Barriers to adherence and retention in HIV care among women

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Rationale for current study

- In 2019, nearly 250,000 women and girls living with diagnosed HIV, 57% of whom were Black/African American and 21% Hispanic[1]
- Women make up minority of people with HIV (PWH) in US (25%),[2] and needs have not been as well studied as those of men with HIV.
- Women disproportionately affected by factors (e.g., poverty, low education, childcare responsibilities) associated with low retention and low adherence[3,4]
- Little is known about which specific practices may be most important for optimal HIV care outcomes among women

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1. CDC. *HIV Surveillance Report, 2019*; vol.32. http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html. Published May 2021; 2. CDC. *HIV Surv Suppl Rep* 2019;24 (No. 1). 2/19. http:/www.cdc.gov/hiv/library/reports/hiv-surveillance.html; 3. Beer, et al. *Clin Infect Dis.* 2016;95(13);e3171; 4. Merenstein, et al. *AIDS Patient Care STDs.* 2009;23(4):289-296.

Importance of HIV care and treatment

- Reduces morbidity and mortality
- Reduces communicability
- Reduces community incidence
- Prevents perinatal HIV transmission

https://www.preventionaccess.org/undetectable

Ending The HIV Epidemic

https://www.cdc.gov/endhiv/index.html

Hogg, et al. *Lancet*. 2008;372(9635):293–9; Nakagawa, et al. *AIDS.* 2012;26(3):335–43; Samji, et al. *PLoS One*. 2013; 8(12):e81355; Nakagawa, et al. *AIDS.* 2012;26(3):335–43; Samji, et al. PLoS One. 2013;8(12):e81355; Attia, et al. *AIDS.* 2009;23:1397–404; Cohen, et al. *New Engl J Med*. 2016;375(9):830-9; Shah et al. *Clin Infect Dis*. 2016;62:220–9; Das, et al. *PLoS One*. 2010;5(6):e11068; Montaner, et al. *Lancet*. 2010;376(9740):532–539; Tanser, et al. *Science.* 2013;339(6122):966–71; Steiner, et al. *Am J Pub Health*. 2013;103(8):1357-66; Suthar, et al. *PLOS Medicine*. 2012;9(7):e1001270; Wainberg, et al. *JAMA.* 1998;279 (24):1977-1983.

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Women centered HIV care practices that facilitate HIV care retention and viral suppression in the presence of adverse sociocultural factors

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Original Article

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Differential Role of Psychosocial, Health Care System and Neighborhood Factors on the Retention in HIV Care of Women and Men in the Ryan White Program

