

ADAPTING MINDFULNESS- BASED INTERVENTIONS FOR RACIAL/ETHNIC MINORITY POPULATIONS



PRESENTERS

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Theoretical & Empirical

Considerations for Adapting MBLs



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*Adapting UPLIFT for African American
Patients with Epilepsy*



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*Adapting UPLIFT for Hispanic Patients
with Epilepsy*



MINDFULNESS

“Paying attention in a particular way; on purpose, in the present moment, and non judgmentally.”

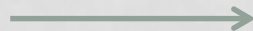
MINDFULNESS

Awareness of present moment
experiences.

Thoughts
Feelings
Sensations

MINDFULNESS-BASED INTERVENTIONS (MBIS)

- Mindfulness-based stress reduction (MBSR)
- Mindfulness-based cognitive therapy (MBCT)
- Acceptance and commitment therapy (ACT)
- Dialectical behavior therapy (DBT)



PARTICIPANTS IN MBI STUDIES

- Across **15** formative clinical trials of MBIs, **White participants comprised 86% of the participant samples.** Seven studies did not report any data on race/ethnicity.

IMPORTANCE OF EVIDENCE

- Need to know if evidenced-based interventions (EBIs) are effective given growing diversification of U.S. population.
- “Disseminating ineffective non-culturally appropriate interventions is not an effective use of resources and may widen the gap in mental health disparities.”

WHY MINDFULNESS-BASED INTERVENTIONS (MBIS)?

- Demonstrated efficacy
- Traditional treatments may have limited cultural congruency
- MBIs aim to validate experiences of oppression, while also promoting action and self-advocacy
- Clinical need

SHOULD MBI'S BE CULTURALLY ADAPTED?

The cultural adaptation of an original EBI is justified under one of five conditions:

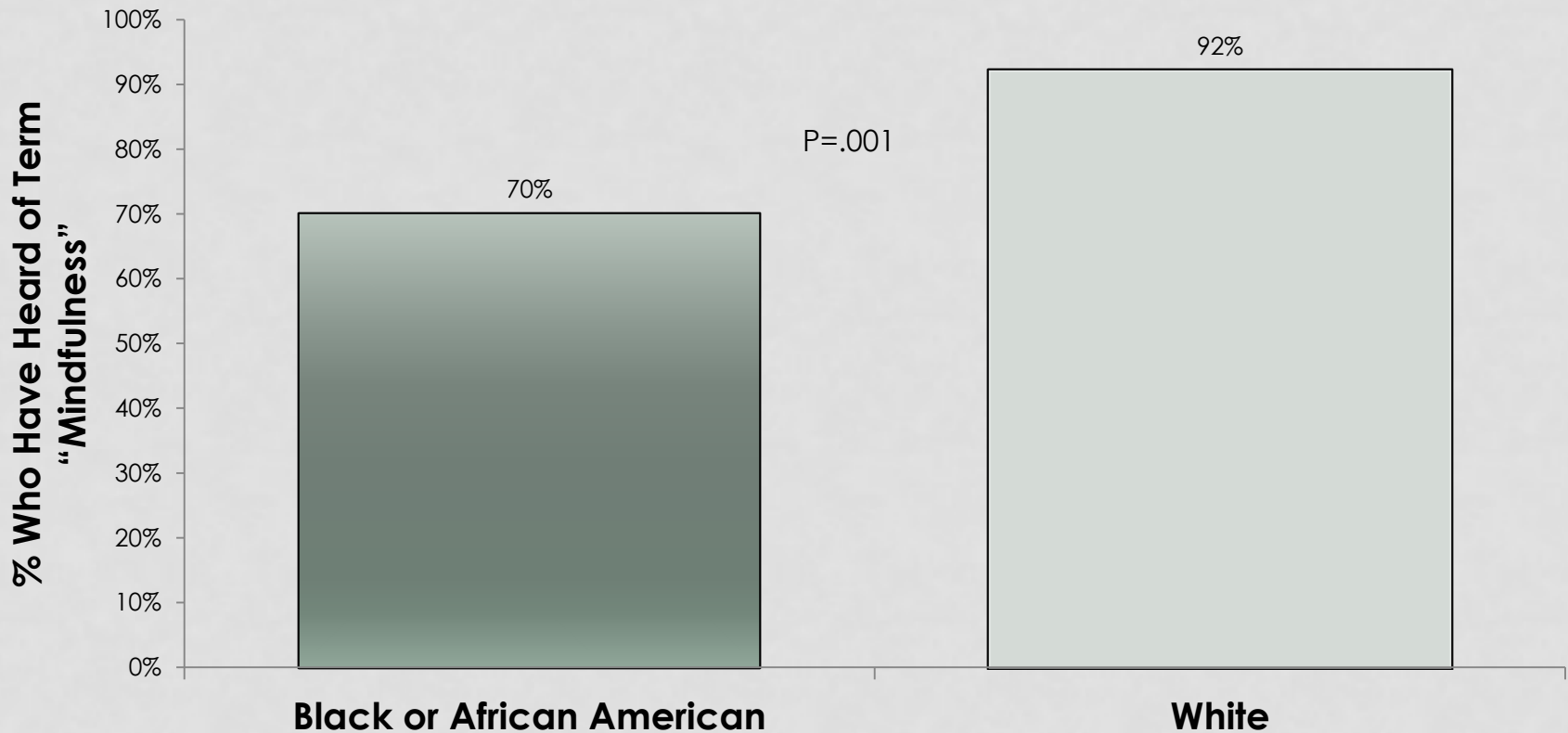
- (1) ineffective clinical engagement
- (2) unique risk or resilience factors
- (3) unique symptoms of a common disorder
- (4) nonsignificant intervention efficacy for a particular subcultural group
- (5) cultural relevance is lacking

