

Effective Women Centered Care Practices from Ryan White Program Client and Provider Perspectives

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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% Hispanic¹
- Women make up minority of people with HIV (PWH) in US (25%),²and 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

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

Case for examining HIV patient centered care

- Definitions:
 - “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 outcomes³⁻⁴
- HIV care
 - Improved adherence,⁵⁻⁷ one study found inverse⁸
 - Improved viral suppression⁹

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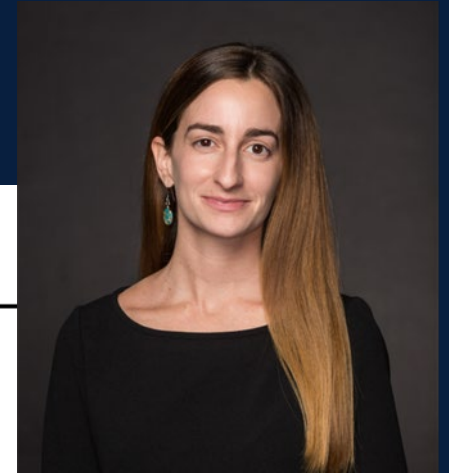
Women centered HIV care

- 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

Aim

Ascertain current and potential health care provider and system-level 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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Clients' Perspectives on Patient-Centeredness: a Qualitative Study with Low-Income Minority Women Receiving HIV Care in South Florida

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Methods

Objective: Explore perspectives of a group of racially and ethnically diverse women served by the Ryan White Program in Miami-Dade County

Sample: 74 Hispanic, Haitian or African American women

Interviews: Audio-recorded semi-structured in-depth interviews

Analysis: After transcription and development of codebook by two coders, coding done independently by four dyads. Each interview coded at least two investigators with one investigator coding all interviews. Thematic analysis was used.

Sample questions in the interview guide

Medical case managers:

- Please describe what your case manager does to help you stay in care.
- Women living with HIV have unique needs and challenges. Please tell me in what ways your case manager understands and is able to help you face these challenges.

HIV care providers:

- Please tell me what your HIV doctor and nurse do to help you take your HIV medications as prescribed.
- What are some things your doctor does to get to know you as a person?



