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Mental and Behavioral Health, Women, and HIV

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Image



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Overview: Considerations for Well-being

Living with HIV is a journey that **intersects with every aspect of health and well-being**, not least of which are mental and behavioral health.

Everything that happens in people's lives, including around HIV, **happens in context** (interrelated conditions in which someone exists or something occurs). That context can include your living situation, access to resources, past trauma, and more – and is entwined with overall wellness.

A lot about who we are and what we do is because of things that happened to us.

We often focus on what individuals can do to increase their well-being. This is very important, and people can make choices and take steps to feel and live better. However, **individual responses are not the whole story** when it comes to health – including mental and behavioral health. It is also important to recognize the effect of context – and especially unequal social conditions based on factors such as race (racism), gender identity or expression (sexism, transphobia), income (poverty, economic injustice), and many more.

This context of inequality influences the conditions of our lives, and advocacy is crucial to fixing it. This is not to suggest that systemic oppression must end before individuals can make moves to increase their well-being. It is to highlight the fact that **mental and behavioral health challenges are not your fault**.

Women across the gender spectrum may experience shame and self-stigma around mental health issues (much like HIV). It is normal to feel this way, but **it is also important not to allow this negative self-talk to block you from getting help**. *A lot about who we are and what we do is because of things that happened to us.* But we do have agency to control how we respond and to take our wellness in our own hands. **Treatment and care, services and support are available in many forms.**

Why is Behavioral Health Important?

Behavioral health describes the connections between actions a person takes and the health of the body and mind. While it is often talked about as being the same as mental health, behavioral health is a more expansive concept. Behavioral health includes:

- [Substance use](#)
- Disordered eating, or an eating disorder diagnosis
- Life stressors and crises, and physical symptoms related to these

Many overall health concerns are connected to behavioral health, and it can have a tremendous impact on quality of life. Issues related to behavioral health are also more likely to affect women than men.

What is Mental Health?

Mental health refers to our emotional, psychological, and social well-being – all of which have an impact on the way people think, feel, and take action in the world. Mental health influences how people function in everyday places such as work and home, and has an impact on sexual well-being.

There are many conditions that affect people's mental health (mental illnesses; mental health disorders). These include, but are not limited to:

- Depression
- Anxiety
- Post-traumatic stress disorder (PTSD)

Mental health conditions also have an impact on physical health in several ways. For instance, when left untreated, they can interfere with the ability to:

- take medications as prescribed (adherence)
- attend appointments, including with healthcare providers
- access supportive people and networks (family, friends, peers)
- experience pleasure
- engage in other activities that help keep you healthy

It is important to note that mental health conditions are treatable. Even though they may mask or be mistaken for a person's personality, and may have gone on for a long time, people can still seek treatment and take other steps to manage these conditions and feel and live better.

Stigma, HIV, and Mental Health Among Women

Stigma, whether tied to HIV, mental health issues, or other aspects of experience, significantly affects individuals' self-esteem and willingness to seek necessary support. Stigma is often rooted in misconceptions and societal judgments.

Mental and behavioral health challenges are not your fault.

Stigma and stress can have a negative effect on the mental and behavioral health of women living with HIV, leading to depression marked by feelings of social isolation, anxiety, and loneliness. In studies among women living with HIV, disclosing (telling) their HIV status to people in their lives has been found to be a major source of stress. Among women of transgender experience (trans women), experiencing greater instances of transphobic stigma is linked with higher rates of anxiety and depression across HIV statuses.

Studies have shown that women living with HIV are more likely to experience mental health conditions like depression than are men living with HIV or women who are not living with HIV. Further, women tend to experience more mental health issues after learning that they have HIV than they did before their diagnosis.

Mental health concerns can also have an impact on how women acquire HIV, as untreated depression has been linked to engaging in sexual activities that may increase the likelihood of coming in contact with HIV. There is also a strong link between depression, childhood trauma, and partner violence among women living with HIV (discussed below).

Stigma and Strategies for Empowerment

To combat stigma effectively, several strategies can be employed:

- Educating oneself and others to dispel myths around HIV and mental health
- Seeking out and engaging with supportive communities that offer understanding and a sense of belonging
- Practicing self-advocacy in various settings to ensure your needs and rights are respected
- If comfortable, sharing personal experiences to humanize and create empathy for these conditions.

Additionally, supporting anti-stigma campaigns and organizations can contribute to a broader societal shift towards understanding and acceptance.

