



Northwest (HHS Region 10)

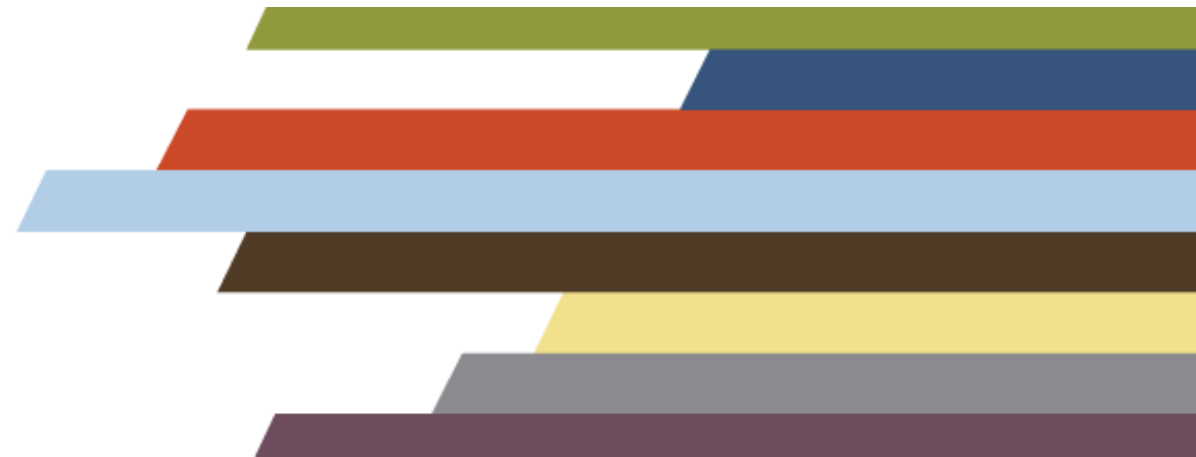
MHTTC

Mental Health Technology Transfer Center Network

Funded by Substance Abuse and Mental Health Services Administration

# Stigma Reduction Among People with HIV to Improve Health Outcomes

## Integrated Care Webinar Series



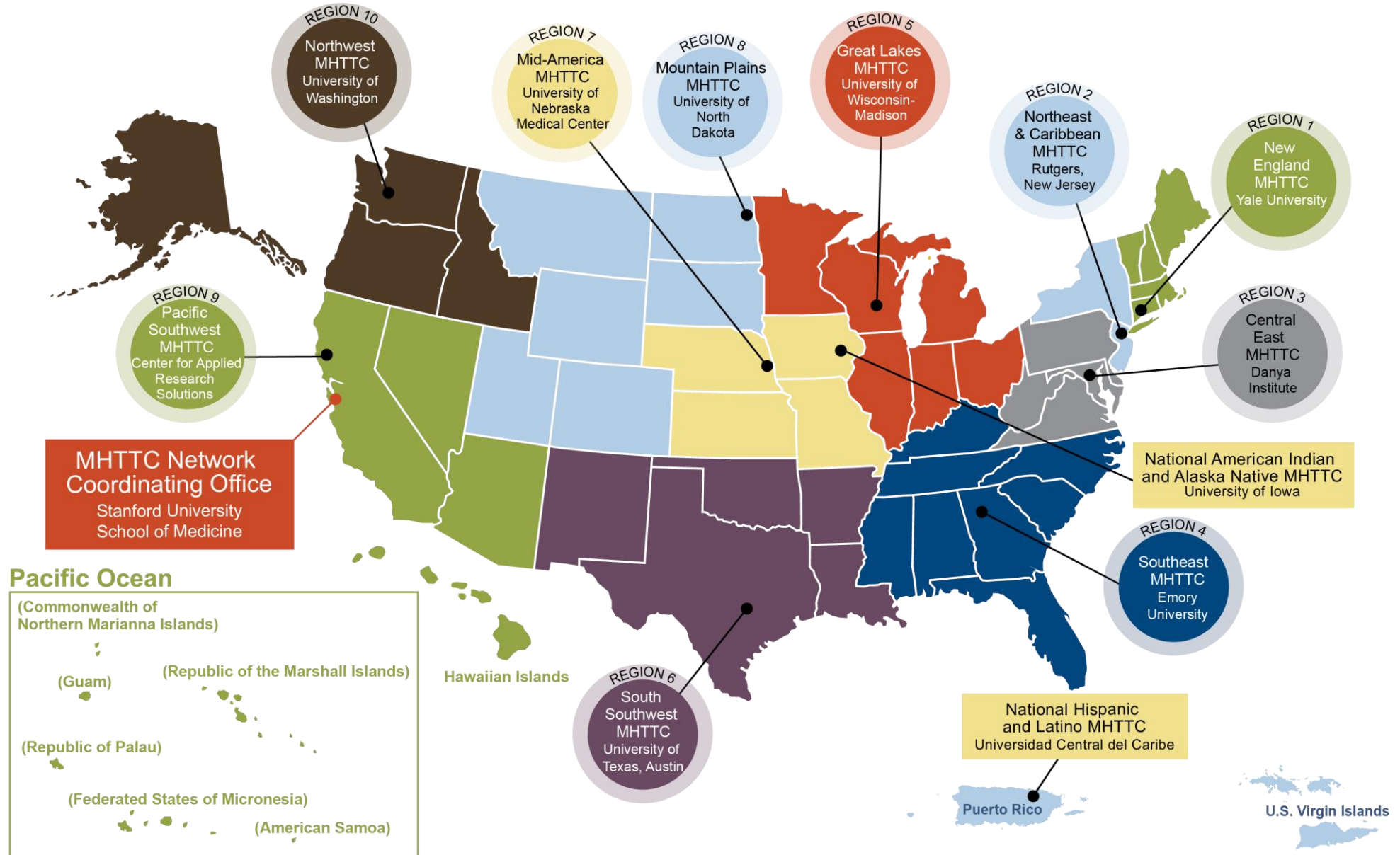


# MHTTC

## Mental Health Technology Transfer Center Network

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# MHTTC Network



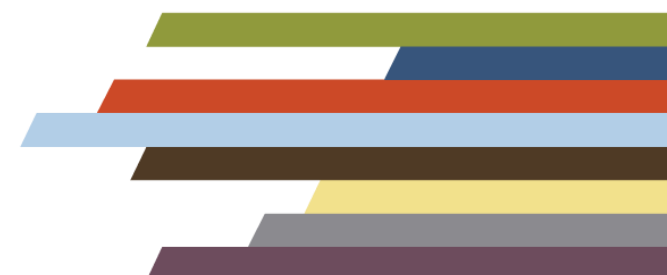
# Northwest Mental Health Technology Transfer Center

## Our Role

Provide training and technical assistance (TA) in evidence-based practices (EBP) to behavioral health and primary care providers, and school and social service staff whose work has the potential to improve behavioral health outcomes for individuals with or at risk of developing serious mental illness in SAMHSA's Region 10 (Alaska, Idaho, Oregon, and Washington).

## Our Goals

- Heighten awareness, knowledge, and skills of the workforce addressing the needs of individuals with mental illness.
- Accelerate adoption and implementation of mental health-related EBPs across Region 10.
- Foster alliances among culturally diverse mental health providers, policy makers, family members, and clients.



The use of affirming language inspires hope and advances recovery.

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LANGUAGE MATTERS.

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**Words have power.**

**PEOPLE FIRST.**

The MHTTC uses affirming language to promote the promises of recovery by advancing evidence-based and culturally informed practices.

