

# Designing a Remote Support Group Intervention for Women with HIV during the COVID-19 Pandemic

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# Learning Objectives

- **Identify HIV treatment non-adherence risks for racial/ethnic minority women**
- **Learn about COVID-19 telehealth strategies used in prenatal care**
- **Explore remote support groups as a retention in care strategy, using established frameworks**

# Background cont.

**Compared to their non-Hispanic White, male counterparts, racial/ethnic minority women living with HIV are at higher risk of falling out of HIV care, due to a variety of risk factors and the intersectional stigma of:**

- **Being a person of racial/ethnic minority**
- **Being a woman *and***
- **Being a person living with HIV** (Mahajan et al., 2008; Bowleg, 2012)

# Treatment Adherence

## Treatment Adherence includes:

- Starting HIV treatment.
- Attending medical appointments.
- Taking HIV medications, as prescribed (daily) (HIVInfo.NIH.gov)

# Treatment Non-Adherence Risk Factors

- **HIV Stigma Experiences in Medical Settings** (Harris et. al, 2020)
- **Co-morbidities**
  - e.g., Diabetes, Cardio-Vascular Disease
- **Accelerated Aging**
  - **Caused by HIV and/or Comorbidities** (Zhao, 2011; Goulet et al., 2007)

- **Lack of Care Coordination between**
  - **HIV Care Specialists and Co-morbidity Specialists** (Sangaramoorthy et al., 2017)
- **Medication Fatigue**
  - **Years (or decades) of pill-taking** (Sangaramoorthy et al., 2017; Warren-Jeanpierre et al., 2014; Harris et al., 2020)



# Treatment Non-Adherence Risk Factors pt.3

- **Low Socioeconomic Status** (Sangaramoorthy et al., 2017; Warren-Jeanpiere et al., 2014, Harris et al., 2020)
  - **Medication Costs**
  - **Transportation Costs**
  - **Childcare (children, other dependents)**

# Treatment Non-Adherence Risk Factors pt.4

- **Social Stigma and Disclosure Concerns** (Cianelli et al., 2020)
- **Racialized Stigma** (Harris et al., 2020; Sangaramoorthy et al., 2017)
- **Mental Health Challenges** (Cianelli et al., 2020; Harris et al., 2020)

**Based on own prior findings, we reported women expressed a need for:**

- **Additional Support**
- **Education**
- **Interest in Technology-based Solutions** (Duthely et al., 2021)

# Current Project, cont.

## As a Result:

- **Designed a hybrid (face-to-face / remote)**
- **group-based psycho-educational and support intervention**
- **Women at-risk for falling out of HIV care**

## The Challenge

- **March 2020: COVID-19 Mandatory Closures / Lockdowns**
- **July 2020: Awarded**
- **July 2020: Phase-in of clinic re-opening**
- **Non-essential activities postponed**

**Simultaneously: a quality initiative examining clinic usage patterns, revealed a high no-show and loss-to-followup rate to specialty gynecologic services.**

## Intervention Design Considerations

- Healthcare delivery systems changes

## New Framework Needed

- **User-centered design** (Norman, 1986)
- **Re-evaluate the intervention**
- **Develop intervention prototype**

## User-Centered Design Steps

- **Assess user context**
- **Define intervention requirements**
- **Evaluate the prototype**



