happy family, and my Mr Perfect always came home on time. He cooked, took care of the kids and made our house a home. Now that we were married, all that was left was to give my wonderful husband the child he wanted.

***“ Then I found my strength, my voice and my love for myself. I realized that, after all the abuse, I couldn’t change what had happened in my relationship, but I could choose how I would go forward. ”***

Then, when I was five months pregnant, my doctor diagnosed me with HIV. I was scared, nervous and flooded with emotion. When I told my husband, his response was simply, “It’s OK.” He never asked what HIV was or what it meant for our child or our relationship. I, however, had a lot of questions about HIV, but my husband immediately told me that it was a closed subject and demanded that I not to say a word to anyone.

My once-sweet husband started treating me very badly in every imaginable way. He became extremely verbally, physically and emotionally abusive. I was cut off from my family or friends. I got slapped many times, but I stayed because I felt out of options. I had nowhere to go, and I didn’t believe that anyone else was going to accept me with my HIV diagnosis. I knew so little about shelters or calling 911. I was quite new to the U.S. and naive in many ways—much of what I knew was based on what I had learned from my husband.

I was raised to be faithful, and I always thought that would be the key to guaranteeing a wonderful and healthy marriage. I knew I needed to leave, but I feared that everyone would blame me for my failed marriage, thinking that I had cheated on my husband. I worried that people would think that I had brought HIV into our marriage, and I feared disappointing my family and disobeying their beliefs of staying married and respecting your husband, so I chose my culture and our values instead of my health and safety. I stayed in the chaos, and I continued to take the abuse.

However, despite my desire to stay, I had to escape when our child was four months old. It was 16 years later that I found out that my husband was HIV-positive before he married me.

I was left with anger. I was angry about my sacrifices when I accepted the abuse, how I had thought that I should just be grateful to have my husband by my side even though I had HIV. I was filled with sadness, pain and anger because no one could see that I was hurting inside.

Then I found my strength, my voice and my love for myself. I realized that, after all the abuse, I couldn't change what had happened in my relationship, but I could choose how I would go forward. I started watching and observing other HIV-positive people, and I saw hope.

I have become an advocate. Now I take a stand to be that person who was not visible then, when I needed someone. I try my best to empower women so that they understand that they can voice their opinions and assert their personal power to make smart and informed decisions. I especially try to help those with backgrounds like mine, women who were taught to be obedient to the will of men and to not talk about what goes on in their homes to anyone outside. I advocate for people living with HIV to help them have the options and education that I did not. I hope sharing this will allow someone else to find her courage, harness her power and break free of the chains of violence that bind far too many women living with HIV.



# 7 ESSAYS FROM LATIN AMERICA





# A LIFE OF FREEDOM, HEALTH AND DIGNITY FOR WOMEN AND GIRLS IN LATIN AMERICA?

— **Gracia Violeta Ross**

*Bolivian Network of People Living with HIV*

Violence against women and girls in most Latin American countries is fueled by a macho culture that can disregard women's interests. In our lives, violence and HIV are married to many of us.

The extent of gender-based violence in Latin America is truly shocking. A report on 12 Latin American countries by the Pan American Health Organization—in collaboration with the US Centers for Disease Control and Prevention (CDC)—found that physical or sexual violence by intimate partners was widespread, showing that between a quarter and a half of women reported experiencing intimate partner violence (63). The report states that physical and sexual violence often are combined with psychological and emotional abuse during the lifetime of many women and girls.

Indigenous women and younger women are particularly vulnerable to all forms of violence. Our vulnerability is based partly on the fact that young women are often considered less valuable in comparison to young men, and therefore many families don't invest in their education. Indigenous women face the hardest expressions of traditional male dominance (64), and they often are isolated from society due to a lack of education, the physical distance of their location and the assumption that they are destined for motherhood and housework.

Some of the consequences of violence are HIV and sexually transmitted infection, unwanted pregnancies, and the inability to work, continue daily life or participate in the economy. It also can result in negative consequences for health (including mental health).



The number of people living with HIV in the region has increased from 1.2 million [1 million–1.5 million] in 2001 to 1.6 million [1.3 million–2 million] in 2013 (26). Due to achievements in treatment access, people living with HIV are living longer, so the number of people living with HIV will increase. Despite this, HIV is seen in Latin America as an issue of gay men, and violence is seen as an issue of women. We have to address this misunderstanding among our policy-makers and communities, pointing to the links between HIV and violence.

