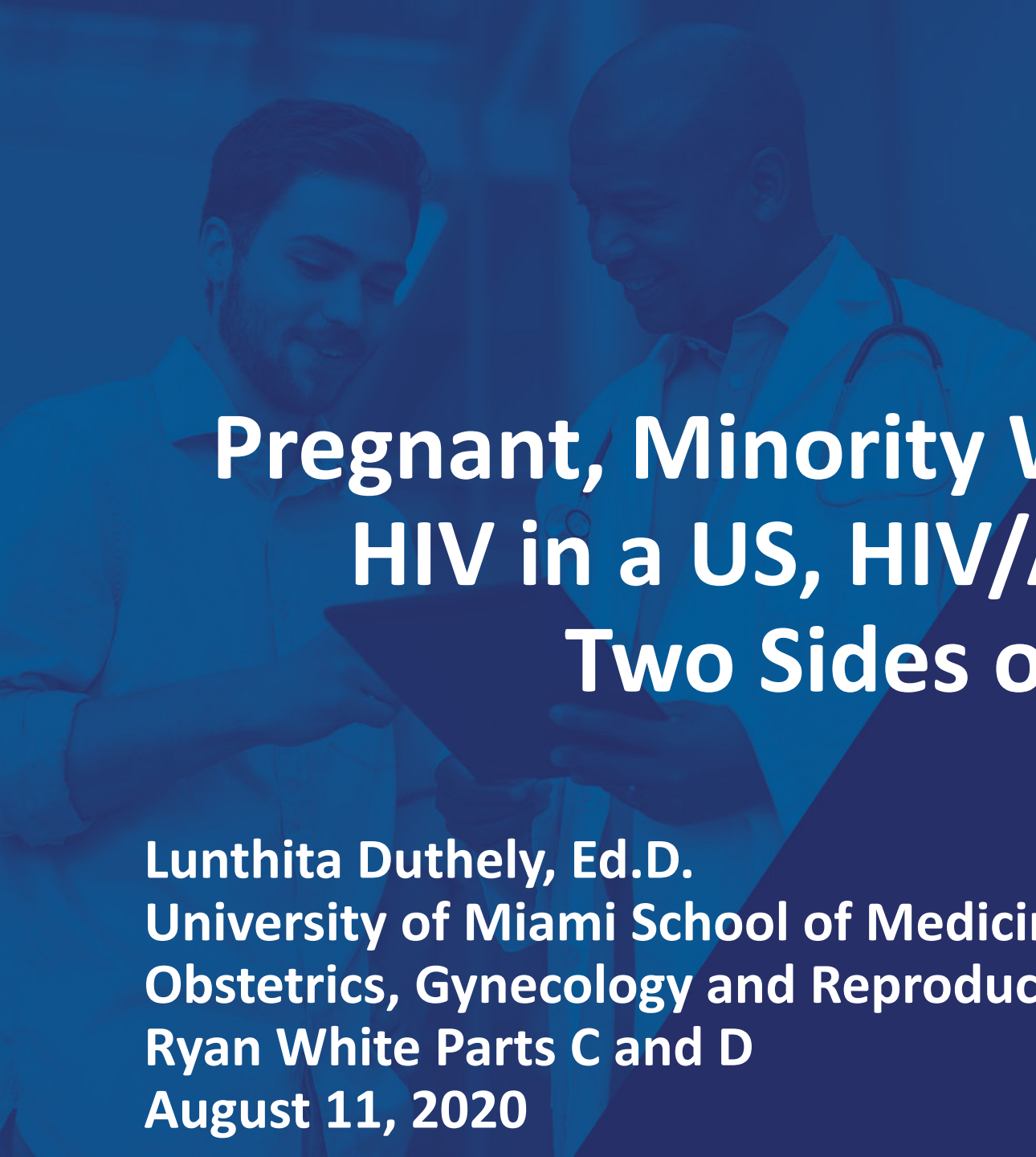

VIRTUAL 2020 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Pregnant, Minority Women Living with HIV in a US, HIV/AIDS Epicenter: Two Sides of the Coin

