

SECURING THE FUTURE OF WOMEN-CENTERED CARE:

Findings from a Community-Based Research Project by
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, Arnetta Rogers, Cynthia Sanchez, Meta Smith, Evany Turk

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Martha Cameron, Nerissa Irizarry, Vanessa Johnson, Sonja MacKenzie,
Bianca De La Piedra, and Jennie Smith-Camejo



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EXECUTIVE SUMMARY

Women currently account for nearly a quarter of the domestic HIV epidemic¹. In 2013, an estimated 9,278 women aged 13 years or older were newly diagnosed with HIV in the United States². An overwhelming majority of these new HIV diagnoses resulted from heterosexual contact³. Women of color, especially Black women, bear a particular burden of the HIV epidemic, representing the majority of US women living with HIV as well as the majority of new infections⁴. Although women with HIV are more likely to be linked to care, they are also more likely to be initially diagnosed late and more likely to die than men with HIV. The majority of women with HIV are not engaged in regular care and only a third are virally suppressed⁵. Among people living with HIV in the US, women, Black Americans, and residents of the South have the poorest health outcomes^{6,7}.

These poor health outcomes have been overwhelmingly correlated with socioeconomic and structural barriers in the literature^{8,9}. In addition, stigma, discrimination, and racism have been linked with lower engagement in care systems, worse provider-patient relationships, and worse health outcomes¹⁰. As the US HIV epidemic has become increasingly an epidemic which 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 people 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. The implementation of the Patient Protection and Affordable Care Act (the “Affordable Care Act” or “the ACA”) presents tremendous opportunities to expand access to healthcare for low-income people and those living with chronic health conditions. However, due to state discretion in adopting some ACA provisions, geographic disparities in access persist. As a crucial source of essential health coverage for people living with HIV, the Ryan White Program is likely to undergo reauthorization within the next several

years. This marks a pivotal moment to understand which supportive services are most needed today, opportunities to fortify the HIV response through additions of new service categories, and how best to construct a Ryan White system that will support and leverage other existing resources.

The last several years have seen an increased biomedicalization of the HIV response, and a declining federal commitment to addressing the needs of women living with HIV (WLHIV) in the context of the domestic epidemic. Care continuum models which narrowly focus on medical visits, prescription refill status, and CD4 and viral suppression measures mask the actual experiences of women living with HIV in their attempts to engage with care as well as their experiences of wellness and quality of life. 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 conducted 180 surveys to assess availability and quality of medical and supportive services.

Findings indicated that women with HIV, by and large, are actively engaged in maintaining their health and seeking to live with dignity.

The Ryan White system is largely working well for women with HIV and should be maintained. However, given the changing landscape of the epidemic and demographics of those impacted, there are areas where improvement is possible. In particular, provision and quality of sexual and reproductive healthcare is inconsistent and differently affects women of reproductive and non-reproductive age. In addition, there is a high level of unmet need for mental health services. Finally, inadequate financial resources, family responsibilities and transportation challenges present ongoing structural barriers to engaging in consistent care for respondents.

BACKGROUND

THE RYAN WHITE PROGRAM

In 1990, Congress passed the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act, most recently reauthorized as the Ryan White HIV/AIDS Treatment Extension Act of 2009 (the “Ryan White Program,” or “RWP”), to address the domestic crisis of the HIV epidemic. The Ryan White Program remains the nation’s largest safety net program for HIV care and treatment, serving approximately half a million people living with HIV annually. In 2014, the RWP served 144,982 women living with HIV (WLHIV), comprising 28.3% of the total number of clients receiving services¹¹.

Ryan White-funded medical care is widely viewed as an early and effective “medical home model”^{12,13,14} and has been held up for its multidisciplinary approach as an exemplar of comprehensive and coordinated patient-centered care.^{15,16} The Ryan White Program is broken down into a number of legislative Parts aimed at addressing the specific medical, emotional, mental, and social support needs of people living with HIV.

THE RYAN WHITE PROGRAM – PART D

Within Ryan White, the Part D program stands out as one of a handful of collaborative models that have developed an evidence-based approach for intervening to improve HIV clinical outcomes¹⁷ and as “epitomiz[ing] the CARE Act’s overall mission.”¹⁸ Part D is known for its integrated, network-based models, which rely on collaboration and communication among a multidisciplinary group of providers, including community-based organizations. During the 2006 Ryan White reauthorization, the legislation was expanded to explicitly permit coverage of a range of non-medical services by Part D funding. These services included family-centered case management, referrals for substance use, mental health services, other social and support services and other services needed to support the patient and patient’s family’s participation in Part D services.

The flexibility under which services supporting engagement in care can be funded by Part D grants contrasts sharply with Parts A, B and C of the Ryan White legislation, each of which have been

bound by a requirement to spend a minimum of 75% of their funds on “core medical services,” such as medical, pharmaceutical, mental health, and insurance premium cost-sharing, since the 2006 reauthorization.¹⁹ Remaining funds in Parts A, B and C may be used to resource the provision of “supportive services”^{*1} that help meet HIV-related medical outcomes. These services facilitate engagement in medical care by reducing barriers to access or by providing emotional, psychological, and other forms of support. To be an allowable cost under the RWP, all services must relate to HIV diagnosis, care and support, and must adhere to established HIV clinical practice standards reflecting HHS treatment guidelines²⁰.

