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

Addressing the Intersection of Trauma, Violence & HIV
July 20, 2015
The California Endowment
Los Angeles, CA
Trauma experiences

Structural

Community

Historical

Interpersonal
Social – Ecological Model for Understanding Sexual Violence

Women’s lives and experiences are intersectional
Historical Trauma

“Cumulative emotional and psychological wounding, over the lifespan and across generations, emanating from massive group trauma experiences”

- Brave Heart, 2011

Multigenerational trauma experienced by a specific cultural group

- Cumulative & collective
Manifestations of Historical Trauma

• **Historical Unresolved Grief**
  – Grief as the result of historical trauma that has not been adequately expressed, acknowledged, or otherwise resolved.

• **Disenfranchised Grief**
  – Loss cannot be voiced publicly or that loss is not openly acknowledged by the public.

• **Internalized Oppression**
  – As the result of historical trauma, traumatized people may begin to internalize the views of the oppressor
POST TRAUMATIC SLAVE SYNDROME

By Joy DeGruy

A new Play by Kamal Sinclair Steele

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

Read Review

Baha'i Center Theater
Wealth Gap & Women of Color

✓ Single Black and Hispanic women have a median wealth of $100 and $120 respectively; median for a single white woman is $41,500.

✓ Nearly HALF of all single Black and Hispanic women have zero or negative wealth (debts exceed assets)

✓ Social Security is the only source of retirement income for more than 25% of Black women
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.**
HIV CRIMINALIZATION
Are You At Risk?

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.

"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.

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."
WLHIV are uniquely vulnerable to violence, coercion, and abuse

“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 loose [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
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
Motherhood is a socially valued identity

- 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
"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."

The effects of trauma/violence do not end with HIV diagnosis and the relationship between them is complex.

This is not an old problem that’s been solved.
PWN-USA conducted a survey of 179 women in 2013: 69% of respondents had been sexually assaulted, 34% had been sexually assaulted for the first time before the age of 13, and 72% identified as survivors of IPV/DV.

HIV diagnosis may trigger or augment physical violence
One large study reported that over 1 in 5 WLHIV reported physical harm since HIV diagnosis; with over half these events attributed to being HIV-positive.
Individual trauma results from:

- An event, series of events, or a set of circumstances

- That are experienced by an individual as physically and/or emotionally harmful or threatening and

- Has lasting adverse effects on the individual’s functioning and mental, physical, social, emotional and/or spiritual wellbeing.

SAMHSA, 2013
Effects of Trauma

Trauma can impact a woman’s:

– Identity
– Sense of purpose
– Relationships
– Expectations of self and others
– Emotional regulation
– Worldview
– Health outcomes
Examples of Potentially Traumatic Life Experiences

• Physical, sexual, or emotional abuse
• Childhood neglect (basic needs are not met for food or shelter)
• Death of a parent
• Violent loss of a loved one (suicide/homicide)
• Rape
• Children living in homes with drug addiction, alcoholism, incarceration, and/or violence
• Serious medical conditions
• Combat/war
What is PTSD?

- Post Traumatic Stress Disorder (PTSD) is a mental health diagnosis in which people experience:
  - **Re-experiencing** of traumatic event(s) through intrusive memories, nightmares, flashbacks, and reactivity to trauma-related cues
  - **Avoidance**
    - Persistent avoidance of reminders of the trauma
    - Avoiding people, places, activities associated with the trauma
  - **Negative changes in mood or cognition**
    - Difficulty experiencing full range of emotions, persistent negative feelings such as fear, horror, guilt or shame, loss of interest in activities, detached from others, sense of foreshortened future
  - **Negative changes in arousal**
    - Sleep trouble, increased irritability and anger, difficulty concentrating, hypervigilance, exaggerated startle response, self-destructive or reckless behavior

American Psychiatric Association, 2013
Complex PTSD

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

**CPTSD**: includes “the core symptoms of PTSD (re-experiencing of the traumatic event(s), avoidance/numbing, negative changes in mood or cognition and hyper-arousal) in conjunction with disturbances in a range of self regulatory capacities”

Symptoms include: trouble regulating and handling emotions and relationships, and feelings low self-worth and low self-efficacy.

