Impact of Lifetime Trauma, Abuse and Violence on Women Living with HIV (WLHIV)

Building a Trauma-Informed Nation
September 30, 2015
Washington, DC
#pwnspeaks
Women’s lives and experiences are intersectional
## Table 1. The Ecological Model

<table>
<thead>
<tr>
<th>Individual</th>
<th>Relationship</th>
<th>Community</th>
<th>Societal</th>
</tr>
</thead>
</table>

**Influences:**
- Attitudes and beliefs that support sexual violence;
- Impulsive and antisocial behavior;
- Childhood history of sexual abuse or witnessing violence;
- Alcohol and drug use

**Influences:**
- Association with sexually aggressive peers;
- Family environment that is emotionally unsupportive, physically violent or strongly patriarchal

**Influences:**
- General tolerance of sexual assault;
- Lack of support from police or judicial system;
- Poverty; lack of employment opportunities;
- Weak community sanctions against perpetrators

**Influences:**
- Inequalities based on gender, race, and sexual orientation, religious or cultural beliefs, economic and social policies

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Trauma experiences

Structural

Community

Historical

Interpersonal
POST TRAUMATIC SLAVE SYNDROME

A new Play by Kamal Sinclair Steele

"Convincing! Intriguing! Potent! Exhilarating!" - The New York Times

Joey DeGruy
Structural Violence
“But I also know that this woman actually has control over what ultimately is a life or death decision with the stroke of her pen. And clearly she is in a bad mood... What I have is a very expensive medical condition and no way to pay for it... it is that simple. I need help. We as women living with HIV are driven into poverty and held there, and we are drowning.”
Laws and policies criminalizing HIV exposure and mandating disclosure may increase potential for coercion and abuse, and can make it harder for WLHIV to leave violent, unhealthy or abusive relationships.
“I dated a guy who knew my HIV status, but when his family found out, he acted like he didn’t know and pressed charges [on] me. I almost lost everything. It has taken me a long time to disclose to anyone since.”

“I have felt ashamed of my body and worthless. My ex would tell me that nobody else would ever want me, because of my HIV.”

“I was in an abusive relationship for 4 years. When I attempted to leave, he threatened to come after me under HIV criminalization laws because I didn’t disclose to him when we first got involved. He also threatened to have my kids taken away.”

“My partner didn’t want anyone else to know about my HIV status. He didn’t even allow me to see my HIV doctor, because he was afraid of people finding out. So I basically had no support and was not getting care.”
WLHIV face internalized stigma

“There is a big black X from head to toe. I am diseased and unworthy of feeling good about my body again.”

“I feel dirty and ashamed.”

“It caused me to lose [sic] all hope as a woman where I felt ugly and that I had to settle for whatever man wanted to date me.”

“I have had a guy tell me that I should have told him before kissing him that I was positive. He was convinced HIV is transmitted through saliva. He even threw in that he could prosecute me for murder. Apparently there is grave misunderstanding about disclosure laws amongst the general public.”

... these and other factors (housing instability, economic insecurity) may complicate leaving an abusive relationship
In a survey conducted in 2013 and repeated in 2015, nearly half of women living with HIV had never been told by a provider that viral suppression was an effective HIV prevention strategy.
Motherhood & partnership

-Increasingly “parenthood”

-For many WLHIV, motherhood may be the only socially valued identity available to them (Barnes, et al 2009)

- Critical for providers to understand motivation, including cultural factors related to conception, sexuality, and relationships for PLHIV
Community violence disproportionately impacts transgender women of color

- Almost three-quarters of LGBTQ homicide victims in 2013 were transgender women. 67% were transgender women of color
- Transgender women were 6 times more likely to experience physical violence when interacting with the police than other LGBTQ survivors of violence
- Transgender people of color were 1.8 times more likely to experience violence in shelters than other LGBTQ survivors of violence

- National Coalition of Anti-Violence Programs (NCAVP) Annual Report, 2014
Rates of trauma and PTSD in WLHIV are much higher than the general population

