

A program of The Well Project



Taking Care: Understanding and Addressing Mental Health Among Women Living with HIV

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

#onewomanatatime

#thewellproject



About 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
- Focus is to provide accessible and comprehensive #information, #community support, and #advocacy building
- Access our resources and join our community at www.thewellproject.org



About WATCH!

- WATCH! Women's Advocacy and Treatment Coalition on HIV is an ongoing HIV treatment advocacy and capacity-building webinar series
- The 2016 WATCH! series will take place throughout the year, and will include 5-6 webinars
- For certification, participants must participate in live webinar or view recording, take a pre- and post-test, and final evaluation survey (end of series)
- Webinars will be recorded and can be accessed up to one month after they take place



Webinar Agenda



Overview of Mental Health, Women and HIV, Vickie Lynn, MSW, MPH, Doctoral student, Instructor at University of South Florida, Tampa, (USF), The Well Project Community Advisory Board, *A Girl Like Me* blogger



From Treatment to Healing – The Promise of Trauma-Informed Care, Edward Machtinger, MD, Professor of Medicine and Director of the Women's HIV Program at the University of California, San Francisco (UCSF)



Krista Martel, Executive Director, The Well Project



Webinar Details

- Webinar will last approximately 90 minutes with Q&A at end
- Use live chat box on left side to enter questions while someone is talking; questions will be put in queue
- If you are listening to webinar via your phone, please enter second audio pin to connect your phone to computer * (3-digit number)#
- Participants' lines will be muted until the Q&A
 - To unmute your phone, press *6, or click on microphone icon at the top of your screen (if using computer microphone)
 - To mute, use your phone "mute" button



Overview of Mental Health, Women, and HIV

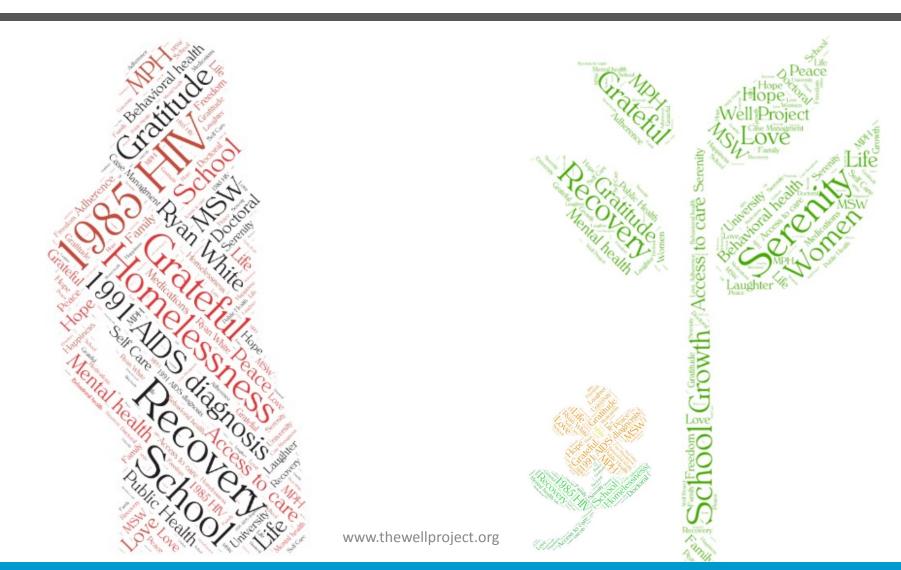
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Vickie Lynn, MPH, MSW





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



Mental Health and HIV

- Mental health conditions affect
 - Physical health
 - Adherence to medications
 - Ability to keep appointments
 - Ability to use support networks
 - Interfere with healthy behaviors
 - Impair ability to cope with the stresses of daily life
- Conditions are treatable
 - People who experience mental health problems can get better and many recover!!



