


# Provider Perceptions of Barriers to HIV Care Among Women with HIV in Miami-Dade County, Florida, and Possible Solutions: A Qualitative Study

Journal of the International Association of Providers of AIDS Care  
Volume 20: 1-10  
© The Author(s) 2021  
Article reuse guidelines:  
sagepub.com/journals-permissions  
DOI: 10.1177/23259582211053520  
journals.sagepub.com/home/jia  


Melissa K. Ward, PhD, MPH<sup>1,2</sup> , Yazmine de la Cruz, MPH<sup>3</sup>,  
Sofia B. Fernandez, PhD, MSW<sup>2,4</sup>, Gladys E. Ibañez, PhD<sup>1,2</sup>,  
Michèle Jean-Gilles, PhD<sup>1</sup>, Jessy G. Dévieux, PhD<sup>1,2</sup>, Petra Brock, MS<sup>5</sup>,  
Robert Ladner, PhD<sup>6</sup>, Mary Catherine Beach, MD, MPH<sup>7</sup>,  
and Mary Jo Trepka, MD, MSPH<sup>1,2</sup> 

## Abstract

In Miami-Dade County, women with HIV (WWH) enrolled in Ryan White Program (RWP) services belong to groups that have historically faced structural barriers to care. To examine provider perceptions of WWH's barriers to care and elicit possible solutions, we conducted semi-structured interviews (n=20) with medical case managers and human immunodeficiency virus (HIV) healthcare providers from medical case management sites serving WWH enrolled in the Miami-Dade RWP. Verbatim transcripts were analyzed thematically by two coders through an iterative process; disagreements were resolved through consensus. Barriers included lack of disclosure and stigma, additional psychosocial barriers to care, structural and logistical barriers, and negative interactions with health care providers. Participant suggestions to address these barriers included strategies that support women and foster individualized services that are responsive to their lived experiences and needs. Other solutions, such as those related to transportation, housing, and general funding for the RWP, will require advocacy and policy change.

## Keywords

HIV, women, barriers to care, providers, qualitative methods

Date received: 16 June 2021; revised: 20 September 2021; accepted: 26 September 2021.

## Introduction

Although great progress has been made in improving human immunodeficiency virus (HIV) care outcomes, women with HIV (WWH) face unique challenges to maintaining care along the HIV care continuum. The Ryan White HIV/AIDS Program (RWP), funded by the Health Resources and Services Administration (HRSA), provides comprehensive HIV medical care, medications, medical case management services, and ancillary support services to over 500,000 individuals in the United States.<sup>1</sup> In 2018, 26.5% of all RWP recipients were female.<sup>2</sup> In Florida, females make up a slightly larger proportion of the RWP recipients at 30.5%.<sup>2</sup> Nationally, the proportion of WWH enrolled in RWP services who are virally suppressed is slightly below the national average (86.8% for

<sup>1</sup> Robert Stempel College of Public Health and Social Work, Florida International University, Miami, FL, USA

<sup>2</sup> Research Center in Minority Institutions, Florida International University, Miami, FL, USA

<sup>3</sup> College of Osteopathic Medicine—Southern Utah, Rocky Vista University, Ivins, UT, USA

<sup>4</sup> School of Social Work, Robert Stempel College of Public Health and Social Work, Florida International University, Miami, FL, USA

<sup>5</sup> Deft Research, Minneapolis, MN, USA

<sup>6</sup> Behavioral Science Research Corporation, Coral Gables, FL, USA

<sup>7</sup> Johns Hopkins University School of Medicine, Baltimore, MD, USA

## Corresponding Author:

Melissa K. Ward, Department of Epidemiology, Robert Stempel College of Public Health and Social Work, Florida International University, Miami, FL, USA.

Email: mward@fiu.edu



WWH compared to 87.1% overall).<sup>2</sup> In Miami-Dade County, WWH enrolled in RWP services belong to groups that have historically faced structural barriers to care: compared to national averages, in Miami-Dade County, a higher proportion identified as Black/African-American in 2018 (67%, including Haitians, compared to 47% nationwide) and Hispanic (29% compared to 23%).<sup>3,4</sup> Compared to their male counterparts, WWH in RWP care in Miami-Dade County are also less likely to achieve a suppressed HIV viral load (78% vs 83%).<sup>4</sup> As the payer of last resort, RWP services represent a critical safety net for individuals who do not otherwise have access to health-care. To be eligible for RWP services in Florida, individuals must be living with HIV, living at or below 400% of the Federal Poverty Level (FPL), and cannot be receiving the same services from Medicaid or another type of insurance.<sup>5</sup>

Women-centered care, which recognizes women's lived experiences and intentionally addresses the barriers to care disproportionately experienced by women, has been proposed as a strategy to improve outcomes across the HIV continuum of care for WWH.<sup>6</sup> Providers of HIV medical care, along with medical case managers and other members of the healthcare team, are key stakeholders in any effort that seeks to improve the extent to which women's unique needs are addressed in HIV clinical care and support services. Those who work closely with WWH may also possess a wealth of insight into the barriers experienced by this group, as well as experience implementing formal or informal programs to address barriers to care and retention among their women clients. However, there is a gap in the literature documenting their perceptions. Although it is important to understand WWH's perspectives directly (we have undertaken projects to do so; results are forthcoming), we also believe that there is much to be gained from interviewing a range of providers who spend every day advocating for and treating WWH.

To more fully understand the unique barriers to care faced by WWH enrolled in Miami-Dade County's RWP, this study explored provider perceptions of barriers to care for WWH, along with their ideas for solutions that would improve access to and retention in HIV care for WWH.

