



POSITIVE WOMEN'S NETWORK
USA

UNSPOKEN:

Sexuality, Romance, and Reproductive Freedom for Women Living with HIV in the United States

a report by Positive Women's Network – United States of America (PWN-USA)

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Dedication

Dedicated to the nearly 200 women living with HIV who generously and courageously shared their insights, experiences, wisdom, and perspectives in this research process, answering a series of deeply personal questions about their sexual and reproductive lives, dreams, and desires.

Also dedicated to the millions of women living with HIV globally who have fought for the right to live as whole, dignified human beings for more than three decades – and sometimes, died for it.

Special dedication to Cicely Bolden, a young woman in Dallas, Texas, who was brutally stabbed to death in September 2012. During the trial, her murderer, Larry Dunn, attempted to use Cicely's HIV status as a defense for his actions. Our hearts and prayers remain with Cicely's loved ones. Positive Women's Network – USA is committed to creating a safer and more just world where women living with HIV are free from stigma, discrimination, and violence.



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Executive Summary

As women living with HIV (WLHIV) have become healthier, and HIV is no longer the death sentence it once was, women living with HIV are living in the present and making plans for the future – including attending school, participating in community activities, entering or re-entering the workforce, and taking on family responsibilities that may include parenting. However, the US HIV epidemic among women continues to be characterized by severe racial, economic, and other disparities, and WLHIV face the consequent downstream impact of discriminatory policies that impact health, rights, and quality of life particularly for women of color, women living in poverty, and women who endure other forms of discrimination, independently of HIV diagnosis.

For WLHIV, abridgement of rights particularly in the arenas of sexuality and reproduction, which are distinct from one another and must be uniquely addressed, takes a uniquely insidious form- and is frequently justified by narratives of public health concern.

Women's health, rights, and quality of life are impacted by policies, practices, attitudes and behaviors that include, but are not limited to, their sexual and reproductive choices, options, and constraints placed upon those.

Although the National HIV/AIDS Strategy set forward ambitious targets for improving diagnosis, treatment and care for people living with HIV (PLHIV), to reduce new infections, and to improve coordination of domestic HIV prevention and care efforts—it failed to set specific or measurable targets for women. In particular, the Strategy neglected to address sexual and reproductive health of PLHIV, and glossed over the troubling prevalence of violence and trauma in the lives of women living with HIV. As the Affordable Care Act creates opportunities to expand health care coverage, screening, treatment and care for low-income people, communities of color, and people with chronic health conditions, there is a window of opportunity ahead to address these critical issues which impact health, rights, dignity and quality of life for women living with HIV.

This framework document - written, researched, and edited entirely by women living with HIV - outlines a review of existing policies that may impact the SRHR of women living with HIV; a review of the literature; and findings from a national survey conducted among HIV-positive women in the US during the summer of 2013. The authors of this paper believe that understanding the actual lived experiences of sexual and reproductive rights for women living with HIV, in context, can provide opportunities to rectify this oversight.

In brief, the findings of this paper are as follows:

- 1) US laws and policies, including but not limited to health insurance policies, eligibility requirements to access services, restriction of access to family planning, fertility and adoption services and criminalization of HIV exposure and non-disclosure, create a hostile environment for women living with HIV and have focused on preventing transmission at the expense of abridging the rights of women living with HIV to fulfill their sexual and reproductive rights;
- 2) Much of the research agenda in the area of SRHR has been narrowly defined for the purposes of public health, rather than individual health and rights, including the emotional, psychological, and



spiritual well being which may derive from upholding women's rights to dignity and pleasure. Thus, available literature is restrictive and monotonous in approach and risks trivializing the rich tapestry of women's lives, stunting further progress and understanding. More explicitly, the sexual and reproductive lives and experiences of women living with HIV have typically been studied only in the context of preventing onward transmission (vertical or horizontal), or for the purposes of understanding behavior change, rather than for the sake of understanding women's experiences and wellbeing. Investigations that fail to examine the lives of women living with HIV across multifaceted dimensions can distort and misrepresent the real-world challenges, resilience, and experience of women affected by HIV. In particular, the ways in which WLHIV experience their bodies, sexuality, self-esteem, and emotional, spiritual, psychological, and romantic intimacy are not well understood.

- 3) Based on findings from a recent survey of US WLHIV, women living with HIV experience SRHR in a nuanced way. There is a complex relationship between body image, self-esteem, lifetime trauma history, socioeconomic variables, and women's choices in relation to sexuality, intimacy, relationships, and reproduction.
- 4) Policy change, advocacy, and further research that integrates biomedical and behavioral science with a structural analysis are urgently needed to ensure that WLHIV in the United States have the opportunity to fulfill their sexual and reproductive rights.



INTRODUCTION

Background

Since the beginning of the HIV epidemic, over thirty years ago, people living with HIV (PLHIV) have faced stigma and discrimination in many forms. In the early days of the epidemic, HIV-related stigma was fueled by lack of information about how HIV could be transmitted and, prior to the advent of highly active anti-retroviral therapy (HAART), a diagnosis of HIV almost certainly led to death. Laws mandating disclosure, criminalizing sexual and reproductive behavior, and policies requiring segregation of PLHIV who are incarcerated were among those established during this era of anti-AIDS hysteria. Over the past three decades, each of these laws and policies have had a devastating effect and exponential consequences on the health, rights, and dignity of people living with HIV, as well as perpetuating an environment that is discriminatory, stigmatizing, and violent.

In 2013, people living with HIV with access to appropriate care and treatment can live long, healthy, full and productive lives. A person diagnosed with HIV in the United States today can, with access to optimal care, treatment, and support, expect to live a near-normal life span.¹ Additionally, research shows that effective antiretroviral therapy can greatly reduce the risk of horizontal HIV transmission (between partners)² and vertical HIV transmission (from parent to child).³

Advances in treatment and consequent better health outcomes, accompanied by increased longevity, have led increasing numbers of people living with HIV to attend school, work and take on family responsibilities that may include parenting, grandparenting, fostering and adoption. In fact, the number of pregnancies among women living with HIV in the US has increased by 30% between 2000 and 2006.⁴

Despite these significant advances in treatment and reduction in infectiousness, however, people living with HIV continue to face discrimination in the health care system, justice system, public and private sectors; stigmatizing portrayals in the media; and high rates of prejudice among the general population. Laws, policies and practice have simply not changed to keep up with current science; many laws remain on the books from the early days of the epidemic when understanding of HIV transmission routes was scarce. Nowhere is this more apparent than in the case of women's sexual and reproductive health and rights.

For women of color living with HIV in the US, this abridgement of sexual and reproductive health and rights based on HIV status is compounded by an historical legacy of criminalization and policing of the bodies, sexuality, and reproductive rights of US-based women of color. Reproduction, the choice not to reproduce, and choices to control reproduction have historically and continue to be acts of revolution by women, especially women of color in the United States.

In her book *Workable Sisterhood: The Political Journey of Stigmatized Women with HIV/AIDS*, Michele Tracy Berger describes the concept of "intersectional stigma," a process by which women already experiencing oppression based on race, class and gender are additionally stigmatized due to their HIV status. Many women living with HIV in the United States are likely to have faced discrimination based on race, ethnicity, class, and gender prior to diagnosis, and partnership, marriage, and motherhood may be among the only socially valued identities available to them.⁵ An HIV diagnosis, understood in this context, can be devastating – stripping a woman not only of her individual health, but of her perceived



or internalized value and social identity as a partner or spouse, her potential to bear children, and her stature in a family structure or community.

Despite the obvious crisis in identity, world construct, and perception of self that may result from an HIV diagnosis, the emotional, spiritual and mental health impact of an HIV diagnosis on women is scarcely studied and not well understood. In addition, as women with HIV live longer, healthier lives, increasing options for informed decision-making by women living with HIV in the arenas of family planning, spacing of children, and support for infertility is an emerging mandate.

Thus, sexual and reproductive health and rights (SRHR) of women living with HIV is an expansive topic which lends itself to a plethora of exploratory subject areas related to desires, behaviors and perceptions. In many ways this topic is the narrative to women's lives; it encompasses puberty and sexual development, identity and self-esteem, romantic and sexual desires and relationships, reproductive health, fertility desires, and life during and after menopause. Women's sexual and reproductive health and rights go beyond just individual experiences, and are grounded in a structural context. Specifically, SRHR are shaped by and simultaneously define cultural norms and expectations, governing laws and policy, and social constructs.

To better understand the ways in which women living with HIV experience their own sexuality, relationships, and reproductive desires and intentions, within this cultural, political and social context, Positive Women's Network – United States of America, a national membership body of women living with HIV, created a research and analysis project designed and implemented entirely by women living with HIV. This report articulates the findings of that project and details recommendations for further research, advocacy, and action.

About Positive Women's Network – USA

Founded in 2008 by 28 diverse women leaders living with HIV, Positive Women's Network – USA (PWN-USA) develops a leadership pipeline and generates policy analysis that applies a gender lens to the domestic HIV epidemic grounded in social justice and human rights and works. PWN-USA is led by and accountable to women living with HIV in the United States.

The mission of PWN-USA is to prepare and involve all women living with HIV, in all our diversity, including gender identity and sexual expression, in all levels of policy and decision-making to improve the quality of women's lives, by:

- ✚ Combating HIV-related stigma and demonstrating that women living with HIV are part of the solution;
- ✚ Training and supporting leaders who are women living with HIV on a local, state and national level;
- ✚ Creating and sharing tools for women and HIV advocates; and
- ✚ Mobilizing for strategic campaigns to change policies.

PWN-USA applies a gender equity and human rights lens to the HIV epidemic to achieve federal policies grounded in the reality of women's lived experiences. In keeping with PWN-USA's mission, this document reflects a view of the reviewed policies, literature, and data utilizing a human rights, gender equity, and social justice framework. For more information about PWN-USA, please visit www.pwn-usa.org.



Understanding Sexual and Reproductive Health and Rights (SRHR)

Sexual and reproductive health and rights (SRHR) was defined as a concept at the 1994 Cairo International Conference on Population and Development. According to the United Nations Population Fund, SRHR is defined as:

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.⁶

This report discusses and explores SRHR specifically in the context of the lives of women living with HIV in the United States in 2013.



The US HIV epidemic among women

Of the more than 1.1 million people living with HIV in the United States, an estimated 300,000 are women.⁷ The epidemic among women is characterized by severe racial and ethnic disparities -- of the estimated 47,500 new HIV infections in the United States in 2010, 9,500 were among women, with Black and Latina women accounting for over three-quarters of those cases.⁸ Black women represent 64% of all new HIV infections among women, and are 20 times more likely to acquire HIV compared to white women and almost five times more likely to acquire HIV than Hispanic women.⁹

Transgender male-to-female women are among the highest group at risk for acquiring HIV. When compared with all adults of reproductive age, transgender women are 49 times more likely to be living with HIV, according to a meta-analysis published in the Lancet in 2013. This disparity persists in low-income, middle-income and high-income countries, including the US.¹⁰

In addition, young women of color are particularly susceptible to acquiring HIV. It is estimated that greater than half of new infections among US women during 2010 were among those aged 25 to 44 years which are prime years for sexual activity, preventative health care for cervical and breast cancer, and reproduction.¹¹

It is estimated that approximately 85% of women living with HIV in the US have been diagnosed, with the remaining 15% unaware of their HIV status.¹² This rate of diagnosis is higher than in other populations, likely because women interact with the health care system with greater frequency than men overall, particularly during reproductive years, and are more likely to be tested in that context. However, only about 70% of women living with HIV nationally are linked to medical care and, alarmingly, only 41% are effectively retained in medical care, pointing to severe challenges in access and utilization of health care services.¹² Just over one-quarter (26%) of women living with HIV in the US are virally suppressed, an important marker of successful care and treatment.

Women living with and vulnerable to acquiring HIV in the US face compounding limitations that are gender-specific and have a direct impact on women's access to care, ability to utilize care, health outcomes, and ultimately, quality of life.

Social, economic, cultural, and political barriers to health including gender-based violence, gender inequity, discrimination, and lack of access to gender-responsive care and treatment throughout the lifespan impact women in varying ways throughout the course of their lives.

In the US context, HIV among women and poverty are inextricably linked, with poverty now understood as both a cause and a consequence of HIV infection. According to the HIV Cost Services and Utilization Study (HCSUS), 64% of women living with HIV in medical care had annual incomes under \$10,000, compared with 41% of HIV-positive men in care.¹³

Women of color, transgender women, current and former sex workers, substance users, women who face challenges with mental health, disabled, unstably-housed, undocumented and immigrant women frequently must also contend with additional challenges, stigma, and discrimination - even within institutions created and mandated to provide services to them.

Furthermore, because many laws and policies in the US are defined and implemented at a local and state



level, women in various parts of the US have differing experiences related to health, rights and access. Consequently, where a woman resides geographically can have a direct effect on her ability to access screening, care and treatment for health, illness and disease, family planning and to fulfill her sexual and reproductive rights. Women bear a particular burden of the HIV epidemic in the Southern US – a geographic region which, not coincidentally, is fraught with political battles ranging from abortion and family planning access to voting rights for communities of color and accurate sex education in schools.



PROJECT DESIGN

Three major sources were used to generate this framework document:

- i) A scan of the current policy landscape; including key political trends that relate to the sexual and reproductive health and rights of women living with HIV;
- ii) A review of existing literature on the sexual lives of women living with HIV, their experiences with sexual and reproductive health care, reproductive justice for women living with HIV, and the romantic lives and intimate partnership experiences of women living with HIV; and
- iii) A survey of 179 women living with HIV in the US which explored their experiences accessing sexual and reproductive health care, desires and experiences related to sexuality, reproduction, and intimate partnership, and perceptions of provider-patient communication on SRHR issues.

A core team of four women living with HIV defined the initial research questions and conducted the literature review, survey design and analysis, policy scan and production of this final document.

An additional team of eight women living with HIV served as key advisors on project, providing input on the research questions, survey goals and design, disseminating the survey to women living with HIV in their communities, and providing feedback on analysis.



UNDERSTANDING THE POLICY AND LEGAL ENVIRONMENT FOR WOMEN LIVING WITH HIV

The political and legal environment provides a context in which the sexual and reproductive rights of women living with HIV can be realized or abridged. To understand this context in the United States, a policy scan was conducted to:

1. Identify policies which impact the sexual and reproductive health and rights (SRHR) of women living with HIV in the United States;
2. Identify gaps in such policies and;
3. Provide recommendations for policy-related action to promote the sexual and reproductive health and rights of women living with HIV.

We conducted an online search of published and grey literature. Sources searched included: mainstream Google search, US Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), World Health Organization (WHO), United Nations Population Fund (UNFPA), and the Joint United Nations Programme on HIV/AIDS (UNAIDS) with the following key words and phrases:

SRHR of women living with HIV; SRHR of people living with HIV; criminalization of HIV nondisclosure; preventative health screening for women living with HIV; HPV and women living with HIV; STI's and women living with HIV; Prison policies for women living with HIV; pregnancy and women living with HIV; access to family planning services for women living with HIV; access to sexual health information and services for women living with HIV; sexual health education for women living with HIV; sexual pleasure and women living with HIV; fertility and HIV; and coerced sterilization of women living with HIV.

Documents were reviewed with the following criteria in mind:

- Positive and negative implications of existing policies which impact the SRHR of women living with HIV in the United States;
- Gaps in policies which impact the SRHR of women living with HIV in the United States;
- Recommendations to improve the policy and legal environment regarding the SRHR of women living with HIV in the United States.

An initial search looked for policies with direct reference to the SRHR of women living with HIV. A secondary search uncovered policies with a direct reference to the SRHR of any person living with HIV, which have implications for women. A third and final search explored general population policies, which have an impact on the sexual and reproductive health of women living with HIV in the United States. The final review includes International, US Federal and State policies, guidance documents and legislation, as well as institutional policies and guiding principles, including healthcare settings, prisons and legal statutes which impact the sexual and reproductive health and rights of women living with HIV in the United States. When available, existing policy evaluations and compliance reviews are also included in the scan. Documents reviewed have been organized by the level of governance they target, including international, federal, state and local jurisdictions.



International Conventions, Treaties and Documents

Human rights standards were first internationally codified in the Universal Declaration of Human Rights (UDHR), a document adopted by the United Nations General Assembly in 1948, following the Second World War. World leaders, including Eleanor Roosevelt, wife of then-US President Franklin D. Roosevelt, were involved in the crafting of the UDHR. While the UDHR and several other human rights documents predate the HIV era, the underlying premise is that these rights are “inalienable” and “inherent.”¹⁴ Thus, they are for *all people*, including people living with HIV.

Sexual and Reproductive Health and Rights (SRHR) are inherent within universal human rights’ norms and standards, which also include the rights to privacy, free thought and expression, freedom from violence, the right to education and information, the right to equality, freedom from all forms of discrimination and the right to the highest attainable standard of health including deciding the spacing and number of children. SRHR is one aspect of human rights and thus indirectly included in many international, federal and state constitutions, laws, conventions, treaties and documents.

International conventions, treaties and documents are developed within the structure of the United Nations (UN) and are governed by International law. These treaties are agreements between 193 UN Member countries, including the United States, and provide the basis for the development and enforcement of laws and policies at the country level as well as the necessary tools for ensuring the implementation of HIV-related rights. Thus they are important to women living in the United States.

Under UN human rights conventions, it is considered the responsibility of the governments of every nation-state in the world to enact or enforce policies and statutes that respect, protect and fulfill these basic human rights, and further, to ensure that such rights are not compromised for vulnerable populations. A UN State’s commitment to doing this is signified by signing such instruments, which indicates a preliminary endorsement of the contents and demonstrates an intention to examine the treaty domestically and consider ratifying it. Ratification of a treaty by a nation-state demonstrates a commitment to be legally bound by the terms of that treaty, through its own legislative mechanisms. In the United States, this mechanism is the US Senate. While some UN international treaties have been both signed and ratified by the US Senate, many have not and several have been ratified with multiple exceptions which create barriers to implementation and enforcement at the country level.

Many international treaties and covenants have expanded upon universal human rights to address rights of specific populations at particular risk for rights violations, and these treaties have an impact on the lives of women living with HIV both globally and domestically. The analysis of the relationship of all of these doctrines to women with HIV is highly complex and is monitored by organizations such as the AIDS Law Project and the Treatment Action Group along with international civil society entities, some of which include women living with HIV. Of particular relevance to this scan are

- (i) the International Covenant on Civil and Political Rights (ICCPR)
- (ii) the Convention on the Elimination of all forms of Discrimination Against Women (CEDAW) and
- (iii) the Convention on the Rights of Persons with Disabilities (CRPD)

The International Covenant on Civil and Political Rights (ICCPR) commits its parties to respect the civil and political rights of individuals, including the right to life, freedom of religion, freedom of speech, freedom of assembly, electoral rights and rights to due process and a fair trial. The ICCPR has



been both signed (1977) and ratified (1992) by the United States. However, contentious issues such as the “right to life” which forms the basis for anti-choice arguments have caused this document to be ratified with several exceptions, making policy and legislation related to pro-choice and the right to access family planning services, including abortion, subject to federal and state laws. Due to inaction by the United States to adapt domestic policy to the ICCPR, as of February 2013, the US was scheduled for a review of its policies under this convention by the United Nations.

The Convention on the Elimination of all forms of Discrimination Against Women (CEDAW) requires UN States ratifying the Convention to enshrine gender equality into their domestic legislation, repeal all discriminatory provisions in their laws, and enact new provisions to guard against discrimination against women. UN member states ratifying CEDAW must also establish tribunals and public institutions to guarantee women effective protection against discrimination, and take steps to eliminate all forms of discrimination practiced against women by individuals, organizations, and enterprises. While the US has a number of laws consistent with CEDAW, it is one of two UN member nations, and the only democracy, which has signed (1980), but not yet ratified the agreement. Thus its provisions do not bind the US. The United States has not yet ratified CEDAW because US Senators cannot come to an agreement on issues such as parental and maternal leave and abortion. The US government has indicated a willingness to sign if these issues are exempt, however other UN Members will not accept this approach as an option, arguing that conditional ratification would weaken the treaty. Since the CEDAW has not been ratified by the US, the rights of women living in the U.S have never been represented on the UN international committee of experts charged with monitoring the country-level implementation of measures to fulfill CEDAW.

The purpose of the Convention on the Rights of Persons with Disabilities (CRPD) is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments that may hinder their full and effective participation in society on an equal basis with others. US President Barack Obama signed the CRPD in 2009, but was unable to achieve the required number of Senate votes to receive ratification despite bipartisan and community support. This is ironic considering the CRPD was modeled after the Americans with Disabilities Act (ADA). The reasons for the failure to ratify include confusion regarding the authority of the convention to override the ADA, which it does not, and the timing of the ratification vote which took place during a so called “lame duck” session. The CRPD is scheduled for a new ratification vote in 2013 and advocates are hopeful that it will pass successfully during the next round of voting.

In December of 2010, a coalition of US-based and international human rights and reproductive rights organizations submitted a joint report entitled Report on the United States’ Compliance with Its Human Rights Obligations in the Area of Women’s Reproductive and Sexual Health to the United Nations Universal Periodic Review Ninth Session of the UPR Working Group of the Human Rights Council (ref)(Appendix Report). Although this report was not specific to the needs of women living with HIV, Positive Women’s Network USA contributed to and endorsed this report. The report provides a thorough background and detailed recommendations for action on three areas of reproductive rights that treaty monitoring bodies have identified as issues of human rights concern: (1) pervasive racial disparities in reproductive and sexual health; (2) obstacles to women’s access to safe, legal abortion; and (3) the practice of shackling incarcerated pregnant women.



Many recommendations contained in the 2010 report are applicable to all women; however, they are uniquely applicable to women living with and vulnerable to acquiring HIV. Black and Latina women together account for over 80% of reported female HIV/AIDS diagnoses, even though they represent only 25% of the US female population.¹⁵ Additionally, there is a high prevalence (52%) of unintended pregnancies among women living with HIV¹⁶ and 1.7% of incarcerated women in the US are living with HIV.¹⁷ With these figures in mind, it may be deduced that the recommendations expressed in this report are critical to upholding the SRHR of women living with HIV in the United States. Recommendations specific to women living with HIV include the integration and co-location of reproductive and HIV healthcare services to reduce the barriers to care and information faced by women living with HIV.

In addition to international treaties and conventions, the United Nations provides a program specific to HIV. The Joint United Nations Programme on HIV and AIDS, or UNAIDS, is the UN program responsible for ensuring a timely, comprehensive and coordinated global response to the HIV epidemic.

“The mission of UNAIDS is to lead, strengthen and support an expanded response to HIV and AIDS that includes preventing transmission of HIV, providing care and support to those already living with the virus, reducing the vulnerability of individuals and communities to HIV and alleviating the impact of the epidemic. UNAIDS seeks to prevent the HIV/AIDS epidemic from becoming a severe pandemic.”

Both UNAIDS and the World Health Organization (WHO) have developed guidance documents relevant to the SRHR of women living with HIV, including:

- Policy Brief on Criminalization of HIV Transmission —issued in 2008 by UNAIDS and the United Nations Development Programme (UNDP)
- Ending Overly Broad Criminalization of HIV Non-Disclosure, Exposure and Transmission: Critical Scientific, Medical and Legal Considerations (UNAIDS 2013)

According to a 2011 article authored by International Planned Parenthood Foundation (IPPF) and the Center for Health and Gender Equity (CHANGE), the United States has been “slow to incorporate lessons learned from the international experience when it comes to integrating HIV/AIDS, SRHR (SRHR), and gender equality in the fight against HIV/AIDS.” The authors highlight the importance of SRHR and lessons learned from SRHR–HIV integration to inform US domestic and global HIV strategies and interventions.¹⁸

United States Federal Policies

In the late 1980’s and early 1990’s, people living with HIV and their allies were paramount in advocating for access to effective treatments and an end to stigma and discrimination. International, US federal and state declarations, guidance documents, policies and laws began to emerge – seeking to provide guidance to international partners and US legislators regarding the diagnosis, treatment, care and support of people living with HIV. In the United States, this advocacy has led to the development of advisory committees, policies and related programs such as the National Commission on AIDS in 1983, the AIDS Drug Assistance Program (ADAP) in 1987, the Ryan White Care Act in 1992, and the President’s Council on HIV/AIDS, formed in 1995.