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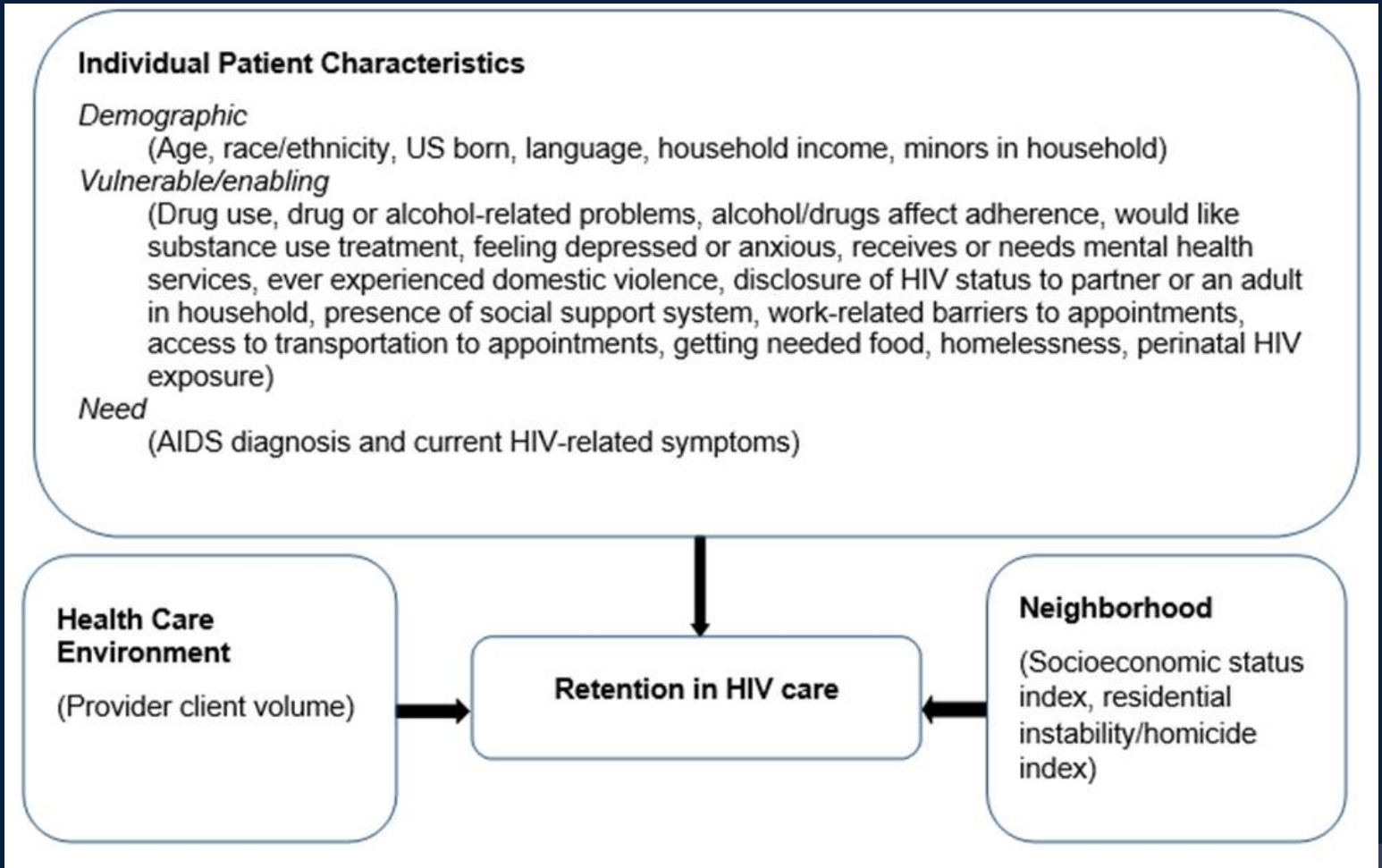
HIV care retention and adapted Andersen Behavioral Model for Health Services Utilization for Vulnerable Populations



Andersen RM. *J Health Socl Behav.* 1995:1-10, based on adaptations by Christopoulos KA, et al. *Clin Infect Dis.* 2011;52(suppl_2): S214-S222, Ulett KB, et al *AIDS Patient Care STDs.* 2009;23(1):41-49.

Methods

Data sources:

- De-identified Ryan White Program intake, health assessment, laboratory, and service billing data
- American Community Survey ZIP code level data

Methods:

- Retrospective cohort study
- Developed two neighborhood indices
- Stratified multilevel logistic regression (medical case management group as level 2 and individuals as level 1)

Dependent variable: retention in care (at least 2 encounters with HIV provider during 2017 at least 3 months apart).

Sample: People enrolled in RWP prior to 2017 who received medical case management or peer services during 2017

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Demographic characteristics of clients by gender, 2017

Characteristics	Women, (n=1609), %	Men (n=5330), %
Age group (years)		
18-34	15.5	24.6
35-49	37.5	38.7
50 or older	47.0	36.7
Race/ethnicity		
Non-Hispanic Black	41.5	19.9
Hispanic	30.2	65.7
Haitian	24.7	6.6
Non-Hispanic white/Other	3.6	7.8
Born in US		
Yes	43.6	30.2
No	56.4	69.8
Household income, percentage of FPL		
≥200%	12.6	26.1
100-199%	35.6	34.6
<100%	51.9	39.3
Number of children in household		
None	71.7	94.9
1	15.4	3.4
2 or more	12.9	1.8

Trepka MJ, et al. *J Int Assoc Provid AIDS Care*. 2020 Jan-Dec;19:2325958220950087.

