Securing the Future of Women-Centered Care

Findings from a Community-Based Participatory Research Project Led by U.S. Women Living with HIV

Coauthors (in alphabetical order by last name):
Shurand Adams, Veronica Brisco, Patricia Clark, Sharon Decuir, Heather Garza, Loren Jones, Patricia Kelly, Naina Khanna, Janet Kitchen, Rachel Moats, Lepena Reid, Arneta Rogers, Cynthia Sanchez, Meta Smith, Evany Turk

Abstract

Background:

As the U.S. HIV epidemic increasingly impacts those living in poverty, people of color, and communities facing multiple forms of discrimination, a spectrum of non-medical services has become progressively necessary to reduce barriers to medical care for women living with HIV, who tend to be poorer and have more family responsibilities than men living with HIV. For the past 25 years, the Ryan White Program has served as a critical gap-filler in helping to deliver these services. Although medicalization of the HIV response has been underway for decades, Ryan White has retained the flexibility to provide services that facilitate access to care, known as "supportive" services. In the context of Affordable Care Act implementation, the Ryan White Program is likely to undergo reauthorization within the next several years. This marks a pivotal moment to understand how best to construct a Ryan White system that will support and leverage other existing resources.

Methodology:

In the face of these changing healthcare needs, quality of life concerns, coverage availability, service delivery infrastructure, and political landscape, Positive Women's Network – USA (PWN-USA), a national membership body of women living with HIV, facilitated a community-based participatory research project led and executed by women living with HIV to inform advocacy efforts around women-centered care. A 14-member team of women living with HIV was trained in community-based participatory research methods, developed a survey, and conducted 180 surveys of women living with HIV to assess access to care challenges.

Principal Findings:

The Ryan White system is largely working well for women with HIV and should be maintained. Women with HIV, by and large, are actively engaged in maintaining their health and seeking to live with dignity. However, improvement is needed in the following areas:

i. **Provision and quality of sexual and reproductive healthcare is inconsistent, particularly for women who are older than non-reproductive age**
ii. **There is a high level of unmet need for mental health services**
iii. **Inadequate financial resources, family responsibilities and transportation challenges present ongoing structural barriers to engaging in consistent care for respondents.**

METHODS

The Project was grounded in community-based participatory research methods (CBPR), which engage those most affected by an issue to conduct research on and analyze that issue, with the goal of devising strategies to resolve it.

For the Project, 14 women living with HIV ("the research team") were recruited and trained in CBPR research values and methods by Dr. Sonja Mackenzie, based at Santa Clara University.

Researchers worked in teams of two to survey WLHIV in their respective communities. Researchers recruited survey respondents through their social and personal networks, local clinics, community-based organizations, AIDS service organizations, and other social service agencies.

In addition to survey data, researchers collected surveillance, epidemiological, and Ryan White service utilization data in their 7 geographic locations across the U.S.: Baton Rouge, Louisiana; San Francisco Bay Area, California; Chicago, Illinois; San Diego, California; Orangeburg, South Carolina; Tampa Bay, Florida; and Southern Michigan.

Survey data were analyzed by PWN-USA staff in collaboration with the research team.

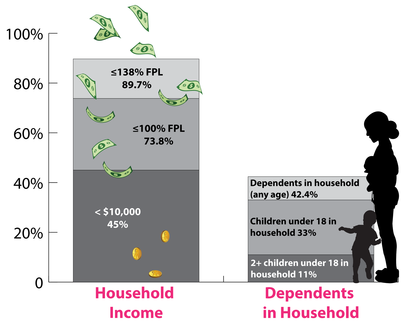
The research team consisted of 14 women living with HIV, all cisgender, including 9 Black women, 3 white women and 2 Latina women. 5 researchers were under the age of 40; 9 were between the ages of 51 and 63.

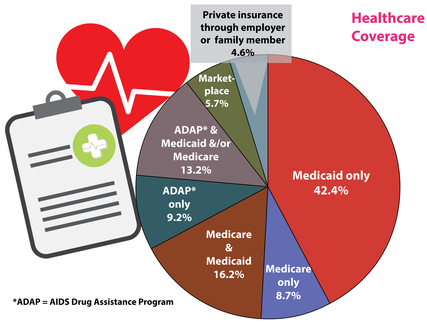
PROJECT PARTICIPANTS

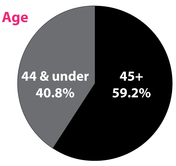
Significant numbers of the women surveyed:

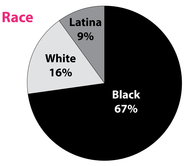
- **were low-income (89.7% below 138% of the Federal Poverty Level [FPL])**
- **were unstably housed and/or reliant on subsidized housing**
- **had family responsibilities (regardless of reproductive age)**
- **relied on subsidized healthcare for primary medical coverage**

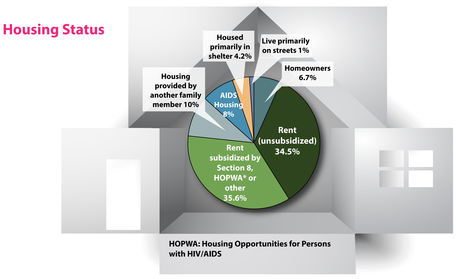
Despite facing barriers to care, participants were deeply committed to their own health and their families' wellbeing.