Importantly, Part D is the only place in the entire Ryan White program where grantees are required to describe their plans to address a range of issues for female clients, including provision of family planning services, domestic violence awareness, health needs of perimenopausal and menopausal WLHIV, and coordination of medical care for pregnant WLHIV, including care after delivery.

In FY 2011, Ryan White Part D provided comprehensive services, including services to reduce perinatal transmission of HIV, to 60,621 female clients, and served a total of 187,819 clients²¹. For three consecutive years, the President’s budget has proposed consolidating Part D into Part C of the Ryan White Program, asserting that because two-thirds of Part D grantees are also funded by Part C, such a consolidation will reduce administrative burden on co-funded grantees.

THE PROMISE OF THE AFFORDABLE CARE ACT

Signed into law in March 2010, the Affordable Care Act offers tremendous opportunity to improve access to healthcare for people living with HIV. The ACA prohibits health plans from charging higher premiums, or placing lifetime and annual benefit limits on individuals with preexisting conditions and Section 1557 protects individuals from discrimination on the

^{*1} Supportive services are defined as services “needed for individuals with HIV/AIDS to achieve their medical outcomes (such as respite care for persons caring for individuals with HIV/AIDS, outreach services, medical transportation, linguistic services, and referrals for health care and support services.”

basis of race, sex, disability, or age²². The legislation also expanded Medicaid eligibility, established state Health Insurance Marketplaces (exchanges), and created new benefit standards with prevention enhancements²³. Qualified health plans in the state-based insurance marketplaces are required by law to include essential community providers serving low-income and underserved communities, including RWP providers.

Under the ACA, all new health plans are required to provide certain prevention services at no cost. This emphasis on prevention shows promise for improving quality of care for women: covered prevention services for women include well-woman visits, counseling and screening for intimate partner violence, HIV screening, and contraception counseling and dispensing.²⁴

The expansion of state Medicaid coverage to individuals up to 138% of the Federal Poverty Level remains one of the most important reforms for WLHIV, who tend to be low income. However, in June of 2012, a Supreme Court decision challenging the law limited the authority of the Department of Health and Human Services Secretary to enforce the expansion throughout the states, effectively making the eligibility expansion optional²⁵. Despite the fact the federal government will pay virtually all of the costs of associated with expansions through 2016, many Southern states remain opposed, using resistance to Medicaid expansion as a political football. Non-expansion states declined an estimated 32 billion dollars of federal funding by electing not to expand²⁶. Refusal to implement this cornerstone of the reform presents a missed opportunity to confront racial, economic, and HIV-related health disparities prevalent in the South.

In non-expansion states and elsewhere, the Ryan White Program will remain critical to filling in gaps as a “payer of last resort” and for providing comprehensive and quality HIV care.

Approximately three quarters of RWP clients are insured but rely on the program to supplement their coverage and to provide critical support services that are not typically covered under insurance plans, such as case management, that can facilitate engagement in care.^{27, 28}

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 it²⁹. CBPR is frequently conducted in collaboration with those who have formal training in research methods, fusing resources and technical skills derived from an academic setting with the invaluable insight of community members of an affected population who may be more likely to design meaningful questions and elicit participation from others who share similar circumstances.

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. Training was conducted via a webinar series; webinars were recorded for later viewing and listening as needed. The research team was also provided with reading materials to support their understanding of CBPR processes.

Following the trainings, the team met regularly via phone and webinar, generating a set of research questions related to the quality and accessibility of care for WLHIV. Based on those questions and areas of interest, domains for an online survey instrument were developed. The survey was developed with support from PWN-USA staff, piloted by the team members, and went through several rounds of revisions with input from the researchers. Researchers then 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 (CBOs), AIDS service organizations (ASOs) and other social service agencies. The survey instrument was administered online through SurveyMonkey. Researchers obtained signed informed consent from survey takers before administering the survey and participants received a \$20 Target or Walmart gift card for their participation in the survey. Due to varying levels of literacy, in some instances researchers read the questions aloud to participants and recorded responses in the survey instrument.

In addition to survey data, researchers collected surveillance, epidemiological, and Ryan White service



utilization data in their seven geographic locations across the United States. Regions were: Baton Rouge, LA; San Francisco Bay Area, CA; Chicago, IL; San Diego, CA; Orangeburg area, SC; Tampa Bay, FL; and Southern Michigan. PWN-USA staff provided support to the research team through monthly calls for the full team, regular check-in calls with regional teams as needed, and ongoing development of materials to support the project.

Survey data were analyzed by PWN-USA staff in collaboration with the research team. Findings were presented to the research team for analysis and discussion in three stages. A webinar was held to present initial data, generate discussion and create opportunity for the research team to pose new questions about the data. Subsequently, a second webinar attempted to address those questions through data introduced and presented for discussion and analysis. Finally, the research team provided comments on the draft report, which were incorporated prior to release.

