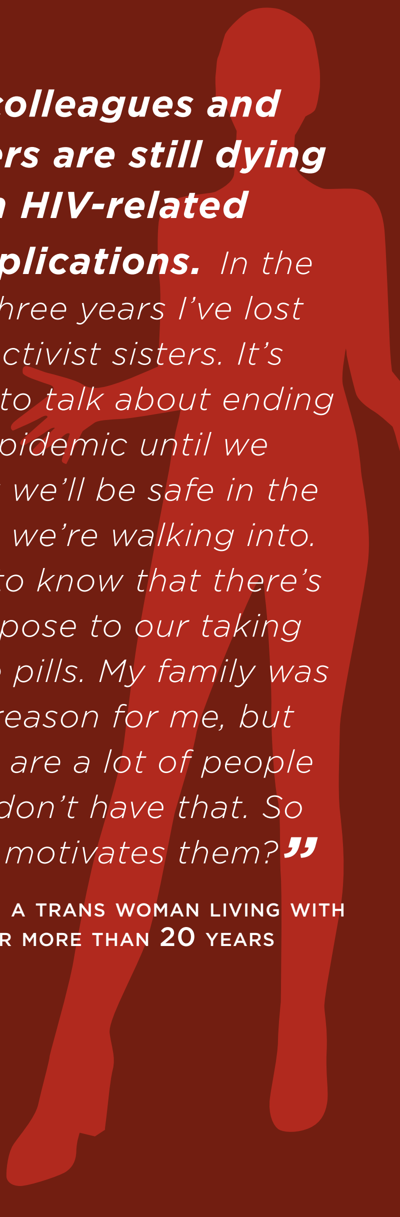
ISSUE BRIEF

WOMEN LIVING WITH HIV
Over the Long Term and Across the Lifespan

WOMEN'S RESEARCH INITIATIVE ON HIV/AIDS (WRI)
a program of The Well Project

HIGHLIGHTS

- **The Women's Research Initiative on HIV/AIDS (WRI), a program of The Well Project, is a multidisciplinary and multisectoral effort dedicated to identifying gaps for women in HIV prevention, treatment, and cure research and policy.** In May 2019, The WRI convened a meeting to broadly address issues related to long-term experiences with HIV across the lifespan, including those relevant to older women who are aging with HIV and younger women who acquired HIV perinatally or as young children and have now been living with HIV for decades.
- **The use of "women" throughout this document is inclusive of trans and cis-women.**
- **Women living with HIV are at increased risk** for age-related co-morbidities compared to women without HIV and, in some cases, men living with HIV.
- **While research has demonstrated that HIV affects a number of factors in women's lives,** including several co-morbidities associated with aging, mental health, and quality of life, significant gaps persist in our understanding of the mechanisms through which they operate and the best ways to address them.
- **Women's experiences living with HIV, especially over the long term, extend far beyond their diagnosis** and are influenced by a multitude of factors, including age, race, gender identity, socioeconomic status, education level, immigration status, experiences of violence and trauma, geographic location, mental health challenges, and substance use issues (among many others).
- **These factors and the lived experiences of women living with HIV need to be considered and addressed** in all levels of research, policy, and programming if we hope to change the course of the HIV epidemic.



> ***"My colleagues and sisters are still dying from HIV-related complications.*** *In the last three years I've lost five activist sisters. It's hard to talk about ending the epidemic until we know we'll be safe in the room we're walking into. And to know that there's a purpose to our taking these pills. My family was that reason for me, but there are a lot of people who don't have that. So what motivates them?"*
>
> -- FROM A TRANS WOMAN LIVING WITH HIV FOR MORE THAN 20 YEARS

thewellproject

BACKGROUND

Women currently represent approximately 23 percent of people living with HIV in the United States, and more than 60 percent of these women are 45 years old or older.[1] For trans women, HIV prevalence is extremely high—14 percent—although data on age is sparse.[2] Remarkable advances over the past several decades mean that a woman diagnosed with HIV today who accesses antiretroviral treatment (ART) soon after her diagnosis and remains virally suppressed, may have a life expectancy comparable to those without HIV. However, as women live and age with HIV over the long term, many experience unique health challenges. Evidence indicates that HIV causes new and exacerbates existing co-morbidities in women as they age, but questions remain about the relative weight of and the relationship between long-term HIV disease, long-term HIV treatment, gonadal aging, and the overall aging process. Addressing these questions is critical, given the rapidly growing population of women who have been living with HIV for decades.