## Methods

### Study Design

Twenty in-depth key informant interviews were carried out with 10 medical case managers and 10 health care providers and administrators who had at least 2 years of experience working with clients in the RWP. Participants were recruited from medical case management sites providing care to women enrolled in the Miami-Dade RWP. Interviews were conducted by the study's principal investigator and co-investigator outside of regular business hours using a semi-structured interview guide. Participants received a \$100 incentive. The interviews lasted approximately 60 to 90 min and were digitally recorded after receiving written informed consent from participants. The recordings were transcribed verbatim, and the

**Table 1.** Sample Questions Included in the Interview Guide.

- 
- Please describe any challenges your clients, especially women, have accessing non-HIV clinical services such as mental health care and substance use treatment.
  - Please tell me some of the most important challenges that women have in HIV care retention.
  - Please provide suggestions about what your organization could do to better support women with challenges in being retained in HIV care.
  - Please tell me some of the most important challenges that women have with ART adherence.
  - Please provide suggestions as to what your organization could do to better support women in being adherent to their medications.
  - Many women report having difficulty in disclosing their status to loved ones. Describe the types of support available to women to disclose their HIV status.
- 

Abbreviation: HIV: human immunodeficiency virus.

transcripts were imported into NVivo 12 (QSR) for data management and analysis.

### Analysis

Thematic analysis of the key informant interviews was completed; sample interview questions are included in Table 1. Coding was completed using an iterative process. To develop the initial codebook, two coders independently coded three interviews; final codes were agreed upon through discussion and consensus. Two additional coders were trained using this initial codebook. As the remaining interviews were coded and additional themes emerged, they were added to the initial codebook after discussion and consensus. A total of 2 coders analyzed each interview; 1 coder coded all 20 interviews to ensure continuity of themes throughout the coding process and prevent drifting. Any disagreements were resolved through discussion and consensus.

**Ethical Approval and Informed Consent.** The Florida International University Social and Behavioral Institutional Review Board approved this study. Participants gave written informed consent prior to completing the interviews.

## Results

### Demographics

Table 2 shows the characteristics of the 20 key informants who participated in the study. The majority were female (85%); most were medical case managers, and more than half were Black or African-American (55%). Half of the participants had worked with HIV clients for 20 years or more; 60% had worked with RWP clients for 10 years or more (Table 2).

**Table 2.** Participant Sociodemographic Characteristics (n = 20).

Characteristics	n (%)
<b>Sex</b>	
Female	17 (85)
Male	2 (10)
Transgender male	1 (5)
<b>Racial background</b>	
Black or African-American	11 (55)
White	4 (20)
Other	4 (20)
Prefer not to say	1 (5)
<b>Ethnic background</b>	
Hispanic/Latino/Latina	6 (30)
Haitian	5 (25)
Non-Hispanic	4 (20)
Other	4 (20)
None	1 (5)
<b>Position<sup>a</sup>, n</b>	
Case manager	11
Advanced practice registered nurse (APRN)	4
Administrator	3
Physician assistant	1
Nurse	1
Physician	2
<b>Years in current position</b>	
0 to 9	12 (60)
10 to 19	6 (30)
≥20	1 (5)
Missing	1 (5)
<b>Years working with clients with HIV</b>	
0 to 9	7 (35)
10 to 19	3 (15)
≥20	10 (50)
<b>Years working with Ryan White Program clients</b>	
2 to 9	8 (40)
10 to 19	5 (25)
≥20	7 (35)
<b>Years worked in South Florida</b>	
0 to 9	5 (25)
10 to 19	4 (20)
≥20	9 (45)
Missing	2 (10)
<b>Estimated percentage of clients who are women</b>	
0% to 30%	7 (35)
31% to 60%	9 (45)
61% to 100%	4 (20)

<sup>a</sup>The total exceeded 20 because two participants belong to more than one category.

Abbreviation: HIV, human immunodeficiency virus.

### Summary of Themes

Barriers that emerged from the data included disclosure and stigma, additional psychosocial barriers to care, structural and logistical barriers, and negative interactions with some health care providers. Participants also provided ideas related to possible solutions to address these barriers to care for WWH.

Table 3 summarizes provider suggestions that arose during the interviews to address barriers to care for WWH through the provision of individualized care that is sensitive to

women's unique experiences. Participants highlighted efforts at their organizations to provide support for HIV disclosure. They underscored the need to avoid accidental HIV disclosure through individualized services that would not be directly identified as HIV-related. Participants also emphasized the importance of increased availability of childcare services and support groups specific to women, as well as peer navigators who are women.

### Disclosure and Stigma

**Lack of Disclosure.** Lack of disclosure was discussed within the context of sexual partners, family, and friends. One of the most frequently mentioned ways lack of disclosure served as a barrier was by causing women to hide their medication through methods such as switching their HIV medications into vitamin bottles. This impacted adherence, as participants noted that their clients sometimes forget where they put their medication after hiding medications from close relations, or their clients do not carry medication around with them because they don't want others to see the medication and ask questions. Another participant noted their clients don't want to take their medication to work with them and highlighted the importance of medication regimens that only consist of one or two pills per day. Secondary to medication adherence, participants highlighted that lack of disclosure of HIV status also limited preexposure prophylaxis (PrEP) use among partners of WWH and, in relation to the postnatal period, potentially impacted follow-up care for high-risk newborns.

