Women centered HIV care practices that facilitate antiretroviral therapy adherence and viral suppression

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Why focus on women?

- 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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HIV care continuum outcomes among women in Ryan White Program 2017

- 84.6% retained in care
- 83.7% virally suppressed (FY ’23 84%)
- 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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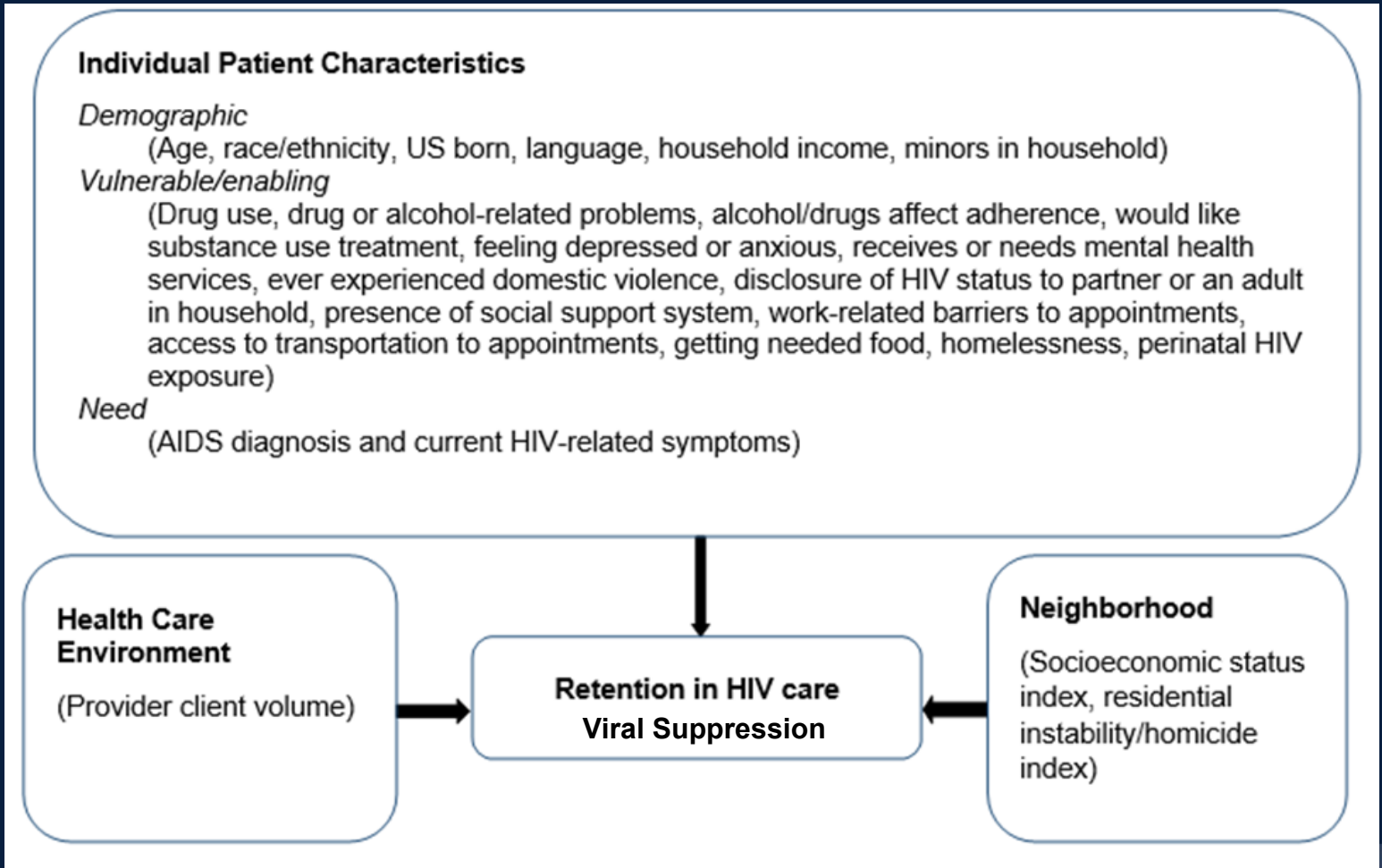
Trepka, et al. *J Int Assoc Provid AIDS Care.* 2020 Jan-Dec;19:2325958220950087. doi: 10.1177/2325958220950087; Ward, et al under review. Caleb-Adepoju, et al. *AIDS Research and Human Retroviruses*. Sep 2021.631-641; Philips. AHEAD: Monitoring Progress Toward Achieving the Nation’s Viral Suppression Goals, http://doi.org/10.1089/aid.2021.0039. https://www.hiv.gov/blog/ahead-monitoring-progress-toward-achieving-nation-s-viral-suppression-goals; HIV/AIDS Partnership. 2024 Needs Assessment Book. Available at https://aidsnet.org/wp-content/uploads/2024/09/September-2024-Needs-Assessment-Book.pdf

