Beyond Research for Research Sake: Centering Equity and Community Engagement to Advance HIV Research

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“The seed must grow regardless of the fact that it’s planted in stone” - Tupac Shakur

“As Black feminists and Lesbians we know that we have a very definite revolutionary task to perform and we are ready for the lifetime of work and struggle before us.” – Combahee River Collective, 1977 Statement
Objectives

Provide an overview of

(a) how equity and community engagement is centered in the SHINE research program in Miami, FL

(b) applicable research studies and findings engaging Black communities living with and placed at risk for HIV and

(c) research findings highlighting the role of socio-structural factors and resilience resources
Miami HIV Prevalence

- Florida is ranked 3rd in new cases per capita
- Florida is #1 in new HIV diagnoses (4,387)
- Miami tops list of new cases per 100,000 people

(VECIANA-SUAREZ, 2021; SULLIVAN ET AL., 2020)
Structural Factors Driving HIV Inequities
Strengthening Health with INnovation and Engagement (SHINE) Research Program

- Enhancing our understanding of the relationships between resilience, trauma, adversities, and health outcomes among individuals with HIV and those placed at risk for HIV

- Investigating psychosocial and structural factors that drive health inequities

- Developing effective prevention and intervention strategies to promote resilience and good health outcomes

- Closely partnering with community members and stakeholders in various research efforts
Beyond a Question to Making a Difference

- Having clarity on the values driving the work
- Recruiting and investing in a team that brings key issues and lived expertise to the work
- Understanding intersectionality, marginalization, and oppressive factors driving inequities
- Producing real world benefits for participants and communities as you collect data and learn

“Is this how you are? Caring. Real. Or is it because it’s a job?” – Research Participant
Values and Approach to Research

- Showing up and being present
- Centering Research Participants
  - They are the assets
  - Showing appreciation
  - Minimizing barriers
  - Attending to needs
  - Advocating
- Recognizing Strength & Resiliency
- Developing Meaningful Interventions
  - Culturally relevant
  - Honors intersectionality
  - Culturally competent team members & clinicians
- Context and Environments Matter
  - Understanding the weight of intersectional oppression
  - Understanding the impact of contextual, socioeconomic, and neighborhood factors
- Partnering with Community Members to Effect Change
## Overview of SHINE Projects

### Active Data Collection
- Monitoring Microaggressions and Adversities to Inform Interventions for Change Among Black Women Living with HIV (MMAGIC)
- Five Point Initiative (FPI): Reaching Miami’s Black Communities to End the HIV Epidemic
- Gentrification, Outcomes, and Living with HIV (GOAL)
- A Qualitative Study to Explore Biomedical HIV Prevention Preferences, Challenges, and Facilitators among Diverse Women Living in the United States (Prep for Us)

### Analyses and Publication Stage
- Five Point Initiative (FPI)
- Burnout among service providers for People Living with HIV: Factors related to coping and resilience
- Motivational Interviewing to Increase Motivation for PrEP Uptake Among Black Woman at Risk for HIV (MI-PrEP)
- Writing to Alleviate Violence Exposure for Transgender Women (WAVE-TW)
- Striving Towards EmPowerment and Medication Adherence (STEP-AD)
- Project SUSTAIN (during COVID-19 Lockdowns) among Black Women Living with HIV
Monitoring Microaggressions and Adversities to Inform Interventions for Change Among Black Women Living with HIV (MMAGIC) (NIMH R01, R56)

- **Aim 1**: To assess whether microaggressions experienced by BWLWH negatively impact HIV viral suppression by way of mental health symptoms and health behaviors. Longitudinally collect data on microaggressions experienced by BWLWH (N=300) via a short daily text message, and more extensively at 3-month assessments.

- **Aim 2**: To test how re-occurring trauma and violence experienced both directly and vicariously (e.g. violence against a relative) by BWLWH negatively predict HIV viral suppression as mediated by mental health symptoms and health behaviors.

- **Aim 3**: Determine if resilience factors moderate the relationships being examined in Aims 1 and 2 and serve as a buffer between microaggressions, discrimination (macroaggressions), trauma/violence, and HIV viral suppression. Measure resilience factors at the individual, interpersonal, and neighborhood level.