Participants also discussed lack of disclosure due to women's fear of retribution or violence from partners, as shown by the following exemplars:

*These are women who haven't disclosed [to] their partners. These are partners who don't give a damn... who may just kick them out of the house... some of these women are very, very dependent on the man and just for one reason or another can't get away or can't get out. [Advanced Registered Nurse Practitioner, Female, 27 years of experience with RWP clients]*

*I have asked patients, in relationships where things happen, have they disclosed to their partner that they are positive, and you'd be surprised how many people don't disclose, for fear, retribution, violence ... [Administrator, Female, 25 years of experience with RWP clients]*

Another participant highlighted a perceived generational difference in comfort with disclosure due to varying levels of HIV awareness:

*...the younger generation... they know that there's so many strides that have been made, they're like well it's not what it used to be ... they're more willing to, "Oh, yeah, I'll tell my mom, I'll tell my sister." With the older generation, I'm not seeing that. [Advanced Registered Nurse Practitioner, Female, 8 years of experience with RWP clients]*

**Table 3.** Provider Perceptions of Barriers to Care for Women Living with HIV and Policy and Programmatic Implications.

Identified Barrier	Provider Suggestions	Selected Quotations
<ul style="list-style-type: none"> <li>• Fear of disclosure of HIV status</li> </ul>	<ul style="list-style-type: none"> <li>• Services to support partner disclosure to prevent violent reactions</li> <li>• Provide support for clients who do not receive it from their families or friends due to lack of disclosure</li> <li>• Create a safe, supportive environment during office visits</li> </ul>	<p>“...we offer to help a woman disclose ... we have this psychiatry team... if they think they’re ready, we’ll work with them and we’ll be together with the partner and we’ll monitor so... there’s no violence...” [Administrator, Male, 25 years of experience with RWP clients] “A lot of them don’t get the care that they need... and since they don’t get the care that they need, they don’t take medications and then their health deteriorates. That’s why it’s so important for us to reach out to these women, and say, ‘Hey we’re here to help, if you have any questions you know we are here to support.’ Because if they can’t get it from family and friends, they can sure come here at least we can provide some sort of support... so they don’t feel alone.” [Medical Case Manager, Female, 19 years of experience with RWP clients] “... they think that it’s a stigma on them. They don’t want nobody to know it, so you have to make them comfortable to let them know, ‘No, you’re here. Nobody’s gonna know ... we don’t even discuss to our own peers.’ My patient[s] come in my office, I will close the room... so we’ll make them feel at home.” [Medical Case Manager, Female, 6 years of experience with RWP clients]</p>
<ul style="list-style-type: none"> <li>• Accidental disclosure through utilization of HIV services</li> </ul>	<ul style="list-style-type: none"> <li>• Additional pharmacy options for clients who rely on AIDS Drug Assistance Program (ADAP)</li> <li>• Rideshare services that aren’t explicitly linked to HIV care</li> <li>• Holding support groups in locations that protect participants from being seen or identified by acquaintances</li> </ul>	<p>“...if we had more... pharmacy... locations... or options for patients, I think that would be great.” [Medical Case Manager, Female, 5 years of experience with RWP clients] “...they shy away from asking for help when they need it because they’re so afraid that they’re going to be associated with something that is clearly for people living with the virus. ...The same way we’re trying to make their healthcare personal but giving them access to things that are personalized for them. Maybe giving them a card every month that allows them to take an Uber, where they don’t have to share a ride with everyone and wonder if everyone is gonna know...” [Advanced Registered Nurse Practitioner, Female, 8 years of experience with RWP clients] “...the agency went as far as covering the window panes so they can feel comfortable.” [Medical Case Manager, Female, 19 years of experience with RWP clients]</p>
<ul style="list-style-type: none"> <li>• Lack of transportation</li> </ul>	<ul style="list-style-type: none"> <li>• Increased funding for rideshare services that aren’t explicitly linked to HIV care</li> </ul>	<p>“...having funding where you’re getting 50 dollars or 60 dollars a month, specifically to be able to go to your appointments ... Once your 50 bucks is up, then it’s up.” [Advanced Registered Nurse Practitioner, Female, 8 years of experience with RWP clients]</p>
<ul style="list-style-type: none"> <li>• Childcare</li> </ul>	<ul style="list-style-type: none"> <li>• Formalized childcare areas</li> </ul>	<p>“They sit there, if they have to go in or something, they probably say ‘Can you watch my kid?’ and the person in the lobby watches their kid. You know we’re not gonna let nobody come in here and snatch your kid and run off with them like that... I might like to see us develop a childcare area... At least the kid can be somewhere where he’s able to color, draw, something, watch cartoons or something... even some type of electronic game where they can sit and play... while their caretaker is in with the provider.” [Medical Case Manager, Female, 19 years of experience with RWP clients]</p>
<ul style="list-style-type: none"> <li>• Conflict with employment</li> </ul>	<ul style="list-style-type: none"> <li>• Flexible scheduling and appointment reminders</li> <li>• Extended and weekend hours</li> </ul>	<p>“We try very hard. I mean we have a great scheduler and we also make phone calls for the week or two before the appointment, so we can talk to them.” [Advanced Registered Nurse Practitioner, Female, 27 years of experience with RWP clients] “Providing healthcare services between our hours of 8 and 5, or even ‘til 6 o’clock is not always reasonable. And not opening from 6 to 10[pm], or on the weekend. So I think those changes could actually make a great impact.” [Medical Case Manager, Female, 12 years of experience with RWP clients]</p>
<ul style="list-style-type: none"> <li>• Lack of social support</li> </ul>	<ul style="list-style-type: none"> <li>• Support groups specifically for women with HIV</li> <li>• Availability of peer navigators who are women</li> </ul>	<p>“...even with Ryan White and everything... [there’s] not too many programs out there to help women with HIV. There are a lot of programs to help MSM. But there’s not a lot of groups... for women. I don’t think that’s equal... I think Ryan White should spend some money or start some program that will really... help women, because some of these women work, they’re mothers, they have to deal with partners, they have to deal with children... there’s no support.” [Advanced Registered Nurse Practitioner, Female, 25 years of experience with RWP clients] “We wanna hire at least 2 or 3 more female peers... they’re the ones that take their information when the person first comes in, so we’ve had women ask, ‘Hey is there a woman I can speak to?’ ...we know they might feel more comfortable with a female.” [Medical Case Manager, Female, 19 years of experience with RWP clients]</p>

