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Across the globe, sexual violence, like HIV, transcends culture, economic status, and age. This is a problem found to one degree or another in almost every society. It is also one that few governments, indeed few leaders, confront as they should, and the result is a social and moral travesty. But sexual violence is also a major source of an increasingly serious threat in the form of HIV/AIDS. Now concentrated in sub-Saharan Africa, HIV/AIDS is spreading rapidly across South Asia into Central Asia, to Russia, and beyond. There are many aspects to the fight against HIV/AIDS, but honestly and courageously addressing the role of sexual violence has been long neglected.

Used as a tool of humiliation and subjugation, sexual violence is primarily directed toward women. Violence takes a tremendous emotional toll on its victims, but a growing body of evidence also links rape, sexual coercion, sex trafficking, and domestic or partner violence with the increased vulnerability of women and girls to HIV/AIDS. Women already infected with HIV are themselves subject to increased rates of violence, which can take the form of abandonment, sexual assault, brutalization, and partner violence.

Around 2 million women were newly infected with HIV in 2005, a number roughly equal to the number of men infected, but evidence suggests that the burden of HIV/AIDS will be increasingly borne by women. The circumstances that attend sexual violence—the brutality of the event itself and the inability of women to protect themselves from sexually transmitted diseases—make it an exceedingly effective medium for spreading HIV. In Rwanda, the connection between sexual violence and HIV has especially dire implications. During the genocide of the mid-1990s, members of the Hutu militia used rape as a tool of eugenics, intending to dilute the genes of the Tutsis and increase disease and mortality among the victims. Of the 250,000 women raped during the Rwandan genocide, more than 70 percent of survivors are now HIV positive.

During her trip to South Africa in 2005, First Lady Laura Bush underlined the urgency of the situation when she declared that an end to domestic violence, rape, and sexual abuse was “essential to fighting the spread of HIV/AIDS.” As this monograph makes clear, women on every continent are subject to the increased risk of HIV infection presented by violence. If we are to halt the epidemic’s rapid growth, pursue the humanitarian goals of improving health and human rights for women, and meet our moral responsibility as members of the civilized world, our response to this worsening crisis must make gender-based violence a priority.

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Women around the world are threatened by HIV/AIDS on a scale unimagined twenty or even ten years ago. Roughly 18 million women are now living with HIV/AIDS—one million more than in 2003—according to UNAIDS. Long-term reversal of this trend is dependent on a thorough understanding of the factors—biomedical, behavioral, social, and cultural—that underpin the susceptibility of women to HIV infection and its consequences, and the development of gender-appropriate interventions to address them.

As the studies and testimony presented in this monograph demonstrate, violence, particularly sexual violence, is one major factor in the growing HIV epidemic among women and girls, but the relationship between the two is rarely discussed. To raise the profile of this issue, particularly in scientific circles, and to spur the development of strategies for reducing HIV-associated violence against women, amfAR sponsored a satellite symposium at the 3rd International AIDS Society Conference on HIV Pathogenesis and Treatment in Rio de Janeiro, Brazil, July 25, 2005. The symposium, titled “Women, Sexual Violence, and HIV,” gathered experts from around the world to present findings that demonstrate the associations between sexual violence and HIV infection and to discuss future directions for research, policy, and advocacy.

The symposium was undertaken as part of amfAR’s Women, Sexual Health, and HIV/AIDS initiative, which aims to raise awareness about the HIV/AIDS epidemic among women and girls in the U.S. and internationally, and to promote research, education, and policy activities to address it. Components of the initiative include research fellowships and small grants for innovative projects in the biomedical and social sciences; a symposium and briefing series to highlight research findings and their application to policies and programs; public and professional education events for HIV care providers and community members; and advocacy work in coalition with other organizations to support sound public policies affecting women and girls.

The proceedings of the symposium are documented in this monograph in an effort to amplify the compelling presentations of the panelists and to extend the reach of the symposium beyond the confines of the conference hall and the researchers in attendance. Concerted action is required for there to be any meaningful reduction in women’s vulnerability to HIV as a result of violence, but it will not materialize without a fuller understanding of the facts among policy makers, law enforcement, the media, the medical establishment, and the public. It is hoped that this publication will help open the door to informed debate on this important issue and to the adoption of policies and strategies for reducing gender-based violence and its deadly aftermath.