More recently, in July 2010, the United States launched its first-ever National HIV/AIDS Strategy to set domestic targets for improving diagnosis, treatment and care for people living with HIV, and to improve coordination of domestic HIV prevention and care efforts. Prior to the release of the Strategy, the Ford Foundation convened a meeting of experts from organizations working on issues related to human rights,



women and HIV, to develop national consensus on policy recommendations to achieve better outcomes for women vulnerable to and living with HIV. Held in March 2009, the Ford Foundation Women and HIV Convening identified a number of overarching priorities for an effective federal response to the US women and HIV and directed these recommendations to President Obama's Office of National AIDS Policy in a landmark document entitled: *Critical Issues for Women and HIV: Health Policy and the Development of a National AIDS Strategy*.¹⁹

Among others, the recommendations included:

- 1) Recognition that fulfillment of human rights obligations correlates positively with access to care, treatment, and support for HIV-positive women as well as reducing vulnerability to contracting the virus for HIV-negative women;
- 2) Integrated health care delivery to ensure that women living with and vulnerable to HIV infection are not lost to care and receive consistent, high quality services for sexual and reproductive health.

The document further recommends that the White House should direct Department of Health and Human Service (HHS) agencies to review public health program guidance and encourage integration of HIV, sexually transmitted infection (STI), and reproductive health services where appropriate. Specifically, advocates recommended reviewing policies set by the Centers on Medicare and Medicaid (CMS) which limit HIV/STI services for Medicaid family planning expansion patients; revising HHS and CDC guidelines to ensure that integration of SRH, HIV, and STI services is encouraged; allowing HIV/AIDS and STI programs to purchase contraceptives and ensuring the provision of comprehensive, integrated and voluntary SRH and HIV prevention and treatment services for women who are incarcerated or recently released, female sex workers, immigrants, and other marginalized populations. Additionally, the document recommended revisions to the Ryan White Care Act and the Violence Against Women Act (VAWA) to encourage integration of services at the point of care.

Following the release of the NHAS, experts from the HIV community strongly criticized the Strategy for failing to explicitly address the needs of women. No women-specific goals or metrics were stated in the Strategy. Further, SRHR and HIV integration was minimally addressed in the Strategy, with only a brief reference to expanding HIV testing in family planning facilities, and no commitments made to expanding access to SRH services, addressing gender-based violence, or upholding sexual and reproductive rights for women living with HIV.

In response to continued criticism of the lack of focus on women in the National HIV/AIDS Strategy, President Obama issued a Presidential Memorandum creating a Federal Interagency Working Group to "address the intersection of HIV/AIDS, violence against women and girls, and gender-related health disparities" in March of 2012.²⁰ Later that same year, the President's Advisory Council on HIV/AIDS (PACHA) passed a Resolution on the Needs of Women Living with HIV which recommended amending the National HIV/AIDS Strategy to include "specific, targeted, and measurable goals and objectives for reducing HIV incidence and HIV-related health disparities and improving health care access and health outcomes for women living with HIV." The resolution further called for making "gender-sensitive care for women living with HIV more widely and readily available through the integration of HIV care and prevention services with sexual and reproductive health care and intimate partner violence prevention and counseling."²¹



Policies relating to health insurance and healthcare coverage have likely impacted the sexual and reproductive health of women living with HIV in a variety of ways. Until the implementation of the Affordable Care Act, people with pre-existing conditions, including HIV diagnosis, could be excluded from healthcare plans or charged higher premiums for insurance. In addition, the practice of “rating” by gender and age has been used by health insurance companies to charge higher premiums for women and mature individuals, who are considered to utilize health care more intensively than their counterparts. Under the Affordable Care Act, gender rating by insurance companies is no longer allowed. These policies, combined with the socioeconomic status of many women living with HIV who tend to be low-income, unemployed, or employed in jobs that do not provide health insurance, have forced women living with HIV into public health systems. While these systems may at times be better equipped or even specialized to account for the SRHR needs of women living with HIV, a disparity in access to cost coverage for services including fertility assistance, some forms of contraception, medications for mental health, and even treatment needed for managing HIV, continues to persist.

Over the last several years, there has also been a trend towards decreased or flat public funding for women-focused HIV services, though the total number of women living with HIV in the US continues to rise. The Ryan White Part D program originally evolved out of a desire to prevent vertical transmission. Early funding was for demonstration grants to “conduct clinical research on therapies for children and pregnant women with HIV and to provide health care, case management, and support services for these patients and their families,” and sprung out of an understanding that in the early days of the domestic HIV epidemic, as now, the majority of women and children impacted by HIV were low-income, unemployed, and lacked health insurance. Until the 2013 implementation of the Affordable Care Act, health insurance and thus a majority of healthcare coverage was generally tied to employment in the United States. Over the years, Ryan White Part D (formerly Title IV) became a family-centered model weaving together a network of medical care and supportive services that facilitate access to care for women and youth living with HIV in the US. Although total numbers of women and youth living with and affected by HIV continue to grow, Part D has been flat funded at \$78 million for fiscal years 2010, 2011, and 2012.²²

In addition, in response to a survey of Part D grantees conducted by AIDS Alliance for Children, Youth and Families in July and August 2013, over a fifth of respondents indicated they were planning to scale back outreach services to women living with HIV and youth as a result of sequestration. 17.8% of respondents reported they would modify primary care and supportive services provided, and 13.3% reported they planned to decrease case management staff in their programs. As a result of these and other planned changes, over a quarter anticipated longer scheduling time between appointments and 22.2% anticipated serving less clients from the WICY (Women, Infants, Children, Youth) population.²³

Recognizing significant gaps in the continuum of care from diagnosis to treatment and viral control, in July of 2013 President Obama released an executive order to Accelerate Improvements in HIV Prevention and Care in the United States through the a newly announced HIV Care Continuum Initiative (HCCI). The HIV Care Continuum Initiative orders revised Federal guidelines, which impact the areas of treatment initiation, prevention and HIV testing. Under the initiative, new CDC guidelines now recommend antiretroviral treatment for all adults and adolescents living with HIV in the US, citing evidence that achieving viral suppression reduces HIV-related complications and may reduce the risk of onward transmission by as much as 96% among heterosexual couples. New testing guidelines recommend screening for all persons 15-65 in the US. It is estimated that about 20% of people living with HIV in the US are unaware of their HIV status. Of the 50,000 new infections each year, the CDC suggests that people



who do not know that they are living with HIV transmit half of those infections.²⁴

Importantly, awareness of one's HIV status provides the opportunity to begin treatments proven to prolong and improve the quality of life of people living with HIV and to reduce transmission rates. Generally, HIV testing is voluntary and may be refused (opt-out) with some exceptions. Under federal law, mandatory testing is still required of federal prison inmates and US military personnel. Some states also mandate testing of incarcerated individuals. Approximately 1.7 percent of incarcerated women are living with HIV. In the case of incarcerated women, many are diagnosed while in prison and have experienced gaps in care or slow linkages to HIV care. The HCCI has committed to closing this gap and improving access to care upon release.

Additional measures currently under development include improved access to testing and insurance through the Affordable Care Act; renewal of Ryan White Act Funding; improving housing and employment opportunities for people living with HIV; a coordinated research strategy; capacity building for healthcare professionals and community organizations and a renewed commitment to reducing HIV related stigma and discrimination, particularly in the justice system.

Community reaction to the HCCI has mostly been positive and applauds President Obama's efforts to initiate evidenced based solutions to the HIV continuum of care. While many of the proposed initiatives have the potential to improve the lives of women living with HIV in the US, the HCCI was released shortly after significant cuts were made to the HIV budget line of the Office of Minority Health and Office of Women's Health, resulting in a \$3.3 million decrease to funds for programs and services that reach some of the most underserved populations of women living with HIV in the United States.²⁵

More recently, in September 2013, the Interagency Federal Working Group on the Intersection of HIV/AIDS, Violence against Women and Girls, and Gender-Related Health Disparities released an important set of federal policy recommendations to address the health and rights of women living with and vulnerable to acquiring HIV.²⁶ Advocates believe these recommendations will help fill an important gap in the US National HIV/AIDS Strategy, which failed to discuss or address intersections between violence, trauma and HIV despite evidence that women living with HIV are disproportionately impacted by childhood sexual abuse, intimate partner violence, and other forms of abuse, before and after diagnosis. The report proposes key next steps, including recommendations to develop, pilot and evaluate programs that provide trauma-informed care as part of HIV care and services for women.²⁷

State Policies

Although the federal government has begun to take steps to address the disparities in the HIV continuum of care as well as to reduce the stigma and discrimination experienced by people living with HIV, many programs and services accessed by women living with HIV are administered at the state level. For example, the AIDS Drugs Assistance Program (ADAP), which provides lifesaving HIV treatment for those who qualify, and the Medicaid program, are distributed to states that then administer the funding, subject to state-specific drug formularies and income eligibility requirements. Statutes pertaining to HIV testing, access to family planning services, and criminalization of HIV are also under state jurisdiction.

Testing and Partner Notification

Most states follow the CDC guidelines for voluntary HIV testing described under Federal Policies, while



others add restrictions to athletes who participate in boxing and some other forms of contact fighting as well as individuals convicted of a sex offense who may be subject to mandatory testing.

Laws for partner notification vary slightly, but generally require identification of sex partners for notification by public health authorities. State laws and policies concerning the confidentiality of an individual's HIV status generally protect people living with HIV. However, many of the policies may be subject to interpretation by the individual enforcing the policy. Although little data is available, women living with HIV have anecdotally reported incidences of coerced disclosure. Until 2010, the rights of women living with HIV in Mississippi to have children were violated under a statute that required people living with HIV to sign a document promising not to get pregnant or impregnate someone, in order to access benefits.²⁸ While this is no longer legal, it is challenging to account for residual effects of such policies, including the internalized stigma that may result from them and retraining, which may be necessary for healthcare and service providers who operated within these discriminatory policies.

Contraception, Abortion, and Pregnancy Planning

Historically, women living with HIV have been discouraged from having children due to high rates of transmission (30%) and uncertainty as to the longevity of the mother. Now with effective antiretroviral therapy to prevent vertical transmission and prolong life, women living with HIV are more likely to start families. As mentioned in the introduction, many women diagnosed with HIV in the US are of childbearing age. Although a majority of pregnancies are unplanned, many others are planned and some require the assistance of fertility experts to achieve success. Other women living with HIV may opt for adoption, and face barriers as outlined above.

As discussed previously, integration of HIV with sexual health and family planning services are essential to ensuring the overall health of women living with HIV.²⁹

Interestingly, in a country where the most advanced contraceptives are available, more than 50% of all pregnancies are unintended and an estimated 80% of pregnancies are unintended among women living with HIV, according to a recent study.¹⁶ Among women living with HIV, 54% did not want to continue the pregnancy. In the United States, contraceptive use saves about \$19 billion in direct medical costs each year. Title X of the Public Health Service Act is a US government program dedicated to providing family planning services for those in need. But funding for Title X as a percentage of total public funding to family planning client services has steadily declined from 44% of total expenditures in 1980 to 12% in 2006. Medicaid has increased from 20% to 71% in the same time. In 2006, Medicaid contributed \$1.3 billion to public family planning. The 1.9 billion spent on publicly funded family planning in 2008 saved an estimated \$7 billion in short term Medicaid costs. Such services helped women prevent an estimated 1.94 million unintended pregnancies and 810,000 abortions.³⁰

The abortion debate in the US is highly politicized. While abortion is legal in the United States in the case of incest, rape or health of the mother, the Hyde Amendment is a federal legislative provision that bans the use of federal funds, primarily Medicaid, to pay for abortions except for rape and incest. US laws also ban federal funding of abortions for federal employees and their dependents, Native Americans covered by the Indian Health Service, military personnel and their dependents, and women with disabilities covered by Medicare. The original Hyde Amendment was passed in response to *Roe v. Wade* and has been routinely attached to annual appropriations bills since 1976, representing the first major legislative success by the anti-choice movement.



The law requires that states cover abortions under Medicaid in the event of rape, incest, and life endangerment however all states do not comply. Some states have expanded coverage through state funds. Private insurance can pose limitations on abortion services and range from full coverage to restriction of coverage of any kind. Private insurance and state laws are subject to change making it difficult to provide accurate and timely information state by state on this topic.

For women who wish to start a family, paramount to planning a healthy pregnancy is a supportive and informed healthcare provider. While many healthcare providers do approach the subject of having children with their HIV-positive patients, many do not, leaving the initiation of the discussion up to the patient. Many women living with HIV fear disclosing their intentions and desires to have children due to fear of stigma and discrimination. For many of these women the result is that they become pregnant without medical supervision and proper prenatal follow up. Provider-initiated discussions about childbearing intentions including fertility options and contraception, could improve health outcomes for women living with HIV, their children and their partners.

Some women require fertility services due to infertility issues that may or may not have resulted from HIV infection. Other women living with HIV require assistance in order to conceive safely. However, due to antiquated policies developed in the early days of HIV (1994) fertility centers in the United States have routinely denied services to people living with HIV. California goes even further and explicitly prohibits tissue donation, sperm and egg donation and breastfeeding. Tissue and organ donation could assist other people living with HIV who require organs and tissue, and there is currently an act under consideration by Congress to examine the potential benefits of organ donation from HIV-positive individuals to other people living with HIV (the HIV Organ Policy Equity Act, or HOPE Act). Additionally, prohibition of egg and sperm donation generally also extends to known donors and recipients creating challenges for same-sex HIV positive and sero-discordant couples (where one is HIV-positive and one is HIV-negative) to access fertility services.

In 2010, the American Society of Reproductive Medicine (ASRM) released an important report entitled *Human Immunodeficiency Virus and infertility Treatment*. In this document, for the first time, the ASRM outlined guidelines for treatment of people living with HIV and openly stated that HIV was not a reason to deny fertility services.³¹ While this was a huge victory for SRHR advocates, treatments remain inaccessible due to individual clinic policies, limitations on tissue donation and high costs for fertility services, which are generally not covered by public or private insurance.

Criminalization of HIV Non-Disclosure and Issues Concerning Women who are Incarcerated

Criminalization of HIV has sparked debate in the courts, among policy makers and people living with HIV. In the early years of the epidemic, states were required to prove that they had sufficient laws on the books to ensure that anyone who intentionally infected another with HIV would be duly prosecuted in order to receive funding under the Ryan White Act of 1990. (Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (Public Law 101-381; 104 Stat. 576). Unfortunately many of these laws were based on misguided information about transmission routes, and have not been revised to include advances in scientific understanding of HIV transmission. In addition, decisions on cases are frequently in the hands of county or state judges who may lack understanding about HIV transmission, and who may also have their own bias and prejudice against people living with or at risk for acquiring HIV.



Currently, more than thirty states have HIV-specific laws or statutes that can be used to prosecute people living with HIV.³² These laws focus explicitly on persons living with HIV. HIV-specific criminal laws criminalize and/or impose additional penalties on certain behaviors, such as: sexual activity or needle sharing without disclosure of positive status; prostitution and solicitation; donation of blood/tissue/fluids; biting, spitting and throwing of bodily fluids; and sex offenses. In the states that do not have HIV specific laws, other laws, such as sexual assault laws and attempted murder may be applied in the case of HIV non-disclosure. Some additional states may include HIV under general communicable disease statutes. Some HIV specific laws have little or no basis in science. For example, in Georgia and Louisiana, spitting saliva or throwing feces or urine at a prison guard or officer of the law if diagnosed with HIV is considered a criminal offense. Another example of stigma and laws fueled by fear exists in Alaska where it is a criminal offense for a person living with HIV to “expose the victim to a risk or “a fear” that the offense could result in the transmission of HIV.³³

Generally, many state laws require full disclosure on the part of the person living with HIV and documented consent of the non- infected partner. In Missouri and several other states, condom use is not a defense for HIV non-disclosure. Such laws only serve to fuel the ever-present stigma and discrimination faced by people living with HIV.

The National HIV/AIDS Strategy provides some guidance regarding the issue of criminalization, noting that in some instances, existing HIV exposure laws may need to be re-examined. Additionally, on 23 September 2011, Rep. Barbara Lee (D-CA) introduced H.R. 3053, The Repeal Existing Policies that Encourage and Allow Legal HIV Discrimination Act or the REPEAL HIV Discrimination Act. The REPEAL HIV Discrimination Act calls for review of all federal and state laws, policies, and regulations regarding the criminal prosecution of individuals for HIV-related offenses.

As mentioned previously, 1.7% of all incarcerated women are living with HIV.¹⁷ Many have experienced outright discrimination including being segregated from the general prison population. South Carolina recently retracted a state policy on segregation of HIV-positive inmates. Just last month, a federal judge approved a settlement to end segregation of HIV-positive inmates in Alabama, which will go into effect in 2014.³⁴

While most women acquire HIV outside of the prison setting, some women acquire the virus while inside. Harm reduction tools including clean syringes and male and female condoms are not generally available in prison.

Women in prison are vulnerable to other violations of their human rights. Recently in California it came to light that nearly 150 female inmates had been sterilized without their consent.³⁵ There is no evidence to-date that any of the women were living with HIV, however considering the large population of HIV positive women in prison, this could indeed have been a factor. While this scan did not produce any documented cases of sterilization among HIV-positive women in the US, sterilization of women living with HIV is a major issue globally. A 2012 decision by Namibian courts found that 15 women living with HIV had been sterilized without their consent. The report fell short of saying that it was specifically due to HIV, only that it was illegal to perform sterilization without consent. High rates of sterilization regret are evident among US women living with HIV in the general population, however,³⁶ with more than half of women in one study citing HIV diagnosis as a reason for choosing sterilization. It is unclear how coercion and shame may influence non-reversible contraception choices for women living with HIV.



Parenting

The ability of women living with HIV to parent has been called into question at various times and on numerous grounds. For example, in 2009, Ms. T, a 28-year-old woman from Cameroon, was arrested for falsified immigration documents in the United States. She was sentenced to 238 days, despite a recommendation by both the federal prosecutor and the defense attorney to sentence her for time served, or 114 days. However, US District Judge John Woodcock delivered a sentence designed to correspond to Ms. T's due date, claiming that the extended sentence would "protect Ms. T's unborn child." Woodcock's paternalistic rationale included an assertion that Ms. T would be more likely to follow a treatment regimen in federal prison than on her own or in the custody of immigration officials. The judge clarified that this sentence enhancement was based purely on Ms. T's HIV status and that his intention was to "protect the public from further crimes of the defendant... and that public, it seems to me at this point, should likely include that child she's carrying. I don't think that the transfer of HIV to an unborn child is a crime technically under the law, but it is as direct and as likely as an ongoing assault... And so I think I have the obligation to do what I can to protect that person, when that person is born, from permanent and ongoing harm."³⁷

HIV status may also affect determinations on custody matters, adoption, foster care, and surrogacy, in judicial systems as well as child welfare systems, according to a survey conducted by the Positive Women's Network – USA in 2010.³⁸ Women considering adoption may be subject to state statutes requiring them to disclose their HIV status. HIV status may also become an issue in custody cases where uninformed workers or uninformed policies and practices may consider HIV as a correlate in a person's ability to parent. The Americans with Disabilities act (ADA) may prohibit adoption agencies from discriminating against couples or individuals living with HIV. This was tested in Nebraska in 2006 after a woman living with HIV was denied the ability to adopt based on HIV status. While HIV status alone is not a reason to prohibit adoption, like fertility clinics, limited understanding of the implications of an HIV diagnosis may influence adoption workers and agencies.

Summary

When it comes to the sexual and reproductive health and rights of women living with HIV, international human rights conventions are not strongly upheld in the design and implementation of US-based federal and state laws and policies. The US refusal to ratify CEDAW, among other treaties, is indicative of a national ambivalence towards upholding women's full rights as internationally recognized.

The fact that it has been legal for health insurance companies to discriminate against, limit coverage for, and charge exorbitant fees to people living with HIV for three decades speaks volumes about the climate in the United States. Further, eligibility requirements for services that have punished people for being well and for being employed have made a clear statement about the value placed on the lives of people living with HIV in the United States.

Laws and policies, such as those limiting access to fertility services and criminalizing non-disclosure, create a hostile environment and have focused on preventing transmission at the expense of abridging the rights of women living with HIV to fulfill their sexual and reproductive rights.

WLHIV who are incarcerated, young women in foster settings, and women who are otherwise in custody by the State are uniquely vulnerable to violations of their sexual and reproductive health and rights.



A REVIEW OF THE LITERATURE

I. Methods:

Over 90 peer-reviewed literary articles were examined, with a focus on literature published from 2005 to present. The most relevant articles are included in this report. Literature was collected from a variety of databases including PubMed Health, the Cochrane Library, Academic Search Complete, Google Scholar, Alt-Press Watch, and BIOSIS Previews. The majority of sources were comprised of published articles describing research findings. Research studies varied in design and approach, and included descriptive, correlational, experimental, meta-analytic and longitudinal studies. In addition to variation by research method, studies fluctuated in sample size, method of sample selection and the sample's representativeness compared with the overall epidemic of women living with HIV in the United States. Publications also included systematic reviews, journals, and intervention guides.

In addition, grey literature including reports, analysis, and intervention guides published by grassroots organizations, committees and working groups with the goal of improving programs or policies were used as sources in this literature review.

Literature was aggregated by subtopic of interest and then analyzed on focal points, research questions posed, approach to investigation and findings. As anticipated, the quality and diversity in the literature was largely dependent on the subtopics examined. For example, a robust selection of articles was prevalent for sexual health, fertility desires and contraceptive use. Comparatively, articles focused on the behavior, cultural contexts, and psychology associated with prevention post-HIV diagnosis— and women's sexual, spiritual, and emotional satisfaction within intimate relationships were sparse, particularly when focusing on US populations. In addition, because of a dearth of research on the sexual and reproductive desires, experiences and intentions of transgender women living with HIV, this literature review is limited in scope to exploring the data on women whose sex at birth was female. The sexual and reproductive health and rights of transgender women living with HIV should be studied further.

Topics explored included body image and self esteem; disclosure; sexual and emotional satisfaction in relationships; reproductive health and gynecological care; contraceptive use; and fertility desires. Each section below provides an overview of some leading issues raised in the literature.

A brief description of the content for each database searched is provided:

- PubMed Health: Specializes in reviews, summaries and abstracts of more than 22 million scientific articles in medicine and health. Provided by the National Center for Biotechnology information at the US National Library of Medicine.
- The Cochrane Library: A collection of six databases that contain different types of high quality, independent evidence to inform healthcare decision-making, and a seventh database that provides information about groups in The Cochrane Collaboration.
- Academic Search Complete: A multidisciplinary index to articles in more than 10,900 journals and other publications in English, Spanish, German, French, Italian and Portuguese; full-text is available for over 5300 journals.
- Google Scholar: Indexes full text of scholarly literature across an array of publishing formats and disciplines. Includes most peer-reviewed online journals of Europe and America's largest



scholarly publishers, plus scholarly books and other non-peer reviewed journals.

- Alt-Press Watch: Alternative, radical, and independent magazines, newspapers, and journals in North America from 1970 to present which report on politics and government, policy and culture, international issues, education, environment as well as reviews of theater, movies and books.
- BIOSIS Previews: A product of UC San Diego, this database covers literature of the biological sciences including journals and selective books, conferences and patents from 1926 to present.



