



HIV's Emotional Toll Can Be Overcome

Mental health services must be part of any treatment plan

By Tamara E. Holmes

The mental effects of living with HIV/AIDS – emotional, psychological, and social well-being – remain woefully unaddressed areas that deeply impact quality of life, according to attendees of the 23rd International AIDS Conference, known as AIDS 2020: Virtual.

“Mental health, emotional well-being, sexual reproductive health and lives of people living with HIV are among the critical and important aspects of prevention, treatment, care, and support services to the HIV response,” said [Lillian Mworeko, executive director of the International Community of Women Living With HIV](#), East Africa.

Mworeko was a speaker during the session titled “An Overlooked Epidemic: Mental Health and HIV” that focused attention on some of the toughest challenges for people living with HIV/AIDS (PLWHA).

“The international community has made pledges to address mental health problems,” she said, but “too many women and men still suffer its effects.”

Understanding the burden

From the day of HIV diagnosis, there is often an emotional burden for PLWHA, Mworeko said. Not only must one process the idea of living with a chronic illness, but one might be anxious about disclosing their status to a partner or family members because of fears that they will be stigmatized.

“Stigma is like cold air. You don't see it, but you feel it,” said [Celeste Watkins-Hayes, Ph.D.](#), a sociologist, and author who published “Remaking a Life: How Women Living with HIV/AIDS Confront Inequality” in 2019. The University of Michigan professor spoke during the “HIV and Storytelling” session.

The stigma PLWHA often experience because of their diagnosis is layered with negative attitudes toward mental health issues – particularly in some communities of color, said [Sara Thapa Magar](#), Nepal-based activist with the [International Community of Women Living With HIV](#), Asia Pacific.



“We have a judgmental society,” she said, adding that people may consider a person to be weak if they admit to mental or emotional health problems.

Mental health challenges also can have a detrimental effect on prevention efforts.

“Research has shown that people who have mental illness tend to have more lifetime sexual partners and limited use of contraception. That leads to unplanned pregnancies among women, but it also leads to a greater risk of HIV infection and sexually transmitted diseases,” Mworeko said.

Unpacking trauma

For people of color, the emotional burden of HIV/AIDS can be particularly cruel, said [Vanessa Johnson](#), a long-term HIV survivor who shared a presentation at AIDS 2020: Virtual on behalf of the [International Community of Women Living with HIV, North America](#). She discussed how trauma disproportionately affects certain groups.

“It is important to understand that not all people are equally impacted by trauma,” Johnson said. “For example, communities of color, the LGBTQ community, sexual and gender minority populations, and native and Indigenous people have a much higher burden of trauma.”

In addition to dealing with stigma, Black PLWHA are also grappling with pressures associated with racism.

“Many people living with HIV domestically and globally are not only dealing with the trauma of being diagnosed with HIV but are also dealing with persistent traumatic living environments,” she pointed out. Factors such as a lack of employment options, inadequate educational opportunities, and substandard housing only exacerbate the problem.

Embracing solutions

Introducing conversations about mental and emotional wellness can go a long way toward normalizing mental health challenges.

“We only talk about mental health when a celebrity or an important person commits suicide,” Thapa Magar said, adding that we need to have regular discussions about the importance of maintaining mental and emotional well-being as a standard of care.



For that reason, care providers should always include a mental health component when creating services for PLWHA, Mworeko noted.

Storytelling is another strategy that can improve the mental well-being of PLWHA.

Watkins-Hayes interviewed women living with HIV for her book, which underscored the power of controlling one's narrative.

"Storytelling is healing, particularly as folks grapple with trauma, stigma, and struggle," she said. "Sharing one's story is part of the cultural fabric of HIV community-building."

In fact, healthcare providers should incorporate storytelling in treatment plans, she said.

"Storytelling is critical in the delivery of HIV services. We've learned from almost 40 years of HIV work that when health and social service providers, as well as peer advocates, are able to safely and carefully draw out people's stories, it improves the effectiveness of care," Watkins-Hayes said.

Acknowledging the risks

However, it is important to recognize that storytelling, too, comes with risk.

"Sharing one's story is an inherently vulnerable act," Watkins-Hayes cautioned, because stories are exploited, misconstrued, and – even more painfully – ignored.

Sharing one's story can also lead to re-traumatization as people confront painful memories, fears and emotional hurts that have been suppressed.

That's where community-based organizations, peer groups and HIV/AIDS activists can join with healthcare providers to create a safe space for sharing.

"We must be prepared to be good stewards and supporters to help hold the space, to walk with people in their sharing – even when our charge is to be 'dispassionate professionals.'" Watkins-Hayes said.

Storytelling also can help to combat stigma, Watkins-Hayes continued.

"So much of stigma is also the unseen, the unspoken, the undiscussed. When people hear these stories, they become better educated, they have an opportunity to reflect



and ask questions, and the person who's telling their story gets to mark the space, gets to acknowledge what is unseen as something that they're nevertheless experiencing.”

There are also more opportunities and larger audiences for storytelling thanks to technology.

“There are more social media platforms than ever, so people can now – whether it's through Twitter or YouTube or Facebook or any other resource – tell their own stories and be the author of their narrative,” Watkins-Hayes said.