(continued)

**Table 3.** (continued)

Identified Barrier	Provider Suggestions	Selected Quotations
<ul style="list-style-type: none"> <li>Culturally rooted Beliefs</li> </ul>	<ul style="list-style-type: none"> <li>Adapt communication/ education strategies to be relevant to the client</li> </ul>	<p>“...one of my group is my Haitian population...I’ve explained it to them in Creole... ‘HIV is a thief... and it’s brought a bunch of its friends... What do thieves do? They rob you ... if you allow them they will rob you of your life... your medication, that is the police...the more you take your medication, the more police that come into your body... When you see your viral load, it says 100,000, and your CD4 count is... 200... you got 100,000 thieves versus 200 police. Who’s going to win?’ ...When they come back...and they see their number is now 100 viral load and their CD4 is 7,000, I say, ‘Look, we got more police officers and less thieves!’” [Advanced Registered Nurse Practitioner, Female, 3 years of experience with RWP clients] “I get to the point where I even draw diagrams for them... showing them how the medication works and different stages of replication.” [Advanced Registered Nurse Practitioner, Female, 8 years of experience with RWP clients]</p>
<ul style="list-style-type: none"> <li>Interactions with healthcare providers</li> </ul>	<ul style="list-style-type: none"> <li>Providing peer navigators to attend medical appointments with clients to reduce levels of intimidation they may feel</li> <li>Better education for providers on care for people with HIV</li> <li>Diverse workforce</li> <li>Cultural competency, and taking cultural differences into account when providing care</li> <li>Training to reduce bias that goes beyond online modules</li> </ul>	<p>“One of things we’re trying to do is if a client asks for a peer educator to go with them to their appointment, we’ll go ahead and we’ll provide that... because sometimes the peer will ask because they already know the doctors.” [Medical Case Manager, Male, 7 years of experience with RWP clients] “We did try to take the culture into perspective, with the understanding the Haitian culture is different from the African American culture which is different from the Latino Hispanic Culture.” [Medical Case Manager, Female, 5 years of experience with RWP clients]</p>

Abbreviations: HIV, human immunodeficiency virus; RWP, Ryan White Program.

As examples of potential solutions for lack of disclosure, participants described the way their agencies provide support services for partner disclosure (Table 3).

**Fear of Disclosure Related to HIV Stigma.** Participants’ discussions of their clients’ disclosure fear frequently cited issues of stigma. For example, fear of disclosure to family or friends was mentioned in relation to HIV stigma, as highlighted by the following:

*Many women, they are afraid to confide in friends or even family for fear of being shut down and judged, I hear that from a lot of women. “Oh, I don’t tell my mom because she’s gonna feel this way,” or “I don’t tell my friend because then she’s gonna judge me and not want me around her... kids.” ...Because believe it or not, we’re in 2019 and there’s still so much stigma behind HIV. [Medical Case Manager, Female, 19 years of experience with RWP clients]*

Participants emphasized the importance of their clients’ disclosure to family members to build a support system to better manage their HIV care, but also noted that their clients are hesitant to disclose their status to family and friends because they often do not want to discuss how they became infected with HIV. For example:

*I try to get my patients to at least... tell one person so that you can have a support system, otherwise it’s eating you up... then also they have to talk about how they got it. And for most of the women it’s... prostitution or a significant other. I have just a couple through drug use. But most of it is prostitution. So they have to reveal, and... a lot of them don’t wanna talk about that. [Medical Case Manager, Female, 5 years of experience with RWP clients]*

Participants also described the mental health burden contemplating disclosure has on their clients:

*...the issue brings that person anxiety, it brings them depression, it brings them a lot of sadness. [Advanced Registered Nurse Practitioner, Female, 3 years of experience with RWP clients]*

Another provider noted:

*...many times, the burden that they have for not disclosing [is] so strong that I end up referring them to [a psychologist]. [Physician, Female, 3 years of experience with RWP clients]*

Participants related the stigma to the history of HIV, and noted that, as they work with their clients, the clients become more comfortable with the idea of disclosing their HIV status:

*...with the history of HIV and... the biases, people are very hesitant at first. And then the more comfortable they become, the more we talk to them about it, they go "Okay, maybe I am ready now to talk to..." [Medical Case Manager, Female, 5 years of experience with RWP clients]*

To address the challenges caused by lack of disclosure, participants highlighted the importance of healthcare professionals creating a support system when family and friends were not aware of their clients' HIV status, as well as the significance of creating a safe place for their clients (Table 3).

**Fear of Accidental Disclosure.** Participants discussed the role stigma plays in relation to issues surrounding their clients' fears of accidental disclosure when utilizing services:

*...you don't wanna be labeled. You know 'cause if they say... support group for Latina women with HIV, they announce it and then what if my neighbor goes to see, and they find me there. [Physician, Female, 6 years of experience with RWP clients]*

Participants also discussed issues surrounding accidental disclosure when their clients utilize facilities and services designated for individuals with HIV. For example, in Miami-Dade County, there is only one AIDS Drug Assistance Program (ADAP) pharmacy available for RWP clients who receive their medication through the program. Participants explained that their clients frequently reported avoiding picking up their medication at this location due to fear of being identified by their family, friends, or acquaintances; this resulted in delays and days of missed medication.