Common Mental Health Disorders Among PLHIV

- PLHIV have higher risk of:
 - Depression
 - Anxiety
 - Substance abuse
 - Post traumatic stress disorder (PTSD)

Past and recent trauma, including gender-based violence and abuse, contribute significantly to the above mental health disorders experienced by women living with HIV



Poll Question



Women Living with HIV Co-morbidity

- Rates of mental health conditions for WLHIV are 2-3x higher than those in the general population
- WLHIV are more likely than men to have at least one psychiatric disorder



HIV, Mental Health, & Substance Abuse

- 25%-50% of PLWH have a history of substance abuse issues
- 12% screen positive for drug dependence
- 50% screen positive for mental health disorders
 - Depression (15-42%)
 - Anxiety (11%-25%)



Depression

Compared to sadness, depression is:

- More intense, lasts more than 2 weeks
- Interferes with day-to-day activities
- Not a normal part of living with HIV
- Can cause serious health problems



Some Symptoms of Depression

- Changes in appetite, weight, sleeping patterns
- Aches or pains for no clear reason
- Feeling sadness, guilt, hopelessness, worthlessness
- Irritability
- Lack of pleasure in activities that usually interest you
- Low sex drive
- Difficulty making decisions/ concentrating
- Fatigue or loss of energy

- Skipping/not going to work
- Poor grooming, personal hygiene
- Being critical/down on yourself
- Not talking to/going out with friends
- Not joining usual social activities or hobbies
- Crying or feeling like crying more than normal
- Using more alcohol or other recreational drugs



Depression in Women Living with HIV

WLHIV more likely to suffer from depression

- Getting HIV diagnosis is life-changing
 - Overwhelmed, helpless, unable to cope
 - Afraid for future health, disclosing HIV status
 - Stigma experienced by WLHIV
 - Large life stressors



Depression Can Cause Serious Problems

WLHIV who are living with depression:

- Seek care less often
- Have more trouble adhering to their medication regimens
- Have increased disease progression

It is important to get diagnosed and treated as quickly as possible to avoid serious problems



Treatment for Depression

- Psychotherapy
- Electroconvulsive therapy (ECT)
- Cognitive behavioral therapy
- Light therapy (Phototherapy)
- Family therapy
- Medication
- Exercise



Anxiety

- A normal reaction to stressful situations
 - Can become excessive
- Generalized Anxiety Disorder
- Other anxiety disorders
 - Panic attack
 - Obsessive-compulsive disorder



Emotional Signs of Anxiety

- Irrational or excessive fear and worry
- Feelings of apprehension or dread
- Trouble concentrating
- Feeling tense and jumpy
- Anticipating the worst
- Irritability
- Restlessness



Physical Signs of Anxiety

- Pounding heart
- Sweating
- Stomach upset or dizziness
- Shortness of breath
- Headaches
- Fatigue
- Insomnia



Dealing with Anxiety

- Deep breathing
- Journaling
- Exercise
- Counseling, talk to someone
- Coping strategies



Anxiety Therapy

- Cognitive therapy examines how negative thoughts, or cognitions, contribute to anxiety
- Behavior therapy examines how you behave and react in situations that trigger anxiety



Substance Use

 Substance: prescription drugs, over-the-counter medications, street drugs, alcohol, and tobacco

 Substance use: putting a substance in your body: drinking alcohol, snorting a line of cocaine, taking a prescription anti-anxiety pill, smoking a cigarette, etc.