I. Self-Perception, Body Image and Self Esteem

It is important to note that the vast majority of studies did not focus exclusively on self-esteem and body image, but rather incorporated self-esteem and body image assessment as a marginal component within a primary topic under investigation, such as treatment adherence, disclosure or condom frequency. Consequently, much of the research lacks depth and insight about how women living with HIV value themselves and the degree to which HIV affect their self-perception at various stages in their lives. Of the existing limited research, most focuses on body image, self-esteem and depression among men, with very little attention focused on women. Furthermore, many studies had a significantly lower participation of women in samples compared to men (1:4), leading many researchers to caution their findings on self-esteem and body image may not be representative of women living with HIV. There remains scarce research and understanding about perceived self-worth, attitude toward body image, and strategies to build self-esteem over the course of the lives of women living with HIV, even though these may impact engagement in health promoting behaviors and overall quality of life.

In *The Dimensionality of Stigma*, Fife et al. compared the effects of stigma associated with HIV and cancer, examining how the type and degree of stigma experienced by people living with HIV and cancer differ, as well as the impact of stigma on the self, in the areas of self-esteem, body image, and personal control.³⁹ The study explored four primary dimensions of stigma: social rejection, financial insecurity, internalized shame, and social isolation, concluding that participants with HIV experienced significantly greater feelings of stigma than those with cancer across all dimensions. Further, the study identified several background factors that correlate with higher measures in each dimension. Among them, older age was associated with stronger reports of internalized shame and gender influenced feelings of social isolation, with women reporting significantly higher feelings of social isolation than men. While the study did not find significant differences between body image-related stigma experienced by the HIV and cancer cohorts, it did find that women consistently reported lower body image than men. Social isolation was found to be strongly correlated with body image.³⁹

On the other hand, a smaller study by Corless et al. studied weight change, including fat redistribution and lipodystrophy, in relation to body image among PLHIV and found that women tended to report higher body image scores than men.⁴⁰ Corless recommended that clinicians should assess patients for self-report measures of weight change and body image to better address quality of life.

Throughout the literature, there is agreement among researchers that HIV illness itself and HIV treatment, including HAART, can significantly alter physical appearance, bodily function and body image. Martinez and Kemper et al. contend antiretroviral therapy can have significant physical, visible, and tangible effects on the body, which can affect self-perceived body image and self-esteem.⁴¹ This is also consistent with Huang et al.'s finding that body image dysphoria is high among women living with HIV, particularly when lipodystrophy is present.⁴² According to Fingeret et al., body image concerns are widespread among PLHIV and HIV infection, presence of symptomatic disease, and an AIDS diagnosis have all been independently associated with poor self-perceived body image.⁴³ Fingeret found that weight concerns were only one aspect of body image among 91 study participants living with HIV, and that body image concerns were significantly associated with depression, anxiety, and stress.⁴³

Several studies and research have documented evidence supporting a correlation between lipodystrophy syndrome, poor body image, problems with social functioning, and depression. Thus, perceived body image and body changes can play an influential role in the lives of women living with HIV, directly and



indirectly affecting psychosocial health, treatment adherence decision-making, coping mechanisms, sexual and romantic life, and quality of life.

Limited studies directly address self-esteem as an issue for women living with HIV. In one small study that utilized focus group interviews to better understand perceived problems and pressures among young women recently diagnosed with HIV between the ages of 17 and 24 years old from Chicago, Baltimore, and Tampa, investigators found participants described varying levels of self-confidence, self-esteem and self-worth.⁴⁴ Participants expressed a perception that their worth or stature in their social networks was lower as a result of their HIV status and cited high levels of rejection from family, friends and significant others, as well as high levels of emotional abuse from partners after disclosure, as evidence. Some participants reported staying with the partner who infected them because of fear of rejection.

Although the literature indicates women living with HIV are vulnerable to lower self-esteem rates, the degree to which HIV diagnosis affects self-esteem in comparison to other causal factors remains unclear. In the article “Trauma, Mental Health, Distrust, and Stigma,” authors found psychosocial factors including depression, anxiety, and posttraumatic stress disorder (PTSD); lack of trust in the healthcare system and government; and experiences of stigma are all prevalent among PLHIV regardless of gender or race/ethnicity.⁴⁵ Studies have shown that rates of PTSD among women living with HIV may be as high as 30%, a rate six times the general population.¹⁰¹

In one Los Angeles-based study of 189 WLHIV of low socioeconomic status, researchers found that women reported both benefits and losses in relation to HIV diagnosis. Changes were assessed in the domains of self-concept, view of body, social relationships, romantic relationships, and life priorities. Women reported significantly positive changes in the areas of self and life priorities, but significantly negative changes in the areas of romantic and sexual relations, as well as their views of their bodies. In positive terms, many participants reported that HIV had changed their attitudes to make them “stronger, wiser, more understanding,” reduced their substance use, and reframed their priorities to focus on family, helping others and living life to the fullest. In contrast, women tended to report negative changes to their romantic relationships and body image, the majority reporting that they felt less physically attractive, less interested in sex, and more fearful about starting and maintaining romantic or sexual relationships. Interestingly, socioeconomic status measures, particularly higher education and greater income, were the most significant predictors of finding benefits post-HIV diagnosis.⁴⁶

Watkins-Hayes et al. assert receiving a serious health diagnosis can greatly influence a person’s identity, beliefs and behaviors.⁴⁷ Coping with a chronic health status is therefore a “complex, multidimensional process” that may be shaped by several factors including the environment; the psychological and social dispositions of individuals; and the family, friends and medical providers that make up an individual’s support network.⁴⁷ Further, she notes that literature suggests many women engage in harmful behaviors upon receiving an HIV diagnosis—including failing to properly manage their health with medication, diet, rest, exercise, and regular doctors’ visits; ignoring depressive symptoms; and sometimes returning to risky behavior as a coping mechanism, including behaviors that may have put women at risk for HIV in the first place.⁴⁷



II. Disclosure

Disclosure of HIV status to current and potential sexual partners complicates sexuality and intimacy for women living with HIV. While disclosure of HIV status may play a role in prevention of sexual HIV transmission, stigma often discourages people living with HIV from disclosing their status to all sexual partners.⁴⁸ In a study of 341 people living with HIV, including 138 men who have sex with men, 116 heterosexual women and 87 heterosexual men, investigators found women and heterosexual men were more likely to disclose than men who have sex with men (85% and 86% respectively, compared with 69% of men who have sex with men). Overall, participants with casual or mixed-HIV status relationships disclosed less than those in exclusive relationships and less to HIV-negative and unknown status partners.⁴⁸

Disclosure may increase risk for intimate partner violence and abuse for women living with HIV. While 4% of women reported physical abuse immediately following a disclosure event, close to half (45%) of the women reported experiencing emotional, physical or sexual abuse at some time after their diagnosis.⁴⁹ The relevance of these studies to understanding the links between disclosure and violence in relationships, however, may be limited by investigators' perception that disclosure of HIV status is a discrete, one-time incident, rather than an ongoing series of events which may have long-term consequences.

Following completion of the *Protect and Respect* intervention, an intervention designed to decrease sexual behavior that places women living with HIV at risk for sexually transmitted infections and for HIV transmission, investigators found that although many women reported feeling more confident about disclosing their HIV status to others and handling receivers' reactions, learning how to disclose did not always result in actual disclosure.⁵⁰ Many women remained very cautious about disclosure and expressed continued fear of rejection or retaliatory behaviors, including physical abuse, from partners.⁵⁰ The extent to which disclosure is influenced by partner-specific variables, such as partner HIV-status and relationship type, for women living with HIV, is unclear. Fear of partner response during and after disclosure may also contribute to celibacy.⁵⁰ Siegel et al. infer some women who chose celibacy or to abstain from sex did so to avoid stress, humiliation and emotional hurt they expected from rejection following disclosure.⁵⁶ These findings are consistent with a small survey of eight women that found HIV-positive women used isolation as a coping method to protect themselves from rejection.⁵¹

In a cross-sectional study which interviewed 611 women (310 HIV-positive and 301 HIV-negative) that examined the role of health care providers on women's decisions to disclose and the efforts of partner violence related to disclosure, investigators found that while many of the participants indicated health care providers had offered them support to disclose, over half reported a health care provider instructed them to disclose to their sex partners.⁴⁹ Furthermore, investigators found women living with HIV for longer spans of time—averaging 5 years—were more likely to disclose their HIV status to partners.⁴⁹



III. Sexual and Emotional Satisfaction in Relationships

Although most women living with HIV in the United States are sexually active following their HIV diagnosis, there remains a large void in the literature examining how intimacy is actually experienced by women living with HIV. There is widespread agreement among investigators and authors that additional research is needed in this area to better understand the sexual and romantic experiences for women living with HIV.^{52,53,56}

Pleasure and Joy: Missing Pieces of the Puzzle

Investigators Keegan et al. contend existing research largely focuses on risk behaviors and transmission when investigating the sexual experiences of people living with HIV rather than the quality of their sexual experiences.⁵² Current research on the sexual lives of women living with HIV primarily centers on risk of HIV transmission from women to their partners, with a heavy concentration on condom use practices, determinants of sexual risk behavior and unintended pregnancy⁵³- reflecting the primacy in academia of socially acceptable public health goals over understanding HIV-positive women's rights to sexual satisfaction, eroticism, romance, and pleasure in relationships. Other aspects of sexual health, including HIV-positive women's satisfaction with their sexual and intimate relationships, have received relatively little attention in the literature.⁵³

Self-Reporting on Sexual Activity

Most women living with HIV in the United States are of reproductive age and 70-80 percent are sexually active.^{34,36,84}

However, women living with HIV may not accurately report their sexual activity in studies. In the article "Contraceptive Use among US Women with HIV," Massad et al. indicate women living with HIV are less likely to report sexual relations compared to HIV-negative women in the Women's Interagency HIV Study (WIHS) longitudinal study. Among 2,784 women evaluated from 1994 to 2005 at six urban study sites (Brooklyn, Bronx, Chicago, Los Angeles, San Francisco, and Washington, DC), investigators found contradictory responses from women living with HIV; more than half of the women in the study who reported having been sexually active in the prior 6 months also reported abstaining from sex to avoid conception.⁵⁴ Furthermore, investigators could not determine if women identified "abstinence" as a contraception choice or as a label to describe sexual inactivity with partners.⁵⁴

Data on the effects that shaming of HIV-positive women's sexuality, stigma, discrimination and cultural values may have on the comfort level of women living with HIV in describing sexual activity is scarce and current findings support the need to improve communication related to sexual activity and sexual satisfaction as well as family planning.

Sexual "Functioning" as an Indicator of Sexuality

A dominant assumption visible among the sparse literature is that women living with HIV are burdened by an increase in sexual difficulties including diminished satisfaction and greater sexual "dysfunction."⁵³ The Female Sexual Function Index (FSFI) is a widely used and commonly accepted measure of sexual functioning with a score of 0 to 36 with higher scores equating to higher sexual functioning. Individuals are assessed based on 19-items in a self-reported survey of their sexual activity over the past four weeks.



The metric investigates areas including sexual arousal and desire, lubrication, orgasm, and pain during intercourse. This scale is frequently used due to its high internal consistency and positive association with clinically diagnosed sexual function disorders. FSFI measures activities that occur with and without physical contact with a sexual partner (e.g. masturbation, foreplay).⁵³

Like any other metric, the FSFI measurement contains flaws. The tool may over-categorize some women as low functioning simply due to minimal or no sexual activity during a recorded period.⁵³ Among women, sexual function problems are commonly characterized as difficulties or limitations in sexual interest, desire, arousal, orgasm and pain during sexual activity. Furthermore, FSFI relies on a strong relationship with clinically diagnosed sexual dysfunction. A clinical diagnosis of female sexual dysfunction requires the presence of both a problem with sexual functioning and a distress due to the identified problem. It is important to note that sexual dysfunction and sexual dissatisfaction, while they can overlap, are not synonymous and are not necessarily related. In addition to evaluating dimensions of sexual function and satisfaction in women's intimate relationships, some researchers have also incorporated measurements to assess psychological distress (e.g. Center for Epidemiologic Studies Depression Scale), HIV symptom severity (e.g. HIV Symptom Experience Inventory, Meaning of Illness Questionnaire) and stigma (e.g. HIV Stigma Scale) as it relates to sexual function and satisfaction.^{52,53, 56}

Sexual Satisfaction Findings

The literature does not reach a general consensus on the overall trend of sexual satisfaction and functioning among women living with HIV in the US. Some investigators find women living with HIV experience more sexual problems than HIV-negative women. Wilson et al. found women living with HIV had lower mean FSFI scores (13.8 SD = 12.7) compared to women without HIV (18 SD = 13.2). Among study participants, higher FSFI scores were associated with women who were younger and married or living with a sexual partner.⁵³ Lower FSFI scores were associated with women who had reached menopause, were diabetic, reported depression symptoms, or were taking medication to treat mental health problems, seizures, hypertension, or heart disease. While other co-variables play a role in sexual functioning, they do not mitigate the impact of HIV status in Wilson et al.'s study.⁵³

The study also revealed that of 1,805 women (1,279 HIV-positive and 526 HIV-negative) evaluated using the FSFI, women living with HIV had a significantly higher rate of sexual problems compared with HIV-negative women. While lower sexual function scores in the WIHS cohort were also associated with older age, menopause, symptoms of depression, and absence of a relationships, investigators concluded these factors did not diminish the influence of HIV infection on impaired sexual function scores in the study.⁵³

It is important to note that research links impaired sexual function to chronic health conditions, mental health issues, and substance use. Because women living with HIV are also at increased susceptibility for depression, post-traumatic stress disorder, and may have other mental health concerns and coping mechanisms including substance use, it is challenging to disaggregate or identify the true impact of HIV infection alone on sexual functioning.

Bova et al. found that of 101 HIV-positive women surveyed, the 59 women who were sexually active were more likely to be younger in age and have more positive meaning associated with HIV infection.⁵⁵ Factors identified that could negatively affect sexual functioning include fear of HIV transmissibility, partner disclosure, potential vertical transmission and, for some women, substance use. Of the women who were not sexually active, reasons included: no partner currently (31%), no interest in sex (27%), because of



HIV (19%), physical symptoms (6%), partner not interested (4%) and other (13%).⁵⁵ The most common “other” reasons listed included hassles of condom use, fear of disclosure to new partners and feeling depressed.⁵⁵

Wilson et al. found that while some women made the conscious choice to become celibate following their diagnosis, others reported having diminished interest in sex that inadvertently led to abstinence from sex.⁵³

Beliefs about Sex, Sexuality and Health

Investigation into personal perceptions of sexuality and intimacy reveal both positive and negative perceptions among women living with HIV. Siegel et al. assessed women’s personal perceptions during the pre-HAART era (1994-1996) and the post-HAART era (2000-2003) in New York. Both cohorts exhibited diminished pleasure in sex, diminished participation in sex, and diminished sense of sexual attractiveness.⁵⁶ Many women --regardless of age, race/ethnicity and relationship status-- reported sex to be less pleasurable or less satisfying since their HIV diagnosis.⁵⁶

Negative perceptions about sex, the body, and sexuality are not limited to women living with HIV. In another study, 81 midlife participants living with chronic illness of varying types expressed their perception that it was “not normal” to be ill. Correlated with this perception, participants felt “different” from “others,” which lowered self-esteem and heightening the perception of feeling vulnerable and insecure.⁵⁷ Because the report did not catalogue diagnoses among participants, it remains unclear whether women living with HIV, or a sexually transmissible illness were included in the study. However these findings align closely with the theory that the effects of illness and disease impair the sexual lives of WLHIV.⁵⁸

Another factor influencing perceptions of sex and intimacy is the possible risk of HIV transmission to partners and concern related to reinfection. Authors of the global report “Sexual Health for People Living with HIV” maintain PLHIV are often labeled as “infected” which can further injure and threaten a person’s sense of identity, self-esteem and self-worth.⁵⁸ Furthermore there remains a tendency for PLHIV to feel they do not deserve or have a right to a fulfilling relationship or to being “normal.”⁵⁸ In a study that assessed 153 WLHIV, the majority of participants felt sex had become too plagued with anxiety, worry, danger and stress associated with possible HIV transmission and/or reinfection by a partner to make sex still pleasurable. Even when protection was used, women reported worrying throughout the act that the condom would break leading them to feel “uptight” or “uncomfortable” during sex.⁵³

Contrary to the above findings, Bova et al. found that the majority of 101 women living with HIV, representative of all phases of illness progression, continued to be sexually active after testing HIV positive.⁵⁵ Few women reported that HIV itself caused worsening of their sexual functioning. Approximately half of the participants reported that the quality of their sexual activity had either stayed the same (31%) or improved (21%) after testing HIV positive and half of the women (50.8%) reported being very happy with the quality of their sexual relationships.⁵⁵

This divergence among research findings related to the intimate lives of women living with HIV demonstrates the need for further investigation to understand women’s sexual and emotional realities and relationships. Greater research is also needed to assess whether reduced sexual activity among women living with HIV is related to a lack of available partners or a conscious decision to abstain.



Safer Sex, Relationship Stress, and Spontaneity

The literature points to an association between safer sex practice and diminished sexual activity and satisfaction. Condom fatigue and a desire for close physical intimacy may contribute to inconsistent condom use as seen in a study of 25 high-risk sero-concordant positive and negative, and sero-discordant heterosexual couples in Hartford, CT.⁵⁹ Research indicates safer sex may also require planning and preparation, leading to a decline in spontaneity and excitement. This may change the meaning of sex from an intimate romantic act to a “tedious chore or dangerous pursuit.”⁵⁹ In FSFI terms, Wilson et al. found that among 1,233 women who reported one or more sexual partners since their last study visit, those who reported having protected sex also had lower sexual function scores compared to women who reported one or more unprotected episodes.⁵³ Not all findings reflect this association. Bova et al. found no relationship between sexual functioning and the use of condoms.⁵⁵

Condom negotiation with partners is also a barrier to safe sex. In an evaluation of *Protect and Respect*, some women expressed that relationships were just too stressful because partners, usually male partners, resisted or refused to use protection.⁵⁰

The intervention reveals that the cultural, psychosocial and structural challenges that hindered women from protecting themselves prior to HIV diagnosis, continue to interfere and limit their ability to practice safer sex once they acquire HIV.⁵⁰ Moreover abuse and fear of abuse—including physical, verbal and emotional abuse— may impede a woman’s ability to successfully negotiate condom use, increasing her risk for sexually transmitted infections and engagement in other risky behaviors, such as substance use and sex work.



IV. Reproductive Health and Gynecological Care

A significant proportion of the literature relevant to sexual and reproductive healthcare evaluated barriers to screening, frequency of screening, and risks associated with non-adherence to screening. Current reproductive health screening guidelines, coupled with elevated risk of disease and infection related to immune suppression for women living with HIV, likely contribute to these research trends. Investigators across several surveys conclude women living with HIV do not adequately access quality gynecological and reproductive healthcare in accordance with national screening guidelines.

Adherence to Pap Smear Screening Guidelines

Studies suggest that women living with HIV are five times more likely to be diagnosed with cervical cancer and have a higher risk of both cervical disease and presenting with advanced stages of co-infection when compared to uninfected women.⁶⁰ Federal guidelines from the US Preventative Services Task Force (USPSTF) and Centers for Disease Control and Prevention (CDC) recommend that all women living with HIV receive two Pap smears within the year following HIV diagnosis. If both Pap tests are normal, one annual Pap is recommended thereafter.^{61,62}

Trends in pap screenings among the general population of women from 1995 to 2002 suggest that women living with HIV generally have higher average rates of a single annual screening,⁶² with several studies indicating high adherence to the recommendation for a first Pap smear after diagnosis.^{63,64}

The majority of research reviewed on screenings came from retrospective cohort studies—in which findings were deduced from patients' past medical records. Information typically included but was not limited to age, race and ethnicity, year of HIV diagnosis, appointment attendance, Pap smear results, history of treatment related to HIV and secondary infection, CD4 count and HIV-1 RNA viral levels. It is important to note that retrospective studies rely on accurate record keeping by medical providers, independent of investigators conducting the study. The potential for bias and human error in reporting has the potential to skew results in retrospective studies.

Despite favorable results indicating strong adherence rates for one annual Pap smear, studies consistently report low adherence and follow up for the second recommended Pap smear within the same year. In one retrospective medical chart review of 200 women living with HIV at a local health department in Florida, it was found that 83% received at least one Pap test the first year after enrollment.⁶³ With regard to follow-up, only 24.5% received the recommended two Pap smears during that first year.⁶³ Another retrospective medical chart review of 69 women living with HIV demonstrated that, among women with one or more abnormal Pap smear results in a county health department in San Mateo, CA, only 62% received the recommended follow up Pap smear screenings within a year.⁶⁴ Low second Pap smear rates may be due to lack of awareness among providers or patients regarding the USPSTF Pap smear guidelines for women living with HIV, which differ from cervical cancer screening recommendations for HIV-negative women.^{60,63,64,66}

There is a lack of consensus on why women living with HIV are not receiving Pap smears per the guidelines. Tello et al. identified three leading factors significantly correlating with poor Pap test adherence for both first and second screenings among women living with HIV: documented substance use, particularly injection drug use; advanced onset of HIV as indicated by low CD4 below 200



or HIV-1 RNA copies above 50; or symptoms of depression leading to missed gynecology appointments.⁶⁵ Among the general population, women of color are less likely to receive recommended Pap testing compared with white women. However, Baranoski et al contend that risk factors associated with inadequate Pap testing among women living with HIV are difficult to gauge and are not well understood. According to Baranoski et al, increased likelihood of recent Pap testing is associated with receiving gynecological and HIV services at the same site, recent pregnancy, and history of abnormal Pap test results.⁶⁶ Factors which have been associated with less frequent gynecological care among women living with HIV include lower education, older age, obesity or low body weight, unemployment, intravenous drug use, cigarette smoking, depression, and receiving primary care from a private infectious disease physician.^{63,66,66}

In a study conducted at Johns Hopkins clinic in Baltimore, MD, where HIV care and gynecologic services are co-located, the rate of completed clinic visits was significantly lower for HIV gynecologic care than for HIV primary care – at 36% compared with 55% -- among the same population of women.⁶⁵ Study results showed that women living with HIV who did not receive any Pap smear in the previous year were more likely to be depressed, of older age, to have an unsuppressed viral load, and to have less than a high school education. Focus groups conducted with study participants elucidated that women living with HIV identified forgetting appointment (61%), sick (52%), and bad weather (42%) as major reasons for missing appointments.⁶⁷

Insurance Coverage and Screening

Logan and Khambaty et al. found that Pap smear frequency correlated with insurance coverage and facility type.⁶³ Women more likely to not have had an annual Pap smear were without insurance (64.7%) and were more likely to receive care solely from sites funded by Ryan White dollars rather than care insured by private, Medicaid or Medicare.⁶³ These findings support a correlation between type of medical insurance and frequency of screenings which is consistent with conclusions from Frost's analysis of patterns and trends in the use of 13 sexual and reproductive health services among the general female population throughout the United States for years 1995 (10,847 respondents) and 2002 (7643 respondents), based on data from the National Family Growth Survey.^{67,69} Frost concluded that wide variation exists in the range of services clinic clients receive, dependent on the clinic and insurance coverage. Women obtaining services at publicly funded and subsidized clinics received a more comprehensive package of sexual and reproductive health care services than women relying on private providers in both 1995 and 2002.⁶⁸

Health insurance policy and payment plans also affected how investigators selected to design studies. For example, although the guidelines suggest a Pap test every 12 months for newly diagnosed women living with HIV, Baranoski et al. elected to apply an 18-month follow-up period for screenings because some insurance companies do not pay for a routine pap test until at least one year has passed.⁶⁶ Baranoski went on to caution that as a result of the 18-month study period, results may over-estimate screening rates among women living with HIV. It is not clear if other researchers who opted for 18-month study periods were also motivated by health insurance and payment practice.