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



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Objective

Identify effective provider and system women centered HIV care practices that positively influence care retention, antiretroviral therapy adherence, and thus viral suppression among women, particularly racial/ethnic minority women experiencing sociocultural challenges

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Case for examining HIV patient centered care (PCC)

- What is PCC?
  - "respectful of and responsive to individual preferences, needs, and values, and ensures that patient values guide all clinical decisions"[1]
  - "knowing patient as a person and engaging the patient as an active participant in his or her own care" [2]

- Associated with increased patient satisfaction, well being and perceived quality of care; limited evidence about clinical outcomes[3-4]
- HIV care
  - Improved adherence,[5-7] one study found inverse[8]
  - Improved viral suppression[9]

1. Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century, 2001; 2. Epstein, et al. *Health Affairs* 2010;29:8:1489-1495; 3. McMillan, et al. *Med Care Research Rev* 2013;70;567-596; 4. Rathert, et al, *Med Care Research Rev* 2013;70:351-79; 5.Bodenlos, et al. *J Assoc Nurses AIDS Care*. 2007 May-June;18(3):65–73; 6. Bakken, et al. *AIDS Patient Care STDS*. 2000 Apr;14(4):189–197; 7. Magnus, et al. *AIDS Patient Care STDS* 2013;27:297-303. 8. Ingersoll & Heckman. *AIDS Behav* 2005;9:89-101; 9. Beach, et al. *JGIM* 2006;21:661-5.

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Women centered HIV care

- Basic care (up to date knowledge, empathy, privacy, confidentiality, dignity) PLUS
- Patient centered care PLUS
- Women's specific care
  - Integrated and coordinated HIV and Women's Health Care
  - Addressing structural barriers disproportionately affecting women including stigma
  - Enabling peer support (i.e., other women) and women's involvement in design and delivery of HIV care

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O'Brien N, et al. *Womens Health Issues*. 2017 Nov-Dec;27(6):721-730.

Aims to be discussed today

- 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. (Qualitative in-depth interviews with clients and providers)
- Identify specific health care provider and system women-centered HIV care practices that most strongly influence HIV care retention, adherence, and viral suppression among all women and in African American, Haitian and Latina women. (Survey of clients)

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Provider in-depth interviews

Objective: Explore provider perceptions of patient centered care and practices that promote it.

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.

Original Research Article

Perceptions and Current Practices in Patient-Centered Care: A Qualitative Study of Ryan White HIV Providers in South Florida