Substance Use and Abuse

- Substance abuse: a pattern of substance use involving serious problems/negative consequences
- Dependence: what happens when the body gets used to a particular substance
- Addiction: substance abuse involving loss of control, continued use despite harmful consequences, and denial



Substance Use Effects on HIV

- Increased viral loads
- Lower CD4 counts
- Increased rates of medication resistance
- Reduced medication adherence
- Increased high-risk sexual behaviors
 - Increased risk of reinfection and other STIs



Post-Traumatic Stress Disorder (PTSD)

PTSD is a mental health disorder that includes 4 symptoms:

- 1. Re-living or re-experiencing the trauma
- 2. Avoiding or staying away from people, places, or activities
- 3. Feeling jittery, or irritable, or easily startled
- 4. Changes in mood and a sense of being detached from self or others



Post-Traumatic Stress Disorder (PTSD)

- 60% of U.S. adults have experienced an adverse life event (trauma) at least once
- Adverse life events (trauma) include:
 - Childhood violence
 - Loss of family/friends
 - HIV diagnosis
 - Intimate partner violence (IPV)
 - Sexual assault
 - Natural disaster



PTSD Treatment

- Cognitive behavioral therapy
- Exposure therapy
- Eye movement desensitization and reprocessing (EMDR)
- Medication
- Accelerated resolution therapy (ART)

Kip, K. E., Rosenzweig, L., Hernandez, D. F., Shuman, A., Sullivan, K. L., Long, C. J., ... & Sahebzamani, F. M. (2013). Randomized controlled trial of accelerated resolution therapy (ART) for symptoms of combat-related post-traumatic stress disorder (PTSD). *Military medicine*, *178*(12), 1298-1309.



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



Mental Health Care

Other treatment and help

- Psychotherapy
- Social support (i.e. family, friends)
- 12-Step programs
- Spiritual guidance
- Alternative therapies
- Combination



Poll Question



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



Other Treatment and Self-Care

- Meditation, massage, yoga, breathing, relaxation exercises can help with mental health, depression, stress
- Acupuncture and acupressure therapies may help reduce stress, improve mood
- Mindfulness techniques may help you get back in touch with what makes life worth living
- Good nutrition and physical activity are beneficial, no matter which treatments are chosen



Silos and HIV

- Treating patients in silos ignores the interaction of mental health, substance use, and HIV
- HIV, mental health, substance abuse, and other medical conditions interact and exacerbate each other
- Neglecting any of these conditions leads to decreased health outcomes and premature death



Integrated Care

Integrated care is defined as:

 The care a patient experiences as a result of a team of primary care and behavioral health clinicians, working together with patients and families, using a systematic and cost-effective approach to provide patient-centered care for a defined population [PLHIV]

Academy for Integrating Behavioral Health and Primary Care



From Treatment To Healing

The Promise of Trauma-informed Care

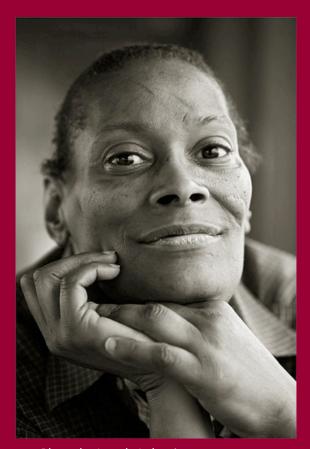


Photo by Lynnly Labovitz; used with artist and patient permission

Taking Care: Understanding and Addressing Mental Health among Women Living with HIV
A Webinar
The Well Project
Wednesday March 9, 2016

Edward Machtinger, MD
Professor of Medicine
Director, Women's HIV Program
University of California, Sa Francisco
Edward.machtinger@ucsf.edu





Objectives

- Understanding trauma
- Discovering partnerships
- Imagining primary care as healing



Photo by Lynnly Labovitz; used with artist and patient permission





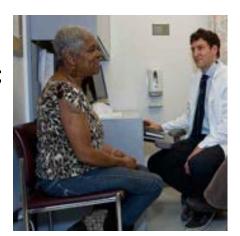
Overview of The thewellproject Women's HIV Program

One of the first programs in country for WLHIV Female-focused services provided in a "one-stop shop"

Primary Care	Gynecology	Obstetrics		
Pharmacy program	Social Work	Case Management		
Therapy/Psychiatry	Breakfast	Partner agencies in clinic		