The relationship of race, ethnicity and language to frequency of gynecological care varied among studies. While Tello, et al. found that African American race was correlated with missed gynecologic appointments, Baranoski et al. found that women who were US-born, white or Hispanic, and non-English speaking were at risk for lower Pap testing.^{65,66} It is not possible to discern from these studies whether



screening was offered at equal rates and not accessed, and what role provider bias may play in these disparities.

Several studies also show that current or recent substance use is correlated with increased likelihood of missed gynecologic appointments.^{65,66}

Breast Cancer Screening

As women age, compounding co-morbid conditions, including breast cancer, are likely to increase among women living with HIV. The USPSTF recommends that all women, regardless of HIV status, undergo baseline mammogram screening at the age of 40.⁶² Only one of the articles reviewed addressed screening rates for breast cancer among women living with HIV. Rahangdale, et al found mammogram screening was performed on 64.7% of women age 40 or older, with variations by race, ethnicity and primary language – 100% of Latinas in the sample received mammograms, compared with approximately 64% of Black women and 50% of white women.⁶⁴ The sample size in this study is too small to extrapolate general characteristics and study investigators did not have access to data on insurance coverage, which may have influenced screening rates.

Sexually Transmitted Infections and Cervical Cancer

A report entitled “Gynecologic Care of Women with HIV Management Overview” published in 2011 provides a comprehensive summary of results from two large and prominent multisite studies; the WIHS and the HIV Epidemiology Research Study (HERS).⁶⁹ Funded jointly by the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC), WIHS and HERS follow women living with and at-risk for acquiring HIV residing across multiple US cities from the early 1990s until 2000. The review provides a comprehensive overview of key findings that relate to the natural history of HIV infection and interrelated health conditions for women and considers under-reported areas of study including menstrual abnormalities, gynecologic surgery and menopause, in addition to more frequently researched areas such as sexually transmitted infections (STIs), HIV testing and preconception counseling.⁶⁸

The frequency of both vulvovaginal candidiasis (VVC), the most common cause of vaginitis among women and bacterial vaginosis (BV), the most common cause of vaginal discharge among women of reproductive age, was found to be the same among women living with HIV and general populations, although infections in women living with HIV are considered more persistent.

Co-infection with herpes simplex virus type 2 (HSV2) increases the risk of shedding both HIV and HSV2 in the genital tract increasing the risk of transmission to sexual partners and the risk for acquisition of other sexually transmitted infections. Women living with HIV may require episodic or suppressive therapy. Data regarding the effects of anti-retroviral treatment on the reduction of HSV shedding is inconsistent. Human Papillomavirus (HPV) infection is also more prevalent and persistent among women living with HIV, resulting in greater occurrence of high-risk strains and cytologic abnormalities that can lead to cervical cancer. Among the general population of sexually active young women, HPV infections are common, frequent and generally asymptomatic, and approximately 91% of HPV infections clear within two years. However for women living with HIV, it remains uncertain how HIV progression may affect invasive cervical cancer. One hypothesis is that HAART may reduce the risk of cervical dysplasia and progression in invasive cervical cancer by decreasing HIV replication, however this has yet



to be been proven by research. Findings from a 2009 HERS publication report show an association between anti-retroviral treatment for HIV and clearance of HPV, but not an association with regression of abnormal Pap smears. Thus, additional research is needed to determine how effective anti-retroviral treatment may influence progression of cervical cancer among women living with HIV.

Sexual and Reproductive Health throughout a Woman's Life Span: Menopause and Aging

As people living with HIV live longer, healthier lives, there are an increasing number of women with HIV reaching menopause; however there remains limited data on menopause in this population and sexual and reproductive healthcare for aging women. Aging with HIV, and its effects, is the focus of a number of current research studies both in the US and globally, however, few results are available at this time. For women, symptoms of menopause such as night sweats, changes in weight, bone loss, mood swings, cardiovascular disease, cognitive changes including memory loss and reduced concentration and abnormal menstrual cycles can also be symptoms of HIV or side effects of HIV medication, complicating diagnosis.

In some studies, WLHIV have reported more symptoms associated with menopause than HIV-negative women. The reasons for such differences are not clear but some researchers think they may be related to age and educational levels. For instance, in one study of HIV-negative women, women 45 years or older were more likely than younger women to link vaginal dryness and hot flashes to menopause.⁷⁰ Also, HIV-negative women who graduated from high school were more likely to make these links between symptoms and menopause than women who had not also graduated from high school.⁷⁰ Similar analyses concerning age and education and menopause have not been widely done among HIV-positive women.

Another study found that women living with HIV were less likely to report symptoms associated with menopause to their doctors because they were not sure if menopause was responsible or if there were other ongoing health issues.⁷¹ This finding underscores the need for HIV-positive women to report their symptoms to their doctor so they can be investigated, and for providers to proactively ask questions. Menopause in the general US population occurs at a median age of 51.4 years and a few studies have shown menopause may occur 2-3 years earlier in women living with HIV. Early menopause has also been found to occur in African-American women, cigarette smokers and people who use substances, populations which are overrepresented among US women living with HIV. Williams et al. cites a prospective study that assessed 302 women living with HIV and 296 women at risk for acquiring HIV which found the average age of menopause was 46 and 47 years old and identified HIV infection, use of street drugs (opiates can reduce estrogen levels) and physical inactivity as linked to the early onset of menopause. Low CD4+ cell counts (less than 200), smoking tobacco (long-term use of tobacco can also lower estrogen levels) and having a low income are also correlates of early menopause.

Women who are experiencing symptoms of menopause may choose to seek treatment with hormone replacement therapy (HRT). Like birth control pills, HRT regimens containing estrogen may interact with components of HAART. Some antiretroviral drug interactions cause increased levels of estrogen while others cause decreased estrogen levels, which could result in ineffective treatment. Also, estrogen can affect levels of some antiretroviral drugs and lead to decreased levels of HAART, which could place viral load management at risk.

More research is needed to explore the links between menopause, HIV and their combined effects on bone loss, cardiovascular disease and brain health among older women living with HIV.



V. Contraceptive Choices

Literature categorized under this section primarily examines use of contraceptive methods among women living with HIV to prevent unintended pregnancy, risks associated with contraceptive methods, and provider-patient communication related to contraception. Little information was available on access to contraception or provider and patient attitudes towards contraceptive options.

Contraception Options

A variety of contraceptive methods exist in the United States: male and female condoms, cervical diaphragm, caps spermicides, combined oral contraception (COC), progesterone only pills (POP), injectables, patches and implants, copper bearing intrauterine devices (IUD), emergency contraceptive male and female sterilization, withdrawal, rhythm method, and abstinence.

The myopic focus of health professionals on promotion of male condoms as a method of contraceptive for PLHIV may come at a cost, paradoxically leading to higher rates of unintended pregnancy among women living with HIV by leading women to neglect other forms of contraception which are more effective and require less negotiation with partners. While condom use has been extensively studied as a form of prevention for both STIs and pregnancy among women living with HIV, the use of other forms of contraception by women living with HIV has not been adequately explored. Thus, recent literature focused on use of contraception options other than barrier methods by US women living with HIV is rare. According to the report “Contraception Choice for HIV-Positive Women”, contraception use and adherence may be related to the range of methods available, patient choice, prevalent health and religious beliefs, perceptions of method effectiveness, and side effects.⁷²

In one cross-sectional survey of 700 women living with HIV from across the United States receiving combination antiretroviral treatment for at least 3 years, 55% of respondents reported never having discussed gender-specific care and treatment issues with their HIV care providers.⁷³

Trends in Barrier Method Use by Women Living with HIV Vary By Study

In one study of 3,066 WIHS participants, Massad et al. found that use of contraceptive methods by women living with HIV changed little over the time period from 1995 to 2005, with barrier use declining slightly and no significant change in hormonal or non-hormonal contraceptive use.⁵⁴ Risk reduction strategies may change over diagnosis time, with HAART initiation, and when oral contraception is used. Much of the research on unprotected sexual activity of women living with HIV comes from outside the US, and US-based literature is primarily focused on condom use.

Massad et al found that among women living with HIV, barrier methods were the most common form of contraception (30.5% - 36.3%) followed by sterilization (21.9% - 26.5%) and hormonal contraception (less than 10%).⁵⁴ Throughout the study, more than 30% of women at risk for pregnancy reported using no contraception, and a majority of reported pregnancies occurred among women living with HIV who were not seeking to conceive. Less than 40% of women reported use of barrier methods at each study visit. In addition, Massad et al. found that use of antiretroviral therapy was not associated with reduction in use of barrier methods.⁵⁴ The study did not explore how, if at all, the rate of using barriers differed with steady versus casual partners.



A decrease in condom use among women living with HIV with a known diagnosis has been documented among women who are over 40 years old; on anti-retroviral treatment; sterilized; in serodiscordant relationships; or among women whose partner is also living with HIV. Mitchell et al. identify factors inhibiting use of male condoms by women living with HIV to include lack of availability, fear of being perceived as having multiple partners or being unfaithful to a regular partner, opposition on religious grounds, and male dominance in decision making.⁷⁴

Other literature suggests that contraceptive use, especially barrier methods, increase upon knowledge of HIV status. A meta-analysis conducted by Marks et al. suggested high-risk sexual behavior, defined as unprotected anal or vaginal intercourse, decreased upon knowledge of HIV status with similar results for men and women.⁷⁵ The analysis integrated findings from 11 independent studies conducted between 1988 and 2003. The model showed 53% of total participants engaged in unprotected anal or vaginal intercourse. Following knowledge of HIV status, unprotected anal or vaginal intercourse decreased by 68% in this group.⁷⁵ Caution must be taken when interpreting modeled results. In addition, a reduction in unprotected intercourse could have been due to HIV hysteria and fear in the 1990s. However, Marks et al.'s analysis along with others suggests that use of contraceptives may increase with knowledge of HIV status.^{76,77}

Investigators of a small longitudinal study that employed narrative data collection found that among 55 women living with HIV in serodiscordant relationships, 32 (58%) were completely abstinent, 13 (24%) used condoms every time they had sex, and 10 (18%) had sex on a regular basis without condoms.⁷⁸ Investigators found unprotected sex occurred among women living with HIV within monogamous partnerships and that women reported difficulty negotiating condom use with partners. Women reporting unprotected sex also reported experiencing trepidation about passing the virus to their partners, pressure to satisfy partners and guilt after having unprotected sexual intercourse.⁷⁸ One study of 724 women enrolled in the WIHS, found that among all sexually active women, unprotected sex was more common after initiation of HAART.⁷⁹

Condom Use Among Young Women with HIV

One of the few studies to look at female adolescents aged 13-18 living with and at risk for acquiring HIV found that of 231 respondents, only half reported using effective contraception consistently, despite its availability.⁸⁰ Use of male condoms was significantly associated with HIV-status in this study. For girls living with HIV who reported male condoms as their sole contraceptive measure, 73% reported using condoms 100% of the time during intercourse, compared to HIV-negative girls who reported using condoms 46% of the time during intercourse.⁸⁰ Belzer et al. suggest women with HIV across age groups appear to feel more compelled to use condoms consistently compared to the general female population.



V. Fertility Desires and Decisions:

Literature assessed on this topic of fertility desires and decision-making for women living with HIV predominately centered on identifying influencing indicators and trends related to pregnancy—including cultural and social factors, perceptions of risk, analysis of desire versus intention, and pregnancy and sterilization rates.

Since HIV began to appear in women in the early 80s, health providers, researchers, policy leaders and the public have taken it upon themselves to engage in an ongoing ethical and moral debate regarding the right of women living with HIV to bear children, ability to care for children with the onset of a chronic life-threatening illness, and perceived risk for HIV transmission to partners and offspring. According to authors Gruskin et al. the prevailing assumption driving public health policy and practice regarding women living with HIV is that an HIV diagnosis will or should mitigate a woman's desire to have children.⁸¹ However, increasingly, women living with HIV are choosing to have biological children.

Today, there are over 300,000 women living with HIV in the United States and the vast majority—approximately 80 percent—are of reproductive age (between 13-44 years old).^{84,85,88} Advancements in HIV treatment and care, increased life expectancy and improved health quality, and reduction of vertical HIV transmission risk to less than 1 percent with effective care and treatment have made it possible to conceive safely and to achieve a healthy pregnancy for mother, child and partner. Despite continuing stigma and discrimination about HIV and pregnancy, an increasing number of women and men living with HIV in the United States are choosing to start families. In fact, the number of pregnancies among women living with HIV in the US has increased by 30% between 2000 and 2006.¹⁶

Desires versus intentions

Findings from the Risk and Prevention Study which surveyed 1,421 men and women living with HIV in the United States in 1996 revealed 28-29 percent of adults living with HIV desire children in the future and, of those, 69% of women and 59% of men expect to have one or more children in the future.⁸² These investigators also compared their findings to the general US population, concluding the percentage of women living with HIV desiring children in the future was less than the general population of women who desire children (29% compared with 36%).⁸⁰ Results from this study also indicated that Black men and women living with HIV were more likely to expect children in the future compared to other racial groups.⁸² Investigators hypothesized that desire for children is likely associated with economic or cultural backgrounds that link parenthood to adult identity.

In the article “Throwing the Dice: Pregnancy Decision-Making Among HIV-Positive Women in Four US Cities,” authors cite data from the HIV Cost and Services Utilization Study (HCSUS) which found that although 29% of women living with HIV acknowledged a desire for children, nearly one third, or 31% of those same women did not intend to have children, indicating a notable difference between desiring children and expecting to have children.⁸³

Similarly, findings from the Risk and Prevention Study revealed that among WLHIV who desire children, only half expect to have one child and just 13% expect to have two or more children. According to the study, the expectation to have at least one child was slightly lower for WLHIV across age groups (82%-89%) compared to the percentage measured among US women as a whole (85% to 94%).⁸² The study further demonstrated that the percentages of women expecting two or more children was consistently



and substantially lower among WLHIV (57-65%) across age groups compared to HIV-negative women (68-81%).⁸²

Investigators of a study published in the 2012 article “Reproductive Healthcare Needs and Desires in a Cohort of HIV-Positive Women” found that of 127 non-pregnant women living with HIV between the ages 18-50 receiving care at an outpatient clinic in Atlanta, Georgia, nearly one third (29.4%) desired future fertility.⁹² However, of these almost half (46%) were unsure when they wanted to become pregnant in the future and only 8.1% desired to become pregnant within the next year. It is also important to note the sample of this study represented a mature reproductive-aged cohort; of the 127 women surveyed the mean age was 37.8 and most had been pregnant in the past (91.3%) and had born at least one child (81.6%).⁹²

A 2004 study focused on evaluating desire for pregnancy among young women living with HIV between the ages of 13-24 from five clinics across the country (Chicago, Los Angeles, Miami, New Orleans, and New York) found 31.5% of 130 women sampled reported some level of desire to become pregnant in the next six months.⁸⁴ In this study, desire for pregnancy was also associated with an increased likelihood of sexual intercourse and decreased condom use. These findings are consistent with previous studies that indicate WLHIV who intend to become pregnant report higher pregnancy rates.

Stanwood et al. surveyed 118 women living with HIV at the Infectious Diseases Clinic at the University of Rochester Medical Center, finding that 20% planned to have children in the future and another 15% stated that they “may want children in the future.”⁸⁵ In contrast to other researchers, Stanwood et al. concluded women living with HIV in the study appear to have reproductive histories and plans similar to HIV-negative counterparts. Most of the participants in the study were mothers and in long-term monogamous heterosexual relationships. Childbirth, miscarriage and abortion were common events in the study population as they are among reproductive-age women in general.⁸⁵

From Desire to Intention: Factors Influencing Decision Making

Not surprisingly, findings in the literature indicate multiple factors aside from HIV status play an equal if not greater influential role in the attitudes and decisions of women living with HIV regarding fertility.^{82,83,84,88} Authors of a report summarizing a 3-day conference “The Pregnancy Intentions of HIV-Positive Women: Forwarding the Research Agenda” held in 2010 concluded a number of common factors worldwide influence desires of WLHIV to bear children including: age, health status, cultural significance of motherhood, number of living children, previous experience of a child’s death from HIV-related causes, the availability of HIV treatment and prevention of mother-to-child transmission (PMTCT) programs, the attitudes and influence of partners, family, and health care workers, and stigma and discrimination on the basis of HIV status especially for women coming from already marginalized populations.⁸⁶

Societal norms can negatively influence a woman’s decision to have children if she is living with HIV. Several authors and investigators throughout the literature discuss dominant and traditional cultural norms associated with a woman’s role in childbearing in relation to women living with HIV. In “Throwing the Dice: Pregnancy Decision-Making Among HIV-Positive Women in Four US Cities,” Kirschenbaum et al. suggest that women living with HIV are in a “sociocultural double bind” in which their desire for children violates beliefs about “acceptable mothering.”⁸³

Two contrasting obligations remain for women living with HIV diagnosed before or during childbearing



years: socially prescribed values that most women should be mothers; however motherhood for women who are living with HIV is socially rejected. Investigators Barnes and Murphy raised the idea that instead of answering the question “When are you going to have a baby?”—a common question asked of women in their childbearing years—women living with HIV are confronted with a different, and difficult question: “Why would you have a baby?”⁸⁷ Women living with HIV have the burden of needing to justify their reproductive choices while simultaneously dealing with social pressures and negative public opinion. Ultimately, the desire for motherhood and cultural influences may have a greater effect on women’s reproductive choices than HIV status and HIV-related conditions. Research demonstrates that women’s decisions may be based on the judgment and meaning given to motherhood.^{87,84}

Several studies also found that a large number of women living with HIV held negative attitudes toward other women living with HIV who either expressed an interest in having children or decided to become pregnant post-diagnosis. Investigators of a study which interviewed 80 living with HIV from 3 regions including Oakland, CA, Chicago, IL, and Rochester, NY found a number of participants shared the opinion that women living with HIV should only have children under specific conditions which included: if they did not already have children that they were mothering; if they were going to follow prenatal care regimens; and if they were potentially healthy enough to raise their child.”⁸⁸

These findings are consistent with another small study which surveyed 56 women living with HIV ages 20 to 55 years old from 4 major metropolitan areas –Los Angeles, Milwaukee, New York City, and San Francisco.⁸³ Investigators found women from the study who did not desire children after diagnosis held strong negative opinions of women living with HIV who choose to become pregnant. These investigators also highlighted that the vast majority of women intending not to become pregnant had borne children prior to diagnosis, hypothesizing their desire for childbearing may have been satisfied.⁸³

Across numerous studies and articles, findings indicate HIV status alone is not a sole factor in reproductive decision-making among women. Kirshenbaum et al. concluded that being HIV-positive “dampens” but does not come close to eliminating individuals’ desires and intentions to have children.⁸³ Researchers identified several factors women living with HIV consider when making fertility decisions. These include: vertical transmission risk assessment, risk reduction strategies, outcomes of previous births that occurred after HIV diagnosis, desire for motherhood, having children prior to diagnosis, opinions of partners and health care providers, religious values and the perceived capacity to parent successfully regardless of HIV status.⁸⁸ Furthermore, Barnes et al. concluded women’s reproductive decisions were more often influenced by the culturally constructed meanings of motherhood and the strongest influence on pregnancy decision making for women living with HIV was the desire for a child.⁸⁷

Pregnancy desires and intentions also differed by perception of vertical transmission risk. Kirshenbaum et al. found that women living with HIV who wanted another pregnancy perceived vertical transmission probability to be low, while those who did not want another pregnancy considered the risk of vertical transmission too high.⁸³

Younger women and women without children are more likely to consider pregnancy

Kirshenbaum et al. found that those who became pregnant after diagnosis tend to be younger, less educated, have been living with HIV longer and have more previous pregnancies, miscarriages and abortions than women who did not become pregnant.⁸³



In a study that compared the fertility decisions of 104 women living with HIV in 1997 and 1998, Bedimo-Rung et al. found women who became pregnant were more likely to be young, single, diagnosed earlier in the epidemic, healthier in terms of CD4 counts and also more likely to have a recent history (within the past year) of non-injecting drug use.⁸⁹ Of perhaps greater interest was the high rate of unplanned pregnancies among pregnant women in this study, consistent with research indicating higher rates of unintended pregnancies among women living with HIV. Among the cohort that became pregnant, over half (55%) reported they had tried to prevent the pregnancy and 33% had not planned to get pregnant suggesting that over three quarters (88%) of these first subsequent pregnancies were unintended.

While the most common predictors linked to pregnancy subsequent to HIV diagnosis included younger age, childlessness, perceiving vertical transmission as low risk, and better overall health, researchers have identified other variables associated with pregnancy among women living with HIV. Investigators of a study that surveyed 403 women living with HIV between 14 and 35 years old found that age under 22 years, single marital status, living with a family member, history of sexual assault, and an entry CD4 count of over 500, were significantly associated with becoming pregnant subsequent to HIV diagnosis.⁸⁹ These investigators concluded that certain characteristics and life experiences among women living with HIV, including young age or a history of sexual abuse should signal health care providers that a patient may be more likely to get pregnant, have abortions or to be sterilized.⁸⁹

While the vast majority of articles reviewed documented fertility rates related to full-term pregnancy, abortion, miscarriage and or non-pregnancy outcomes, it is important to note that not all researchers designed studies to measure respondents' desires, intentions and attitudes related to fertility or conception. Desire does not equate to intention or expectation; several studies show a discernible difference between desiring or wanting children and intending or planning to have children.⁸² Chen et al. demonstrated that the desire for children is affected by personal and cultural traits, while the intention to have children is influenced by timing and situational factors.⁸²

Pregnancy Rates

Despite an increase in pregnancies among women living with HIV in recent years, research findings consistently indicate women living with HIV have lower rates of pregnancy overall compared to the general female population. Findings from WIHS carried out between 2002-2009 that compared the frequency of pregnancy and relative time to pregnancy for women living with HIV and HIV-negative women living in the US indicate women living with HIV had longer time to conception and lower incidence rates of pregnancy compared to the general population.⁹⁰ Of 1,412 women surveyed, investigators found HIV infection was associated with 40% reduction in the incidence rate of pregnancy and the time for women living with HIV to become pregnant was 73% longer relative to HIV-negative women. Investigators could not conclude whether the lower incidence of pregnancy was due to behavioral differences or reduced biologic fertility and suggested follow-up research in this area.⁸⁰

Data from the HIV Cost and Services Utilization Study (HCSUS), which ran from 1994-2000, revealed that 12 percent of all women living with HIV surveyed and 26% of those younger than 20 years old conceived after diagnosis.⁸³ An additional 10% were diagnosed with HIV during their pregnancy and carried to term. However women living with HIV who intended to have children had fewer births compared to the general population.



Communication with Healthcare Providers

Although it is clear that women living with HIV desire pregnancy and are indeed having children, there is an obvious gap in communication about reproductive health between healthcare providers and women living with HIV. Of the few articles that examined provider-patient communication related to reproductive health, many found a notable paucity of meaningful and adequate discussions related to fertility desires and planning. Consistent with the 2011 Women Living Positive Survey, published in the article “Do HIV-Infected Women Want to Discuss Reproductive Plans with Providers, and Are Those Conversations Occurring?” investigators report significant communication breakdown between health providers and women living with HIV regarding fertility choices and planning. Of 181 women living with HIV of reproductive age, nearly 40% reported a desire for children and a desire to talk with their providers, however almost a quarter (23%) of these women had not had a discussion with their provider about pregnancy.⁹¹ Investigators of a 2010 study which surveyed 127 non-pregnant women living with HIV in Atlanta, GA, found that while 29.4% desired future fertility, only half of those sexually active had spoken with a provider in the past year regarding family planning and approximately one third (32.1%) reported either never speaking with a provider about contraceptive plans or indicated the conversation took place more than five years ago.⁹²

Squires et al. found that among 227 women living with HIV who were considering pregnancy or had been pregnant but were not pregnant at the time of the survey, nearly half (48%) were never asked by their health care provider if they had or were considering having children.⁷³ The investigators theorized that HIV practitioners do not anticipate family planning and pregnancy discussions with their patients either because their focus is on disease management or because of an expectation that this is discussed with other health care providers.⁷³ However, many women living with HIV may not interact with other health care providers unless they face a medical emergency.