Meta-analysis of all studies among US WLHIV

<table>
<thead>
<tr>
<th>Categories</th>
<th>Number of Studies</th>
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<th>Prevalence (%)</th>
<th>95% Confidence Interval</th>
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<tbody>
<tr>
<td>Intimate Partner Violence</td>
<td>8</td>
<td>2285</td>
<td>55.3</td>
<td>36.1 - 73.8</td>
<td>24.8</td>
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<td>33.9 - 44.8</td>
<td>16.2</td>
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<tr>
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<td>1582</td>
<td>42.7</td>
<td>31.5 - 54.4</td>
<td>22.9</td>
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<tr>
<td>Childhood Abuse Unspecified</td>
<td>2</td>
<td>232</td>
<td>58.2</td>
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<td>1065</td>
<td>71.6</td>
<td>61.0 - 81.1</td>
<td>39.0</td>
</tr>
<tr>
<td>Recent PTSD</td>
<td>6</td>
<td>499</td>
<td>30.0</td>
<td>18.8 - 42.7</td>
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29 studies met our inclusion criteria, resulting in a sample of 5,930 individuals.

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Table 2  
Heath-related Characteristics

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<thead>
<tr>
<th>Description</th>
<th>Sample size</th>
<th>Number (percent) of participants with each characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health</td>
<td>111</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td>53 (47.7%)</td>
</tr>
<tr>
<td>Bipolar</td>
<td></td>
<td>8 (7.2%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td>9 (8.1%)</td>
</tr>
<tr>
<td>Schizophrenia/psychosis</td>
<td></td>
<td>3 (2.7%)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>4 (3.6%)</td>
</tr>
<tr>
<td>Low self efficacy</td>
<td>109</td>
<td>18 (16.5%)</td>
</tr>
<tr>
<td>Trauma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abused, threatened, and/or victim of</td>
<td>110</td>
<td>19 (17.3%)</td>
</tr>
<tr>
<td>violence in the past 30 days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abused, threatened, and/or victim of</td>
<td>110</td>
<td>79 (71.8%)</td>
</tr>
<tr>
<td>violence in lifetime</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coerced to have sex in the past 30 days</td>
<td>110</td>
<td>9 (8.2%)</td>
</tr>
<tr>
<td>Coerced to have sex in lifetime</td>
<td>110</td>
<td>71 (64.5%)</td>
</tr>
<tr>
<td>Median CD4 count (cells/µl) at survey</td>
<td>93</td>
<td>387 (range 0 – 1363)</td>
</tr>
<tr>
<td>Viral load (copies/ml) at survey</td>
<td>90</td>
<td></td>
</tr>
<tr>
<td>&lt;75</td>
<td></td>
<td>33 (36.7%)</td>
</tr>
<tr>
<td>75-9,999</td>
<td></td>
<td>30 (33.3%)</td>
</tr>
<tr>
<td>10,000+</td>
<td></td>
<td>27 (30.0%)</td>
</tr>
<tr>
<td>Antiretroviral therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>On ART*</td>
<td>112</td>
<td>63 (56.2%)</td>
</tr>
<tr>
<td>On ART and detectable viral load</td>
<td>90</td>
<td>17 (18.9%)</td>
</tr>
<tr>
<td>Self-reported adherence &lt; 90% by VAS**</td>
<td>63</td>
<td>15 (23.8%)</td>
</tr>
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*ART = highly active antiretroviral therapy; **VAS = visual analog scale
WHP establishes a formal partnership with Positive Women's Network-USA (PWN-USA), the largest membership and advocacy group of HIV-positive women in the United States.

WHP and Positive Women's Network-USA (PWN-USA) have established a formal partnership to realize a new model of trauma informed primary care for US women living with HIV. This partnership is exciting for many reasons because PWN-USA has wide ranging influence, insight and credibility that will ensure that the new model of primary care is truly patient-centered and successful. PWN-USA is among the most effective advocacy organizations in the country. Its work is truly inspired, effective, and grounded in the inherent wisdom of its members.
The HIV Care Continuum in the United States, 2011.

The HIV Care Continuum in the United States, 2011.