**Who do we have with us today?**

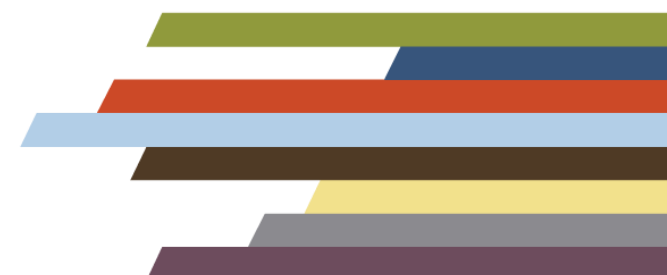


**Hello**  
my name is

# Today's Trainer: Deepa Rao



- Professor in the Departments of Global Health and Psychiatry and Behavioral Sciences at the University of Washington
- Licensed Clinical Psychologist
- Associate Director of the Center for AIDS Research Behavioral Science Core
- Associate Director of Global Mental Health
- Associate Director of the MPH program in Global Health at the University of Washington



# Stigma Reduction Among African American Women with HIV

Deepa Rao, PhD, MA

Professor

Department of Global Health

Department of Psychiatry and Behavioral Sciences

University of Washington

# What Is Stigma?

## How familiar are you with the concept of stigma?

- 1 – Not at all familiar
- 2 – Slightly familiar
- 3 – Somewhat familiar
- 4 – Moderately familiar
- 5 – Extremely familiar

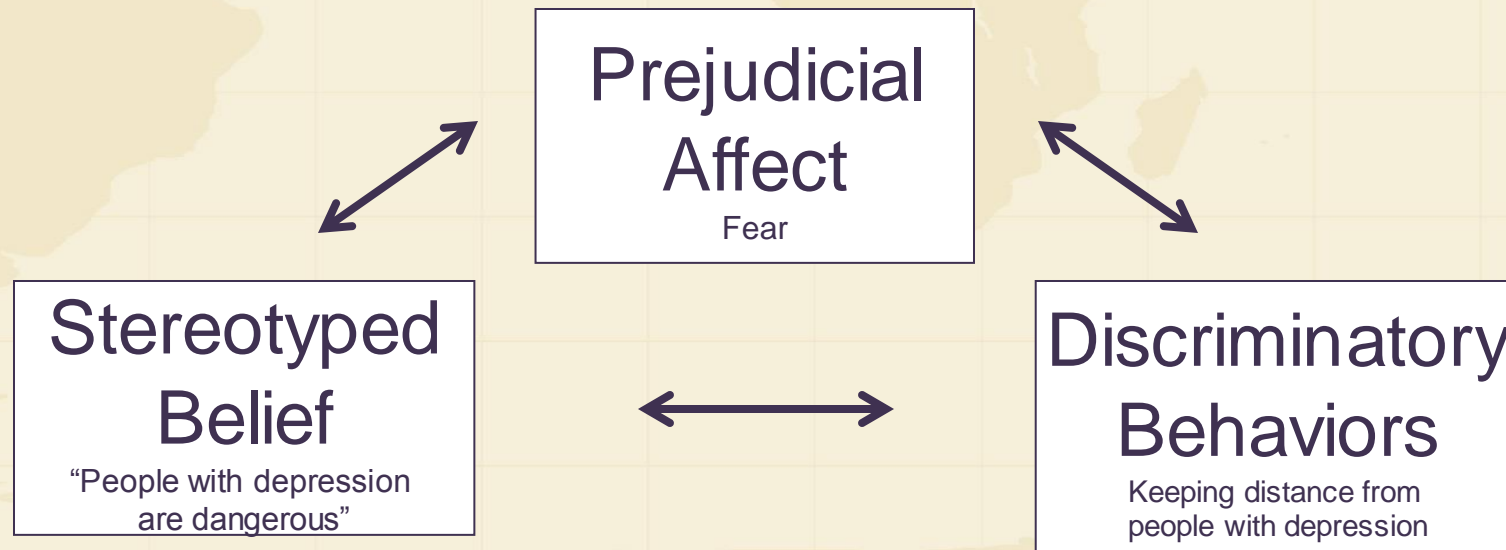


## Have you have experienced stigma in some way or another?

- Yes
- No

# Stigma

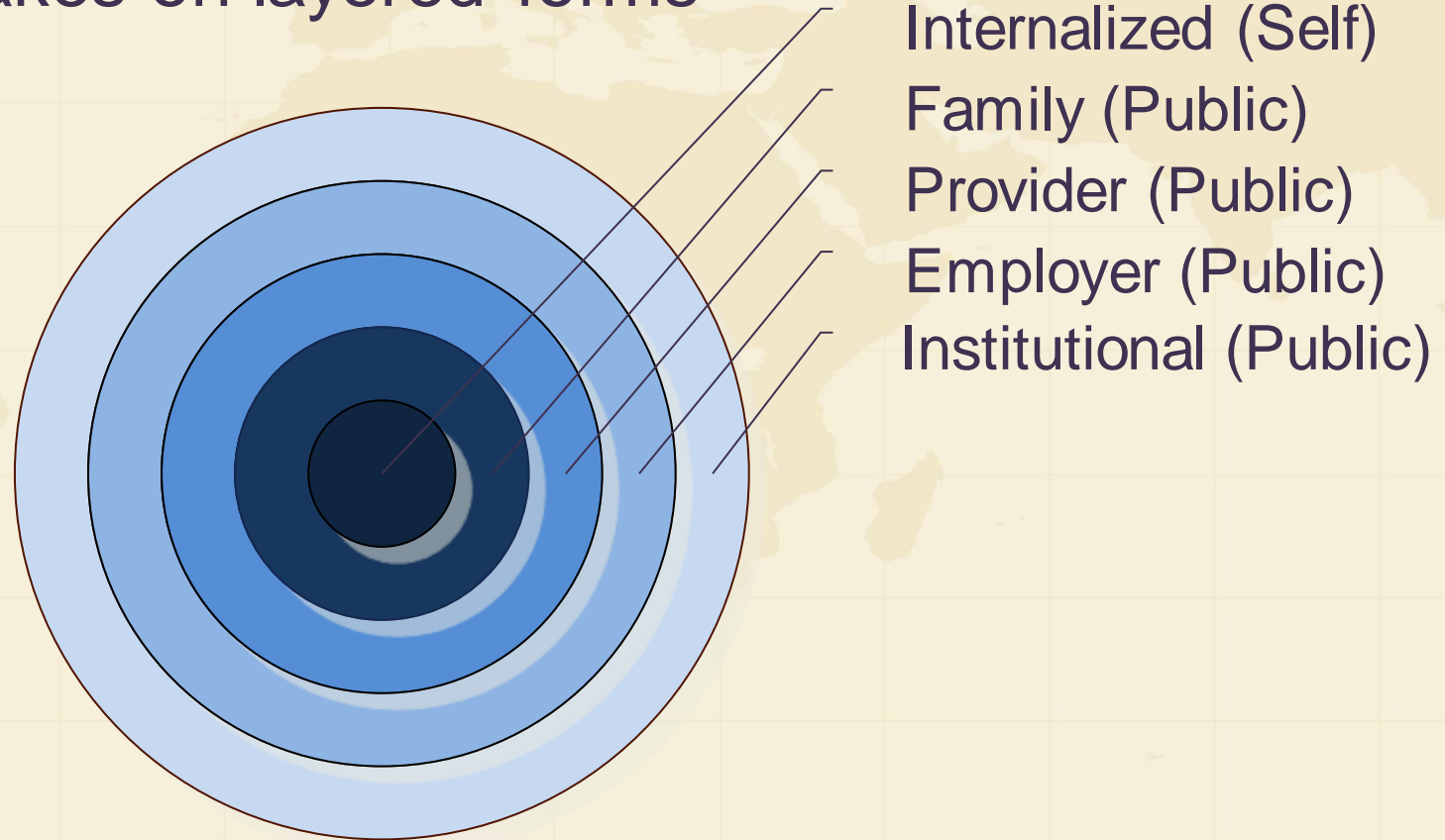
- A label given based on perceptions of behavior, associations, or the presence of an undesirable condition<sup>1</sup>
- An attitude with cognitive, affective, and behavioral forms<sup>2</sup>