*I know I had... a couple of patients that have gone to the... location and didn't go in because they saw family members nearby... I'm like, "You didn't pick your medication up, why?" "I saw them, so I just kept walking." And it's like sigh, so you've been out of your medication for a couple of weeks because you saw them? [Medical Case Manager, Female, 5 years of experience with RWP clients]*

In addition to the issues related to the ADAP pharmacy, participants detailed issues with accidental disclosure caused by utilization of other services, such as participation in support groups. For example:

*...we saw that they had stopped coming to the groups...it's a door and it has like a glass window. They felt like people were watching them, and they were afraid that someone coming in might recognize them and be like, "Hey what is she doing in [facility name], you know she must have HIV." [Medical Case Manager, Female, 19 years of experience with RWP clients]*

To prevent accidental disclosure, participants emphasized the importance of additional pharmacy options for their clients (Table 3). They also pointed out the importance of HIV interventions that are personalized and take stigma into consideration, such as holding support groups in locations

that protect participants from being identified by acquaintances and providing credits for rideshare services like Uber or Lyft that aren't explicitly linked to HIV care (Table 3).

**Stigma Unrelated to Disclosure.** Stigma also emerged as a major barrier to care independently from fears related to disclosure. One participant highlighted the isolation that can be brought on by the stigma:

*I just feel there's still a big stigma about the virus... that's the biggest challenge because they feel alone and I feel like every human being wants a sense of belonging... So when they feel like no one understands, no one knows what I'm going through, everything is magnified. Taking a pill is magnified, coming to the doctor's appointments is magnified, transportation is magnified... [Advanced Registered Nurse Practitioner, Female, 8 years of experience with RWP clients]*

In some instances, stigma overlapped with denial. One participant highlighted the stigma surrounding women and HIV, and noted that issues related to HIV and women are not discussed as much as they should be. Still another described fear around HIV, and how they have to explain to their clients that HIV is not a death sentence.

When discussing how stigma impacts HIV care for women compared to men, one participant described the burdens society's caregiving expectations place on women:

*The thing is that women, we're supposed to be always strong and taking care of the family... For males... I'm talking about the non-gay [males], they will come in and they don't care, they tell me "I don't care who knows, this is me and I'm gonna take care of me," whereas women, it's more like... they are ashamed, so they have to hide it. Men are more like, you know who cares... [Medical Case Manager, Female, 19 years of experience with RWP clients]*

Another participant emphasized the intersection between culture and gender norms, and the need as a provider to be sensitive to the varying stigmas and challenges women may face within their communities:

*...one of the things I noticed with the women is some of them will stay with their husband even though they were infected by their husband... basically because their husband has threatened them saying that they will let the whole community know that, "You're the one that infected me" ... so they'll kind of stay and be quiet... and trying to work around that sometimes is, it's a little bit difficult. Because if you don't sit and understand that culture...that they look, when that person leaves here it's a totally different world. It's that reality for her... a lot of times you have to be careful. [Medical Case Manager, Male, 7 years of experience with RWP clients]*

### Additional Psychosocial Barriers to Care

**Lack of Social Support.** Participants explained the importance of positive social support for retention and adherence. Participants discussed the ways a positive support system lifted some of the burdens of managing HIV care alone from their clients, and one participant shared an anecdote of what they perceived to be deadly consequences for a client who lacked positive social support:

*I had a 26 year old die because she was suffering from the woulda coulda shoulda's, and she'd tell me... "I wish I could go back to when I was 18." And I'm like "But you can't, but we can get you beyond this..." ...she had started on that road, and then somebody came in and just swiped all of that away. [Medical Case Manager, Female, 5 years of experience with RWP clients]*

Several participants discussed the lack of support groups focused on WWH, noting this approach has been geared toward other groups living with HIV. For example:

*... with MSM [men who have sex with men] there's so many places they can go, there's so many things they can do ... What about the women? ...where [is] their help? Where is it? There's none. [Advanced Registered Nurse Practitioner, Female, 25 years of experience with RWP clients]*

However, other participants noted that it would be difficult to get women to attend the support groups due to hours, childcare responsibilities, or other competing priorities. When discussing a peer navigator program, one participant described the fact that peers are frequently men and not women as an additional barrier to women utilizing this program.

**Culturally Rooted Beliefs.** In other instances, participants described culturally rooted beliefs against the use of antiretroviral medications, and the desire to incorporate traditional practices into their treatment regimen. For example:

*...there's always you know that belief of, back at my home in my country we do herbal remedies... they'll say "Do you really believe that this medication is working... I'm going to go to my country and I'm going to do these herbal [remedies]... I feel that's going to wash my blood and take away whatever may be there." And again we have to go back to educating them... [Advanced Registered Nurse Practitioner, Female, 8 years of experience with RWP clients]*

Participants described culturally adaptive strategies they use in their educational approach when discussing the importance of antiretroviral medications with their clients (Table 3).

