

## Gender-Based Violence and HIV in Rwanda: Respecting Women's Voices

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**O**F THE 24.7 MILLION PEOPLE living with human immunodeficiency virus (HIV) in sub-Saharan Africa, 58 % are women.<sup>1</sup> Structural, socioeconomic, biological, behavioral, and cultural factors contribute to this high prevalence among women.<sup>2</sup> Gender-based violence is recognized as a violation of human rights and is specifically addressed in United States and international guidelines on women with HIV.<sup>3</sup> Despite such recognition, women with HIV have few resources to identify and address gender-based violence and its consequences, with poor integration at the clinical or community level.

Responding to a call from leaders of Rwandan women's associations in 2003, Women's Equity in Access to Care and Treatment (WE-ACTx) began providing comprehensive HIV services for women, many of whom were raped during the 1994 genocide and intentionally infected and now a decade later were becoming clinically ill as a result of this mass-synchronized infection.<sup>4</sup> WE-ACTx's women-centered approach included access to HIV counseling and testing; treatment for HIV with transport support; and integrating care for post traumatic stress and depression, economic empowerment, food supplements, family planning services, children school fees, and legal advocacy, services that were at the time seen as luxury going way beyond usual treatment but which turned out to be basic for any program that seriously expected to effectively treat a population such as the women impacted by HIV in Rwanda.

During the past decade, WE-ACTx patients have continued to experience the impact of gender-based violence and gender inequity (including intimate partner violence and rape), stigma, and poverty on HIV transmission, adherence to antiretroviral therapy, HIV disease progression, posttraumatic stress, depression, and quality of life.<sup>5</sup> We have been impressed with how women heroically face these multiple vulnerabilities and create successful lives and alternatives. Here, we describe two poignant examples illustrating the types of initiatives that will be required if we are to address the human rights of women living with HIV worldwide.

In 2009, we surveyed women with HIV attending the WE-ACTx clinic in Kigali, Rwanda, about intimate partner violence experienced since the 1994 genocide. Of the 414 women interviewed, 256 (62%) reported a history of abuse

lifetime prevalence of intimate partner violence reported by a cohort of women with HIV in the United States<sup>7</sup>). The Rwandan women described a variety of abusive behaviors such as their husbands forcing them to have sex, withholding money for food, or preventing them from leaving the house or seeing friends. Sadly, a number also reported yet another form of abuse—husbands who refused to go for HIV care themselves, but instead took their partner's supply of anti-retroviral medications—in this case, an especially lethal form of abuse, leaving their partner without her medications to treat her HIV infection.

In response, the Rwandan counseling staff began conducting weekly support groups for the women who reported various forms of intimate partner violence. Working with the counselors and in support of each other, the women acquired negotiating skills and courage. As is often the case, many of the women continue living with the husbands who had abused them<sup>8</sup>; during the support groups they requested the counselors start a separate group for the men in order to mitigate the abusive behaviors. Gratifyingly, many men attended the group and shared their frustrations about being unemployed and poor and their inability to provide for their family. They discussed, often in emotionally moving stories, how they turned to alcohol, predisposing them to lash out at their partners and children. This support group not only brought the men into the clinic for such meaningful conversations, but it also led them to overcome their own inhibitions and stigma about seeking out HIV care. The clinic staff began treating and prescribing antiretroviral medications for these men. In addition, with the multifaceted support and better coping skills, women reported reduced abuse, more egalitarian relationships, and more peaceful households.

In 2011, to better address the needs of young single mothers with HIV who were struggling to care for themselves and their young children, WE-ACTx started a twice monthly young mothers support group. In Rwanda, single mothers are referred to disparagingly as *Ikinyendaro* or "girls who have children while still living at home." Stigmatized and poor, these young women were depressed, isolated, and often hopeless. In one group of 20 young mothers (aged 18–30 years), 6 were infected with HIV perinatally, 6 were infected when raped, 6 from unprotected sexual activity, and 2 were unsure how they were infected. Most gave birth to their first

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child when they were under 18 years of age. Twelve of the women were illiterate, having little or no reading and writing skills. Eighteen were on antiretroviral therapy.

The support groups allowed the young mothers to express their major concerns. These included unstable housing, history of and continuing vulnerability for sexual assault, and issues related to illiteracy. In response to the identified need for more resources, an intensive 3-hour weekly program was developed and facilitated by a team including a psychologist, vocational counselor, and music therapist. The counselors and therapists worked together with the women, implementing a one-year program designed to improve life skills, increase effective problem solving, process trauma, increase self-esteem, and promote social cohesion. Lunch was provided for these often hungry and malnourished mothers whose own food needs often took a back seat to feeding their children. During the year, 12 women also enrolled in and graduated from a 6-month literacy program, attending classes at the clinic four afternoons each week. The young women collectively developed a plan that included opening up a joint bank account, depositing half of their transport funds each week, and using the shared savings for group projects. Small loans were given to 4 women who created a cogent business plan. Each time the loans are repaid, the funds are reallocated to new projects. The changes in the group are remarkable. Members who once sat depressed and despairing as they cried and shared their problems are now looking for solutions, helping and supporting, and truly enjoying each other. Their joy is only surpassed by ours, working with them and watching this remarkable transformation.

Asking, listening, and hearing what women with HIV who have experienced trauma want and need is an obvious first step to overcoming and ultimately preventing gender-based violence. Women who joined the support groups to address partner violence defined their needs and wanted to develop more proactive strategies from the outset. The *Ikinvendaro* group in the Clinic, however, needed more time to articulate their needs, process their experiences, and collectively develop strategies to overcome their experiences of abuse. Thus this capacity for women to respond to what they identify as their needs more broadly and address basic human rights has emerged as an essential component of quality HIV services.

In traditional clinical settings, women's voices largely go unheard—not heard and ignored—because we are constrained by our narrow clinical paradigm. Hearing women's voices can open the door to incubate and enable local solutions. Few programs engage women's partners when intimate partner violence is identified or challenge gender roles by

helping to create new skills and identities; fewer provide avenues to increase women's agency to collectively fight stigma, support each other, and find jobs.

Although now widely recognized as a major public health priority, policy recommendations on gender-based violence are often top-down approaches, underfunded, and with insufficient resources. Starting with a social justice/integrated agenda that includes women's voices and trauma experiences understood within the broader context of social determinants of health and on the ground barriers will allow women to pave avenues that are more likely to be successful for them as well as those that follow—a lesson learned at WE-ACTx from the women with a history of interpersonal violence and the young mothers.

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