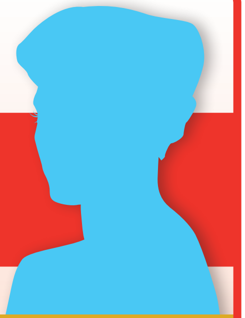
The WRI addressed two different aspects of living with HIV over the long term that are relevant to women. The first applied to the range of medical, psychological, and social issues that women living with HIV experience over time, regardless of when they acquired HIV (at birth, infancy, adolescence, or adulthood). The other relates more specifically to the aging process, including the possibility of "accelerated aging" that many people with HIV report experiencing.

Women's lived experiences

Throughout this document we will use the phrase "women's lived experiences" to refer to "knowledge gained through direct, first-hand involvement in everyday events, rather than through representations constructed by other people."[3] Such everyday events include women's interactions with the HIV care system, but also interactions with other medical, psychological, social, and environmental factors that influence how they understand, feel, and act in relation to their HIV disease in the broader context of their whole lives.[4]

In the ***WORDS*** *of* ***WOMEN*** *who have been* ***living with HIV*** *for* ***20 YEARS*** *or longer:*

"I get sick and tired of being sick and tired."



"I'm taking more pills that are not related to HIV than I am that are related to HIV."

"I had to decide that the HIV medications drugs aren't who I am – they are part of my team, part of what I'm doing to take care of myself, but I can't let them define who I am."

"I wanted to show people I was a normal kid. We are all people. Having a chronic illness doesn't make me less of a person."

"I had a GED when I was diagnosed and I realized that if I was going to die, I wanted to die with some letters behind my name. So I went back to school."

"There's no one that I know who is a long-term survivor who hasn't dealt with a pretty significant level of trauma and mental health challenges."

Women's experiences of living with HIV extend far beyond their diagnosis and management of the disease itself, particularly among women who received their diagnosis many decades ago (regardless of their current age). Numerous intersecting factors—including age, race, gender identity, socioeconomic status, education level, immigration status, experiences of violence and trauma, geographic location, mental health challenges, substance use issues, access to healthcare, and family support—play a significant role in how women approach HIV in the context of their whole lives and sense of self.

WOMEN AND HIV OVER THE LONG TERM: WHAT WE KNOW

Comorbidities: Living with HIV over multiple decades is a new frontier. Research to date has demonstrated that women living with HIV are at increased risk for age-related co-morbidities compared to women without HIV. There are also some differences in the experience of women living with HIV compared to their male counterparts. By 2030, it is expected that 84 percent of people living with HIV will have at least one co-morbidity, while 28 percent will have at least three.[5] Some of the co-morbidities to which women living with HIV are susceptible include:

- **Heart disease:** The rate of coronary heart disease is significantly greater in people living with HIV, even after controlling for known traditional risk factors.[6] Women living with HIV are less likely than men living with HIV to be offered prescription medication that addresses equivalent coronary heart disease.[7]
- **Stroke:** Women living with HIV have higher rates of stroke than women without HIV, while there is no difference between men living with HIV and men without HIV.[8]
- **Fracture:** Rates of fracture are higher among all people living with HIV, but research has not demonstrated a difference between men and women.[9]
- **Weight gain:** Weight gain is associated with a number of HIV medications and is more significant in women living with HIV than their male counterparts.[10]
- **Mental health:** Women living with HIV are more prone to having a major depressive disorder than women without HIV and five times more likely to experience neurocognitive impairment.[11]

Impact of Long-term Treatment: HIV is not the only driver of age-related effects, however. Many chronic conditions occur at higher rates in people living with HIV who are taking antiretroviral therapy, especially over multiple decades. The effects of HIV medications may also be worse in women than men, leaving them more vulnerable to metabolic complications.[12]

CO-MORBIDITIES

occurring at higher rates in people living with HIV taking ART[13]

Diabetes

Frailty

Non-AIDS cancers

Depression

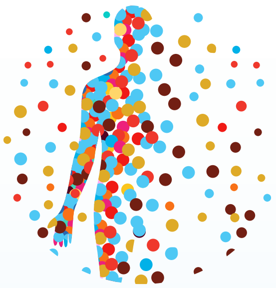
Chronic liver disease

Chronic obstructive pulmonary disease (COPD)

Chronic heart disease

Cognitive disorders

Chronic renal disease



STRESSORS

that may affect women living with HIV[16]

Early-life trauma

Negative life events

Violence exposure

Financial instability

Food insecurity

Limited healthcare access

Low education

Neighborhood level factors

Internalized stigma

Sadness & grief from initial diagnosis

Stress of living with chronic illness

Mental Health: Stress and depression play very important roles in the lives of women living with HIV. Stress affects everyone but long periods of high stress can damage the immune system and cause physical and emotional illnesses. Research has also shown that stress can speed up the progression of HIV.[14] Women living with HIV are more likely to suffer from depression than women without HIV and studies have demonstrated a direct connection between depression and poorer health among people living with HIV. Compared to women living with HIV who are not depressed, those who are seek HIV care less often, have more difficulty adhering to their HIV drug regimens, and have more rapid disease progression.[15]

