

**Patient centered care practices
that positively influence
adherence and viral suppression:
what we learned from
Ryan White Program clients**

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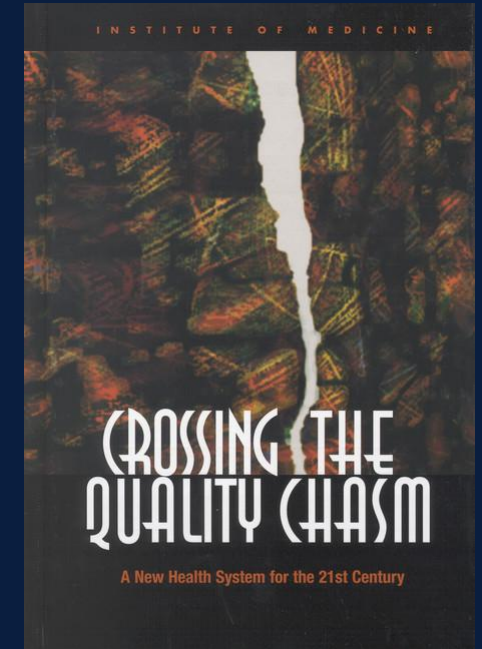
Outline



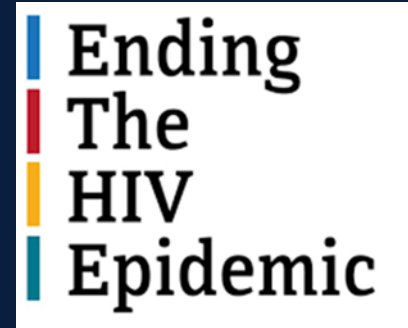
- Overview of Patient Centered Care (PCC)
- Rationale for examining PCC in context of HIV care
- Objectives and designs of studies
- Findings
 - PCC practices that support adherence and viral suppression: client and provider perspectives
 - What we learned from COVID
 - Evidence that PCC practices improve adherence and viral suppression
- Q&A

Overview of 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 outcomes³⁻⁴



Case for promoting patient centered care within Ryan White Program



- US goal: 95% of people with diagnosed HIV being virally suppressed¹
- US Ryan White Program clients: 91.4% in 2024, very close²
- Those not yet suppressed tend to have most challenges, some difficult to modify
- Health care system may be able to help these clients navigate challenges

1. CDC. Diagnoses, deaths, and prevalence. Published April 29, 2025. <https://www.cdc.gov/hiv-data/nhss/hiv-diagnoses-deaths-prevalence.html>. 2. HRSA. Ryan White HIV/AIDS Program Annual Data Report 2024. Published 2025. <https://ryanwhite.hrsa.gov/>

Existing evidence on PCC in HIV care delivery

- Strong, trusting relationships with providers and lack of provider mistrust associated with patients' engagement in care and ART adherence
- For viral suppression, mixed results: some studies finding that strong relationships with providers associated with viral suppression and other finding no relationship

Bakken S, et al. *AIDS Patient Care STDS*. 2000;14(4):189–97; Beach MC, et al. *J Gen Intern Med*. 2006;21(6):661-5; Brincks AM, et al. *ad. AIDS Behav*. 2019;23(10):2859-69; Edmonds KA, et al. *AIDS Care*. 2021;33(2):154-8; Flickinger TE, et al. *JAIDS*. 2013;63(3): 362-6; Gaston GB, et al. *AIDS Behav*. 2013;17(1):31-40; Johnson MO, et al. *AIDS Patient Care STDS*. 2006;20(4):258-68; Magnus M, *AIDS Patient Care STDS*. 2013;27(5):297-303; Michel KG, et al. *AIDS Patient Care STDs*. 2022;36(1):17–25; Mitchell MM, et al. *AIDS Behav*. 2017;21(6):1768–74; Ramírez-Ortiz D, et al. *Ethn Health*. 2022;27(8):1859–99; Saha S, et al. *AIDS Patient Care STDS*. 2010;24(7):415–20; Schneider J, et al. *J Gen Intern Med*. 2004;19(11):1096–103; Wood TJ, et al. *Patient Prefer Adherence*. 2018;12:919–27; Zhang C, et al. *AIDS Patient Care STDS*. 2020;34(1):27–37; Karver TS, et al. *AIDS Behav*. 2022;26(9):3056-67.

Objectives

- Identify women-centered provider and system HIV care practices that promote adherence and viral suppression
- Identify HIV provider patient centered care factors that buffer the effect of individual client characteristics on viral suppression