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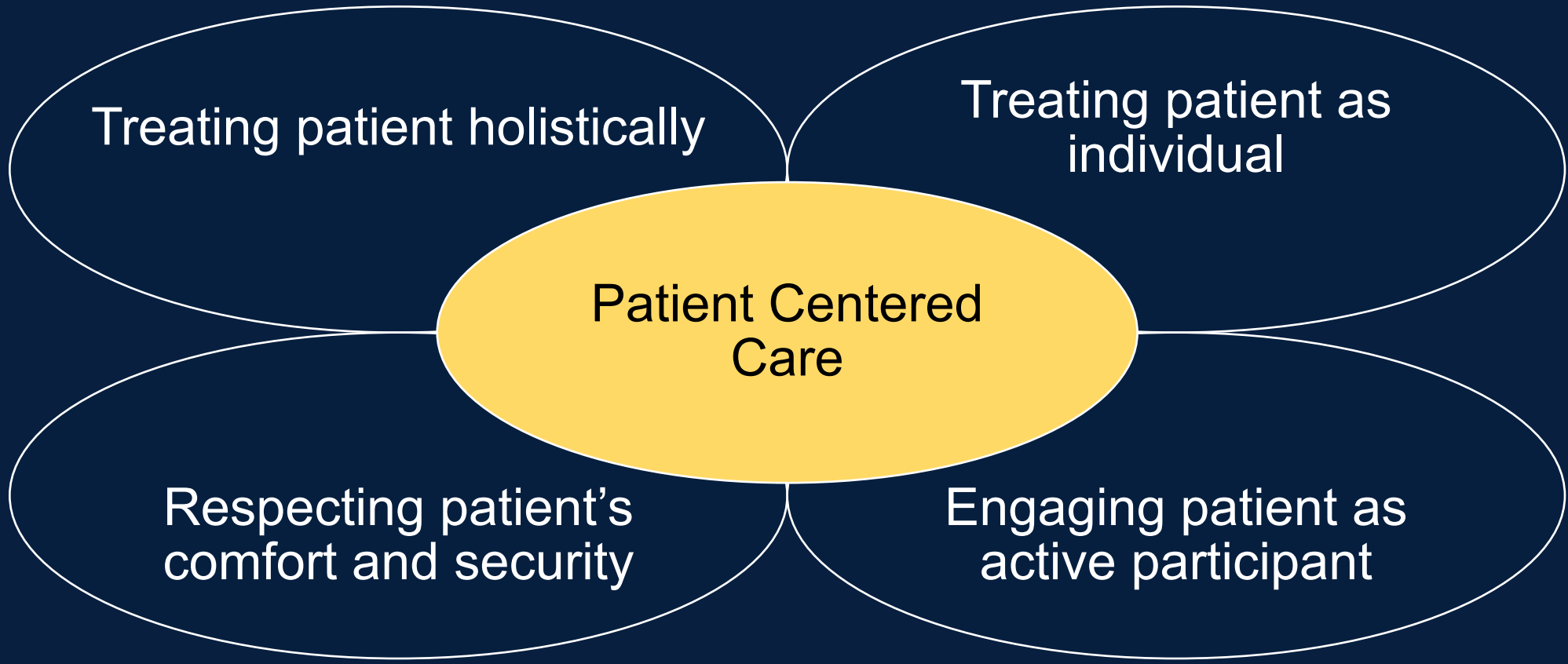
journals.sagepub.com/home/jia

Jennifer M. Knight, MD, MPH[1], Melissa K. Ward, PhD, MPH[2,3], Sofia Fernandez, PhD, MSW[3,4], Becky L. Genberg, PhD, MPH[5], Mary Catherine Beach, MD, MPH[6], Robert A. Ladner, MA, PhD[7], and Mary Jo Trepka, MD, MSPH[2,3]

Providers' interpretation of patient centered care



Knight JM, et al. J Int Assoc Provid AIDS Care. 2024 Jan-Dec;23:23259582241244684. doi: 10.1177/23259582241244684.

Practices promoting PCC

Individual	Interpersonal	Institutional
Psychosocial support • Individualized counseling • Patient advocacy/peer navigation • Allowing involvement of family • Support groups/disclosure support	**Respectful, empathetic communication and interaction** • Safe, secure environment • Respect for privacy • Focus on building patient trust • Meeting patients where they are	**Service integration** • Integrated specialist & primary care • Integrated women's health services • Family-oriented environment
Logistical support • Reminders and assisting with referrals • Mitigating barriers to care (e.g. housing referrals & transportation) • Child-friendly services or childcare	**Active engagement of patient in care** • Education and information-sharing • Team-based approach to share power • Shared decision-making	**Convenient and accesible services** • Scheduling to accommodate patient needs • Patient preference to determine clinic location
		Staffing and Resources (Staff diversity, accomodate patient's provider preferences, continuous staff training in cultural competence, multilingual resources)
		Patient and staffing feedback mechanism (continuous client feedback with response)
		Interdisciplinary collaboration (team-based approach, regular communication)

Client in-depth interviews

Objective: Explore perspectives of women in the Miami-Dade County Ryan White Program about their experiences around patient-centered care components.

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. Content analysis was used.

Sample: 75 women receiving services from Ryan White Program (30 African American, 30 Hispanic and 15 Haitian)

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Fernandez SB, et al. J Racial Ethn Health Disparities. 2023 Apr;10(2):930-941. doi: 10.1007/s40615-022-01281-y.