The research team consisted of 14 women living with HIV, all cisgender, including nine black women, three white women and two Latina women. Five researchers were under the age of 40, while the remaining nine were between the ages of 51 and 63.

FINDINGS

The majority of respondents were long-term HIV survivors. Mean time since diagnosis was 16 years. 76.7% of respondents had been diagnosed with HIV for 10 years or longer and 36.3% reported they had been diagnosed with HIV for 20 years or more. 11% of respondents had been diagnosed with HIV for less than five years.

Table 1. Selected Demographic Characteristics of Survey Respondents

	Percentage of HIV epidemic in US	Percentage of survey respondents
Race		
Black/African-American	63%	67%
Caucasian/White	18%	16%
Latina/Chicana	18%	9%
Age		
44 and under	45.8%	40.8%
45 or over	54.1%	59.2%
		Mean: 46.7 years
Sexual Orientation		
Heterosexual	unknown	78%
Lesbian or Gay		6.1%
Bisexual		4.9%
Residence		
Urban		65.2%
Rural		22%
Suburban		12.8%
South	48%	43%
Non-South	52%	57%

According to the 2014 Ryan White Services report, 83.1% of female clients were at $\leq 138\%$ of the FPL, while 72.5% of female clients were at $\leq 100\%$ FPL, compared with 76.3% and 64.2% of Ryan White clients overall respectively. Our sample thus tended to be even lower income than women in the Ryan White client population, at 89.7% of respondents below 138% of the FPL and 73.8% below 100% of the FPL. 45% of our sample was living on less than \$10,000 per year. 24% of

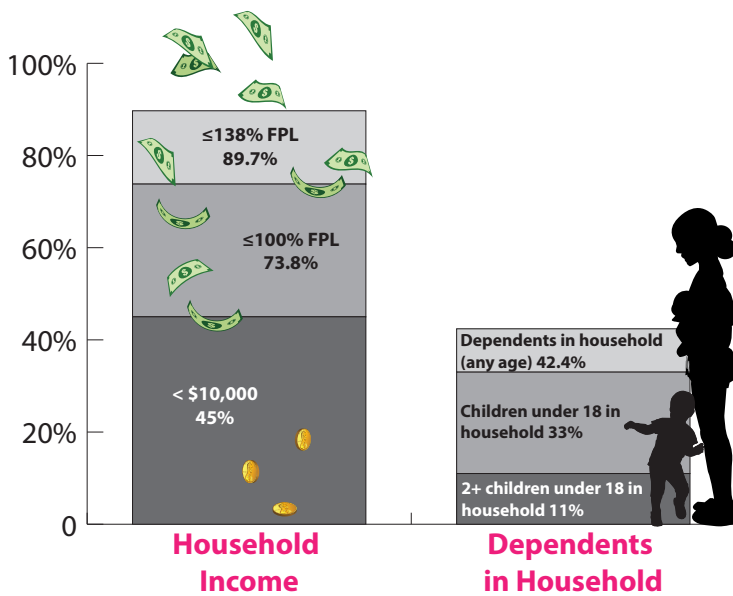


Figure 1. Household Income and Number of Dependents in Household

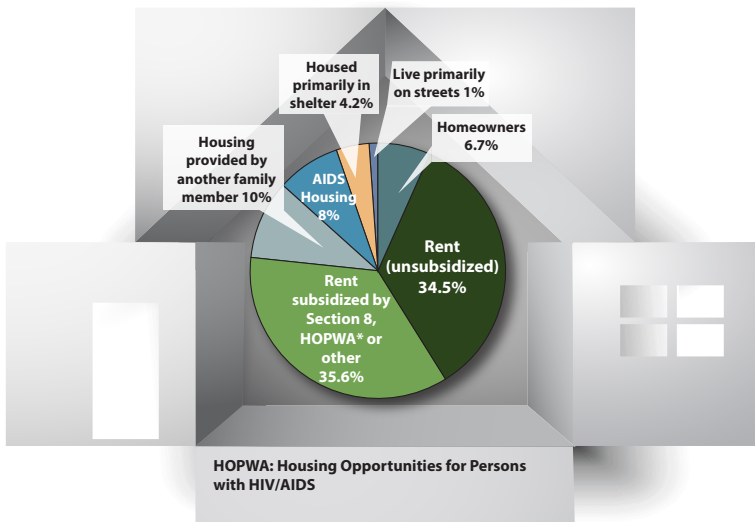
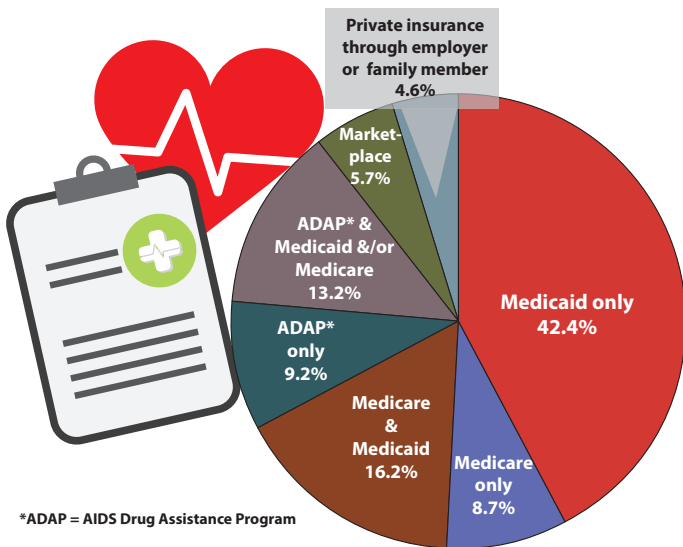


