HIV Risk Reduction

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Women, Violence, and HIV

The impact of trauma on medication adherence and health outcomes for women living with HIV

Edward Machtinger, MD

Edward Machtinger is one of those extraordinary individuals who discovered his life's calling at a very early age.

"In 1985, as a 17-year old gay kid in New York City at the height of the most deadly chapter of the early HIV epidemic in this country, I was profoundly affected by the historic events unfolding around me," says Dr. Machtinger.

"The AIDS epidemic came into being because of a unique intersection between medicine, politics, sexuality, and stigma. The combination of tragedy and heroism that I witnessed in the efforts of advocacy groups like Act Up, Gay Men's Health Crisis, and grassroots organizations throughout the country were incredibly moving to me. I began volunteering with Gay Men's Health Crisis and served as a buddy to a number of dying men. In a societal context of profound stigma, it was my role and my priviledge to help bring dignity to their final days and it made an indelible impression."

"That's when I decided to go into medicine. I envisioned being part of a creative, loving care center for people living with HIV."

Dr. Machtinger is a Professor of Medicine and Director of San Francisco's Women's HIV Program; he has worked in HIV/AIDS for more than two decades. His research focuses on the impact of trauma and PTSD on medication adherence and health outcomes of HIV-positive women. Recent publications include a meta-analysis describing high rates of trauma and PTSD among HIV-positive women in the U.S. and a study demonstrating a sigificant association between recent trauma and HIV antiretroviral failure. He is currently researching interventions to empower women to safely disclose their HIV status as a means to reduce the likelihood of intimate partner violence.

"My hope was to work in a creative and innovative primary care setting - which is exactly what I'm doing now. I imagined that my work would be predominantly taking care of gay men, but I got lucky when I finished my medical residency and was hired to work in the Women's HIV Program (WHP) in San Francisco where I discovered that I love working with women."

"I think it's important to work with whomever you can most easily love and care for. Some people like working with men, some people like working with the homeless. I am most effective working with HIV-positive women."

Study: Over 70 percent of HIV-positive women reported lifelong abuse.

WHP was the first program in the country to be designed specifically for women and girls living with HIV. "At the time, HIV clinics were staffed by gay men; there were beefcake posters on the walls, and the waiting rooms were filled with primarily white gay men. Women and girls arriving for treatment at these clinics, many of whom were black and Latina, felt really out of place. Compounding that, they were dealing with emotional and social challenges specific to minority women. Most had not disclosed their status and they were further stigmatized by a myth, common at the time, that HIV was not a disease that affected women of color. Often they would not return or follow through with referrals like gynecological care," said Dr. Machtinger.

In response, WHP created a safe space with a comprehensive, culturally sensitive array of family-focused programs housed under one roof. "And the women did remarkably well. They came back; they connected with the program and with one another, and they did as well as patients in the men's program, despite coming from backgrounds that were often far more challenging."

And yet, many patients were not doing well. "A significant number of our patients remained isolated and ashamed, not 'out' about their diagnosis, depressed, addictied to drugs - and too many were getting sick and dying. We knew that there was something missing from our model of care, but we didn't kow what that was."

So Dr. Machtinger and his team conducted detailed behavioral assessments of 113 patients looking for associations with key health outcomes. "We spent two hours on each individual assessment and included questions about sexuality, substance use and an array of demographic questions. We also happened to ask a question about recent and past trauma."

The results "awakened us to the role of trauma and abuse in the health of HIV-positive women. It was an ephiphany," says Dr. Machtinger. "Over 70 percent of our respondents reported lifelong abuse and almost one in five reported recent violence or abuse within the past 30 days. Those who cited re-

cent abuse were over four times more likely to be failing their anti-retroviral medicines and over four times more likely to have an HIV-negative sexual partner who did not use a condom."

"While people who work with women in substance abuse recovery and mental health settings have understood for a very long time the impact of trauma on many domains of health, it was now apparent to us that trauma was significantly associated with the key medical outcome of our HIV patients."

To see if the high rates of trauma in their clinic matched those across the country, WHP performed a meta-analysis, comparing many existing studies that calculated the rates of trauma and post-traumatic stress disorder (PTSD) in all U.S. women living with HIV. Among the findings: HIV-positive women are more than twice as likely to experience intimate partner violence and over five times more likely to suffer from PTSD than women in the general population.

"It's heartbreaking. No one in our program is dying from AIDS-related complications. It's trauma that's hurting and killing our patients."

"Sadly, the mental health consequences of lifelong abuse, including isolation, depression, PTSD, addiction, and hopelessness, can lead to behaviors and situations that are threatening and sometimes even fatal to our patients. In the last two and a half years, we've had eight deaths in our program, all in one way or another attributable to trauma. One woman was murdered by her partner and one by an unknown assailant. Three died from overdoses, two committed suicide and one young woman died from a completely preventable opportunistic infection because she just couldn't take her antiretroviral medicine. It's heartbreaking. No one in our program is dying from the typical AIDS-related complications. It's not that these women aren't at risk for cardiovascular disease and cancer, but it's this other realm that's hurting and killing our patients," said Dr. Machtinger.

"The young woman who died because she couldn't take her medication," he continued, "was someone we had known since she was first diagnosed at 15 years old. She lost her mother to AIDS and had been in the juvenile justice system and foster care for most of her youth. She had also experienced both sexual and physical abuse. When a psychologist evaluated her for why she wasn't taking her HIV medicines, her answer was very simple. She did not believe taking them would have an actual, positive, meaningful outcome on her life. So, she didn't take them and she died. Her story illustrates the type of hopelessness and low self-efficacy that can come from the lifelong abuse that is affecting many of our patients and may explain some of their behaviors."

Innovative Program Seeks New Model

Minyon, WHP Client

Women's HIV Program (WHP) is on a quest. And they have joined forces with a team of specialists who are passionate about creating an effective response to trauma for women who live with HIV.

"We're working to develop a new model of trauma-informed primary care for HIV-positive women that includes screening and interventions not only for immediate safety but for the impact of lifelong abuse," explains WHP Director Dr. Edward Machtinger.

To ensure that the new model is guided by the experiences of HIV-positive women, WHP has joined forces with Positive Women's Network-USA. The team also includes experts from government, the military, academia, and community organizations.

"I think many of us knew about the lifelong abuse our patients had experienced, but we didn't have a name for it and we didn't know it was treatable," said Dr. Machtinger. "And the diagnosis of Complex PTSD, an anxiety disorder that results from serial or lifelong abuse, helps to explain why a significant number of our patients simply do not respond to many of our interventions."

"PTSD is an increasingly well-recognized diagnosis with evidence-based treatments that have been demonstrated to be highly effective. We have piloted a number of interventions to help women recover both from abuse and from Complex PTSD. Our goal now is to define the necessary elements of trauma-informed primary care for HIV-positive women so that we can demonstrate and evaluate it. We want to develop a model that will help other programs for HIV-positive and at-risk women become trauma-informed primary care centers."

- 25 percent of all U.S. HIV/AIDS diagnoses are in women.
- 77 percent of all U.S. women with HIV/AIDS are black or Latina.
- HIV/AIDS is the number 3 cause of death for black women in the U.S. between 30 and 44.
- 55.3 percent of American women with HIV/AIDS suffer intimate partner violence (more than twice the national rate).
- 30 percent of American women with HIV/AIDS suffer PTSD (over 5 times the national rate).

Source: www.ucsf.edu