1. National Minority AIDS Council; 2. Corrigan and Watson, 2002

# Ecological Framework

Stigma takes on layered forms<sup>1</sup>



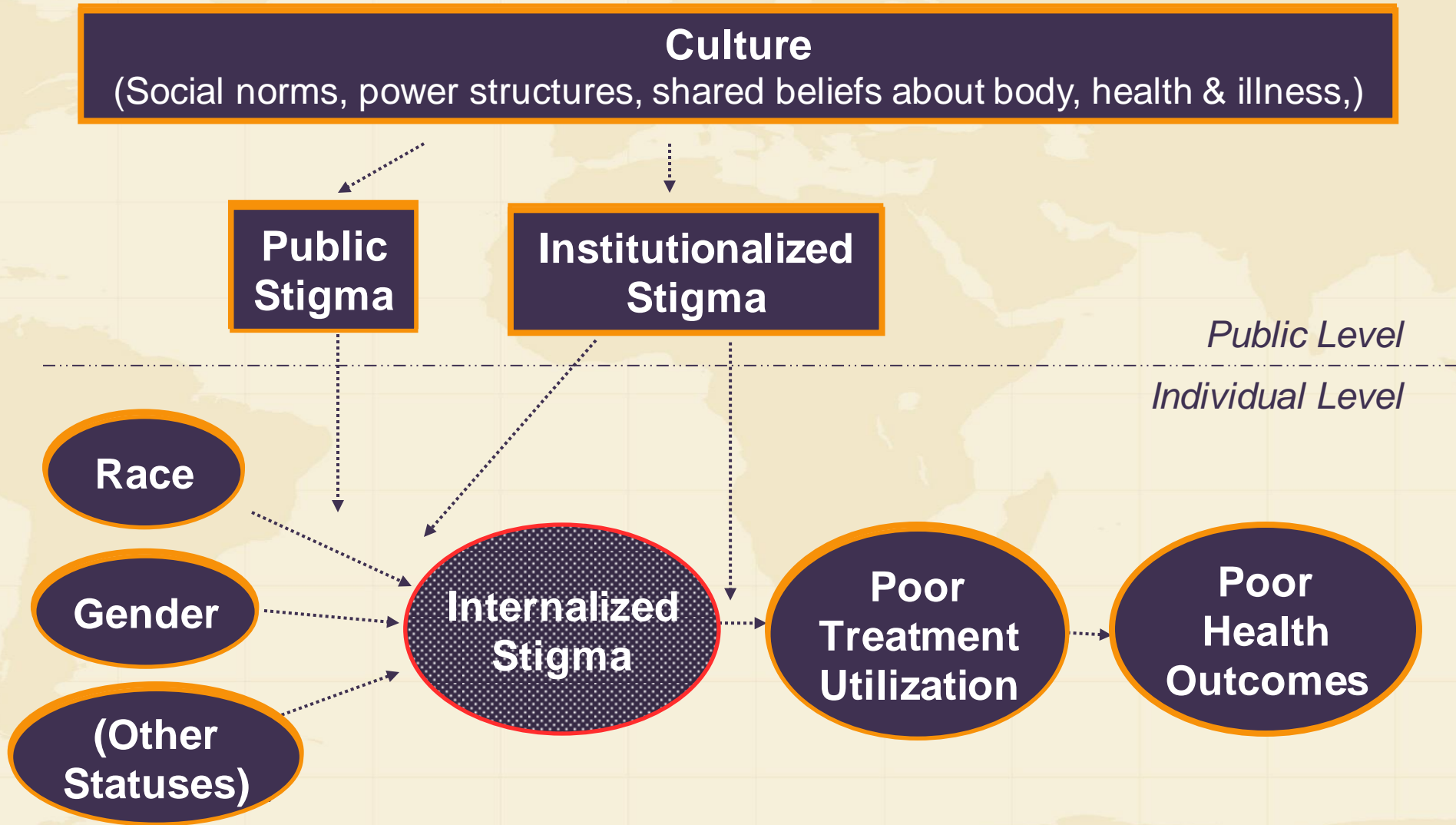
<sup>1</sup>Corrigan & Watson,  
2002

# Consequences of Stigma

- Isolation and loss of social support<sup>1</sup>
- Depression, other psychological distress<sup>2</sup>
- Poor quality of life<sup>3</sup>
- Poor medication adherence & service utilization<sup>4</sup> → morbidity & mortality

<sup>1</sup>Galvan et al, 2008; <sup>2</sup>Kang et al., 2005; <sup>3</sup>Buseh et al., 2008; <sup>4</sup>Rao et al., 2007

# Conceptual Model



<sup>1</sup>Rao et al., 2007 <sup>2</sup>Rao et al., 2011

# Measurement of Stigma

- Public Stigma
  - Corrigan's Attribution Questionnaire (AQ)<sup>1</sup>
    - vignettes
    - Fear, responsibility, pity
  - Link's adaptation of the Bogardus Social Distance Scale<sup>2</sup>
- Internalized/Self Stigma
  - Stigma Scale for Chronic Illness
    - experienced and internalized stigma
    - validated with persons with neurological disorders<sup>3</sup>
    - adapted for African Americans with HIV<sup>3</sup>

# Reducing Stigma

- Societal/structural level<sup>1,2</sup>
  - Removal of institutional stigmas (e.g. ADA)
  - Economic independence → microfinance programs
  - Community organizing
  - Contact between stigmatized and potential/actual perpetrators of stigma
- Individual level<sup>3,4</sup>
  - Education/Information
  - Coping Skills Acquisition
  - Contact with peers → Social Support

<sup>1</sup>Link & Phelan, 2001; <sup>2</sup>Sen, 1995; <sup>3</sup> Brown, Trujillo, Macintyre, 2001

# The Pilot

AIDS PATIENT CARE and STDs  
Volume 26, Number 10, 2012  
© Mary Ann Liebert, Inc.  
DOI: 10.1089/apc.2012.0106

ORIGINAL ARTICLE

## Feasibility, Acceptability, and Preliminary Efficacy of the Unity Workshop: An Internalized Stigma Reduction Intervention for African American Women Living with HIV

Deepa Rao, Ph.D., M.A.,<sup>1</sup> Michelle Desmond, M.S.W., M.P.H.,<sup>1</sup> Michele Andrasik, Ph.D.,<sup>2</sup>  
Tonya Rasberry,<sup>3</sup> Nina Lambert, B.S.N.,<sup>4</sup> Susan E. Cohn, M.D., M.P.H.,<sup>2</sup> and Jane Simoni, Ph.D.<sup>5</sup>