Figure 2. Housing Status



*ADAP = AIDS Drug Assistance Program

Figure 3. Healthcare Coverage

respondents in our sample were being paid for work (performed part of time or full time). 80% of survey respondents reported that their income was the sole source of income in their households.

Table 2. Diagnosed Co-morbidities Reported by Respondents

Co-Morbidity	% of Respondents Diagnosed
Hypertension	30%
Hepatitis C	21.6%
Diabetes	17.2%
Chronic lower respiratory disease	12.7%
Cervical cancer	9%
Chronic liver disease	7%
Heart disease	6%
Another form of cancer	5%

WOMEN ON THE CARE CONTINUUM

MEDICAL CARE

The success of the Ryan White Program in providing a spectrum of high quality care and services should not be understated. Because our researchers recruited respondents primarily through Ryan White clinics, ASOs and other HIV service providers, it is unsurprising that our engagement in care picture appears more favorable than national statistics on the care continuum for all US women living with HIV.

Most respondents reported a high level of confidence in their provider's expertise on HIV care (86%), and a high level of trust in their providers to maintain confidentiality of their medical information (82%). 51% of respondents reported they had not missed a medical appointment in the past year. 96% of respondents reported medical or supportive receiving services through community based organizations or clinics funded by Ryan White.

The survey inquired about all medications prescribed to respondents. Survey participants reported an average of three prescriptions, with 12% of respondents indicating they had five or more

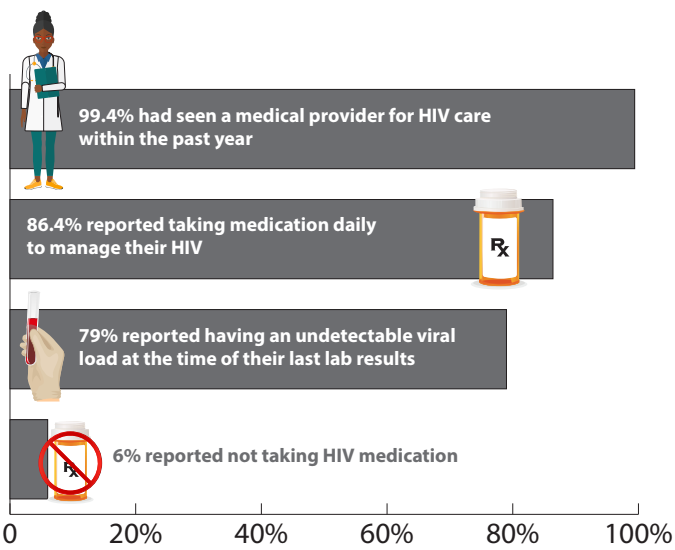


Figure 4. Engagement in Care

prescriptions. 30% were prescribed a single tablet daily HIV regimen.

Over 14% of respondents reported that their out-of-pocket medication costs for copayments had increased over the past year, with 37% of those reporting increases of \$11-20 and an additional 15% reporting increases of \$21-40 a month.

SEXUAL AND REPRODUCTIVE HEALTHCARE

While a majority of respondents reported having received a pap smear within the last 3 years as recommended by current cancer screening guidelines, age disparities were apparent in screening rates, with women of reproductive age (44 and younger) more likely to be screened than women 45 years of age and older. Additionally, most respondents of reproductive age had not been asked in the past year whether they wanted to get pregnant or needed birth control.

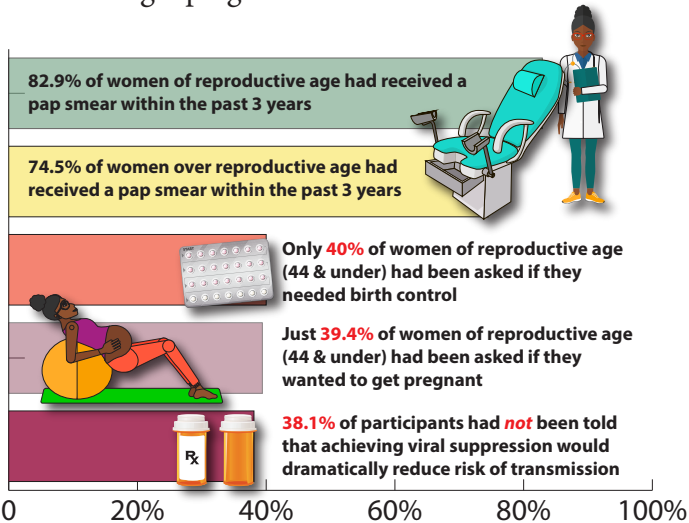


Figure 5. Sexual and Reproductive Healthcare Needs

MENTAL HEALTH

Respondents demonstrated a high need for mental health services. 17% of respondents reported they had been diagnosed with post-traumatic stress disorder (PTSD). In addition, 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% reported being able to access these services as often as they needed. A quarter of those who reported needing group therapy had been unable to access these services.