Methods

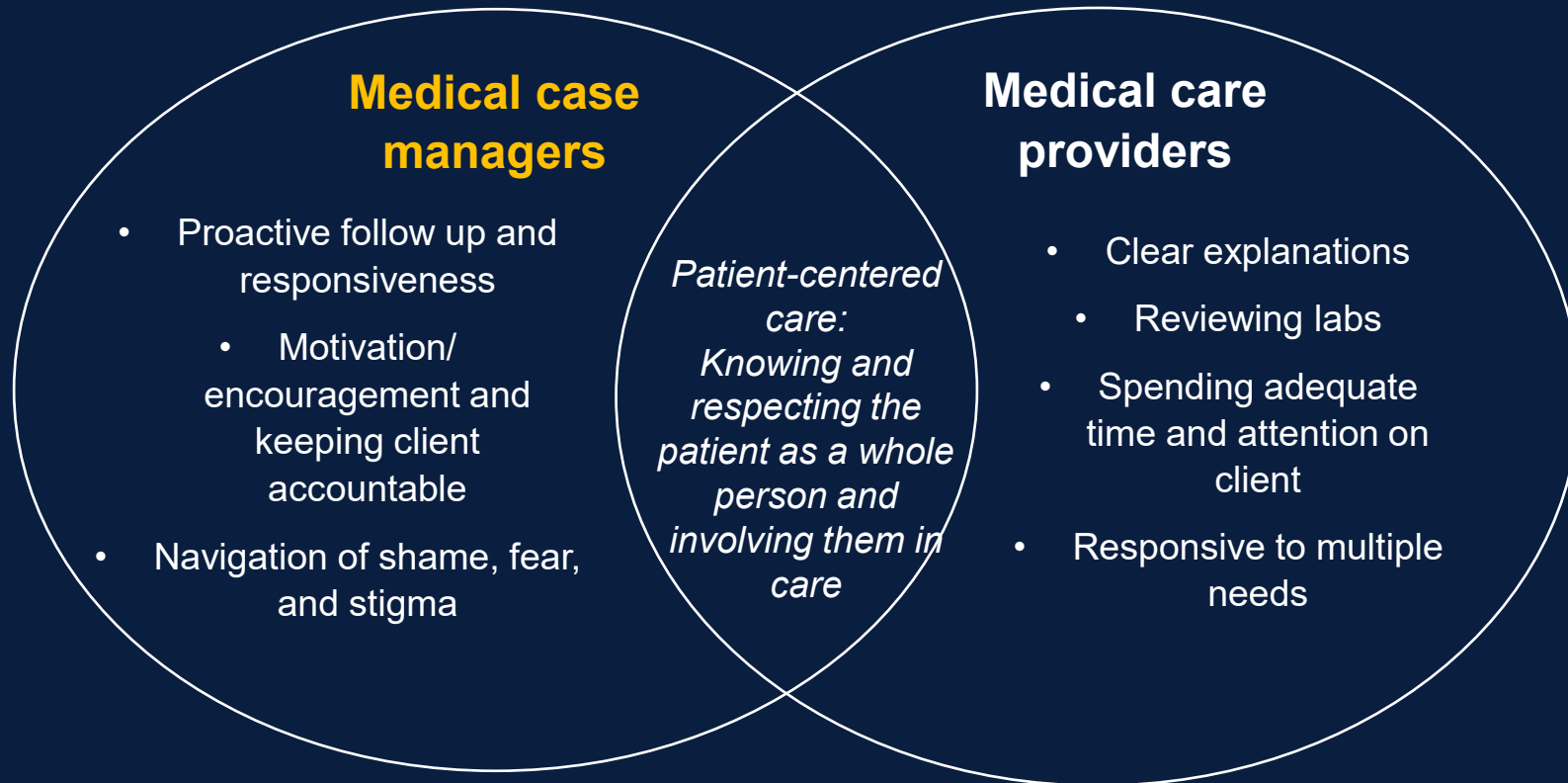
- Qualitative
 - In-depth interviews of female clients
 - In-depth interviews of medical case managers and health care providers
- Quantitative
 - Survey of clients about provider practices
 - Analysis of Ryan White Program administrative data

Client and provider perceptions and
ideas about PCC:
results from in-depth interviews

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Findings from in-depth interviews with 74 women in RWP: key themes related to PCC and 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]

