Heart to Heart

NYU RORY MEYERS COLLEGE OF NURSING

CDUHR
CENTER FOR DRUG USE AND HIV | HCV RESEARCH

PLWH who delay, decline, or discontinue ART: A mixed methods study to understand the mechanisms of action of a new efficacious intervention to increase ART initiation

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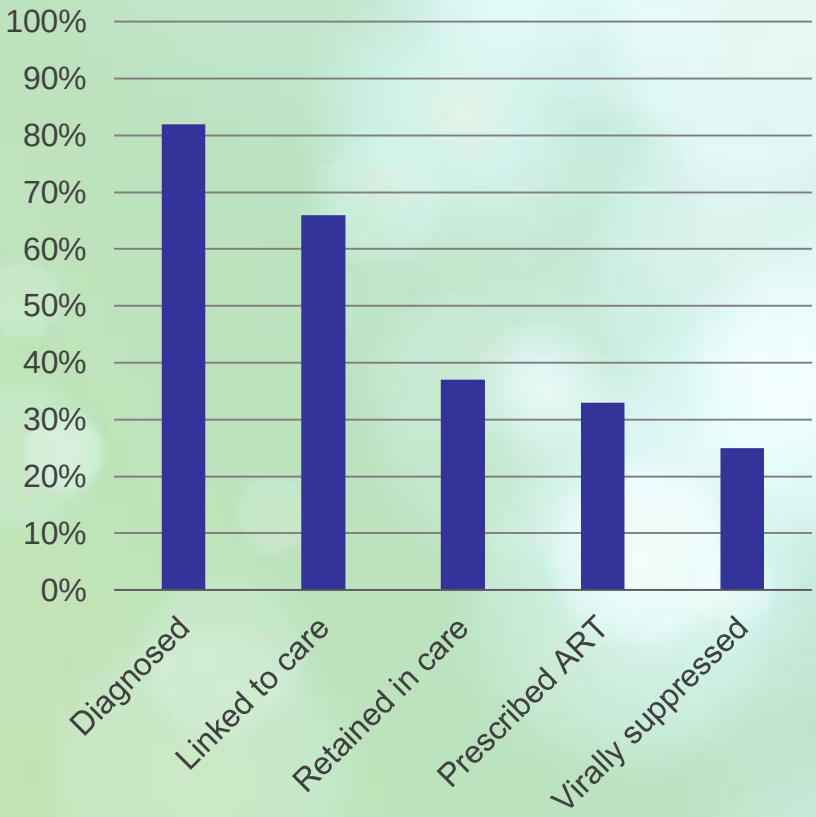
Conflict of Interest Disclosure

Gwadz, Marya

Has no real or apparent

conflicts of interest to report.