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Learning Objectives

1. Summarize HIV care engagement, among pregnant and post-natal minority WLWH in the US.
2. Brief overview of perinatal transmission of HIV.
3. Characterize HIV care disengagement among WLWH, followed in an academic medical center in Metropolitan Miami
4. Provide an Overview of the UM Prenatal (PRIM) Model
5. Describe a community engagement pilot project to:
    a. Reduce perinatal transmission;
    b. Keep women in care: Prenatally and postnatally.

- **Track**
- RWHAP Planning and Resource Allocation: Community Engagement and Collaborative Partnerships
- Areas: Ending the HIV epidemic; patient engagement; Women Infant and Youth

Ryan White: Project Team

- **Principal Investigator:** JoNell E. Potter, PhD
- **Project Coordinator:** Lunthita M. Duthely, EdD
- **Part D Coordinator:** Barbara Messick, MPH
- **Nurse Practitioners:** F Doyle, N Diaz, M Dorleus, C Orfield
- **Health Educator:** Olga M. Villar-Loubet, PsyD
- **Psychologist:** Maria I Echenique, PsyD
- **Research Assistant:** Alex P Sanchez-Covarrubias, PhD (c)
- **Social Workers:** Ashton RB Sanchez; Roxana Ocon
- **Support Staff:** J. De Nicola; A. Cardenas; E. Montgomerie
- **CW Programmer:** Johnny Galli
- **MFM Specialist:** Anna Sfakianaki, MD

Background 1

Our Experience:

During the Prenatal Course

WLWH engage in HIV care in Pregnancy

- Even under challenging circumstances.
- Poor HIV care engagement postnatally (after birth).

Background 2

Our Experience:

After Pregnancy

Postnatally:

- Women who may have been HIV diagnosed in pregnancy:
  - may not have a primary care provider.
- Regardless of when diagnosed,
  - may have lost insurance coverage.

Background 3

Our Experience: After Pregnancy (cont'd)

Postnatally, face a multitude of challenges:

- Caregiving Responsibilities
- Social challenges and issues
- Financial / economic challenges

Background 4

Post-natal: HIV Care Engagement

Why

Are we not

Keeping Women in Care ?

What we know:

Two Intertwined and Complex Issues:

Eliminating Perinatal HIV

Keeping Women Engaged into Care

Eliminating Perinatal HIV 1

Historically: Biological Approach

- 1980s
  - 1987: AZT is first approved ARV Regimen
- 1990s
  - 1994: 076 Protocol–Reduced Perinatal Transmission by 67%
  - 1997: P.I.s / HAART / cART (“cocktails”)

Eliminating Perinatal HIV 2

Perinatal HIV Transmission

Doing pretty good …

But why have we not reached

0%

?

Eliminating Perinatal HIV 3

- 2000s: Multi-pronged, Individual Approach
  - Single-pill Regimens
  - One-stop; Integrated; Multi-disciplinary
  - Viral Load Suppression: Individual
- Today: Multi-level Approach
  - Viral Load Suppression: Partners (PrEP)
  - 2020 … 2030
    - Injectables
    - Vaccine?

U.S. and Regionally

ONE SIDE OF THE COIN:

In the United States (US):

- Country with lowest rate of viral suppression among high income countries
  - Only 54% population viral suppression (Keiser Family Foundation)
  - 11% of those IN care, not suppressed accounted for 20% new infections (MMWR; Li et al., 2016)
  - 23 % of those NOT in care, accounted for 43% new infections (MMWR; Li et al., 2016)
- 6 mo PP 52% on ART; 48wks 43% ART (PACTG; Bardeguez, 2008)
- 6 mo PP 43% Suppressed; 1yr 34%; 3 yrs 27% suppressed; (Alabama; Smith et al., 2014)

In Miami-Dade County (MDC):

- The region with one of highest rates of new HIV infections in the US:
  - Only 60% of WLWH who know their status are engaged in care;
  - More than a third (35%) are not on cART (CDC, 2017).