PILOT STUDY

- 140 White & Black Participants (n=70 in each group)
- Recruited across the U.S. using web-based survey
- Assessments
 - Depression
 - Perceived stress
 - Emotion regulation/coping
 - Psychological risk factors for depression (e.g., rumination)
 - Experience with mindfulness
 - Cultural relevance of MBIs

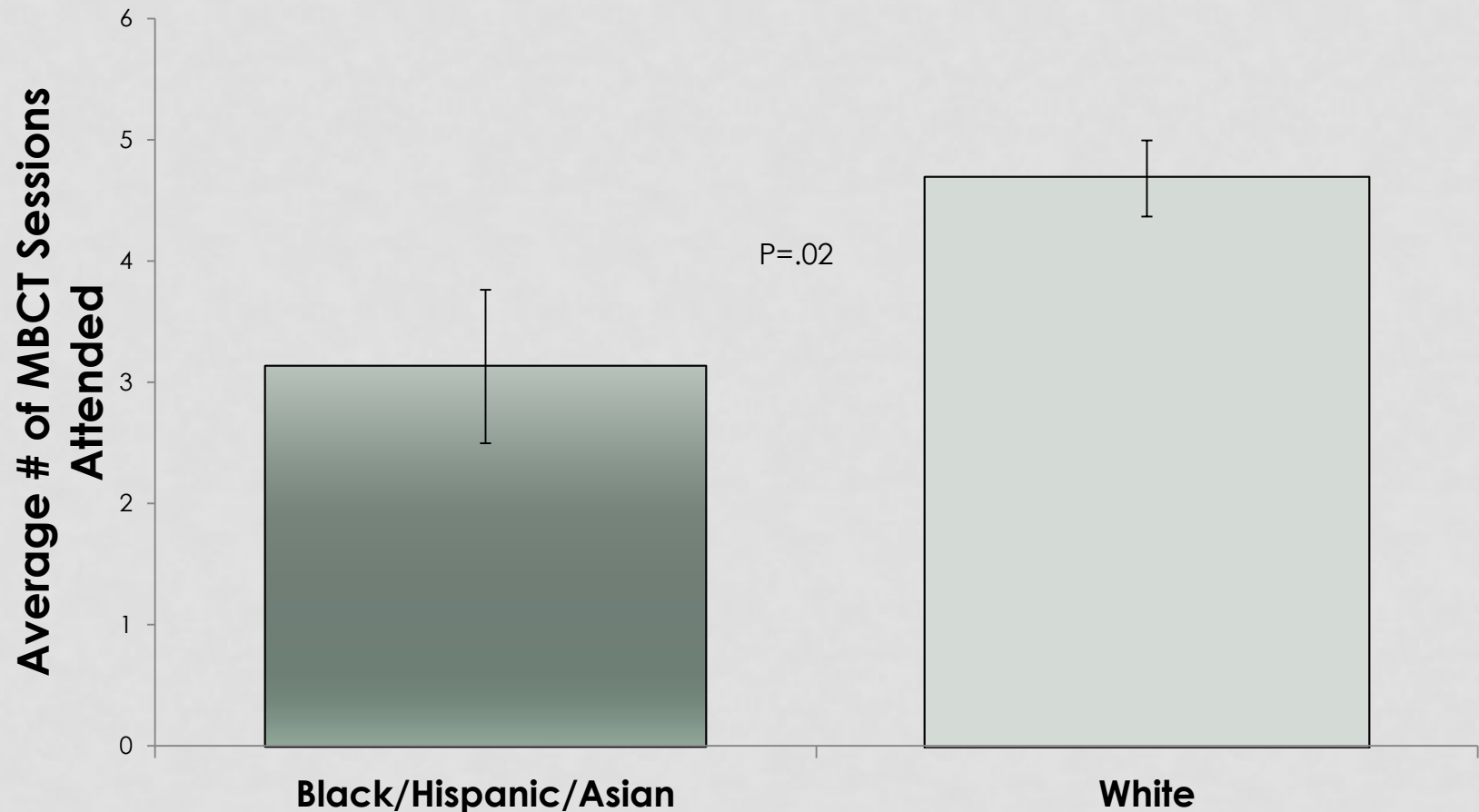
INEFFECTIVE CLINICAL ENGAGEMENT

- Awareness of treatment availability