For their participation in the “Women, Sexual Violence, and HIV” symposium, amfAR is extremely thankful to Dr. Agnès Binagwaho of Rwanda’s National AIDS Control Commission; Dr. Andrea C. Gielen of the Johns Hopkins Bloomberg School of Public Health in Baltimore, Maryland, U.S.; Gracia Violeta Ross of the Bolivian Network of People Living with HIV and AIDS; and Dr. Robin Shattock of London’s St. George’s Hospital Medical School. The symposium was made possible in part by the generous support of Roche. amfAR is also grateful to the International AIDS Society, which organized the 3rd International Conference on HIV Pathogenesis and Treatment.
Gender-Based Violence and HIV Among Women: Assessing the Evidence

In 2003, the number of new HIV infections among women worldwide reached parity with that of men. In some locales and among certain age groups, the percentage of females with HIV/AIDS has surpassed that of males. In sub-Saharan Africa, for example, females account for 76% of HIV infections among young people aged 15 to 24.1

A number of biological, behavioral, and social factors contribute to the increased vulnerability of women—particularly young women—to HIV infection. One factor that has been receiving increasing attention is gender-based violence (GBV).

The President’s Emergency Plan for AIDS Relief (PEPFAR), for instance, states its support for “interventions to eradicate prostitution, sexual trafficking, rape, assault, and sexual exploitation of women and children” as a part of its global AIDS strategy, although little has yet been achieved in this regard.2 Decisions about which interventions to fund should be informed by a review of the scientific evidence elucidating the relationship between GBV and HIV.

What is Gender-Based Violence?

Gender-based violence refers to a range of harmful customs and behaviors against girls and women, including intimate partner violence, domestic violence, assaults against women, child sexual abuse, and rape. It generally derives from cultural and social norms that imbue men with power and authority over women.4

Prevalence estimates for GBV vary widely as a result of differing definitions of violence, data collection methods, and time periods used in different studies. Current estimates indicate that between 8% and 70% of women worldwide have been physically or sexually assaulted by a male partner at least once in their lives.5 In the United States, one third to one fifth of all women will be physically assaulted by a partner or ex-partner during their lifetime.6 This variation in estimated prevalence may also be a consequence of significant underreporting due to stigma, shame, or other social and cultural factors that deter women from disclosing episodes of gender-based violence.7 GBV can include physical, sexual, and psychological abuse by a person with whom the victim has had an intimate relationship or by a stranger.

- Physical abuse can take the form of hitting, slapping, punching, or kicking.7,8

- Sexual abuse/forced or coercive sex includes rape within marriage or dating relationships, rape by strangers, unwanted sexual advances or harassment, forced marriage, denial of the right to use contraception or other measures to protect against sexually transmitted infections (STI), forced abortion, forced prostitution, and trafficking of people for the purpose of sexual exploitation. Childhood sexual abuse is sexual abuse that occurs before 18 years of age.8

- Psychological abuse includes belittling, humiliating, and intimidating an individual.9
Gender-Based Violence as a Cause of HIV Infection

There is emerging evidence connecting the rapidly expanding HIV epidemic and gender-based violence, particularly among young women.\textsuperscript{9,10} A growing number of studies indicate that the first sexual experience of young women is often coerced,\textsuperscript{7,11} and that such coercion is often viewed as a routine part of a relationship.\textsuperscript{12}

Gender-based violence may increase a woman’s risk for HIV infection through forced or coercive sex in several ways:

- The physiology of the female genital tract makes women—especially young women—inherently more susceptible to HIV infection than men. Women are twice as likely to acquire HIV from men during sexual intercourse than vice versa. And forced or violent intercourse can cause abrasions and cuts, which facilitate entry of HIV through vaginal mucosa.\textsuperscript{13}

- Forced sex limits a woman’s ability to successfully negotiate HIV prevention behaviors such as condom use.\textsuperscript{14-16}

Several psychosocial factors also increase a woman’s vulnerability to both sexual violence and HIV infection. These include age, alcohol or drug consumption, previous history of abuse, number of sex partners, involvement in sex work, educational level, and socioeconomic status.\textsuperscript{7}

- Several studies link a history of childhood sexual abuse to an increase in HIV risk-taking behavior, including drug abuse, having a male partner at risk for HIV, having multiple partners, and exchanging sex for drugs, money, or shelter.\textsuperscript{8,17-19}

- A study of racial and ethnic minority women in the United States found that those who had more sex partners, were unemployed, had more STIs, had a more severe history of physical and sexual trauma, and were less educated were more likely to be HIV infected.\textsuperscript{20}

- A study in South Africa found that experience of violence and controlling behavior from male partners was strongly associated with increased risk of HIV infection among women.\textsuperscript{21} Similar to other research,\textsuperscript{10,22,23} this study also noted that multiple partners, transactional sex, and substance abuse increased HIV risk among women.\textsuperscript{21}

Rape—the most extreme version of forced sex—occurs in many different settings and situations, including intimate relationships, schools, health-care facilities, refugee camps, and during periods of armed conflict.