Adjusted odds ratios (aOR) of factors significantly associated with lack of retention in care among women and men

Factors	Women, aOR (95% CI)	Men, aOR (95% CI)
Age group (years)		
18-34 vs 50+	**2.0 (1.3-3.1)**	**1.9 (1.5-2.3)**
35-49 vs. 50+	1.4 (1.0-1.9)	**1.4 (1.2-1.7)**
Born in US (yes vs. no)	**2.1 (1.3-3.4)**	**1.3 (1.1-1.7)**
Number of minors in household (vs. none)		
1	1.1 (0.7-1.7)	1.0 (0.6-1.5)
2	1.3 (0.8-2.3)	0.9 (0.4-1.8)
3 or more	**2.0 (1.1-3.8)**	0.6 (0.2-2)
Work-related barriers to attending appointments		
Not working vs. no barriers	**1.7 (1.2-2.4)**	**1.8 (1.5-2.2)**
Yes has barriers vs. no barriers	1.1 (0.5-2.9)	1.4 (0.8-2.4)
Infected perinatally with HIV (yes vs. no)	**3.0 (1.2-7.9)**	0.9 (0.4-2.3)
Getting food he/she needs (no vs yes)	1.5 (0.5-4.6)	**2.0 (1.2-3.1)**
HIV-related symptoms at time of assessment (yes vs. no)	0.7 (0.3-1.5)	**0.5 (0.3-0.9)**
Number of Ryan White clients (vs. 200+)		
1-9	**1.9 (1.0-3.6)**	**2.9 (1.9-4.3)**
10-29	0.6 (0.3-1.5)	**1.6 (1.1-2.3)**
30-99	1.1 (0.7-1.7)	1.0 (0.8-1.3)
100-199	0.7 (0.4-1.0)	1.2 (1.0-1.5)
Unknown	1.4 (0.8-2.5)	**2.1 (1.5-2.9)**

Model also included race/ethnicity, household income, AIDS diagnosis, problematic drug use, feeling depressed or anxious, experienced domestic violence, transportation barriers, homelessness, disclosure, and neighborhood indices

Sustained viral suppression

AIDS CARE
https://doi.org/10.1080/09540121.2022.2080800

Taylor & Francis
Taylor & Francis Group

Sex differences in psychosocial and demographic factors associated with sustained HIV viral suppression in the Miami-Dade County Ryan White Program, 2017

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Methods

Data sources:

- De-identified Ryan White Program intake, health assessment, laboratory, and service billing data
- American Community Survey ZIP code level data

Methods:

- Retrospective cohort study
- Stratified multilevel logistic regression (medical case management group as level 2 and individuals as level 1)
- Dependent variable: failure to achieve sustained viral suppression (any viral load ≥200 copies/mL)
- Sample: People enrolled prior to 2017 who had at least 2 viral loads during 2017 or at least 1 viral load in 2017 and 1 viral load in 2016.

Ward MK, et al. AIDS Care. 2022 May 27:1-6. doi: 10.1080/09540121.2022.2080800.

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Adjusted odds ratios (aOR) of factors significantly associated with lack of sustained viral suppression in women and men

Factors	Women (N=1503) aOR (95% CI)	Men (N=4989) aOR (95% CI)
Age group (years)		
18-24 vs 50+	**2.8 (1.3-6.8)**	**2.7 (1.9-3.9)**
25-34 vs 50+	**2.8 (1.8-4.2)**	**2.3 (1.8-2.9)**
35-49 vs. 50+	**2.3 (1.7-3.1)**	**1.5 (1.3-1.9)**
Race ethnicity		
Haitian vs. White/Other	1.6 (0.7-3.8)	**2.3 (1.5-3.6)**
Hispanic vs. White/Other	0.9 (0.4-2.1)	1.1 (0.8-1.5)
Non-Hispanic Black vs. White/Other	1.3 (0.6-2.8)	**1.8 (1.3-2.6)**
Household income as percentage of Federal Poverty Level (FPL)		
100-199% FPL vs. < 100% FPL	**0.7 (0.5-0.9)**	**0.6 (0.5-0.8)**
200%+ FPL vs. < 100% FPL	**0.3 (0.1-0.5)**	**0.5 (0.4-0.7)**
Experiencing homelessness (yes vs. no)	**2.3 (1.3-4.1)**	**2.0 (1.5-2.7)**
Feeling depressed or anxious (yes vs. no)	**1.5 (1.1-2.2)**	**1.6 (1.3-2.0)**
Infected perinatally with HIV (yes vs. no)	**3.3 (1.1-10.3)**	1.8 (0.8-4.3)
Disclosure		
Partner/adult in household doesn't know status vs. knows status	0.8 (0.5-1.2)	1.2 (0.9-1.6)
No partner/adult in household vs. partner/adult who knows status	**1.4 (1.0-1.8)**	1.0 (0.9-1.2)