With regard to the response to sexual violence and HIV so far, post-exposure prophylaxis is not always available or accessible for women, even though access to it is included in the laws of some countries. In order for post-exposure prophylaxis to be widely accessible for women and children who are raped, we need more information and training for police officers. Most importantly, we need a framework for human rights and gender.

Although there has been some disaggregation of HIV data according to sex and gender in response to the demands of civil society, there still is no accurate data at the country level that draws connections between HIV and violence in the Latin America region. Some studies have shown the links between violence against women and HIV; others have explored the realities of women living with HIV, sex workers and transgender women. As members of these groups, we face specific and additional forms of violence because of the stigma that surrounds us, our perceived association with the spread of the AIDS epidemic, our alleged lack of morals and the discrimination of society (65–71).

Perhaps the reason for our collective inability to respond effectively to the interconnected realities of intimate partner violence and HIV has its origins in our lack of understanding of the difference between risk and vulnerability. In other words, one woman can change her behaviour (i.e. the risks she takes), but she can't change the environment in which she is living (i.e. the factors outside of her control to which she is vulnerable). For that to happen, a woman will need the support of men, of other women, of policy-makers and of governments. Preventing and ending violence against women is not the responsibility of women alone.

In order to prevent increased cases of HIV and higher rates of violence among women and girls, we need to address both together, empowering women and girls at the individual and community levels. We need to transform our communities in order to make them safer for women and girls.

We also need better integration of HIV services and those of the police, particularly when it comes to care and prevention services for cases of rape. We need communities that are safer for women and children, especially girls, not because of the HIV epidemic, but because all women and girls are entitled to bodily integrity.

Women living with HIV and those who have experienced violence are best-placed to guide this work. Understanding how the life of a woman is affected by gender-based violence and HIV is not difficult—if we listen to the women affected.

## MY BODY, MY TERRITORY

— **Mariana Iacono**

*Argentine Network of Women Living with HIV and ICW  
Global*

As a girl, I was taught that the word of my father was final, that when a man yells, women are silent, and that if a man is angry, he can be dangerous. My father was never physically violent with my mother, but he was physically violent with one of my sisters. None of us four women could do anything about it.

When you're a girl, you don't know what to say if someone is sexually violent towards you. You don't know how or when to talk about it, and you feel guilty. When I was seven and I was wearing a pair of short and tight shorts, I reasoned that it was my fault when my relative touched my intimate parts; I provoked him, so how could I speak of it? If I did, my dad would get angry and scold me. And every night that I spent in my relatives' house, I could not sleep. I couldn't say that I was afraid to go; each situation of symbolic violence that he exerted over me, I kept to myself like a state secret.

At the same time, I would go with my friends in the afternoons to the plaza, where there was a little kiosk. The man who worked there would invite us to go inside, and he would show us porno magazines. None of us would say anything. We never spoke about it; we never said anything at home. The man would suggest that if we showed him our underwear, he would give us tokens to play. I wouldn't do it, but my friend would, and so we would spend more time playing there. How could we say this at home? If we spoke of it, would mother believe us? And what if she told dad and he got angry?

At school, sexuality was not spoken of, nor was the empowerment of girls and women. So I followed a mistaken path, of not knowing how to say what I wanted when I had sex or how to negotiate my sexual and reproductive health needs. At 19, I met a man who went on to harm me emotionally and damage my self-esteem. He sought to control me through harassment, restrictions, manipulation, isolation and excessive jealousy.

I can say this today, when I am 31 years old. When I was 19, I knew it, but I didn't know how to stop it. This man would ask me each day to have sex without a condom and, one day, to please him—because I did not know how to say “no”—I accepted.

For centuries and centuries, women pleasing men has been the family mandate, the cultural mandate, the social mandate. This man was living with HIV and he knew it. His historical role in society made him the boss, and from that unequal relationship, I was harmed, acquiring HIV. This relationship ended because he caused me pain and harm that affected my physical integrity. Then came the HIV-positive diagnosis.

**“ Understanding how the life of a woman is affected by gender-based violence and HIV is not difficult— if we listen to the women affected. ”**

It took a year for me to come to terms with the impact of the HIV diagnosis. There was the constant association of HIV with death or poor health, and a fear of not being able to plan for the future. Women living with HIV live with the fear of becoming victims of obstetric violence (through forced sterilization), that health-care workers will exert this against our bodies because we have the virus inside—or later, against our babies, because they are the children of mothers with HIV. I received my HIV diagnosis without the recommendations indicated in care protocols, without sexual and reproductive health services for diagnosing HPV, and without any integration and coordination with psychological support services.