Quality of Life: Co-morbidities, psychosocial factors, and medication challenges all affect the quality of life for women living with HIV, regardless of when they acquired the disease. Many women who have been living with HIV over the long term experience AIDS Survivor Syndrome, which is the psychological state that comes from living through the HIV/AIDS pandemic. The most vulnerable are those who acquired HIV in the 1980s and 1990s, when HIV was considered a terminal diagnosis. The effects may include depression, anxiety, emotional numbness, anger, survivor guilt, insomnia, nightmares, hypervigilance, hopelessness, substance abuse, sexual risk-taking, low self-esteem, avoidance, social withdrawal and isolation, and/or a lack of future orientation.[17]

Post-traumatic Stress Disorder (PTSD) is also a significant challenge for people living with HIV over the long term. PTSD is psychiatric disorder that can occur among people who have experienced or witnessed a traumatic event. For many women living with HIV over the long term, PTSD can be result of having received their HIV diagnosis before effective treatment was available, losses of friends and family members, years of managing health challenges, and rejection by families and friends.[18]

For many women, the counterbalance to the profound burden of these challenges is resilience. While “injuries of inequality produce, and are produced by, a compromised ability to protect oneself from harm,”[19] resilience is the capacity to adapt to and recover from challenges and difficulties. Women who thrive with HIV, rather than merely survive with it, demonstrate resilience.[20] Research has demonstrated the importance of the HIV safety net in supporting and reinforcing resilience, but more research is needed to better understand the characteristics and impact of resilience among those women living with HIV who have demonstrated it and to determine how best to cultivate it further in this community.

Perinatal and Early Childhood HIV Acquisition:

Women who acquired HIV at birth or very early in life have some of the same issues as women who acquired HIV later, but they also face unique challenges, including around dating and disclosure, trauma related to learning about their diagnosis, managing medication adherence at a young age and for the entirety of their lives, shifting care from a pediatric to adult setting, and the impact of life-long medication on their bodies.

ISSUES RELATED TO EARLY HIV ACQUISITION

PSYCHOSOCIAL Challenges[21]
Stigma
Disclosure
Limited support systems
Poor adjustment to illness/status, self efficacy, outcome expectancy
Denial/guilt
Limited health literacy
Poverty
Unemployment/underemployment
Logistic barriers: insurance, children, transportation, housing
Attempting to be “normal”

MEDICAL Challenges[22]
TREATMENT
Treatment experienced
More complicated ART
Even one pill a day is too many!
Treatment fatigue
Drug-resistance
Transition from pediatric to adult care
HIV DISEASE
Advanced disease/immunosuppression
Co-morbidities
Mental health (anxiety, depression, PTSD), substance use
Neurocognitive delay and dysfunction
Delayed puberty and short stature

RESEARCH AND POLICY AGENDA

In the context of current policy initiatives to “end the HIV epidemic,” focusing on women who have been living with HIV over the long term makes it clear that viral suppression—the endpoint highlighted in these initiatives—is only one important metric of success. Moreover, viral suppression will not be sustained unless other medical, psychological, and social issues affecting the lives of women are addressed. If we hope to truly change the course of the HIV epidemic, it is imperative to attend to the full range of women’s lived experiences at all levels of research, policy, and programming.

The WRI identified a number of research, policy, and advocacy gaps that need to be addressed. The WRI is committed to working collectively with all relevant stakeholders, including WRI members to advance these efforts.

> ***“There’s a notion that because there are lower rates among women, including black women, we don’t have to worry about them. We need to fight that perception. In order to end the epidemic, we still need to decrease rates in women, and we can only do so by addressing their lived experiences.”***

- Advocate for qualitative, community-based participatory research to identify salient medical, psychological, and social factors influencing the experiences of diverse women living with HIV over the long term
- Undertake a series of efforts to ensure that women are incorporated into the End the Epidemic (ETE) plan (including modeling the limited impact of ETE without specifically addressing women, engagement with plan executors, etc.)
- Assess existing measures that collect the medical, psychological, and social factors that affect women’s lives (e.g., substance use, violence, poverty, depression, sexual health, immigration status); determine their ability to collect meaningful data and identify new measures if necessary; develop a set of standards and incorporate into biomedical research
- Collect data on the impact of addressing the medical, psychological, and social factors affecting women’s lives in a clinical setting, with an emphasis on successful care models; create and promote repository
- Conduct research, develop policy on structural factors that allow women to be virally suppressed/decrease co-morbidities and the services that support them (housing, behavioral/mental health treatment, substance abuse care, services to address food insecurity, etc.)
- Assess and report on cost-effectiveness of incorporating women’s lived experiences into research and care models
- Develop and disseminate materials highlighting the value and impact of capturing and reflecting the lived experiences of women living with HIV among all relevant stakeholders
- Develop an outreach strategy to engage with policy-making bodies, including listening sessions, participation in public events, one-on-one meetings, public comment periods
- Collect, highlight, and amplify personal stories of women living with HIV through the development of a speakers bureau; pursue opportunities to leverage women’s voices at scientific conferences, government meetings, drug company advisory boards, etc.