SUPPORTIVE SERVICES

While the survey found overall high levels of engagement in care, adherence to medication, and robust support systems, barriers to care were significant and respondents often reported facing multiple obstacles.

CASE MANAGEMENT AND TREATMENT ADHERENCE

Most respondents (76.2%) reported they were receiving case management services at the time the survey was administered, and the majority receiving such services were satisfied with them. However, 15% of respondents reporting that they needed medical case management had not received any in the past year, and respondents reported a particular need for support with treatment literacy and medication adherence.

Nearly a fifth of respondents who said they needed help understanding their prescribed medications and how to take them did not receive such support.

CHILDCARE

14.8% of respondents reported needing childcare services on-site at their HIV medical service provider in the past year; however, of those who needed this service over half (52%) did not receive it. Women who had not received this service tended to be older (mean age 36, compared with 32 for those who had received this service). Over half of respondents who needed childcare services on site at a non-medical HIV service provider had not received those services. An age disparity was visible here as well: the mean age of those who had received childcare services was 32.2 years, and of those who had not, 39.5 years.

TRANSPORTATION

Over a third of respondents (34.2%) reported an unmet need for rides to medical appointments in the past year. 38.5% of respondents who needed transportation vouchers to get to medical appointments in the past year had not been able to get such vouchers. Of the 88 respondents who had missed at least one medical appointment in the 12 months prior, 50% of this group cited lack of transportation as the primary reason, and a quarter of respondents reported that transportation to and from medical appointments was the single biggest factor that would improve their ability to remain in HIV care. Another 18% of respondents (mean age = 36.3 years) reported they specifically needed medical transportation that would allow dependent children to travel with them. Respondents who reported being unable to access transportation that would allow dependent children to travel with them tended to be older (mean age = 40.3 years).

Nearly a third of respondents reported they had missed filling a prescription for HIV medications within the past year, with the primary reasons being lack of transportation (24%) and cost of copays (15%). 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. Each of these respondents was on Medicaid.

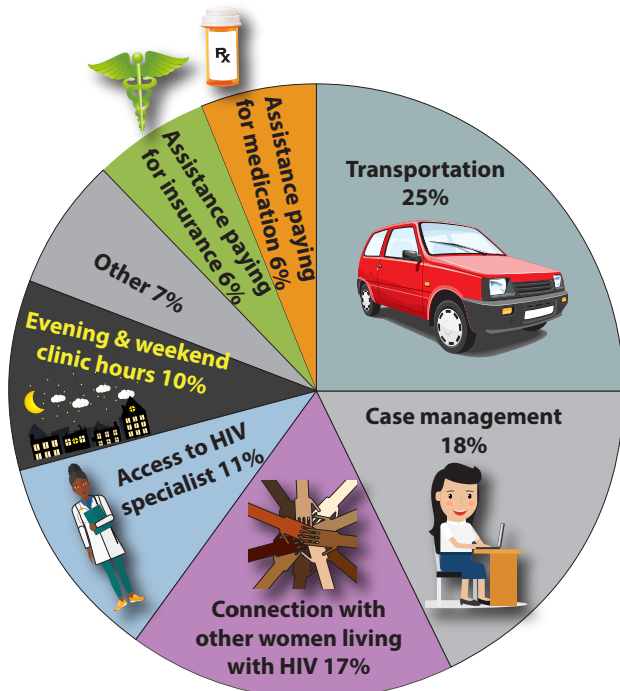


Figure 6. What One Thing Would Improve Your Ability to Stay in Care?

DISCUSSION

Significant advances have been made in medical treatment for HIV and in our understanding of the potential of viral suppression to prevent onward transmission of HIV. However, the findings from this community-based participatory research project indicate that women with HIV face significant barriers to engaging in care and living life with dignity. Many of these challenges are related to a system that has not adequately evolved to address the needs of a population who are simultaneously aging with HIV, living in extreme poverty, managing co-occurring health conditions, coping with the impacts of lifetime trauma and structural racism, and continuing to face stigma, discrimination, and microaggressions. These barriers may impede unfettered access to healthcare delivered in any setting.

ECONOMIC INSECURITY PRESENTS AN OBSTACLE TO ACCESSING MEDICAL CARE AND PRESCRIPTIONS

It is well documented that women with HIV tend to be lower-income than the overall population of people living with HIV in the US³⁰. Although 31% of respondents were either volunteering or working full-time, nearly three-quarters of respondents reported incomes at or below 100% of the FPL. Severely limited economic resources were directly or indirectly linked with many of the reported barriers to care. Despite respondents' commitment to their care, lack of financial flexibility to manage copayments, transportation, childcare, and other basic needs presented a challenge.