Patients

- Mostly African American or Latina (20% White); 15% transgender women
- 15-71 years old
- Marginally housed, low income
- Medically and psycho-socially complex







Our Journey Towards thewellproject Understanding Trauma



Photo by Keith Sirchio; used with artist and patient permission





Recent Deaths at WHP

1. Rose *murder*

2. Amy *murder*

3. Patricia suicide

4. Regina suicide

5. Vela suicide

6. Iris addiction/overdose

7. Mary addiction/organ failure

8. Nadine *addiction/lung failure*

9. Lilly pancreatic cancer

10.Pebbles non-adherence



Photo by Lynnly Labovitz; used with artist and patient permission





Trauma

"... an event, series of events, or set of circumstances [e.g., physical, emotional and sexual abuse; neglect; loss; community violence, structural violence, war] that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being."





A Few More Important Definitions

Complex Trauma: repeated trauma, physically or emotionally (e.g., repeated childhood physical and/or sexual abuse, witnessing ongoing IPV, experiencing long-term IPV)

PTSD: includes 4 types of symptoms: 1) re-experiencing of the traumatic event(s); 2) avoidance of situations that remind you of the event; 3) negative changes in the way you think about yourself, other people or the world, and 4) feeling "keyed up"

Complex PTSD: Includes all of the symptoms of PTSD + trouble regulating and handling emotions and relationships, and feelings of low self-worth and powerlessness





Rates of Trauma and PTSD in WLHIV are Much Higher

Meta-analysis of all studies among U.S. WLHIV

Categories	Number of Studies	Pooled <i>n</i>	Prevalence (%)	95% Confidence Interval	Reference Prevalence
Intimate Partner Violence	8	2285	55.3	36.1 - 73.8	24.8
Childhood Sexual Abuse	7	3013	39.3	33.9 - 44.8	16.2
Childhood Physical Abuse	6	1582	42.7	31.5 - 54.4	22.9
Childhood Abuse Unspecified	2	232	58.2	36.0 - 78.8	31.9
Lifetime Sexual Abuse	8	1182	61.1	47.7 - 73.8	12.0
Lifetime Abuse Unspecified	6	1065	71.6	61.0 - 81.1	39.0
Recent PTSD	6	499	30.0	18.8 - 42.7	5.2

29 studies met our inclusion criteria, resulting in a sample of 5,930 individuals.

Machtinger EL, Wilson T, Haberer J, Weiss, D. **Psychological trauma in HIV- positive women: a meta-analysis.** AIDS and Behavior. January 17, 2012





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*National Comorbidity Survey Replication, 2005

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Impact of Trauma on the Lives of People with HIV

Recent or lifetime trauma associated with:

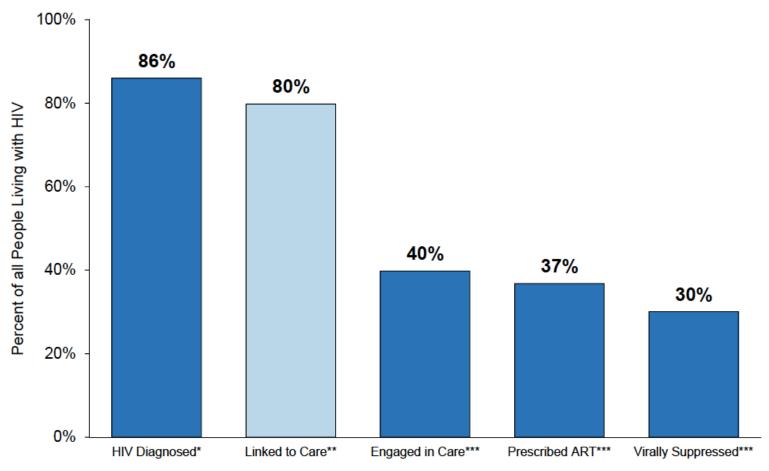
- HIV risk factors/HIV incidence
- 4x the rate of HIV medication failure
- Faster disease progression
- More hospitalizations
- Almost twice the rate of death