CONCLUSION

The WRI 2019 tackled the multitude of issues related to long-term experiences with HIV across the lifespan, among both older women who are aging with HIV and younger women who acquired HIV very early in life, inclusive of trans and cis-women. Women's lived experiences, which extend far beyond their HIV diagnoses, must be elevated both as factors contributing to how they live with HIV and their health outcomes. Stakeholders committed to advancing and improving care for women living with HIV must consider and address their lived experiences at all levels of research, policy, and programming. If we fail to do so, we will lose the opportunity to change the course of the HIV epidemic. In the words of a WRI member who has been living with HIV for multiple decades, "we are not going to end the epidemic by testing people…or giving out a pill…We need to educate our way out of this epidemic, and make sure we turn to the community."

REFERENCES

1. Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2010–2015. HIV Surveillance Supplemental Report 2018;23(No. 1). http://www.cdc.gov/ hiv/library/reports/hiv-surveillance.html. Published March 2018.
2. https://www.cdc.gov/hiv/group/gender/transgender/index.html
3. Oxford Reference: https://www.oxfordreference.com/view/10.1093/oi/authority.20110803100109997
4. IBID
5. Smit et al. *Lancet Infect Dis*. 2015 Jul; 15 (7):810-818
6. Freiberg, 2013
7. Harleberg CI, et al, 12th Int Cong Drug Therapy HIV November 2014
8. Chow F, et al CROI 2016
9. Triant VA et al. *J Clin Endocrinaol Metab*. 2008;93(9):3502
10. https://www.poz.com/article/starting-hiv-treatment-women-gain-weight-men
11. Cook JA et al *AIDS & Behavior* 2018; Palar K et al AIDS & Behavior 2018; Rubin et al Curr HIV/AIDS Report 2019
12. Lake, JE et al, CROI 2019, Risk Factors for Excess Weight Gain Following Switch To Integrase Inhibitor–Based ART
13. Sutton, S.S., et al., Chronic kidney disease, cardiovascular disease, and osteoporotic fractures in patients with and without HIV in the US Veteran's Affairs Administration System. *Curr Med Res Opin*, 2018: p. 1-9.
14. https://www.thewellproject.org/hiv-information/stress-management
15. https://www.thewellproject.org/hiv-information/depression-women-and-hiv
16. IBID
17. https://letskickass.hiv/what-is-aids-survivor-syndrome-dc0560e58ff0
18. https://www.thebodypro.com/article/post-traumatic-stress-disorder-and-long-term-survi
19. Watkins-Hayes, 2019, "Remaking a Life: How Women Living with HIV/AIDS Confront Inequality"
20. IBID
21. Murphy JAMA 2003; Martinez Pediatrics 2014; Mofenson JIAS 2015; Rudy *AIDS Pt Care* 2009 & 2010; Lee & Hazra JIAS 2015
22. Agwu *JIAS* 2013; Lee JIAS 2013

ABOUT THE WRI

Since 2003, the Women's Research Initiative on HIV/AIDS (WRI), a program of The Well Project, has advocated for "more, better and faster research" in HIV disease in women. The WRI brings together an extraordinary group of leaders in HIV to identify key opportunities to accelerate our understanding of HIV disease in women. WRI members represent a broad range of stakeholders in the fields of clinical care, research, academia, community-based services, advocacy, government, the pharmaceutical industry, and women living with HIV. This diverse membership operationalizes the multidisciplinary approach advocated by the WRI. By addressing issues that affect women through a variety of lenses, the WRI is able to expand understanding of effective treatment and prevention for women and girls living with or vulnerable to HIV. Please click here for more information on the WRI.

ABOUT THE WELL PROJECT

The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls. The Well Project is the premier online resource on women and HIV both nationally and globally, revolutionizing the availability and accessibility of meaningful and relevant information designed specifically for women living with HIV. The Well Project leverages technology to dramatically improve health outcomes and quality of life for women living with HIV. Please click here for more information on The Well Project.

thewellproject

The WRI 2019 convening received sponsorship support or grants from Gilead, Janssen, Merck and ViiV Healthcare.