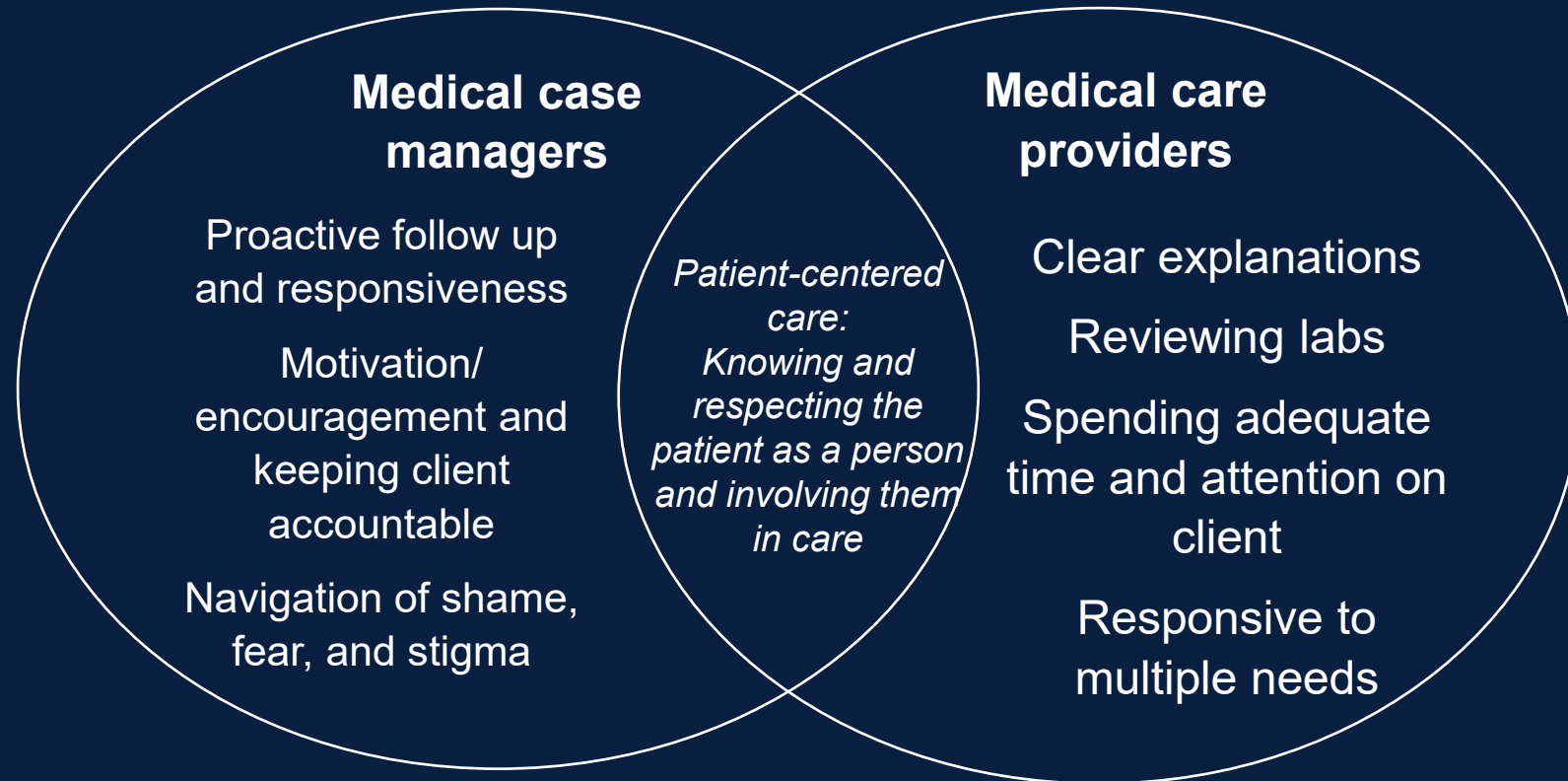
Participant characteristics

- Race/ethnicity: 39% Hispanic, 20% Haitian and 41% African American
- Language of interview: 51% English, 32% Spanish and 16% Haitian Creole
- Country of birth:
 - 74% outside mainland US from 14 different countries and Puerto Rico with the largest number born in Haiti, Honduras, Jamaica, or Bahamas
 - Only 12% (9) lived in US fewer than 10 years

Participant characteristics (continued)

- Age:
 - 18-35 7%
 - 36-49 31%
 - 50-59 37%
 - 60 and older 26%
- Education: 34% less than high school, 31% completed high school, and 35% had some education after high school
- Marital status: 47% single, 20% married/cohabitating, 16% widowed, and 16% separated/divorced

Client perspectives on patient-centeredness: key themes related to medical case managers and medical care providers



Medical case manager relationships

Proactive involvement and responsiveness

“...If she notices that I don’t show up at the clinic, she calls me to know how I am doing and if everything is okay. This is a person who has been assigned to me, a person who is there for me, and who assists me through all sorts of obstacles...”

[40 y.o., Haitian]

Encouragement and keeping client accountable:

“She always checks if I am okay... If she sees that I am slacking off, she says, ‘Ah, fam you’re slacking off.’ When I take it, she can see that and she says, ‘You’re okay, you’re good.’” [60 y.o., Haitian]

“Sometimes I feel like, where I just don’t want to take my medicine or I just get discouraged and they always uplift and let me know, you don’t have to be afraid of it. This doesn’t mean you’re dead. You can live, and it just gives me hope... She lets me know that I’m not a monster because I have this health condition and that I am one out of millions of people that go through things like this and I’m not by myself.” [38 y.o., African American]