# HIV and African-American Women

- 66% of HIV infections in women (~1/4 of all infections), occur in African-American (AA) women<sup>1</sup>
- AIDS leading cause of death for AA women between the ages of 25-34<sup>2</sup>
- Death rate of AA women with HIV 15 times higher than HIV-infected white women<sup>1</sup>

<sup>1</sup>HPTN press release, March 8, 2012; <sup>2</sup>CDC,

# Stigma and Health Outcomes

- African Americans have lowest medication adherence rates compared with other US groups<sup>1</sup>
- Studies among African Americans living with HIV: reported efforts to avoid stigma resulted in poor adherence<sup>3</sup>

<sup>1</sup>Kahn et al, 2003 Halkitis et al, 2002; <sup>2</sup>Chesney et al, 2000; <sup>3</sup>Johnson et al, 2009

# Program Backdrop

- HIV Stigma Toolkit developed by the International Center for Research on Women (ICRW)<sup>1</sup>
  - Developed in Zambia
  - Facilitators trained globally
  - 40+ exercises
- Adapted exercises based on focus group discussions
- Developed trigger videos

<sup>1</sup>Kidd, Clay, Chiiya, 2007

# Focus Groups

- We conducted 8 focus groups
- 2 with men, 2 with women in Chicago
- 2 with men, 2 with women in Seattle
- Varying numbers of participants from 3 to 9 per group
- Provided feedback on existing interventions

# Focus Group Results

## Themes from women

- family and community support
- health care workers', friends', and family members' moral judgments
- trust within social networks
- misconceptions among members of Black communities, and
- multiple stigmas/racism, particularly within treatment settings

# Focus Group Results (continued)

## Themes from Men

- A preference for internet based program (more comfort with the anonymity)
- “Make sure you [note the importance of] incentives...We don’t want to go to workshops and all that stuff.”

# Intervention Format

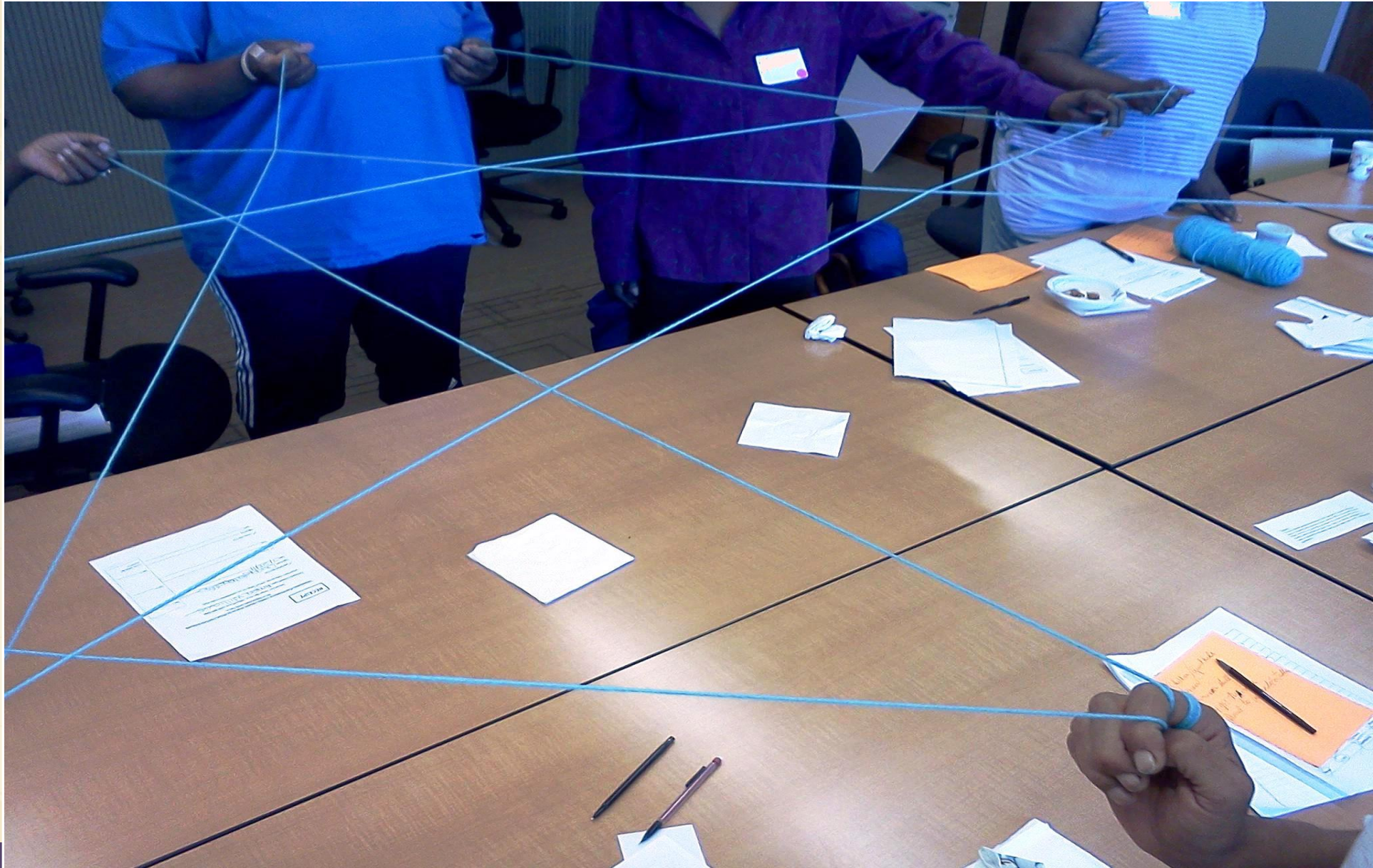
- Two afternoons, 4 hours each afternoon
- Workshops with
  - Video
  - Discussion in groups
  - Role play in pairs
- Peer facilitated