IPV/recent trauma

- 3x more likely to wait >90 days*
- 2x rate of lost-to follow
- 2X missed gyn appts
- ½ as likely on ART*
- 2-3x non-adherence*
- 2x non-adherence*
- >2x rate of failure
- >4x rate of failure

* Includes both men and women
† Includes “Stressful Life Events

Siemieniuk RA, et al. AIDS Patient Care STDs. 2010*
Kalokhe, A.S., et al. AIDS Patient Care and STDs. 2012*
Keshawary, L. et al. AIDS PATIENT CARE and STDs. 2008*

Mugavero M, et al. Barriers to antiretroviral adherence: the importance of depression, abuse, and other traumatic events. AIDS patient care and STDs. 2006 Jun;20*


1.7 greater odds of not being on HAART when medically indicated

Significant association of numbers of lifetime traumas and ART nonadherence: OR 1.14, (95% CI 1.05, 1.25)] ●*

Significant association of numbers of lifetime traumas and ART nonadherence: 1.13 (95% CI 1.03, 1.24) ●*

* Includes both men and women
● bivariate data; association also significant on multivariate analysis
Impact of trauma on other HIV-specific outcomes

Recent or lifetime trauma associated with:

• **HIV risk factors/HIV incidence**

• **Faster disease progression**

• **More hospitalizations**

• **Almost twice the rate of death**

* Study included both men and women
Predictors of Mortality in WLHIV over time

‘She Killed Me, So I Killed Her’: Man Allegedly Stabs Girlfriend to Death after She Tells Him She’s HIV Positive

Cicely Bolden's children discovered their mother's body after she was allegedly killed by a boyfriend, angered after she told him she had the virus.

By Madison Gray @madisonjgray | Sept. 12, 2012 | 32 Comments

Dallas Woman Killed By Boyfriend For Admitting To Having HIV [VIDEO]

California Man Convicted For Murder Of Woman He Thought Gave Him HIV

We’re not saying he was right, but we understand. Word to Chris Rock...

Man arrested in San Antonio suspected of killing woman because she had HIV

BY ALIA MALIK, SAN ANTONIO EXPRESS-NEWS : JUNE 17, 2014 : Updated: June 17, 2014
Federal Response

The White House
Office of the Press Secretary

For Immediate Release
March 30, 2012


MEMORANDUM FOR THE HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

Federal Interagency Workgroup: Next Steps (Oct 2014)

• Increased screening for both HIV and IPV in primary care clinics

• Scale up effective interventions to help HIV-negative and HIV-positive women who have experienced violence

• Expand outreach and prevention in communities with high rates of HIV, including economic empowerment
"Social ideals of equality cannot be pursued in relations that promote inequality. The way we do things is not just a means to an end, but an end in itself."

Positive Women's Network Releases New Model for Trauma Awareness

Tuesday May 26, 2015

Positive Women's Network - USA, a national membership body of women with HIV, is proud to announce the release of a new model for bringing trauma awareness and healing into primary healthcare settings.

The conceptual framework, developed in partnership with University of California - San Francisco (UCSF) clinician-researchers, provides a practical guide to help providers incorporate trauma-informed care into clinical practice.

"Trauma-informed care is the missing ingredient to engage women with HIV in care successfully and to ensure good health outcomes," said Naina Khanna, Executive Director of PWN-USA, who co-authored the paper presenting the new model.
Trauma-informed Primary Care

SCREENING
Inquiry about current & lifelong abuse, PTSD, depression and substance use.

ENVIRONMENT
Calm, safe, empowering for both patients and staff.

FOUNDATION
Trauma-informed values, robust partnerships, clinic champions, support for providers and ongoing monitoring and evaluation.

RESPONSE
Onsite and community-based programs that promote safety and healing.
Retention in Care and Viral Load Suppression by Gender – RSR 2012 data

- Male: Retention in Care 82.1%, Viral Suppression 75.9%
- Female: Retention in Care 83.5%, Viral Suppression 73.1%
- Transgender: Retention in Care 80.4%, Viral Suppression 68.9%
- All: Retention in Care 82.5%, Viral Suppression 75.0%
“Interestingly, while women had higher levels of retention [in the Ryan White program] than men, their viral suppression was lower, suggesting that there may be a significant gap in ART use and/or adherence.” – Doshi et al


Clinical Infectious Diseases Advance Access published September 15, 2014
National Day of Action to End Violence against Women Living with HIV
October 23, 2015
Everywhere

Sisterhood, solidarity, action... #endvawhiv #pwnspeaks
Thank you!
Thank you

Naina Khanna
Positive Women’s Network - USA
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510.681.1169
@nainadevi
@uspwn
www.pwn-usa.org

In memory of
Cicely Bolden
Elisha Henson