Pence BW, et al. J Acquir Immune Defic Syndr. 2012 Apr 1;59(4):409-16*
Mugavero, MJ, et al. AIDS Patient Care STDS 2007 Sep;21(9):681-90.] *
Leserman, J, et al. Psychol Med Aug;32(6):1059-73.*
Maman S, Campbell J, Sweat MD, Gielen AC. Soc Sci Med. 2000;50:459–78.*
Jewkes RK, Dunkle K, Nduna M, et al. Lancet. 2010;376:41–8.
Weber, K., et al. International AIDS Conference 2012.
Machtinger EL, et al. Aids and Behavior. 2012





The HIV Care Continuum in the U.S., 2011



Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—
United States and 6 dependent areas—2012. HIV Surveillance Supplemental Report 2014;19(No. 3).

http://www.cdc.gov/hiv/library/reports/surveillance/. Published November 2014. Accessed January 16, 2014



Poll Question



The Power of Partnerships



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Power of Partnerships Part 1

- Peer support/political advocacy: Positive Women's Network – USA
 - + Guidance from people with lived experience
 - + Introduction and mentorship about the power of political action
 - Access for patients to sisterhood and leadership training





Naina Khanna, Executive Director, Positive Women's Network - USA





What is Trauma-Informed Care?

- Expert meeting
- Follow-up consultations
- Literature review
- Also referred to as "TIPC" – Trauma Informed Primary Care









What are Trauma-Informed Care Values?

- 1. Safety
- 2. Trustworthiness and transparency
- 3. Peer support
- 4. Collaboration instead of hierarchy
- 5. Empowerment, voice, and choice
- 6. Cultural, historical, and gender understanding



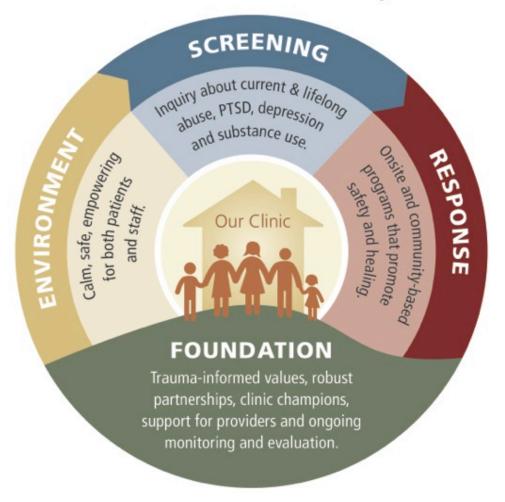


What is Trauma-Informed Care?

A program, organization, or system that is trauma-informed realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization.



Trauma-informed Primary Care



Machtinger, E. L., Cuca, Y. P., Khanna, N., Dawson Rose, C., & Kimberg, L. S. (2015). From Treatment to Healing: The Promise of Trauma-Informed Primary Care. Women's Health Issues, 25(3).





Healing from Lifelong Trauma: Improving Damaged Connections

Improving Connections with Others

1. Trauma-specific individual and group therapy

Trauma-specific cognitive behavioral therapy (CBT); motivational interviewing; prolonged exposure therapy for PTSD; evidence-based multimodal programs including STAIR Narrative Therapy and Seeking Safety for co-occurring substance abuse and PTSD.

2. Peer-led empowerment, support and leadership training.

Examples: Leadership training by the Positive Women's Network-USA; expressive therapy with theater by the Medea Project: Theater for Incarcerated Women

Improving Physiological Connections

3. Trauma specific psychiatry and physiologic techniques

Medications can help with symptoms of PTSD such as hyper-arousal; Techniques such as Eye Movement Desensitization and Reprocessing (EMDR)

Improving Connections with Our Bodies

4. Body/Mindfulness-Focused Healing

Mindfulness-based Stress Reduction; yoga

The National Center for PTSD. http://www.ptsd.va.gov/. Last accessed February 4, 2016. Van der Kolk, Bessel A. The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma. Penguin group. New York, 2014.

