

***UNSPOKEN:
Sexuality, Romance and
Reproductive Freedom
for US Women Living with HIV***

Positive Women's Network – USA

May 5, 2014

www.pwn-usa.org



Overview

- Welcome
- Background
- Policy Scan – Key Points
- Literature Review – Key Points
- Survey Methodology & Findings
- Q & A



Background

Responsibilities of core team members:

- Defined research questions
- Conducted policy scan & lit review
- Led survey design & analysis
- Produced final document



Context

- ✧ HIV no longer a death sentence
- ✧ Severe racial and socioeconomic disparities persist in HIV epidemic & in health outcomes
- ✧ Vertical transmission risk has been greatly reduced & WLHIV not perceived as major sources of sexual transmission

Sexuality, reproductive rights, and intimate partnership choices of WLHIV have public health implications and are mediated by policy and culture ... most importantly, they are human rights issues



Sexual & Reproductive Health & Rights

“A state of complete physical, mental and social well-being that implies people are able to have a **satisfying and safe sex life** and that they have the **capability to reproduce and the freedom to decide if, when and how often to do so**. Implicit in this last condition are the **rights of men and women to be informed** and to have **access** to safe, effective, affordable and acceptable methods of **family planning of their choice**, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant. **[R]eproductive health... also includes sexual health, the purpose of which is the enhancement of life and personal relations, and not merely counseling and care related to reproduction and sexually transmitted diseases**. Reproductive rights... rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. It also includes their **right to make decisions concerning reproduction free of discrimination, coercion, and violence.**”

- UN Population Fund, from Cairo Int'l Conf on Pop & Dev't, 1994



Intersectionality

- feminist sociological theory
- method of studying relationships between multiple systems of oppression or discrimination

Intersectionality seeks to examine how various biological, social and cultural categories such as gender, race, class, sexual orientation, and other axes of identity interact on multiple and often simultaneous levels, contributing to systematic injustice and social inequality.

- Crenshaw (1989), McCall (2005), Berger (1999, 2009)



Intersectionality: example

In one study of 85 people living with HIV with a history of substance use in the Bronx, NY, researchers found that participants who internalized HIV stigma experienced greater depressive symptoms *only if they also internalized substance use stigma.*

Intersectionality of internalized HIV stigma and internalized substance use stigma: Implications for depressive symptoms. Earnshaw VA et al. *J. Health Psychol* 2013
Oct 29



Understanding the Policy & Legal Environment



Federal Laws & Policies

State Laws & Policies

Human Rights

International Laws & Policies

Other laws & policies
(institutional,
municipal, county, etc)



Federal Policies

- **National HIV/AIDS Strategy (2010)**

- Align HIV-related laws & policies with science and evidence
- Addressed HIV criminalization
- Failed to meaningfully address integration of SRH/HIV
- Neglected to mention SRHR of PLHIV

- **Ryan White Program**

- Purchase of contraceptives, access to family planning services

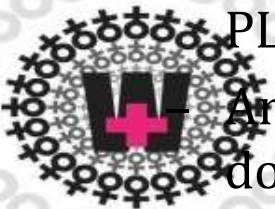
- **HIV Care Continuum Initiative (July 2013)**

- CDC guidelines for ARV treatment

- **HIV Organ Policy Equity Act (Nov 2013)**

- Lifts ban on research into HIV-positive organ transplants
- Permits donated HIV organs to be used for transplantation in PLHIV

– Amends federal law regarding HIV transmission to clarify that such donations are not barred





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Addressing the Intersection of HIV/AIDS, Violence against Women and Girls, and Gender-Related Health Disparities

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Posted by Dr. Grant Colfax and Lynn Rosenthal on September 06, 2013 at 03:15 PM EST



Relevant Working Group report recommendations

Objective 2. Improve outcomes for women in HIV care by addressing violence and trauma

“Because IPV is prevalent among WLHIV, increasing IPV screening rates in this population may be especially important and require special focus within HIV-specific programs. Programs that provide trauma-informed care as part of HIV/AIDS care for women should be piloted and evaluated.”

– p.9

Recommended Action 2.1: Screen WLHIV for IPV and link them to appropriate care and services

Recommended Action 2.2: Develop, implement, and evaluate models that integrate trauma-informed care into services for women living with HIV.