INEFFECTIVE CLINICAL ENGAGEMENT

- Participation in treatment activities

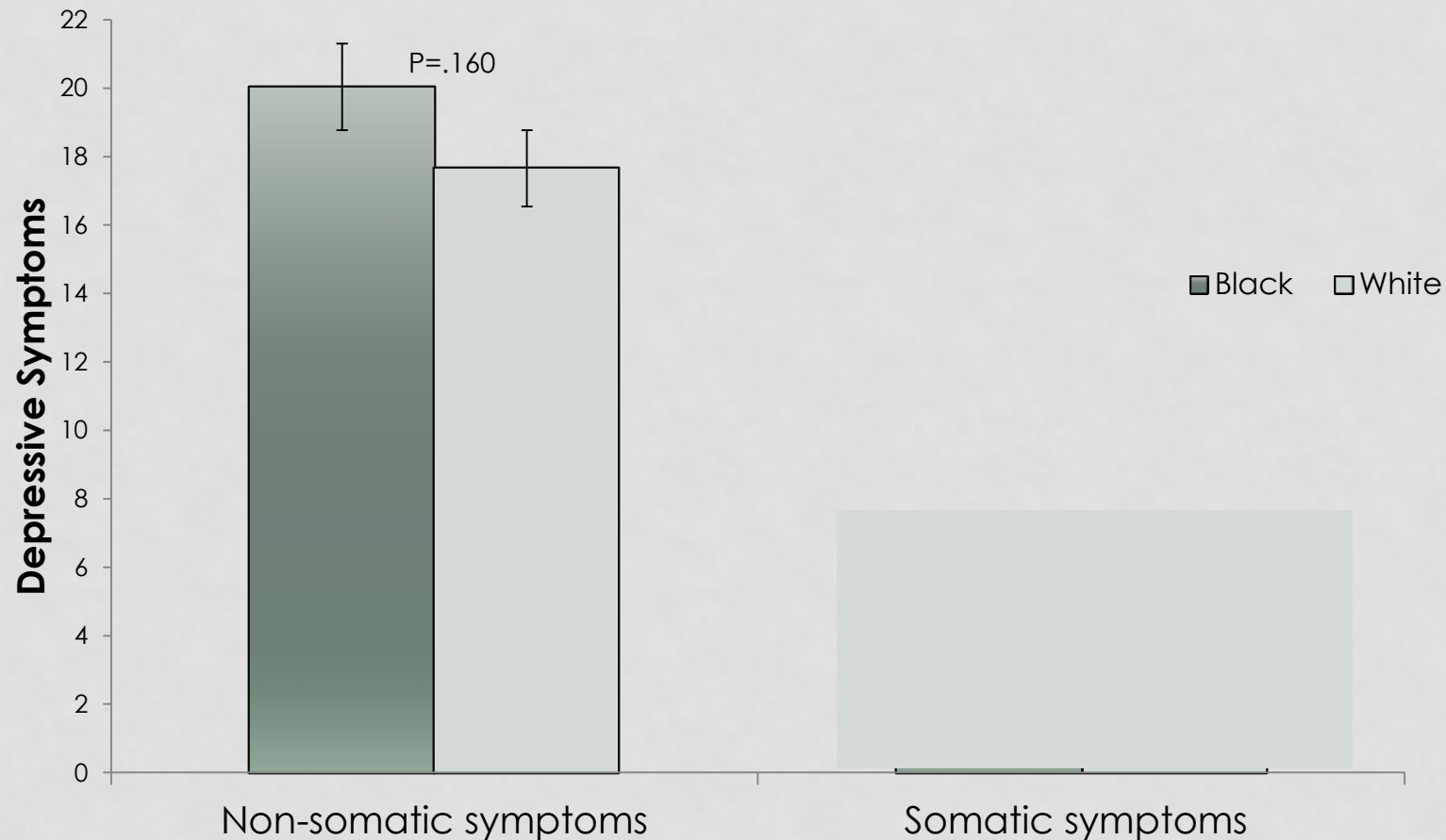


UNIQUE RISK OR RESILIENCE FACTORS

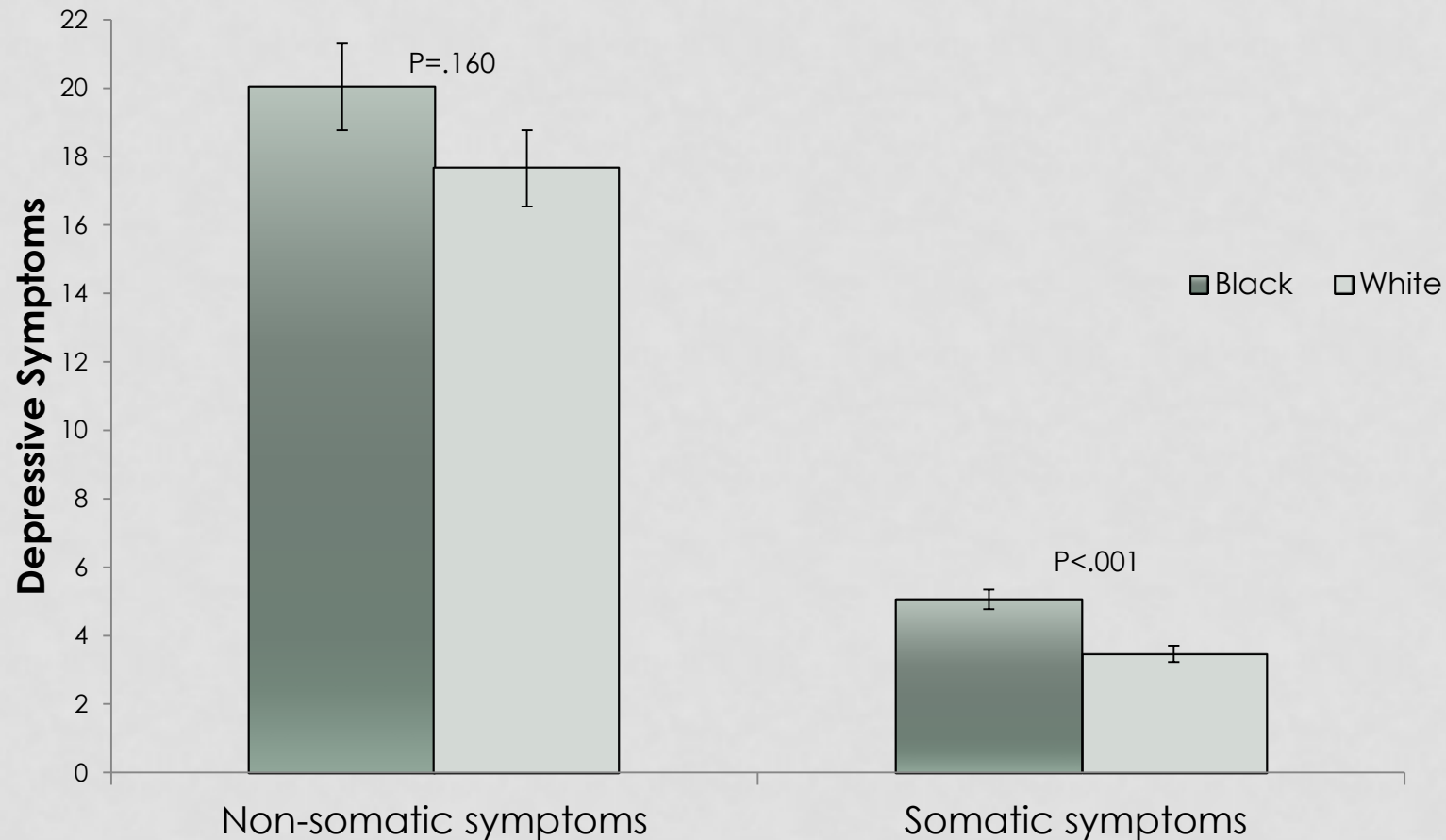
Risk Factors for Depression

Risk/Resilience Factors	Black/African American	White	P-value
Discrimination, M (SD)	18.2 (11.0)	14.0 (7.5)	.008
Suppression, M (SD)	4.3 (1.3)	3.6 (1.3)	.005
Rumination, M (SD)	53.8 (12.6)	47.8 (11.3)	.004
