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Beyond Viral Suppression: Addressing Stigma, Mental Health and Well-Being

**U.S. Conference on AIDS
September 9, 2018
9:00 am – 11:00 am ET**

Together, we can change the course of the HIV epidemic...one woman at a time.

#onewomanatatime

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Agenda

- Introductions
- The HIV Continuum of Care
 - What the continuum misses
 - Looking beyond viral suppression
- Your Voice Counts: The Well Project 2016 User Survey
- HIV stigma
- Mental health and self-care
- Discussion



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Session Goals

Participants will leave this session with:

- Knowledge of the HIV care continuum, including its limitations
- Insights into factors that contribute to the quality of life for women living with HIV
- An understanding of why it is important to expand outcomes of interest beyond viral suppression



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Speakers



Krista Martel,
executive director, The
Well Project



Gina Brown, MSW
community advisory
board, The Well Project;
community organizer,
Southern AIDS Coalition



Vickie Lynn, MSW, MPH,
community advisory board,
A Girl Like Me, The Well
Project; doctoral
candidate, University of
South Florida, College of
Public Health



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The Well Project

- Non-profit organization with a mission to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls
- Leverages technology to improve health outcomes and increase quality of life for women and girls living with HIV
- Provides accessible and comprehensive #information, #community support, and #advocacy building
- Access our resources and join our community at www.thewellproject.org



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The HIV Continuum of Care

Together, we can change the course of the HIV epidemic...one woman at a time.

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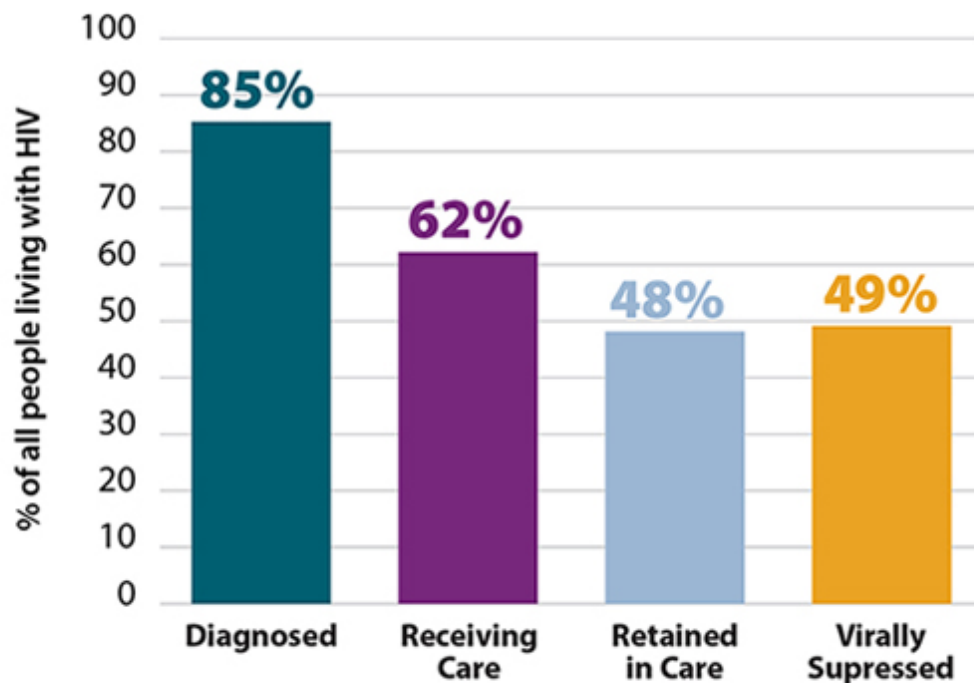


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What is the HIV Continuum of Care?

HIV Care Continuum, United States, 2014

An estimated 1.1 million people are living with HIV in the United States.





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Why is the Continuum of Care Important?

- It has become the predominant framework for assessing progress in HIV treatment and prevention
- UNAIDS' "90/90/90" campaign aims to get 90% of all people tested for HIV, 90% of those diagnosed on treatment, and 90% of those on treatment virally suppressed
 - From a medical perspective, viral suppression is the **ultimate** outcome of HIV treatment
 - 90/90/90 has been adopted by a great many countries
 - Botswana, Cambodia, Iceland, Singapore, the United Kingdom, city of San Francisco have achieved this goal



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What Does the HIV Continuum of Care Miss?