Cloitre, M., et al., The ISTSS Expert Consensus Treatment Guidelines for Complex PTSD in Adults 2012,



Now Specifically Recognized in WLHIV



Recommended Action 2.2:

"Develop, implement, and evaluate models that integrate traumainformed care into services for women living with HIV".







Interagency Federal Working Group





The Power of Partnerships (2)

Peer Support: Sisterhood and Storytelling:

The Medea Project

- Provides healing for patients that is not possible in clinic
- Incredibly fulfilling relationships with Rhodessa Jones and with my patients who participated
- = Leaned that it's possible to heal from lifelong trauma but requires hard work and a deliberate method



Rhodessa Jones, Founder and Director, The Medea Project: Theater for Incarcerated Women





An Expressive Therapy Disclosure Intervention for WLHIV

Sisterhood

The formation of deep, honest, and supportive relationships among group members

Catharsis

Freedom from the burden of secrecy about HIV, childhood and adult traumas, and other stigmatizing experiences

Self-acceptance

Reframing the understanding of what it means to be a woman living with HIV, normalizing life with HIV and embracing a stronger and more positive self-identity

Safer and healthier relationships *

Developing safe, honest, authentic, and fulfilling relationships

Gaining a voice

Gaining a sense of purpose and accomplishment as an educator and activist and the skills and confidence to change the social norms that create trauma, stigma, isolation, and HIV risk



* 4 of 8 initial participants reported leaving or avoiding abusive relationships as a result of the intervention

Table 1. Five Impact themes



What Can You Do Tomorrow?

First know this: the model is aspirational. Very few clinics have these services in place. These is an increasing awareness that trauma is important and that trauma is treatable. In the meantime, you can:

- 1. Stop and think about the connection between trauma your own health.
- 2. Realize that a lot about who we are and what we do are because of things that happened to us.
- 3. Get help in any way that is available and feels comfortable to you.
- 4. One key is avoiding isolation: find peer-groups, substance use groups, therapists, friends, who you trust...anything but staying alone.
- 5. If you feel comfortable, ask you providers if they have services to help overcome trauma and PTSD.
- 6. If you are experiencing intimate partner violence, there is a national DV hotline that you can always call for confidential advice: 1-800-799-SAFE (7233)



Photo by Keith Sirchio; used with artist and patient permission





Poll Question



Conclusions

- People can heal; deep cycles of violence can be broken; ACEs in children can be reduced, and entire communities can benefit by addressing trauma in adults
- The problems faced by many WLHIV can be more effectively treated if primary care becomes genuinely trauma-informed
- TIPC holds the potential to transform the care-giving experience for providers, creating environments and supporting them to be healers



Photo by Lynnly Labovitz; used with artist and patient permission





Thank You for Participating!







The Well Project 2014 Survey Findings

- In order to maximize effectiveness/strengthen impact of our programs, we need to understand how they are experienced, integrated and applied
- We aim to provide accurate information, online support, tools to build advocacy and leadership
 - To improve health outcomes, quality of life of WLHIV, their allies, providers, friends, family—as well as those seeking information on prevention



The Well Project 2014 Survey Findings

"I personally like the way the information here is presented in a positive, caring tone. I have been reluctant through my 22 years with HIV to do much research online because it always scared and depressed me so much. This site is truly a lifeline for women who have few places to just talk about how difficult and unique this disease can be."