Medical case manager relationships: navigating shame, fear and stigma

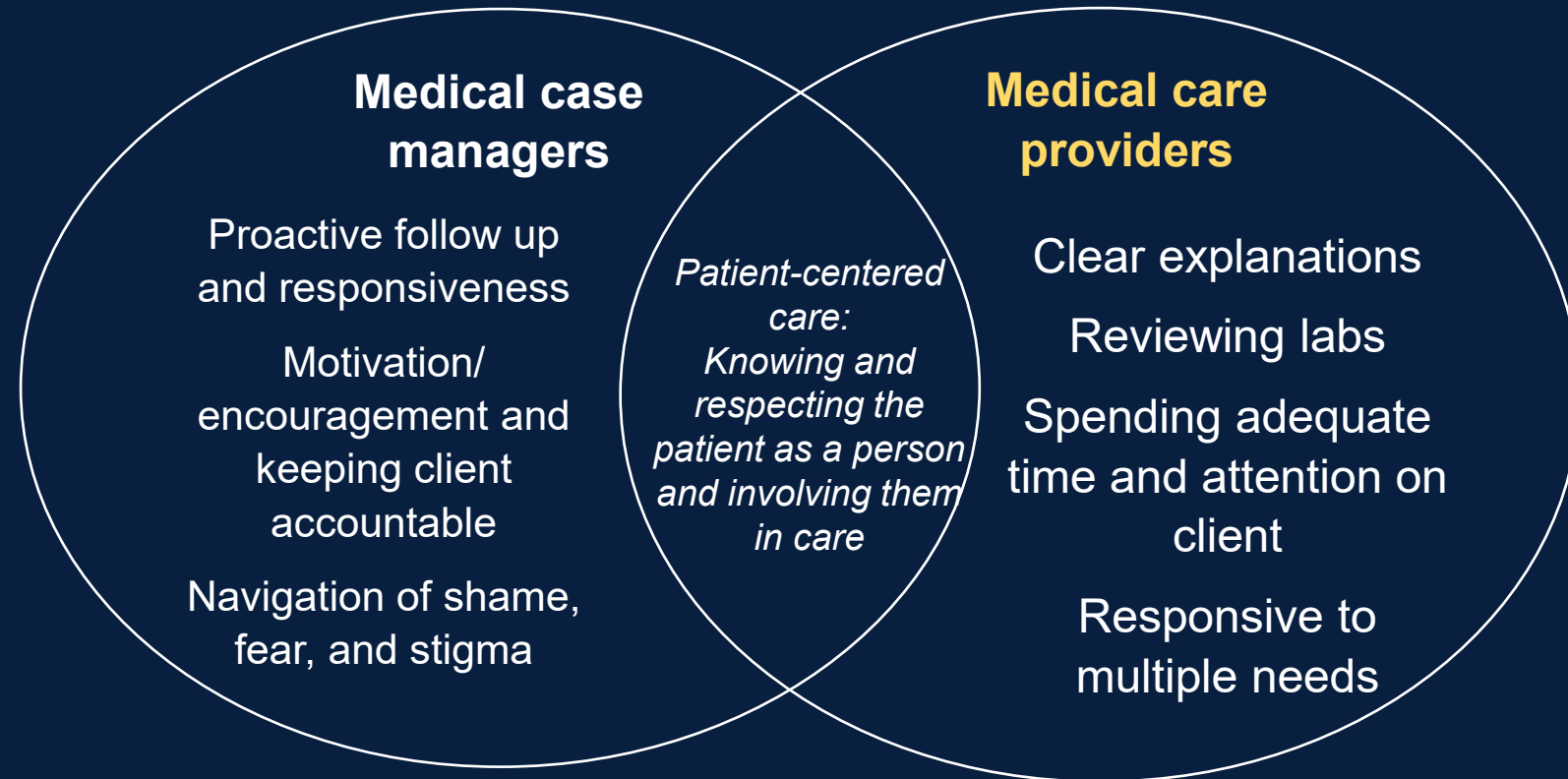
Question: “What is the biggest challenge for a woman with HIV today?:“

Client answer: “having to say it”

Medical case managers help clients navigate stigma and fear

“When I found out I had it, it was like a shame was killing me. I was dealing with depression, a lot of issues and I ain’t have nobody to talk to. And [case manager], when I go to them, I talk to them, they talk to me about what it is. In my thoughts, it’s shame but, for them, it’s like, ‘People who better than you have it. Just go to take your medication. Do activity. Don’t just be depressed. Do this, do that.’ It kind of helps... Go out, go to church, you know. You could start dating, it’s okay. You’re gonna live. Do not stay depressed or down and think about it. It’s nothing to be ashamed of.” [47 y.o., Haitian]

Client perspectives on patient-centeredness: key themes related to medical care providers



Medical provider: clear, simple explanations

“He didn’t just come and blurt it out. He like walked me through the steps.... You know, he prepared me for that diagnosis... And you know what I like about him, he tells you and then he asks questions. Then, he waits on your feedback...” [45 y.o., African American]

“Sometimes he even draws for me. He draws to explain disease or medications that I don’t understand. He does the drawing on a paper so that I can then understand it well.” [64 y.o., Hispanic]

Medical provider: reviewing labs

“Whenever she gets the report, she’s always on the computer. She’s always turning the computer around showing me exactly what’s on the computer so that she’s not only telling me, I’m seeing exactly what’s there.” [56 y.o., African American]

