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

Naina Khanna, Positive Women’s Network - USA
Woodrow Wilson Center Dialogue
January 13, 2014
www.pwn-usa.org
Diagnoses of HIV Infection and Population among Adult and Adolescent Females, by Race/Ethnicity 2011—United States

Diagnoses of HIV Infection
N=10,257

- 15% American Indian/Alaska Native
- 17% Asian
- <1% Black/African American
- 2% Multiple races
- 1% Native Hawaiian/Other Pacific Islander
- 1% Hispanic/Latino
- <1% White

Female Population
N = 132,402,857

- 66% White
- 15% Hispanic/Latino
- 12% Black/African American
- 5% Asian
- 1% Native Hawaiian/Other Pacific Islander
- 1% Multiple races

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting.

* Hispanics/Latinos can be of any race.
In U.S. Cities, HIV Linked More To Poverty Than Race

Can I Reach for the American Dream?
Posted on April 20, 2012 by pwnusa

Can I Reach for the American Dream?

by Sonia Rastogi

April 17th, 2012 was Tax Day as well as Equal Pay Day (read Teresa Sullivan’s Wage Gap blog), a day established to bring attention to the pay gap for women in the U.S. For many women living with HIV, Tax Day brings home the truth that regardless of a woman’s financial status, an HIV diagnosis is frequently a sentence to a lifetime of poverty.
“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.**”
Intersectionality

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

*Intersectionality* seeks to examine how various biological, social & 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)

**Intersectional stigma:** Encompasses interconnectedness of race, class and gender subordination (forms of oppression) with stigma Michele Tracy Berger, *Workable Sisterhood: The Political Journey of Stigmatized Women with HIV/AIDS*
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 for PLHIV
DIAGNOSIS, SEXUALITY AND CHOICE:
Women living with HIV and the quest for equality, dignity and quality of life in the U.S.

ANALYSIS AND RECOMMENDATIONS FROM THE U.S. POSITIVE WOMEN’S NETWORK 2010 HUMAN RIGHTS SURVEY
MARCH 2011
Coerced Abortion & Trauma

“I was told by several providers to abort my pregnancy. I was in my 2nd trimester before I knew I was pregnant. I ran out of many a doctor’s office in tears after being told I was selfish, or that ‘if that was my wife, I’d make her have an abortion.‘” - PWN 2010 survey respondent

“Being forced to have an abortion and getting my HIV diagnosis at the same time was like a double trauma. Where are the mental health services for women in my situation?’” - PWN survey respondent
PWN-USA SRHR Research Project

2012

4 core team members (all WLHIV) plus 6 advisory team members (all WLHIV)
- Defined research questions
- Conducted i) policy scan ii) lit review iii) survey design & analysis
- Wrote & edited report

Survey methodology: web-based & paper*, 70 questions

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

www.pwn-usa.org
Survey 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
## Survey Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>N = 179 (74% online, 26% paper)</td>
</tr>
<tr>
<td>Reproductive Age (44 years or younger)</td>
<td>41% of online respondents; 43% of paper respondents</td>
</tr>
<tr>
<td></td>
<td>Age range: 22-65</td>
</tr>
<tr>
<td>Gender</td>
<td>98% female, 2% transgender MTF</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td>80% H, 9% (B), 5% (L), 4% (A)</td>
</tr>
<tr>
<td>Geography</td>
<td>47% urban, 19% suburban, 17% rural 39% from Southern US</td>
</tr>
</tbody>
</table>
### Survey Participants - Socioeconomic Indicators

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Housing</strong></td>
<td>30% in subsidized housing</td>
</tr>
</tbody>
</table>
| **Income**                      | 47% under $20,000  
29% under $10,000  
HCSUS: 64% WLHIV compared with 41% MLHIV  
*Federal poverty level for an individual in 2013 was $11,430*                                                                         |
| **Employment status**           | Over half work or volunteer part time/full time                                                                                                                                               |
| **Childcare responsibilities**  | 52% >=child under 18 in the home                                                                                                                                                              |
## Survey Participants – Race/ethnicity