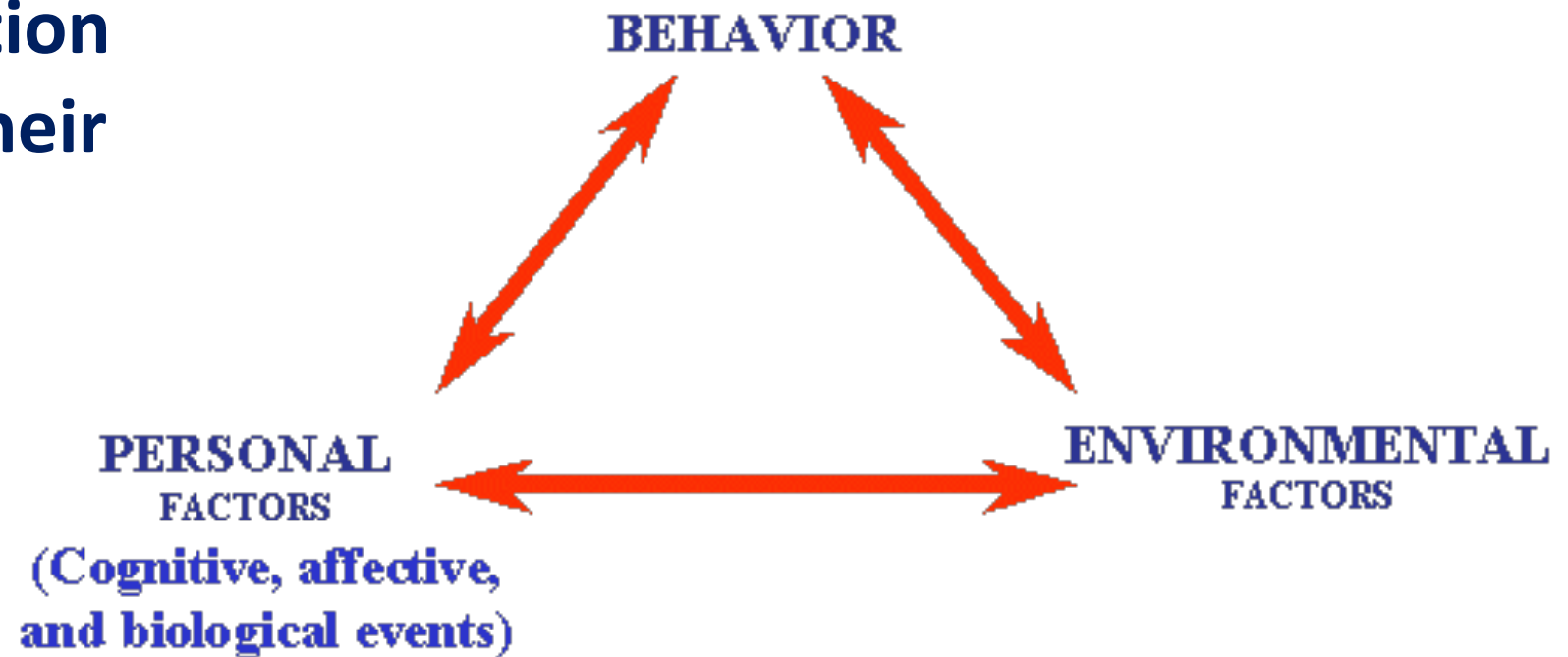
# Behavior Change Framework

- **Two predominant theories considered**
  - **Social Cognitive Theory (SCT)**
  - **Self Determination Theory (SDT)**
- **SCT is more appropriate at an environmental level**
  - **i.e., In an intervention to reduce obesity in a community, creating green spaces to promote exercise**