- A recent national survey in South Africa that included questions about experience of rape before the age of 15 found that school-teachers were responsible for 32% of the disclosed adolescent rapes.\textsuperscript{24}

- In Rwanda, where rape was used as a form of ethnic cleansing during the 1994 genocide, it is estimated that of the 250,000 women who were raped and are still alive, 70% are HIV infected.\textsuperscript{25}
Gender-Based Violence as a Consequence of HIV Infection

Studies have shown that anywhere from 17% to 86% of women choose not to disclose their status for fear of abandonment, rejection, discrimination, violence, upsetting family members, and accusations of infidelity from their partners, families, and communities.26-29

- In a recent review of 17 studies conducted in developing countries to assess the outcomes of disclosing HIV serostatus, 10 reported violence directed toward women as a reaction to disclosure at rates ranging from 3.5% to 14.6%.26
- In a study conducted in the United States, 18% of HIV-positive women reported disclosure-related violence, including verbal abuse and physical assault.30
- In another study conducted in the United States, 4% of HIV-positive women reported physical abuse after disclosure, and 45% reported experiencing emotional, physical, or sexual abuse some time after diagnosis.31,32

Certain risk factors are associated with experiences of abuse after HIV diagnosis, including prior history of abuse, drug use, lower socioeconomic status, younger age, length of time since diagnosis, and having a partner whose HIV status is negative or unknown.31

Interventions Addressing Gender-Based Violence and HIV

Although awareness of the role of GBV in the HIV epidemic among women has grown, to date there have been few rigorously designed and evaluated interventions to address it.33 Those in progress include microfinance interventions to increase women’s self-efficacy, negotiation skills, and economic independence from men.34 Other programs work with men and boys to address male gender norms that associate masculinity with risky behaviors such as having multiple partners, alcohol and drug use, the domination of women, and violence.35 The impact of such interventions on HIV incidence or prevalence is not yet known.

As a way to mitigate the likelihood of acquiring HIV infection following rape, some communities have established programs to provide post-exposure prophylaxis to survivors of sexual assault. This involves administering antiretroviral therapy within 72 hours of assault and over a period of days. This approach has been reported to be effective,36,37 although studies to date have not included data on untreated individuals as a comparison, so their interpretation is problematic.

Conclusion

In summary, there is a great deal of evidence to establish the significant link between gender-based violence and rising rates of HIV infection among women and girls throughout the world. In order to mitigate the epidemic among females, we must dedicate resources to the development, testing, and implementation of effective behavioral, biomedical, and social interventions that address violence as both a cause and a consequence of HIV infection.
Sexual Trauma and the Female Genital Tract

There is clear evidence suggesting that women in developing countries who experience sexual violence are at increased risk of HIV infection. Because women are economically dependent upon men, they have little bargaining power when it comes to negotiating protective measures. Many live in fear of being abandoned or beaten if they resist their husband’s or partner’s sexual demands. In times of hardship, they may feel pressured to exchange sex for favors or may turn to prostitution. The fear of being labeled barren appears often to be a far greater concern than contracting AIDS. It is within this context that many HIV infections occur—14,000 every day, more than 95% in developing countries and 80% due to heterosexual transmission. The vast majority of those new infections, about 12,000 daily, are among people 15 to 49 years old. It’s even more sobering that nearly 50% infected in that age group are women 15 to 24 years old.

So we increasingly see that young women are particularly vulnerable to HIV infection. It’s a poignant truth that many women in developing countries cannot control when or with whom they have sex. In some parts of Africa, one in four teenage girls is infected, compared to one in 25 teenage boys. Of these young women, 10% reported that they were physically forced to have sex and 28% of those said that they either did not want or really did not want to have sex the first time. On some Caribbean islands, the infection rate among girls aged 15 to 19 is five times greater than among boys.

What are the contributing factors? Certainly the initiation of young women into sex by older men increases the likelihood of being exposed to someone who is already HIV positive. Immaturity of the female reproductive organs also increases the chance of infection due to physical damage during intercourse.