Depression Stigma, M (SD)	44.5 (12.1)	8.5 (4.9)	.006

UNIQUE SYMPTOMS OF A COMMON DISORDER



UNIQUE SYMPTOMS OF A COMMON DISORDER

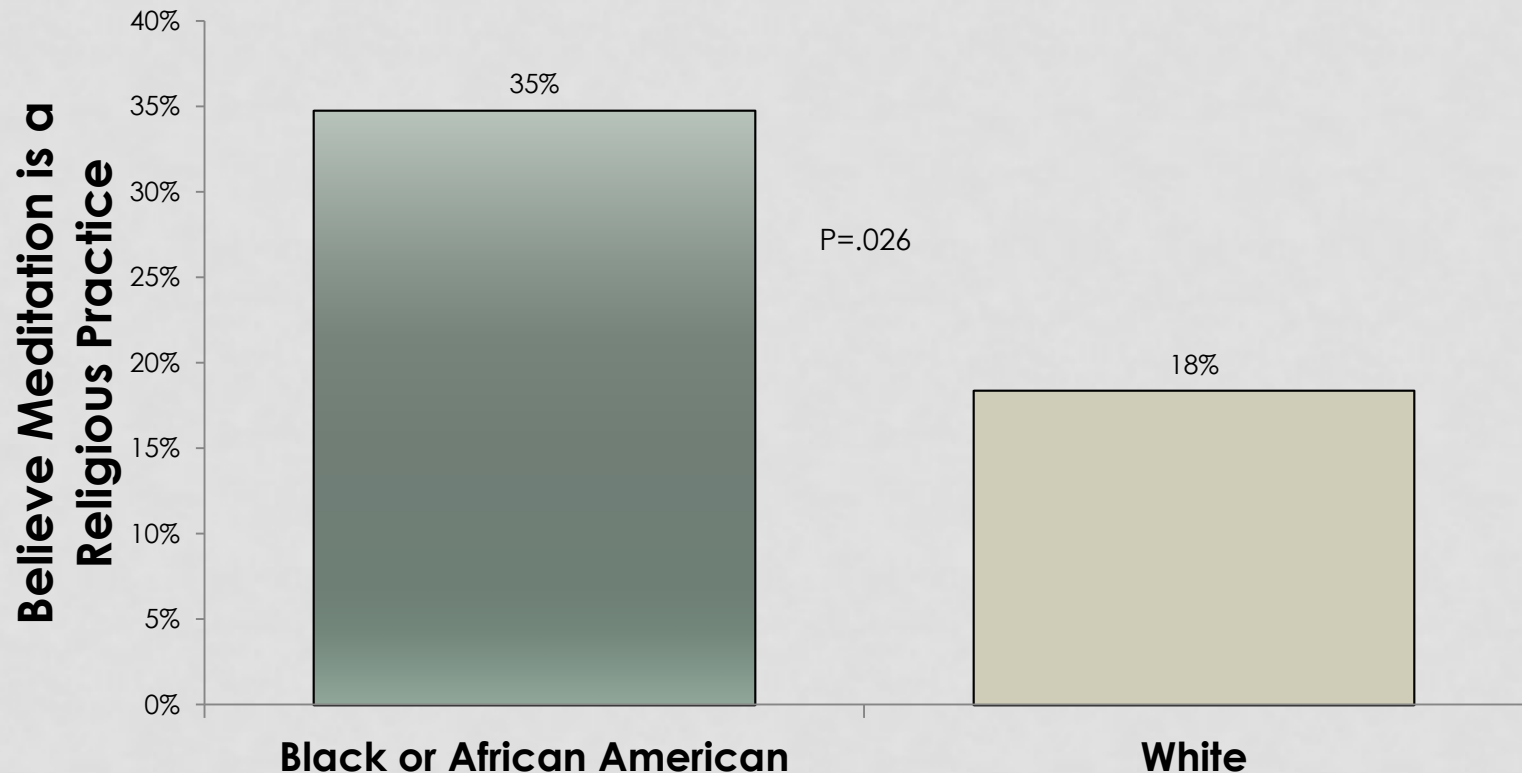


NONSIGNIFICANT INTERVENTION EFFICACY

- 4 RCTs of MBIs in predominately racial/ethnic minority samples.
- Only 1 study tested a culturally tailored intervention; effect size was twice as large as other studies.
- Median number of participants in each study (n=28).