Rahangdale et al found that among 178 women living with HIV receiving care at twelve sites in the US, only about one-fifth of pregnancies among study participants were planned.⁶⁴ Women in the study were majority Black, median age was 28 years, and 86% had seen a healthcare provider in the previous year. Close to half (45%) reported having initiated conversations with their providers about their interest in pregnancy, and 60% reported that their providers had initiated a similar conversation. Nearly all (97%) reported having received counseling about condom use and over half stated that when they became pregnant they did not want the baby. Rahangdale further demonstrated that planned pregnancies were associated with patient-initiated conversations about conception and pregnancy.⁶⁴

Natural Conception

Studies documenting that risk of vertical and horizontal transmission risk when viral load is suppressed are extremely low, coupled with the cost of assisted reproductive technology, should prompt medical providers to consider counseling women living with HIV about natural conception. Safer natural conception has become a viable option for serodiscordant couples, and several recent papers review the literature and consider appropriate recommendations to reduce transmission risk.^{93 94} According to Barreiro et al, “natural conception [can] now be considered a possible alternative for HIV-serodiscordant couples, as long as complete suppression of viremia with HAART is achieved in the infected partner.”⁹⁵ We were not able to identify research documenting to what extent WLHIV are counseled about natural conception options.



Sterilization Among Women Living with HIV

Worldwide, sterilization of women (32%) is the most common contraceptive practice, followed by the use of intrauterine devices (22%), and the oral contraceptive pill (14%).⁹⁶

Authors of the article “Contraceptive Use among US Women with HIV” observe in studies conducted before the introduction of highly active antiretroviral therapy (HAART), women living with HIV selected tubal sterilization more often than HIV-negative women. Investigators of a study assessing 403 women living with HIV between the ages of 14 and 35 years old, prime childbearing years, enrolled in the HIV Outpatient Program in New Orleans, Louisiana between 1987 and 1995 found women living with HIV tended to have higher rates of sterilization and abortion compared to HIV-negative women.⁵⁴ Bedimo et al. found 34% of the women in the sample were sterilized by the end of the study period, and 84 women (24%) underwent sterilization after learning their HIV diagnosis.^{89,91}

Another study conducted in 2004 found that of 118 women living with HIV receiving care at the Infectious Diseases (ID) Clinic at the University of Rochester Medical Center nearly half (47%) had been sterilized. In that study, one-third of the women surveyed desired future children and 12% of those had already been sterilized.⁸⁵

More recent research conducted in the last decade indicates there is still a high propensity for sterilization globally⁹⁷ and in the US, despite the established effectiveness of HAART on health of mothers and reduction of risk for vertical transmission. Badell et al. found of 127 women living with HIV surveyed between 2008 and 2010, 56 (44.4%) had opted for sterilization as contraception and more than half (56.4%) reported that HIV was one of the reasons they chose to be sterilized.⁹² High rates of sterilization regret were also reported – with 36.4% reporting regret, and 18.2% of women who had been sterilized expressing a desire to still have children in the future. These rates of sterilization remorse are higher than those in the general population of women who have undergone sterilization. Badell et al. conclude while a substantial number of women living with HIV had undergone sterilization, their contraception and fertility desires suggest that effective and reversible contraceptive methods may be more appropriate. The literature is unclear with respect to what role provider-patient communication, provider bias, and internalized stigma may have played in sterilization among WLHIV.⁹²



Findings from a National Survey of Women Living with HIV in the United States

A. Introduction

To better understand the current experiences of women living with HIV in the United States with respect to sexual and reproductive health, in their own words, Positive Women's Network – United States of America (PWN-USA) conducted a survey of US women living with HIV in August and September 2013. This survey was conducted among 179 women living with HIV in the United States. The purpose of the survey was to collect quantitative and qualitative data on sexual and reproductive health and rights as they are currently experienced by women living with HIV in the US, in order to recommend program planning, policy change, and further research to uphold the full rights of women living with HIV as sexual and reproductive beings. The survey explored the following key areas of interest: 1) Engagement in HIV care, including viral load; 2) women's self-perceptions of their bodies and sexuality; 3) sexual activity; 4) women's navigation of disclosure to romantic and sexual partners, 5) to what extent women understand and are being counseled on viral suppression as a prevention strategy, 6) efforts to prevent HIV transmission and 7) access to and utilization of SRH services. The survey was conducted via a questionnaire, distributed online and on paper.

B. Background: Survey Planning Team and Process

1. SRHR Project Team. The Project Team described earlier in this paper in "Project Design" provided input into the development of the survey instrument as well as dissemination. The Project Team was comprised of a project coordinator and three subject matter experts: a literature review consultant, a technical advisor on policy, and a lead on survey design and implementation. All members of the Project Team were women openly living with HIV.
2. SRHR Advisory Group. In addition to the Project Team, PWN-USA convened a diverse six member advisory group composed of women living with HIV from across the nation to provide essential input and feedback to the SRHR Project Team during development of the survey tool and distribution process. Each member represented a region of the US. The advisory group served as pilot survey respondents, focus group members, recruiters and group facilitators. PWN-USA sought a diverse group of survey respondents and utilized the reach of Advisory Group members to ensure this diversity. The combined efforts of these two groups resulted in a consensus survey instrument and process which was sensitive to participant concerns and ensured participant confidentiality.

C. Participants

The total number of individuals, including women living with HIV, who attempted to complete the survey was 200. A total of 179 women living with HIV living in the United States (respondents) completed the 70-question survey. Of the total, 133 (74%) respondents completed the survey online and 46 respondents (26%) completed the survey in paper form. Respondents were offered a \$20 incentive as appreciation for their time spent completing the survey.



D. Data Collected

The survey collected two forms of data: qualitative data, including participant comments and quantitative data, including metrics.

Both the online and paper survey collected the following data: 1) demographics, 2) HIV serostatus and care, 3) relationships, 4) sexual practices including disclosure of HIV serostatus, 5) sexual health and reproductive practices, 6) SRH services and access and 7) confidentiality. The table below provides a breakdown of the total number of questions asked for each section.

TABLE A: Questions Per Survey Section

Name and Number of Survey Sections	Total Number of Questions per Survey Section	Questions per Survey Section by Number
1. Demographics	Total questions: 15	Questions #2 thru #16
2. HIV Serostatus and Care	Total questions: 8	Questions #17 thru #24
3. Relationships	Total questions: 9	Questions #25 thru #33
4. Sexual Practices	Total questions: 14	Questions #34 thru #48
5. Sexual Health Practices	Total questions: 10	Questions #49 thru #58
6. SRH Services & Access	Total questions: 8	Questions #59 thru #66
7. Privacy, Confidentiality & Disclosure	Total questions: 3	Questions #67 thru #69

E. Methods:

The 70-question survey instrument was accessible online and in paper form. For the online survey, outreach was conducted via email and social media, including listservs and social media of PWN-USA members and allies.

Participants were automatically screened out of the survey if ANY of the following conditions were met: i) did not complete consent form ii) identified gender as “male”, “not sure”, or “prefer not to respond” iii) did not currently reside in US iv) answered “What is your HIV status?” with “HIV-negative”, “not sure” or “prefer not to respond.”

For the paper survey, advisory group members were instructed to recruit women living with HIV 18 years or older from their geographic areas, inclusive of women who were postmenopausal. Advisory group members also supported participation of women living with HIV by conducting in-person and phone-based groups for women living with HIV who either did not have access or limited access to computer and online technology.



F. Survey Results:

Following are the survey results for the following areas: 1) demographics, 2) HIV serostatus and care, 3) relationships, 4) sexual practices including disclosure of HIV serostatus, 5) sexual health and reproductive practices, 6) SRH services and access and 7) confidentiality.

I. Demographics

- Age:
 - Respondents ranged in age from 22 years old to 65 years old. Overall, the respondent sample was mature, with the paper survey respondents skewing slightly younger.
 - 41% of electronic survey respondents and 43% of paper survey respondents were of reproductive age (defined as 44 years or younger). The remainder were postmenopausal.
- Gender: 98% of respondents identified as female, 2% as transgender. 1 participant identified as intersex.
- Sexual Orientation: Heterosexual 80%, bisexual 9%, lesbian 5%, asexual 4%, queer 1%, pansexual 1%.
- Race/Ethnicity (self report):
 - 54% African American or Black
 - 30% Caucasian/White
 - 8% Hispanic or Latina
 - 4% African
 - 3.6% multi-racial or bi-racial
 - 1% Asian, Pacific Islander, Native American, and other

There was a marked disparity in self-reported race/ethnicity among respondents to the online survey and respondents to the paper survey. While 31.7% of online survey respondents identified as Caucasian or white, only 2% of paper survey respondents self-reported as Caucasian/white. In addition, 21% of paper survey respondents self-reported as Hispanic or Latina, while only 3% of online survey respondents self-reported as Hispanic/Latina. This may be indicative of disparities in technology access that impacted the electronic survey, in addition to the simultaneous power and limitations of network-based outreach that impacted the paper survey results. Respondent rate for African American/Black for the online and paper surveys was similar, at 53.8% for online and 54.1% for paper surveys.

- US Residence Status:
 - 89% US citizens by birth (93.8% of respondents to online survey and 71% of paper survey respondents)
 - 4% documented immigrants
 - 1% naturalized US citizens
 - Paper survey respondents were more likely to report that they were living in the US with immigrant status



- Education:
 - Respondents were asked to report their highest level of formal education completed.
 - Online survey respondents tended to be more educated.
 - 39% of online respondents had a 2- or 4 year college degree, while 11% of paper survey respondents had a 2 or 4-year college degree.
 - 15% of online respondents had completed a graduate degree program, compared with 4% of paper survey respondents.
 - 12% of respondents overall had not completed high school: 6% of online survey respondents did not complete high school and nearly 30% of paper survey respondents had not completed high school.
 - 11% of paper survey respondents had completed a vocational, technical, or professional schooling program after high school, compared with 16.5% of online survey respondents.
- Geography
 - 25 states were represented
 - Regionally:
 - 39% of responses overall came from the Southern US (SC, TX, FL, GA, LA, TN, WV, VA, NC)
 - 21% came from the Midwest (MI, IL, OH, ID, IA)
 - 23% came from the Northeast and Mid-Atlantic region (DC, NY, NJ, PA, MD, CT, DE)
 - 14% came from the West Coast region (CA, WA)
 - 2% came from the Southwest (CO, AZ)
 - Within these, the majority of paper survey responses came from a handful of metropolitan areas: Atlanta, GA, Chicago, IL, Dallas, TX, San Diego, CA, and the New York City metro area, where recruiters were based.
 - Areas of residence:
 - 47% urban
 - 19% suburban
 - 17% rural
 - Paper survey respondents were slightly more likely to characterize their area of residence as urban, less likely to live in suburban or rural areas.

Economics, Housing, Health Insurance and Employment Indicators

- Housing:
 - 30% of respondents lived in subsidized housing
 - 27% renting at market price (unsubsidized)
 - 26% were homeowners
 - 10% shared housing
 - 2% homeless
- Work Status:

Participants were asked whether they worked or volunteered, part time or full time.

 - Overall, we found that respondents were very active.
 - 62% of online respondents were working or volunteering part or full time and 54% of paper survey respondents were working or volunteering part time or full time.
 - Online survey respondents were more likely to be paid for their time and paper survey



respondents were more likely to volunteer.

- Nearly a third of paper respondents reported volunteering their time (30.4%), while 7.5% of online survey respondents reported volunteering their time.
- The online sample was more likely to be employed. 37% were employed full time and 19% were employed part-time, compared with 13% and 11% respectively of the paper sample.
- 23% of respondents overall reported they were unable to work. The survey did not ask respondents to specify reasons for being unable to work.

- Income:

It is clear that most survey respondents are living at the economic margins.

- Nearly half of all respondents (47%) reported an annual income of under \$20,000.
- At least 29% of all respondents were earning \$10,000 or less, well below the federal poverty level for a 1-person household.
- 30% of paper survey respondents and 11% of online survey respondents reported an income of under \$5000 per year.
- Only one paper survey respondent reported an annual income over \$50,000, compared with 15% of online survey respondents.
- Just over a fifth of online survey respondents (21.5%) had an income of \$40,000 or more.
- Women with an annual income of \$10,000 and less were more likely to live in subsidized housing.
- Most women with an annual income of \$50,000 or more owned their own home or apartment.
- There was no discernible relationship between income and relationship status.

- Health Insurance Coverage:

- 43% were on Medicaid. Over a third of women on Medicaid were also on Medicare.
- 19% were on AIDS Drugs Assistance Program (ADAP)
- 29% of online respondents had access to a private insurance plan provided by an employer, compared with 8% of paper survey respondents.
- Only 1% of respondents had private insurance plans through other sources (school or coverage provided by a parent or guardian).
- 4% of online survey respondents were paying for their own private insurance coverage.
- 8% of paper survey respondents reported they did not have any health insurance coverage. All were in the South.
- In contrast, only 5% of online survey respondents reported they did not have any health insurance coverage. The majority were in the South.
- Immigrant women were likely to be on ADAP.

- Access to Technology:

Access to technology differed greatly between online and paper survey respondents.

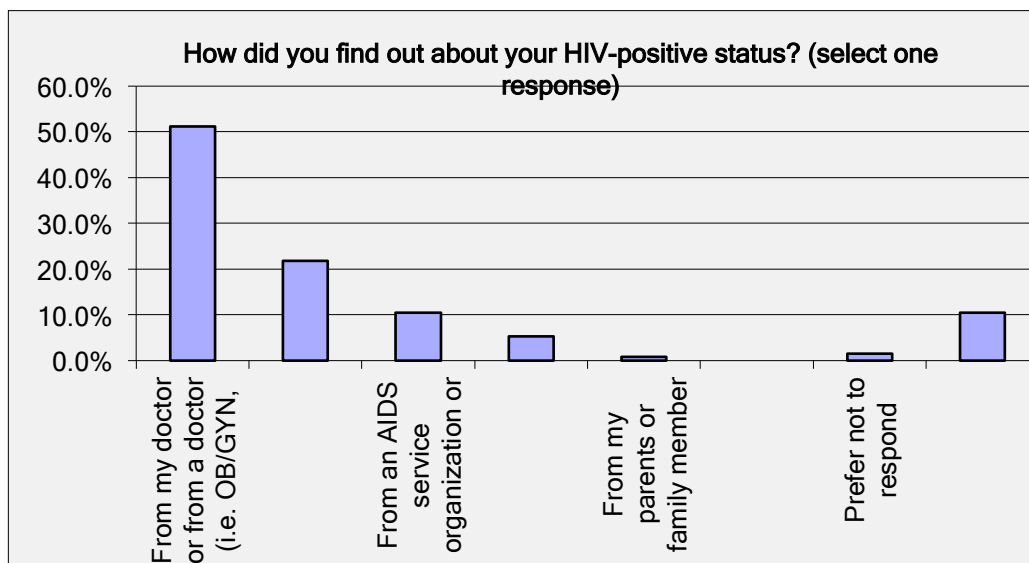
- For online respondents, over 62.6% reported having a smart phone, 59% had a laptop, and 54.7% had internet service.
- For paper survey respondents, 37% had access to a smart phone; 28% had a laptop and 26% had internet service.



- Childcare and Family Responsibilities:
52% of paper survey respondents and 29% of online survey respondents reported having at least one child under the age of 18 in their homes. Many women reported having multiple children in their homes, some of which were grandchildren.

II. HIV Diagnosis and Engagement in Care

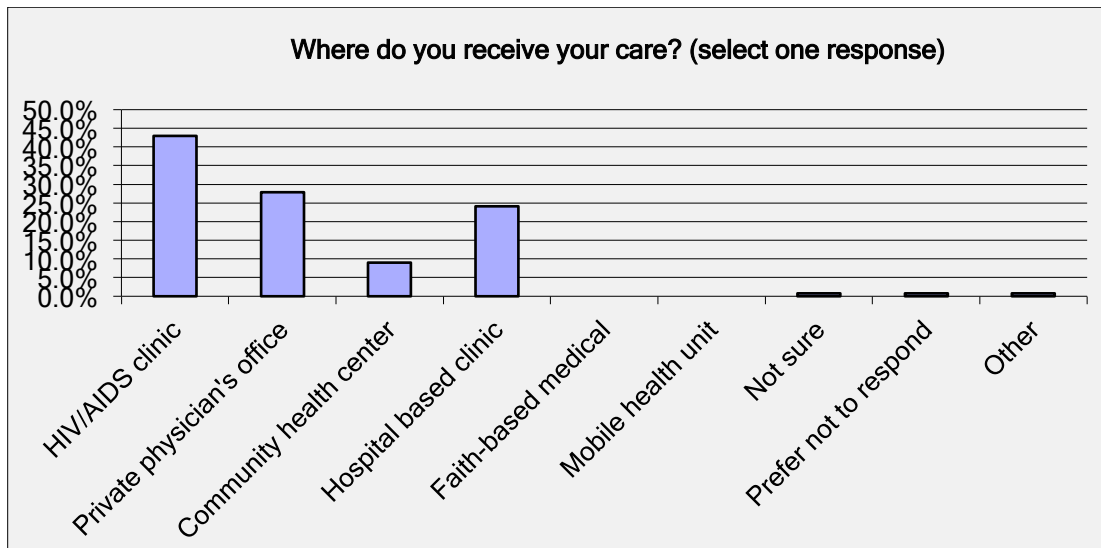
- Diagnosis Timeframe:
 - 14% of respondents had been living with HIV for over 20 years.
 - Over half (51.1%) were diagnosed prior to 2001.
 - 13% had been diagnosed since 2010.
- Notification of Diagnosis:
 - All respondents were most likely to have learned of their diagnosis from a doctor (ob/gyn, family doctor, emergency room doctor) – 67% of paper survey respondents and 52% of online survey respondents.
 - About a fifth (22%) of online respondents learned of their diagnosis from the health department, compared with only 13% of paper survey respondents.
 - 11% of online survey respondents learned of their diagnosis from an AIDS service organization or community-based organization.
 - 6.5% of paper survey respondents were initially informed of their diagnosis by a family member, compared with less than 1% of online survey respondents.



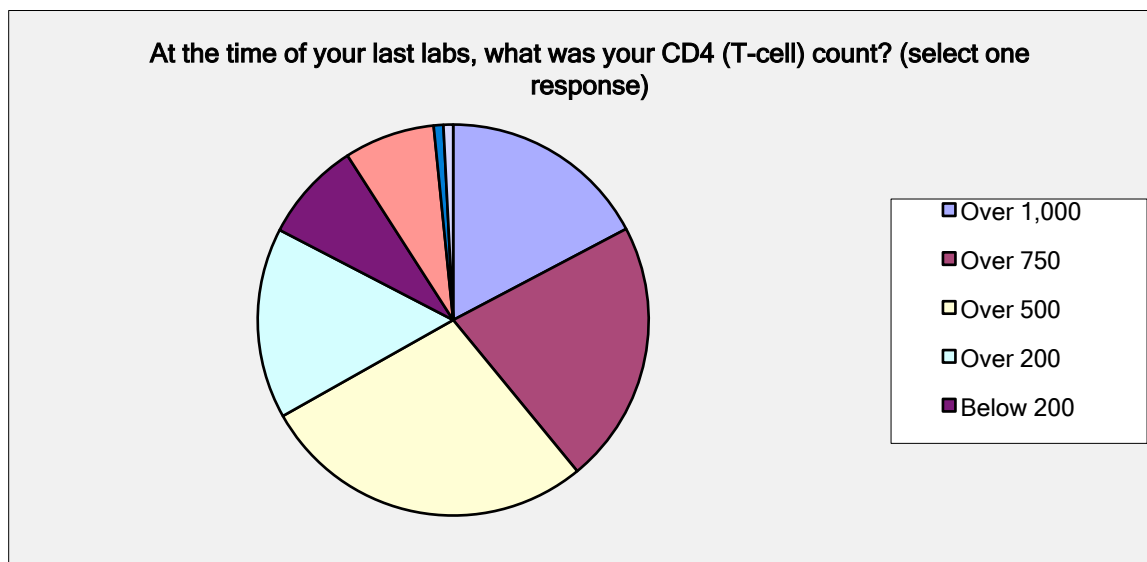
Receiving HIV Care:

- 96% of respondents were currently in care
 - Receiving care at HIV-specific clinic: 42% of online respondents and 56.5% of paper respondents.
 - Receiving care from private physician: 28% of online respondents and 13% of paper respondents.
 - Receiving care from hospital-based clinic: 24% of online respondents and 26% of paper respondents.

- Receiving care at community health center: 9% of online respondents and 2% of paper respondents.



- Currently taking HIV medications: 91% on HAART.
- Suppressed Viral Load (SVL): 80% had a SVL at the time of their last labs.
- CD4 (T-cell) count: 66% had CD4 counts above 500.



III. Relationships

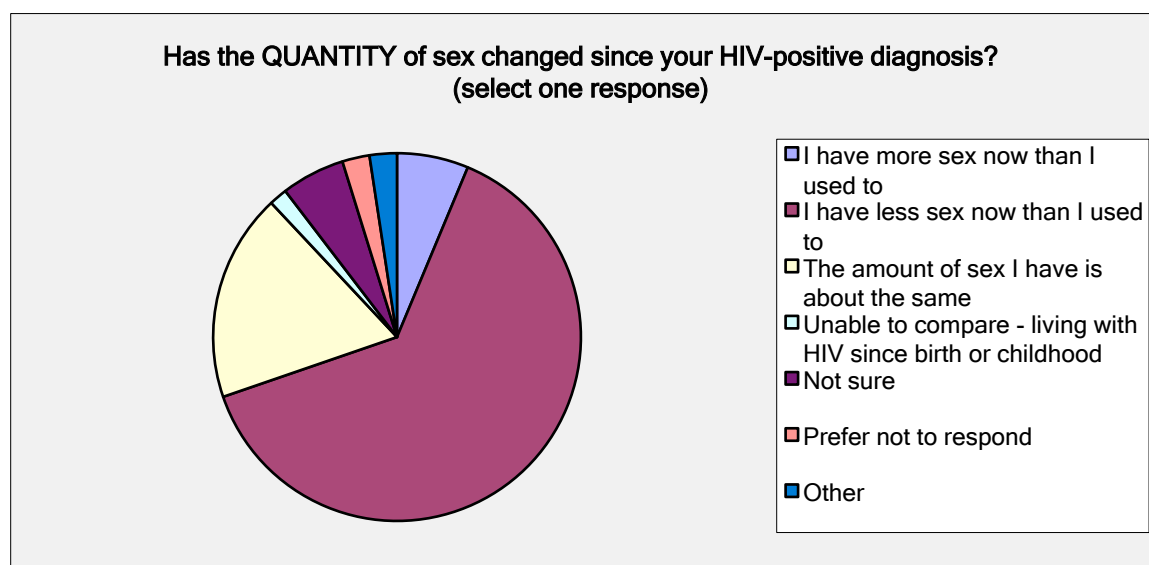
Relationship Status:

38% of respondents identified themselves as being single, 31% stated they were currently married or had a significant other, and 28% described themselves as widowed, divorced, or separated.