Medical case manager relationships: encouragement and keeping client accountable

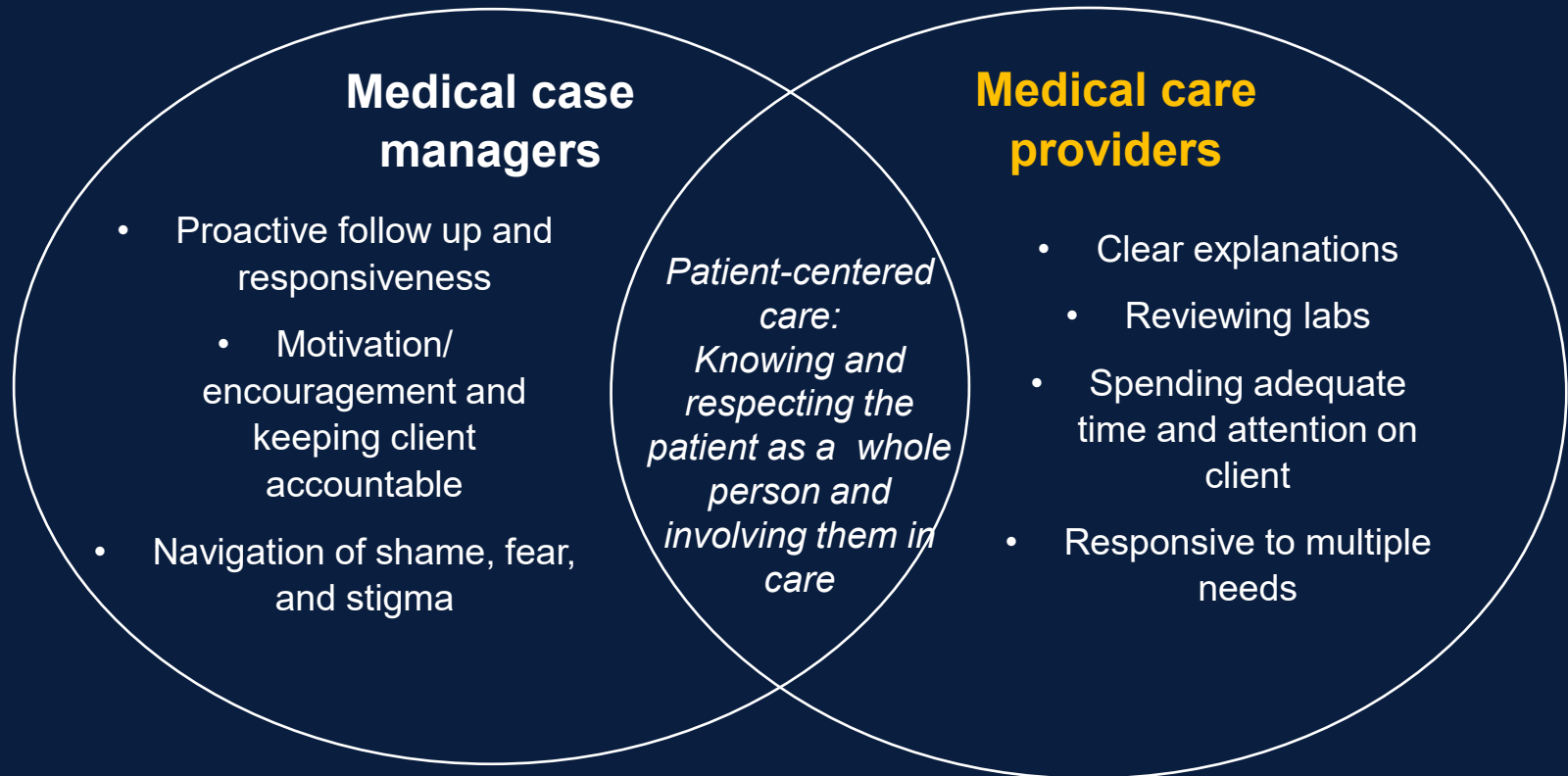
“She always checks if I am okay... If she sees that I am slacking off, she says, ‘Ah, fam you’re slacking off.’ When I take it, she can see that and she says, ‘You’re okay, you’re good.’” [60 y.o., Haitian]

“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: helping clients navigate stigma and fear

“When I found out I had it [HIV], 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 case managers and medical care providers



Medical provider: clear, simple explanations

“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]

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]

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]

Summary of provider perceptions of challenges and gaps in patient-centered care

- Lack of team-based approach
- Insufficient time for patients due to patient load
- Need more patient navigation services
- Need more integration of care among RWP service providers
- Problems with referral process
- Restrictive RWP policies particularly around referrals
- Long wait times
- Lack of cultural competency
- Need for more multilingual resources and diverse staff

Practices promoting PCC

Individual

Interpersonal

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

Logistical support

- Reminders
- Referral assistance
- Mitigating barriers to care (e.g. transportation)
- Child-friendly services or childcare

Active engagement of patient in care

- Education and information-sharing
- Shared-decision making

Practices at institutional level supporting PCC

- **Service integration**
 - Integrated specialist & primary care
 - Integrated women's health services
 - Digital tools such as EMR flags
- **Convenient and accessible services**
 - Scheduling and clinic hours to accommodate patient needs
 - Patient preferences for clinic location
 - Flexible hours and scheduling
 - Digital tools (e.g. to view lab results and online scheduling)
- **Staffing and resources**
 - Accommodate patient's provider preferences
 - Staff diversity
 - Multilingual resources
- **Patient and staff feedback mechanisms**
 - Continuous client feedback with timely response
 - Environment receptive to staff feedback
- **Interdisciplinary collaboration**
 - Team-based approach
 - Regular communication between providers

