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## Co-creating a Community-led Mindfulness Instruction Intervention with Urban Female Sex Workers in the Dominican Republic to Reduce Intersectional Stigma and Improve Mental Health and HIV Outcomes

Deanna Kerrigan<sup>1</sup>, Andrea Mantsios<sup>2</sup>, Luis Moreno<sup>3</sup>, Hoisex Gomez<sup>3</sup>, Martha Perez<sup>3</sup>, Yeycy Donastorg<sup>3</sup>, Tahilin Sanchez Karver<sup>4</sup>, Virginia Savage<sup>5</sup>, Erica Sibinga<sup>6</sup>, Clare Barrington<sup>5</sup>

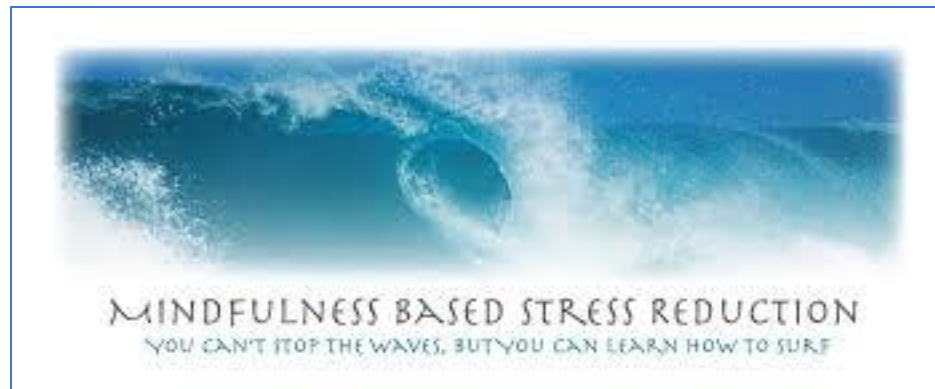
1-George Washington University, Washington DC, USA; 2-Public Health Innovation and Action, New York, USA;  
3-Instituto Dermatologico y Cirugia de Piel, Santo Domingo, Dominican Republic; 4- Johns Hopkins Bloomberg School of Public Health, Baltimore, USA; 5-University of North Carolina, Chapel Hill, USA; 6-Johns Hopkins University School of Medicine, Baltimore, USA



# Background

- Practicing mindfulness involves bringing awareness to one's present moment experience (thoughts, feelings, sensations) without judgment and with acceptance
- Mindfulness and mindfulness based interventions (MBIs) shown to significantly improve mental and physical health outcomes in diverse populations and settings

Mindfulness-based stress reduction (MBSR) one of most common MBIs



- 8-10 week program
- Group format: 10-40 people
- 2 hours per session & 1 full day retreat
- Practical training in bringing awareness to present moment through breathing exercises, body scan, yoga and meditation