**Lack of Valuing One's own Health.** Participants also discussed clients who didn't seem to care about their health status for reasons the participants didn't understand, which served as a barrier to engagement in care. One participant described the

importance of their clients valuing their own health to achieve the best outcomes:

*...we're coming...to this age where women need to value themselves. I have so many patients who received HIV from a significant other... because of either their culture, the time that they were growing up, the area where they were taught that women have to be so submissive and take whatever...it [has] caused them to neglect themselves... my female patients that are doing wonderfully, it's like they came to that realization to value themselves... [Medical Case Manager, Female, 5 years of experience with RWP clients]*

### Structural and Logistical Barriers to Care

**Lack of Transportation.** Lack of transportation was another frequently cited barrier to care, arising in all but two interviews that were conducted. It was cited as a barrier to engaging women in their own care, as well as adherence to treatment and accessing non-HIV-related care. In relation to adherence, one participant gave the following example, noting the limited availability of assistance for bus passes:

*...she... sometimes decides...unless I get a bus pass, 'cause she can't get it every month, am I going to use [her money] to go down there to get my medication or am I going to wait another week? So sometimes she would go a week, not pick up her medications...today, we have bus passes so I have to make sure she gets one. But in months when she's not able to, it's a challenge ... [Medical Case Manager, Female, 12 years of experience with RWP clients]*

One participant noted that clients need money upfront to fund transportation to even pick up their bus passes and the challenges this presents to those who live a far distance from services. Other transportation-related challenges described by participants included wait times and length of time navigating transportation services. Participants also noted challenges related to the distance between their clients and the location of services or providers, often in reference to the only available ADAP pharmacy in the county, as well as a limited number of providers for specialty medical care which forced their clients to travel long distances to visit them as needed. When probed on challenges related to bus pass distribution, participants highlighted bureaucratic issues related to the number of monthly appointments a client must have to be eligible to receive a bus pass, as well as the limited availability of bus passes necessitating distribution to clients on a first come, first served basis. Participants noted that increasing funding for transportation and rideshare services would help address this barrier to care (Table 3).

**Conflict with Employment.** Participants reported that conflicts with employment often arose for clients when they sought HIV care, for example, having to take time off from work or trying to access appointment times that did not conflict with their work hours. Some participants discussed efforts their

agencies made to accommodate these challenges, such as extending hours a few times per week or offering appointments on the weekends. One participant described the particular challenges related to shift work, and the efforts clinic staff makes to help with those challenges:

*...many of these women work... they work at jobs that don't schedule until the week before... they don't have any kind of time off, or ... they're told what days off they're going to have every week or every two-week period, and they have to do their schedule that way... [Advanced Registered Nurse Practitioner, Female, 27 years of experience with RWP clients]*

Another participant highlighted barriers associated with requesting days off for HIV-related appointments that take an extended period of time, lost income due to lack of paid leave, and fear of losing employment. Participants also mentioned the need for extended time off as a barrier to accessing RWP-covered residential treatment services for substance use disorders.

**Childcare and Caretaking Responsibilities.** Participants discussed the challenges their clients face related to childcare, particularly balancing available appointment times with picking their children up from school or childcare responsibilities. For example:

*I have... several patients... that have issues with childcare, and trying to get them to their appointments can be difficult... if the appointment is... between 2 and 3, and they need to pick up a child at a certain time, that can keep them... and that's the only appointment available. I got patients leave like, "I gotta go pick my child up." [Medical Case Manager, Female, 5 years of experience with RWP clients]*

Regarding support groups, another participant noted:

*Sometimes, those meetings are after hours, I mean like after 5 or something like that, and they don't go, because if a mother has to take care of the kids, they're not gonna go to those meeting[s]. [Medical Case Manager, Female, 24 years of experience with RWP clients]*

Participants pointed out that their clients often have caretaking responsibilities that extend beyond their own children to their grandchildren or other dependent family members, such as elderly parents or sick siblings. Participants also emphasized that women's childcare responsibilities may impact their ability to be engaged in their own care and contrasted this with men's engagement, as shown in the following exemplar:

*Most people that are in the HIV program, they're men. Men come in, they're... involved. Women... maybe it's because the women have kids to take care of at home. They gotta see about the kids, they must get the kids off to school, then they gotta get to work, then by the time they get off of work they gotta get home with the kids, take care of the kids. So you know women ... they're not even particularly... active in coming to their appointments like*

*the men do. [Medical Case Manager, Female, 19 years of experience with RWP clients]*

In the absence of other childcare support, participants noted the informal role facilities play, and suggested their agencies may want to consider developing formalized childcare areas to support women's retention in care (Table 3).

**Housing Instability.** Participants described extensive challenges related to housing instability among their clients and the ways it presents challenges related to retention in care and medication adherence:

*I think unstable housing... has a lot to do with your care 'cause first of all you may not be getting... enough to eat ... I gotta worry about where I'm gonna leave my head at tonight, where I'm sleeping, I don't know if I'm out here on these streets... if I leave my stuff down, somebody steal my bag, my meds are gone...it's a lot.. if you have stable housing, you might have more of a stable mental attitude about everything too. [Medical Case Manager, Female, 19 years of experience with RWP clients]*

Participants described additional challenges for their clients experiencing homelessness, including food instability, substance use, and—for women specifically—risks related to their physical safety if they engage in sex work for survival. For example:

*...without that you're pretty much gonna try to either sell your medication to try to get food... you're always looking around to see hey, am I going to survive this night? [Medical Case Manager, Male, 7 years of experience with RWP clients]*

Participants cited lack of space in shelters (particularly for women and children), lack of housing vouchers, and long waiting lists of 2 to 4 years for housing assistance programs as major barriers to navigating how best to assist their clients with finding stable housing options. Housing instability was perceived as a larger, structural barrier that was outside of their agencies' control.