Relevant Working Group report recommendations

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State Policies

- Disclosure forms
- Fertility treatment access, tissue donation
- Contraceptive access
- Abortion restrictions
- HIV Criminalization Laws
- Parenting, Adoption & Custody Issues



Key Takeaways

- International human rights conventions and treaties relating to SRHR are weakly reflected in US laws and policies.
- Policing of sexual behavior of PLHIV continues in the form of criminalization laws and disclosure requirements
- Laws and policies continue to perpetuate inaccurate perceptions of HIV transmission risk at the expense of abridging SRHR for PLHIV – eg. Limiting access to fertility services
- WLHIV who are incarcerated or otherwise in custody by the State are uniquely vulnerable to human rights violations



A Review of the Literature



Literature Review: Methodology

- Over 90 peer-reviewed articles, preference on articles published post-2002
- 6 databases
- Majority of sources consisted of published articles in the areas of: research studies, systematic reviews, journals, and intervention guides



Subtopics Explored

1. Body Image & Self-Esteem
2. Disclosure
3. Sexual and Emotional Satisfaction in Relationships
4. Reproductive Health & Gynecological Care
5. Contraceptive Choices
6. Fertility Desires, Intentions and Decisionmaking



Overview of Findings

1. Quality and diversity of literature was dependent on subtopics

2. Majority of research focused on:

- HIV prevention to partners and offspring
 - Condom frequency & disclosure
 - ART adherence
- Sexual health (defined narrowly as gynecology care, STIs, etc.)
- Fertility desires and intentions

3. Limited research available on:

- Self-perception and self-esteem, especially throughout various phases of life and diagnosis
- Body image
- Sexual and emotional relationship satisfaction



Presentation of Leading Issues

- Discussion of leading issues for the six areas will be presented in the following order:
 - **Leading Issues: Findings Available**
 - Leading Issues: Findings with Gaps
 - Leading Issues: Findings are Sparse



Leading Issues: Findings Available

Disclosure

- Disclosure complicates sexuality and intimacy for WLHIV
- Disclosure linked to stigma, rejection, intimate partner violence, retaliatory violence, and celibacy
- Pressure from providers to disclose to partners
- Providers are an important source of disclosure support



Leading Issues: Findings Available

Reproductive Health & Gynecological Care

- WLHIV are at elevated risk for cervical cancer
- Higher rates of single annual Pap smear
- Low rates of recommended second Pap smear
- Access to quality gynecological and reproductive healthcare linked to health insurance and coverage plans



Leading Issues: Findings Available

Fertility Desires and Intentions

- Increasing number of PLHIV in the United States are choosing to start or expand families
- Multiple factors aside from HIV influence attitudes and decisions towards fertility
- Childbirth, miscarriage and abortion were common events among reproductive-age women living with HIV as they were among reproductive-age women in general
- Limited data on reproductive decision-making and on natural conception



Leading Issues: Findings Available

Sexual and Emotional Satisfaction in Relationships

- WLHIV regardless of phase of disease progression continue to be sexually active
- Chronic illness linked to diminished sexual activity, lower self esteem, diminished intimacy satisfaction



Key Takeaways #1

HIV--positive women use isolation as a coping method to protect themselves from rejection.

- This finding may have profound implications for overcoming gaps in linkage to care and treatment adherence among women living with HIV.
- Furthermore, research needs to be conducted to determine how self-perception, body image and self-esteem & time of living with HIV impact disclosure.



Key Takeaways #2

- Research is needed to determine impact of cultural attitudes, policies and practices toward sexual activity and reproductive decision-making of WLHIV, including utilization of family planning and reproductive services



Key Takeaways #3

- Research is needed to assess the impact of trauma and violence on the utilization of gynecological services by women living with HIV.



Findings from a National Survey



Purpose

- Address gaps in the literature
- Centralize WLHIV's lived experiences in their own voices
- Begin to address questions that WLHIV want answered



Data Collected

- Demographics
- HIV Status & Engagement in Care
- Relationships, including IPV
- Body image perceptions & self-esteem
- Changes to sexual practices, including disclosure
- Sexual health & reproductive decisionmaking
- SRH services & healthcare
- Confidentiality



Methodology

- 70 questions
- Web-based & paper versions

Online: distributed through email, social media & word of mouth

Paper: Advisory group members conducted one on one and group sessions, in person & on phone to complete survey with WLHIV



Advisory Group

6 members in total, all women living with HIV

- Input on research questions
- Survey goal and design
- Pilot tested survey
- Recruitment & distribution
- Provided feedback on analysis