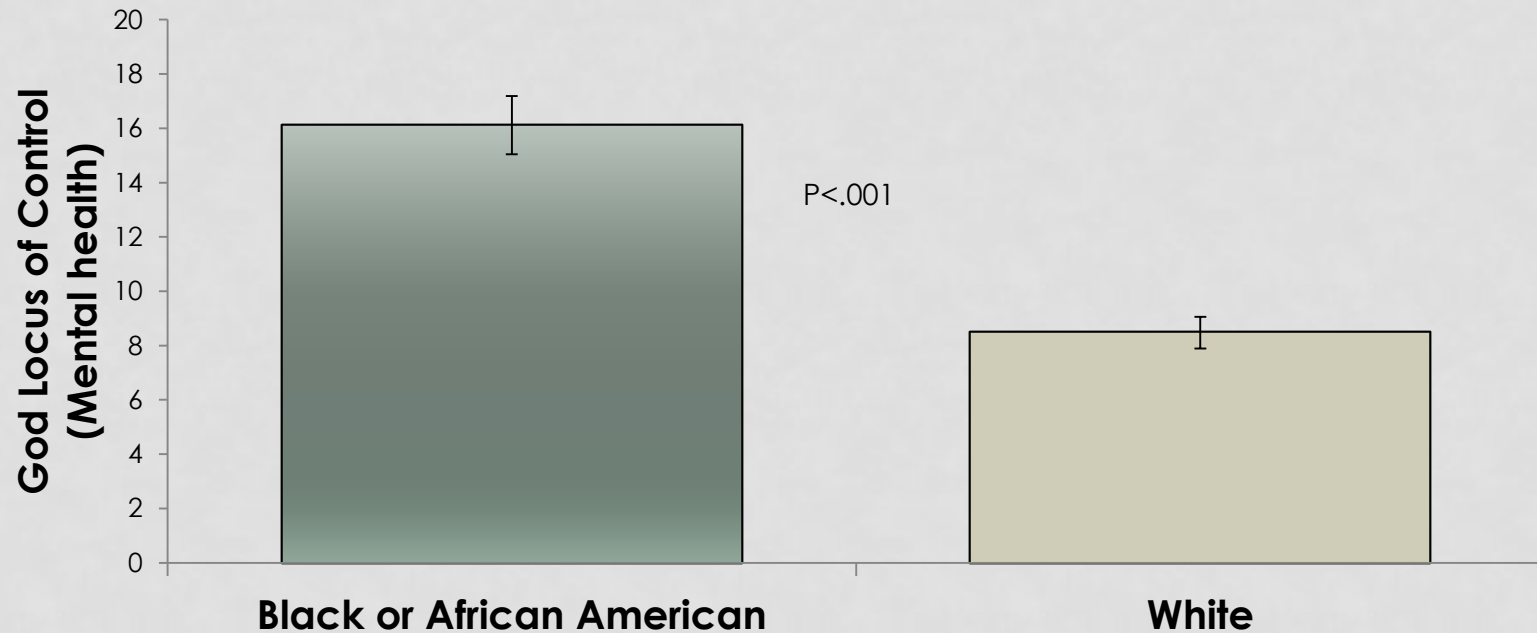
CULTURAL RELEVANCE

- Match intervention to values, beliefs, preferences



CULTURAL RELEVANCE

- Match intervention to values, beliefs, preferences



“God, the sacred, or a higher power is in control of my mental well-being.”

SUMMARY

MBIs have potential to target specific risk/resilience factors relevant to racial/ethnic minority populations.

Some empirical support for adapting MBIs:

- (1) ineffective clinical engagement
- (2) unique risk or resilience factors
- (3) unique symptoms of a common disorder
- (4) nonsignificant intervention efficacy for a particular subcultural group
- (5) cultural relevance

OPEN QUESTIONS

- What level of adaptation is needed?
 - Structural (e.g., language) vs. deeper level (e.g., content)
- Cross-cultural adaptations?
 - Targeted changes that cut across features common to multiple subgroups (e.g., stigma)

ACKNOWLEDGMENTS

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- Azizi Seixas, PhD
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Adaptation of UPLIFT for African Americans with Epilepsy

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MOREHOUSE SCHOOL OF MEDICINE

ATLANTA, GA



Background

- What is epilepsy?

- A brain disorder characterized by two or more seizures

- Epilepsy Statistics

- 4th most common neurological condition
 - 4.3 million diagnosed in U.S.
 - 1 in 26 people will develop epilepsy in U.S.
 - \$15.5 billion in annual medical care and reduced or lost productivity and earnings

	Blacks	Hispanics	Whites
Active Epilepsy	5.2/1,000	6.3/1,000	5.9/1,000
Lifetime Prevalence	7.5/1,000	7.5/1,000	5.9/1,000

- Rates of depression: 30-55%

Using Practice and Learning to Increase Favorable Thoughts



Project UPLIFT



- Developed by Nancy Thompson, PhD
- Delivery of MBCT by Telephone in Groups & on Web
 - To people with epilepsy for depression
 - Randomly assigned to groups of 6
 - Groups used for support surrounding Epilepsy
- 8 Sessions
- Facilitators
 - Peers and Graduate Students
 - Co-facilitated by a person with epilepsy
 - Supervised by a licensed psychologist



8 Sessions

Session #	Topic
1	Monitoring Thoughts
2	Checking and Changing Thoughts
3	Coping and Relaxing
4	Attention and Mindfulness
5	The Present as a Calm Place
6	Thoughts as Changeable and Impermanent
7	Pleasure and Reinforcement
8	Relapse Action Plans

UPLIFT Outcomes



- Both Treatment and Prevention UPLIFT Effective in:
 - Reducing depressive symptoms
 - Intervention group showed significant improvement compared to the waitlist
 - Both phone and web were significantly more effective in reducing depression than waitlist condition
 - Reduction in depressive symptoms maintained
 - Teaching knowledge and skills associated with reducing depression
- Prevention UPLIFT Effective in
 - Reducing incidence of MDD
 - Reducing reported seizures (and severity?)
 - Increasing satisfaction with life