Journal of Racial and Ethnic Health Disparities (2023) 10:930–941
https://doi.org/10.1007/s40615-022-01281-y

Clients' Perspectives on Patient-Centeredness: a Qualitative Study with Low-Income Minority Women Receiving HIV Care in South Florida

Sofia B. Fernandez[1,2] · Melissa K. Ward[2,3] · Daisy Ramírez-Ortiz[2,3] · Annette Flores[3] · Taidiana Gonzalez Santander[3] · Rahel Dawit[3] · Cynthia Ibarra[3] · Ashley Garcia[3] · Robert Ladner[4] · Petra Brock[5] · Michele Jean-Gilles[6] · Gladys Ibañez[3] · Jessy Dévieux[6] · Mary Catherine Beach[7] · Mary Jo Trepka[2,3]

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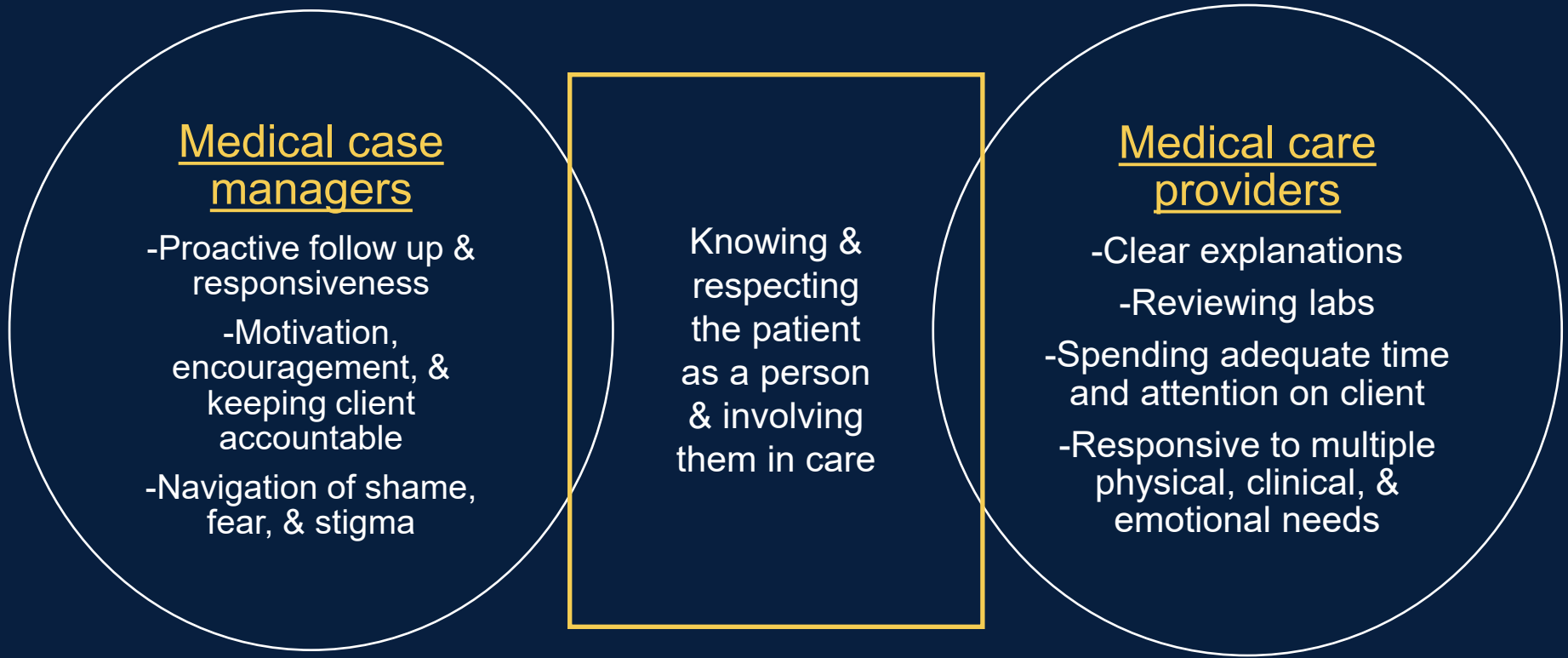
Key themes around patient-centered care for women with HIV



