Women in Rwanda
Another World Is Possible

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Knowing that when we are sick with AIDS, we have no shelter on our head and no school fees for our children, that is what kills us.

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IN 2003, RWANDAN WOMEN'S ASSOCIATIONS ISSUED AN international call to aid women who had been raped and infected with human immunodeficiency virus (HIV) during the genocide, and who were becoming sick and dying. As difficult as it was for the world to comprehend the tragedy of the 1994 events, it was even more incomprehensible that while women with HIV were not receiving antiretroviral medications, alleged perpetrators were receiving treatment in prison.[1]

The associations, often led by survivors themselves, care for thousands of widows, rape survivors, and orphans, some specifically caring for those infected with HIV. The leaders of these associations knew their members needed antiretroviral therapy immediately to survive. However, they also understood the physical, emotional, familial, and economic struggles caused by the civil war and genocide that continued to traumatize these women and knew that successful management of HIV infection would require more than medications. Rwandan women with HIV infection needed counselors and therapy for posttraumatic stress, support groups, food, housing, education about their illness and treatment, and job training as well as income for their children's food, school fees, uniforms, and pencils.

The intersecting epidemics of gender-based violence, HIV infection, and poverty can be found on every continent.[2] The majority of women affected by these problems live in southern Africa, where they comprise more than 60% of the 25.4 million adults with HIV infection.[3] Rwanda represents a particularly poignant example of this synthesis of problems. In 1994, while the United Nations, the United States, and other powerful countries did not intervene, Rwandan soldiers and Hutu gangs systematically slaughtered 800 000 Tutsis and moderate Hutus in 100 days.[4] It is estimated that 250 000 women were raped.[5] Gender-based violence resulted in the synchronized HIV infection of tens of thousands of women causing the current predictable AIDS epidemic in thousands of Rwandan women.[6]

Sexual violence during war is more than a soldier's callousness against an individual woman. In Rwanda, the Hutu extremists fostered their political goals through mass sexual violence. They sexually assaulted young girls and women because of their gender in a systematic attempt to exterminate the Tutsis and their supporters, and they used the weapon of HIV. According to one source, "Eyewitnesses recounted later that marauders carrying the virus described their intentions to their victims: they were going to rape and infect them as an ultimate punishment that would guarantee long-suffering and tormented deaths."[6]

International legal and humanitarian constructs now define gender-based violence during conflict as a way to demoralize communities, as an instrument of genocide, and as a crime against humanity when it is systematically directed against targeted civilian populations.[6-8] These intentional acts violate human rights principles, including the right to life, equality, protection under law, and freedom from torture. In 1998, for the first time, an international tribunal convicted a Hutu rapist of a crime against humanity for his actions.[9] Although gender-based violence during war is now condemned, the underlying attitudes and behaviors fostering this violence stem from long-standing gender inequality, which is also present during peace time. The United Nations Development Fund for Women estimated that 1 in 3 women will sustain gender violence through rape, coercion, and physical or emotional abuse during their lifetime.[10]

Justice has not come easily, quickly, or at all for many Rwandan women who were raped, mutilated, and/or watched their family members die.[11] Many women experience severe emotional crisis, anger, and humiliation as they share their testimonies. Most are still grieving; they find testifying overwhelming and isolate themselves from the judicial process and their communities. Few perpetrators have been

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prosecuted and long delays often prevent trials from starting.[12] Physical and psychological illnesses continue to plague these women, including sexually transmitted diseases in addition to HIV and AIDS, as well as fistulas, scars, chronic pain, depression, posttraumatic stress, and flashbacks.[13,14] As a matter of justice, treatment for the wide array of health problems must be provided.

The human rights abuses encompassed in gender-based violence and its sequelae of HIV infection and other illnesses are impossible to separate from the extreme poverty imposed on women in Rwanda. Living on less than US $0.70 a day, most women are hungry and have insecure housing.[13] If widowed, they are often without any family income. If sick, they are unable to work. Multiple family members frequently are infected with HIV, causing households to become poorer and poorer with no way to reverse the trend in future generations.[15] Sexual, reproductive, and health rights are inseparable from economic rights for women in Rwanda.

Women and young girls are infected at an earlier age than men and boys because of their profound vulnerability to gender-based violence and poverty.[16] However, other significant factors also perpetuate this violence and HIV transmission in Rwanda and worldwide. Young age, low literacy, subordinate status, lack of empowerment, geography, ethnicity, and race form the foundations for violence and the HIV epidemic.[9] These demographic and social factors are critical for understanding the spread of HIV and to defining effective interventions.[17] The historical and economic realities allow "racism, sexism, political violence, poverty and other social inequalities . . . [to] sculpt the distribution and outcome of HIV/AIDS" and the denial of human rights.[18] These inequalities influence the disease pathogenesis and course by determining who is vulnerable to infection, who gets sick, who has access to counseling and testing, who receives timely HIV diagnosis and antiretroviral treatment, and who will be stigmatized and further marginalized. Such structural factors and inequalities also distinguish countries that will provide access to treatment from those that will see their population decimated by HIV and AIDS. Only by addressing these underlying structural inequities will a practical model of comprehensive primary health care and HIV care be defined and the public health advocacy agenda for HIV-related policy be informed.