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>CDC 2010</th>
<th>Online Survey</th>
<th>Paper Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>60%</td>
<td>55%</td>
<td>57%</td>
</tr>
<tr>
<td>Latina</td>
<td>19%</td>
<td>3%</td>
<td>13%</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>18%</td>
<td>31%</td>
<td>2%</td>
</tr>
</tbody>
</table>
Engagement in Care

<table>
<thead>
<tr>
<th></th>
<th>Retained in Care</th>
<th>On ART</th>
<th>Suppressed VL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PLHIV</strong></td>
<td>37%</td>
<td>33%</td>
<td>25%</td>
</tr>
<tr>
<td>CDC (2012)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>WLHIV</strong></td>
<td>41%</td>
<td>36%</td>
<td>26%</td>
</tr>
<tr>
<td>CDC (2012)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PWN-USA Sample</strong></td>
<td>96%</td>
<td>91%</td>
<td>80%</td>
</tr>
<tr>
<td>(2013)</td>
<td></td>
<td></td>
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</tbody>
</table>

* Self report
Over half of women living with HIV in medical care have not been counseled about treatment as prevention.
Has any provider (doctor, nurse, case manager, or peer advocate) ever told you that when your VL is undetectable, you are less likely to pass HIV to an HIV-negative sexual partner?

- Yes
- No
- I don't remember
- Prefer not to respond
Where do you get information about sexual and reproductive health?

<table>
<thead>
<tr>
<th>Source</th>
<th>Percent obtaining SRH information – paper respondents</th>
<th>Percent obtaining SRH information – online respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV specialist</td>
<td>57%</td>
<td>76%</td>
</tr>
<tr>
<td>Internet</td>
<td>20%</td>
<td>47%</td>
</tr>
<tr>
<td>Support Groups</td>
<td>45%</td>
<td>42%</td>
</tr>
<tr>
<td>Magazines or books</td>
<td>12%</td>
<td>29%</td>
</tr>
</tbody>
</table>

83% of respondents had not visited a family planning clinic since diagnosis. 51% reported provider had not talked to them about sexual health
Many WLHIV 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 influencing factors
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
AIDS Patient Care and STDs

AIDS Patient Care STDS. 2010 May; 24(5): 317–323.
doi: 10.1089/apc.2009.0293

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Do HIV-Infected Women Want to Discuss Reproductive Plans with Providers, and Are Those Conversations Occurring?

Sarah Finocchario-Kessler, Ph.D., M.P.H., 1,† Jacinda K. Dariotis, Ph.D., 2
Michael D. Sweat, Ph.D., 1 Maria E. Trent, 3 Jean M. Keller, P.A.C., 4
Quratulain Hafeez, M.D., 5 and Jean R. Anderson, M.D. 4
Reproductive Health and Rights

Women who want to have a child in the future
N=107 (59%)

Women who want a child AND want to talk with HIV provider about pregnancy
N=71 (66%)

Had general discussion with HIV provider

No
16 (23%)

Yes
55 (77%)

- mean age = 35
- parity = 1.6

Had personalized discussion with HIV provider

No
40 (56%)

- mean age = 30.9
- parity = 1.5

Yes
31 (44%)

Woman Initiated
22 (71%)

= unmet reproductive counseling needs
HIV CRIMINALIZATION
Are You At Risk?

when sex is a crime & spit a dangerous weapon:

Man kills 'HIV positive' wife
Recommendations

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

Advocacy is needed: Repeal of HIV-specific criminalization laws, access to fertility treatment, support and adoption services
Acknowledgments

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Advisors: Michelle Anderson, Margot Kirkland-Isaac, Stephanie Laster, Sonia Rastogi, Cristina Rodriguez, Marissa Smith, Evany Turk, Juanita Williams

& most of all, to the 179 women who completed PWN-USA’s survey

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