High Risk From Genital Inflammation or Ulceration

Research into the risks of HIV transmission generally demonstrates that oral sex has a very low or nonexistent rate of transmission, vaginal sex is relatively low (1 in 200–1,000), and anal sex has a much higher rate (1 in 25). However, this research may present a false picture as far as young women are concerned because it looks at overall transmission rates. The risks of sexual transmission are critically dependent upon the infectiousness of the male partner (or assailant) and the susceptibility of the woman. The infectiousness of a man is dependent upon the level of virus in the semen, which is highest over the period of acute infection during the first few weeks, and is exacerbated by the presence of other sexually transmitted diseases. A woman’s susceptibility is also greatly increased by sexually transmitted infections, with genital ulceration being one of the highest risk factors for HIV-1 infection in young women. Frequency of unprotected sexual contacts, number of partners, genital trauma, immaturity of the reproductive tract, and anal intercourse are also high risk factors. Thus while overall transmission rates may be relatively low, cumulative risk factors may greatly increase transmission to this vulnerable group of young women.

HIV transmission occurs either vaginally or rectally on surfaces vulnerable to infection. These include areas inside and outside the genital tract. Studies increasingly show that there are indeed natural preventive barriers to infection, including the multi-layered stratified epithelium that lines the vagina and the cervix. So it appears likely that there
must be a physical breakdown in these barriers for transmission to occur. The single-layered columnar epithelium higher up the genital tract, for example, is relatively protected within the endocervical canal. However, it is still quite vulnerable to physical abrasion around the cervical os. Furthermore, in many young women, the more delicate columnar epithelial cells also grow out of the endocervix onto the external face of the cervix, thereby increasing the chance of physical abrasion. Thus the immaturity of the reproductive tract in young women may make them particularly susceptible to HIV-1 infection.

**Multiple Injuries From Rape**

We know from research in various countries that rape is the most common cause of coital injury. According to one study in Nigeria, rape was responsible for 88% of coital injuries suffered by teenagers and 68% of coital injuries suffered by adults. Other research observed colposcopic evidence of genital trauma in 87% to 92% of rape victims, compared to about 10% in women who engaged in consensual intercourse. Some 76% of rape victims had evidence of three or more sites of injury; 8% of women who engaged in consensual intercourse had only one site. It may only require a small internal or external genital injury to provide the virus access to susceptible cells. Abused women previously infected by sexually transmitted diseases are even more vulnerable. The risk of HIV transmission is heightened due to the increased influx of susceptible cells already fighting STD infection. Rectal penetration is reported in 13% to 20% of rape cases, and this is associated with eight- to tenfold more efficient transmission rates than vaginal transmission. Anal or rectal tears or abrasions were observed in 73% of women subjected to anal penetration. All this has profound implications when there is mass rape. Men become infected very rapidly and are often the most infectious during the period of multiple assaults on many women, which very much fuels transmission.

In summary, good biological evidence suggests that women who experience sexual violence have a greater chance of HIV infection. Exposure to a partner who conceals his HIV positive status or refuses to allow condom use is itself a kind of sexual assault. Because women in developing countries have no prevention mechanisms within their control, they are particularly vulnerable. Micro-abrasion, the most associated risk factor, or larger macro-abrasion provide the virus with easy access. This speaks volumes about the urgency to develop microbicides.

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Sexual Violence and Abuse in Intimate Relationships

WHO’s *World Report on Violence and Health* describes intimate-partner violence as behavior within an intimate relationship that causes physical, psychological, or sexual harm. These actions can be physical aggression, psychological abuse, sexual coercion, and various other controlling behaviors. Battering implies that the abuse has occurred repeatedly within the same relationship. These are the more measurable definitions of intimate-partner violence, but make no mistake: Intimate-partner violence is really about power and control in relationships.

How big is the problem? The WHO report looked at 48 population-based surveys around the world and found intimate-partner violence rates of between 10% and 60% over the course of women’s lifetimes. Over a single year, rates also range widely: 3% or less in Australia, Canada, and the United States; 27% among ever-partnered women in Leon, Nicaragua; 38% of currently married women in the Republic of Korea; and 52% of currently married women in the West Bank and Gaza Strip. These variations are due in part to the kinds of instruments that are used to measure intimate partner violence as well as differences in populations. But any percentage is too much.

Women rarely experience only one type of violence. Physical violence in intimate relationships is often accompanied by psychological abuse. In one-third to over one-half of cases, it’s accompanied by sexual abuse. Data among 360 ever-partnered women in Leon, Nicaragua, show that almost 90% who were sexually abused also experienced psychological and physical abuse. The increased risk for HIV/AIDS can be a huge problem accompanying intimate partner violence, but there are also a number of other health consequences, such as psychological and behavioral problems, alcohol and drug abuse, depression, and anxiety. Physical consequences other than broken bones can include gastrointestinal disorders and chronic pain syndromes, a host of sexual and reproductive problems, fatalities from AIDS-related conditions, homicide, and suicide.