The law of Argentina classifies three types of violence against women: physical, psychological and sexual. I have experienced them all—in my childhood, youth and womanhood.

My body, my territory. I did not learn this at home. I did not learn it through my education. I did not learn it from my peers as a youth. I learned it from my body, through suffering, scars and HIV.



# 8 ESSAYS FROM THE CARIBBEAN





## NEVER BLAME YOURSELF. IT IS NOT YOUR FAULT. YOU DESERVE BETTER.

— **N.N.\***

*\* At the author's request, her identity has been protected*

I never thought of myself as someone who would be at risk of violence, but it happened. I still have a hard time believing it, and I have only told a couple of people. I still feel alone in my experience.

He was a boy from school: tall, handsome and smart. Everyone liked him, including me. We started dating, and I was surprised to find out that he had a lot of insecurities. He didn't like that I did better than him in school. He would get angry when I talked about the different things I wanted to do in life. He said I didn't care about him, that I had my whole life planned out without concern for what he would do.

At the beginning, he just got angry; then, suddenly, it was more than that, and he was hitting me in a back room at a friend's party. He was angry because I had said "hi" to another guy. He kept hitting me, and I was so shocked, I ran away and out to the street, making it to a friend's house. I wanted to tell her what had happened; I wanted help. She wasn't home, though, and while I waited for her to come home, I cried and cried. Somehow, I changed my mind about telling her. I thought I shouldn't make a big deal about it, that everyone liked him, that he wasn't a bad guy.

He apologized the next day; he was so embarrassed. He said he loved me. I said I loved him. After that, things only got worse. He would get so jealous and angry; he would grab my wrists, throw me against the wall and hurl things at me. Once he choked me to the point that I passed out.

I wanted to leave him, but I was ashamed that I had stayed, and I didn't dare tell anyone about what he was doing to me. At school, some people would see the bruises on my arms and once even on my back where he had kicked me. They would joke, "What does he do, hit you?" They would laugh. I didn't know how to answer. "Yes, he does," I answered. They didn't want to know.



Finally, I told him I wanted to end it. He begged me not to, and I agreed to go to therapy so we could work on our issues together, even though he was the one hitting me. We went to three different therapists, and all of them told me to stay with him, that I needed to understand a man's need to be dominant. I tried to say I didn't feel safe, but they were the professionals, and they told me to stay.

After almost two years, I managed to end it. It was so hard, and everyone kept saying how cold I was. He kept coming after me until I told him I had reported him to the school administration, and they would kick him out if he came near me again. That was a lie; I never told anyone, but it worked. He didn't try to get back together with me after that.

I wasn't with anyone after him. Years later, I started to get sick. I had always been healthy, and suddenly I felt sick all the time. I felt weak. After a lot of tests and examinations, the doctors told me I had HIV. I was sick for two years, and then with my medication, I started to get better. Now I am doing better, but I will never be the same. I can't even have real relationships with my family and friends because I can't tell them about this.

I've started to do some advocacy work, but I don't tell people that this has been my story, too. Disclosure is such a tough thing because there is so much stigma. I hear what people say: that women who are beaten must have done something to deserve it, that they are the stupid ones for putting up with it, that you should have known better than to get HIV. If you're sick, it's your own fault. I hear what people say, and I hear these voices in myself, too.

I am working so hard to overcome that, but I need help. That is why I am writing this. I want to ask for people to stop joking about violence against women. It's never OK. I want to ask that they realize that the person next to them may have been beaten, and that it is never, ever, their fault. It can happen to anyone.

One day, maybe I will be able to tell people that I was in an abusive relationship and that I have HIV, but for now, I hope writing this helps other people learn from my experiences. Never stay if he is hitting you. Never blame yourself. Don't be ashamed. It is not your fault. I deserve better. You deserve better, too.

## IT IS AT THE LEVEL OF COMMUNITY THAT WOMEN AND GIRLS CONFRONT THEIR GREATEST CHALLENGES

— **Olive Edwards**

*Jamaica Community of Positive Women*

The Caribbean has one of the highest rates of violence in the world. There are many contributing factors, but it is increasingly recognized that ending all forms of violence will require confronting harmful stereotypes of masculinity in our patriarchal society (72). Emotional and psychological abuse is endemic, and spousal abuse is normalized in attitudes and behavior.