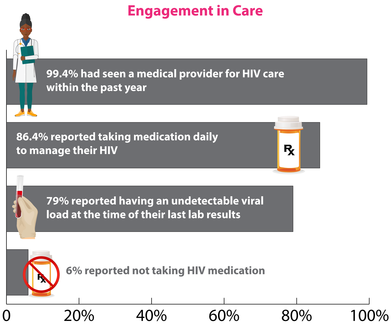










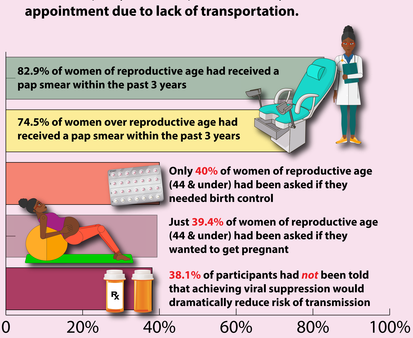


Results

What services do women with HIV need to stay in care?

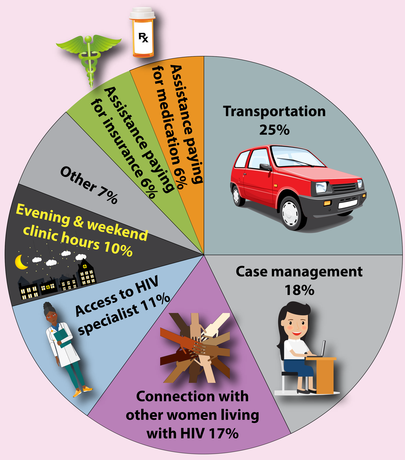
While most participants were consistently in care, many faced significant barriers.

- 50% of respondents who had **missed a medical appointment** in the past year cited transportation as the reason.
- 32% of respondents had **missed filling a prescription for HIV medications** in the past year. Primary reasons were: lack of transportation (24%), copay cost (15%), and pharmacy hours (11%).
- 50% of participants who reported **needing child care services** on site at their medical provider did not receive those services.
- **Financial and structural barriers were interrelated.** All respondents who reported they had **missed filling a prescription due to copay cost** in the past year also reported that they had **missed a medical appointment due to lack of transportation.**



While providers appeared to be doing a fairly good job at screening for cervical cancer (for which women with HIV are at high risk), lack of attentiveness to sexual and reproductive needs and desires may be related to stigmatizing attitudes toward sexuality of women living with HIV.

Q: What one thing would improve your ability to stay in care?



Gaps in Mental Health Services

17% of respondents had been diagnosed with post-traumatic stress disorder (PTSD). An alarming 64.9% had been diagnosed with depression.

- Nearly two-thirds (64.6%) of respondents reported that they would like to see someone for counseling or therapy. Of those, 59% were able to access therapy as needed. Others reported that **cost, lack of coverage, lack of available services or waitlists for services** presented a barrier.
- 87% of Project participants reported interest in attending an HIV support group, yet of those, **nearly 20% were unable to access one.**

Recommendations

Care for women with HIV in the Ryan White system is generally working, when they are able to access it. However, as women live longer with HIV and increasingly contend with extreme poverty, co-occurring conditions, and the effects of lifetime trauma, focused support is needed to secure engagement in care and address quality of life concerns. Our recommendations:

1. Improve the **quality of care** provided by:
   a. expanding the availability of **high-quality sexual and reproductive health care (SRH) services** through all parts of the Ryan White Program; and
   b. instituting **trauma-informed practices** and enhancing the availability of **mental health services** for people living with HIV.
2. Implement interventions that **improve the fundamental economic conditions** of women's lives.
3. Institutionalize mechanisms to **strengthen navigation between HIV care and other systems.**
4. Invest in **services that support access to care,** with an emphasis on addressing transportation, copayments, child care for adults of all ages with dependents, and other structural and cost-related barriers.
5. **Address stigma** by expanding availability of peer support, psychosocial support, and stigma reduction interventions and ending HIV-related criminalization.

Ryan White will continue to be urgently needed to fill gaps in other health care systems and through other payer sources. Services currently provided through Ryan White Part D funding remain necessary, including peer support, childcare, medical transportation that includes transportation for minors, and high-quality SRH. In particular, culturally relevant and non-stigmatizing SRH services should become a standard of care for all women with HIV, including women of trans experience, independent of clinic type or payer source.