Project WAVE in Baltimore City

The mechanisms by which intimate-partner violence can increase a woman’s risk for HIV have been enumerated as follows: an established pattern of victimization and risk-taking associated with victims of childhood abuse; forced or coercive sex with an infected individual; abuse if a woman tries to negotiate HIV-prevention behaviors; and increased violence when intimate partners learn of a woman’s status.

We conducted a study called Project WAVE in Baltimore City, Maryland, a few years ago, funded by the National Institute of Mental Health. It looked at the prevalence and consequences of intimate-partner violence among urban low-income women and whether factors associated with that violence vary by HIV status. We wanted to identify whether there are overlapping or unique intervention needs for HIV-positive and HIV-negative women living in similar environments.

A sample of 310 HIV-positive women was recruited from outpatient centers and an outpatient drug treatment program, along with a sample of 301 HIV-negative women from outpatient gynecology clinics, a homeless shelter, and a neighborhood Healthy Start center. We conducted one-time interviews with the women. With a subset of the women we talked more about experiences of intimate-partner violence. Among the women in our HIV-positive sample, 39% were age 40 or older—somewhat older than our HIV-negative
sample. The vast majority were African American, and about 40% had less than 12 years of formal education. Most were poor, with 59% of the positive women and 68% of the negative women having less than $300 income per month. We found that about 40% of both samples had experienced some kind of abuse as children. The HIV positive women were much more likely, 15% versus 9%, to have experienced both physical and sexual abuse.

From our qualitative interviews, we tried to make these numbers more meaningful by listening to the women's own words. Here are two examples:

“Even though he [the intimate partner] was abusive to me, I still loved him because I was brought up where I felt that I wasn’t loved. I was looking for someone to love me…. I was the main one who was being abused by my family, my mother’s boyfriends, and babysitters. Each of my mom’s boyfriends saw me as a sex symbol.”

“If you ask me, it started when I was 12 years old with the actual rape…. I do think that abuse [as a child] had something to do with the adult abuse. Then, when you take sex and use it as a weapon, and you take a man’s physical size, what’s the message I got? Men are always stronger. If I had been taught how to empower myself back then, then none of this [adult abuse] would have been possible.”

Partner Status and Characteristics Elevate Violence Risk

Here’s a first look at the data from the Baltimore City study as it relates to abuse and HIV. We used the Conflict Tactics Scale, which measures psychological and physical abuse, sexual coercion, and injuries due to violence. We found psychological abuse high, at roughly 60%, physical abuse at about 40%, and sexual abuse at about 25%, for a total of any experience of abuse at over 60% in both the HIV-positive and HIV-negative samples. About 19% of the total, or 29% of the abused women, were physically injured. Almost 90% of the women who reported sexual abuse also reported both physical and psychological abuse—similar to the results from Leon, Nicaragua. Within our Baltimore City samples, 42% of the women said they experienced abuse 13 or more times in the past year. A woman’s HIV status per se was not the significant factor. Instead, what was significant was her status in relation to her partner’s HIV status and other partner characteristics. A woman was at significantly greater risk of severe violence if she was with a discordant partner or with one whose HIV status she didn’t know. This was a much bigger issue for HIV-positive women. Forty percent of our HIV-positive women were with an HIV-negative partner, while only 2% of our HIV-negative women were with an HIV-positive man.

As you might expect, HIV positive women in the study were significantly more likely to use condoms. However, when we asked whether they used a condom the last time they had sex with their partner, we found a 60% reduction in condom use among those women who were experiencing more abuse (13 or more abusive events in the past year). Clearly, there is a relationship between women’s ability to use protection and their experiences of intimate-partner violence.

Need for Counseling About Disclosing HIV Status

In earlier studies, we had asked women if anyone became violent or physically attacked them after finding out they were HIV positive. One of our studies and another comparable report found that 4% said yes. When we looked closer at our HIV-positive sample in Baltimore City, we found that 6% experienced sexual abuse both before and after learn-
ing they were HIV positive and an additional 8% said that they were sexually assaulted only after disclosure. This highlights the continuing concern that we must have for women and the importance of counseling and assisting women with disclosure.

In one woman’s own words, “When my daughter was diagnosed in December with HIV, the abuse started then…. He didn’t want to accept the blame for it and he wanted to throw it on me. So he used to do things mentally to try to make me feel like I was responsible. Then he started disrespecting me in public, especially in front of his family.” Another woman recalled, “He was abusive before I had told him I was HIV positive, and afterwards, well, the beatings got worse…. They happened more regularly. I say that because I remember him making a statement, ‘I should kill you since you’re trying to kill me.’” And still another remarked, “After I found out I was positive, I let him do what he wanted. It didn’t make any difference. I was just going to stay.”