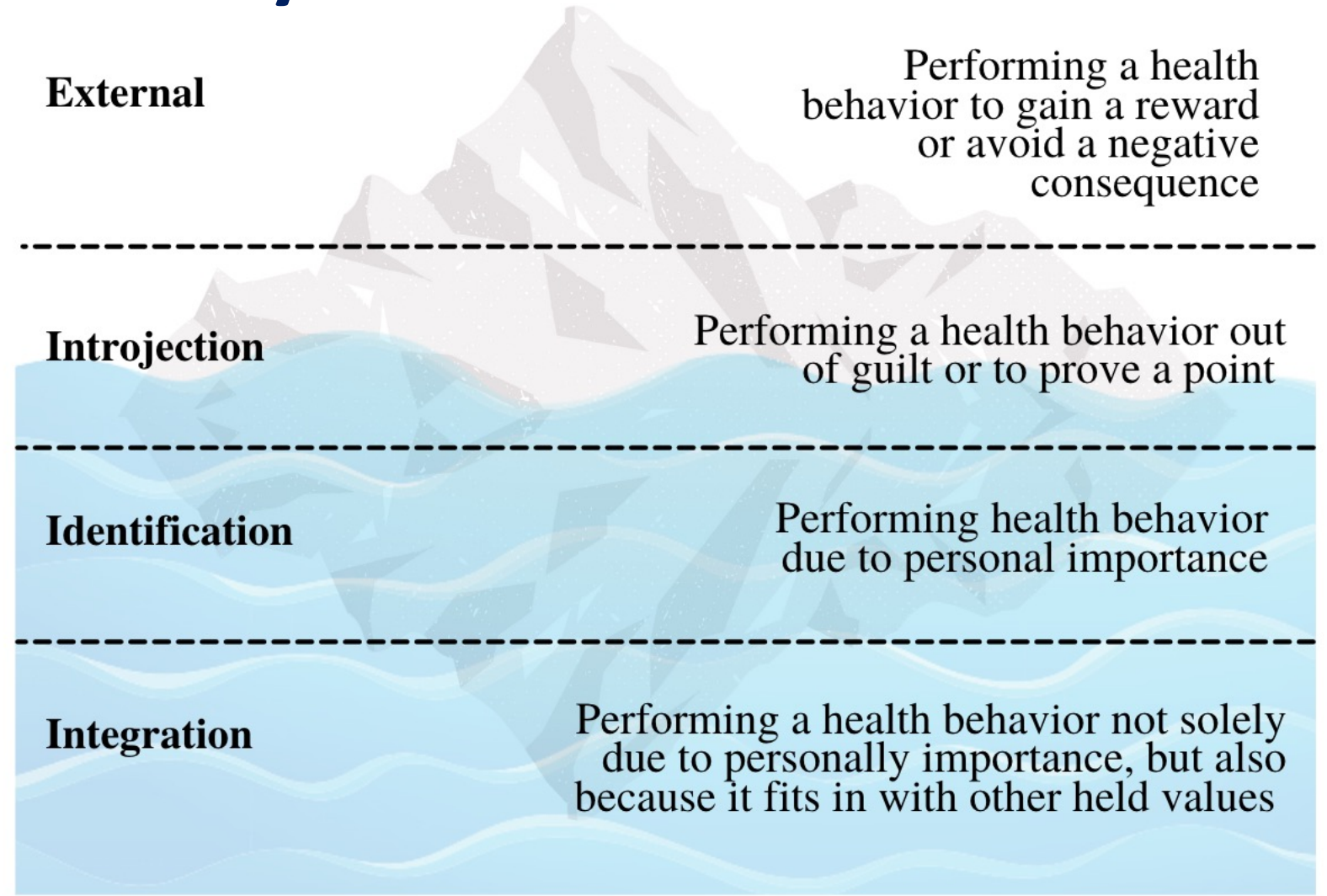
# Social Cognitive Theory

**Adopting a health behavior occurs through the “reciprocal interaction between the person, their behavior, and their environment”**

(Boston University School of Public Health, 2019)



# Self-Determination Theory: Levels of Internalization



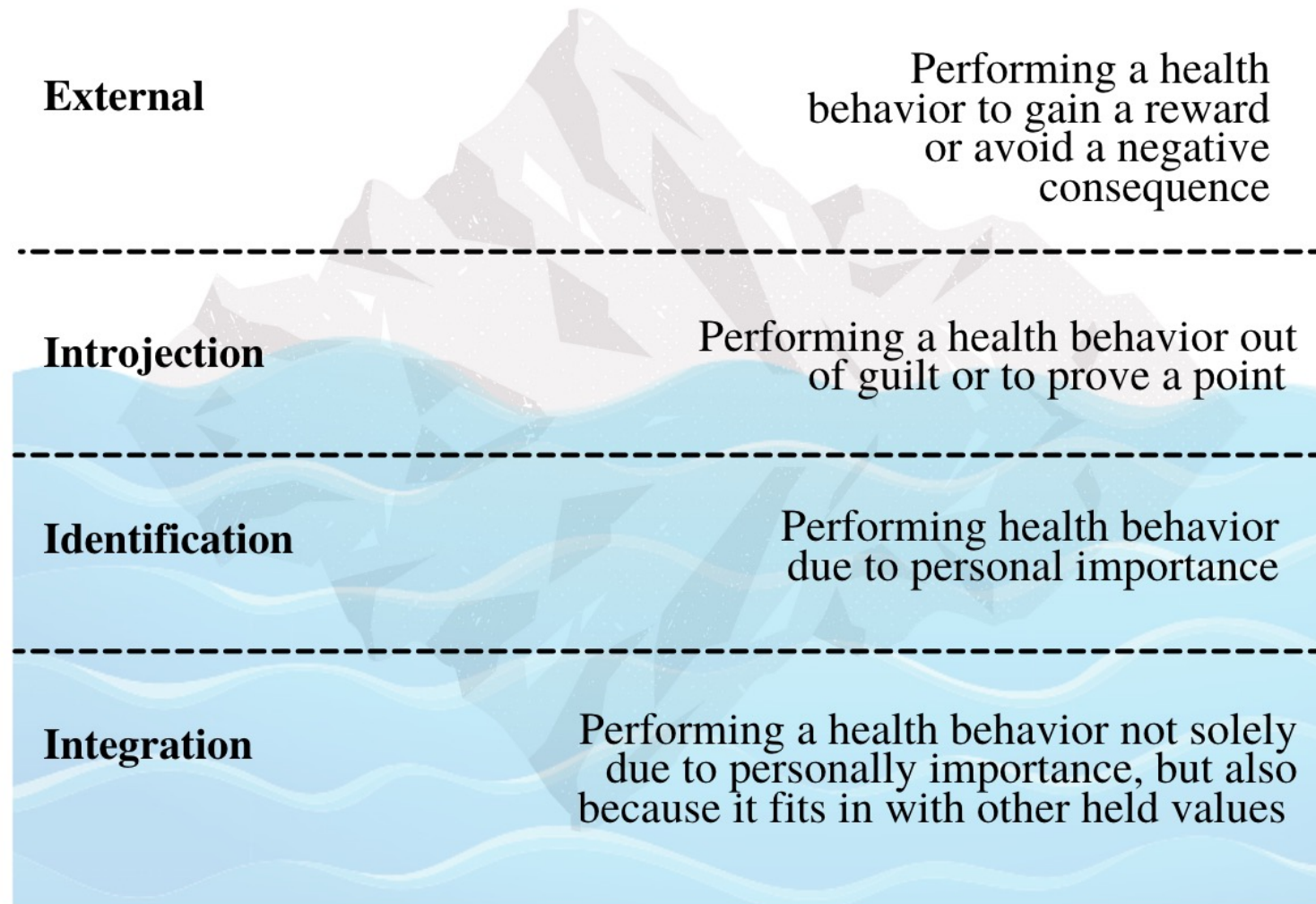
**SDT was the most appropriate at the individual level**