Access to care during COVID-19

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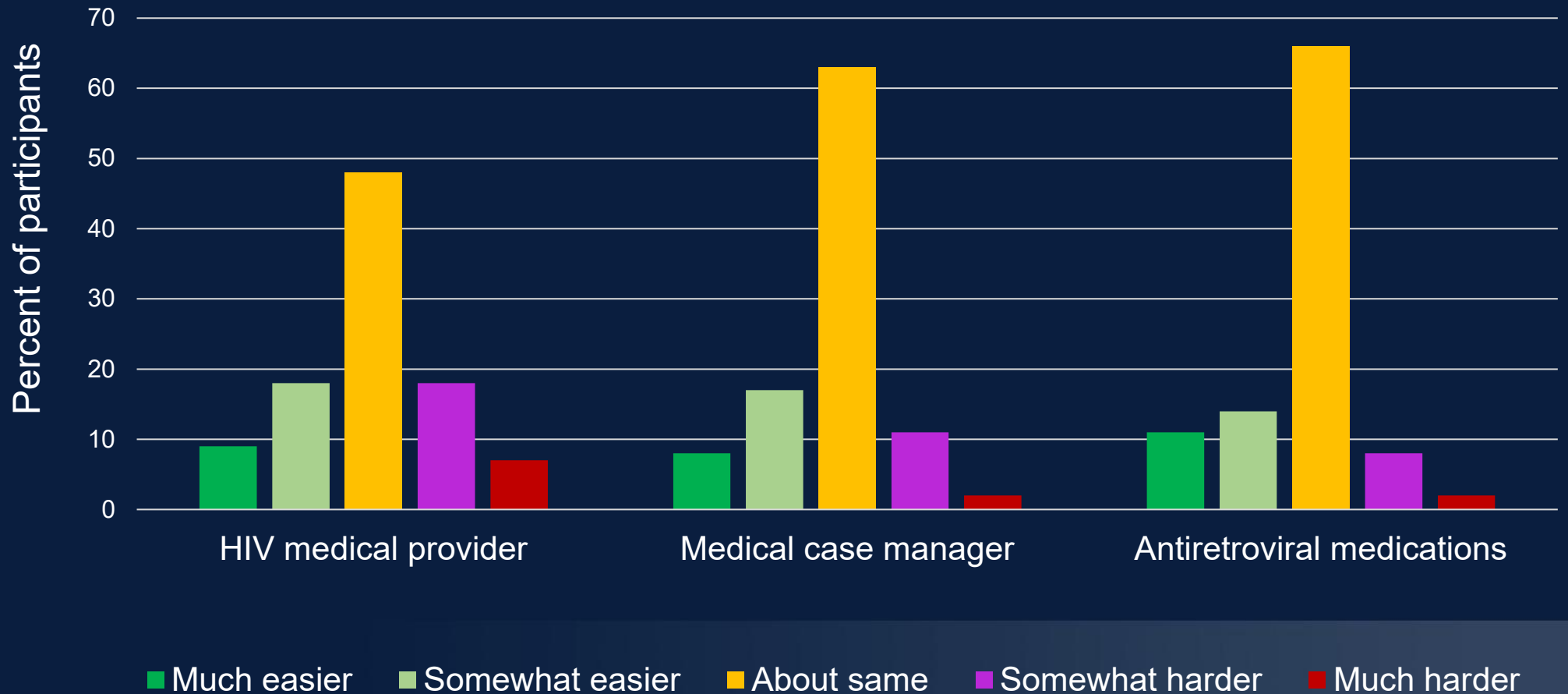
RWP response to COVID-19 pandemic

- Federal (Health Resources and Services Administration), State (Florida), and Miami-Dade County allowed improved flexibility
- Resulted in----
 - Waiving requirement of viral load test results for enrollment and 6-month recertification for AIDS Drug Assistance Program (ADAP) in Florida and RWP Part A/Minority AIDS Initiative in Miami-Dade County
 - Allowing ADAP and RWP Part A/Minority AIDS Initiative recertification without in-person eligibility specialist/medical case management visits
 - Expansion of drive-through, mail, and home delivery of antiretroviral therapy
 - Waiving of RWP Part A and Minority AIDS Initiative HIV care programs re-enrollment lab tests and increased flexibility with re-enrollment timelines
 - Increased availability of and access to telehealth services (including telemedicine, tele-medical case management, tele-dentistry, tele-mental health, and tele-substance use disorder counseling)

Survey

- Conducted October 2020—January 2021
- Fully remote, telephone-administered survey
- 298 RWP clients enrolled
 - Race/ethnicity
 - 53 (18%) Haitian
 - 129 (43%) Hispanic
 - 116 (39%) African American
 - Gender
 - 148 (50%) Cis-gender women
 - 143 (48%) Cis-gender men
 - 7 (2%) Other

Compared to before the Pandemic, how easy was it to access...



PCC and adherence and viral suppression: Findings from surveys and RWP administrative data

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Client survey about providers

Objective: Obtain estimate of patient centered care practices for each of 50 health care providers with largest caseloads

Sample: 1353 RWP clients

Survey instrument:

- Health Care Relationship Trust Scale and Agency for Healthcare Research and Quality Consumer Assessment of Healthcare Providers and Systems Survey
- Administered in 3 languages

Survey of female clients

Objective: Assess influence of patient-provider relationship on antiretroviral therapy adherence and durable viral suppression, that is all viral loads less than 200 copies/mL for entire year

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

Survey instrument:

- Items on patient-provider relationship
- Psychosocial factors
- Adherence

Methods (Continued): survey of women

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 ($\geq 90\%$) and not adherent ($<90\%$)

Findings of survey of women

Adherence:

- 71.6% at least 90% adherent
- Associated with higher patient-provider trust and provider communication
- Also strongly associated: no significant depressive symptoms, no alcohol use and no transportation problems

Durable viral suppression:

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

Patient-provider relationship characteristics by race/ethnicity

Characteristics	Black (n=198), %	Haitian, (n=158), %	Hispanic, (n=186), %	p-value
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
I feel comfortable talking to provider about personal issues at least most of the time	91.4	14.3	90.7	< .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	.25
In last 12 months, provider never talked too fast when talking with you	98.5	98.1	97.3	.72
In last 12 months, provider always listened carefully to you	94.4	97.4	92.5	.13
Provider discusses options and choices with you about your HIV care at least most of the time	87.2	82.0	86.5	.37
Provider is committed to providing best care possible at least most of time	98.5	99.4	97.3	.33
Provider excellent listener at least most of the time	97.5	99.4	97.3	.33

Blue means associated with adherence

Patient-provider relationship characteristics by race/ethnicity

WCC Survey

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 sincerely interested in you as person at least most of the time	96.5	98.7	89.0	<.0001
Provider treats me as an individual at least most of the time	99.5	99.4	91.5	<.0001
Provider knows me as a person	81.3	96.2	73.0	<.0001
Provider makes me feel that I am worthy of his/her time and effort at least most of the 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 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	.28