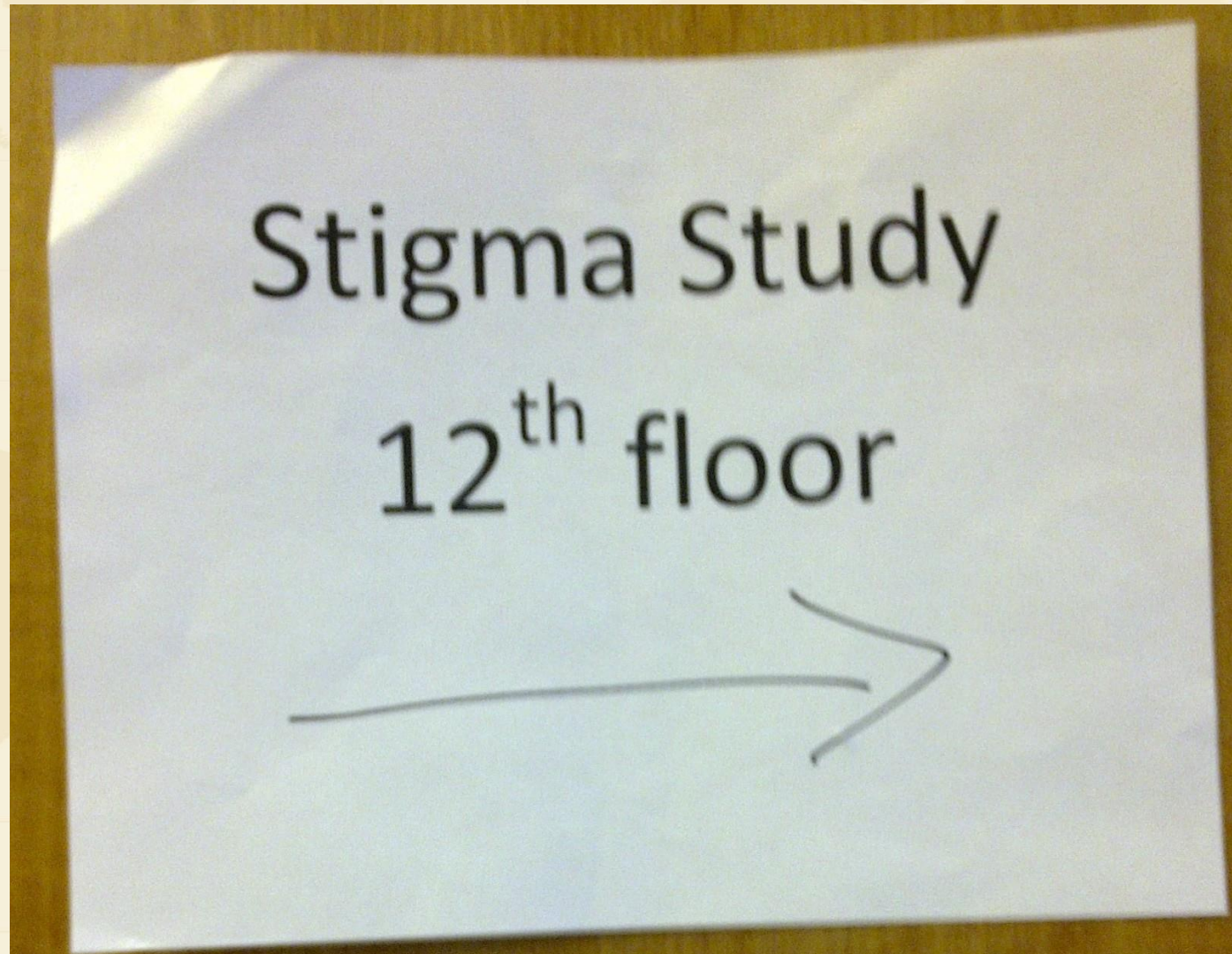
# Content Examples

- Group member expectations
  - Mutual respect
  - No right or wrong answers
- Experiences of stigma
- Sharing coping resources
- Seeking comfort; practicing relaxation
- Understanding assertiveness
- Role playing stigmatizing situations



# Web of String





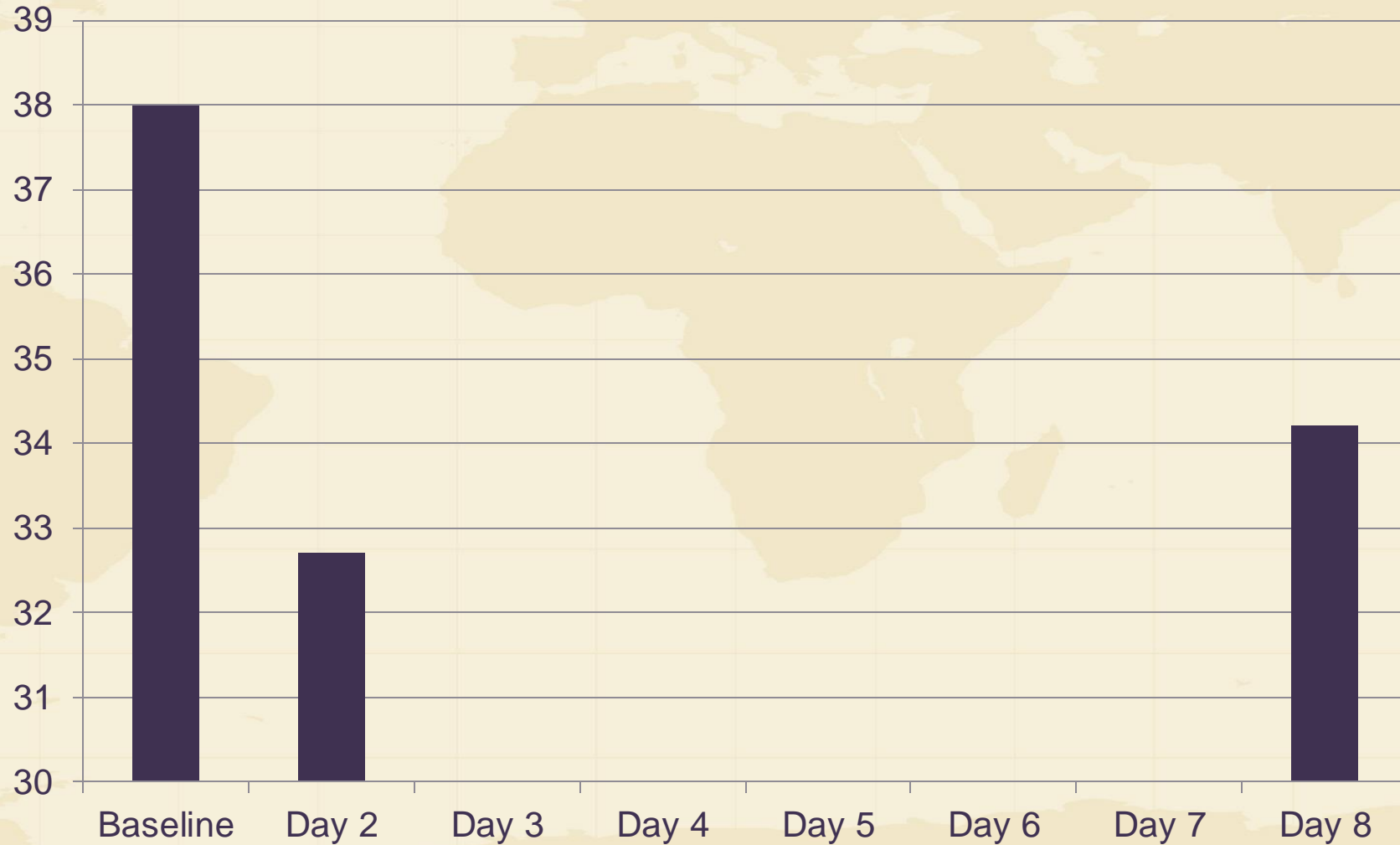
# Pilot: Methods

- Pre-test post-test design (no control)
- Paired t-tests
- Primary outcome: 14 items from the Stigma Scale for Chronic Illness, adapted for African-Americans living with HIV<sup>1</sup>

