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
The time is now.

- Diagnose
- Treat
- Prevent
- Respond
Persistent disparities in sustained HIV viral suppression by race/ethnicity

48% 56% 41% 50%

Overall White PLWH Black PLWH Latino PLWH

Crepaz, MMWR 2018
We focus on AABL PLWH with non-suppressed HIV viral load

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>White PLWH</th>
<th>Black PLWH</th>
<th>Latino PLWH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>48%</td>
<td>56%</td>
<td>41%</td>
<td>50%</td>
</tr>
</tbody>
</table>

Crepaz, MMWR 2018
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

1. Define the Research Question
2. Select Studies
3. Extract data
4. Coding and Theme Development
5. Quality Assessment
6. Synthesis
7. Interpretation
<table>
<thead>
<tr>
<th>Study 1 (HTH1)</th>
<th>Study 2 (HTH2)</th>
<th>Study 3 (SCAP2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot RCT</td>
<td>Large optimization trial</td>
<td>Small optimization trial</td>
</tr>
<tr>
<td>(N=95)</td>
<td>(N=512)</td>
<td>(N=80)</td>
</tr>
</tbody>
</table>

**Eligibility criteria**

**Study 1 (HTH1)**
- Age ≥ 18 years
- African American/Black or Latine race/ethnicity
- Last CD4 ≤ 500
- Eligible for ART
- Not on ART in past 30 days
- Resides in NYC
- Activities in English

**Study 2 (HTH2)**
- Age 18 – 65 years
- African American/Black or Latine race/ethnicity
- Non-suppressed HIV VL (lab report)
- Not well-engaged in care
- Resides in NYC
- Activities in English or Spanish

**Study 3 (SCAP2)**
- Age 18 – 65 years
- African American/Black or Latine race/ethnicity
- Non-suppressed HIV VL (lab report)
- Resides in NYC metro area
- Activities in English

**Qualitative sample size**
- N=37
- N=48
- N=41
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 substance use impedes HCC engagement

Analyses
- Unpacking forgetting ART
- Selling ART*
- Experiences not taking ART*
- Using symbolic violence to understand living with HIV
- Stopping and starting ART

Analyses
- Systemic/structural factors
- Acceptability,

Qualitative sample size
N=37

Qualitative sample size
N=48

Qualitative sample size
N=41

10 analyses from 3 projects

* Not published
PARTICIPANTS (N=126)

- Assigned male sex at birth (~75%)
- Sexual/gender minority (~34%)
- ~60% African American/Black, 40% Latino
- Diagnosed with HIV 15 years ago, on average
- Substance use challenges past and/or present (~80%)
- Not HIV virally suppressed at enrollment
- Chronic poverty (100%)
- Can be located/engaged but with time, expertise, & effort

Long-term HIV survivors
THEORIES/APPROACHES

Critical Race Theory

Harm Reduction

Self-determination Theory

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

<table>
<thead>
<tr>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>• the macro-level systems that create, sustain, and reinforce inequities among racial and ethnic groups</td>
<td>• social segregation</td>
</tr>
<tr>
<td>• 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</td>
<td>• biased policing and sentencing</td>
</tr>
<tr>
<td></td>
<td>• unfair lending practices, barriers to home ownership</td>
</tr>
<tr>
<td></td>
<td>• other barriers accumulating wealth</td>
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<tr>
<td></td>
<td>• unequal housing quality</td>
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<tr>
<td></td>
<td>• environmental injustice</td>
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<td></td>
<td>• voter suppression policies</td>
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<tr>
<td></td>
<td>• transportation inequities</td>
</tr>
<tr>
<td></td>
<td>• for PLWH, inequities in access to high-quality, personalized HIV care and ancillary services</td>
</tr>
</tbody>
</table>

“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)

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

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

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
<table>
<thead>
<tr>
<th>Health care settings serving AABL PLWH are overly institutional and dehumanizing</th>
<th><strong>Settings are still siloed</strong> and hard to access (staff and providers overburdened and under-resourced)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providers are valued and trusted but medical institutions less so</td>
<td><strong>Distrust of settings and ART is serious</strong>, AABBL PLWH feel pressured to take ART when it is offered</td>
</tr>
<tr>
<td>AABBL PLWH feel excluded from the health care decision-making process; autonomy is not supported</td>
<td></td>
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</tbody>
</table>
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)

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.

Stigmatizing patient-provider interactions and restricted autonomy in HIV care and other settings (e.g., parole) reduce HCC engagement.

Resilience

Poor HIV management is internalized as a personal failure.
SYNTHESES
Root Causes

STRUCTURAL/ENVIRONMENTAL
Historical and present-day systemic/structural racism
Chronic poverty, Intergenerational poverty
The history of HIV (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)

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)

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

Feel better physically and mentally ← Re-start or continue ART ← Less stress, depression, negative affect and/or heavy substance use ← Re-group, get treatment (MH, SU), and stabilize
IMPLICATIONS & RECOMMENDATIONS
<table>
<thead>
<tr>
<th>Topic</th>
<th>Text</th>
</tr>
</thead>
</table>
| "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 practice, truth and reconciliation, community-centered public health practice, elevating trusted sources, and leveraging intergenerational community connections |
| Eliminate poverty                          | Draw on substantial literature on universal basic income and other poverty elimination programs  
"They got money for wars, but can't feed the poor" - Tupac Shakur |
| Research needed on experience of LT survivorship | Research on LT survivorship is needed  
LT survivors stop and start ART but prediction and prevention of stops/starts is poor  
 Likely need on-going or repeated intervention as people move through time  
The level of resilience cannot under-estimated (but why rely on resilience?) |

*EHE:* Equivalent Health Endstate  
*LT:* Long-term
Thank you

>100 participants who shared their perspectives and experiences

Program Official at NIDA, Dr. Rich Jenkins

NYU Silver