Fernandez et al. BMC Medical Ethics (2024) 25:39
https://doi.org/10.1186/s12910-024-01015-1

BMC Medical Ethics

RESEARCH Open Access

How patients experience respect in healthcare: findings from a qualitative study among multicultural women living with HIV

Sofia B. Fernandez[1,2*], Alya Ahmad[3], Mary Catherine Beach[3], Melissa K. Ward[2,4], Michele Jean-Gilles[5], Gladys Ibañez[4], Robert Ladner[6] and Mary Jo Trepka[2,4]

Physician orientation towards patient

- Treats as a person
- Treats as an equal
- Treats without blame or prejudice
- Treats with concern & emotional support

Medical professionalism

- Physician availability
- Considerations of privacy

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WCC survey

Objective: Assess influence of patient-provider relationship on antiretroviral therapy adherence and durable viral suppression

Sample: 560 adult, cis-gender women who were enrolled in in Miami-Dade County Ryan White Program for at least 6 months

Survey instrument:

- Health Care Relationship Trust Scale and Agency for Healthcare Research and Quality Consumer Assessment of Healthcare Providers and Systems Survey
- Piloted in English, translated into Spanish and Creole by 2 translators each, followed by consensus meeting with 3 native speakers
- Piloted in Spanish and cognitive interviewing for Creole version

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Trepka MJ, et al. AIDS Patient Care STDS. 2023 Jul;37(7):361-372. doi: 10.1089/apc.2023.0029.

Methods (Continued): WCC survey

Interviews: By telephone June 2021 to March 2022 in English, Spanish or Haitian Creole

Durable viral suppression: no viral load ≥ 200 copies/mL over 1 year period

Adherence: 3 previously validated questions about last 30 days. Items linearly transformed and categorized into adherent (≥ 90%) and not adherent (<90%)

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Trepka MJ, et al. AIDS Patient Care STDS. 2023 Jul;37(7):361-372. doi: 10.1089/apc.2023.0029.

Analysis: WCC survey

- All variables with a *p* value <0.2 for given dependent variable (adherence/durable viral suppression) entered into respective model.
- Adherence: empty models indicated no variation across medical care management site or providers, LOGISTIC procedure for backward stepwise regression. Variables removed until no *p* value >0.15 except for age group and race/ethnicity
- Durable viral suppression: Empty models indicated that random effect for provider was significant. Multilevel backward stepwise regression modeling with random effect of provider using GLIMMIX procedure.
- Interactions assessed between provider variables and age, race/ethnicity and all significant variables.

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Trepka MJ, et al. AIDS Patient Care STDS. 2023 Jul;37(7):361-372. doi: 10.1089/apc.2023.0029.

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Patient–Provider Relationships and Antiretroviral Therapy Adherence and Durable Viral Suppression Among Women with HIV, Miami-Dade County, Florida, 2021–2022

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Characteristics of 560 participants

Characteristics	No. (%)
Age group (years)	
18–34	36 (6.4%)
35–49	168 (30.0%)
≥50	356 (63.6%)
Race/ethnicity	
Non-Hispanic Black	198 (35.4%)
Hispanic	186 (33.2%)
Haitian	157 (28.0%)
Non-Hispanic White/Other	19 (3.4%)
US born	
Yes	280 (50%)
No	280 (50%)
Household income	
≥200%	116 (20.7%)
100%–199%	198 (35.4%)
<100%	246 (43.9%)
No. minors in household	
None	403 (72.0%)
≥1	157 (28.0%)
Employment status	
Does not work	263 (47.0%)
Works full or part time	297 (53.0%)

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Patient-provider relationship characteristics (N=560)

Characteristics	No. (%)
Has been with provider for at least a year	
Yes	506 (90.4)
No	54 (9.6)
Health care relationship trust score (median/interquartile range)	60 (56−61)
Provider communication score	
Low (<19)	83 (14.8)
Moderate (19)	64 (11.4)
High (20)	413 (73.8)
Did provider or someone from provider's office ask if there are things that make it hard for you to take care of your health?	
Yes	217 (38.8)
No	343 (61.3)
Did provider talk about things in your life that worry you or cause you stress?	
Yes	262 (46.8)
No	298 (53.2)
Provider rating	
≥9	491 (87.7)
<9	69 (12.3)
Does provider know you as a person?	
Yes	462 (82.5)
No	54 (9.6)
Don't know	44 (7.9)