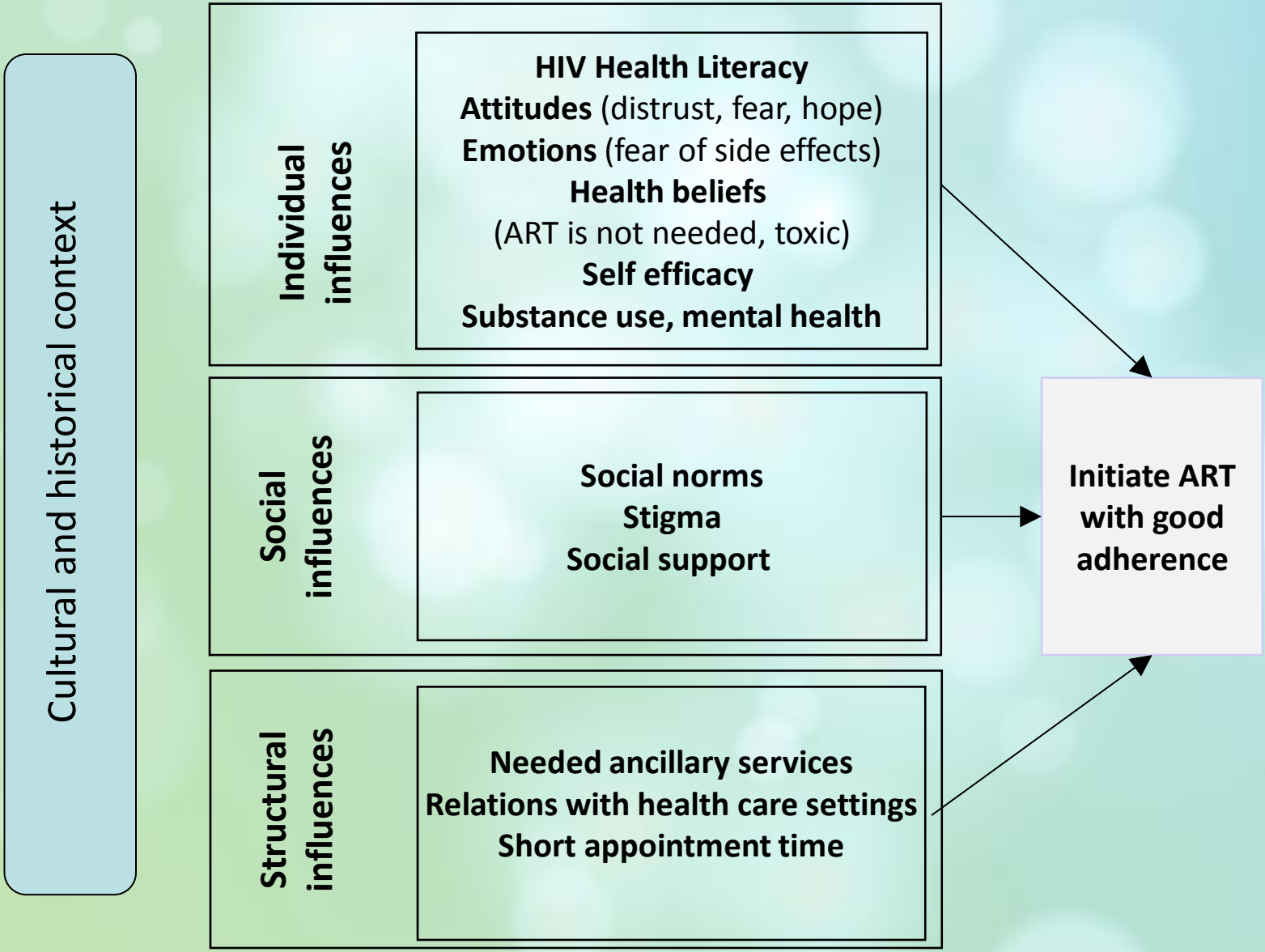
PLWH commonly delay, decline, & discontinue ART



CDC, 2012

- Initiation is an under-studied step in the cascade
- >25% delay ART ≥ 6 months (Hanna et al, 2013)
- >50% discontinue within a year (Kempf et al., 2009)
- Starting and stopping ART is common (Gwadz et al., 2015)
- 30-50% not on ART (CDC, 2012; Xia et al., 2016)