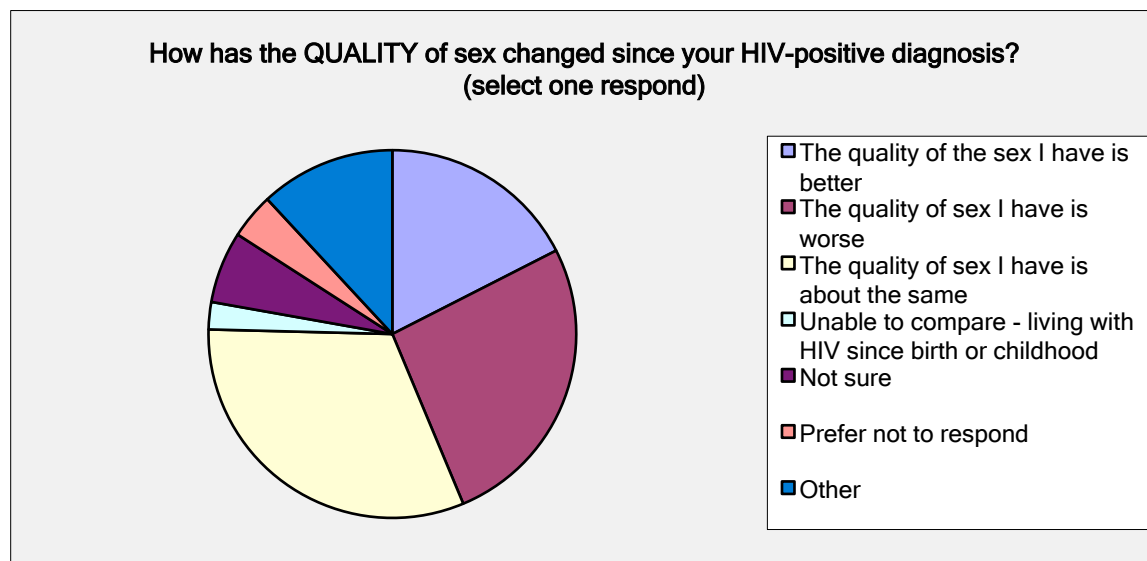
- In Relationship: 58% currently describe themselves as being in a relationship and 40% described themselves as not being in a relationship.
- Not in Relationship: Of those not in relationships - 25% stated they could not find a suitable partner, 21% were no longer with partner and 20% preferred not to be in relationship.
- Length of Relationship: 59% had been in relationship with their current partner 3 years or more and, of this group, 38% were in relationship with the same person at the time of diagnosis with HIV.
- Partner's HIV Status: 64% of respondent's partners are HIV-negative.
- Proximity to Partner: 78% of respondents live with or in the same city/town as their partners.
- Nature of Relationship: 68% described their relationships as monogamous.
- Relationship Satisfaction: The majority of women who stated they were very satisfied with their relationship identified friendship as a fulfilling factor in their relationship (52%), while 45% who stated they were dissatisfied reported money as an issue – identifying as either financially responsible or financially dependent within the relationships.

IV. Sexual Practices

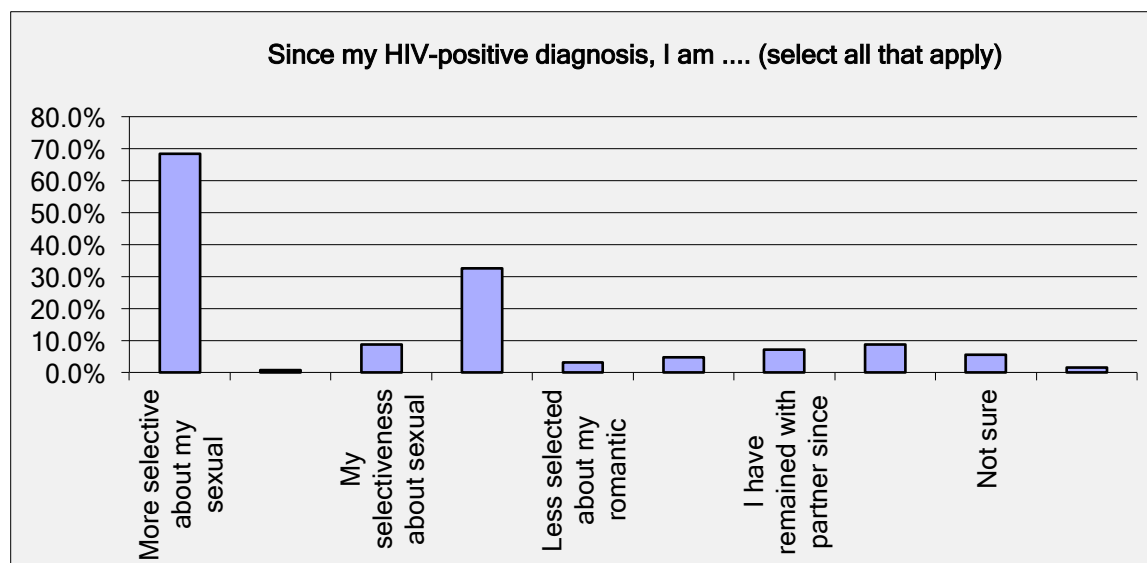
- Change in Sexual Practices or Behaviors: 75% reported a change in sexual practices or behaviors since being diagnosed as HIV-positive.
- Quantity of Sex: Nearly two thirds, or 63%, reported a decrease in the frequency of sex since being diagnosed HIV-positive.



- Quality of Sex: 32% reported no change in quality of sex, 26% reported that quality of sex is worse and 18% reported that quality of sex is better.

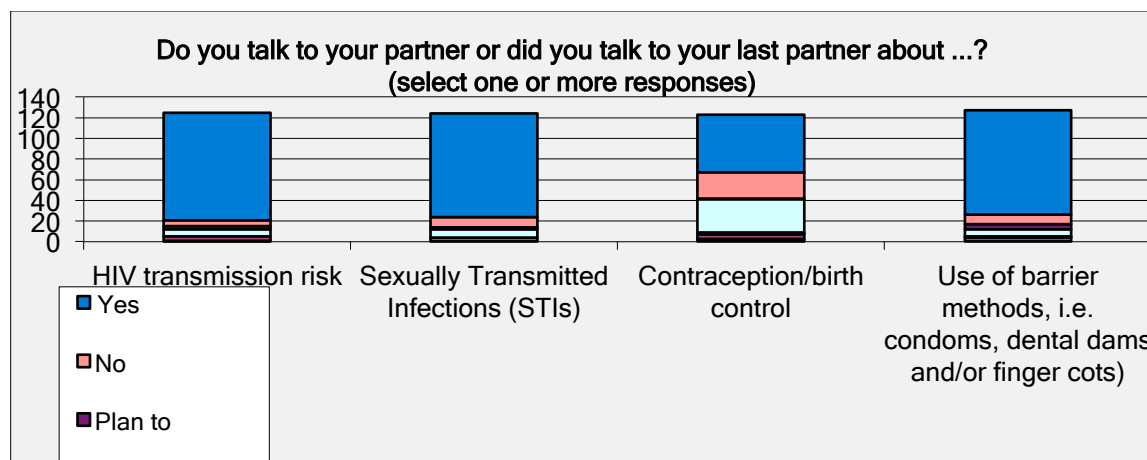


- Partner Selectivity: 68% reported being more selective about their sexual partner(s) and 33% reported being more selective about their romantic partner(s).

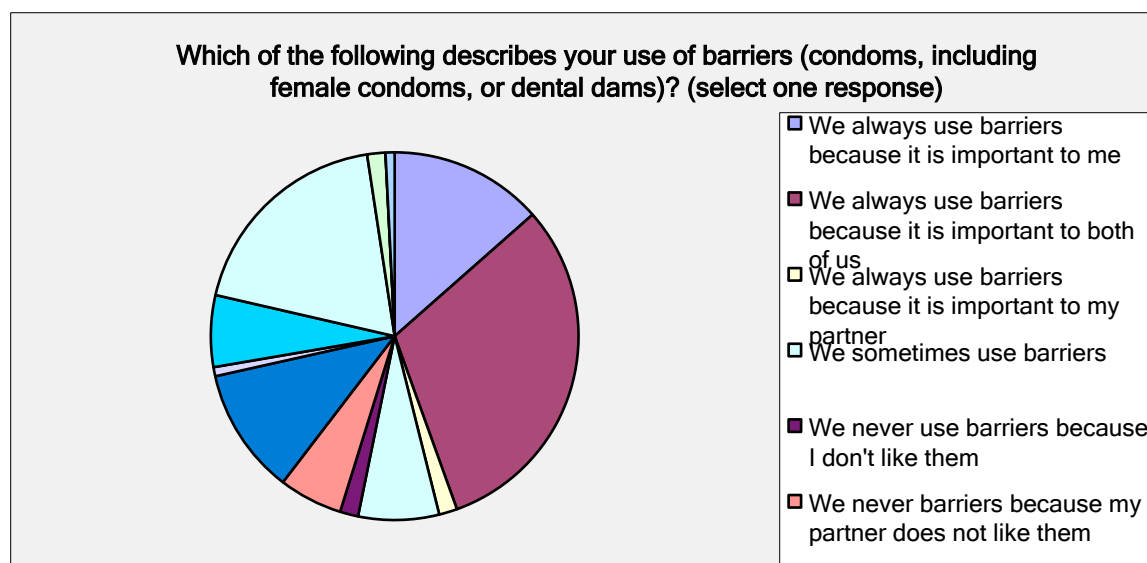


- Current Sexual Activity: 42% reported having sex on a regular/consistent basis with one partner, another 38% reported having sex with self, 14% are not having sex because they cannot find a partner, and 11% are not having sex because they do not want to disclose HIV status. 10.4% reported they hook up regularly with someone they know and 4% reported regular hookups with more than one partner.

- Talking with My Partner: Over 80% respondents talk to their partner(s) about HIV transmission risk, sexually transmitted infections (STIs) and use of barrier methods.

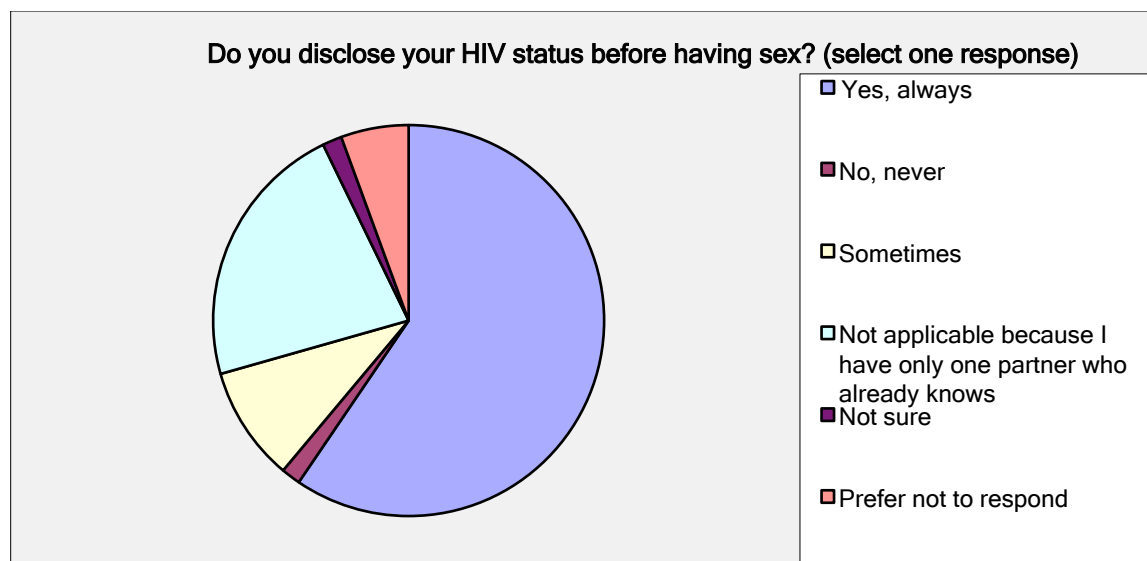


- Knowledgeable about Barrier Methods: 97% are knowledgeable about latex male condoms, 93% are knowledgeable about non latex male condoms, 84% are knowledgeable about female condoms, 79% are knowledgeable about dental dams and 64% are knowledgeable about finger cots.
- Use of Barriers: 46% reported they always use barriers. 18% reported they never use barriers, over half of those stated they had an agreement with their partners not to use barriers. 9% stated they sometimes used barriers, or “it depends on the partner”. 26% stated that barriers were not relevant because they were not currently sexually active.

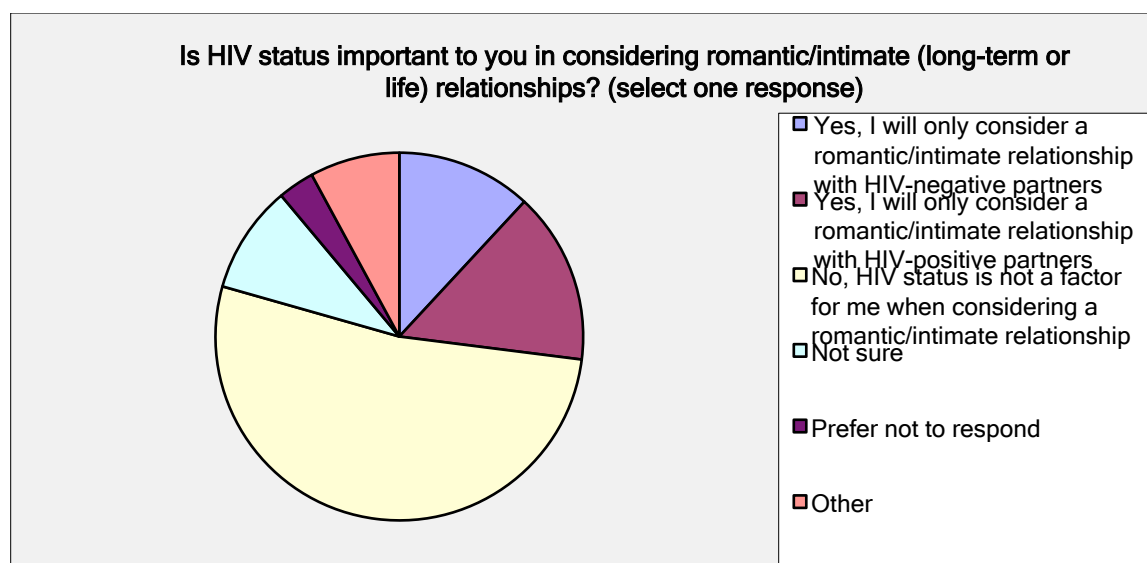


- Access to Male and Female Condoms: Respondents get their male and females condoms from ASO/CBO, 72%), health department (63%), community events (46%) and stores (43%).

- Pre-Sex Disclosure of HIV Status: 60% reported they always disclose their HIV status before having sex, 10% stated they disclose sometimes and 2% reported that they never disclose.



- HIV Status of Sexual Partner(s): For 42% of respondents, HIV status of their sexual partner was unimportant. However, 18% reported a willingness to be sexually involved only with HIV-positive partner(s). Another 14% reported they would only consider being sexually involved with HIV-negative partner(s).
- Importance of HIV Status for Romantic Partner(s): For 52% of respondents, HIV status was not a factor in romantic partnerships. However, 15% were only willing to consider HIV-positive romantic partner(s) and another 12% were only willing to consider HIV-negative romantic partner(s).



V. Body Image

Approximately 75% reported a change in sexual practices or behaviors and 63% reported a decrease in frequency of sex since being diagnosed as HIV-positive. This change may be a result of feelings around body image and perceptions about being a sexually desirable woman. When asked how HIV has affected their body image, a quarter (25%) of respondents reported that they were currently accepting of their bodies. However, of the group who are currently accepting, respondents were split in how they had felt about body image immediately following diagnosis.

Half (12.5%) of respondent comments reported no change or were celebratory about how they felt about their body image ("I am very happy with my body. HIV has not affected the way I feel about my body") and half (12.5%) of respondents acknowledged that, although they initially experienced a negative view of their body, they grew to appreciate their body once again as they learned to accept their HIV diagnosis ("At first I felt dirty and ashamed. However, over the years I have come to terms with my diagnosis and accept my situation, which allows me to feel better about my body").

Another 12.5% of total respondents indicated experiencing an awareness of their body and how it might be changing as a result of HIV but this group was not specific as to how they felt about these changes ("I'm more health conscious now and I'm more aware of my physical appearance"). Conversely, 62.5% of respondents reported experiencing moderate to severely negative changes in body image. This latter group expressed that the HIV, in particularly the impact of the anti-retroviral therapy, made them anxious, more fearful and self-deprecating about their bodies. One respondent offered this comment about how the medications made her feel about her body, "I was very secure about my body before my diagnosis. After the diagnosis and the long term medication effects, not so much because of the side effects of the medications, that is the body changes have made me a little insecure." Another respondent expressed absolute devastation from the effects HIV has had on her body, "There is an invisible big black X from head to toe. I am diseased and am unworthy of feeling good about my body again." Some respondents described isolating themselves as a coping strategy – specifically mentioning coping with poor body image by not thinking about it, or by gaining weight to avoid being asked out. Other stated that that they regained appreciation of their bodies through others, especially a significant partner, which can also be understood as a coping mechanism.

Use of Barrier Methods and HIV Status of Sexual Partners

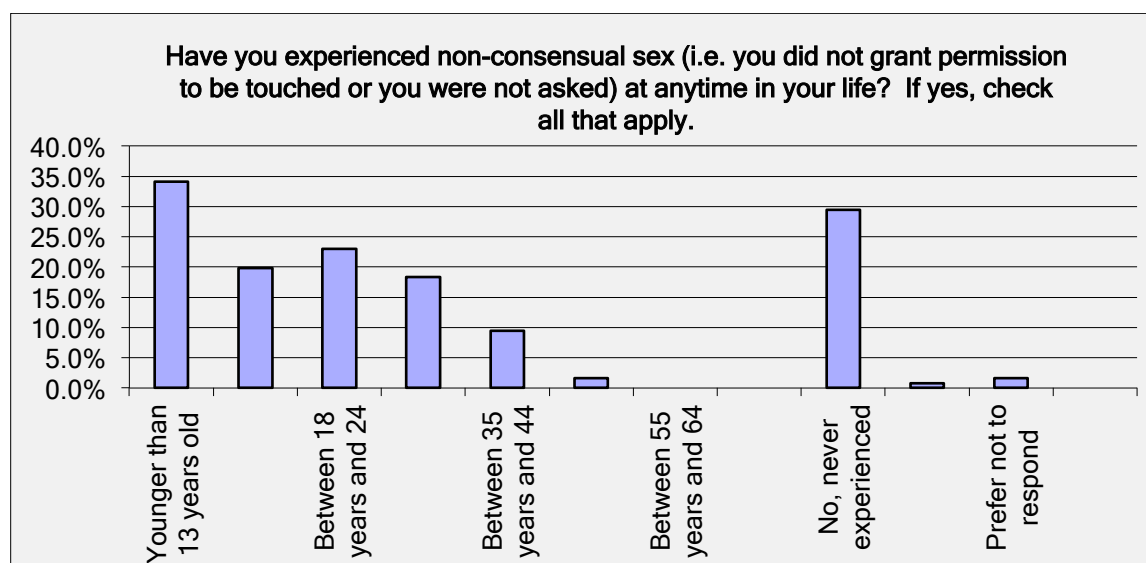
- 31% reported always using barriers "because it is important to both of us"
- 18% reported not being engaged in sexual activity
- 13.5% reported always using barriers because "it is important to me"
- 11% respondents stated that they do not use barriers, "because we have agreed not to use them"
- About 8% of respondents stated they "sometimes" use barriers, or that it depends on the partner
- Another 5% stated that they do not use barriers because their partners do not like barriers

VI. Sexual and Reproductive Healthcare

- Present gynecological (or "female") problems: 78% responded they do not have gynecological (or "female") problems that would interfere with sexual experiences or ability to have sex.
- Experienced Sexual Dysfunction: Within the last 12 months, 50% have not experienced any symptoms while 30% have experienced low sexual desire (e.g., lack of interest in sex, poor libido, etc.), 20% difficulty achieving orgasm and 19% experience non-arousal.

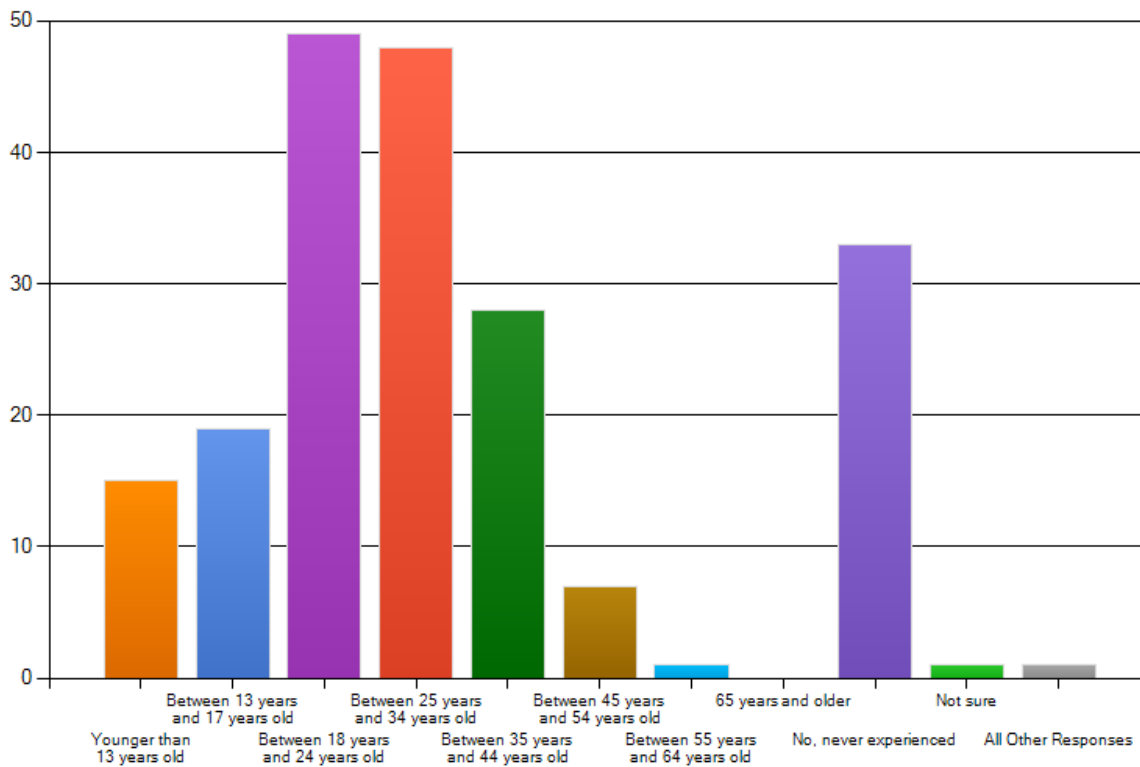


- Experienced sexually transmitted infection after HIV diagnosis: 68% responded no while 29% responded yes.
- Experienced non-consensual sex: The majority of respondents 69% had experienced nonconsensual sex. 29% reported they had never been sexually violated. 34% of respondents were younger than 13 years old when they first experienced nonconsensual sex.



- Fertility Desire: 39% of respondents do want to have children, 26% had had a surgical procedure that interferes with having a child and 29% are menopausal or post-menopausal.
- Information from Provider: 27% of respondents who do want children want information from their provider about which HIV medication regimen is a good choice when considering pregnancy.
- Experienced intimate partner violence (IPV): The majority of respondents (72%) had experienced IPV.