Our Experience 1

ONE SIDE OF THE COIN:

In our Prenatal HIV clinic *(2012-2017: Quality Project)*

- 70% known to be HIV+ (pre-pregnancy) entered PNC with detectable HIV viral loads.
- In the immediate post-natal period, a third (33%) were lost to care (within 3 months)
- Proportions increase over time at 6 months and at one year, after the birth of a child.

In our Prenatal HIV clinic *(2016-2017: Published Data)*

- 24% diagnosed in pregnancy
- 53% entered PNC not VL suppressed
- 20% Substance Use; 25% Overweight/Obese at Entry; 32% STI; 35% Mental Health Diagnosis;
- 26% Low Birth Weight; 21% Delivered Preterm; 20% Hypertensive Disorders

(Potter, Duthely et al., 2019; Journal of Midwifery & Women's Health)

Our Experience 2

OTHER SIDE OF THE COIN:

In our Prenatal HIV clinic

WLWH in the clinics fare well, in terms of HIV and perinatal outcomes.

In our Prenatal HIV clinic

70% Were VL suppressed at Birth (up from 53%)

0% Neonatal Deaths; 0% Maternal Deaths

1% Perinatal Transmission ***(Potter, Duthely et al., 2019; Journal of Midwifery & Women's Health)***

Our Experience 3

ONE SIDE OF THE COIN:

In our Prenatal HIV Clinic *(2012-2013: Published Data)*

- 23% Reported Trauma Exposure (n=45 of 194)

Of These Trauma-Exposed Women: (All Current/Past Physical/Sexual Abuse)

- 36% Abused w/in 1 yr; 67% Abused as Child;10% Abused at time of Screening
- 71% entered PNC not VL suppressed
- 21% Substance Use; 2% Refused cART / no cART in Pregnancy
- 33% UTI / STI *(Villar-Loubet al., 2014; Journal of the Association of Nurses in AIDS Care)*

Our Experience 4

OTHER SIDE OF THE COIN:

In our Prenatal HIV clinic

- **Of These Trauma-Exposed Women:**

64% Were VL suppressed at Birth (up from 29%)

0% Neonatal Deaths; 0% Maternal Deaths

0% Perinatal Transmission (1 LTF)

(Villar-Loubet al., 2014; Journal of the Association of Nurses in AIDS Care)

In Summary:

In our Women's HIV Clinics

- Pregnant WLWH in the clinics fare well, in terms of HIV and perinatal outcomes.
- The majority of pregnancies are complicated with a host of obstetrical, medical complications, and mental health challenges, while faced with a variety of psycho-social and structural barriers, such as trauma and interpersonal violence.
- Women drop out of care; Return with VL > 200 or Sick
- To address these disparities, we have instituted several initiatives in the past year. Most recently, we instituted a multidisciplinary, multi-agency collaborative approach to screening for risk factors, and an enhanced referral system to mitigate these challenges. Today, we describe the processes and the outcomes to date.

Let’s Stop Tossing the Coin

Let’s stop tossing / flipping the coin!

A Patient-based Treatment Adherence Program for Engaging Post-natal Women Living with HIV:

