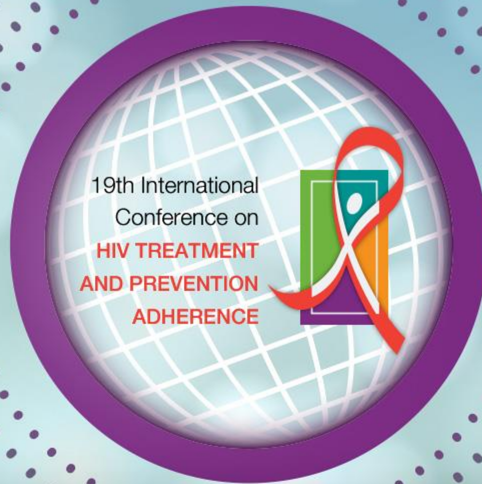


CDUHR
CENTER FOR DRUG USE
AND HIV | HCV RESEARCH

# The other half: Integrating qualitative analyses across three cohorts of Black and Latine persons living with HIV who are not HIV virally suppressed

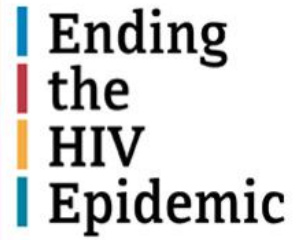
Gwadz, M., Cluesman, S. R., Freeman, R., Campos, S., Wilton, L., Cleland, C.M., Serrano, S., Sherpa, D., Israel, K., Amos, B., Downey, D., Filippone, P.

Continuum 2024 · June 9-11, 2024 · Puerto Rico

# A note

Positionality

Cultural and structural humility



Diagnose

Treat

Prevent

Respond

# Persistent disparities in sustained HIV viral suppression by race/ethnicity

#CONTINUUM2024

| | Value |
|---|---|
| Overall | 48% |
| White PLWH | 56% |
| Black PLWH | 41% |
| Latino PLWH | 50% |



Crepaz, MMWR 2018

# We focus on AABL PLWH with non-suppressed HIV viral load

#CONTINUUM2024

100
90
80
70
60
50
40
30
20
10
0

| | Overall | White PLWH | Black PLWH | Latino PLWH |
|---|---|---|---|---|
| Upper segment | | | 59% | 50% |
| Lower segment | 48% | 56% | 41% | 50% |

Crepaz, MMWR 2018

#CONTINUUM2024

# Research question

What are the factors that promote or impede HIV viral suppression,

**from the perspectives of African American/Black and Latine PLWH with non-suppressed HIV VL?**

# METHODS

# **Qualitative synthesis** of qualitative studies w/similar eligibility criteria we carried out from the past 10 years

Define the Research Question → Select Studies → Extract data → Coding and Theme Development → Synthesis → Quality Assessment → Interpretation

| Study 1 (HTH1) | Study 2 (HTH2) | Study 3 (SCAP2) |
| --- | --- | --- |
| Pilot RCT (N=95) | Large optimization trial (N=512) | Small optimization trial (N=80) |
| **Eligibility criteria**<br>Age ≥ 18 years<br>African American/Black or Latine race/ethnicity<br>Last CD4 ≤ 500<br>Eligible for ART<br>Not on ART in past 30 days<br>Resides in NYC<br>Activities in English | **Eligibility criteria**<br>Age 18 – 65 years<br>African American/Black or Latine race/ethnicity<br>Non-suppressed HIV VL (lab report)<br>Not well-engaged in care<br>Resides in NYC<br>Activities in English or Spanish | **Eligibility criteria**<br>Age 18 – 65 years<br>African American/Black or Latine race/ethnicity<br>Non-suppressed HIV VL (lab report)<br>Resides in NYC metro area<br>Activities in English |
| Qualitative sample size N=37 | Qualitative sample size N=48 | Qualitative sample size N=41 |