- The continuum of care is a valuable resource, but it shouldn't be used in isolation
- WLHIV need and deserve a holistic approach that addresses other issues of importance to them, including
 - Stigma and isolation
 - Mental health (depression, PTSD, anxiety)
 - Substance use
 - Self care
 - Intimate partner violence (IPV)
- Our Voice Counts: The Well Project 2016 User Survey

Your Voice Counts: The Well Project 2016 User Survey





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The Well Project 2016 User Survey Report

- Final sample size for analysis was 229
- WLHIV made up 60% of the overall sample (136 women)
 - They knew their HIV status for an average of 16.3 years
 - 98% were currently seeing a healthcare provider to manage their HIV
 - 98% had taken HIV meds at some point since their diagnosis; same percentage were currently doing so
 - 77% had undetectable viral loads at last testing
- WLHIV identified their primary goals in using The Well Project's resources as:
 1. Increasing their knowledge of HIV and its treatments
 2. Improving their health outcomes
 3. Becoming more empowered to advocate for themselves



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The Well Project 2016 User Survey Report

- Pointed to the need to look beyond the care continuum and viral load suppression
- The following data show The Well Project's impact on women's basic HIV knowledge (a precursor to engaging in care), self-care, and outlook on living with HIV

ENGAGEMENT IN CARE

When asked about how The Well Project's resources had influenced specific aspects of their engagement in care with providers, WLHIV responded they were **"somewhat" or "much" more likely to:**



Talk with healthcare providers about how HIV affects women differently than men

76.7%



Talk with providers about medication options, concerns, and side effects

74.8%



Communicate well with healthcare providers

68.9%



See healthcare providers regularly

56.3%



Take HIV medication regularly as prescribed

54.4%



Talk with providers about PrEP*

47.6%

*PrEP stands for Pre-Exposure Prophylaxis, a prevention method that involves taking one pill a day to prevent the transmission of HIV.

SELF-CARE

When asked how The Well Project's resources had affected aspects of self-care related to their emotional well-being, WLHIV responded they were *"somewhat"* or *"much"* more likely to:



Accept only respectful, caring behavior from partners, family and/or friends

70.9%



Make an effort to get enough/good rest and eat healthy foods

68.0%



Exercise or move regularly

63.1%



Seek out care for depression or other mental/emotional health issues

56.3%



Practice safer sex

53.4%



Seek out support for past or current violence or trauma

51.5%

OUTLOOK ON LIVING WITH HIV

When asked to assess The Well Project's influence on their outlook on living with HIV, WLHIV responded they were "somewhat" or "much" more likely to:



Advocate for themselves

82.5%



Feel connected to a community

81.6%



Advocate for the needs of others living with HIV

80.6%



Feel hopeful about the future

75.7%



Experience less HIV self-stigma

65.0%



Not feel alone

63.1%

61.2%

Experience less HIV stigma from others





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The Well Project 2016 User Survey Report

- Survey also included women's experiences around stigma in healthcare systems, stigma outside of healthcare systems, mental health issues, and trauma, which we are going to explore further



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Stigma

- Stigma is an attitude or belief about a person or group of people that discredits or shames them
- It can be external or internal (self-stigma)
- Stigma works its way into policy decisions that affect:
 - Access to care
 - Access to health insurance
 - Employment discrimination
 - Research funding allocations
- Stigma among WLHIV may lead to **social isolation** and **loneliness**



Stigma

- Stigma continues to have a significant impact on the HIV epidemic
 - The Well Project believes that stigma is the single biggest obstacle to ending the HIV epidemic
- If a WLHIV is virally suppressed but still affected by stigma, it can have a negative impact on her quality of life and health outcomes

STIGMA IN HEALTHCARE SETTINGS

49.6% of WLHIV reported having personally experienced HIV stigma or discrimination in healthcare settings



41.3%
healthcare
staff



38.1%
dentists



22.2%
registered
nurses



19.0%
social
workers



36.5%
emergency
department
physicians



23.8%
OB/GYNs



23.8%
primary-care
physicians



17.5%
nurse
practitioners



15.9%
physician
assistants

STIGMA IN THE LIVES OF WLHIV

62.7% of WLHIV reported having personally experienced HIV stigma or discrimination in their personal lives



50.6%
from family
members



46.8%
from
friends

39.2%
in their
neighborhoods



31.6%
at places of
employment



24.1%
in online
forums/chats/
groups



39.2%
with romantic
partners

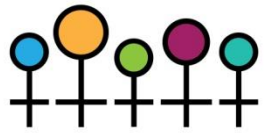


27.8%
at places
of worship



14%
at HIV service
organizations





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What is Mental Health?