Roots of Mental Health Concerns and Barriers to Well-being

Determinants of Health Inequity

Social determinants of health are the social circumstances that have an impact on a person's physical health, such as poverty, inability to access education, and racism. These environmental factors are linked to **health disparities** (differences in health, including mental health, resulting from unequal or unjust social conditions). One example of a health disparity is higher rates of HIV along lines of race, income level, neighborhood or region, gender identity, and other aspects of experience due to conditions of injustice. Social determinants of health are also called **determinants of health inequity** because their role in defining poor health outcomes is so deeply ingrained.

Research has shown that stress can speed up the progression of HIV.

For example, in a large US survey of trans people, determinants of health inequity were far more pronounced among trans people of color than their white counterparts in the trans community as well as the general population. Latinx (43 percent), Indigenous (41 percent), and Black (38 percent) trans individuals were more than three times as likely as the US population (12 percent) to be living in poverty. Unemployment among transgender people of color was found to be 20 percent compared to the overall US unemployment rate of 5 percent. Worse health outcomes were associated with conditions like housing instability, lower access to education, and lack of family support.

It is unjust systems, and not individual failures or weakness, that cause vulnerabilities that can lead to mental health challenges. Addressing determinants of health inequity requires a layered approach that goes beyond the individual to tackle the systemic injustices that perpetuate these conditions. It demands a collective effort to dismantle barriers to healthcare access, education, and economic opportunities, while also confronting and eradicating discrimination in all its forms.

For more information about health disparities across communities, please see our fact sheet, [Factors Affecting HIV Among US Women of Different Races/Ethnicities](#).

Stress

Everyone deals with a certain amount of stress every day. But for many women, especially women living with HIV, the factors affecting their lives cause levels of stress that can become overwhelming. Living under the social conditions described above can itself be a cause of stress. Being a woman in a society that puts a lot of responsibility on women, withholds supports that could help, and then punishes them for not being able to “do it all” is stressful. This becomes especially important for women living with HIV because research has shown that stress can speed up the progression of HIV.

For Black, Latina, and other women of color across the gender spectrum, additional stressors related to racial and ethnic bias (along with stigma associated with HIV status and gender) may heighten mental health issues like depression. For example, Black and Latina women are more likely than white women to experience poverty or to be unemployed, and 4 out of 5 Black women earn most to all their household's income, despite making less on the dollar than their white counterparts.

Further, each determinant of health inequity that an individual experiences can compound the others and make for worse health outcomes. Research has revealed that people experiencing ongoing, relentless stress at high levels due to racism, poverty, patriarchy, and other forms of injustice age more quickly than their "calendar age" and have poorer health outcomes. This phenomenon is known as *weathering*, as bodies are worn down by stress like a rock might be by wind and rain. Black women, who experience racism and sexism as well as higher rates of other traumas, were found to have the highest levels of weathering compared with men and white women in these studies.

It is also well documented that women tend to take care of everyone else (children, partners, elder family members, community) before themselves, including delaying physical and mental health treatment. If this sounds like you, we encourage you to talk with your provider about getting your health needs met and managing stressful conditions in your life.

For more information about signs of stress and how to cope with stress, please see our [Stress Management](#) fact sheet.

Trauma

Surviving trauma can have profound effects, but it does not have to determine your destiny.

Several studies have shown that experiences of trauma are much more common among women living with HIV than among those in the general population. *Trauma* refers to a deeply disturbing or distressing experience. Trauma can result from a situation, an event, or a series of events that you experience as physically and/or emotionally harmful. A traumatic experience can affect your ability to function, including your mental well-being, for a long time.

A key thing to understand about trauma is that **your experience of an event or situation as deeply disturbing is what makes it traumatic**. Different people will have different experiences of the same event. While some people will find a particular situation traumatic, others may not find it as distressing and may not be as affected by it.

Examples of potentially traumatic life experiences include, but are not limited to:

- Accidents (car, plane, fall, etc.)
- Childhood neglect (basic needs for food, care, and/or shelter were not met)
- Climate-related disasters (hurricanes, wildfires, floods)
- Death of a loved one
- Displacement/being forced to move (due to war, political unrest, eviction, etc.)
- Effects of racism, gender bias, and other forms of oppression (system of unjust treatment)
- [Physical, emotional, or sexual abuse](#) (e.g., domestic violence, intimate partner violence, sexual assault, rape, incest)
- Serious physical injury or illness

Trans women are subject to transphobic discrimination, violence, and even murder at shocking rates in the US and around the globe – even more so for trans women of color. These traumas are part of the reason why trans women are 66 times more likely to be living with HIV than the general population worldwide.