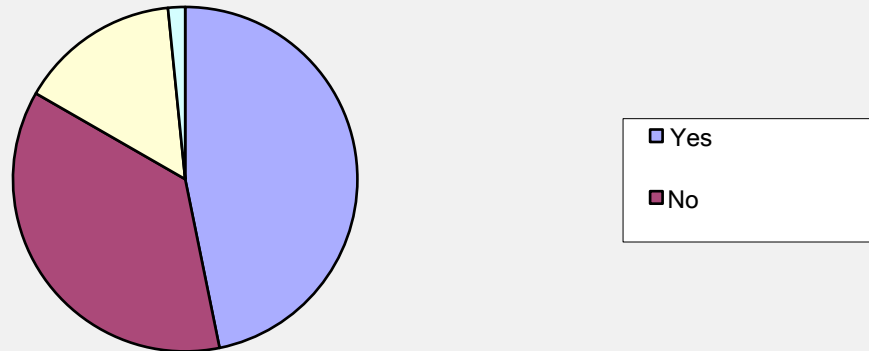
Have you experienced intimate partner violence (IPV) or domestic violence (DV) at any in your life? There are many forms of violence. The type of violence experienced can be physical, mental or emotional. If yes, check all that apply:



Sexual and Reproductive Health Information and Choices

- Obtaining SRH Information: Online respondents get their SRH information from the following primary sources - 76% from an HIV specialist, 47% from the internet, 42% from support groups and 29% from magazines/books. Paper survey respondents also relied on HIV specialists for SRH information from an HIV specialist (57%) and support groups (45%), but were much less likely to get SRH information from the internet (20%).
- Treatment as Prevention/Suppressed Viral Load: 50% of respondents agreed that HIV transmission can be reduced dramatically where the HIV positive partner has a suppressed viral load.
- Provider Education: 46% reported that their provider had informed them about the relationship between suppressed viral load and transmission risk.

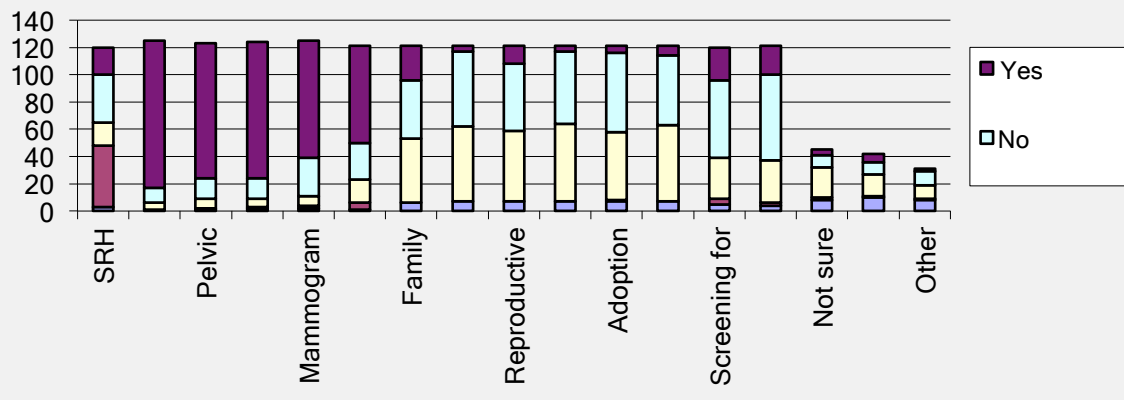
Has any provider (doctor, nurse, case manager or peer advocate) ever told you that when your viral load is undetectable, you are less likely to pass HIV to an HIV-negative sexual partner? (select one response)



Sexual and Reproductive Health Services & Access

- SRH Access (in order of importance with a rating of 70% or higher except the last two responses which rated under 45% and 35% respectfully): Prevention and treatment of reproductive tract infections and sexually transmitted infections; early diagnosis and treatment for breast and cervical cancer; sexual and reproductive health throughout the ages; family planning services, including contraceptives; prevention and management of gender-based violence; menopause; prevention and appropriate treatment of sub-fertility and infertility; and SRH assessment.

Within the last 12 months, which of the following services have you used or received? (select one or more responses)



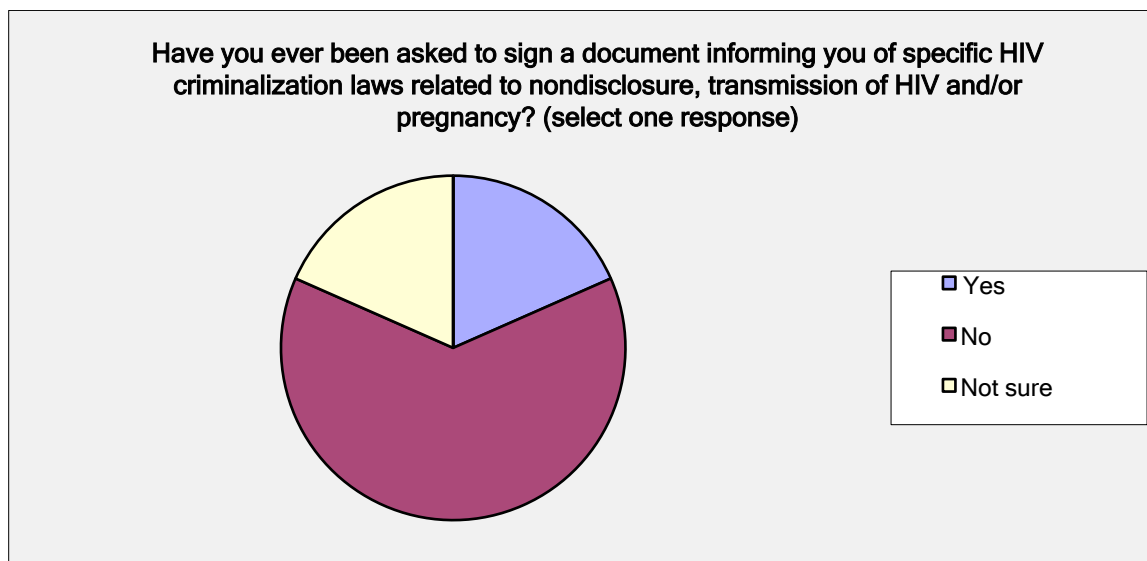
- Provider Service Offerings: The most (over 50% in descending order) - Breast examination, Pap smear, pelvic examination, mammogram, STI screening and hormonal therapy. The least 5 (under 50% in descending order) - screening for menopause, adoption services, abortion services, fertility services, emergency contraception pill, reproductive services and family planning services.
- Utilization of SRH Services (in descending order): Pap smear, breast examination, pelvic

examination, mammogram, STI screening, family planning services, screening for menopause, hormonal therapy, SRH assessment, reproductive services, abortion services, adoption services, fertility services and emergency contraception.

- Family Planning Clinic: 83% respondents have not visited a family planning clinic since being diagnosed.
- Provider SRH Discussion: 51% yes and 42% no in terms of provider talking to them about “being sexually healthy”.
- Discussion of Sexual Health (SH) Issues: Respondents who experience SH issues speak with (in descending order) their provider, other WLHIV, partner, support group members, friends, family and online.
- Respondent SRH Discussions with Providers (in descending order): Was helpful, asked additional questions, offered helpful advice, performed an examination, and encouraged additional screening for undiagnosed ailments

VII. Privacy, Confidentiality & Disclosure

- Confidentiality of SRH Information: 70% are confident that sexual health information will remain confident.
- Violation of Confidentiality Pertaining to SH Information: 74% report no violations while 15% report such a violation.
- HIV Criminalization Documentation: 18% reported they had been asked to sign such a document.



G. Analysis of Survey Findings

Demographics

Results from the survey indicated that some characteristics of the respondent group are generally mirror characteristics of the general population of women living with HIV in the US. These demographics include age, gender, sexual orientation and geography.

For example, in terms of sexual orientation, the majority of respondents (80%) identified as heterosexual, which is consistent with CDC findings that the majority of women (84%) acquire HIV through heterosexual sex (CDC 2013). However, it should also be noted that although the survey results indicate that the majority of respondent identified as heterosexual there is a range of sexual and gender expression, identity and orientation among respondents.

On the other hand, there were other characteristics for which the respondent population percentage skewed differently than the average of the general population of women living with HIV in the US. These demographics included race/ethnicity, gender identity, education, housing, employment, health insurance coverage, technology, childcare responsibilities, and annual income. Respondents were less likely to be Latina, more likely to be Caucasian, and less likely to be transgender than national averages. Respondents were overall more likely to have access to technology and to have higher incomes than the national average for women living with HIV.

Please see table below for an example of how PWN-USA survey respondent race/ethnicity compared with known race/ethnicity data for Black, Latina and white women living with HIV in the United

Table B
Comparison of Survey Respondents with Surveillance Data for Women Living in the United States

Race/Ethnicity	Data Sources		
	CDC 2010	PWN SRHR Survey 2013 (Online)	PWN SRHR Survey 2013 (Paper)
Black	60%	55%	57%
Latina	19%	3%	13%
Caucasian/White	18%	31%	2%



The results from geographic location are roughly reflective of geographical distribution - by state and region - of women living with HIV in the US Data collected from women residing in 25 states in total was obtained from the survey. The table below illustrates response rate on PWN-USA's survey in ten states where HIV heavily impacts women.

Table C
Number of Survey Respondents in Relationship to the Top Ten States with Highest Numbers of Women and Girls Diagnosed with HIV in the United States

Top Ten States	State Ranking by Survey Response Rate	
	PWN Survey 2013 (Online)	PWN Survey 2013 (Paper)
1. New York	5	5
2. Florida	3	
3. Texas	7	1
4. California	2	3
5. New Jersey	5	
6. Maryland	8	
7. Pennsylvania	1	
8. Georgia	4	4
9. North Carolina	9	
10. Illinois	6	2

It should be noted that outside of these ten states where women bear a high burden of the HIV epidemic described above, South Carolina and Michigan topped Pennsylvania as respondent sources from the states listed in the table.

Over half (52%) of paper survey respondents and 29% of online survey respondents reported having at least one child under the age of 18 in their homes. The survey did not ask about other family responsibilities such as caring for parents, grandparents, relatives, and in-laws. However it is important to understand this aspect of HIV-positive women's lives in order to more fully comprehend challenges and opportunities women may deal with in light of engagement in care.

HIV Status and Engagement in Care

Diagnosis was viewed in five-year increments beginning with the year 1983, the start of the AIDS epidemic, and ending with the current year 2013, the 30th year of the AIDS epidemic. The results show that 40% of the respondents were diagnosed HIV positive between 1991-2000 and 34% were diagnosed between 2001-2010. 12% reported receiving an HIV diagnosis within the last three years – 2011 to 2013.

An overwhelming majority (96%) of survey respondents are in care. The majority of respondents receive their care from an HIV specialist located at an HIV clinic. Other respondents receive their care from private physicians and hospital-based clinics. In terms of the HIV Continuum of Care, results for respondents are skewing higher than the national averages for people living with HIV (PLHIV) and women living with HIV (WLHIV). See table below for a comparison.



Table D
Comparison of Stages of Care for PLHIV, WLHIV and Survey Respondents

Source	HIV Continuum of Care Categories		
	Retained in Care	On ART	Suppressed VL
PLWHA CDC (2012)	37%	33%	25%
WLHIV CDC (2012)	41%	36%	26%
Women* PWN-USA (2013)	96%	91%	80%

*Self-reported

Relationships

The majority of respondents (58%) are in a self-described romantic or intimate relationship with one primary partner. Of this group, 78% of respondents cohabit with or live in the same city/town as their partners. Over two-thirds (68%) of respondents in relationship view their relationships as being monogamous and 64% of respondents identified their partners as being HIV-negative. Additionally, 52% of respondents reported being very satisfied with their relationship while 45% stated they are dissatisfied. The respondents who stated they were dissatisfied were most likely to state that they are either financially responsible or financially dependent in the relationship. Meanwhile, 40% of the respondents did not describe themselves as being a romantic or intimate relationship. Of those respondents who do not have relationships, 25% indicated that they can't find a suitable partner, 21% are no longer with their partner (widowed, separated or divorce) and 20% prefer not to be in relationship at this point of time in their lives.

Change in Sexual Practices and Behaviors

Three-quarters of respondents reported that their sexual practices and/or behaviors had changed since their diagnosis. When invited to elaborate on changes to sexual practices and behaviors, common responses followed these themes:

- (i) Use protection more frequently: "started using protection", "always use condoms, wear it or keep moving"
- (ii) Reduction in number of partners: "less open to sexual and romantic partnerships", "more cautious emotionally", "prior to HIV I was more casual sexually", "careful on who I sleep with" "very careful about who I get involved with"
- (iii) Low perceptions of body image or attractiveness: "too unattractive to attract a partner"
- (iv) Fear of sex: "I have so much fear of sex that I have not been able to be social or consider dating or having sex", "I can't relax and enjoy sex at all – I'm too afraid I will infect my partner although we remain protected"



Sexual Practices

Women living with HIV are sexually active. Despite body image and desirability challenges, lack of partner availability, and fear of transmitting HIV, 46% of respondents reported having sex on a regular/consistent basis with one or more partners, and another 38% respondents reported sexually pleasuring themselves. This finding is consistent with research that shows that people living with HIV in the United States remain sexually active after being diagnosed HIV-positive (Northeast AETC, 2013).

Respondents report regularly communicating with partners about HIV transmission risk, sexually transmitted infections (STIs) and use of barrier methods, which is also consistent with attempts by people living with HIV in general to “reduce the risk of sexual HIV transmission by modifying their sexual practices.” Condom use among respondents is higher than condom use among the general PLHIV population and WLHIV population.

Communications with Partner - Disclosure of HIV Status and Barrier Methods

In terms of pre-sex communications, 60% always disclose their HIV status before having sex, 10% stated they disclose sometimes and 2% never disclose. The remainder stated that disclosure was not applicable because they either have one partner, who already knows, or because they are not sexually active at this time. In addition, over 80% respondents reported talking to their partner(s) about HIV transmission risk, sexually transmitted infections (STIs) and use of barrier methods. This may be because a high percentage of respondents report they are aware and knowledgeable about barrier methods to reduce transmission of HIV, from 64% reporting understanding of how to use finger cots to 93% reporting comfort with using male condoms.

Interestingly, although there may be little correlation between the two questions, 42% responded that HIV status of their sexual partners was not important to them, while 18% are only interested in being sexually involved with HIV-positive partner(s) and another 14% are only interested in being sexually involved with HIV-negative partner(s).

Sexual Function

Within the last 12 months, 50% have not experienced any symptoms that would interfere with sex, although 50% have experienced low sexual desire (e.g., lack of interest in sex, poor libido, etc.), difficulty achieving orgasm, and/or non-arousal. While the survey did not specifically ask respondents experiencing sexual dysfunction why this might be so, responses to the question pertaining to gynecological (or “female”) problems indicate that 78% of respondents do not have gynecological (or “female”) problems that would interfere with sexual experiences or ability to have sex.

Experiences of Non-Consensual Sex and Intimate Partner Violence

Over two-thirds of respondents (69%) had experienced nonconsensual sex. More than a third of respondents (34%) had experienced nonconsensual sex when they were younger than 13 years old. For many respondents, sexual abuse and violence continued throughout their lifetimes.

Only 29% of online respondents and 22% of paper respondents reported they had never experienced nonconsensual sex. Some respondents reported they were “not sure”.



Nearly three-quarters of respondents (72%) reported having experienced intimate partner violence (IPV) or domestic violence (DV) at some time in their lives. For many women, IPV started young. About a third reported at least one experience of IPV or DV before the age of 25. One respondent commented that “when not being raped physically I was being blackmailed.”

Fertility Desires, Intentions and Decision-making

In terms of childbearing, 39% of respondents do want to have children, 26% had a surgical procedure that interferes with having a child and another 29% are menopausal or post-menopausal. Respondents who are interested in having children indicated that they receive fertility planning information from a variety of sources. Most respondents who do want children desire information from their provider about HIV medication.

Sexual and Reproductive Health Information

Respondents indicated that they get their SRH information from a variety of sources: 76% from a HIV specialist, 47% from the internet, 42% from support groups and 29% from magazines/books. Although 76% of respondents indicated they get sexual health information from HIV specialists, less than half (46%) reported being informed by a health care provider about the importance of having a suppressed viral load (SVL), especially in the context of a sexual relationship where having a SVL can dramatically reduce HIV transmission. This finding correlates with the percentage of responses to the question pertaining to providers having discussions with respondents about “being sexually healthy”: 51% of respondents indicate that their providers do talk to them about “being sexually healthy” while another 42% responded no in terms of provider talking to them about “being sexually healthy”.

Utilization of SRH Services

The majority of respondents have utilized the following SH services: Pap smear, breast examination, pelvic examination, mammogram, STI screening, family planning services, screening for menopause, hormonal therapy, SRH assessment, reproductive services, abortion services, adoption services, fertility services and emergency contraception. These results correlate with provider service offerings. An interesting finding indicates that the majority of reproductive services utilized by respondents are pap smear, breast examination, pelvic examination, mammogram, and STI screening while the least used SRH services are family planning services, screening for menopause, hormonal therapy, SRH assessment, reproductive services, abortion services, adoption services, fertility services and emergency contraception. This finding may correlate with the fact that 60% of respondents were born between the years 1960-1979, spanning between ages 34 and 53. Additionally, respondents indicate that at least 26% of respondents had a surgical procedure that interferes with having a child and another 29% are menopausal or post-menopausal. These findings may also account for why the majority of respondents (83%) have not visited a family planning clinic since being diagnosed.

Confidentiality

The majority of respondents feel relatively confident that their sexual reproductive and health information will remain confidential. At issue is whether or not the continuance of HIV criminalization laws will change this.



Discussion

As previously described, the HIV epidemic among women in the US is characterized by severe racial, ethnic and socioeconomic disparities. Respondents to PWN-USA's survey reflected some of these disparities, with women of color representing 71% of respondents, and 54% of respondents identifying as African American or Black.

Although PWN-USA's respondent sample tended to be less poor, presumably slightly older, and more engaged in care than national averages, responses provide a window into understanding the lives, realities and desires of women living with HIV today. As women living with HIV have become healthier, and ceased to perceive HIV as a death sentence, women living with HIV are living in the present and making plans for the future – including attending school, participating in community activities, entering or re-entering the workforce, and taking on family responsibilities that may include parenting.

These themes are borne out by responses to the PWN-USA survey. 14% of survey respondents had been living with HIV for over 20 years and over half (51%) of respondents had been diagnosed with HIV for over 10 years, a testament to increased longevity of people living with HIV. The majority of respondents with an income of \$50,000 or more owned their own home or apartment, demonstrating that women living with HIV are making long term plans and investments in their own futures when they have the financial flexibility to do so.

Family responsibilities, including but not limited to childbearing and child rearing, play an increasingly important role in the lives of women living with HIV. Over 40% of our sample was women of reproductive age, and regardless of age, over half of paper survey respondents and nearly a third of online survey respondents reported having at least one child under the age of 18 in their homes. Many women reported several children, including grandchildren, in their homes.

Disparities between paper and online survey respondents make it clear that women living with HIV who tend to have access to technology, including the internet, have a different set of privileges than women who do not, and the reasons for this are complex. Over 62.6% of online respondents reported having a smart phone, 59% had a laptop, and 54.7% had internet service. Internet access and technology literacy may play an important role in women's ability to access medical and legal information, to enter or re-engage with the workforce, and to make informed decisions about their lives and futures.

As seen in the survey results, there was a marked disparity in formal education, employment, housing status, and health insurance types between online survey takers and paper survey takers. Among online respondents, 39% had a 2 or 4-year college degree. Of PWN-USA's overall sample, 12% had not completed high school; while nearly a third (30%) of paper survey respondents had not completed high school, only 6% of online survey respondents had not completed high school. Of online survey respondents, 37% were employed full time and 19% were employed part-time, compared with 13% and 11% respectively of the paper sample.

Findings from the HIV Cost Services and Utilization Study (HCSUS), conducted in the mid 1990's, demonstrated that women living with HIV were more likely to be living in extreme poverty, compared with HIV-positive men (64% of WLHIV compared with 41% of MLHIV had annual incomes of \$10,000 or less). Nearly twenty years later, in PWN-USA's study, 29% of respondents reported annual incomes of



\$10,000 or less. The limitations of a survey administered largely online are clear: respondents are more likely to be employed, to have more money, more access, more education, greater social mobility, and more privilege overall than national averages of women living with HIV. Understood in this context, PWN-USA's findings relevant to economics and financial security are alarming. Nearly half of all respondents (47%) reported an annual income of under \$20,000, and nearly a third of paper respondents (30%) and 11% of online survey respondents reported an income of under \$5,000 per year. Income eligibility requirements to access benefits such as Medicaid, ADAP, and housing and other services may force women to keep their incomes low in order to get medications, stay in care, and provide for their dependents. 43% of respondents were on Medicaid, and only 8% of paper respondents and 29% of online respondents had access to private insurance plans provided by employers or family members.

As a point of reference, the federal poverty level for an individual in 2013 is \$11,430. For a woman taking care of one or two children, the federal poverty level for a family of two or three is \$15,510 or \$19,530 respectively. Many of the respondents came from urban areas with a relatively higher cost of living and are likely economically challenged to ensure their own well being, let alone the well being of others they may be responsible for. PWN-USA's survey results also show a high level of dissatisfaction with financial contributions by partners towards living expenses and, in fact, this was the area in which women living with HIV reported the greatest dissatisfaction with their relationships. These findings suggest that women living with HIV may be financially supporting their partners to some extent on their own limited incomes.

Women living with HIV demonstrate high levels of internalized stigma, which emerges immediately following an HIV diagnosis, and may be related to body image and self-esteem issues. This internalized stigma may play out in sexual as well as reproductive choices, and interactions with partners as well as providers. Judgmental attitudes documented in the literature by WLHIV towards other WLHIV choosing to conceive or parent further demonstrate this internalized stigma.

Nearly two-thirds (62.5%) of respondents reported experiencing moderate to severely negative changes in body image and frequently using words like "dirty", "unattractive", "diseased", "ugly", "unwanted" to describe themselves. Similar to themes described in studies by Siegel et al.⁹⁸ and Hackl et al.⁹⁹ some PWN-USA respondents described isolating themselves as a coping strategy – specifically mentioning dealing with poor body image by not thinking about it, or by gaining weight to avoid being noticed. "I don't feel as pretty as I used to. I let myself gain weight to avoid being asked out," reported one PWN-USA survey respondent.

Although a quarter of respondents report they are now comfortable with their bodies, half of that 25% reported negative self-perceptions of body image immediately following diagnosis. Their hard work to claim, or re-claim, a positive self-image in light of their diagnosis can be seen in these statements.

"In the beginning I felt dirty, like poison. In the almost 18 years since my diagnosis I have slowly regained some of my confidence as a beautiful human being."

"At first I felt dirty and ashamed. However, over the years I have come to terms with my diagnosis and accept my situation, which allows me to feel better about my body."

"Crazy as it sounds, it's been "freeing" ... I've had to learn true self-care."

"I hated the person I saw in the mirror. I have since began exercising which gives me more energy



and I feel better about my appearance”

Women living with HIV also report high levels of fear and anxiety about sex, and although 96% of respondents were currently in medical care, many (54%) have not been adequately counseled on the relationship between suppressed viral load and reduced likelihood of transmission. As Siegel et al. found, respondents reported being worried and anxious about sex and not being able to enjoy sex even when using condoms, because of their fear of infecting partners. Despite the fact that over 80% of respondents had suppressed viral loads, and most are using condoms, many PWN-USA respondents still felt high levels of stress, worry, or anxiety associated with possible HIV transmission and/or re-infection by a partner took away from pleasure and ease during sex.