### Negative Interactions with Healthcare Providers

Participants discussed the significance of their client's trust in their healthcare providers, and the importance of providers spending adequate time educating their clients on the basics of how HIV behaves in their bodies if they do not take their medications. Participants also described how various interactions with members of the healthcare team present barriers to care. One participant explained how their clients seem to be intimidated by medical experts, leading to a fear of asking questions:

*...that person knows so much and... I may not know as much. So the question I may ask...that person might look at it and say, "That's a stupid question." [Medical Case Manager, Male, 7 years of experience with RWP clients]*



This same participant pointed out the importance of providing peer navigators to attend medical appointments with clients to reduce the levels of intimidation clients may feel (Table 3).

Other participants described HIV-related stigma among healthcare providers, and the negative effect that has on access to care for WWH:

*...it would be nice if the residents or the attendings... that I send them to don't freak out because they have an HIV-positive patient... HIV should have a long time ago become more mainstream in medical school... but it's not. It's still treated as an unusual thing, and it's not an unusual thing, and it's very easy to manage, you know? ...I guess there's still some stigma out there ... I mean, you would be surprised at how quickly a doctor will find out that their woman, their pregnant patient is HIV [positive], and just ... "I can't see you, go here; just give her the number" and has nothing else to do with them, just out the door. [Advanced Registered Nurse Practitioner, Female, 27 years of experience with RWP clients]*

Participants suggested better provider education on caring for people with HIV infection as one solution to address this stigma. Others highlighted the importance of a diverse workforce, cultural competency, and training that goes beyond online modules to reduce bias in the treatment of WWH (Table 3).

### Other Barriers

Participants pointed out several other barriers to care as well. Although antiretroviral therapy (ART) medication has improved greatly, participants reported that side effects and complex medication regimens are still sometimes barriers to adherence for their clients. Others discussed clients who needed basic education and information related to HIV and HIV medications. One participant shared an anecdote about a client who did not believe the HIV medication really worked:

*...another patient she was, 32, 33, recently died...she was like "I don't think that it actually works," and I'm like, "But you took it when you were pregnant, and none of your children have it." [Medical Case Manager, Female, 5 years of experience with RWP clients]*

### Discussion

In semi-structured interviews conducted among 20 RWP medical case managers, providers, and administrators, participants discussed perceived barriers for WWH. Perceptions of barriers included issues related to disclosure (such as lack of disclosure and accidental disclosure) and stigma, lack of social support, culturally rooted beliefs, lack of transportation, time-related conflicts with employment, childcare and caretaking responsibilities, and negative interactions with healthcare providers.

Provider perceptions of barriers to care for WWH align with previous findings in studies examining barriers to care among WWH. WWH has identified fear of accidental disclosure, HIV-related stigma from providers,<sup>7-9</sup> and lack of social

support<sup>7,8</sup> as barriers to care. Transportation challenges,<sup>8,10-12</sup> access to childcare,<sup>11,12</sup> competing priorities,<sup>8</sup> conflict with employment,<sup>10</sup> and the complexities of coordinating care from multiple specialists for treatment of comorbidities<sup>11</sup> have also been identified as barriers to care by WWH.

The focus of the solutions proposed by participants (Table 3) echoes previous calls for women-centered HIV care.<sup>6</sup> Improving provider-patient relationships and offering clinic-based appointment reminders are also within the scope of programmatic changes that will advance women-centered care for WWH.<sup>6,13,14</sup> It is important to note, however, that the solutions to some of the identified barriers will require policy solutions that are outside of the realm of programmatic changes to the RWP. For example, addressing chronic housing instability experienced by WWH through improving the availability of temporary shelter beds, providing housing vouchers, and creating permanent housing options that prioritize women with children will likely require active advocacy and policy change at county and state levels. Increasing funding within the RWP to augment the availability of transportation vouchers will require advocacy and policy change at the federal level.

One strength of this study is the degree to which provider perceptions of barriers to care among WWH aligned with previous studies conducted among WWH. Furthermore, because few previous studies have examined provider perceptions related to barriers to care for WWH, this study is an important addition to the literature. Others have examined provider perspectives on contraception counseling for WWH<sup>15</sup> and the role of gender in patient-provider relationships in Western Kenya.<sup>16</sup> Another study examined provider perspectives about the importance of the RWP and potential challenges in relation to Affordable Care Act implementation, but did not address barriers to care for women.<sup>17</sup> To our knowledge, the current study is among the first to detail provider perceptions of barriers to care for WWH enrolled in the RWP.

One limitation to this work includes the representativeness of the participants. During recruitment, the research team reached out to numerous RWP medical case managers and providers in Miami-Dade County; those who completed the interviews volunteered to do so outside of regular business hours and were compensated for their time. Since we could not feasibly use random sampling to select study participants, the responses to the interview questions may represent the views of individuals who are particularly cognizant of the issues facing WWH and may not be representative of the general perceptions of all medical case managers and providers who interact with WWH. Additionally, 85% of participants in this study were women, and perceptions may vary for male providers. Finally, although the findings of this study align with previous studies conducted with WWH, results should be further triangulated with findings among WWH served by the RWP in Miami-Dade County; this work is forthcoming.

### Conclusions

RWP services are a critical source of care for WWH. RWP medical case managers, providers, and administrators in

Miami-Dade County identified perceived barriers to care for WWH, which included issues related to lack of disclosure about HIV status, accidental disclosure, and HIV stigma. Participant suggestions to address barriers to care for WWH included strategies that support women and foster individualized services that are responsive to their lived experiences and needs. Programmatic changes within the RWP suggested by participants, including advanced training to reduce bias and increased availability of peer navigators, should also be considered to improve the interactions of WWH with RWP services and providers. Other possible solutions to barriers encountered by WWH, such as those related to transportation, housing, and general funding for the RWP will require advocacy and policy change at county, state, and federal levels.