“He tells me, ‘Keep it up, [participant name].’ He gives it to me – shows it to me. Yeah, he shows it to me, ‘[Participant name,’ you are this level, you are ten, you are these. You are everything. Keep it up.’” [41 y.o., Haitian]

Medical provider: spending adequate time and attention with client

“He always remembers how my kids are, how’s my relationship with my children, how I’m doing... I feel seen.” [51 y.o., Hispanic]

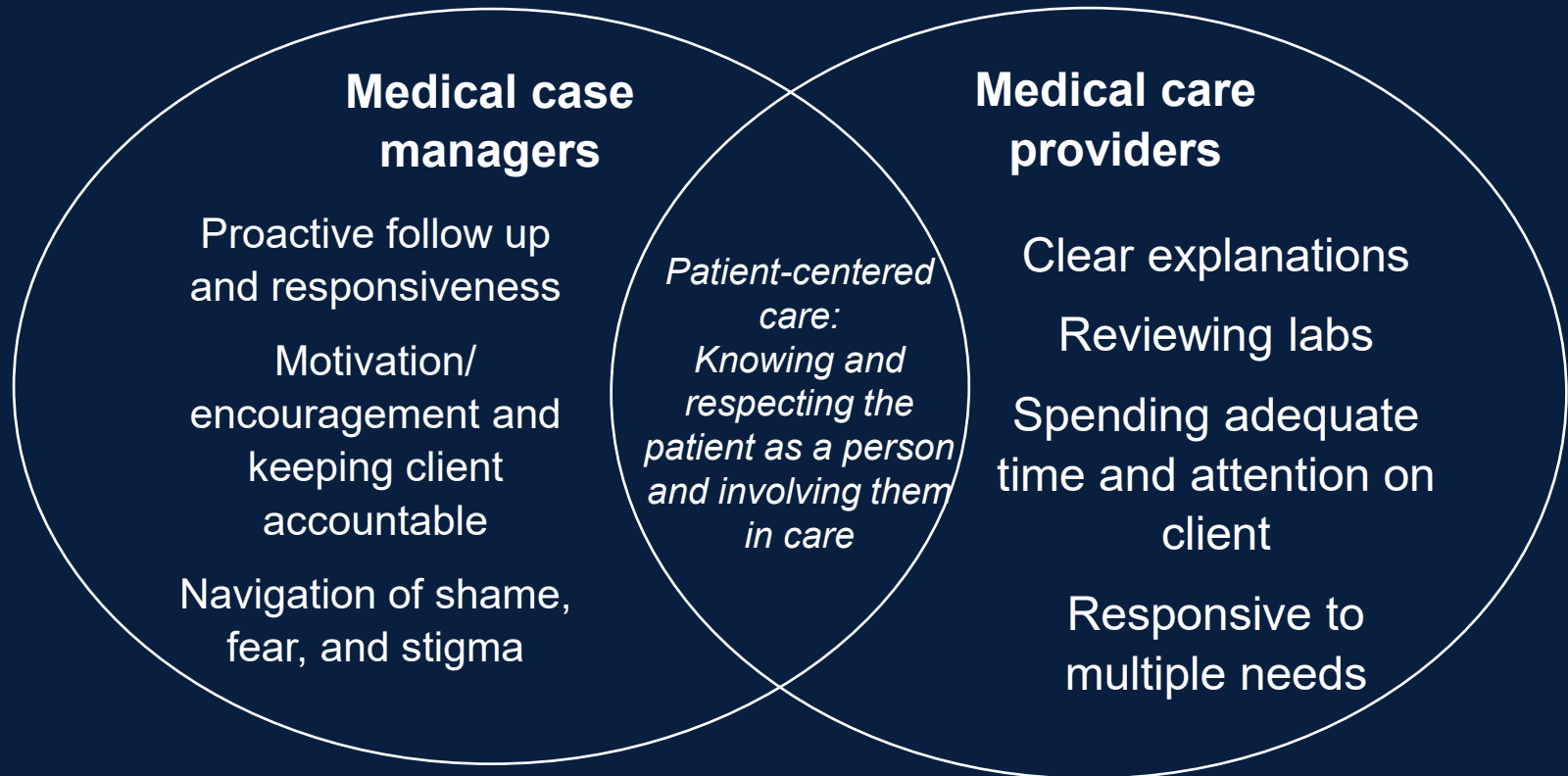
“Every time I see her, she shows me that she cares because she asks me about my family or what I have done over the weekend and what I have done to visit my sisters or my family. [50 y.o., Hispanic]