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Ward MK, et al. AIDS Care. 2022 May 27:1-6. doi: 10.1080/09540121.2022.2080800.

Adjusted odds ratios (aOR) of factors significantly associated with sustained viral suppression among women and men (continued)

Factors	Women (N=1503) aOR (95% CI)	Men (N=4989) aOR (95% CI)
Access to food needed (no vs. yes)	1.4 (0.5-4.0)	**2.2 (1.3-3.7)**
Substance use problems (yes vs. no)	1.1 (0.6-2.1)	**1.6 (1.2-2.1)**
Ever received AIDS diagnosis vs. not	**1.8 (1.4-2.3)**	**1.8 (1.5-2.1)**
Number of Ryan White clients (vs. 200+)		
1-9	1.1 (0.5-2.4)	0.9 (0.5-1.6)
10-29	0.9 (0.4-1.9)	1.0 (0.6-1.5)
30-99	1.2 (0.8-1.8)	1.3 (1.0-1.6)
100-199	1.4 (1.0-2.0)	1.2 (0.9-1.4)
Unknown	1.5 (0.8-2.6)	**1.8 (1.3-2.5)**

Model also included US born, minor in household, social support, ever experienced domestic abuse, work barriers, access to transportation, and SES and neighborhood instability/homicide indices

Ward MK, et al. AIDS Care. 2022 May 27:1-6. doi: 10.1080/09540121.2022.2080800.

HIV care continuum outcomes among women in Ryan White Program 2017

- 84.6% retained in care
- 83.7% virally suppressed
- 76.5% sustained viral suppression

Ending the HIV Epidemic

National Goals	Increase ↑ virally supressed people to 95% by 2025.	In 2019, 65.5% of people living with diagnosed HIV have low viral load (<200 copies/mL).

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Trepka, et al. *J Int Assoc Provid AIDS Care.* 2020 Jan-Dec;19:2325958220950087. doi: 10.1177/2325958220950087; Ward, et al under review. Caleb-Adepoju, et al. *AIDS Research and Human Retroviruses*. Sep 2021.631-641; Philips. AHEAD: Monitoring Progress Toward Achieving the Nation's Viral Suppression Goals, http://doi.org/10.1089/aid.2021.0039. https://www.hiv.gov/blog/ahead-monitoring-progress-toward-achieving-nation-s-viral-suppression-goals

Summary of factors associated with adverse care outcomes for women

Factor	Lack of retention	Lack of viral suppression (VS)	Lack of sustained VS
Demographic/vulnerable enabling			
Young age	X	X	X
Infected perinatally with HIV	X		X
Not working	X		
US born	X	X	
Household income < 100% FPL		X	X
Feeling depressed or anxious		X	X
Homeless		X	X
Drug use resulting in problems (e.g., legal, hazardous)		X	
3 or more children in household	X		
Transportation barriers		X	
Lives alone			X
Need			
AIDS diagnosis		X	X
Health care environment			
Health care provider cares for small number of RWP clients	X	X	
Neighborhood			
Residential instability/homicide index		X	

Trepka, et al. *J Int Assoc Provid AIDS Care*. 2020 Jan-Dec;19:2325958220950087; Ward MK, et al. AIDS Care. 2022 May 27:1-6. doi: 10.1080/09540121.2022.2080800, Caleb-Adepoju SO et al. *AIDS Research and Human Retroviruses*. Sep 2021.631-641.