Project Aims

1. Explore the knowledge and perceptions of African Americans with epilepsy, and their caregivers
2. Evaluate the cultural appropriateness of Project UPLIFT for African Americans
3. Evaluate the efficacy of UPLIFT for reducing symptoms of anxiety, depression, and PTSD among African Americans with epilepsy

Project Activities

1. Form Epilepsy Community Advisory Board
2. Conduct interviews with healthcare providers
3. Conduct focus groups with African Americans with epilepsy
4. Conduct focus groups with caregivers of African Americans with epilepsy

Epilepsy Community Advisory Board (E-CAB)



Epilepsy Community Advisory Board

■ Membership:

- Persons with Epilepsy (3)
- Main Support Persons (1)
- Healthcare Providers (2)
- Community Advocates (1)

■ Lessons Learned

- Language modification
 - Caregiver vs. Support person
- Recruitment
- Introduction to research needed

Healthcare Provider Interviews



Methodology



■ Inclusion criteria:

- Treat patients living in Georgia
- At least 5% of epilepsy patients are African American

■ Study Sample

- **Chiropractor**
- **Nurse Practitioner**
- **Psychologist**
- **Neurologist**
- **Epileptologist**

■ Time Period

- May – September 2015

■ Methods

- 1-hour semi-structured interview
- 5 subject areas (not including demographics), with 23 questions overall

Summary of Key Findings

1. Different ways depression and psychosocial concerns can present in African Americans
2. More barriers and challenges when accessing quality care and accurate information
3. Gender-based differences
4. Strong informal support systems but support persons need help also

Focus Groups

Persons With Epilepsy



Methodology



■ Inclusion criteria:

- Self identify as Black or African American
- Diagnosed with epilepsy
 - >3 months
- 18 years +

■ 4 Focus Groups

- In person (1)
- Conference call (3)

■ N=22

■ Time

- May – November 2015

■ Methods

- 2-hour focus group discussion
- Survey (demographics)

Results

1. Lack of **control**

“...It’s pretty much the unpredictably of the whole situation and being that you have family, you have a fear of not really being there for them”

2. Misinformation/Lack of knowledge resulting in **stigma**

“I’m oftentimes having to explain to people that it’s not a disease. It’s a disorder. You know you’re not going to catch it. People are even still saying it’s a demon. I mean there’s a whole lot of ignorance and just lack of education around the disorder. “

Results

3. Disclosure of condition

“My main place that I hide it at is on my job—my supervisor is aware that I have them but the other coworkers, I don’t let them know because I don’t want them surrounding me as if I’m incapable of taking care of my duties at my job.”

4. The experience of **depression** and other psychosocial concerns

“...I feel like just the frustration of just the day-to-day living, not knowing what’s going to happen is pretty like depressing. It takes effort to keep yourself uplifted and remaining positive because it’s real easy to get down on yourself.”

“....You weren’t in a depression. You were [just] in a little funk. That’s all.”

UPLIFT Results



■ UPLIFT in general:

I think all of these are nice little anecdotes just to help you become more relaxed so you can control your thinking. This is not the first time I've heard of any of these things, and I never thought of them as ways to help my epilepsy. I just thought of them as ways to help me as a person, to help me be a better person, you know the exercises like this. So, I can't see how it could hurt if I tried to relate it to the epilepsy.

UPLIFT Results



- Relaxing muscles in order exercise:

I personally think that's a good technique just because one thing I do notice about myself is that I'm tense but it's kind of like I'm not aware that I'm tense..... So, I think being aware could be useful because I think sometimes that tenseness can kind of lead to you feeling kind of stress and then the stress leads to you feeling like you're going to have a seizure.

Focus Groups

Main Support Person (MSP)



Support Person Findings

1. Perceived general lack of knowledge in the community about epilepsy
2. Desire for more educational and support resources related to epilepsy
3. Unpredictable nature of having seizures and related limitations present concerns
4. African Americans may express depression and psychosocial concerns differently from other groups

Overall Key Findings

- Community advisory boards can be very helpful for tailoring interventions and recruitment
- African Americans may express depression and psychosocial concerns differently from other groups
- Feedback on UPLIFT was favorable and indicated it's cultural appropriateness and acceptability
- Dissemination should be a priority for African Americans living with epilepsy and their support persons

Next Steps...

- Pilot UPLIFT
 - as originally designed
- Evaluate Efficacy of UPLIFT in African Americans
 - Conduct UPLIFT RCT (N=60)
- Future directions...
 - UPLIFT for support persons