**SELF-DETERMINATION THEORY: LEVELS OF INTERNALIZATION**

# Self-Determination Theory

- **People are more likely to adhere to a health behavior when they are intrinsically vs. extrinsically motivated** (Patrick, 2012)
- **Intrinsic motivation = internalization via motivational interviewing techniques** (Patrick, 2012)
- **The deeper the level of internalization, the more likely the person will consistently perform the health behavior long-term** (Patrick, 2012)

# Self-Determination Theory: Levels of Internalization 2



SELF-DETERMINATION THEORY: LEVELS OF INTERNALIZATION

# Social Determination Theory

## Three main aspects of SDT Autonomy:

- **Behavior change begins with self**
  - **People are the originators of their own actions**
- **Competence: Self-Efficacy (the feeling that one is capable)**
  - **“I have what it takes to address challenges and strive for a healthy life”**
- **Relatedness: Feeling connected to others**
  - **Sense of community with peers of common experiences** (Patrick, 2012)

## In Next-Stage Field Testing...

### Autonomy

- “You” focused questions, i.e. “Are there any ways *you* have found that have worked to protect *yourself* from abusing alcohol?” (emphasis added)

### Competence

- “Resilience” section of Mental Health module
- Questions provoking reflection on a person’s own previous and current healthy habits

## Relatedness

- **Breakout rooms for more private discussions of personal experiences**



# SDT Applied to the Intervention

## In Next-Stage Field Testing...

### Integrated Internalization: Concluding Reflection Questions

- How can what we learned today fit into your life and your current health goals?

# Intervention Description

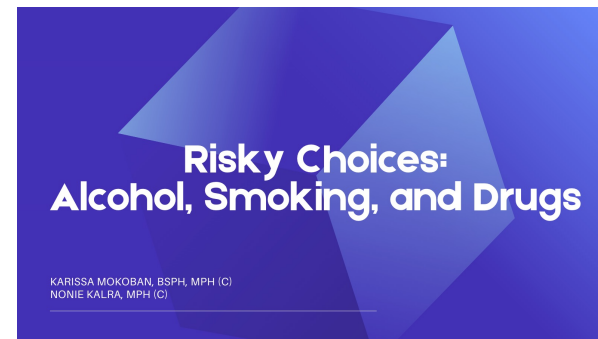
- **Quality Improvement Project**
- **Feedback from participants**
- **Research Phase (English, Spanish Creole)**

## Intervention Description, cont.

- **Online format to accommodate COVID precautions**
- **Application submitted pre-COVID, approved during lockdown**
- **This intervention is designed to ensure patients stay in care, even if they are not ready to return in person**

# Online Psycho-Educational Modules

- **Stress Management**
- **Mental Health**
- **Illicit Drugs, Alcohol, and Tobacco**
- **General Health (Primary Care, Nutrition, etc.)**