#top3

Top three reasons participants use The Well Project's resources:

Increase knowledge of HIV disease and its treatments:

41%

Connect with other women living with HIV:

20%

Learn to advocate and obtain skills to help themselves & others:

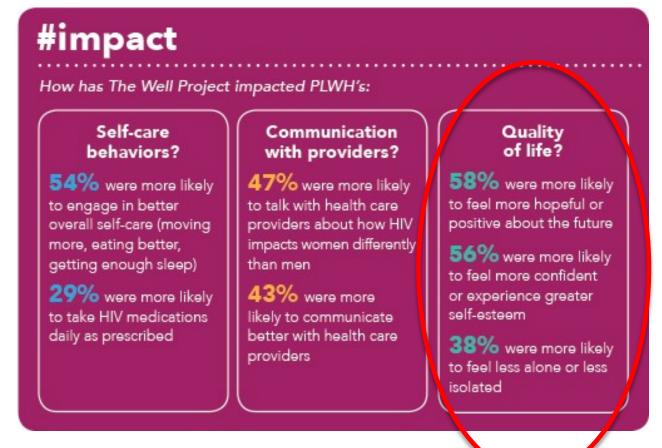
17%

The Well Project website user

www.thewellproject.org



The Well Project 2014 Survey Findings



To view the full survey report, please go to our website, or <u>dick here</u>.



The Well Project 2016 Survey Findings

- Please note, The Well Project 2016 User Survey will be launching very soon!
 - Allows us to collect feedback from users of our website, A Girl Like Me, Una Chica Como Yo, and Voices from our Allies, webinars and treatment advocacy training
 - Everyone completing 2016 Survey will be entered into raffle to receive a \$20 Amazon gift card,
 - There will be at least 20 winners!
 - Help us improve our programs/demonstrate program impact

Securing the Future of Women-Centered Care

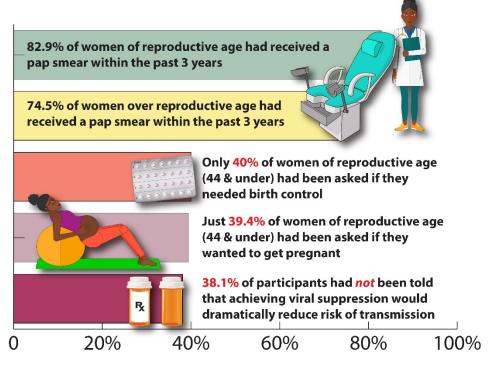
Findings from a Community-Based Participatory Research
Project

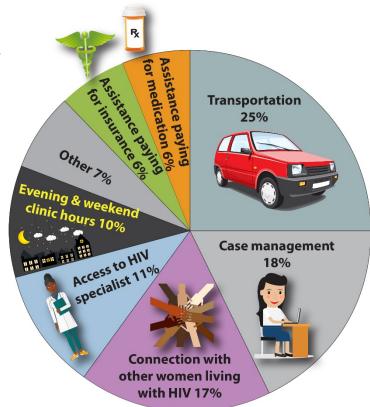
National Women and Girls HIV/AIDS Awareness Day March 10th, 2016 1pm EST

Register & download executive summary of our exclusive report at: www.pwn-usa.org/securing-the-future-of-women-centered-care



What one thing would improve your ability to stay in care?





Assessing gaps in sexual & reproductive care

Join Positive Women's Network - USA, Greater Than AIDS & The Well Project



Thurs., March 10 3 PM EST

for a Twitter Chat in honor of



thewellproject



#NWGHAAD

#PWNspeaks

@uspwn @greaterthanAIDS @thewellproject



Resources

- To learn more, and for links to articles featuring more details, please read the full fact sheets:
 - Depression, Women, and HIV
 - Stress Management
 - Violence Against Women and HIV
 - Trauma and HIV
- A Girl Like Me blogs
 - More than 40 blogs written and published on A Girl Like
 Me touching upon trauma and violence



Resources

- Resources on the Intersection of Women, HIV,
 Violence and Trauma
 - Scientific and policy data, publications, survivors' personal stories, and community-based fact sheets
- 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



Additional Resources

- Women's HIV Program at UCSF
- Positive Women's Network USA

In the U.S.

- call 1-800-SUICIDE (1-800-784-2433) or
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