Acknowledgments

Study Participants

E-CAB Members

MSM Epilepsy Study Team

April Nellum

Elizabeth Olorundare

Candace McCloud

Contessa Davis

Emory Epilepsy Study Team

Dr. Nancy Thompson

Dr. Cam Escoffery

Josalin Hunter-Jones

Matthew McCurdy

Robin McGee

Misha Sharp



Adapting UPLIFT for Hispanic Adults with Epilepsy and Depression

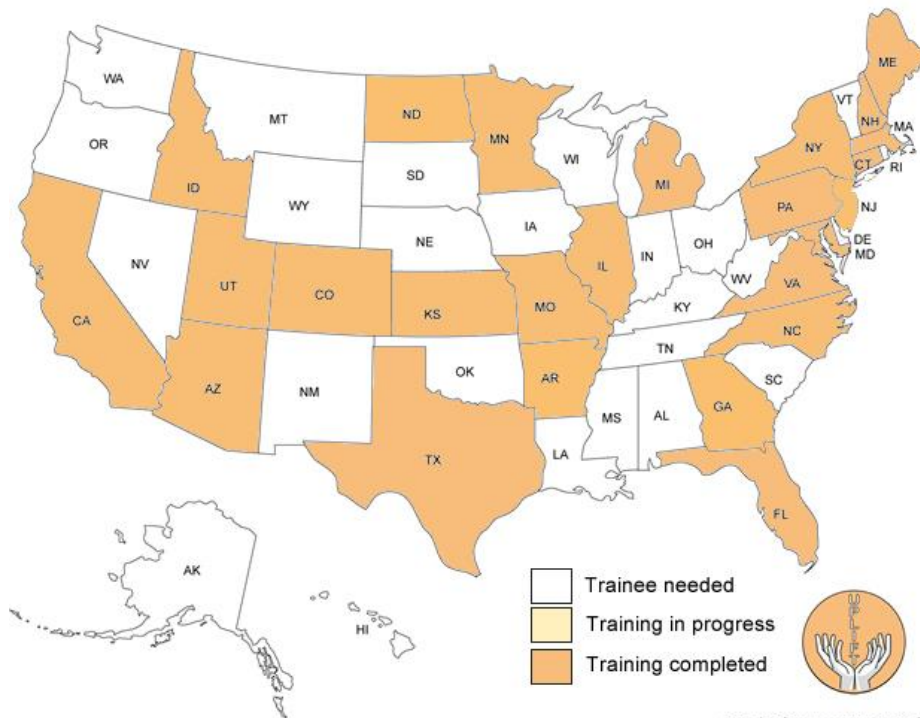
Tanya M. Spruill, PhD

Department of Population Health
NYU School of Medicine

March 31, 2016

Dissemination of UPLIFT

- 10-week program to train UPLIFT facilitators is ongoing

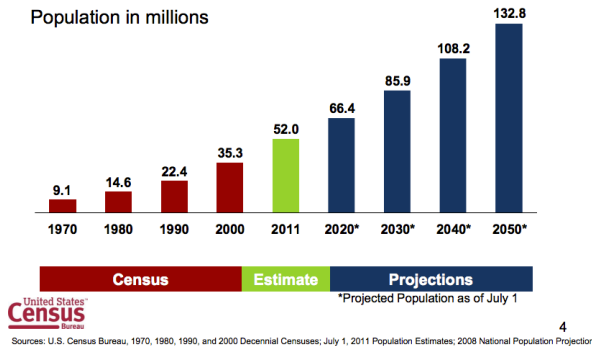


- Facilitators are trained in 26 states (so far)
- Supported by
 - CDC
 - Epilepsy Foundation
 - Healthcare systems (Parkland, Henry Ford)
- **Only evaluated and disseminated in English**

Need for a Spanish version of UPLIFT

- Hispanics are the largest and fastest growing racial/ethnic minority group in the U.S.
- ~ 1/3 of Hispanic Americans have limited English proficiency (LEP)
- Language barrier contributes to social isolation, limited access to care → contributes to psychological distress
- < 10% of Hispanic Americans with psychological disorders contact mental health care providers

Hispanics: 1970 to 2050

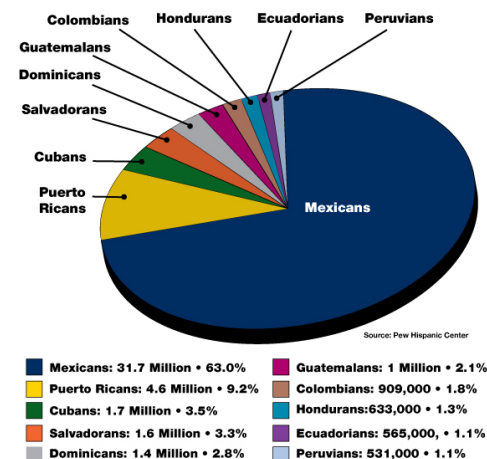


Tailoring for a diverse population

- Heterogeneity of U.S. Hispanic population:

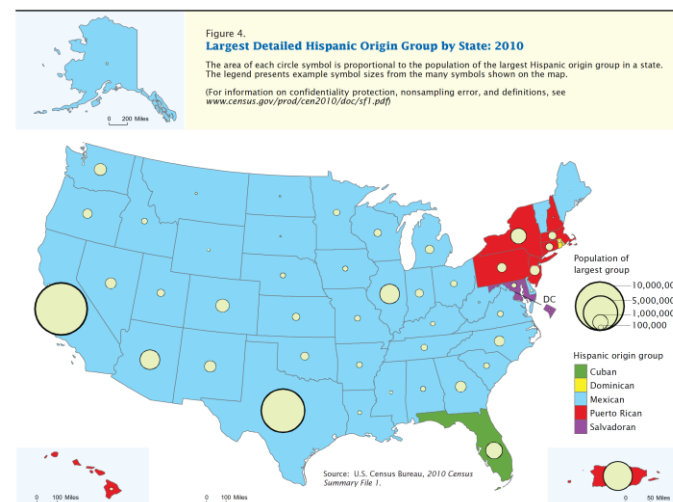
- Country of origin
- Race
- English proficiency
- Acculturation level
- Socioeconomic status
- Documentation status

The 10 Largest Latino Ethnic Groups in the U.S.



