

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

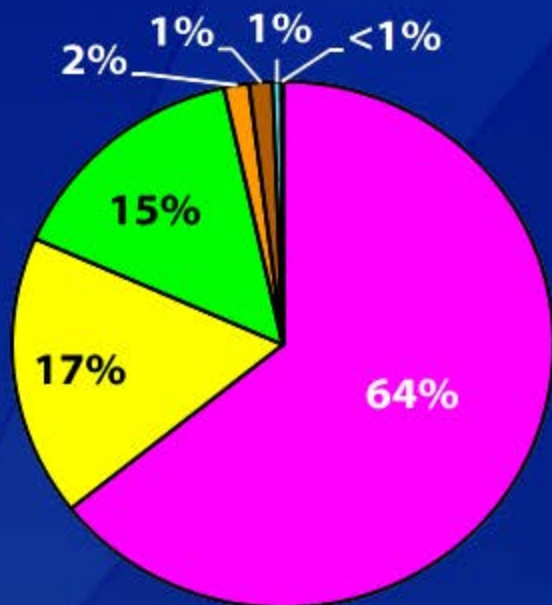
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Diagnoses of HIV Infection and Population among Adult and Adolescent Females, by Race/Ethnicity 2011—United States

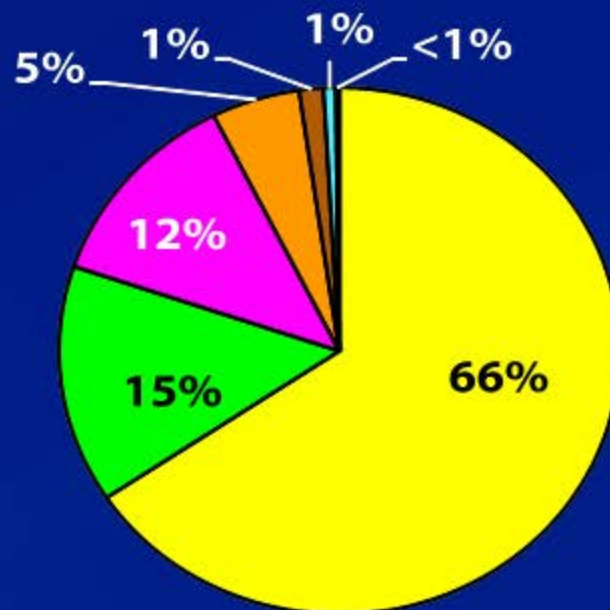
Diagnoses of HIV Infection

N=10,257



Female Population

N = 132,402,857



■ American Indian/Alaska Native
■ Asian
■ Black/African American

■ Hispanic/Latino^a
■ Native Hawaiian/Other Pacific Islander
■ White

■ 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.

^a Hispanics/Latinos can be of any race.



PUSHING THE GLASS CEILING: Life, Liberty and Justice for HIV+ Women

In U.S. Cities, HIV Linked More To Poverty Than Race



MIKE STOBBE | 07/19/10 06:23 AM ET | AP

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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.

Under Surveillance by Medicaid

by [ADMIN](#) on APRIL 19, 2012 · [LEAVE A COMMENT](#)



By [Kat Griffith](#) in Peoria, IL

“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



POSITIVE WOMEN'S NETWORK
USA

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



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

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



Survey Participants- socioeconomic indicators

Characteristic	Result
Housing	30% in subsidized housing
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

Race/ethnicity	CDC 2010	Online Survey	Paper Survey
Black	60%	55%	57%
Latina	19%	3%	13%
Caucasian/White	18%	31%	2%



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

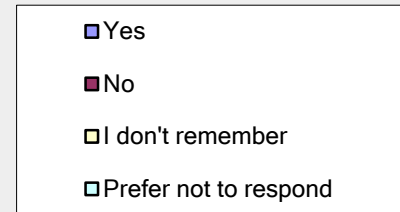
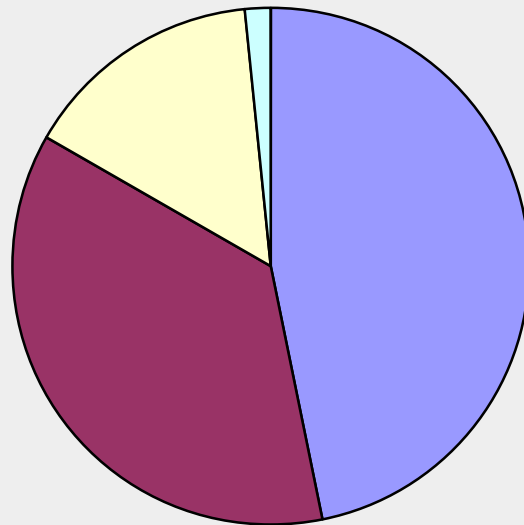


Over half of women living with HIV
in medical care have not been
counseled about treatment as
prevention.



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?