Rates of trauma and PTSD in WLHIV are much higher

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<thead>
<tr>
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<th>Prevalence (%)</th>
<th>95% Confidence Interval</th>
<th>Reference Prevalence</th>
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<tbody>
<tr>
<td>Intimate Partner Violence</td>
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<td>61.0 - 81.1</td>
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<td>499</td>
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29 studies met our inclusion criteria, resulting in a sample of 5,930 individuals.

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Machtinter EL, et al. Recent trauma is associated with antiretroviral failure and transmission risk behavior among HIV-positive women and female-identified transgenders. AIDS and Behavior. March 12, 2012

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<tr>
<th>Description</th>
<th>Sample size</th>
<th>Number (percent) of participants with each characteristic</th>
</tr>
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<tbody>
<tr>
<td>Mental health</td>
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<td></td>
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<tr>
<td>Depression</td>
<td>111</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>
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<td></td>
</tr>
<tr>
<td>Coerced to have sex in the past 30</td>
<td>110</td>
<td>9 (8.2%)</td>
</tr>
<tr>
<td>days</td>
<td></td>
<td></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>
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<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>
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*ART = highly active antiretroviral therapy; **VAS = visual analog scale
The HIV Care Continuum in the United States, 2011.

- HIV Diagnosed*: 86%
- Linked to Care**: 80%
- Engaged in Care***: 40%
- Prescribed ART***: 37%
- Virally Suppressed***: 30%

The HIV Care Continuum in the United States, 2011.

IPV/recent trauma

86% 3x more likely to wait >90 days*

80%

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

Percent of all People Living with HIV

HIV Diagnosed*  Linked to Care** Engaged in Care*** Prescribed ART*** Virally Suppressed***

40% 37% 30%

* 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*
Lesserman, J. 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*


Includes both men and women

+Bivariate data; association also significant on multivariate analysis
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%
Viral Load Suppression and Retention in Care by Race/Ethnicity for Women, 2012

Retained in care: had at least 1 OAMC visit before September 1, 2012, of the measurement year and had at least 2 visits 90 days or more apart

Viral suppression: had at least one OAMC visit, at least one viral load count, and last viral load test <200
“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
Impact of trauma on other HIV-specific outcomes

Recent or lifetime trauma associated with:

- **HIV risk factors/HIV incidence**
  
  

- **Faster disease progression**
  
  
  Mugavero, MJ, et al. Predictors of AIDS-related morbidity and mortality in a southern U.S. Cohort. AIDS Patient Care STDS 2007 Sep;21(9):681-90.] *  
  

- **More hospitalizations**
  

- **Almost twice the rate of death**
  

* Study included both men and women
**The ACE Study**

- 17,000 patients completed surveys about 10 categories of childhood abuse, neglect and family dysfunction.

- Compared answers to an array of current health behaviors and conditions.

- **Conclusion:** ACEs are common; and are strong predictors of later health risks and disease.

---

**Adult Trauma & PTSD ➔ Poor health**

**Associated with IPV:**
*(partial list)*
- Cardiovascular disease
- Gastrointestinal disorders
- Musculoskeletal disease
- High-risk sexual activities
- Chronic pain
- Suicide attempts
- PTSD
- Inadequate social support
- Depression
- Substance abuse
- Homelessness

**Associated with PTSD:**
*(partial list)*
- Cardiovascular disease
- Gastrointestinal disorders
- Musculoskeletal disease
- High-risk sexual activities
- Chronic pain
- Suicide attempts
- Risk of perpetration of violence
- Inadequate social support
- Depression
- Substance abuse
- Homelessness


Towards an Anti-Oppressive Framework in HIV Care, Treatment and Prevention
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.
‘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
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

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In memory of
Cicely Bolden
Elisha Henson