Original Research Article

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

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SAGE

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Aim 2: Ascertain current and potential health care provider and system women centered HIV care practices that may mitigate the effect of adverse sociocultural factors on HIV care retention and antiretroviral therapy adherence

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Methods: Provider in-depth interviews

Objective: Explore provider perceptions of barriers to care for women with HIV

Sample: 20 in-depth interviews (10 case managers, 7 medical care providers and 3 administrators)

Interviews: Audio-recorded semi-structured interviews

Analysis: After transcription and development of codebook, coding done independently by at least two investigators. Thematic analysis used.

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Ward MK, et al. *J Int Assoc Provid AIDS Care.* 2021 Jan-Dec;20:23259582211053520.

Summary of themes of provider interviews

- Lack of disclosure
- Stigma
- Lack of women-specific support groups
- Culturally rooted beliefs
- Lack of transportation
- Conflicts with employment
- Access to childcare & caretaking responsibilities
- AIDS Drug Assistance Program (ADAP) Pharmacy
- Negative experiences with providers

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Lack of disclosure

“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]

Methods: client qualitative interviews

Objective: Explore barriers and facilitators to retention in care and adherence to antiretroviral therapy (ART) among diverse racial/ethnic minority women with HIV in Miami-Dade County, Florida.

Instrument: Semi-structured interview asking about barriers and women centered care practices and barriers experienced by women conducted from September 2019 to March 2020.

Analysis: Interviews were audio-recorded, transcribed, and translated. After codebook developed, coding done independently by at least two investigators. Thematic analysis used.

Sample: 74 women receiving services from Ryan White Program (30 African American, 29 Hispanic and 15 Haitian)

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Ramirez-Ortiz D et al. Under review.

Barriers and facilitators to retention in care and treatment adherence identified by women

Retention in HIV Care Only	Retention in HIV Care and Treatment Adherence	Treatment Adherence Only
Barriers		
Childcare and Family Responsibilities	Employment	Food Insecurity
Feeling Unwell	Forgetfulness	Medication-related Concerns and Burden
Frequency of Medical Appointments	Mental Health and Substance Use Issues	Issues with the ADAP Program
Negative Experiences with HIV Clinic Facilities and Processes	Stigma and Discrimination	--
--	Transportation and Parking Issues	--
Facilitators		
Appointment Accommodations and Reminders	Personal Responsibility for Health	Spiritual Beliefs
--	Social Support	Simplification of Medication Regimen
--	Personal Reminder Practices and Tools	Pharmacy Services and Locations
--	Medical Transportation Services	--

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Fear of accidental disclosure at the ADAP Pharmacy

"… And it was my worst experience to go renew my card in the ADAP, my worst experience ... A lot of people, lots of people, everybody can see you. You're then exposed, Haitians will never take you ... Because when people know you're sick, they look at you differently. You're not the same person anymore to them. People will tell others this and that, that you have AIDS, that is a word that you don't like to hear because it means that you're sick." [37 y.o. Haitian woman]

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Simplifying medication regime

"…in the last [HIV] treatment… I had to take it with food so I forgot. But now I take the new [HIV] medication, because I can take it at any time, it doesn't matter if I have an empty stomach or not." [41 y.o. Hispanic woman]

Vulnerable/enabling barriers identified during aims 1 and 2

Barriers	Recommendations
Non-disclosure/fear of disclosure/ isolation/fear of retribution	Case manager/provider coaching, peer navigator, support groups
Denial	Extensive support, especially during first appointment
Lack of transportation	Increase resources to provide enough transportation vouchers or to provide access to medical Uber.
Housing instability/homelessness	Documentation of instability not just homelessness, referral for services and social support, and more housing resources
Food insecurity	Extended referrals and linkage to community services
Forgetfulness	Peer navigators/case managers share best practices (e.g., phone reminders, calendars, routines)
Mental health/substance use	Reduce barriers to services including stigma

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Demographic groups at risk of low retention or lack of viral suppression identified during aims 1 and 2

Groups	Recommendations
Younger age groups	Targeted support
Those with perinatal HIV exposure	Targeted support
US born	Further exploration of this
Unemployed/disabled	Targeted support
Low income	Targeted support
Multiple children in household	Targeted support

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Thank you!!

Discussion questions

- What barriers do you think we did not identify?
- Referring back to the two slides with recommendations, what recommendations would you modify or add?