<sup>1</sup>Rao, Choi, et al., 2009; Rao, Molina, et al., under review

# Pilot Results (N = 24)

Average Stigma Scores



# The UNITY Health Study

EPIDEMIOLOGY

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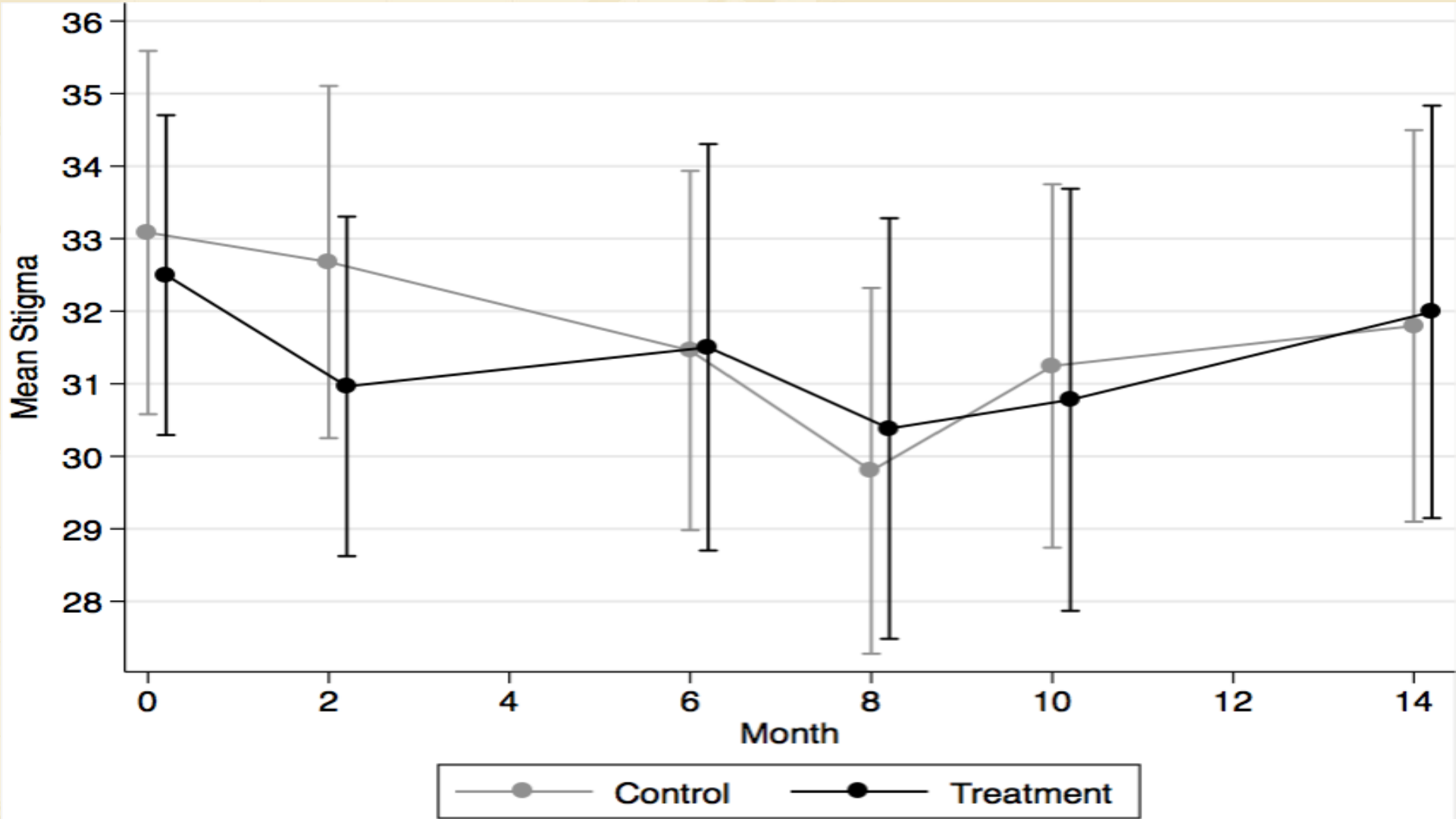
## Stigma Reduction Among African American Women With HIV: UNITY Health Study

*Deepa Rao, PhD, MA,\* Christopher G. Kemp, PhD, MPH,† David Huh, PhD,‡ Paul E. Nevin, MPH,†  
Janet Turan, PhD, MPH,§ Susan E. Cohn, MD, MPH,|| Jane M. Simoni, PhD,¶ Michele Andrasik, PhD,\*\*  
Yamile Molina, PhD,†† Michael J. Mugavero, MD,‡‡ and Audrey L. French, MD§§*

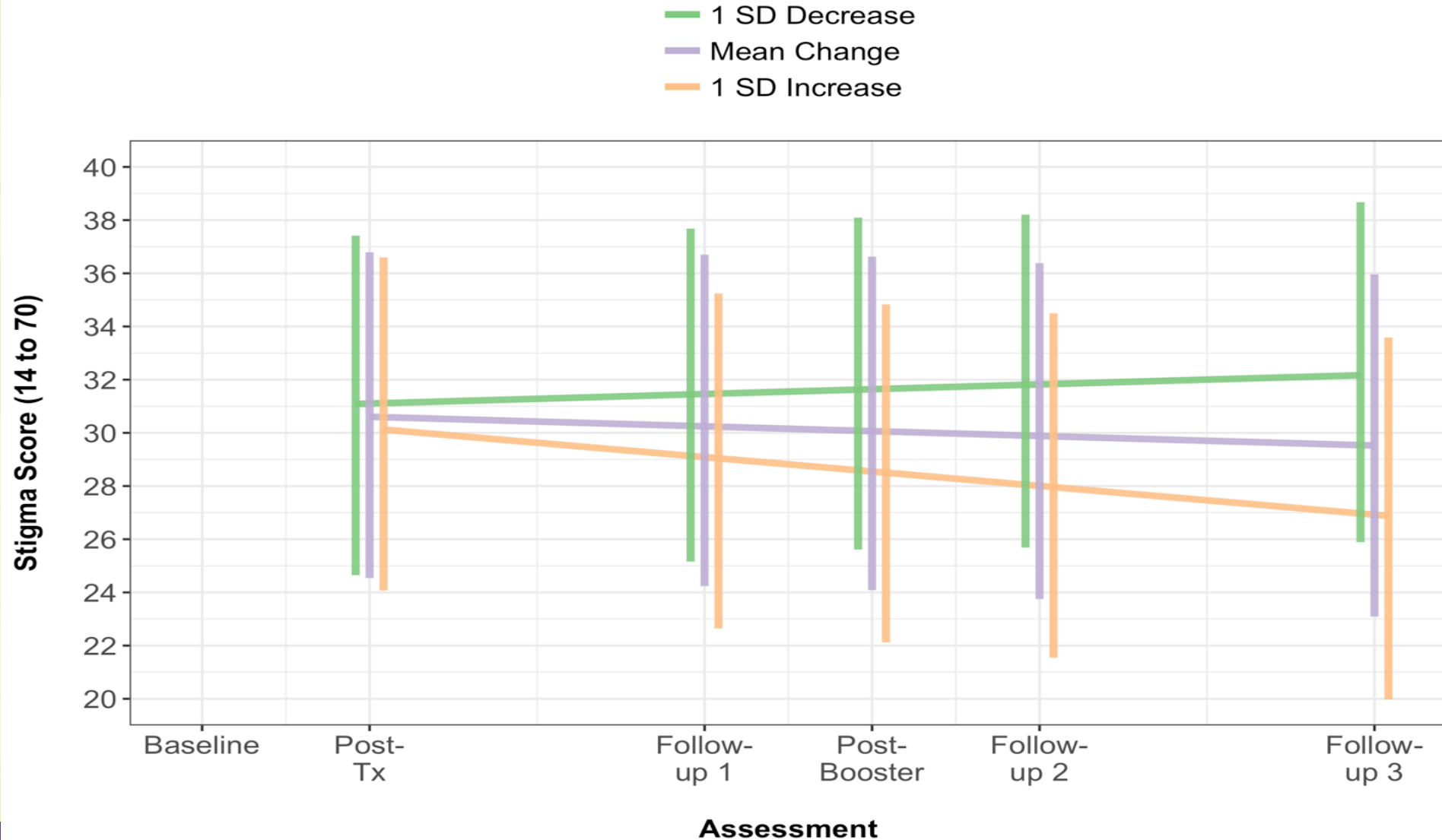
# Methods

- **Setting**
  - Chicago (Private & Public Hospital Clinic)
  - Birmingham (University Hospital Clinic)
- **Randomized Controlled Trial Design**
  - UNITY workshop vs. Breast Health workshop
  - Mixed Effects Regression
  - Data collected May 2013 to December 2016
- **Participants**
  - African American women over the age of 18
- **Self-reported data**
  - Primary Outcome → 14-Item Stigma Scale for Chronic Illness (SSCI)
  - Baseline, post-intervention, 6, 8, 10, and 14 months

