Including Women

In an opinion piece titled "Why Including Women in HIV Research Matters," the Elizabeth Glaser Pediatric AIDS Foundation lays out concerns about research and offers solutions for inclusion. Below is an edited excerpt.

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When Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) Ambassador Martha Sichone Cameron, MPH, walked into a conference room in 2012 as a member of the consumer advisory board for an HIV cure research initiative, she noticed that she was the only woman in the room. She soon discovered that women were underrepresented at every level of the research initiative, including clinical trials.

"Everybody else [on the board] was gay and white, which was OK, but not OK if the cure is going to be for everybody," Cameron says. "I became concerned and frustrated because the investigators were not invested in including women."

Cameron was born and raised in Zambia. In 2003, after losing family, friends and community members to AIDS-related illnesses in the early years of the epidemic, she discovered that she, too, was living with HIV.

Beyond her decades of lived experience, Cameron had had an extensive career serving communities of women and children living with HIV in Zambia by the time she moved to the United States, where she earned a master's degree in public health. In 2012, she was the director of prevention at an AIDS service organization in Washington, DC, so she was beyond qualified to serve on this advisory board—but where were the other women at the table, and why were there no women in the clinical trials?

Cameron recalls later approaching the lead investigator of the research initiative and asking why the clinical trials lacked women when there are such unique gendered biological and social factors to consider in developing a successful cure for HIV. The answer she got was, "It's just too hard."

Why Is It Important to Engage Women Living With HIV in Research?

Resource-rich countries conducted initial HIV treatment research with a focus on gay men, the predominant HIV risk group in those countries. However, the greatest burden of the HIV pandemic has been borne by resource-limited countries, where HIV manifests primarily among heterosexual people, over half of them women.

“Globally, if one focuses on young women ages 15 to 24 years, the risk of acquiring HIV infection is twice that of young men of similar age,” says Lynne Mofenson, MD, senior HIV technical adviser to EGPAF. “This is most pronounced in sub-Saharan Africa, where young women, despite representing just 10% of the population, accounted for 25% of new HIV infections in 2020 compared to 8% in young men.”

Yet women still represent only a fraction of HIV research participants. This means existing treatment guidelines for HIV-related medications and interventions lack sufficient data on drug dosage and safety for more than half of people living with HIV globally, simply because those guidelines were developed for and researched in men.

“It is evident that gender has to be a crucial consideration in medical research for prevention, treatment and a possible cure for HIV,” Cameron says, “and yet women continue to be underrepresented without a real investment or capacity building for research.”

How to Move Forward

Despite the tremendous efforts and progress made with respect to HIV over the past 30 years, we are still a long way from having sufficient evidence regarding many HIV interventions for women, given their unique and diverse biological and social contexts.

“We need to continue to advocate for women being included and involved in research,” Cameron says. “Researchers have to remember that they may be interacting with communities that have [harmful] historical and social contexts with academic institutions and people.

“To that end, here are the three key terms I have for researchers looking to engage people living with HIV and women in research: cultural competency, cultural humility and reflexivity.”