Barriers to ART initiation in vulnerable populations



Steps to ART adherence for AA/Black and Hispanic PLWH

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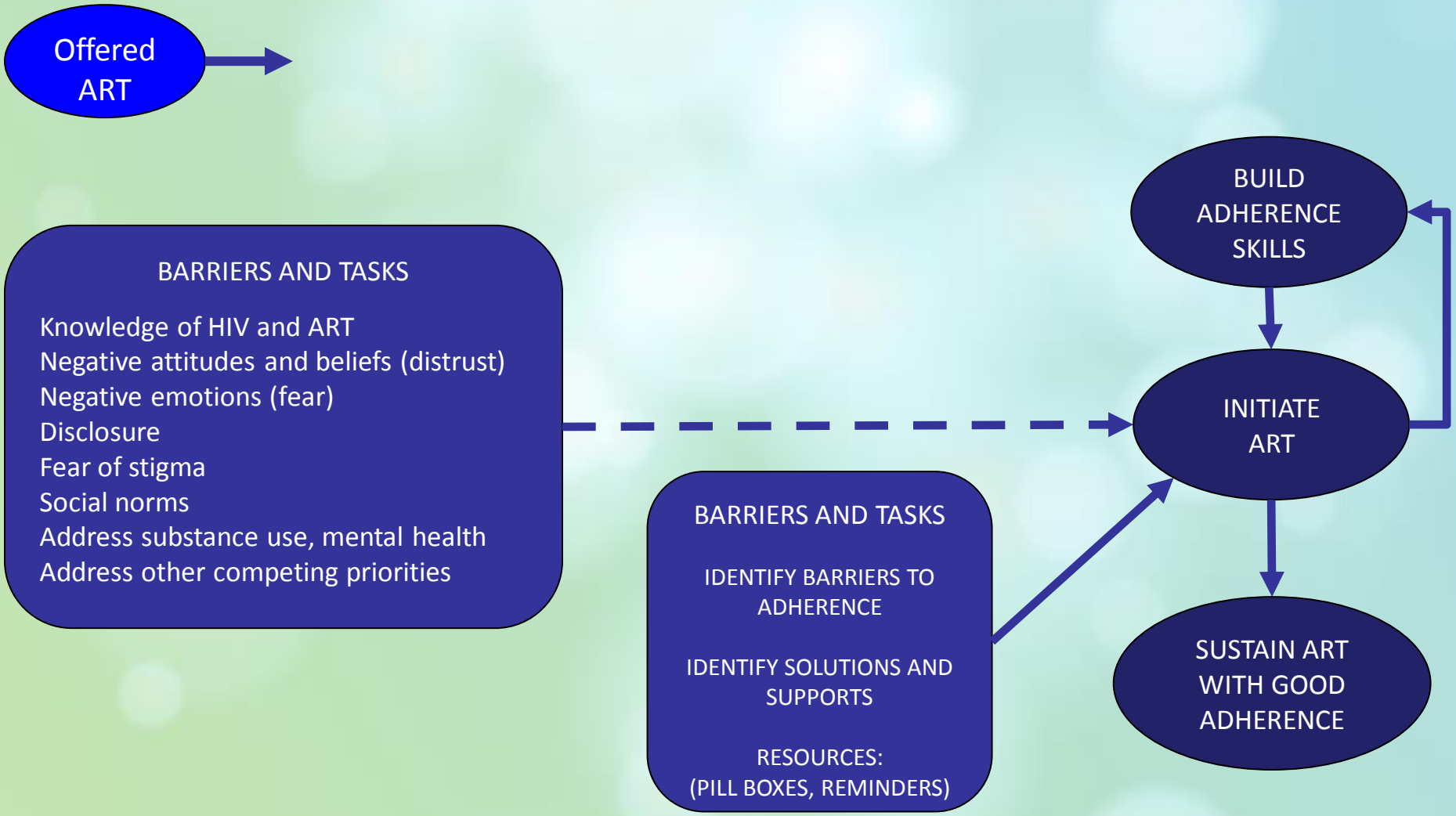

Steps to ART adherence for AA/Black and Hispanic PLWH

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Goal: Motivation and Readiness for ART Adherence

Offered ART → Consider ART → Prepare for ART → Decide to Initiate ART → BUILD ADHERENCE SKILLS → INITIATE ART → SUSTAIN ART WITH GOOD ADHERENCE

BARRIERS AND TASKS

Knowledge of HIV and ART
Negative attitudes and beliefs (distrust)
Negative emotions (fear)
Disclosure
Fear of stigma
Social norms
Address substance use, mental health
Address other competing priorities

BARRIERS AND TASKS

IDENTIFY BARRIERS TO ADHERENCE

IDENTIFY SOLUTIONS AND SUPPORTS

RESOURCES:
(PILL BOXES, REMINDERS)

Mixed methods study aims

- **Briefly describe** the Heart to Heart (HTH) intervention
  - ART initiation
  - Highly vulnerable AA/Black & Hispanic PLWH not on ART
  - Culturally appropriate
  - Tested in a small RCT (N=95)

- Uncover and describe **active intervention components** from the perspectives of AA/Black and Hispanic PLWH not on ART

- Explore the utility of explicitly highlighting and addressing **barriers associated with race/ethnicity/class**