A large majority of respondents (91%) were currently on HAART, and respondents shared that HIV medications are a source of stress and anxiety when it comes to body image and sex. Side effects from long-term anti-retroviral therapy made them anxious, more fearful and self-deprecating about their bodies.

Some women who had been infected sexually reported that the trauma of diagnosis itself had affected their feelings about sex.

“I have lost a lot of desire to have sex because that is how I became infected.”

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

“I waited until I was 26 to have sex and have led a pretty uneventful sex life in comparison to other people I know, only to find out that I contracted the virus just months after losing my virginity... When I was diagnosed, I felt dirty and wouldn't let my boyfriend near me. I didn't see why he would want to have sex with me and when we finally did, I was in constant fear and did not enjoy it. I have come to realize that the initial fears and negative feelings toward sex weren't really about sex but rather a lack of self-acceptance and denial about the diagnosis. I still have a difficult time. 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.”

Many women who reported currently being celibate had not been sexually active since their diagnosis. For some women, sex was correlated with risk or with the partner who infected them.

“I do not want to be intimate with no one. I hated men at one time because I felt like it was their fault. My ex-husband gave me the disease so all men were cheaters and I didn't want any intimacy at all. But I have let go of all the anger and opened up my heart, mind and soul.”

“HIV has changed everything about my sex life... [Since my partner passed] I feel dirty and I feel like no man would ever want to touch me. I just avoid it and do not date at all since he passed, 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.”

“There is a big black X- saying, 'Do not have sex with this woman; she has been X'd from physical pleasure. Forever.”

Nearly two-thirds (63%) of PWN-USA's respondents reported a decrease in the frequency of sex being diagnosed HIV-positive. Consistent with Bova et al.'s findings¹⁰⁰, however, the majority of respondents to



PWN-USA's survey reported currently being sexually active, independently of time since diagnosis. PWN-USA's findings were also similar with Bova et al.'s with respect to women describing the quality of sex and intimacy experiences. Bova et al. found that half of participants reported that the quality of the sexual activity had stayed the same (31%) or improved (21%) since an HIV diagnosis. PWN-USA found that 32% reported no change in quality of sex, 18% reported that the quality of sex was better, and 26% percent reported that the quality of sex was worse.

The majority of women living with HIV-- at all phases of disease progression-- are having sex, and most report having one consistent partner. Most respondents (68%) described themselves as being in monogamous relationships, and 64% of respondents reported that their partners were HIV-negative. Women who described themselves as single were slightly more likely to report they were regularly having sex with one partner than women who reported being in relationships or married (30.2% compared with 28.3% and 24.5% respectively). There was no clear correlation between time since diagnosis and current sexual activity. 14% of PWN-USA's respondents stated they were not currently having sex because they could not find a partner.

Many women (75%) reported changes in sexual behavior and practices since their diagnosis. These included increased condom use - 75% of sexually active respondents reported they "always" or "sometimes" use condoms with their partners. Separately, some respondents discussed changes to perceptions around sex and sexual partners in a positive light:

"It has made me pay more attention to how a man handles me in bed." "It makes me more cautious, but I've learned what I like and what I don't like from sex positive workshops."

Several respondents described the ways in which HIV diagnosis forced them to examine or reassess sexuality and relationships.

"At first I felt unworthy. I took 4 years away from any kind of sexual relationship so I could work on my self-esteem. A year ago I came to terms with the idea that I am worthy of love and sex."

In addition, over two-thirds of respondents (68%) reported being more selective about their sexual partners since their diagnosis. Over a quarter (28%) of women who reported that they are currently in a relationship (spouse or partner) were in relationship with the same person at their time of diagnosis with HIV.

Within relationships where a woman is living with HIV and her partner is not, stress on the relationships associated with an HIV diagnosis is not well understood and there is limited, if any, support available for WLHIV and their partners in terms of services available or peer support networks. PWN-USA's survey did not ask questions about this. However, respondents alluded to relationship tension in some of their comments about sex: "I have a lot of anxiety about exposing my husband but don't feel able to express it for fear of pushing him away."



Unmet Sexual and Reproductive Health Counseling Needs

In general, women living with HIV report that they rely on their providers, particularly HIV specialists, for guidance on SRH issues. Further, when they do discuss SRH issues with providers, trends show that WLHIV report providers are “helpful,” “ask additional questions,” “offer helpful advice,” and “encourage additional screening.” However, findings among survey respondents indicate that providers may be focusing on secondary prevention and screening for gynecological health issues at the expense of discussing sexual health more generally, including women’s reproductive or family planning desires.

Despite the fact that women living with HIV are sexually active, and that 29% of respondents indicated they had been diagnosed with a sexually transmitted infection *after* HIV diagnosis, nearly half (42%) of survey respondents reported that their providers had not talked to them about “being sexually healthy.” Further, although 39% of PWN-USA’s respondents reported desiring children in the future, when asked about SRH services offered by providers, women were least likely to report being offered reproductive services, fertility treatment, adoption support, and family planning services including abortion, oral contraception, and emergency contraception.

Because of the triggering nature of the question and the impersonality of the research design, PWN-USA’s survey did not explore women’s history of unwanted pregnancy or choices to terminate pregnancy post-diagnosis; however this is an area that warrants further research. It should be noted that a number of respondents reported having received their initial HIV diagnosis during pregnancy or childbirth.

Importantly, ambivalence by WLHIV about perceiving themselves as sexual and reproductive beings may negatively impact patient-provider communication. Research findings show that women living with HIV—not providers—are more likely to initiate conversations about fertility, and women whose desires and intentions are congruent are more likely to have these conversations. Women living with HIV who are ambivalent toward pregnancy are especially vulnerable to having unmet reproductive counseling needs, because nuanced discussion related to preventing unintended pregnancies, HIV prevention that does not prevent pregnancy, choices that can protect women and their partners during conception, and learning to cope with indecision regarding childbearing are likely to be missed.

Violence and Abuse

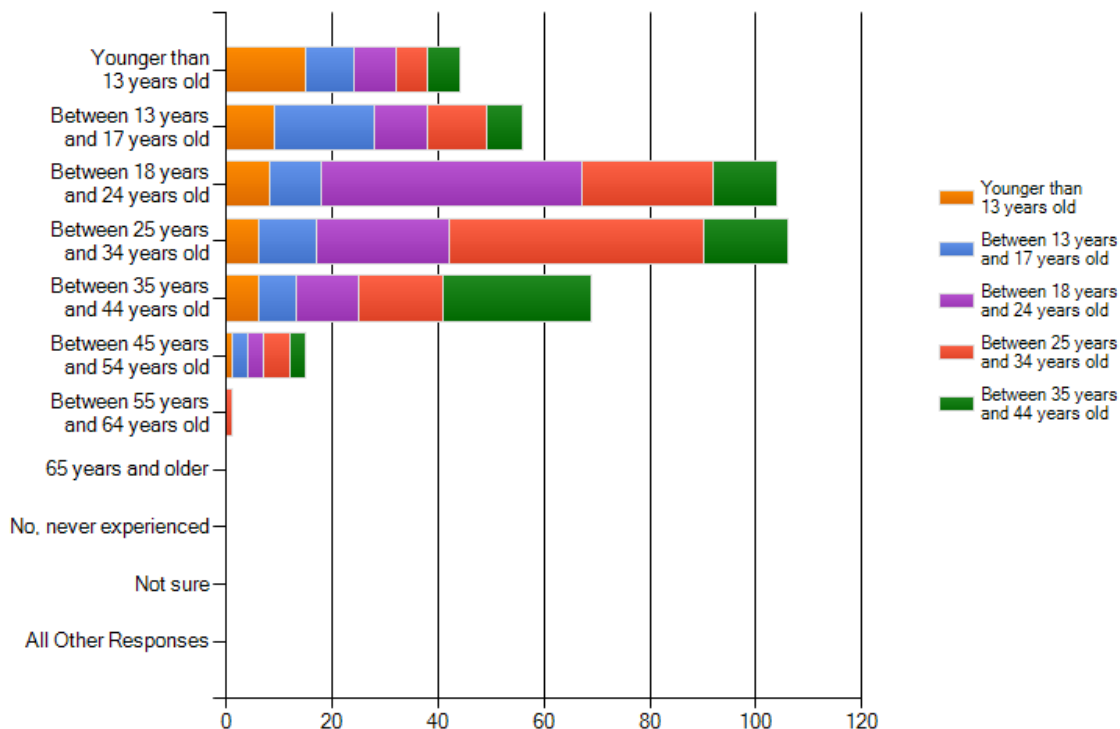
As demonstrated in the literature and by PWN-USA’s survey findings, violence and abuse at all stages of life are prevalent among women living with HIV. Only 29% of respondents reported they had never experienced nonconsensual sex. Over a third of respondents (34.1%) first experienced nonconsensual sex before the age of 13, and nearly a fifth (19.8%) experienced nonconsensual sex before the age of 18. The survey did not ask about other forms of childhood sexual abuse (CSA).

Only a quarter of survey respondents reported they had never experienced intimate partner violence (IPV) or domestic violence (DV). The survey did not specifically ask whether respondents had experienced IPV or DV following HIV diagnosis. Findings show that women who had experienced nonconsensual sex at a young age were likely to also have experienced IPV at a young age. For example, 63.2% of women who had been sexually assaulted before the age of 13 experienced IPV or DV between the ages of 13 and 17. Women who experienced IPV at a young age were also likely to experience IPV later. For example, over half of women who experienced IPV between the ages of 18 and 24 also experienced IPV between the ages of 25 and 34. The chart below shows how patterns of abuse persisted



among respondents who experienced IPV early in life.

Have you experienced intimate partner violence (IPV) or domestic violence (DV) at any in your life? There are many forms of violence. The type of violence experienced can be physical, mental or emotional. If yes, check all that apply:



These findings suggest that given a history of violence, abuse, and trauma, compounded by body image and self-esteem issues resulting from HIV diagnosis, as well as negative perceptions of sex and sexuality, women living with HIV may face challenges securing and navigating healthy and fulfilling intimate relationships. In addition, data shows that rates of post-traumatic stress disorder (PTSD) and complex post-traumatic stress disorder (C-PTSD) are high among women living with HIV in the United States – at 30%, a rate 6 times higher than the general population¹⁰¹. The survey did not ask whether respondents had been screened for intimate partner violence or history of trauma and this is an area that requires further inquiry and intervention.



Recommendations: A Way Forward

Much work is needed to achieve sexual and reproductive health and rights for women living with HIV in the United States. The following comprise initial recommendations from the authors. It is the hope of PWN-USA that this report will serve as a catalyst to further dialogue, research efforts, and advocacy towards dignity for all people living with HIV.

Meaningful involvement is necessary

Women living with HIV must play a vital role in the design and development of research studies, program and service delivery design, lead in education efforts and in holding decision makers accountable for developing policies which support and uphold sexual and reproductive health and rights for all people living with HIV.

When decisions are made that impact SRHR of women living with HIV, networks representing WLHIV must be consulted and involved. To achieve this, ongoing support is needed for local, national and international efforts that build capacity of women living with HIV and their communities to engage, mobilize and ensure that policies which impact their health and rights are appropriate in the context of HIV.

Addressing Stigma, Discrimination and Misperceptions about HIV

To achieve sexual and reproductive rights for women living with HIV it is necessary to address the social, political and institutional context of WLHIV's lives. In particular, stigma, institutionalized discrimination, and misperceptions about HIV transmission and what it means to be living with an HIV diagnosis must be addressed. HIV criminalization laws and statutes should be eliminated. In addition, any sentence where HIV diagnosis was used as a sentence enhancement or as a factor in determining sentence length or severity should be reviewed. Judges and law enforcement officials should receive trainings designed to improve understanding of HIV medical information and transmission routes, and to reduce stigma and discrimination.

It is also important to correct and proactively address inaccurate media portrayals of life with HIV, especially as they relate to inaccurate portrayals of transmission risk, sex, sexuality and reproductive capacity post-diagnosis, and ability of PLHIV to parent.

Research and provider training for young and mature WLHIV is especially needed

Based on our assessment, there is striking limited data and research on a number of relevant areas of interest related to sexual and reproductive health and rights for women living with HIV in the United States, including the specific needs of young WLHIV and mature WLHIV.

There is a specific lack of available data on young PLHIV and perinatally infected WLHIV entering adolescence/adulthood. The literature reviewed revealed scarce research on gynecological health habits, self-perception, intimate partnerships, and sexual health experiences of adolescents and young women living with HIV.



While studies typically were designed to evaluate women ranging from 18 to 69 years of age, the vast majority of research reviewed, as indicated by the sample mean and median age, centered on mature women—women ranging from 40 to 50 years old. Many studies failed entirely to capture information on young adult women transitioning from adolescence to adulthood, particularly from 18-21 years old and none of the literature assessed specifically identified study participants living with HIV since birth or childhood. Study design remained a critical factor for determining “who” was eligible for each study and perhaps due in part to ethics in child research requiring consent, much of the literature solely focuses on women 18 years of age and over rather than minors.

As young people born with HIV enter the tumultuous period of adolescence, adulthood, and early sexual activity, research is needed to understand clinical factors that may affect sex, sexuality and reproductive options, as well as the potential psycho-social, emotional, and behavioral effects of an HIV diagnosis prior to becoming sexually active. Specific research is needed to understand how people living with HIV prior to becoming sexually active experience and understand their sexuality, their intimate partnership needs, and how this may influence romantic and sexual relationship choices, physical and mental health and quality of life.

In addition, the sexual and reproductive health and rights of mature women living with HIV are often entirely overlooked. Once a woman living with HIV is no longer perceived as a potential risk to an unborn fetus, interest in her SRH seems to disappear. Clinical research is required to determine how the progression of HIV physically impacts women who are menopausal or post-menopausal. Literature shows that women living with HIV tend to begin menopause early, and under-report symptoms of menopause to their providers, likely due to assumptions that symptoms are related to HIV disease progression or other ongoing health concerns, rather than menopause. Thus it is imperative that providers are trained to ask questions about menopause of their mature HIV-positive women clients. Mature WLHIV are also sexually active and have needs for intimate partnership. Available surveillance data indicates that women are sexually active well into their 70's and 80's. Like their younger counterparts, mature women require affirming and age appropriate SRHR services and protections.

Factors influencing Engagement in SRH Care

Limited research is available assessing attempts to improve quality of SRH care by addressing factors that may influence WLHIV's engagement in SRH care. Furthermore, much of the literature on reproductive health places a questionable onus on women in regards to gynecological screening rates rather than provider behavior, clinic policies, and insurance access which may impact care and adherence.

Data shows that factors including provider-patient communication, provider's understanding of health guidelines for WLHIV, and provider accessibility may all play a key role in the engagement of WLHIV in care. As PWN-USA's survey results demonstrated, women living with HIV rely heavily upon providers for guidance when it comes to making decisions about sexual and reproductive health. Thus, provider bias and provider communications skills may play a critical role in determining the extent to which WLHIV identify their concerns and communicate and realize their desires with respect to body image, sexuality, and reproductive decision-making.

However, we were not able to identify studies in the literature that focused on evaluating interventions at the point of provider-patient communication on SRH issues, or increases in knowledge and



understanding of their own sexual and reproductive health by women living with HIV as a result of provider education.

In addition, little information is available on how well HIV primary care clinics perform cervical cancer and breast cancer screenings over an extended period of time.

Improving programs and service delivery

Regardless of specialty, HIV and SRH providers should be held to the highest standard to provide medically accurate and nonjudgmental information, about sexual and reproductive options for WLHIV, including counseling on viral suppression as one aspect of risk reduction for women in serodifferent relationships and WLHIV exploring conception. PWN-USA's finding that over half of the respondent sample did not recall being counseled about viral suppression as an aspect of transmission risk reduction is troubling and indicates that, over three decades into the HIV epidemic, despite data showing that viral suppression may be excellent strategy to reduce horizontal and vertical transmission, providers are either inadequately informed about this revolutionary scientific development or are fundamentally uncomfortable having nuanced conversations about risk reduction with their clients and patients – at an enormous cost to health, decision-making, dignity and quality of life. This may also reflect a deeply held stigmatizing attitude towards women living with HIV as sexual and reproductive beings. A more robust analysis of how effectively PLHIV in the United States have been counseled on viral suppression as a risk reduction strategy is needed, with data disaggregated by race, ethnicity, gender, point of care, provider type, geography and other factors. Concurrently, it is necessary that providers receive training to counsel WLHIV about their sexual health, sexual choices, and reproductive options in a way that is informative, compassionate and nonjudgmental.

Integration of services

The literature shows that consolidating and bundling HIV primary care with gynecology care improves SRH care for women, and PWN-USA's survey findings demonstrated that WLHIV who are in medical care are not generally accessing family planning clinics. Thus, it is imperative that sexual and reproductive health care services are well integrated with HIV care and services, in both clinical and community settings. This recommendation is well documented in the literature. Tello, et al. recommended structural and clinic system changes including integration of HIV and SRH care. In addition, as detailed in Barroso et al., service integration and coordination is necessary, and those staffing HIV and reproductive health services should be adequately trained to provide integrated services as well as referrals with compassion and respect for individual rights.

Corollary factors that may impact and influence SRHR for women living with HIV should also be accounted for in SRH/HIV service integration goals. The high prevalence of violence and trauma among women living with HIV indicates it is necessary to improve screening for factors which influence SRHR of WLHIV, including screening for physical and emotional violence, intimate partner violence (IPV), sexual coercion and forced sex. Women living with HIV suffer from high rates of PTSD, complex PTSD, and the downstream effects, which may include coping mechanisms that impact SRHR, for example, by putting women at risk for staying in violent and abuse relationships. Clinical and community based care settings should focus on screening for PTSD as well as IPV and implementing interventions that help women heal from trauma and leave abusive relationships. Such screenings should be linked with intervention, including but not limited to meaningful referrals for legal, housing, domestic violence shelters, substance



use recovery programs and medical services, as well as interventions that reduce PTSD-related symptoms and help women heal from the emotional, mental and physical long-term effects of trauma.

Issues pertaining to SRHR are deeply personal for WLHIV, as for most people, and correlate with cultural values and personal history. Culturally relevant SRH services for WLHIV can strongly facilitate provider-patient communication about sex, sexuality, intimate partnership and relationship desires, decision-making as it pertains to family planning, and current and past trauma or violence. However, cultural relevance in SRH services for WLHIV is frequently lacking and should be an emphasis in designing future programs. In addition, the use of interdisciplinary care teams, including teams which provide psychosocial support and integrate peer role models, has great potential for improving SRHR for WLHIV.

Increase prevention options and access to tools

Failure to offer WLHIV options to control family planning may result in unplanned pregnancies, which in turn can lead to a decreasing sense of personal agency over events in a woman's life. The literature shows that up to 80% of pregnancies among WLHIV in the US may be unplanned, and a significant number are also unwanted. In addition, there is little discussion in the literature of the trauma that may result from termination of pregnancy by WLHIV, let alone the complex trauma that a woman may experience if she is diagnosed with HIV during pregnancy, particularly if she was encouraged or coerced to terminate the pregnancy. It is not unlikely that such experiences could influence future engagement in medical care and services – however, we were not able to find literature addressing this issue.

To uphold their sexual and reproductive rights, women living with HIV need access to a range of options for pregnancy prevention and for prevention of HIV transmission. Further research and development is needed to develop long-acting biomedical HIV prevention options that can be used by male partners of WLHIV attempting to conceive naturally.

WLHIV's sexual pleasure continues to be negatively impacted by fears related to transmission and challenges related to negotiating male condom use. Providers should counsel WLHIV on, and ensure accessibility of, birth control options other than male condoms. This includes scaling up availability and improving affordability of female condoms, ensuring that WLHIV are counseled about oral contraception, birth control injections, intra-uterine devices, and other forms of family planning which do not depend on negotiation with male partners.

HIV clinics and HIV specialty medical associations should expand partnerships with healthcare providers in the field of sexual and reproductive health through the American Society of Reproductive Medicine and similar professional organizations to ensure that issues that are critical to the sexual and reproductive health and rights of women living with HIV are included in policies and clinical practice.

Understanding Resilience Factors – Self Esteem and Economic Survival

Loving yourself when society has chosen to discard you because you no longer appear to serve a socially defined purpose is itself an act of revolution. Body image, self esteem, and internalized stigma continue to present major challenges for women living with HIV and are likely to impact ability to realize their sexual and reproductive rights, including choosing healthy relationships and engagement in sexual and reproductive health care. However, some women have overcome these obstacles. There are rich lessons to be learned from the resilience of women who have healed to become accepting and celebratory of their



bodies, and sexuality.

More research is needed to understand how internalized stigma, feelings of WLHIV about their own sexuality, bodies, partnership and reproductive capacity intersect with women's agency in relationships, including relationships characterized by violence. Women's considerations for economic survival frequently involve sexual and romantic partners and further research is needed to understand how this may operate for women living with HIV. For example, specific research is needed to understand how women's willingness to support partners financially may intersect with HIV-positive women's perceptions about their self-worth, sexuality, and value as partners or spouses.

Federal policies and guidance should reflect a commitment to SRHR of WLHIV

The implementation of the Affordable Care Act (ACA) may provide many opportunities to improve SRHR for WLHIV. Expanded access to healthcare for low-income communities and for individuals with chronic health conditions represents a major step towards greater coverage. Within Medicaid programs, coordinated and family-centered care models may provide better co-location of services at one point of care. In addition, the ACA provides opportunities for integration of SRH/HIV and integration with factors that suggest corollary risk. For example, screening for sexually transmitted infections, cervical cancer, mammograms, and intimate partner violence will all be covered without copays as preventive care measures for women. Realizing these promises for WLHIV has the potential to greatly improve SRHR for WLHIV, however, many challenges remain. Restrictions on copays for birth control, for example, may continue under ACA implementation, forcing WLHIV to continue negotiating condom use with their male partners as a family planning method.

Specifically, the National HIV/AIDS Strategy should be updated with goals and metrics that focus on improving SRHR for WLHIV. Examples of such metrics could include: increased rates of recommended second Pap smear screening for newly diagnosed women; increased rates of screening for IPV among WLHIV in care; and goals to improve PTSD symptoms among WLHIV who suffer from PTSD.

Because women's SRHR is inextricably linked with socio-economic status, including factors as diverse as access to employment and healthcare options that employment may confer, as well as financial flexibility within relationships, expanding employment opportunities for WLHIV should be a priority.

Ongoing advocacy will be needed

Ongoing advocacy and mobilization will be needed to inform and monitor existing strategies and policies issued at the Federal level including the Ryan White Care Act, Medicaid and Medicare, The Affordable Care Act and the National AIDS Strategy. In addition, advocacy efforts should focus on monitoring guidance documents from federal agencies to ensure that issues specific to the SRHR of WLHIV have been considered.

State-run programs including ADAP, Medicaid, and health exchanges and formularies in the Affordable Care Act should be monitored to ensure that the sexual and reproductive rights of women living with HIV are considered when developing and rolling out state programming. In addition, policies and guidance pertaining to assisted reproductive technology (ART) should be closely monitored for their potential impact on WLHIV.



Health care workers should be monitored to ensure they are well trained on legislation, policies and professional standards on human rights (such as criminalization and disclosure) and patient care and improve their capacity to promote confidentiality, informed consent, gender equality, and a non-discriminatory and stigma-free environment for women living with HIV.

Advocacy that focuses generally creating a facilitative social and legal environment for women, girls, people living with HIV, and/or sexual minorities is critical to upholding the SRHR of WLHIV.

Finally, partnerships, collaborations, and coalition building between HIV and reproductive justice movements are necessary to ensure vibrant advocacy and ongoing monitoring of the sexual and reproductive rights of women living with HIV.



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