Strikingly, transportation presented the single largest barrier to women of all ages accessing healthcare and filling their prescriptions, independently of urban/rural residence. 8% of respondents who had missed a medical appointment in the past year reported that it was because they were too sick to go. Navigating public transportation to go to an appointment may be much more formidable than getting in the car to drive when one is sick.

In addition, facing poverty while occupying the role of primary caretaker complicates several aspects of engagement in care. Many respondents needed but could not get transportation access to medical

appointments that would allow children to travel with them.

As housing costs in large urban areas continue to rise, people living with HIV in major metropolitan areas may face displacement, having to move further from accessible services and public transportation options.

In addition, inconvenient hours—the reason given by 19% of those who had missed appointments and by 11% of those who had not filled a prescription—generally present the largest barrier to those with inflexible work hours, lack of transportation or who have family responsibilities.

WOMEN WITH HIV ARE AGING AND HAVE SIGNIFICANT FAMILY RESPONSIBILITIES

Women in our sample, as in the general epidemic among women, are aging with HIV, due to treatment advances. This has implications for individual health, family structures, and healthcare access needs. As women with HIV cope with long-term medication side effects as well as other co-morbidities, their healthcare needs become increasingly complex. A lack of dedicated treatment education support may undermine abilities of WLHIV to manage co-morbidities and long-term HIV care, including side effects, particularly as they are living longer with HIV and with other co-occurring conditions. However, the robust availability of case management services may provide a ready opportunity to expand treatment education services.

Despite challenges to accessing culturally relevant and comprehensible treatment education, our respondents were committed to their health and very active in their lives, families and communities. Most were able to name all medications they were taking and were actively making an effort to stay in care.

As women age with HIV, family structures are changing. Older women living with HIV often serve as family matriarchs and may be coping with feeding their families, as well as the effects of community violence, intergenerational effects of racist policing and incarceration, diminishing availability of social services, HIV, and myriad other health issues. As a result, they may find themselves physically and

emotionally responsible for the wellbeing of multiple generations simultaneously - younger and older generations. With these added family and household responsibilities, severely limited financial resources are often stretched and ultimately affects their ability address their overall health, including HIV.

Traditionally, childcare and family services to support engagement in care have been available primarily or solely to women with HIV of reproductive age. However, as older women with HIV find themselves handling a host of evolving family responsibilities, they may require access to childcare, transportation support that allows family members to travel with them, and flexible clinic, pharmacy, and health consultation hours, in order to effectively engage in care.

QUALITY OF SEXUAL AND REPRODUCTIVE HEALTHCARE SERVICES IS INCONSISTENT AND VARIES BY AGE

Changing age demographics of WLHIV may also be a factor in securing access to sexual and reproductive healthcare services. Although significant scientific advances have occurred that provide an opportunity to expand sexual and reproductive health and rights (SRHR), project data reflect a persistent and significant communication breakdown between health providers and women living with HIV regarding sexual behavior, fertility choices and family planning, as similarly reported in previous studies³¹.

Treatment as prevention, including viral suppression and pre-exposure prophylaxis (PrEP), combined with developments in reproductive health technologies have made having sex and building families safer, easier and less expensive for WLHIV. Yet respondents had not consistently been informed by their providers that viral suppression decreases the likelihood of passing HIV to a partner, many had not been asked whether they were interested in conceiving, and over half of reproductive age had not been offered birth control. Women over the age of 45 were less likely to have received essential preventive screenings such as pap smears.

Thus, the data show that WLHIV may still be experiencing sex negativity and reproductive stigma in healthcare settings and are too often denied the full range of sexual and reproductive health options. Stigma about sexual behavior may particularly affect

provision of services for women who were diagnosed earlier in the epidemic and women with HIV over 44. Such stigma may be internalized, which can contribute to depression and other mental health issues.

NEED FOR MENTAL HEALTH AND PEER SUPPORT SERVICES

WLHIV are more likely to suffer from depression and post-traumatic stress disorder than women in the general population, prevalence which may derive from a history of abuse and/or living with a chronic stigmatized illness itself.³² In addition, mental health of WLHIV is almost certainly negatively affected by racial discrimination and the persistent stress of poverty.

Our data show an inadequacy of available mental health services, with participants reporting high levels of unmet need for individual counseling, group therapy, and peer-based support groups.

Our data also demonstrate that many women with HIV would choose to participate in support groups with other WLHIV if available.

Geographic disparities are apparent in access to peer support services. Nearly all Michigan respondents reported they were unaware of any support groups in their area. By contrast, in Louisiana, respondents tended to be aware of support groups but reported that support groups available were not convenient for them. Among Southern respondents, 29% of those who were unable to access support groups reported not knowing of any such groups in their area, while 42.9% reported that support groups were inconvenient or hard to get to.

RECOMMENDATIONS

Care for women with living HIV in the Ryan White system is generally working, when they are able to access it. However, given the growing correlation between extreme poverty and HIV diagnosis, as well as increased longevity complicated by co-occurring conditions and mental health concerns, there is significant room for improvement in the following areas:

I. Mandate meaningful involvement of women living with HIV in community planning processes:

The Health Resources and Services Administration HIV/AIDS Bureau (HRSA HAB) and the Centers for Disease Control and Prevention (CDC) must make a joint commitment to mandate and support meaningful involvement of women living with HIV in integrated HIV prevention and care planning processes.