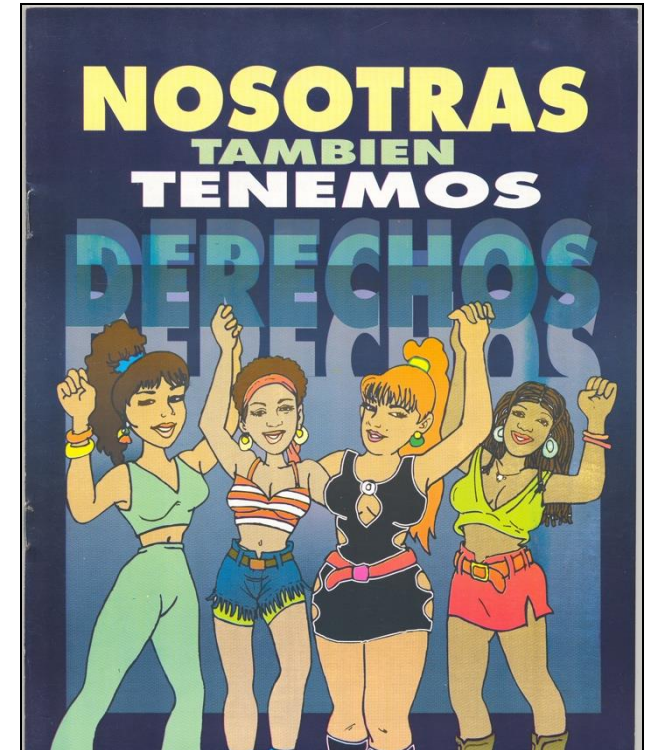
## Prior Research

- Mindfulness interventions among people with HIV in urban settings have had promising results including in groups facing intersectional stigma
  - We conducted an RCT of MBSR in urban African American youth in Baltimore, Maryland, USA (NCCIH R01AT007888: Sibinga; PI)
    - MBSR participants had greater increases in adherence to ART ( $p = 0.001$ ) and decreases in HIV viral load ( $p = 0.052$ )
    - Participants learned to observe stress and stigma related to HIV without judgment, facilitating self-acceptance and adherence
    - Importance of group dynamics: trust, acceptance and solidarity

# Study Setting

## Dominican Republic (DR)

- Middle income Caribbean country: 11 million people
  - 33% of the population resides in greater Santo Domingo
- 100,000 cisgender women work as FSW
- Strong FSW-led groups/grass-roots response
- Inequitable HIV and mental health outcomes in FSW
  - HIV prevalence of 4.2% in FSW vs. 0.9% overall
  - 30.8% of FSW vs. 51.0% of PWHIV in on ART
  - 69.5% of FSW experience depressive symptoms



*We too have rights!*

## *Abriendo Puertas (Opening Doors)*



- Community-driven, multi-level intervention to improve HIV care continuum and prevention outcomes among FSW with HIV in the DR
  - Significant improvements in HIV care engagement, ART use and adherence
  - Mindfulness techniques (breathing, relaxation, visualization, meditation) integrated into activities
  - Mindfulness quantitatively associated with lower depression and greater ART adherence



# Parent Study & Current Specific Aim

***Stigma, Cohesion and HIV outcomes among vulnerable women across epidemic settings***  
(NIH R01MH110158; Kerrigan, PI)

- Observational mixed-methods study of 400 FSW with HIV in the DR and Tanzania examining longitudinal pathways between social determinants and HIV outcomes

**Current specific aim:** Describe development of a community-led mindfulness intervention with urban FSW with HIV in Santo Domingo



## Mixed Methods

- Longitudinal in-depth interviews with FSW with HIV (n=20) to identify psycho-social stressors and the potential role of mindfulness practices to manage ongoing stressors
- Leveraging formative findings, we co-developed and conducted initial piloting of adapted group-based mindfulness instruction intervention with FSW peer leaders or those with some prior intervention exposure in Santo Domingo (n=11)
- In-depth interviews and focus groups conducted to explore program experiences and pre-post test surveys were used to examine changes in mindfulness using the Cognitive Affective Mindfulness Scale-Revised (10-item CAMS-R; Alpha=0.85)
- Thematic analysis and descriptive statistics used to assess acceptability and feasibility of initial model implementation

# Sample Characteristics

Sociodemographic variables	Overall cohort	Qualitative cohort
	Median/frequency (n=240)	Median/frequency (n=20)
<b>Age in years</b>	39	40
<b>Education</b>		
Secondary or university +	32%	45%
No school or primary	68%	55%
<b>Relationship status</b>		
Not single	33%	30%
Single	67%	70%
<b>Children</b>	3	2

Most women in 30s/40s, with low levels of formal education, single and at least two children, often primary income earner



# HIV, Sex Work & Intersectional Stigma

**They knock you down** if you say you have HIV, they start talking about you, they put you aside, they throw you out.

(50 years)

Living with HIV

Neighborhood, police, clinic and beyond

When you go to file a complaint... **the police don't pay attention to you...because they think that you are the least of everything**, that you are an animal ...I have been through this, they have said ugly things to me in front of my children and I have gone to the prosecutor's offices to file complaints, they have not listened to me. (37 years)

Being a sex worker

I'm afraid that **someone knows me and says in my neighborhood**, "oh look I saw so-and-so in such and such a place or so-and-so has that". I'm afraid of that. I put on glasses and a hat in case I see people who know me.