We can help women in abusive relationships by providing information and services. In our sample, 29% said they didn’t know of any services for abused women. Only 4% said they would ever talk to the police. The women said they needed jobs and money and housing. One woman expressed a common theme about moving from an abusive relationship toward freedom:

“When we first started seeing each other, I won’t say I didn’t detect some obsessiveness. But I wore the flower-colored glasses: You know, ‘He just cares about me’ kind of thing. I recognized the abuse as a problem when the hits got harder. It wasn’t a slap or something. I can’t leave, not right now. But as soon as I can get myself together where I can stand on my own two feet without needing anybody to help me, then I’ll be gone. I’ve been trying to find a job. I won’t ever take him back. I’ll never look back. I see myself now as just struggling, taking it day to day and doing the right thing.”

The themes that we identified in our Baltimore City sample are consistent with the themes identified in the WHO study of violence among countries in Latin America. That study sought to record the process that women who suffer domestic violence go through after deciding to seek assistance. It found that several factors triggered action, including increased violence and a woman’s recognition that the abuser was not going to change. Factors that inhibited women from seeking help included fear of consequences, fear of economic hardship, fear of corruption, and gender stereotyping by the judicial system and the police—some of the same obstacles that we encountered in our study.

We all need to work together to form partnerships with a unified voice for women across the globe. We need to partner with child-abuse professionals. We need HIV people to partner with domestic violence people and substance abuse people. Health-care providers need to be comfortable screening and treating women who have experienced abuse. The courts need to enforce laws properly and consistently. We can’t just keep working individually in our own silos, on our own specific agenda items. Rather, we must take a holistic approach to the reality of women’s lives. Women’s independence, through educational and economic empowerment, is key.

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Surviving Rape and HIV

A
fter I experienced sexual violence in 1998, I became HIV positive. I’m not saying that the two men who raped me in the street infected me. Rather, the consequences of that experience damaged my sexuality to the point that I didn’t take care of myself. I considered myself dirty and believed nobody was going to love me. So I took many risks, and that’s why I am HIV positive now.

It’s not easy to deal with an experience of sexual violence. It really damages the life of a woman forever. For me, it has been even more difficult to handle than HIV. I’m an activist, an international speaker, and a person who got medication by putting pressure on my country’s government. But I still live with the consequences of sexual violence every day. I don’t trust men. I’m always suspicious and I always think they’re lying. That’s why I’m not married and why I doubt I will be.

This problem is big, and unfortunately there are parts of the world where nothing is being done. However, some wonderful things are happening, such as the provision of post-exposure prophylaxis after rape. There is also an excellent program in Peru for men who decide to stop being violent, launched by the Pan-American Health Organization. It is difficult for them too: they also need support. When I was raped, I didn’t even know that words like post-exposure prophylaxis existed, I didn’t know about HIV, and I didn’t even know about counseling. I just felt so lonely. The only person I told was my older sister, who said, “You should be tested for HIV because we don’t know those guys and maybe they transmitted something to you.” Because I was so scared and didn’t want anybody to touch me any more, I didn’t want to go for a test. I didn’t want to go to the police. I couldn’t do many of the things involved in post-exposure prophylaxis such as accepting counseling or support to deal with the emotional trauma of rape.

Why Rape Survivors Don’t Go for Counseling

A Human Rights Watch report on post-exposure prophylaxis in South Africa discusses the reasons why women who have been raped don’t look for counseling. One major obstacle is their fear that nobody will really listen to them without judging them. Researchers, policy makers, and others must ask themselves whether they are truly ready to listen to women who have been raped because it’s not easy to talk about. If a woman becomes HIV-positive, it’s even more difficult for her to disclose.

Everyone working in the HIV/AIDS field must deal with these realities. Scientists must understand the real-life emotional aspects of gender-based violence, and counselors must know the medical and scientific issues. We must look for ways to give more people the courage to talk about rape. I am doing that myself. That’s why I started a master’s course on gender and sexual and reproductive health, to better understand some of the issues. Rape is not new; AIDS more or less is, but we are already doing things too late. Children are being raped. Women are being raped. Men are being raped. It’s a huge problem around the world, involving poor people and rich people. Everyone is at risk. We must do more, and at least the AIDS pandemic has brought more attention to the problem of rape.

When I share my experience, often women come to me and tell me they have experienced rape or many other forms of violence. We should all be aware that violence against women including rape is happening to women in every walk of life—academics, housewives, UN officers, politicians, young women, and girls.