# Results: N = 239



# Post-hoc Analysis: Social Support





# Discussion

- Some reduction in stigma scores for both groups
- UNITY and Breast Cancer awareness shared active ingredients (contact)
- A key mechanisms may be social support
- Future studies: use waitlist or other non-comparison arms for control

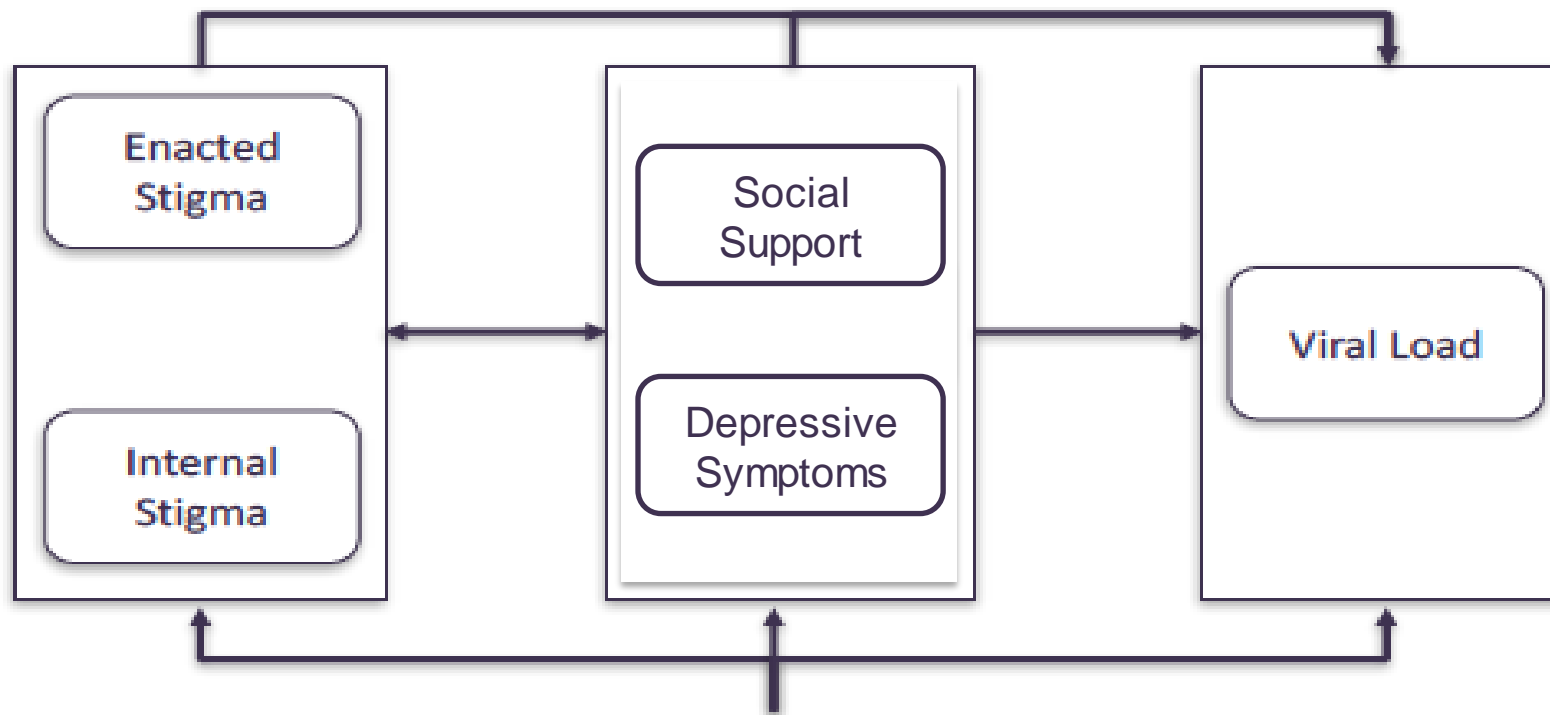
Stigma, Social Support, and Viral Load  
among African American Women Living  
with HIV:  
An Exploratory Longitudinal Mediation  
Analysis

Christopher G. Kemp, Jane M. Simoni, Janet  
Turan, Susan E. Cohn, Paul E. Nevin, Lauren  
Lipira, David Huh, Miesoak Bahk, Baiba  
Berzins, Deepa Rao

# Study Objectives

- Assess the relationship between multi-dimensional HIV stigma and viral load in this population
- Explore social support and depressive symptoms as potential mediators of this relationship

# Conceptual Model



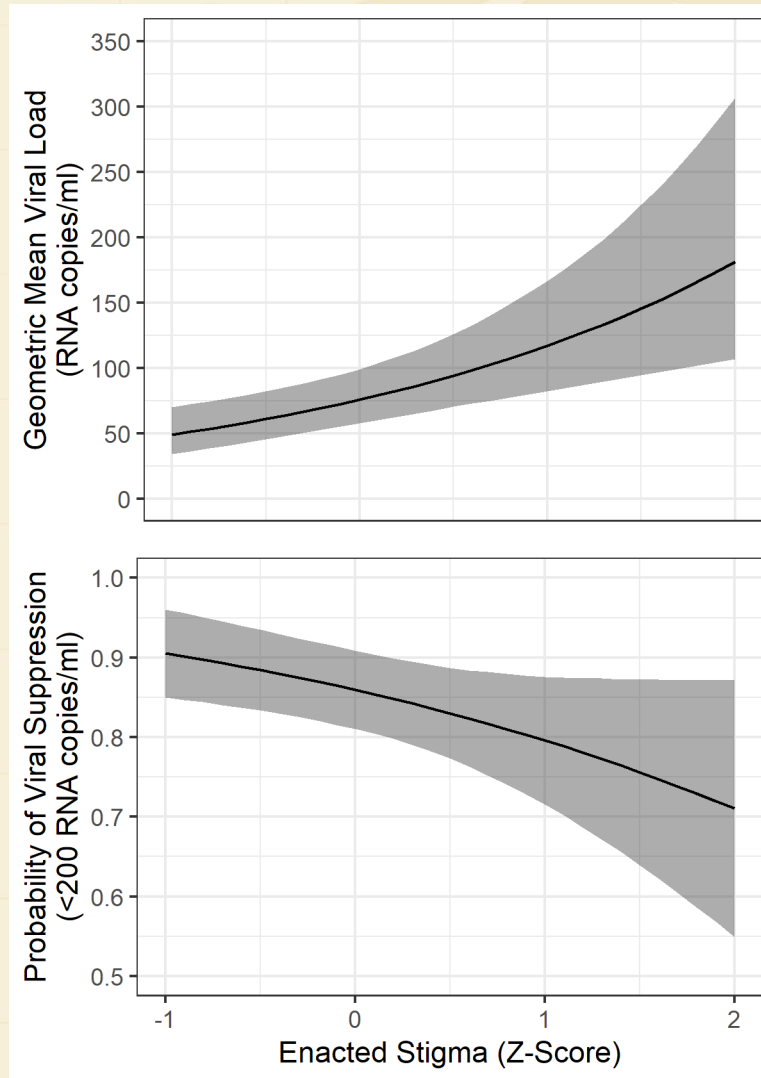
Confounders: age, years with HIV, education, occupation, marital status, children, location