### Acknowledgments

The authors wish to gratefully acknowledge Carla Valle-Schwenk, Ryan White Program Administrator, and the entire Ryan White Part A Program in the Miami-Dade County Office of Management and Budget, for their active assistance, cooperation, and facilitation in the implementation of this study. The authors would also like to thank Sikeade Caleb-Adepoju for her research support on this project. Preliminary results of this study were presented as a virtual poster at the 2020 Annual Conference of the American College of Epidemiology, the proceedings of which were published in the December 2020 issue of the journal *Annals of Epidemiology*.


### Declaration of Conflicting Interests


The authors declare that there is no conflict of interest.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was supported in part by National Institute on Minority Health and Health Disparities (NIMHD) under Awards R01MD013563 and 3R01MD013563-02S1. The authors gratefully acknowledge partial support by the National Institute on Minority Health and Health Disparities of the National Institutes of Health under Award Number NIMHD (U54MD012393), Florida International University Research Center in Minority Institutions. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

### ORCID iDs

Melissa K. Ward  <https://orcid.org/0000-0001-9296-981X>

Mary Jo Trepka  <https://orcid.org/0000-0002-6585-1194>

### References

1. Health Resources & Services Administration. About the Ryan White HIV/AIDS Program. 2020. Accessed August 1, 2020. <https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/about-ryan-white-hiv-aids-program>.
2. Health Resources & Services Administration. Ryan White HIV/AIDS Program Clients Served, by State, 2018. 2018. Accessed August 1, 2020. <https://hab.hrsa.gov/stateprofiles2018/#/profile>.
3. Health Resources & Services Administration. *Ryan White HIV/AIDS Program Annual Client-Level Data Report 2018*. 2019. Accessed August 1, 2020. <https://hab.hrsa.gov/sites/default/files/hab/data/datareports/RWHAP-annual-client-level-data-report-2018.pdf>
4. Miami-Dade HIV/AIDS Partnership. 2020 Needs Assessment. 2020. Accessed August 1, 2020. <http://aidsnet.org/wp-content/uploads/2020/08/2020-Needs-Assessment-Book-7-2-20-version-FINAL-read-version.pdf>
5. Florida Department of Health. AIDS Patient Care Eligibility Information. 2020. Accessed August 1, 2020. [http://www.floridahealth.gov/diseases-and-conditions/aids/patient-care/eligibility-information1.html#:~:text=You%20have%20to%20be%20HIV,Federal%20Poverty%20Level%20\(FPL\)](http://www.floridahealth.gov/diseases-and-conditions/aids/patient-care/eligibility-information1.html#:~:text=You%20have%20to%20be%20HIV,Federal%20Poverty%20Level%20(FPL)).
6. O'Brien N, Greene S, Carter A, et al. Envisioning women-centered HIV care: perspectives from women living with HIV in Canada. *Womens Health Issues*. 2017;27(6):721–730.
7. Geter A, Sutton MY, Hubbard McCree D. Social and structural determinants of HIV treatment and care among black women living with HIV infection: a systematic review: 2005–2016. *AIDS Care*. 2018;30(4):409–416.
8. Buchberg MK, Fletcher FE, Vidrine DJ, et al. A mixed-methods approach to understanding barriers to postpartum retention in care among low-income, HIV-infected women. *AIDS Patient Care STDS*. 2015;29(3):126–132.
9. Geter Ferguson A, Sutton MY, Hubbard McCree D. Social and structural determinants of HIV treatment and care Among hispanic women and latin@s living with HIV infection in the United States: a qualitative review: 2008–2018. *Health Equity*. 2019;3(1):581–587.
10. Moneyham L, McLeod J, Boehme A, et al. Perceived barriers to HIV care among HIV-infected women in the deep south. *J Assoc Nurses AIDS Care*. 2010;21(6):467–477.
11. Sangaramoorthy T, Jamison AM, Dyer TV. HIV Stigma, retention in care, and adherence Among older black women living With HIV. *J Assoc Nurses AIDS Care*. 2017;28(4):518–531.
12. Messer LC, Quinlivan EB, Parnell H, et al. Barriers and facilitators to testing, treatment entry, and engagement in care by HIV-positive women of color. *AIDS Patient Care STDS*. 2013;27(7):398–407.
13. Momplaisir FM, Storm DS, Nkwihoreze H, Jayeola O, Jemmitt JB. Improving postpartum retention in care for women living with HIV in the United States. *AIDS*. 2018;32(2):133–142.
14. O'Brien N, Hong QN, Law S, et al. Health system features that enhance access to comprehensive primary care for women living with HIV in high-income settings: a systematic mixed studies review. *AIDS Patient Care STDS*. 2018;32(4):129–148.
15. Coll AS, Potter JE, Chakhtoura N, Alcaide ML, Cook R, Jones DL. Providers' perspectives on preconception counseling and safer conception for HIV-infected women. *AIDS Care*. 2016;28(4):513–518.
16. Knight J, Wachira J, Kafu C, et al. The role of gender in patient-provider relationships: a qualitative analysis of HIV care providers in western Kenya with implications for retention in care. *AIDS Behav*. 2019;23(2):395–405.
17. Sood N, Juday T, Vanderpuye-Orgle J, et al. HIV Care providers emphasize the importance of the ryan white program for access to and quality of care. *Health Aff (Millwood)* 2014;33[3]:394–400.