Meaningful involvement of people living with HIV/AIDS (MIPA) is a globally recognized principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives.³³ Mandating and supporting involvement is essential to ensuring communities receiving services have a say in how service priorities are determined, designed and implemented.

WLHIV should not only be passively consulted in such processes, but should be engaged in leadership in decision making bodies that govern the administration of care.

This will require dedicated support, training, and capacity building so that communities most impacted are prepared to participate in decision-making. Networks of people with HIV can serve as resources on the ground to prepare, support, and organize input from their constituents.

II. Implement interventions that improve the fundamental economic conditions of women's lives

Integrating access to services that support a pathway out of poverty is a critical next step for the future of HIV care and service delivery. Interventions such as micro-enterprise projects and building proficiency in financial management, budgeting, banking, and associated life skills should be institutionalized as part of HIV service delivery to support long-term financial security.

Healthcare systems, including the Ryan White Program, should consider ways to structurally incorporate linkages to job readiness and training, vocational rehabilitation, computer and Internet literacy and other services that provide opportunities for integration into the workforce.

Case managers and peer advocates have the potential to play a critical role in successful implementation of such programs. However, cross-training, linkage and coordination between HIV care systems, vocational rehabilitation, and workforce participation at the local level is necessary and should be resourced through structured funding opportunities.

There is not a one-size-fits-all approach to the issue of economic insecurity. Steady wages may present a new obstacle to healthcare coverage and ability to meet basic needs because women with HIV are required to maintain incomes below eligibility requirements in order to qualify for lifesaving benefits, such as ADAP, food and housing assistance, and Medicaid. Thus, individual level benefits advisement is needed to support informed decision-making as people with HIV attempt to transition into the formal workforce or to increase taxable wages earned.

To ensure success, structural barriers to employment should be eliminated, including but not limited to hiring practices that discriminate against people with criminal records.

Increasing technological literacy and Internet access also offers the potential to extend the success of telemedicine delivery in regions where transportation presents a major barrier to access, as well as enhancing the ability for people to manage, utilize and maximize their own electronic health records.

III. Improve the quality of HIV care provided, with a focus on mental health services, sexual and reproductive health, and addressing co-morbidities

Comprehensive HIV care must address the prevalence of co-morbidities and co-occurring conditions for

WLHIV. Our data on Hepatitis C prevalence among women with HIV is consistent with national estimates that approximately a quarter of US people living with HIV are also living with Hepatitis C.

The President's FY2017 budget, released in February 2016, includes \$9 million in funding for a Special Projects of National Significance initiative to identify and treat Hepatitis C among people living with HIV in the Ryan White care system. Such a focus on Hepatitis C should become a consistent priority within the Ryan White Program as long as it is necessary and we fully support this model as an example of leveraging an existing care system that is working well to cure and treat other co-morbidities and/or chronic conditions impacting people with HIV on a mass scale. In addition, as managing long-term life with HIV increasingly requires managing multiple complex health concerns, there is a growing need for treatment literacy programs and medication adherence support which address HIV along with other health concerns.

Similarly, given the high prevalence of depression and post-traumatic stress disorder among women living with HIV, implementation of trauma-informed primary care³⁴ in care settings serving WLHIV should be a priority.

Trauma-informed care offers tremendous potential to improve quality of services and the care environment for clients as well as providers.

Availability of mental health services and interventions that promote healing from trauma for people with HIV should be scaled up, starting with but not limited to Ryan White settings. Peer support structures, including support groups and peer advocacy programs, remain vital to support wellness and life goals of women with HIV, and should be consistently resourced.

Incredible progress has been made in our understanding of the potential for viral suppression to support HIV prevention goals. Despite a significant body of compelling data, it is unclear that providers serving people with HIV are up to date on the current state of the "treatment as prevention" (TasP) science.

To support accurate counseling on sexual health and reproductive rights, all healthcare and social service providers at clinical and community-based institutions serving people with HIV should receive regular trainings on the current state of the science around treatment as prevention and pre-exposure prophylaxis (PrEP).

Such trainings should be grounded in sex positivity and human rights, reproductive justice principles, and provide accurate, up-to-date information on the state of the science. Trainings should be directed to a range of professionals who engage with people living with HIV, including doctors, nurses, social workers, case managers, peer advocates, mental health professionals, and other providers. AIDS Education Training Centers (AETCs) should be utilized as an existing resource to create and deliver such trainings, in meaningful collaboration with local, regional or national networks of people living with HIV.

Ryan White Part D has historically provided high-quality, non-stigmatizing sexual and reproductive health (SRH) care to women with HIV of reproductive age and youth and adolescents living with HIV. Given the disparities in access to quality SRH care, we should build on Part D's successes by leveraging best practices and implementing standards for culturally relevant, non-stigmatizing, sex positive sexual and reproductive healthcare services for all people with HIV, independent of gender, gender identity, age, clinic type or payer source.