Conclusion of analysis by race/ethnicity

- Patient experiences significantly varied by race and ethnicity for just 9 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; women less likely to report experiencing 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; women less likely to report this practice than most of the other good practices.
- Viral suppression: no association with any measure

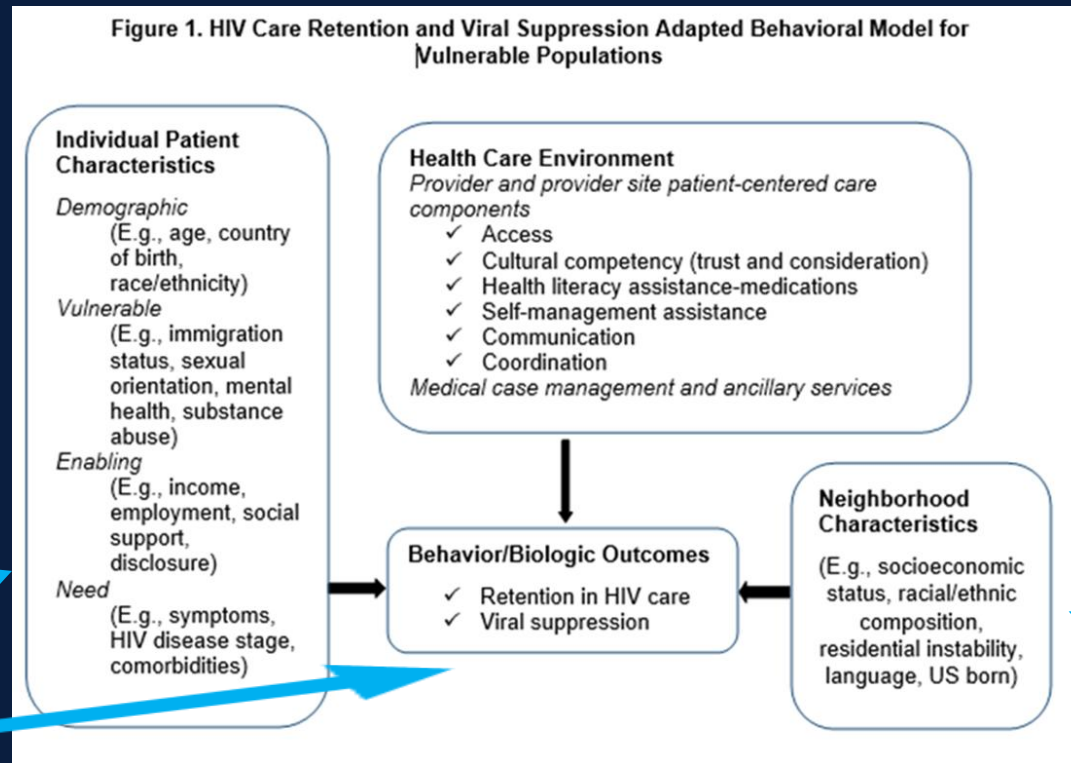
Patient centered care and viral suppression among men and women in RWP

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Design and source of data

Design: Retrospective cohort study of adult Miami-Dade County Ryan White Program (RWP) clients enrolled before Jan. 2019



Deidentified RWP administrative data

Client survey about providers and medical case management (MCM) inventory; merged by assigned provider and MCM name

American Community survey merged by ZIP Code

Cross-sectional analysis of durable viral suppression

Objective: Assess if patient centered care could mitigate the adverse effects of barriers to viral suppression