In 2004, Women's Equity in Access to Care and Treatment (WE-ACTx), a group of US-based activists, physicians, and scientists, joined with 4 Rwandan women's associations serving widows from the genocide, orphans, and women with HIV, to launch a grassroots HIV treatment program. Through a public-private partnership within the Rwandan Ministry of Health, WE-ACTx developed a clinic in Kigali to address the desires and needs of women infected with HIV that it serves. The women's associations refer their members to this clinic. Women have easy access to their trauma counselors and nurses, whose support is needed when the women remember how they became infected and relive the rapes and abuses they experienced. The women also receive antiretroviral treatments, food, school fees for their children, and HIV testing and treatment for their children. Some women are also given community health worker jobs so they can help other women and orphans with HIV.

The clinic provides food, transportation, and medical care, free of charge. In partnership with the public health system and women's associations and using medications from the Global Fund to Fight AIDS, Tuberculosis, and Malaria, the program has in the past 10 months evaluated more than 1500 women and initiated antiretroviral treatment to 550 women. These women are now getting stronger and are requesting more and different services. The program will soon provide comprehensive family-centered care, including voluntary counseling and testing and treatment for women and children within 2 additional associations.

Women infected with HIV also asked the WE-ACTx program to study the effectiveness and toxicity of antiretrovirals, as well as the influence of malnutrition and multiple types of trauma on their disease progression. The program recently was awarded funding by the US National Institutes of Health and the National Cancer Institute to establish a cohort study (The Rwandan Women's HIV Cohort [RWISA]) designed to explore these questions and modeled after the US Women's Interagency HIV Study.[19]

Thirteen associations representing and advocating for women, youth, and individuals infected with HIV are now partnered with WE-ACTx—Society of Women with AIDS in Africa, Urunana, Uyisenga n'Imanzi, Association de Veuves et Vulernables Affectes et Infectes de SIDA Solidarity, Igihozo, Hope After Rape, Inkuge, Icyuzuzo, Association National pour le Soutien des Personnes vivant avec le VIH/SIDA+, Avega, Ibereho, and the Rwandan Women's Network—and will in time assume full responsibility for the clinical partnership with the government. Rwandan women with HIV have thus demonstrated that they are ready and capable of adhering to treatment for HIV infection, and their leadership will be a critical force in taking the treatment battle forward. The Rwandan women and their associations have identified their needs and a care system has been developed that mitigates and challenges the social inequities brought by gender-based and structural violence.

This work in Rwanda has demonstrated that providing HIV care to survivors of genocidal rape requires integrating medical care with psychosocial support and addressing barriers to care for these women, including poverty. This grassroots empowerment model can serve women and children experiencing mass rape and sexual violence in other conflict zones, including the Darfur region of Sudan, northern Uganda, the Democratic Republic of Congo, and Burundi.[20]

Unfortunately, the recent United Nations report "AIDS in Africa: Three Scenarios to 2025" challenges none of the inequities being addressed in Rwanda and projects a bleak future for Africa.[21] In the United Nations report, 3 models

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postulate different levels of spending, government and international concern, and care outcomes. The most optimistic scenario forecasts 53 million African deaths and 48 million new infections, whereas the most pessimistic estimates 66 million deaths and 89 million new infections. Even more problematic is the markedly insufficient funding allotted by each of the scenarios over the next 25 years: between $70 and $195 billion. Where in this accounting is the cost of having waited so long to distribute antiretroviral medications or to treat tuberculosis or prevent opportunistic infections? What is the moral cost of not providing care to Africans because they lack resources?

Only a radical new vision can hope to surmount this bleak prescription. The HIV epidemic calls for a new model that recasts and overcomes the constraints in our current thinking and practice. Lessons from women in Rwanda demonstrate that providing HIV care is an urgent matter of both justice and human survival. There is a moral imperative to work with these women to rebuild their families, futures, and country. The importance of these reparations is 2-fold: first, they are necessary for the survival of Rwandan women and children and millions more in Africa; and second, reparations will allow individuals from resource-rich countries to transform into true-world citizens, who are knowledgeable about history, tragedy and exploitation, and the ability to transform the world to one in which women's rights, human rights, and the right to health are not violated but respected, supported, and fully integrated into public health policy and government practice.

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