**Immediate Benefit**
- Social Support
- Validating/supportive interactions with trained mental health clinicians
- Timely response to elevated distress ratings following microaggressions
- Information and linkage to community resources
- Assistance/advocacy around health access
Daily Microaggressions and Related Distress among Black Women Living with HIV during the Onset of the COVID-19 Pandemic and Black Lives Matter Protests

- Baseline viral suppression was associated with significantly lower odds of microaggressions (64%) compared to non-suppression (OR = 0.36, 95% CI = 0.14, 0.90, p value = 0.028).

- Higher income at baseline was associated with lower odds of microaggressions (OR = 0.75, 95% CI = 0.56, 0.99, p value = 0.045) compared to lower income.

- Alcohol use in the past 30 days (at baseline) was associated with higher odds of microaggression-related distress (OR = 2.71, 95% CI = 1.07, 6.83, p value = 0.035).

Microaggression as a Function of Time

The probability of daily microaggression and distress as a function of time (day) is shown in Fig. 1. The probability of daily microaggression was around 23% at baseline in October 2019, and decreased steadily to over 15% and remained flat around the holiday season (late November to December, 2019), then continued to decline to below 10% and remained flat with COVID-19 onset (after late March 2020). The probability of distress shows a different pattern where it increased from 52% and peaked at 70% during the holiday season (November to December 2019), then decreased steadily and bottomed around 55% at the start of the COVID-19 pandemic (March 2019), then began to increase rapidly to 83% through July 2020.
Neighborhood Characteristics, Intersectional Discrimination, Mental Health, and HIV Outcomes among Black Women Living with HIV

- Within Neighborhood Factors
  - Higher crime was associated with higher gendered racial microaggressions (GRM) frequency and appraisal.
  - Higher employment was associated with lower HIV microaggressions and lower HIV-related discrimination.
  - Higher number of low-income/subsidized rental housing was associated with lower HIV microaggressions.
  - Higher neighborhood median income was associated with higher HIV microaggressions and higher sexual orientation related discrimination.

- Neighboring Factors
  - Higher education in neighboring areas was associated with lower GRM appraisal.
  - Higher Median Income was associated with higher GRM appraisal.
Neighborhood Characteristics, Intersectional Discrimination, Mental Health, and HIV Outcomes among Black Women Living with HIV

Within-Neighborhood

- Higher crime was associated with higher depressive symptoms and post-traumatic cognitions.

- Higher crime was associated with higher likelihood of diagnoses of PTSD and substance use disorder.

- Higher employment was related to lower PTSD symptoms and lower likelihood of alcohol use disorder.

- Higher education was associated with lower likelihood of suicidality.

- Higher number of Christian organizations was associated with lower post-traumatic cognitions and lower likelihood of depression diagnosis.

Neighboring Factors

- Higher education in neighboring areas was associated with lower number of traumas, lower depressive symptoms, lower PTSD symptoms, and lower likelihood of depression diagnosis.

- Higher employment was associated with higher traumas, higher PTSD symptoms, and higher likelihood of depression diagnosis.

- Higher median income was also associated with higher traumas.
Neighborhood Characteristics, Intersectional Discrimination, Mental Health, and HIV Outcomes among Black Women Living with HIV

**Within Neighborhood**
- Higher crime was associated with lower medication adherence within the past month and higher VL log.
- **Higher education** was associated with lower VL log and higher likelihood of HIV viral suppression and undetectable VL.
- **Higher employment** was associated with higher likelihood of undetectable VL.
- Higher median income was associated with lower likelihood of HIV viral suppression and undetectable VL.

**Neighboring Factors**
- Contrary to the direction for within neighborhood, neighboring higher median income was associated with higher likelihood of undetectable VL.
A Structural Equation Model of Intersectional Microaggressions and Discrimination, Resilience, and Mental Health among Black Women Living with HIV

(DALE ET AL., UNDER REVIEW)
Planning Aim: Partner with five venues in five Miami Dade zip codes with the highest number of Black individuals living with HIV; collaborate with community health organizations; and host outreach events in which residents complete an electronic survey in exchange for a venue voucher and were offered voluntary HIV/STI counseling and testing, condoms, and PrEP information.