* Not published

#CONTINUUM2024

**Study 1 (HTH1)**
Pilot RCT
(N=95)

**Study 2 (HTH2)**
Large optimization trial
(N=512)

**Study 3 (SCAP2)**
Small optimization trial
(N=80)

**Analyses**

- Understanding poor engagement through critical race theory

- How subs

impedes HCC

**Analyses**

- Unpacking forgetting ART

Determination Theory

**Analyses**

- Systemic/structural factors

ntability,

**10 analyses from 3 projects**

Qualitative sample size
N=37

Qualitative sample size
N=48

Qualitative sample size
N=41

# PARTICIPANTS (N=126)

#CONTINUUM2024

Assigned male sex at [...] (~75%)

Substance use [...] past

Long-term HIV survivors

Can be located/engaged but with time, expertise, & effort

Not HIV suppressed at enrollment

minority (~34%)

ago, on average

Chronic poverty (100%)

# THEORIES/APPROACHES

#CONTINUUM2024

Self-determination Theory

Critical Race Theory

Harm Reduction

Theory of Triadic Influence (multi-level social-cognitive)

# How results will be presented

- Major themes (briefly)
  - Focused on systemic/structural, social, individual levels of influence
- Synthesis: Integrated comprehensive visual model
- Implications and recommendations

# RESULTS

# Systemic/structural racism is a fundamental cause of poor HCC engagement

#CONTINUUM2024

## Definition

- **the macro-level systems that create, sustain, and reinforce inequities among racial and ethnic groups**
- deeply embedded in systems, laws, written or unwritten policies, and entrenched practices and beliefs that produce, condone, and perpetuate widespread unfair treatment and oppression of people of color

## Examples

- social segregation
- biased policing and sentencing
- unfair lending practices, barriers to home ownership
- other barriers accumulating wealth
- unequal housing quality
- environmental injustice
- voter suppression policies
- transportation inequities
- **for PLWH, inequities in access to high-quality, personalized HIV care and ancillary services**

Braverman et al, 2022. Systemic and structural racism.

“Every system is perfectly designed to get the result it gets”

# Systemic/structural racism is a fundamental cause of poor HCC engagement

AABL PLWH **do attribute challenges to HCC engagement as grounded in racism** (systemic/structural or other forms of racism)

Generally positive experiences with health care providers, **but high-quality care is hard to access**

**** Chronic poverty is a fundamental cause of poor HCC engagement ****

**Housing type/quality is often not optimal** (e.g., congregate versus private housing settings trigger substance use and social isolation)

**Low benefit levels/poverty permeate every aspect of life and health care decision-making**

# Health care settings and providers

Health care settings serving AABL PLWH are overly **institutional and dehumanizing**

**Settings are still siloed** and hard to access (staff and providers over-burdened and under-resourced)

**Providers are valued and trusted but medical institutions less so**

AABL PLWH feel excluded from the health care decision-making process; **autonomy is not supported**

**Distrust of settings and ART is serious**, AABL PLWH feel pressured to take ART when it is offered

# Perspectives on HIV viral suppression and non-suppression

**HIV viral suppression is generally understood and valued in the abstract.** But, external circumstances often prevent PLWH taking ART.

**LT survivors stop ART, often for long periods, and re-start ART, often for long periods.**

**It's complicated.**

**Not taking ART can cause anxiety, stress, worry, and experiences of stigma/shame**

People fear the long-term side effects of ART, and distrust health system and ART. **But may take ART for long periods** to reduce VL **or** achieve VS .

# Interpreting long-term survivorship through the lens of symbolic violence (SV)

#CONTINUUM2024

**AABL PLWH are "ground down" over time** by material, social, and emotional challenges and this diminishes self-worth and, at times, the will to live

**Social isolation and self-isolation,** based in part on feeling devalued and dehumanized, serve as stigma-avoidance strategies and mechanisms of social exclusion

SV is nonphysical violence

**Resilience**

Stigmatizing ... interactions and **restricte...** HIV care and other settings (e.g., parole) reduce HCC engagement

**...internalized as a personal failure**

# SYNTHESIS

# Root Causes

STRUCTURAL/ENVIRONMENTAL

Historical and present-day **systemic/structural racism**

Chronic **poverty**, Intergenerational poverty

The **history of HI**V (AZT monotherapy, changing guidelines)

Stability, type, and quality of **housing**

**Stigma**

**Pharmacies buy ART**, encourage ART diversion

ASPECTS OF HIV AND ANCILLARY CARE

Quality of medical services is high and providers are appreciated but the general **quality of HIV care** is poor (wait times, experience, ease of access, etc.)