Has any provider (doctor, nurse, case manager or peer advocate) ever told you that when your viral load is undetectable, you are less likely to pass HIV to an HIV-negative sexual partner? (select one response)



Where do you get information about sexual and reproductive health?

Source	Percent obtaining SRH information – paper respondents	Percent obtaining SRH information – online respondents
HIV specialist	57%	76%
Internet	20%	47%
Support Groups	45%	42%
Magazines or books	12%	29%

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





POSITIVE WOMEN'S NETWORK
USA



Mary Ann Liebert, Inc. publishers

AIDS Patient Care and STDs

Journals

Search

Alerts

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

PMCID: PMC3120085

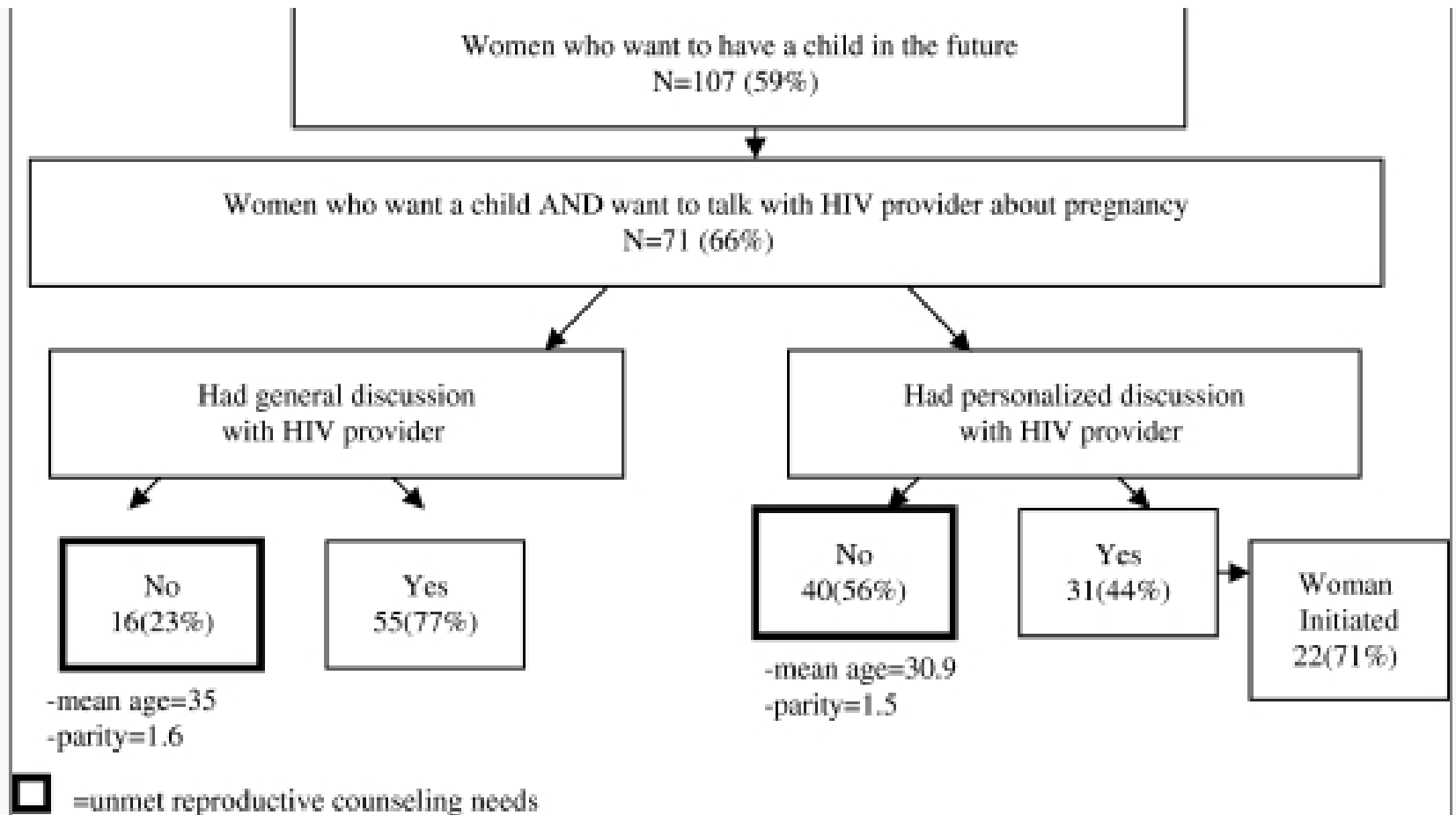
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Do HIV-Infected Women Want to Discuss Reproductive Plans with Providers, and Are Those Conversations Occurring?

Sarah Finocchiaro-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

AIDS Patient Care ST

Reproductive Health and Rights





HIV CRIMINALIZATION

Are You At Risk?

when
sex is a
crime
& spit a
dangerous
weapon:



Man kills 'HIV positive' wife

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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



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

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