- Implications for clinical practice

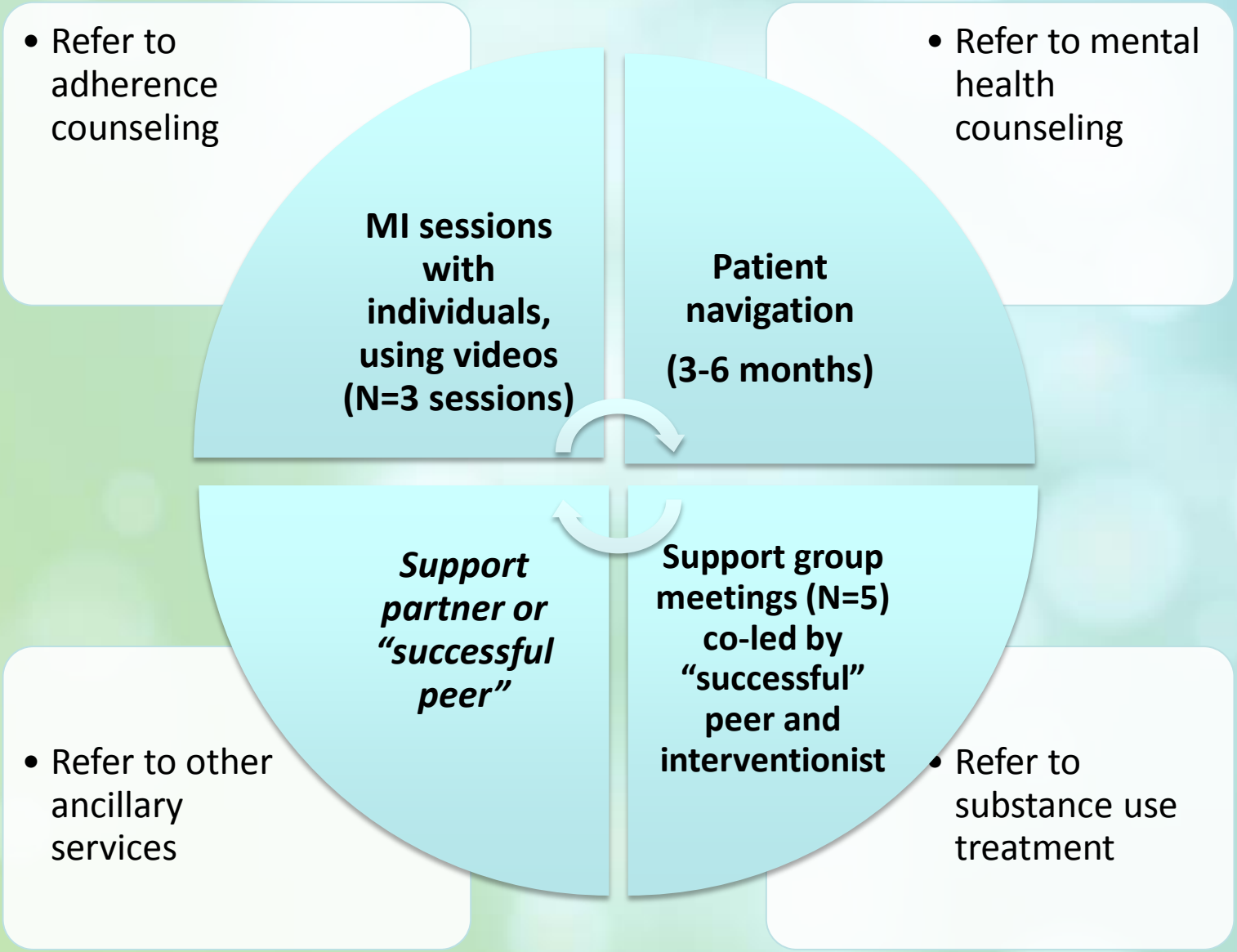
Considerations & context

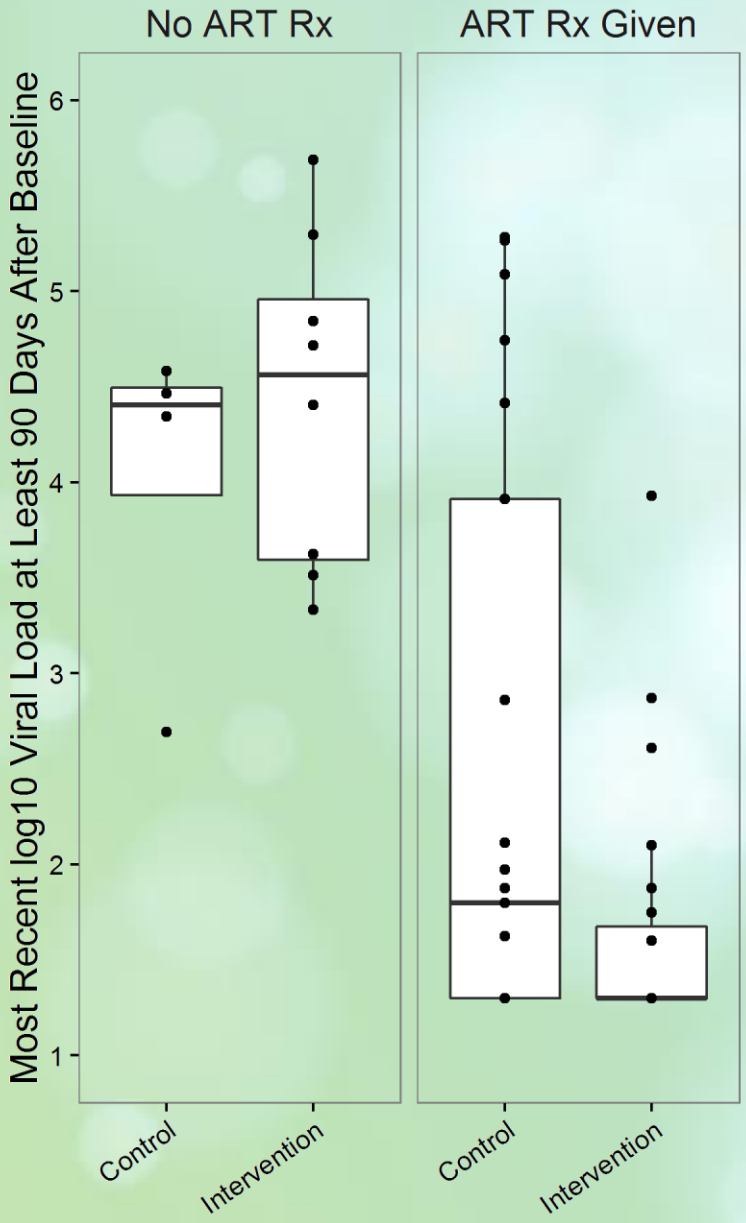
- Relationships with HIV primary care providers were positive
  - All had access to HIV care and ART

- PLWH not on ART **avoid HIV care**
  - Fear and distrust of ART lead to avoidance
  - Not taking ART is stigmatized
  - Providers under pressure
  - Can be recruited through peers, CBOs, ASOs (not HIV clinics)

- Motivational Interviewing (MI)
  - Emphasis on engagement
  - Ethos of “no pressure, no judgment”
  - Experienced clinicians (MA, MSW, doctoral students)

Heart to Heart Intervention components





Brief snapshot of findings

Most initiated ART (58%)

Participants in the intervention arm who initiated ART evidenced significantly lower $\log_{10}$ VL 8 months post-intervention

Intervention arm - 1.63 (0.67)
Control arm 2.51 - (1.55)

OR = 3.70 ($p < 0.05$)