Numbers and percentages are based on the total U.S. Latino population of 50.5 million

- Not feasible (or likely necessary) to tailor for every subgroup



Cultural adaptation process

- Hispanics are more likely to want counseling vs. medications for their depression, but adherence is often poor
 - Goal of culturally tailoring UPLIFT is to be sensitive to important cultural differences to enhance engagement, retention, efficacy
- Five stages of culturally adapting interventions:
 - (1) Information gathering
 - (2) Preliminary adaptation design
 - (3) Preliminary adaptation tests
 - (4) Adaptation refinement
 - (5) Cultural adaptation trial

NYU Managing Epilepsy Well Center: Specific Aims

- **Aim 1:** Translate UPLIFT into Spanish and culturally adapt intervention for Hispanic population
- **Aim 2:** Conduct RCT to evaluate feasibility, acceptability, effects of adapted UPLIFT on depression over 12 months in 72 Hispanic adults with epilepsy
- **Aim 3:** If effective, support dissemination of adapted UPLIFT to Hispanic communities

Information Gathering

- **Literature review**
- **Provider input:** two neurologists caring for Hispanic epilepsy patients at NYU/Bellevue (one is also a Hispanic woman)
- **Expert consultant:** Fernando de Torrijos, experience delivering MBIs to Hispanic communities for >20 years
- **Patient input:** Focus groups, individual interviews, surveys
- **Research staff input:** focus group, interview facilitators

Preliminary Adaptation

- Will incorporate features to demonstrate understanding of and respect for culture
 - UPLIFT will be delivered by a Hispanic, bilingual facilitator and a Hispanic co-facilitator/layperson with epilepsy
 - Ethnic matching of provider is associated with longer treatment duration, better treatment response in Hispanics
 - Interventions using *promotoras* have been effective
 - Will frame epilepsy and depression as disorders that affect the entire family; emphasize potential benefits of UPLIFT for individual AND family

Initial Translation into Spanish

- Professional translation of UPLIFT participant and facilitator manuals, recording of Spanish audio exercises
- Decided NOT to translate the UPLIFT acronym
 - [English] Overview: UPLIFT stands for Using Practice and Learning to Increase Favorable Thoughts.
 - [Spanish] Descripción general: UPLIFT son las siglas de Using Practice and Learning to Increase Favorable Thoughts (Uso de la práctica y el aprendizaje para aumentar los pensamientos favorables).
- Replaced one of the poems used in the original UPLIFT (*Enlightenment*, by John Welwood) with one by a Spanish poet (*Last night, as I was sleeping*, by Antonio Machado)

Refining the Translation

- Patients were thrown off by the Spanish translation of “mindfulness” as “conciencia plena”.
 - Replaced with “atención plena” (awareness vs. consciousness)
- Reduced overall reading level, modified word choices to more commonly used, less “proper” words
 - e.g., Replaced “concentrate on...”, with “take your attention to...”
- Replaced second-person with first-person plural; less directive, consistent with *personalismo* (formal friendliness)
 - Ahora, siéntese. Concéntrese en los pies.
 - *Now, sit down. Concentrate on your feet.*
 - Ahora, sentémonos en una silla o un sillón. Llevemos la atención a los pies.
 - *Now, let ’s sit on a chair or a couch. Let ’s bring our attention to the feet.*

Importance of family, social connection, stigma

I have a boyfriend that takes care of me a lot and maybe that makes me have a high self-esteem to be able to take care of myself better and not let this get in the way.

Like I told her [RA], I usually don't talk about it to other people because I am embarrassed.

I basically don't know anyone else who has the same thing I do [epilepsy]. Not in my country and not here. So I would like to share with other patients the experience and how it feels.

Perceived need for UPLIFT

I also know when I am stressed out, bothered, worried, the whole combo, and that's when I feel the seizures come more frequently.

When you fall into depression, you lock yourself up in your thoughts.

It is great for people like us that have epilepsy since we have a lot of stress, anxiety, depression ... because I also don't like taking too many medicines, it makes me feel even sicker.

I get depressed ... these things sometimes hit you differently ... I see her [another patient] very optimistic, very strong ... what you have said, that helps me to get that strength.

Feedback about UPLIFT

I really enjoyed both exercises ... by simply breathing that way you change your way of being at the moment.

It's good to meditate ... not think about stuff, clear my mind. It's like I forget everything.

The guide in the audio, he sounded a bit instructional, as if he were teaching a class. His voice needs to be more slow and passive.

You do that at church when you go and meditate with God. You relax and think about your problems and ask God for help, it is very similar except you do it on your own.

Thank God it doesn't mention the word "epilepsy" because if it did, the tranquility would simply vanish!

Evaluating culturally adapted UPLIFT

- **Preliminary adaptation:** Conduct pilot UPLIFT group to inform further modifications prior to RCT
- **RCT design:** Initially proposed 3-arm RCT (n=72) comparing telephone-based UPLIFT, web-based UPLIFT and usual care
 - Will drop web arm based on feedback
 - Considering skype calls
- **Other open questions:**
 - Add in-person meeting at start or end of 8-week UPLIFT program?
 - Incorporate family member? If so, when/how? (several participants brought spouses to individual interviews)

Considerations for Dissemination

- Final modifications will be informed by results of RCT and feedback from UPLIFT participants and facilitators
- Study limitation: exclusively NYC sample may not be generalizable to other Hispanic communities.
 - We will provide translated, adapted materials to colleagues in Texas and Florida for clinical use with epilepsy patients.
 - Pre-post data and patient feedback will enable comparisons with NYC sample and may inform additional modifications to UPLIFT.

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- NYU/Bellevue epileptologists: Anuradha Singh, MD; Blanca Vazquez, MD
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- Nancy Thompson, PhD, Emory University
- Fernando de Torrijos
- CDC Managing Epilepsy Well (MEW) Network
- NYU-CUNY Prevention Research Center

OVERALL SUMMARY

- Theoretical framework to guide adaptation approach
- Integrate quantitative and qualitative data
- Level of intervention modification (attunement vs. deeper adaptation)

FUTURE DIRECTIONS

- Comparative effectiveness research
- Active components/mechanisms: test cultural characteristics that have been adapted and relative effect(s) on outcomes

THANK YOU!

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