IV. Invest in supportive and facilitative services and reduce structural barriers to care

Transportation presents a clear barrier to consistent engagement in healthcare for women with HIV in urban, rural, South, and non-South settings. Medical transportation access should be improved and should consider the needs of women of all ages with family responsibilities. To further promote accessibility of care and treatment, clinics and pharmacies should consider extending or diversifying hours.

Childcare should be available for women with HIV who need it, both at clinics and at service delivery

access points such as support groups, independently of the age of the client.

Lifting the AIDS Drugs Assistance Program (ADAP) restriction which bars provision of more than a month's supply of medication at once may reduce barriers to filling prescriptions, particularly where transportation and/or schedule are a factor.

In addition to medical case management, the RWP allocates funding for non-medical case management services (NMCM) to provide clients with guidance and assistance in accessing medical, social, community, legal, financial and other services, as well as fostering links between institutional and personal systems of support for their clients and key family members³⁵. Redefining the spectrum of services covered by both medical and non-medical case management may be important future considerations for the Ryan White Program.

V. Addressing stigma, including institutionalized stigma and discrimination

WLHIV continue to experience the negative consequences of HIV related stigma and discrimination. HIV stigma is further compounded by oppression and discrimination experienced on the basis of race, class, gender, sexuality, and gender identity. These multiple and intersecting stigmas may perpetuate internalized stigma and have negative consequences for the physical and mental health of WLHIV.

Interventions that reduce stigma, including internalized stigma, should be resourced and prioritized. In addition, providers, healthcare workers, case managers, outreach workers, health educators and peer counselors must be equipped with the tools and training to deliver non-judgmental and affirming care.

Laws that criminalize, unfairly target, or more harshly penalize people on the basis of their HIV positive status create a hostile environment and should be eliminated.

STUDY LIMITATIONS AND FUTURE CONSIDERATIONS

Study limitations include the overall sample size (n=180) and recruitment strategy. The research team recruited participants from points of entry in the health service delivery system including AIDS service organizations (ASOs), local clinics, or other social service providers and support groups. As a result, our sample was far more likely to be engaged in care than the national average, and data reflecting our sample's overall engagement and maintenance in care may not reflect national trends.³⁶

We did not access medical records for this study, so data on health conditions, viral suppression and other lab tests, prescriptions, and other health information is based on self-report, which may be inaccurate in some cases. Further, it is possible that responses may have been affected by respondent bias if some participants feared negative repercussions answering questions related to adherence to medical treatment and their medication regimens.^{37, 38, 39, 40, 41}

The survey was only administered in English due to funding constraints; this is the likely reason for relatively low participation of Latina-identified WLHIV. Also, this report does not adequately address specific health and access to care concerns of lesbian, bisexual and transgender women living with HIV or young people with HIV transitioning to adult care. Over 10% of our respondents identified as lesbian, gay, or bisexual (LGB) and there is inadequate research considering how LGB women with HIV may experience healthcare settings and quality of care differently. These populations require specific attention and focus in future research. Further, many issues which may affect engagement in care were not addressed in this study, such as food insecurity, which is likely to play a significant role in medication adherence and health outcomes.⁴²

CONCLUSION

Women living with HIV are deeply committed to their health, their families, and their communities. As women are living longer and aging with HIV, they are managing multiple health challenges and family responsibilities while living in poverty. Over thirty years into the epidemic, HIV stigma continues to take a toll on health and well-being of people living with HIV, impacting engagement in care and quality of care provided, particularly in the arena of sexual and reproductive health.

The Ryan White Program is a medical home model that is working well for women with HIV and will continue to be urgently needed to fill gaps in other healthcare systems and other payer sources. However, the RWP should be updated to address the needs of a population living long term with a chronic, stigmatized illness. Supportive services that have historically been available primarily to women of reproductive age, such as childcare and medical transportation that allows transportation for minors, should be expanded to women with HIV of all ages. Our data demonstrates a continued necessity for existing supportive services^{*2}, which facilitate engagement and retention in care, and indicates new or reframed service categories may be necessary to support living with HIV long-term.

Specifically, future iterations of Ryan White should: i) ensure meaningful involvement of women with HIV; ii) reduce structural and cost-related barriers to care, especially transportation iii) support women with HIV to get out of poverty iv) prioritize stigma reduction, and v) expand the scope of service provision, with a focus on trauma-informed service delivery and affirming sexual and reproductive healthcare for all people of all ages and genders living with HIV.

*2 Supportive services include AIDS Drug Assistance Program Treatment (ADAP) pharmaceutical assistance; child care services; early intervention services (EIS) emergency financial assistance; food bank/home delivered meals; health education/risk reduction; health insurance premium and cost sharing assistance for low income individuals; home- and community-based health services; home health care; hospice; housing; legal services; linguistic services; medical case management, including treatment adherence services; medical nutrition therapy; medical transportation; mental health services; non-medical case management services; oral health care; other professional services; outpatient/ambulatory health services; outreach services; permanency planning; psychosocial support services; referral for health care and support services; rehabilitation services; respite care; and substance abuse services. The specific list of allowable services varies by Ryan White Part.

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