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HIV Risk Related to Sexual Violence During War and Conflict: Rwanda’s Solutions

Rwanda is a little country in the heart of Africa. We have 8.2 million people and the majority of our population, 83%, lives in rural areas. We have a high level of TB/HIV co-morbidity—about 40% to 60% of those with tuberculosis are also HIV positive. As one of the least developed countries, 70% of the population lives below the poverty level, illiteracy is at 50%, and Rwandan life expectancy is only 38 years. Like most African countries, we don’t have enough doctors—only one for every 57,000 people. We have enough nurses by WHO standards but most do not work in public service because of low salaries. The rates of maternal mortality, infant death, and malnutrition are very high.

In 1994, Rwanda experienced genocide—by UN definition, a specific series of acts committed with intent to destroy, in whole or in part, a national, ethnic, racial, or religious group. Due to genocidal violence in Rwanda, immediate mortality was one million people over 100 days, an average of 10,000 people every day. Those are the ones who were killed immediately—others died later or are still dying slowly because they contracted HIV when they were raped. Rape was used methodically to torture and exterminate women. It also left a big part of the population with physical, sexual, and emotional dysfunction. How many rape victims were there? Ten years later, we really don’t know.

HIV Rates to Rise as Prisoners Return Home

The rate of HIV/AIDS in Rwanda is 7% to 11% in urban areas and 2% to 5% in rural areas. We believe the growing rate in rural areas was affected by the 1994 genocide, during which massive rape and population movement occurred. And we have to be prepared for higher numbers because a prison study shows the rate of HIV/AIDS at around 8%, and we are releasing thousands and thousands of prisoners who are going back to rural areas. We should also expect a new wave of violence against women, in part prompted by the stress and difficulties these men will face upon their return home.

We tested 5,000 female survivors of the genocide and their HIV rates were very high, 60% to 80%. Many of those tested were not sexually active prior to the genocide. (We always focus on men as the perpetrators of rape, but some women were guilty also. There is a famous case of a female official at that time who forced her own son to rape women.) The impact of
the genocide on children was huge. Rwanda has 264,000 children who lost one or both of their parents, and 400,000 children are out of school. Thousands of children are living alone in their own homes without any parents to take care of them.

Women cannot negotiate safe sex. Most of the time they are obliged to have sex with their husbands even if the men are not faithful and don’t use condoms. This is another form of violence against women.

**Rebuilding Rwanda and Offering Treatment**

During the 11 years since the genocide, we have been trying to rebuild Rwanda by bringing democratization. We have held two elections and we are working very hard on decentralization and reconciliation. If we pursued conventional justice for the thousands of people in prisons, it would take us 200 years and we don’t have that time. So we have reinvigorated a traditional community justice process. The genocide also handicapped us in reconstruction because many skilled people died or left the country. Reconstruction costs a lot of money and, like many poor countries, we are dependent on external support for many social needs. We have also promoted women to leadership positions. Women now comprise 48% of our parliament and 30% of our government. We hope that putting women in leadership positions will change the face of our country.

Our vision is HIV treatment for all. However, the death rate from HIV/AIDS currently remains high. We are reaching only 13,500 Rwandans out of the approximately 100,000 who need treatment. We have passed a law requiring that treatment for HIV be based on a family approach, which is the only way to be sure that women and children are not left out. We had a problem treating children because programs have been almost entirely directed to adults. We are now building an infrastructure for the entire population, including the children of the women raped during the genocide. That is ongoing now that we have trained doctors. We know we can achieve results based on our experience of helping women who have been raped and because of our work in poor communities. We have passed a law against rape that can bring the perpetrator a long prison sentence. The challenge we face is making women aware that the law is there and confident that they can use it. We also have programs with dual counseling for women on both HIV and rape issues. We know that many women will not be treated unless counseling considers both of these concerns.
Community Participation is Key to Treating Survivors

One of the current projects to treat survivors in our country is led by the First Lady of Rwanda. Another is the Rwanda Women’s Inter-Association Study Assessment (RWISA). For these and other programs to succeed, we need to acknowledge that massive rape happened. We also need to recognize both the immediate and the long-term psychological effects on women who have been raped, on other witnesses to the genocide, and on those who were obliged to commit the atrocities.

The principal investigators of RWISA are Dr. Kathy Anastos, an American from Chicago and a member of WE-ACTx; Dr. Anita Asiimwe, who is in charge of all HIV treatment in Rwanda; and myself. RWISA came at a good time. Access to programs aimed at preventing mother-to-child transmission steadily increased from 53 sites in 2003 to 150 today. Under these programs, the percentage of HIV-infected pregnant women receiving a complete course of ARVs has increased from 67.7% in 2003 to 72% by the end of 2004. This increase is largely due to scaling up interventions. Likewise, the number of visits for voluntary counseling and testing rose from 44 in 2003 to 130 by the end of 2004.