(30 years)

Living with HIV and being a sex worker

# Stigma, Mental Health and HIV Care

I always think that the health of the person who lives with HIV is based on adherence to medications and... mental hygiene because people think that the person does not need mental hygiene. **Sometimes you have dirty thoughts, ugly thoughts, sometimes you have to get them out.**

I believe that there is no study that indicates that but for me your emotional state determines your health a lot because when you are sad and you remain depressed, your CD4 never goes up, never... Your time to be adherent is eight in the morning, eight at night...**but if you have low self-esteem and you are very depressed...I forget that [ART].**

(53 years)

Role of internalized HIV stigma on depression and in turn ART adherence

# Mindfulness Practices

Most participants (16/20) described using some form of mindfulness-related practices to manage or reduce stressors including various forms of stigma

## *Types of strategies utilized:*

- Mindfulness meditation
- Breathing
- Visualization
- Self-talk related to self-acceptance
- Reflection rather than reactivity

## *Frequency and continuity:*

- Some used mindfulness-practices frequently on an ongoing basis
- Others used practices sporadically or in moments of acute stress

## *Barriers:*

- Noise and lack of privacy at home
- Lack of time
- Forgetting in during major stress
- *“It was too hard to concentrate”*

# Mindfulness & Mental Health

- Relief and regain sense of control after being overwhelmed
- Recognize and alleviate stress, anxiety, and depression
- Manage negative experiences and acute stressors (stigma)
- Reduce substance use and other unhealthy coping

I didn't want to comb my hair, because I, I recognized it, **one day I recognized it, "I'm falling into a depression"** I didn't want to comb my hair, I didn't want to put dye on it..(I asked myself) "what's happening to me?"

What I have to do is relax, count, like this from back to front and so on. And so I have **relaxed a lot** and I have gotten through many things like that. (39 years)

Yes, when I did it [**mediation**], it **calmed my mind**...because I forget about such and such a thing, one goes far away, reacts again and relaxes a lot. I did it a few times and I relaxed a lot. I **know that if I feel like this again instead of taking drugs, I will do that.** (41 years)

# Intervention Development

- MBSR was used as a reference point for intervention development
- Formative work and prior mindfulness exercise experiences informed drafting of initial modules
- Total of 7 group intervention sessions of 2-3 hours each in the initial pilot program
  - 5 group instruction modules with home based practice exercises, 1 introductory session, 1 final all day retreat



Leveraging team members with training in mindfulness meditation and holistic yoga

- Modules developed in partnership with FSW community/peer leaders
- Each session allowed for iterative refinement of language, content and format of curriculum, homework and exercises
  - Learning to observe conditioned thinking patterns (e.g., self-judgment) and cultivate present moment awareness and self-acceptance

# Impact on Mental Health and Well-Being

- **All participants found program beneficial**
  - Techniques brought a sense of well-being
  - Provided them with tools to deal with challenging situations in their everyday lives
- **Many noted improvements in mental health**
  - Lower stress, anxiety and depression
  - Manage negative thoughts and feelings
  - Less pain
  - Better sleep
  - Improved adherence to HIV medication
  - Changes linked to mindfulness training and strategies including self-reflection, breathing, meditation, yoga and body scan exercises

Sometimes when I want to get stressed, I start doing **meditation** and in the morning when I stretch my body, I feel more relaxed, with more spirit...**it helped me a lot and it is easy because you only need your body and your mind, you don't have to go anywhere, you can do it at home, even sitting here.**

**Learning to work with your mind, I think it is a very gigantic step for each of us who live with this condition [HIV], because you know that many times illnesses are mental...if ...you have in your mind that you are going to get well, then the body acts.**  
(32-year-old participant)