Survey Participants

- 179 completed survey: 74% online, 26% paper
- Age range: 22 to 65
 - Reproductive age (44 years or younger): 41% of online respondents; 43% of paper respondents
- Gender: 98% female, 2% transgender
- Sexual orientation: 80% (H), 9% (B), 5% (L), 4% (A)
- Race/ethnicity (self-report): 54% AA/Black, 30% Caucasian, 8% Hispanic, 4% African, 3.6% multiracial, 1% Asian



Immigration Status & Geography

- 89% US citizens by birth
- 25 US states represented
 - 47% urban, 19% suburban, 17% rural
 - 39% of respondents from Southern US (SC, TX, FL, GA, LA, TN, WV, VA, NC)



Socioeconomic Indicators

- Housing: 30% in subsidized housing
- Employment: Over half work or volunteer full-time or part time
- Annual income: 47% under \$20,000, 29% under \$10,000
- 52% of paper survey respondents had at least one child under the age of 18 years old in household. Many had multiple children



Engagement in Care

	Retained in Care	On ART	Suppressed VL
PLHIV CDC (2012)	37%	33%	25%
WLHIV CDC (2012)	41%	36%	26%
PWN-USA Sample* (2013)	96%	91%	80%

* Self report



Over half of women living with HIV in medical care have not been counseled about treatment as prevention.



Women Living with HIV are Sexually Active

- 80% talk to their partners about HIV transmission, STIs and barrier methods
- 68% are *more* selective about their sexual partners after diagnosis
- 60% always disclose HIV status before sex
- 62% of sexually active women reported that they always use barriers
- 42% have sex on a regular basis with one partner



Many are Partnered

- 59% describe themselves as being in relationship
- 64% of partners are HIV-negative
- 52% were very satisfied with relationship
 - Friendship is an important facilitating factor
- 45% were dissatisfied with relationship
 - Financial responsibility or dependency as debilitating factor



Body Image and Self Esteem

HIV diagnosis negatively impacts body image, self-esteem and engagement in sexual activity for many WLHIV

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

Negative body image and self esteem may be linked with social isolation and depression.

“I don't feel as pretty as I used to. I let myself gain weight to avoid being asked out”



Body Image and Self Esteem

Internalized stigma and the trauma of diagnosis are linked with social isolation and impact sexual and romantic relationships for women living with HIV.

“I don’t feel sexy at all, I don’t feel like any man could ever be physical with me without thinking about the virus.”

“I feel like that is what got me into this health issue”

“It's like there was a light switch that was turned off and has been hidden since my diagnosis that has left me believing that I don't have a right to have or really enjoy sex.”



Rates of Violence & Past Trauma are High

- 69% had been sexually assaulted
- 34% had been sexually assaulted before the age of 13
- 72% were survivors of intimate partner violence or domestic violence



Sexual & Reproductive Healthcare

- 83% of respondents had not visited a family planning clinic since diagnosis. Unclear whether this is correlated with age (pre or post menopausal) or surgical procedures which prohibit future pregnancies.
- 51% reported a provider had talked to them about sexual health
- WLHIV look to providers first for guidance on sexual health issues.



Takeaways

- WLHIV are sexually active
- Although many are engaged in care, they are not being informed of viral suppression as a prevention strategy.
- Provider discomfort with sexual behavior of WLHIV may present barriers to women receiving comprehensive treatment information, sexual health and reproductive counseling



Takeaways

- Sexual practices and behaviors of WLHIV change after diagnosis.
- Stigma significantly impacts body image, self-esteem, and perceptions of desirability as a romantic or sexual partner for WLHIV



Takeaways

- Additional research is needed on access to family planning options for WLHIV
- Further research is needed to study reproductive decision making of WLHIV in an era when risk of vertical transmission has been almost eliminated



Conclusions

Research and counseling on sexual activity of WLHIV should go beyond risk behavior and transmission to include:

- Nonjudgmental & affirming attitude towards WLHIV sexuality
- Understanding that sexual activity and intimacy are important quality of life issues for WLHIV
- Investigation of SRHR throughout the lifespan – from sexual debut to post-menopause

Reproductive decision-making and intimate partnership choice for WLHIV are complex and may be impacted by social and cultural factors, as well as by policies and practice



Questions?



Thank you

For more info and full report: www.pwn-usa.org