- Emotional, psychological, and social well-being
- Affects the way people think, feel, act
- Determines how people handle stress
- Can change how people function at work and home
- Good mental health is a sense of well-being, confidence, and self-esteem



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Mental Health

- WLHIV experience 2-3x greater rates of mental health issues than the general population
- WLHIV are more likely than men to have depression, anxiety, substance abuse, post-traumatic stress disorder
- Mental health helps determine how people handle stress, relate to others, make choices



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Addressing Mental Health Needs

*"Dealing with undiagnosed and untreated depression, anxiety, and substance use ultimately led me to increased drug use and unhealthy coping behaviors, which limited my ability to deal with reality or handle any major life decisions. **Addressing my HIV care needs became impossible.**"*



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Hotlines/Help

- In the U.S.
 - call 1-800-SUICIDE (1-800-784-2433) or
 - 1-800-273-TALK (1-800-273-8255)
- To find a suicide hotline
<http://www.suicide.org/suicide-hotlines.html>



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Mental Health

- Mental health problems can affect physical health by
 - Making it harder to take HIV medications on time
 - Making it harder to keep appointments/take advantage of support networks
 - Interfering with healthy behaviors
 - Impairing ability to cope with the stresses of daily life
- People living with HIV are at higher risk to develop mood, anxiety, cognitive disorders, but remember!
 - These conditions are treatable
 - ***People who experience mental health problems can get better and many recover completely!!***



thewellproject Accessing Mental Healthcare

Barriers Identified by WLHIV to Engaging in and Accessing Mental Healthcare





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Self-Care

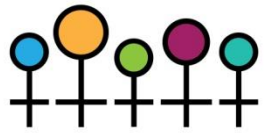
- Continuum of care doesn't address importance of self-care: strategies that PLHIV can use to fight mental/physical health challenges
- Without self care, PLHIV are at risk for burnout and depression
 - Burn out: feeling cynical about your work, doubtful of your effectiveness, overwhelmed, numb, frustrated, bored, unappreciated
 - Depression: feeling hopeless, lacking interest in many activities, having trouble sleeping or concentrating, not taking HIV treatment or managing your disease



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Self-Care

- Self-care can break the stress cycle that leads to burnout, enable you to recover energy and passion
- What drains you? What fills you up or re-energizes you?
 - Do you need more sleep? Time outdoors? A good laugh? Time to journal? Evening out with friends?
- You will have so much more to share with others if you take time to care for yourself



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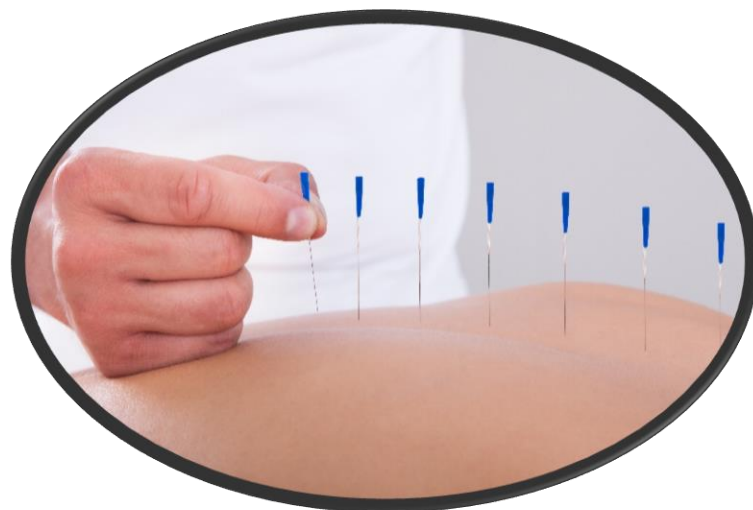
Social Support

- For all areas of mental health, it may also be helpful to ***seek support of other WLHIV***
 - Support groups
 - Peer counseling
 - Online communities such as The Well Project's *A Girl Like Me*
- Social support from friends and family has been found to help PLHIV avoid depression, cope better



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Other Treatment and Self-Care





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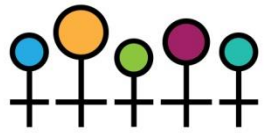
In Our Own Words

“We have come a long way in the treatment of HIV and the medical advances over the past few decades have allowed me to live a life I never dreamed possible. Today, I have the opportunity to focus not only on my physical health but also on my mental and spiritual well-being. I am looking forward to what tomorrow might bring.”

-Vickie Lynn

“I’ve learned how to look at my whole being, recognizing if one part is out of whack, it can throw everything off. I take a holistic approach to living; mind, body, and soul all need attention. Today I take time to appreciate my life, not just my work!”

– Gina Brown



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Thank You!



Questions & Answers



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Learn More!

- To learn more:
 - [Depression, Women, and HIV](#)
 - [Stress Management](#)
 - [Trauma and HIV](#)
 - [My Depression, Trauma, HIV and Getting Help](#)
 - [The Importance of Taking Care of Yourself on the Inside and Outside](#)
- For more fact sheets and to connect to our community of women living with HIV, visit:
 - www.thewellproject.org
 - www.facebook.com/thewellproject
 - www.twitter.com/thewellproject