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Adjusted odds ratios of factors associated with adherence (71.6% adherent, 28.4% not adherent)

Characteristics	aOR (95% CI)
Age group (years)	
18−34 vs. ≥50	0.80 (0.36−1.74)
35−49 vs. ≥50	1.05 (0.67−1.63)
Race/ethnicity	
Non-Hispanic Black vs. Hispanic	0.92 (0.56−1.51)
Haitian vs. Hispanic	0.77 (0.46−1.30)
Non-Hispanic White/Other vs. Hispanic	0.88 (0.28−2.75)
Health Care Relationship Trust Score per 4 points	**1.30 (1.07−1.59)**
Provider communication	
High vs. low	**1.99 (1.14−3.46)**
Moderate vs. low	**2.59 (1.18−5.63)**
General perceived health	
Very good vs. excellent	**0.51 (0.29−0.91)**
Good vs. excellent	**0.45 (0.25−0.80)**
Fair/poor vs. excellent	0.78 (0.36−1.68)
Alcohol use during last 30 days (yes vs. no)	**0.62 (0.40−0.96)**
Depressive symptoms (significant vs. nonsignificant)	**0.59 (0.38−0.94)**
Transportation problems affecting care (yes vs. no)	**0.42 (0.24−0.88)**

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Adjusted odds ratios of factors associated with durable viral suppression (80.4% suppressed, 19.6% not suppressed)

Characteristics	aOR (95% CI)
Age group (years) 18−34 vs. ≥50 35−49 vs. ≥50	 **0.42 (0.19−0.95)** 0.61 (0.37−1.00)
Race/ethnicity Non-Hispanic Black vs. Hispanic Haitian vs. Hispanic Non-Hispanic White/Other vs. Hispanic	 **0.50 (0.27−0.92)** **0.48 (0.25−0.94)** 1.35 (0.31−5.86)
Did provider or someone from provider's office ask if there are things that make it hard for you to take care of your health? (yes vs. no)	0.65 (0.39−1.07)
Has had this provider for ≥ 1 year (yes vs. no)	0.56 (0.26−1.13)
Illegal drug use in last 12 months (yes vs. no)	**0.32 (0.11−0.95)**
Alcohol use during last 30 days (yes vs. no)	0.65 (0.40−1.06)

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Conclusions of WCC survey

Adherence:

- 71.6% adherent
- Associated with higher patient-provider trust and provider communication, consistent with qualitative studies and 2 quantitative studies
- No significant depressive symptoms, no alcohol use and no transportation problems also strongly associated

Durable viral suppression:

- 80.4% suppressed
- Not associated with any provider variables, other studies have mixed findings
- Associated with older age, lack of drug use, and Hispanic ethnicity

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Trepka MJ, et al. AIDS Patient Care STDS. 2023 Jul;37(7):361-372. doi: 10.1089/apc.2023.0029.

Racial and ethnic differences in association of patient-provider relationships on antiretroviral therapy adherence and viral suppression

Objective: Determine association of ART adherence and viral suppression with specific provider behaviors and measures of the patient-provider relationship as perceived by WHIV among each of three racial/ethnic groups

Analysis:

- Frequencies of patient-provider experiences by Black/African American (excluding Haitian), Haitian, and Hispanic race and ethnicity
- Assessed association between patient-provider experiences and adherence and viral suppression controlling for age, education, and US born status

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Patient-provider relationship characteristics by race/ethnicity