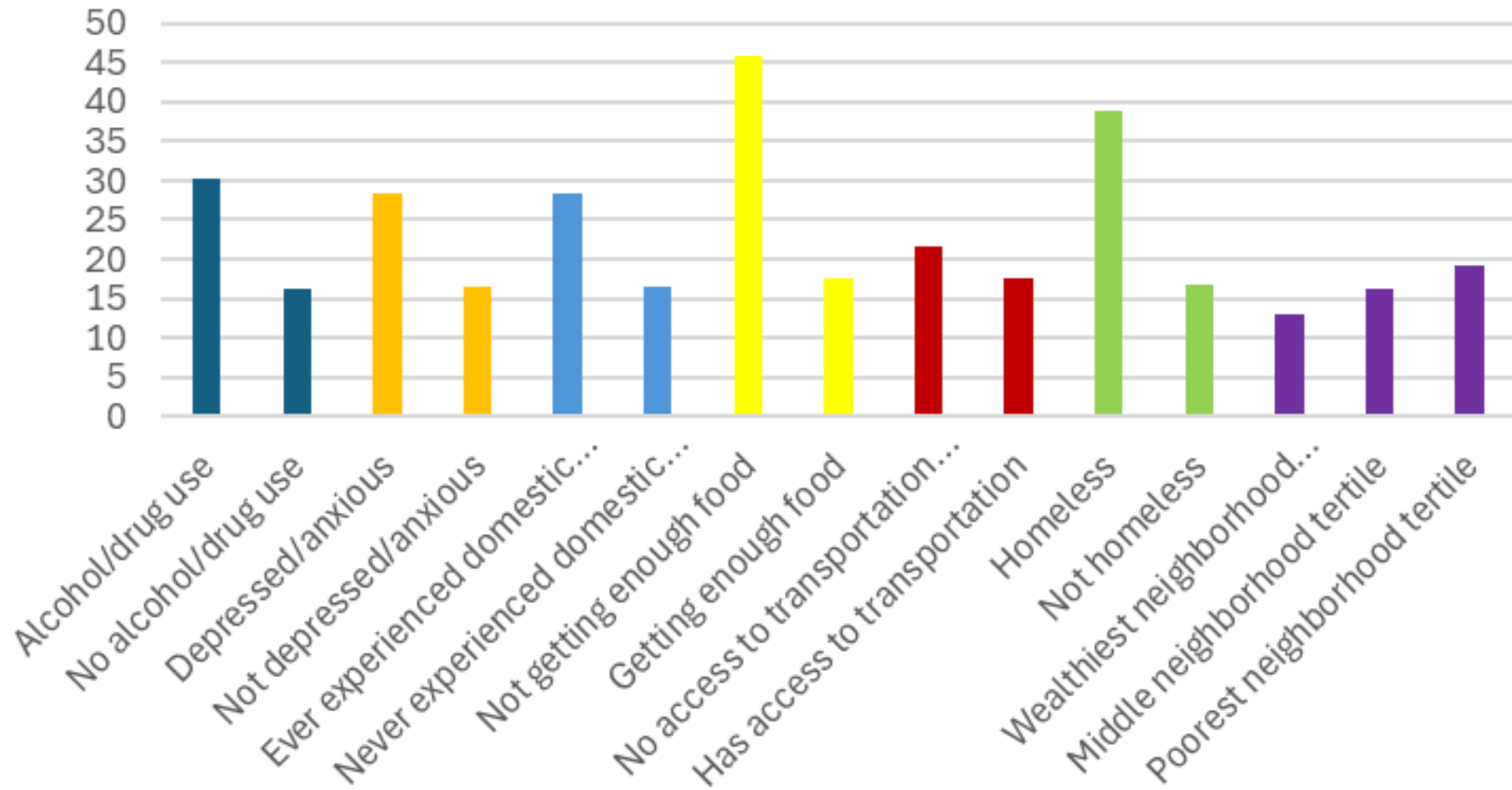
Sample: 5037 RWP clients with RWP during 2019

Methods: Causal Bayesian modeling

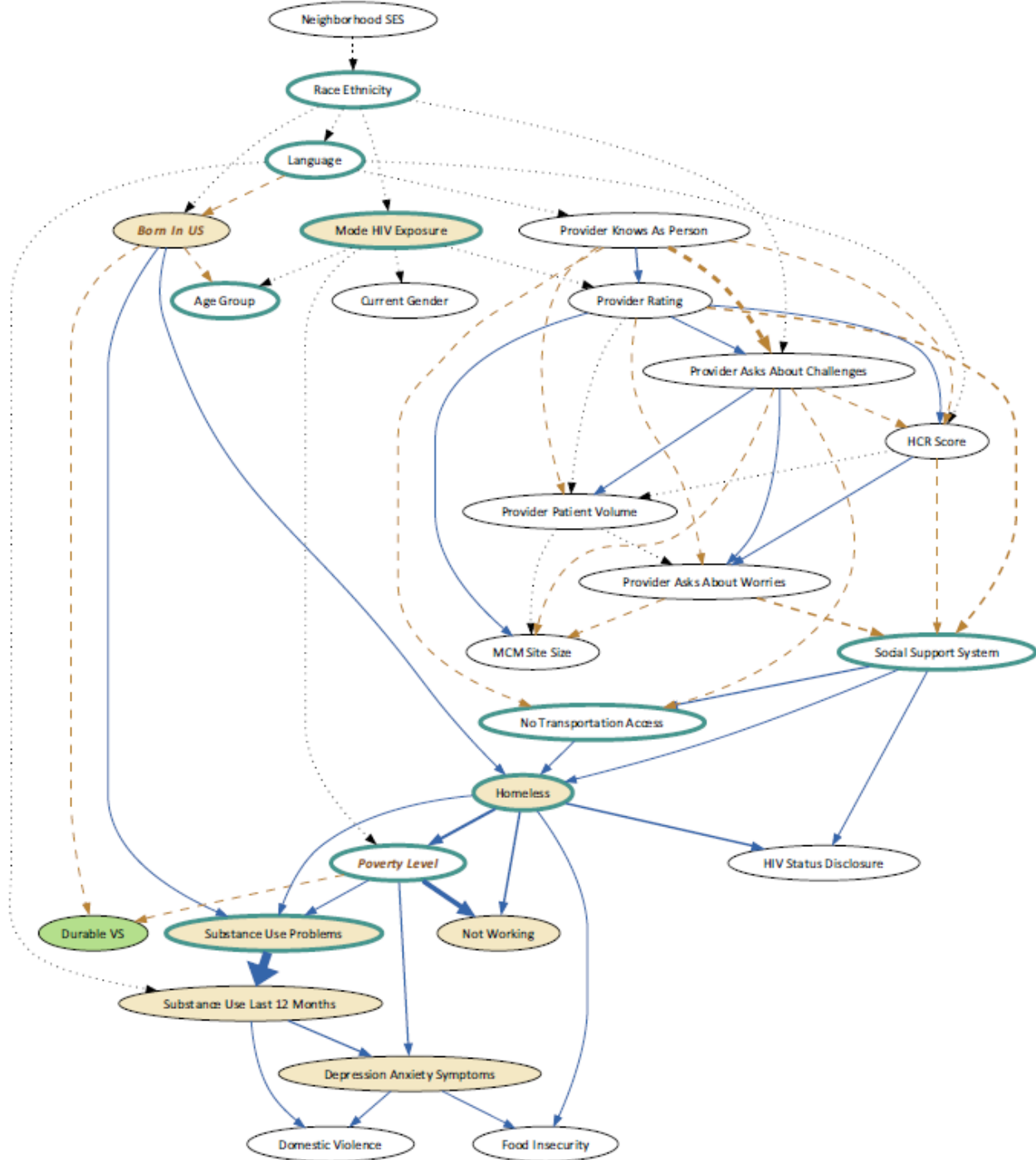
Outcome: Viral suppression for all tests during 2019