HIV care settings **under pressure** to get patients to undetectable VL levels

Providers may not evidence sufficient **structural competence**

Settings/services are generally still siloed and/or **services insufficient to meet need** (substance use, mental health, navigation)

# Addressable Barriers

INDIVIDUAL LEVEL

Cognitive biases
Gaps in health literacy
Medical distrust
Disclosure concerns
Fear of ART and LT side effects
Sensitivity to being pressured to take ART
Competing priorities related to poverty including mental health concerns, substance use problems
Environments impede habits/steady routine
Long term "symbolic violence" is internalized
Negative emotions re: HIV, ART
ART is sold to meet needs

ORGANIZATIONAL

Settings are dehumanizing
Autonomy not sufficiently supported
Harm reduction approaches lacking

SOCIAL LEVEL

Complex stigma
Social isolation, self isolation

STRUCTURAL LEVEL

Poverty
Difficulties accessing care
Housing

**BARRIERS AND STRENGTHS CO-OCCUR**

Motivation for good health
Desire for lower VL or VS
Resilience
Activism & advocacy
Altruism
Willingness to take ART
Ability to take ART

# Concrete example: One common pattern for AABL LT survivors in the context of these root causes and barriers

Life event/disruption → Stress, depression, negative affect and/or substance use → Unable to take ART → Feel bad physically and mentally, health crisis (may start ART)

↓

Re-group, get treatment (MH, SU), and stabilize → Less stress, depression, negative affect and/or heavy substance use → Re-start or continue ART → Feel better physically and mentally

↑ (back to Life event/disruption)

# Points for prevention, intervention, and support

Life event/disruption → Stress, depression, negative affect and/or substance use → Unable to take ART → Feel bad physically and mentally, health crisis (may start ART) → Re-group, get treatment (MH, SU), and stabilize → Less stress, depression, negative affect and/or heavy substance use → Re-start or continue ART → Feel better physically and mentally → Life event/disruption

# IMPLICATIONS & RECOMMENDATIONS

## "Every system is perfectly designed to get the result it gets"

- A system at odds with itself – we want to EHE but not structured to EHE
- Bowleg: National responses to the HIV epidemic inadequately address long standing socio-systemic issues (Bowleg et al., 2022, *Ending the HIV epidemic for all, not just some*)

## Move beyond assessing race to racism and its effects

- Structural/systemic racism is a fundamental cause of poor engagement
- Bowleg: Ending systemic racism as an essential step to ending the HIV epidemic in the United States (2022)

## Systems need to earn trust and be trustworthy

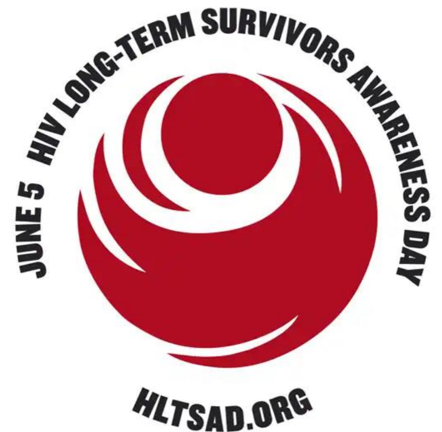
- The public health system has not meaningfully addressed distrust and increased trustworthiness (Madorsky et al, 2021)
- Recommendations include ethical public health reconciliation, community-centered public hea sources, and leveraging intergenerational comr

## Eliminate poverty

- Draw on substantial literature on universal basic elimination programs
- ”They got money for wars, but can't feed the po

## Research needed on experience of LT survivorship

- Research on LT survivorship is needed
- LT survivors stop and start ART but prediction ar
- Likely need on-going or repeated intervention a
- The level of resilience cannot under-estimated (



# IIT-LAB COLLABORATIVE RESEARCH TEAM

#CONTINUUM2024

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Thank you

>100 participants who shared their perspectives and experiences

Program Official at NIDA, Dr. Rich Jenkins

NYU Silver

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