Recognition of violence against women as a health and development issue began in the 1990s, when UN agencies, government-mandated organizations (such as the Bureau of Women and Gender Affairs) and women's associations took the lead in sensitization interventions and advocacy. Now, we are more aware that violence against women has a historical, cultural and social context. Gender studies have assisted research into the attitudes and behaviors that contribute to violence against women in the Caribbean in all of their diversities (73).

The Caribbean has a record of signing international conventions, developing plans and setting targets with good intentions. Periodic spurts of advocacy followed by lethargy makes follow-up and achieving set targets very difficult. As with many other countries, there also is no definition of discrimination against women in the Jamaican Constitution or other legislation.

In the Caribbean, women often experience violence in the form of stigma and discrimination, sexual and reproductive oppression, and spousal and emotional abuse. It is at the

community level that women and girls confront their greatest challenges (74). The stereotype of women as nurturers is often manipulated to shift attention away from gender inequality, the oppression of women and the neglect of their physical, emotional and financial needs. Similarly, a neighbour in the community is expected to ignore signs of abuse and not interfere in another family's quarrels, thus normalizing violence. Unfortunately, ignoring violence has resulted in the death of many women; some people even ask what fault or deed was committed by the woman that led to her untimely death.

Living with HIV exacerbates these challenges. HIV programmes and policies do not sufficiently address the rights, realities and needs of women and girls. Often, women living with HIV do not disclose their status to sexual partners because of real threats of violence in their home and perceived threats that are based on comments in the community (75).

According to UNAIDS data, young women in the Caribbean between the ages of 15 and 24 are one and a half times more likely to be living with HIV than young men of the same age (76). Despite this, HIV programme budgeting for women continues to revolve around prevention of mother-to-child transmission. There is no real commitment to challenge gender dynamics and violence against women in the context of HIV.

Threats and acts of stigma and discrimination also occur in health-care settings. This includes forced or coerced sterilization, as well as the failure to provide information and contraceptive options for women living with HIV (77).

There is a need for more defined, coordinated, measured and accessible research across the region. People living with HIV should advocate for the use of existing instruments, such as the People Living with HIV Stigma Index, to expand understanding of factors related to violence. Systems, services and social support must assist affected families to cope with the trauma, stigma and discrimination associated with an HIV diagnosis and to ensure that it does not lead to violence.

## Women living with HIV take action

Women's organizations (such as the Women Resource and Outreach Center and Woman Incorporated Crisis Center) continue to mobilize women, creating CEDAW shadow reports and reports for the Human Rights Commission. The Bureau of Woman's Affairs enables advocacy with policy-makers to sensitize them and build awareness about gender-based violence among them.

Women living with HIV across the Caribbean also are working together to implement projects to sensitize women of all ages about gender equality, sexual and reproductive rights, and gender-based violence. Two organizations of women living with HIV—Stitching Double Positive in Suriname and the Jamaica Community of Positive Women—are the result of years of capacity building.

A documentary on the lives of 12 women living with HIV in Jamaica is in production. Developed with the professional help of qualified psychologists and psychiatrists, the video of their stories is a first step in screening for potential psychological challenges facing women after their experiences of abuse. We hope this will be an important step towards raising awareness of the needs and rights of women living with HIV in the region.

**“ Now, we are more aware that violence against women has a historical, cultural and social context. ”**



# **9 A CALL TO ACTION: URGENT STEPS TO END THE AIDS EPIDEMIC AND VIOLENCE AGAINST WOMEN**



# A CALL TO ACTION: URGENT STEPS TO END THE AIDS EPIDEMIC AND VIOLENCE AGAINST WOMEN

Through powerful articles and stories that share real life experiences, it is clear that women living with HIV endure diverse forms of violence and are courageously standing up and taking action. Women are resilient, and many live and work to address human rights violations, despite a lack of effective political and social environments that could support women to enjoy their rights and be free from violence.

Women living with HIV and UNAIDS stand in solidarity and call for urgent action to end the AIDS epidemic and violence against women. We call for the following five key areas to be urgently addressed.

## 1

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### **Ensure laws support women's rights as human rights**

We call for greater political commitment, leadership and laws that are essential to ensure that all women are able to enjoy all human rights. Women's rights are human rights.

We call on policy-makers to repeal all laws that violate or fail to protect women's rights and human rights, and to put in place laws that uphold them.