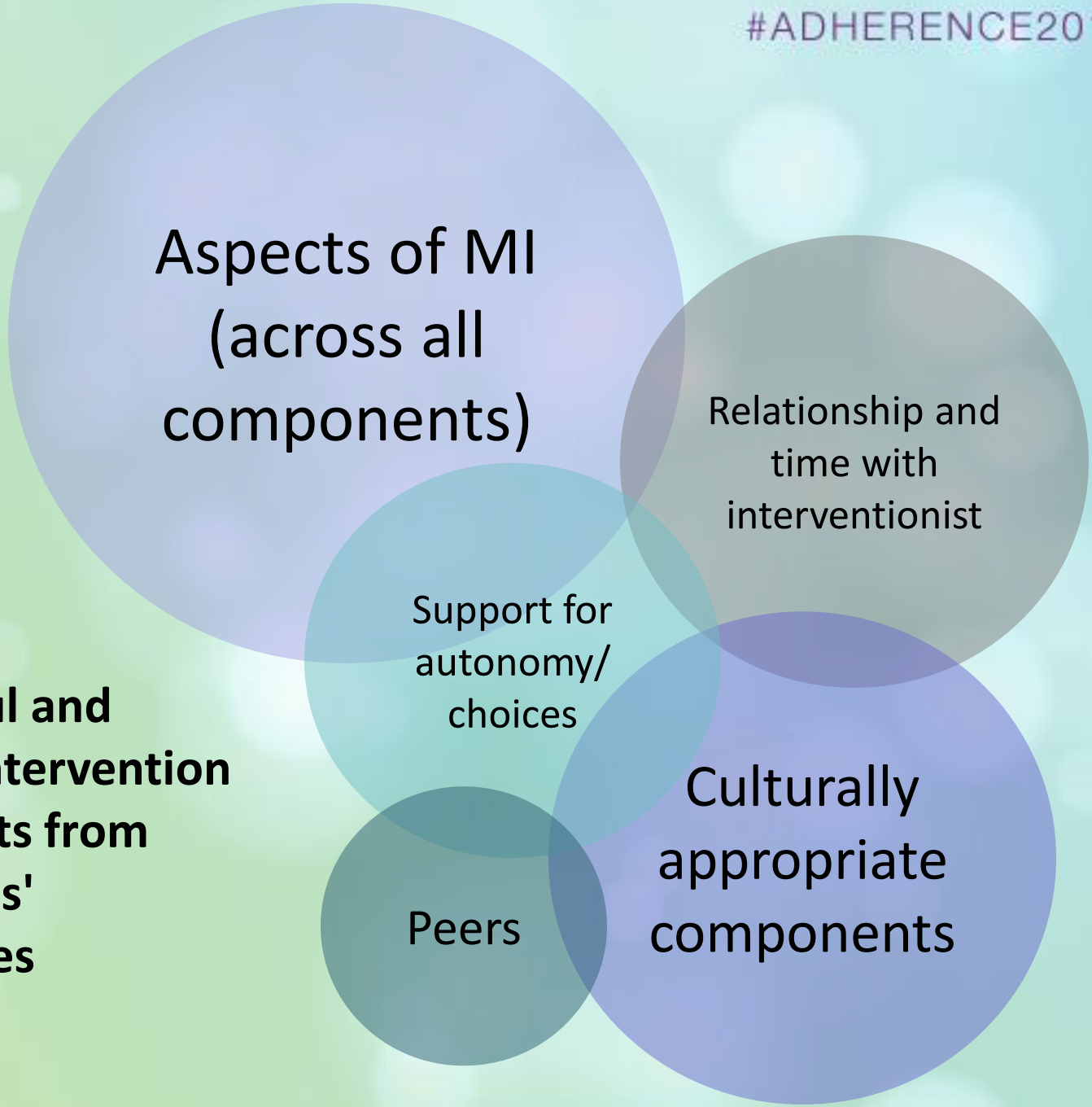
Gwadz et al, 2015, *AIDS and Bx*

Qualitative methods (N=37)

- **Embedded explanatory mixed methods design**
- **Purposive sampling for maximum variation on HIV and ART history**
- In-depth interviews, professionally transcribed
- Team-based systematic latent content analysis approach
- Theory of Triadic Influence, Critical Race Theory, Self Determination Theory
- Dedoose platform

	Mean (SD) or %
Age in years	48.7 (9.37)
Male sex	60%
If male, non-heterosexual	59%
African-American/Black	78%
Latino/Hispanic	22%
Low SES	97%
Years Since HIV Diagnosis	13.88 (8.11)
Ever taken ART in the past	54%
Number of times started/stopped ART	5.17 (5.44)
CD4 at enrollment	291.9 (144.2)

Results:
Most useful and effective intervention components from participants' perspectives



1. Aspects of MI (across components)

Main findings

- Absence of pressure and judgment
- Dialog/exploration fostered engagement, trust, and honesty
- Treated like a whole person
  - "I'm more than the pill"
- Opportunity to discuss why **not** on ART
- These aspects of HTH fostered a process of **personal decision making**
  - Individualized intervention needed
  - Some did not want to discuss ART
  - Some were not ready for ART
  - Some continued to decline ART

Representative quotes

- There's no pressure. You know (HTH is) about getting somebody to take their medication but no pressure. **If you decided you going to take meds, then you take them. If not, that's fine too….And I don't feel like I'm being judged. Like I'm the worst person in the world.** "You just so stupid. You don't take your medication. You know you could die." (511038)
- I think it was the attitude that they had. **I figured I'll sit down and listen and it will all be over. And then they'll let me go.** But it was more than that. You know, people were really sort of reaching out to me, but not in a preachy kind of way. You know, it was more a conversation. **They never said I had to do anything that I didn't want to do. That's a big plus in my book**. 411001

2. Support for autonomy/choices

Main findings

- One important aspect of MI
- Validation of the option to not initiative ART helped to legitimize participants' experience
  - Paradoxical
- Allowed participants to express concerns about ART that they reported could not be expressed elsewhere
- Again, these aspects of HTH fostered personal decision making