Characteristics	Black (n=198), %	Haitian, (n=158), %	Hispanic, (n=186), %	*p*-value
Has been with provider for at least one year	85.9	94.3	91.9	.02
Provider rating ≥ 9	87.7	76.8	90.3	.004
In last 12 months, provider or someone from provider's office asks if there are things that make it hard for you to take care of your health	38.4	17.7	56.6	< .0001
In last 12 months, provider talks about things in life that worry you or cause you stress	59.1	10.1	64.0	< .0001
In last 12 months, provider always shows respect for what you had to say	96.5	94.7	97.9	.35
In last 12 months, provider always spends enough time with you	88.9	96.2	86.0	.006
In last 12 months, provider never used medical words you did not understand	98.5	95.7	97.2	0.25
In last 12 months, provider never talked too fast when talking with you	98.5	98.1	97.3	0.72
In last 12 months, provider always listened carefully to you	94.4	97.4	92.5	0.13
Provider discusses options and choices with you about your HIV care at least most of the time	87.2	82.0	86.5	0.37
Provider is committed to providing best care possible at least most of time	98.5	99.4	97.3	.33
Provider sincerely interested in you as person at least most of time	96.5	98.7	89.0	<.0001
Provider excellent listener at least most of the time	97.5	99.4	97.3	.33

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Patient-provider relationship characteristics by race/ethnicity

Characteristics	Black (n=198), %	Haitian, (n=158), %	Hispanic, (n=186), %	*p*-value
Provider accepts me for who I am at least most of the time	98.5	100	99.5	.24
Provider tells me complete truth about my health-related problems at least most of the time	98.0	100	97.3	.14
Provider treats me as an individual at least most of the time	99.5	99.4	91.5	< .0001
Provider makes me feel that I am worthy of his/her time and effort at least most of time	97.0	99.4	95.7	.12
Provider takes the time to listen to me at least most of the time	97.5	99.4	97.3	.32
I feel comfortable talking to provider about personal issues at least most of the time	91.4	14.3	90.7	< .0001
I feel better after seeing provider at least most of the time	94.4	96.9	97.9	.19
Provider considers my need for privacy at least most of the time	96.0	100	96.7	.06
I never think of changing to a new healthcare provider	97.5	94.9	97.8	0.28
Provider knows me as a person	81.3	96.2	73.0	< .0001

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Adjusted odds ratios for patient experience associated with adherence adjusted for age group and education level

Characteristics	Black, OR (95% CI)	Haitian, OR (95% CI)	Hispanic, OR (95% CI)
In last 12 months, provider asks if there are things that make it hard for you to take care of your health vs. no			2.1 (1.0, 4.3)
In last 12 months, provider always spends enough time with you vs. never sometimes, usually	5.2 (2.0, 13.7)		2.7 (1.1, 6.5)
In last 12 months, provided always listened carefully to you vs. never sometimes, usually			4.1 (1.3, 12.9)
Provider discusses options and choices with you about your HIV care at least most of the time vs. never sometimes, usually		5.7 (2.2, 15.2)	3.0 (1.2, 7.6)
Provider considers your need for privacy at least most of time vs. never sometimes, usually	7.3 (1.3, 40.4)		

Adjusted for age, education level and if born in US or not

Conclusion of analysis by race/ethnicity

- Patient experiences varied by race and ethnicity for just 7 of 23 measures
- Adherence
  - Associated with several communication items (e.g. listen carefully, spend enough time)
  - For Haitians and Hispanics, adherence associated with discussing options and choices; participants were less likely to report this good practice than many of the other practices
  - For Hispanics, adherence associated with providers asking if there are things making it harder to take care of health; participants were less likely to report this practice that most of the other good practices.

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Conclusion of analysis by race/ethnicity (continued)

- Viral suppression
  - No provider factors associated with viral suppression
  - Psychosocial factors more important

Limitations

- Participants rated providers very highly
  - Social desirability bias may be inflating ratings
  - Participants likely not representative as in care and older
- Difficulties with some questions for Haitian participants such as many missing responses to question about feeling better after seeing provider
- Cross-sectional survey
- Perceptions of providers influenced by other medical experiences

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Overall results

- Participants overall rate their providers very highly
- Patient-provider relationships important to clients
  - Qualitative data indicate importance of relationships with both medical providers and medical case managers
- Patient-provider trust and communication measures associated with self-reported adherence
- Evidence for viral suppression weaker; may be due to stronger effect of unmet needs and psychosocial factors such as mental health and substance use

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Recommendations

- While patient centered practices prevalent, there is need for training to increase the practices of shared decision-making and treating patients holistically by understanding patient's challenges
- Clinics need to be staffed to allow providers sufficient time with individual patients to allow for effective, meaningful communication
- Optimizing care delivery necessary but likely not sufficient to reach 95% viral suppression; improvements in addressing unmet needs such as housing, transportation, and food insecurity also needed.

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