The United Nations estimates that girls and women who experience physical violence at the hands of their partners are almost twice as likely to be living with HIV than those who have not endured such violence. In the US, women living with HIV more often report having been physically or sexually abused as children and/or having experienced intimate partner violence (IPV) than women who are not living with HIV. Women living with HIV suffer from PTSD at significantly higher rates than women in general. For more information on the connection between violence against women and HIV, including powerful advocacy by women living with HIV to respond to these unjust conditions, see our fact sheet on [Violence Against Women and HIV](#).

Recent studies have also shown that the trauma experienced by women living with HIV often seriously affects their health, whether the trauma occurred before or after acquiring HIV. Women living with HIV in the US who had suffered recent trauma were much more likely to have their HIV treatment stop working and/or to have sex without a condom with someone whose HIV status they did not know than did women who had not experienced trauma.

Surviving trauma can have profound effects, but it does not have to determine your destiny. It is possible to heal from trauma, to establish a sense of safety in your life, and to improve the health of your body, mind, and relationships – and you do not have to do it alone.

For example, *trauma-informed care* is an approach that recognizes and anticipates that many people we serve or interact with have histories of trauma – and that the environment and person-to-person interactions within an organization can trigger physical, mental, and behavioral expressions of trauma. Trauma-informed care requires that all staff are trained to be aware of trauma and avoid processes and practices that may re-traumatize survivors.

Managing mental health is not one-size-fits-all, but there are methods that can be beneficial to most!

It is important to note that very few clinics have trauma-informed care and services in place – and transforming an organization around these issues is an extensive process. However, in recent years, awareness that trauma is crucial – and treatable – has greatly increased. If you feel comfortable, you can ask your provider about whether their work is grounded in trauma-informed practices, or if they have services to help overcome trauma and PTSD.

Important: *If you are feeling threatened right now, call 911 in the US or the National Domestic Violence hotline in the US at 800-799-SAFE [1-800-799-7233; or 1-800-787-3224 (TTY)]. You can also search for a safe space online at [Domestic Shelters](#).*

For more information on this topic, see our fact sheet [Trauma and HIV](#).

Lifetime Survival with HIV

Among women and girls who acquired HIV perinatally (during pregnancy, birth, or infancy), known as *lifetime survivors of HIV* or *Dandelions*, existing research shows higher rates of behavioral health concerns. Conditions including depression, anxiety, anger, PTSD, social isolation, cognitive issues, and worries about the future are common, and some research suggests that young women are especially vulnerable.

Survivor's guilt is also a concern for lifetime survivors and may have an impact on mental health. Survivor's guilt is common among survivors of traumatic events. It refers to the feeling that they have done something wrong in surviving when others did not. Lifetime survivors are likely to have lost parents, friends, and peers who were also living with HIV.

Unfortunately, research findings that could support this often-neglected population (most of whom are now adults) are limited. Their unique experiences and challenges must be better understood and

addressed. Please see our fact sheets, [Lifetime Survivors of HIV](#) and [Medical Concerns for Women Lifetime Survivors of HIV](#), for more information.

Image



Responding with Care to Challenging Conditions

While there are many needs for women living with HIV around mental and behavioral health and supporting greatest well-being that are not yet adequately met anywhere (such as the lack of culturally competent providers of this kind of care), there is still so much you can do to manage mental health challenges.

Managing mental health is not one-size-fits-all, but there are methods that can be beneficial to most! Think of these points below as a toolkit, where you need many tools to build the life you deserve – not just one.

Avoiding Isolation

Find peer groups, recovery groups, therapists, and/or friends who you trust.

Support from a Mental Health Professional

It is important to talk to your healthcare provider about your mental health, especially if you are experiencing symptoms or having trouble sticking to your HIV drug regimen. You can ask for a referral to see a mental healthcare provider. You can also ask your provider or a member of the staff at your clinic to help you find a therapist that shares aspects of your identity – as a Black woman or other woman of color, a person of trans or gender-expansive experience, an immigrant, etc. – or that, at least, has expertise in working with members of communities you belong to.

Overcoming Judgment

Some people do not believe in the value of mental health treatment. You or those you love may have heard that people who see therapists ("shrinks") or take antidepressants are "crazy," or weak. Try not to let these judgmental opinions keep you from getting treatment that will help you feel and live better. When we experience physical problems, it is best to get treatment. If someone breaks their leg, we encourage them to see a healthcare provider to get the leg checked and treated so it heals properly. Similarly, when we experience emotional difficulty, there is no need to suffer when effective treatment is available.

Medication Treatment

There is a wide range of mental health conditions from which medications can potentially provide relief. For example, research among women living with HIV experiencing depression has shown that antidepressant medication for those who needed it greatly improved HIV drug adherence and increased the likelihood of ongoing survival.

Mindfulness-Based Practices

More formal approaches like yoga or meditation, and even informal practices like slowing down and watching your breathing, can help in coping with stress and have been shown in studies to decrease mental health effects like depression and anxiety.