Representative quotes

- **And as I went through, actually they helped me make a decision to take HIV meds. And they made me feel that, listen, this is your decision**. This is up to you. You know, you don't have to-if you don't want to. Like you do have options and that's important. (411001)
- (We talked) about medical adherence and taking medication and what are the benefits, like what could be the benefits, **just for me to weigh this whole thing out overall. This way, it's still my decision**. Also to consider the recommendations of the medical staff. (211009)

3. Culturally appropriate intervention components

Main findings

- Content resonated with participants (video components)
  - Historical context of medical distrust (ART = experimentation?)
  - Fear of side effects, toxicity, stigma
  - Substance use
  - Structural factors
- Fostered exploration of personal barriers to ART
- Fostered exploration of emotions, as well as attitudes, beliefs, norms underlying ART decisions

Representative quotes

- The videos **made me feel like, that's me**. (421101)
- You know, some I found funny, but, I understood a lot. **They had a lot of videos where people were asking similar questions to what I might have had in my mind, but never really asked** or didn't know who to ask. (411001)
- Well they asked you what you thought about it, see? **Not what you heard or what you learned about it but how you feel about it.** And that was very helpful. (511030)

4. Relationship and time with interventionist

Main findings

- Skill and training of interventionist
  - MI, Substance use, "Structural competency" (Metzl, 2014)
- Takes time to elicit and process decisions, emotions, individual concerns
- Linkage to ancillary services and behavior change takes time
  - Substance use
  - Mental health
- Individualized interventions
  - Not high-intensity interventions
  - **Longer duration** of intervention

Representative quotes

- I guess the facilitator matters, that you have someone you can talk to, (who can) actually walk you through the process. That's what this particular cycle of Heart to Heart did**. Because I came and I hadn't talked about (ART) in years and years and years, because I don't always have the platform in which to talk about this stuff because people don't really care or be interested in the whole story.** They like to hear little bits and pieces, but they don't want to hear all of that. (512038)
- **(Deciding about ART was) something I took my time with**. (HTH) sat there and gave me time to get ready for it. Y'know what I mean? It wasn't forced on me. (211009)

5. Peers

Main findings

- Peer were powerful influences
  - "Successful peers" on ART
  - Other PLWH not on ART
- Reduced stigma
- Challenged unsupportive social norms
- Reduced isolation
- Modeled management of ART
  - In context of substance use

Representative quotes

- **I like (knowing) that I'm not just the only one that was feeling the same way about not taking my medication**. **And hearing other people's reasons for not taking their medication**. Some girl was saying the same reason that I was saying because of the side effects and the feeling that taking this medication was toxic. So I wasn't feeling like I was going crazy. Other people were saying the same thing. (511037)
- **If you can talk to somebody that's been through it or, or testimony, that's better than reading it**. Hell we read about a lot of stuff. But to see somebody that's living in front of you is a different story and they can tell you what happened and how they got from here to here [taps table]**. Show you a little road map**. 511030

Note: Adherence

Main findings

- Adherence was not described as challenging, once motivation and readiness were in place
  - Emotional readiness
  - Practical readiness
- Social support was a key factor

Representative quotes

- I don't like doing it. Trust me, I don't like it. I don't like having to remember to do it. But it's right in my bed stand and it's a habit now. I tell my boyfriend to go get my juice, I drink it with (juice). That's how I take my medicine. He takes his and I take mine. **It's just what I do, just like I'm making this sweater, or scarf, I just take my medicine. (**511042)
- I gave (ART) a name, "Combi," and I had a relationship (with Combi) to where it's like clockwork, I take that medicine at six-thirty and that's it. There's nothing to think about, I just do it. And I'm comfortable. (211009)

Implications for clinical settings & research

- From the perspective of AA/Black & Hispanic PLWH
  - MI was a good "fit" for this problem/population
  - Culturally appropriate components are useful
  - Peers are needed
  - Individualized intervention of reasonable duration has utility

- Anticipate & normalize ART delay/decline/discontinuation
  - Readiness for ART varies at diagnosis
  - Disruptions and life changes
  - "Diversion" (selling ART to pharmacies)
  - Many do not tell providers they have stopped

Implications for clinical settings & research 2

- Barriers in health care settings
  - Short health care encounters
  - Providers pressured to get pts undetectable
- Interventions such as HTH can complement clinical care
- Research
  - How to locate and engage PLWH not on ART
  - Most cost effective approaches for increasing and supporting ART initiation with good adherence

Research team

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- Study participants

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