Medical provider: responding to multiple physical, clinical and emotional needs

“She hugs me, she smiles, she laughs, she tells me stories. But, she genuinely asks how I’m really feeling, not just physically, mentally, if there’s something bothering me, she becomes the psychiatrist...” [51 y.o., African American]

She describes how her doctor says “Take advantage of the time you have with me because it’s every 3 months that you see me. If you need something, tell me, so that I can push you forward... I’d tell her, ‘Doctor, listen, one day, I have a pain’. I tell her. “Here in the back and it hurts in this part here.” ‘Well, look at what you have told me. I will send you to do a liver sonogram because that is from the liver’. Well good, thank God everything turned out well. And she felt happy because, since then, I am operated of the gall bladder.” [70 y.o., Hispanic]

Client perspectives on patient-centeredness: key themes related to medical case managers and medical care providers



Preliminary results of provider perceptions, practices and opportunities for improvement in patient-centered care

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Methods: Provider in-depth interviews

Objective: Explore provider perceptions, practices and opportunities for improvement in patient-centered care

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 being used.

Provider participant characteristics

- Position: 11 case managers, 4 advanced practice registered nurses, 3 administrators, 1 physician assistant, 1 nurse, and 2 physicians (2 belong to more than 1 category)
- Sex: 17 (85%) females, 2 (10%) males, 1 (5%) transgender male
- Race: 11 (55%) Black, 4 (20%) White, 5 (25%) Other/prefer not to say
- Ethnicity: 6 (30%) Hispanic, 5 (25%) Haitian, 9 (45%) Other
- Years working with Ryan White Program clients:
 - 8 (40%) 2-9 years
 - 5 (25%) 10-19 years
 - 7 (35%) 20 or more years

Preliminary summary of provider perceptions of what patient centered care is

- View patient as a whole person, involve family in care and ensure care is culturally competent
- Ensure patient feels comfortable and respected
- Create partnership with patient, engage patient in decisions on care

Preliminary summary of provider perceptions of current practices embodying patient centered care

- Provider level
 - Build patient trust and respect for privacy
 - Personalize adherence counseling
 - Advocate for patients and create inclusive environment
 - Provide “personal touch’ during care
 - Incorporate patient preferences in decision making
 - Empower and educate patients, shared decision making
- Institutional level
 - Diverse staff, flexible hours and scheduling, service integration
 - Women-centered: disclosure support, family planning services, support for women experiencing domestic violence

Preliminary summary of provider perceptions of challenges and gaps in patient-centered care

- Provider level
 - Lack of motivation among some providers
 - Lack of team-based approach
- Institutional level
 - Need for more patient navigation services
 - Need for more integration of care
 - Restrictive RWP policies
 - Problems with referral process
 - Long wait times
 - Insufficient time for patients due to patient load
 - Lack of awareness about cultural competency
 - Need for more multilingual resources and diverse staff

Recommendations from providers

- Additional women-centered services such as providing childcare and support groups
- Hiring more female providers
- More education on intersection of women's health and HIV
- Provide more flexibility with appointments
- Involve family and partners in care
- Offer care sensitive to women's needs
- Further integration of services especially mental health
- Further seeking and incorporation of patient feedback

Limitations

- Qualitative interviews not meant to yield generalizable results to all RWP clients who are women
- Providers who volunteered were disproportionately women
- Client participants are more likely to be in care than nonparticipants and thus have a stronger relationship with case managers and providers than non-participants. Thus, findings inform what makes quality relationships.

Summary

- Clients valued case managers and providers who
 - Treated them holistically as individuals as opposed to just HIV patients (providers identified this too)
 - Were hands on and proactive
 - Served as advocate, motivator, and cheerleader
- Providers also identified system-level issues
 - Suboptimal integration of services, problems with referral systems
 - Need to improve cultural competence and improved inclusivity
 - Time constraints

Recommendations

- Practices valued by clients require significant time, energy and commitment on the part of case managers and health care providers. Thus, these practices are facilitated by reasonable case loads and minimal paperwork to provide for necessary time.
- Training for medical case managers and providers on effective patient-centered care strategies so that clients can more effectively self-manage and be engaged in their HIV care.
- Assessment by each organization of organization-specific gaps and challenges related to patient-centered care practices

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Thank you!!

Questions for discussion

- Do these results resonate with your own experiences?
- What do you think is missing that is also important to consider for providing better HIV care for women?