Implementation Aim: Implementation of HIV testing, PrEP information/linkage, and condom distribution across 12 high impact zip codes using our locally developed Five Point Initiative approach.
Five Point Initiative (FPI): Model and Geography

(DALE ET AL, UNDER REVIEW)
Community Consultants

Roxana Bolden
CEO A Sister with a Testimony Ministry (SWAT)
Coordinator SHINE Research Lab
Community Advisory Board
CAB Member for CHARM
Healing Hands Ministry
Community Advocate for The Homeless
Peer Outreach at Care 4U

Sherkila Shaw
Local outreach and HIV activist
CAB Member for CHARM
Asst CEO A Sister with A Testimony (SWAT)
Model & Storyteller for ViiV Healthcare

Kalenthia Nunnally
CEO of Blessing Hands Outreach
Founder of Sista’s Organizing to Survive (SOS)
Community Chair of the Florida Black HIV/AIDS Coalition (FBHAC)
CAB Member for CHARM
In the Context of COVID-19

- Safety Precautions
- Warmth that transcends masks/goggles
- Offering COVID-19 testing & vaccines
- Gathering information on COVID-19 Impact & views on COVID-19 vaccine
Five Point Initiative Preliminary Outcomes

FPI 1
- Community Business Partners: n=13
- Health Partners: n=5
  - Community Residents engaged: n=677
  - Voluntary HIV Tests: n=131
- Condoms Distributed: n=12,434

FPI 2
- Community Business Partners: n~76 (5 repeats)
- Health Partners: n=8
  - Voluntary HIV Tests: n=1,459
  - COVID Tests: n=112
  - COVID Vaccinations/Boosters: n=22
- Community Residents Engaged: n > 1,600
- Condoms Distributed: n=61,031
Implications and Lessons Learned

- Support for feasibility and acceptability of the FPI implementation approach
- FPI approach is promising for EHE initiatives and beyond (e.g., applicability to COVID-19)
- Direct benefit to all partners involved fosters strong collaborations and interests
- Having community consultants at the table is key
- Community residents will show up and be an on-the-spot referral system (e.g., estimate 50 residents, some locations attracted 100)
- A clustered randomized R01 study can help to assess the efficacy of the FPI approach
- Driven by purpose, commitment, and adaptability
Mentorship & Investment in the Next Generation

- “Pay it forward”
- Needs of minoritized communities will not be addressed without hiring, accepting into program training, and mentoring and sponsoring those with lived expertise.
- Mentor graduate & undergraduate students, community members/partners, post-doctoral fellows, high school students, and junior faculty.
Culturally Focused HIV Advances through the Next Generation for Equity (CHANGE) Training Program (NIMH T32)

MPIs: Dale, Feaster, Horrigian

- The Primary Goal is to help develop the next generation of researchers with the expertise to successfully address HIV and Mental Health disparities throughout the HIV prevention and treatment cascades using community-engaged research, implementation, and dissemination

- Training focuses on the following two linked areas: Culturally informed interventions for racial/ethnic, sexual, and gender minority populations Innovative bio-behavioral interventions including scale up, linkage, and dissemination/implementation programs for pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP) in populations who need it most.
The Center for HIV and Research in Mental Health (CHARM) at the University of Miami aims to bridge the boundaries that have traditionally divided behavioral and biomedical research to catalyze mental health HIV science in one of the regions of the United States hardest hit by HIV/AIDS, with the over-arching theme of “Reducing the Impact of Mental Health and Minority Health Disparities across the HIV Prevention and Care Continua.”

The MHD-CE Core promotes rigorous, multilevel, culturally competent research addressing mental health (MH) disparities faced by communities most impacted by the HIV epidemic due to racism, heterosexism, cisgenderism, and ethnocentrism.

To ensure that community voices drive CHARM’s research priorities and activities through genuine, meaningful, and bi-directional benefits for local communities and CHARM.

To ensure that processes are in place to prioritize ethics, safety, fairness, informed consent, and data quality while minimizing risk when carrying out human subjects research among and in collaboration with marginalized populations.

https://charm.miami.edu/index.html
https://www.facebook.com/charmcentermia/
CHARM Community Advisory Board (CAB)

- ~12 members
- Participating in speed review: reviewing specific aims and community engagement plans
- Reviewing the applications submitted for full review
- Participation in scientific review committee
- Meet investigators and pilot awardees to provide feedback on recruitment, study implementation, and study instruments
CHARMing Conversations & Speakers Series
Acknowledgments

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