Community participation is key to RWISA. Most women who are coming for treatment are traumatized in different ways—some very deeply, others not deeply, but all are traumatized. We want to be sure that women will be recruited properly, have good follow-up, and many possibilities to return to the study.

RWISA will allow us to investigate the link between stress and immunology. We’re running a study that will identify the viral subtypes and the multiple infections we face in Rwanda. Other areas of RWISA investigation include the effectiveness and adverse effects of adherence to antiretroviral treatment among women, the challenges of compliance with treatment, viral resistance, the incidence of cervical dysplasia, and the link between stress and compliance.

These are just some steps. All of us, all around the world, must look for more and better solutions to help rescue and help treat those who experience violence during wars or revolutions. I would like to see an international mobile unit created that can rush to areas where women and children cannot be protected. We know that revolutions can result in rape—even by close neighbors. During upheaval, even the good guys can become crazy bad guys. In refugee camps, gender and violence issues become worse without regular laws protecting women, children, and physically weak men. We must take action. Education and empowerment on these issues should also begin at an early age; we should start with the kindergarten curriculum. And we must also find more ways to put more women into positions of power to change things.

Due to genocidal violence in Rwanda, immediate mortality was one million people over 100 days, an average of 10,000 people every day. Those are the ones who were killed immediately—others died later or are still dying slowly because they contracted HIV when they were raped.

Dr. Agnès Binagwaho is the executive secretary of the National AIDS Control Commission in Rwanda and co-principal investigator of the Rwanda Women’s Inter-Association Study Assessment.
In response to the steady rise in HIV infections among women and girls, in 2004 amfAR launched the Women, Sexual Health, and HIV/AIDS initiative. Its goal is to raise awareness about the HIV/AIDS epidemic among women and girls, both in the U.S. and globally, and to promote research, education, and policy activities to address it.

Supporting Research

amfAR provides targeted, early-career awards and fellowships to support scientists focusing on women, sexual health, and HIV across a range of disciplines, including basic biomedical, clinical, behavioral, and social sciences. To support the continued development of female-controlled prevention methods, amfAR funds innovative projects such as those pursuing an effective anti-HIV microbicide. amfAR convenes consultations and think tanks that rely on the expertise of researchers, policy makers, advocates, and community members to identify effective ways of ameliorating the social, political, and economic vulnerabilities that intensify the HIV/AIDS epidemic among women.

Evaluating, Translating, and Disseminating Research Results

amfAR’s TREAT Asia program targets many Asian countries in which women’s vulnerability to HIV/AIDS is especially acute. TREAT Asia is a network of clinics, hospitals, and research institutions working to ensure the safe and effective delivery of HIV/AIDS treatments throughout Asia and the Pacific. Through this network, TREAT Asia is building HIV/AIDS care, treatment, and management skills among health-care professionals and working with civil society groups to strengthen the understanding of treatment among Asia’s most affected communities.

As part of its continuing medical education program, amfAR will continue to focus attention on the unique needs of women and HIV/AIDS. The Foundation’s programs have highlighted often-neglected women-specific aspects of epidemiology, prevention, treatment, and adherence. amfAR will also continue to hold briefings and symposia for Congressional members and staff and at national and international conferences to address the HIV/AIDS epidemic among women and girls and will continue to educate the public about the disparate impact of HIV/AIDS on women throughout the world, using targeted media campaigns, publications, and the internet.

Putting Research Results into Practice

In 2005, in collaboration with other organizations, amfAR facilitated the creation of the Women and HIV/AIDS Coalition (WHAC), whose goal is to raise awareness and advocate around the invisible epidemic of HIV/AIDS among women in the U.S., and around the U.S. government’s HIV/AIDS-related policies as they affect women globally. amfAR remains committed to supporting WHAC as it further develops its membership, operating structures, and policy and advocacy agenda.

The Foundation will continue to develop issue briefs, fact sheets, and reports that evaluate and summarize the scientific evidence on issues related to women and HIV/AIDS. These are distributed to Congressional members and staff, educators, the media, advocacy groups, and other community members to help inform evidence-driven policies that benefit women.
References

amfAR is one of the world’s leading nonprofit organizations dedicated to the support of AIDS research, HIV prevention, treatment education, and the advocacy of sound AIDS-related public policies. Since 1985, amfAR has invested more than $233 million in its programs and has awarded grants to more than 2,000 research teams worldwide.

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