We call for laws that protect women to be implemented, including through national response frameworks to mitigate, prevent and end violence against women in the context of the HIV response.

We call for laws to be supported by adequate services such as victim support units within police stations and the court system, with officers who work in the units receiving gender sensitivity training. Action must be taken to increase accessibility and availability of post-exposure prophylaxis to all rape victims.

We call for all women living with HIV – including transgender women, women who use drugs and women who are sex workers to be protected under all laws and all constitutions. The protection of the law must extend to all women, without any form of discrimination.



We demand that legal frameworks be grounded in the respect for human rights and gender equality. This requires that countries ensure genuine and accessible means of legal redress for survivors of violence, especially women living with HIV. Functioning social protection mechanisms that foster women's autonomy and address the specific rights and needs of women must complement this. It also is essential to strengthen the capacity of women and girls to identify and report forms of violence, and to know and claim their rights when it comes to sexual and reproductive health, gender identity and sexual orientation.

# 2

## **Link the HIV response to our sexual and reproductive rights**

We call for robust and effective HIV responses that base public policy and programmatic decisions on the needs, rights and realities of women in all our diversity. This means ensuring that HIV national strategic plans (NSPs) are informed through a gender lens that speaks to national epidemics, contexts and responses, to better address the linkages between HIV, gender inequality and violence against women. NSPs must be tailored to the needs and rights of all women, and they must counteract harmful sociocultural gender norms and practices in order to ensure safety and freedom from fear of violence against women, especially women living with HIV.

We call for the HIV response to enable all women to access sexual and reproductive health services and commodities. We call for guaranteed access to integrated, rights-based, non-discriminatory sexual and reproductive health and HIV services for all women, including transgender women. This must be seen as an essential component of effective HIV responses.

We call for services to provide safe spaces for women to access care; as such, it is paramount that we break the trajectory of sexual and reproductive health violations of key affected women, including but not limited to forced and coerced sterilization.

We call for education, especially comprehensive sexuality education, as a critical building block for ending AIDS and violence against women. All levels of education curricula should be required to address gender equality and identity, sexual orientation, human rights in order to advance equal power relationships and reduce violence against women.

# 3

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## **Increase capacity of service providers**

We call for all service providers, particularly health providers and law enforcement officers, to be equipped and able to interact in a gender-sensitive manner with survivors of violence, to be ready to address gender and intimate partner violence, and to be prepared to manage a comprehensive response.

We call for providers of services linked to HIV, sexual and reproductive health, and social services to be sensitized to all forms of violence, so that their services become an entry point to multisectoral management of violence, including Post Exposure Prophylaxis (PEP), STI treatment and emergency contraception.

# 4

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## **Galvanize and empower communities of women living with HIV**

We call for partners to respect our communities as the backbone of any effective response to AIDS and to violence against women and girls. Community, opinion and religious leaders, as well as policy-makers, public service providers, men and boys must stand in solidarity and take immediate action to end violence against women and its consequences. Initiatives led by women living with HIV as well as other community-based initiatives, must be supported and taken to scale as effective community actions.

We also call on the media to raise public awareness around violence in all its forms and to promote an urgent call for safety and security for all. Media should make this a public issue by reporting on violence against women in well-informed and constructive language, by implementing public campaigns aimed at shifting societies towards being more inclusive and respectful of all women and by creating opportunity for women and girls to describe what safe spaces mean to us.

We call on our partners in the United Nations and government to include women in all our diversity to be meaningfully involved in public policy design, implementation and monitoring.

# 5

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## **Collect better data, and monitor spending and results**

We call for actions to be effectively informed by the realities and experiences of women living with HIV and women in all our diversity. We call for timely, systematic collection of high-quality data, disaggregated by sex and age, as well as the distribution of strategic information that documents multiple forms of violence against women and that charts progress and challenges, as seen through the experiences of women.

We call for systematic, transparent monitoring of spending on AIDS and on addressing violence against women in the AIDS response. This will ensure that expenditures for women and gender equality match the scale of the task.

We call for wider use of existing assessment and monitoring tools, such as the UNAIDS Gender Assessment Tool, Human Rights Count, and the People living with HIV Stigma Index and call for the findings of these instruments to be publically disseminated.

We call for programmes that achieve safe environments to have systematic and sustained funding, further research and high-quality roll-out.

We call for an international award system that commends countries that achieve safety and security for women in all our diversity, as part of effective HIV responses.

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