# Measures

- **Outcomes**
  - Log of mean viral load
  - Durable viral suppression (<200 copies/ml)
- **Predictors**
  - HIV-related stigma; 14-item Stigma Scale for Chronic Illness (SSCI)
- **Mediators**
  - Social support; MOS-SSS
  - Depressive symptoms; PHQ-8
- **Other covariates**
  - Age, education, occupation, marital status, children, site, years with HIV
  - Treatment, time, and treatment\*time interaction

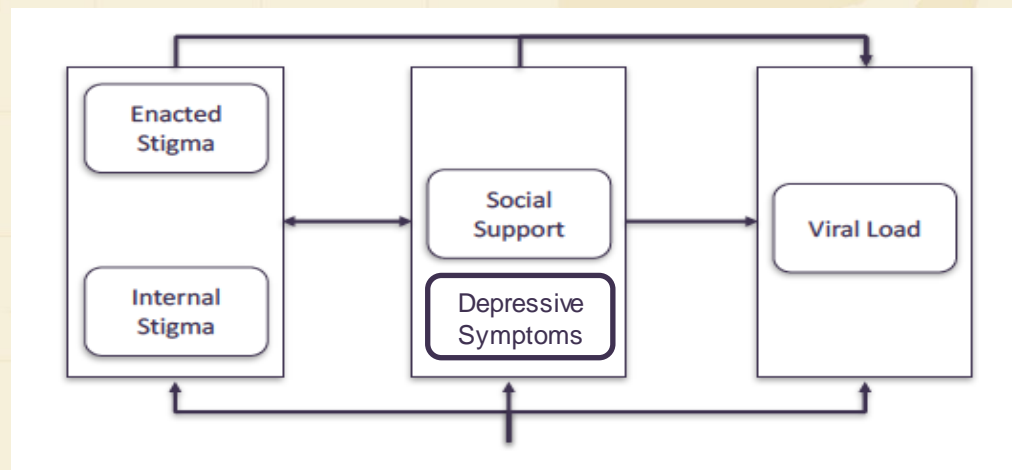
# Analysis

- **Descriptive statistics**
  - Mean, median, inter-quartile range, t-test, chi-square tests
- **Inferential statistics**
  - Multiple imputation
  - Normalized predictors
  - Longitudinal mixed-effect models
    - Subject-specific random intercept
    - Unadjusted and adjusted models
    - Mundlak (within-between) correction
  - Counterfactual simulations
  - Longitudinal causal mediation analysis



## Longitudinal Causal Mediation

	Social Support			Depressive Symptoms		
	$\beta$	95% CI	p	$\beta$	95% CI	p
Overall HIV Stigma → Mediator	-0.32	-0.39, -0.25	<0.001	0.50	0.43, 0.55	<0.001
Mediator → Log Mean Viral Load	-0.14	-0.29, 0.01	0.076	0.00	-0.17, 0.17	1.000
Average causal mediation effect	0.09	-0.02, 0.20	0.111	0.00	-0.19, 0.19	0.998
Direct effect	0.40	-0.01, 0.81	0.059	0.48	0.03, 0.93	0.036
Total effect	0.49	0.07, 0.90	0.022	0.48	0.07, 0.89	0.021
% Mediated	18%	-67%, 104%	0.675	0%	-82%, 82%	0.996





# Discussion

- HIV stigma is common in this sample of African American women receiving treatment for HIV
- Enacted stigma appears to be closely tied to viral load
- Social support and depressive symptoms do not appear to mediate the relationship between HIV stigma and viral load in this population.

# Implications

- HIV stigma may predict viral load outcomes
- Ongoing experiences of stigma may hinder the transition to viral suppression
- Interventions should aim to mitigate the sources of HIV stigma, in addition to internalized HIV stigma

# Future Directions

- COMPASS/Southern Coalition/Duke University
- Stigma Reduction for African American Men and Women in the Deep South
- Gilead Foundation \$100 million over 10 years
  - Community Based Organization Capacity Building
  - Anti-Stigma Campaigns
  - Trauma Informed Care



The South accounts for 49% of all deaths of people diagnosed with HIV in the U.S.

[View source](#)



In the South, black women accounted for 71% of women with diagnosed HIV

[View source](#)

<https://www.gilead.com/purpose/partnerships-and-community/compass>

# Thank You

## **Our Participants**

### **National Institutes of Health**

- Cynthia Grossman
- Greg Greenwood

### **University of Washington**

- Christopher Kemp
- David Huh
- Meheret Endeshaw
- Paul Nevin
- Sarah Frey
- Jane Simoni
- Michele Andrasik
- Lauren Lipira
- Erick Seelbach

### **University of Alabama**

- Michael Mugavero
- Janet Turan
- Stephanie Gaskin

### **Northwestern University**

- Susan Cohn
- Baiba Berzins
- Nina Lambert

### **Stroger Hospital of Cook County**

- Audrey French
- Sandra Micci

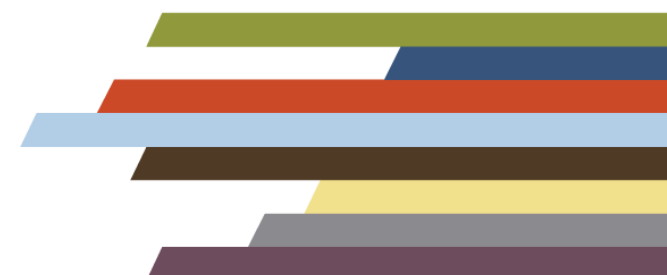
### **University of Illinois at Chicago**

- Yamile Molina



# Additional Training Opportunities

- Behavioral Health Crisis Response Systems Live Webinar Series
  - March 30 with Dr. Ken Minkoff - “Designing and Implementing Ideal Behavioral Health Crisis Systems”
  - April 15 with Dr. Michael Flaum - “Implementing New Crisis Services: The View from the Ground Up”
- eCourse: The Psychiatrist’s Guide to Population Management of Diabetes



# Get in Touch!



**Visit us online:**

[www.mhttcnetwork.org/northwest](http://www.mhttcnetwork.org/northwest)



**Follow us on social media:**

[@NorthwestMHTTC](https://twitter.com/NorthwestMHTTC)

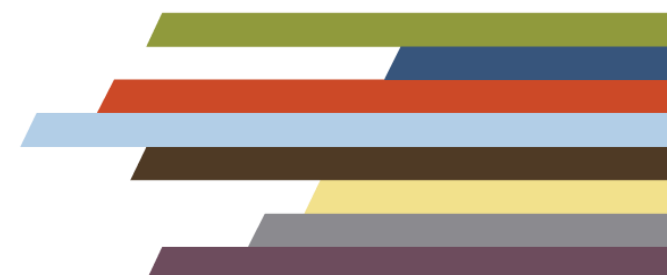


**Email us:**

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- Upcoming trainings
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