# Better Mental Health & ART Adherence

**Well, I say that [the program] is very useful because as one changes one's mood, one has another vision, one feels better, healthier, you feel good in your mind, that helps you when you have that condition [HIV]. If one is mentally well, we go forward: “Es pa'lante que vamos”**

**The tranquility that one feels, that's it. When they tell me the program, I see health and tranquility, I know that I have to take care of myself. When you're discouraged, you don't give a damn, ah, I'm not going to take anything like that [medication]...but if you feel in good spirits, you go and take your medicine. (47-year-old participant)**

**If I want to be mindful, I have to be a punctual person, I have to be a person who does things as they should, I have to be connected with my medication every night. I take them at nine at night...on Monday, Tuesday, Wednesday and so on and I already know that I can't overlook it. (52-year-old participant)**

# Mechanisms of Effects

- Greater self-awareness, knowledge and control generated by **learning to pause**
- More **aware of fear and painful, stigmatizing feelings**, letting go of things not happening in the present
- Able to more easily connect to **strengths** in themselves and to **forgive themselves** and others and to be less reactive
- “Opportunity to reflect” and “to **heal wounds in the heart**”; “**internal review**” of inner experience



What I liked the most [about the program was]... **introspection, taking a, like a trip towards my own interior** to look for things that I didn't know were there hurting me and getting it out of me, that was one of the things that I liked the most. The other thing is **learning tools to manage stress**, small exercises that are not something out of the other world so to speak, something that I can do in a hospital waiting room. (45-year-old participant)

Many of my colleagues, I saw that they talked about things, **like thorns that they had stuck in since they were little and maybe they didn't even realize that they had them stuck there.** (45-year-old participant)



# Pre-Post Changes in Mindfulness

**Increases in participants’ ability to identify and accept thoughts and feelings non-judgmentally, and stay with the present moment: 10.5% increase in CAMS-R scores (10 items); overall +4.20 from 28.90/40 at pre-intervention to 33.10/40 at post-intervention.**

<b>Responses:</b>		<b>Pre</b>	<b>Post</b>	<b>Change</b>
(1) Rarely/Not at All (2) Sometimes (3) Often (4) Almost Always				
<b>1</b> It’s easy for me to keep track of my thoughts and feelings.		2.91	3.63	+0.72
<b>2</b> I try to notice my thoughts without judging them.		2.54	2.82	+0.28
<b>3</b> I am able to accept the thoughts and feelings I have.		2.82	3.36	+0.54
<b>4</b> I am able to focus on the present moment.		3.18	3.72	+0.54
<b>5</b> I am able to pay close attention to one thing for a long period of time.		2.82	3.36	+0.54

# Suggestions & Community Ownership

**“We want to multiply what we learned.”**

(52-year-old participant)

- Strong interest in making the program available to others and in being trained as facilitators.
- More sessions, more exercises, longer sessions
  - More time for leaning, theory, practice
- Ensure private space for sessions
  - To minimize disruptions/distractions
- Open air sessions
  - Outdoor session more “freeing”, “relaxing”
- Smaller groups, more contact with facilitator
  - Having mentor to support consistency

For me it would be wonderful to learn more so I can **teach others** and I would love to because I would like to teach what I have been taught and help as I have been helped. **I would need more learning.** (38-year-old participant)



# Conclusions & Next Steps

- Results indicate promise of tailored mindfulness intervention model to:
  - Increase mindfulness
  - Reduce stigma
  - Improve mental health & HIV outcomes
- Ongoing training of FSW peer leaders as group facilitators
  - Deepening practice
  - Group facilitation
  - Ongoing group support/mentorship



- Further larger-scale evaluation of community-driven mindfulness interventions in urban FSW warranted including RCT
  - Component of multilevel interventions
  - Exploration of potential for mindfulness interventions to increase social cohesion and community mobilization
  - Address social-structural constraints
- Partnership with community led organizations and government mental health & HIV services

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