Supportive Relationships

Connect with the people in your life who have your back – family, friends, partners, and online community like the one that can be found on the [A Girl Like Me blog](#) and [group](#) on The Well Project's website and social media platforms.

Peer Support

Peer support has a long, important history in the HIV community and in managing mental health issues. Connecting with other women across the gender spectrum who are living with HIV and may share other aspects of your experience in a nonjudgemental, understanding setting can be extremely empowering, liberating, and supportive.

Faith/Spirituality

Connection to a higher power, the teachings and guidance of a system of belief, and the communities that surround these engagements are tremendously important in the lives of countless people around the world, and can be a source of support and affirmation as well as healing practice.

Self-Care

While these by themselves may not be treatment for serious mental health challenges, people draw on all kinds of practices to soothe anxiety and cope with stress. Some examples include listening to or playing music, a warm bath or shower, physical activity like walking or dancing, making art, engaging in a beloved hobby, or journaling.

Harm Reduction Services

Harm reduction aims to minimize the negative health, social, and legal impacts associated with drug use without necessarily stopping the use. Services include needle exchange programs and providing access to Naloxone for overdose prevention. The Harm Reduction Coalition offers guidance and resources for accessing these services.

Sense of Purpose

Contributing time, energy, and focus to something that matters to you is powerful – whether it is the life of an elderly neighbor whose pets you care for, or an ongoing movement for social justice. Having a sense of purpose can build hope and reduce stress, and has been linked to improved physical and mental health.

Advocacy and Activism

There are many points in this fact sheet that relate to conditions of injustice – and there are many people worldwide who are fighting to improve those conditions and ensure that all people, regardless of their identity, can live their best life. Working with others to make change in the world can provide a sense of purpose as well as community!

Resources for Support

SAMHSA's National Helpline

This free, confidential, 24/7, 365-day-a-year treatment referral and information service (in English and Spanish) for individuals and families facing mental and/or substance use disorders
800-662-HELP (4357)

Suicide and Crisis Lifeline
Languages: English, Spanish
Hours: Available 24 hours
988

Trans Lifeline's Hotline

A peer support phone service run by trans people for our trans and questioning peers. Call us if you need someone trans to talk to, even if you're not in a crisis or if you're not sure you're trans.

877-565-8860

Oprime 2 para hablar con alguien en español

Mental and Behavioral Health Information from The Well Project

[WRI 2023 — Optimizing the Behavioral Health of Women Living with and Vulnerable to HIV](#)

[Depression, Women, and HIV](#)

[Trauma and HIV](#)

[Navigating Mental Health Care: A Girl Like Me LIVE](#)

[Stress Management](#)

[Violence Against Women and HIV](#)

[Black Women Living with and Vulnerable to HIV in the US: Leadership Exchange LIVE](#)

[Substance Abuse and Addiction](#)

[Combatting Loneliness and Isolation with HIV - Building A Village: A Girl Like Me LIVE](#)

[Getting Through COVID-19 Together \(Virtually\) - The Importance of our Online Support Community](#)

[Coping with Mental Health around the Holidays: A Girl Like Me LIVE](#)

[Mental Health, Women and HIV: Resources and Personal Stories](#)

[Five Factors That Influence the Health of Women With HIV \(POZ\)](#)

[HIV Work in the COVID-19 Era: Recaps from USCHA 2021](#)

[Webinar – Taking Care: Understanding and Addressing Mental Health Among Women Living with HIV](#)

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Additional Resources

Select the links below for additional material related to mental and behavioral health, women, and HIV

- [What is Mental Health? \(SAMHSA - Substance Abuse and Mental Health Services Adm...](#)
- [HIV, Mental Health & Emotional Wellbeing \(aidsmap\)](#)
- [Mental Health and HIV \(HIV.gov\)](#)
- [Integration of Mental Health and HIV Interventions \(UNAIDS; PDF\)](#)
- [Mental Health and HIV: Entire Lesson \(US Department of Veterans Affairs\)](#)
- [HIV and AIDS and Mental Health \(National Institute of Mental Health\)](#)
- [HIV and Mental Health \(HIVinfo\)](#)
- [Depression Linked to Cognitive Dysfunction in HIV-Positive Women \(TheBody\)](#)
- [Mental Health and HIV/AIDS: The Need for an Integrated Response \(AIDS\)](#)
- [Depression \(Terrence Higgins Trust\)](#)
- [Considerations for Antiretroviral Use in Special Patient Populations: Substanc...](#)
- [Harm Reduction \(International Association of Providers of AIDS Care\)](#)



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