Results: 82.1% durable viral suppression

Percent not durably virally suppressed by unmet needs/psychosocial factors



Causal Bayesian network structure

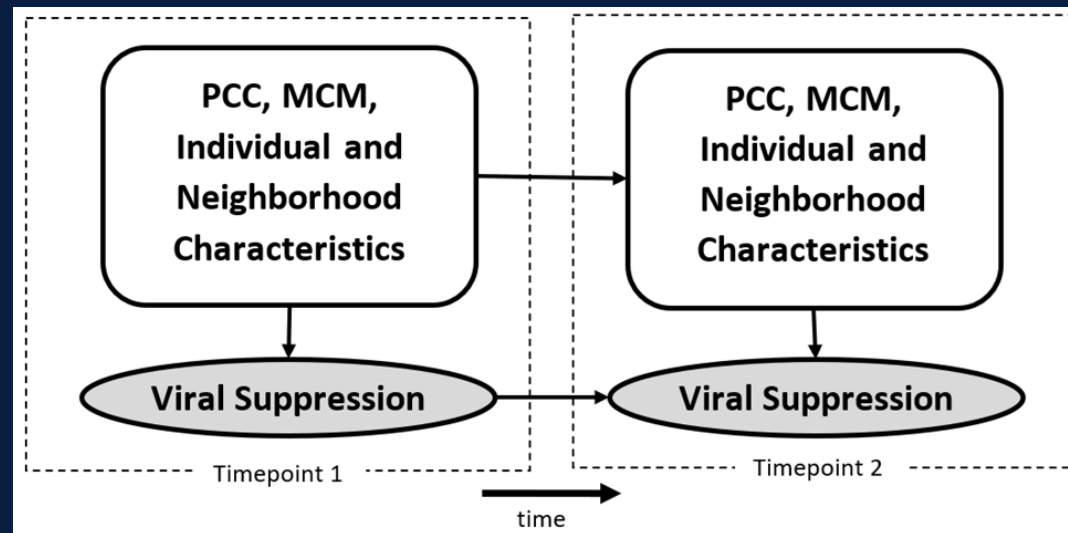


Conclusions of cross-sectional analysis of durable viral suppression

- Poverty level had strongest association with durable viral suppression
- Stronger patient-provider relationships associated with durable viral suppression, but influence small compared to poverty and unmet needs
- Influence of good patient provider relationship was stronger on those living under 100% of the Federal Poverty Level than those with household income two to four times that FPL
- Results support promotion of environment for providers to develop and maintain strong relationships with clients but not in the absence of providing wrap-around support to clients navigating psychosocial stressors and unmet needs