- **PrEP**
  - Our previous work revealed in women's interest in learning about PrEP for their HIV negative partners (Duthely et al., 2021)
- **The Effect of HIV Medication on Relationship with Food**
- **Using Food to Fight HIV Medication Side Effects**



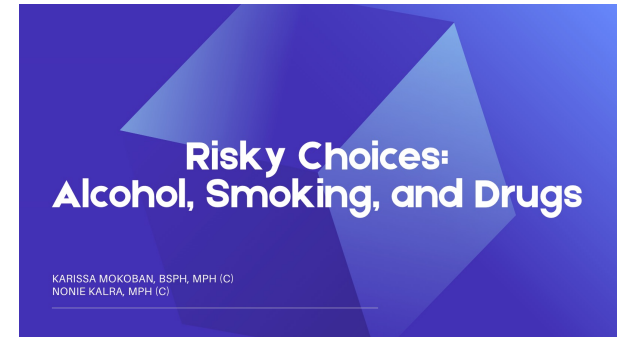
**Effects of:**

**Excess Alcohol**

**Prescription Drug Misuse**

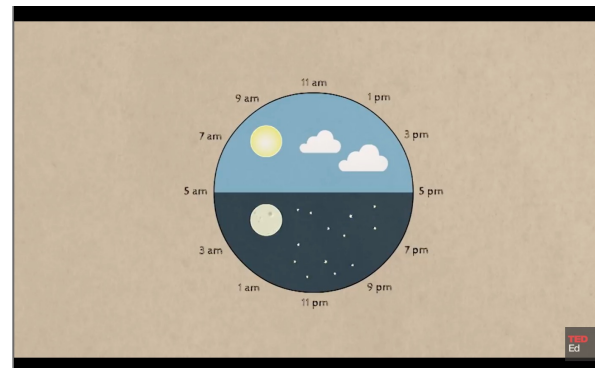
**Effect of Illegal Drug Use, and Tobacco on HIV Progression and HIV Treatment**

- **HIV Concept Review**



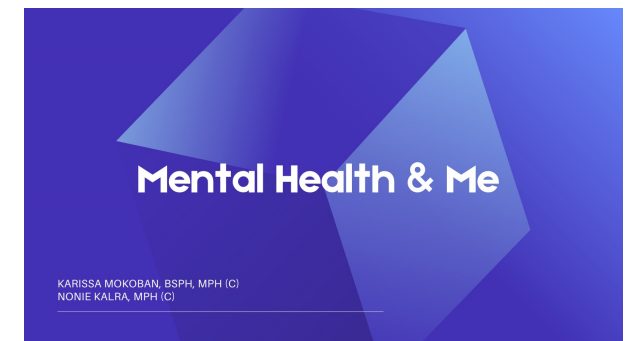
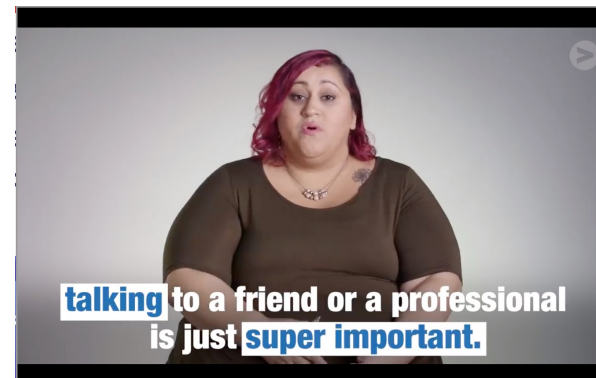
# Stress Management and HIV

- **Common Causes of Stress for Women Living with HIV**
- **Importance of Stress Management**
- **Ways to Reduce Stress (changing diet, getting better sleep, etc.)**
- **How HIV Treatment Adherence Can Reduce Stress**



# Mental Health & Me (Living with HIV)

- **Maintaining Mental Health**
- **The Most Common Mental Illnesses (Depression and Anxiety)**
- **Getting Help for Mental Illness**
- **Building Resilience to Protect Mental Health**





## Intervention Sessions Connect Back to Adherence (Viral load suppression and appointments)

- **Examples:**
  - “At primary care appointments they check your CD4 count and viral load to ensure the virus is being checked with your meds, which is why appointments are important to attend.”
  - “Depression can discourage people from fully sticking with their treatment.”