Longitudinal analysis of viral suppression

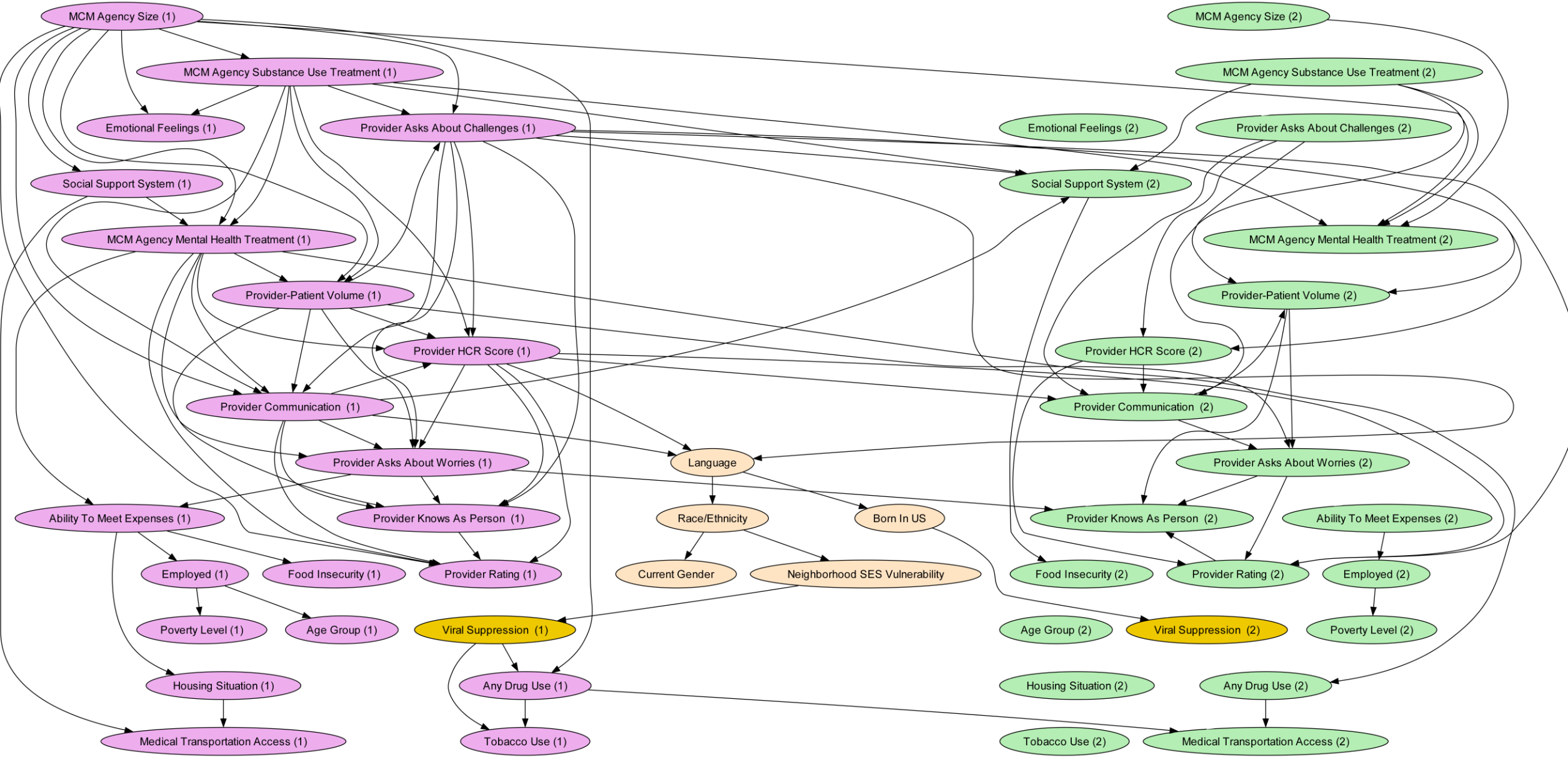
- Objective: Examine effect of patient centered care on viral suppression over time
- First 2 time points during 2020-2022



Results: Descriptive analysis

- Of 1539 in cohort, 86.2% virally suppressed at T1 and 87.5% at T2
- At T2, 9.4% newly suppressed and 8.1% newly non-suppressed.
- Of modifiable factors, viral non-suppression associated with household income <100%, not working, non-permanent housing, inability to meet expenses, fair to poor emotional feelings, any drug use, tobacco use, and poorer neighborhood
- Of health care provider variables, non-suppression associated with small MCM agency size, lower health care provider trust scores, low provider rating, less likely to say that provider knows them as a person

Dynamic causal Bayesian network structure



Conclusions

- 17.5% of the group changed viral suppression status between 2 time points (9.4% became newly suppressed and 8.1% became newly non-suppressed)
- Of the modifiable factors assessed, drug use and tobacco use significantly predicted a low probability of viral load suppression, while provider rating and provider's Health Care Relationship trust score and living in a wealthier neighborhood significantly predicted a high probability of viral load suppression.
- Results highlight the need for interventions promoting strong patient-provider relationships and targeting reductions in tobacco and illegal drug use.

Conclusions

- Clients value strong relationships with their providers
- Patient centered care practices are associated with adherence
- Weak overall association between PCC and with viral suppression, but PCC seems to be particularly beneficial to those at highest risk of non suppression (e.g., persons with substance use disorder or persons living in poverty).
- Must be coupled with wrap around support for unmet needs

Recommendations to improve PCC practices

- Maximize contact time of providers with clients
- Address challenges shared by providers as relevant to specific sub-recipient (e.g., needs related to patient navigation services, integration of care, referral processes, mechanisms for staff input)
- RWP should provide flexibility for sub-recipients to make these changes

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Additional slides to discuss if
questions

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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

Table 1 Measures of Patient-Centered Care

A. Health Care Relationships Trust Score Questions

Possible responses included none of the time (0), some or a little of the time (1), occasionally or a moderate amount of time (2), most of the time (3), all of the time (4), and don't know

- (1) How often does [this provider] discuss options and choices with you about your HIV care before health care decisions are made?
- (2) [This provider] is committed to providing the best care possible
- (3) [This provider] is sincerely interested in me as a person
- (4) [This provider] is an excellent listener
- (5) [This provider] accepts me for who I am
- (6) [This provider] tells me the complete truth about my health-related problems
- (7) [This provider] treats me as an individual
- (8) [This provider] makes me feel that I am worthy of his/her time and effort
- (9) [This provider] takes the time to listen to me during each appointment
- (10) I feel comfortable talking to [this provider] about my personal issues
- (11) I feel better after seeing [this provider]
- (12) How often does [this provider] consider your need for privacy?
- (13) How often do you think about changing to a new health care provider? (reverse coded)

B. Three individual items from Consumer Assessment of Health Care Providers and Systems (CAHPS) Survey

- (1) "Using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate [this provider]?" (range from 0 to 10)
- (2) In the last 12 months, did [this provider] or someone from [this provider's] office ask you if there are things that make it hard for you to take care of your health? (yes (1), no (2), don't know)
- (3) In the last 12 months, did you and [this provider] or someone from [this provider's] office talk about things in your life that worry you or cause you stress? (yes (1), no (2), don't know)

C. Know as a person

Does [this provider] know you as a person? (classified as "yes" (1) or "no"/"don't know" (0))