# Group Questions: Examples

- **Group questions were posed to the group to illicit their opinions about content effectiveness and to share similar experiences (relatedness)**
- **In later field testing, group questions will be designed to also address competence and autonomy**
  - **i.e. “What do you feel are barriers that women living with HIV encounter when it comes to quitting smoking? Is there a way to quit that has worked for you or someone you know?”**

## Likert scale

- i.e. “To me, taking care of my mental health is...”
- **Extremely Important**
- **Important**
- **Neither Important Nor Unimportant**
- **Unimportant**
- **Extremely Unimportant**

# HIV Quiz Questions: Example

## What is “viral load”?

- (A)** The amount of HIV in someone’s body
- (B)** The load of stress that can come with living with HIV
- (C)** The dose of HIV medication someone takes
- (D)** The load of views from a viral video

# Health Quiz Questions Examples

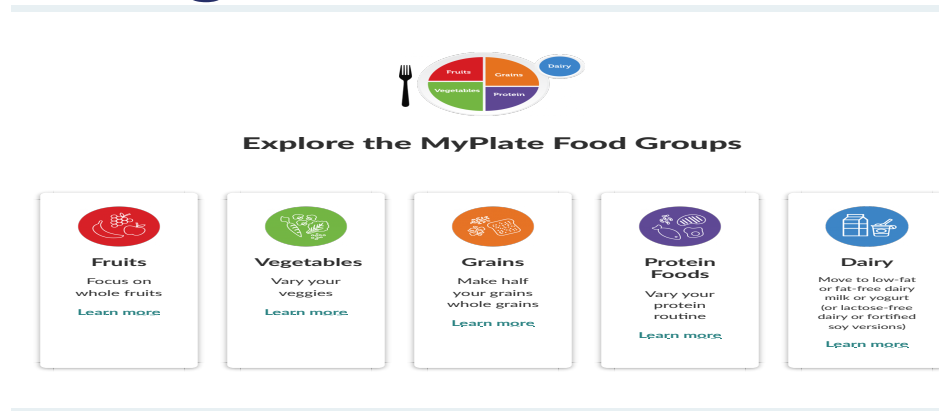
**Among others, the following questions are planned to be field tested:**

- **Which is an example of using your diet to treat a side effect of HIV medication?**
- **When living with HIV, what are the effects of taking illegal drugs?**
- **What does too much caffeine (sodas, coffee, some chocolates) have to do with stress?**

- **Participants felt comfortable to share their stories**
- **Participants said they appreciated:**
  - **Information on cancer screening**
  - **Diet tips, specifically the one about using ginger to treat nausea**
  - **The *myplate.gov* nutrition resource**
  - **Primary care information, specifically the reminder about getting lab work done**

# Participant Feedback cont.

- One participant said the presentation is useful, and especially helpful for someone newly diagnosed
- Note on online format: “I don’t mind being on zoom and talking”



**Participant Quote:**  
“Instead of thinking about dying, rejoice in living.”

# Telehealth for Prenatal Education

**Evolution of our prenatal care, childbirth, post-partum, and infant care education program:**

***Where:***

**Prenatal Immunology Clinic (PRIM), Department of Obstetrics and Gynecology, University of Miami Miller School of Medicine and Jackson Memorial Medical Center**

***Population Served:***

**Primarily low-income and minority women (African-American, Haitian-Creole, and Hispanic)**



**Inception: July 2009**

**Goal: To improve maternal and infant mental health outcomes among pregnant women and adolescents living with HIV**

## **Format:**

### **6 Module/Session Topics:**

- **#1: Pregnancy and Prenatal Care**
- **#2: Nutrition and Health in Pregnancy**
- **#3: Labor and Delivery**
- **#4: Postpartum and the Newborn**
- **#5: Family Planning and Infant Mental Health**
- **#6: Community Resources**

## Program Adaptation

- **2009-2019: *Group***
- **2019-2020: *Individual In-Person***
- **2020-Present: *Telehealth***

## Program Adaptation:

- **2019: Group to Individual In-Person**
  - **Why?**
  - **How did we adapt?**

## Program Adaptation:

- **March 2020: Pivot to Telehealth**
  - **Making the transition**
  - **What changed?**

## Where are we now?

## Lessons learned:

- **Be ready for change: Accept and Adapt**

## Takeaways

**Reinforcement of Adherence (e.g. appointments and viral suppression)**

**Women may be looking for additional education and support**

**Incorporating education into the support groups fulfills both needs**

**Remote Groups (flip phone; smart phone; table; PC) were acceptable/feasible**

# In Summary, cont.

## Takeaways

### Designing intervention

Consider a framework/model

Involve your consumers

Don't re-invent the wheel: Consider online resources

Remain flexible!



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