A Multi-disciplinary, Multi-Agency Initiative

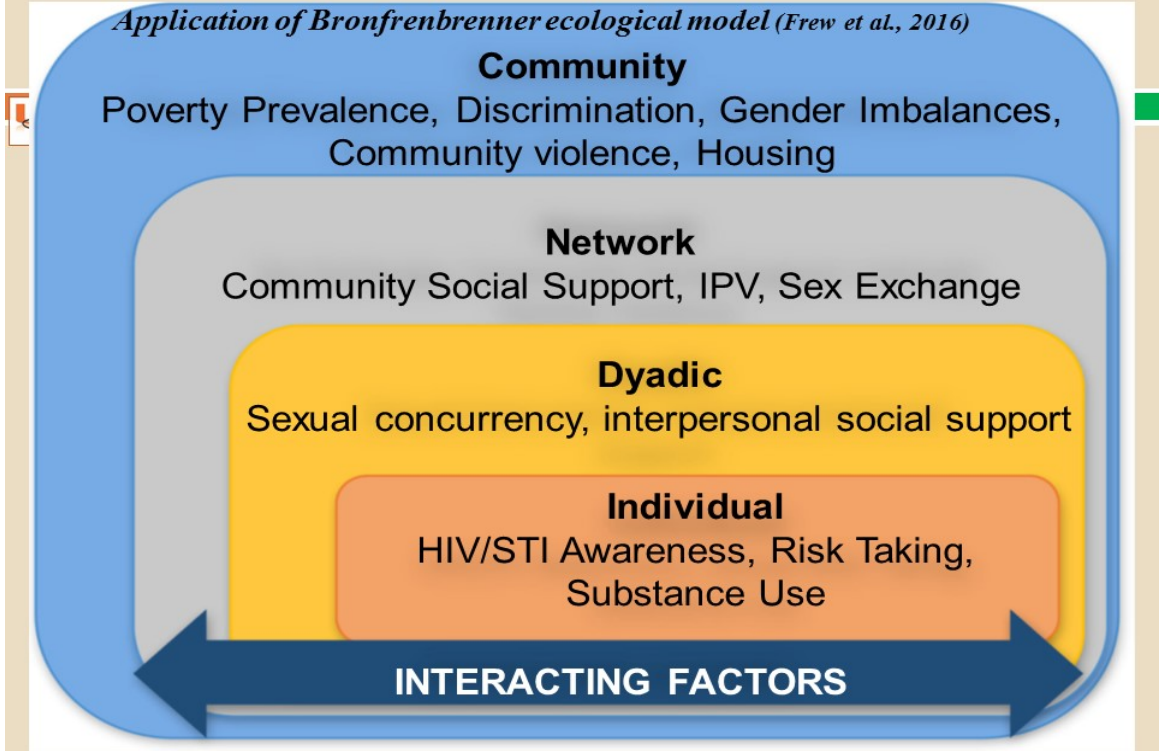
Post-Partum Adherence Safety Net Tool

Describe …

- A Patient-Centered Model for Post-natal Engagement
- Components of the Model
- Strategies to Implement this Program
- Share our Experience to-date

Women and HIV Risk: A Framework

Diagram: Adapted from Frew et al (2016) Socioecological factors influencing HIV risk in the U.S: Qualitative Findings from Women's HIV HPTN 064 Study



Factors occur at multiple levels for HIV Risk (Frew et al, 2016):

- **Exosystem** (Community Level)
- **Mesosystem** (Network)
- **Microsystem** (Individual and Dyadic)

Women & HIV Risk

- **Results Frew (2016):** The following themes were identified at 4 levels, including
  - **Exosystem** (community**): poverty prevalence, discrimination, gender imbalances, community violence, housing challenges**;
  - **Exosystem** (network): **organizational social support, IPV, sex exchange**;
  - **Microsystem** (dyadic): **sexual concurrency**; **interpersonal social support**
  - **Individual Level**: **HIV/STI awareness, risk taking, and substance use**.
- Over 80% of responses linked to the fundamental role of financial insecurity underlying risk-taking behavioral pathways.

Conclusion:

Multilevel syndemic factors contribute to women's vulnerability to HIV in the US. Financial insecurity is a predominant theme, suggesting the need for tailored programming for women to reduce HIV risk (Frew et al., 2016).

Perinatal HIV Prevention Cascade

(Interventions outlined, which CDC adapted from IOM 1998 Report)

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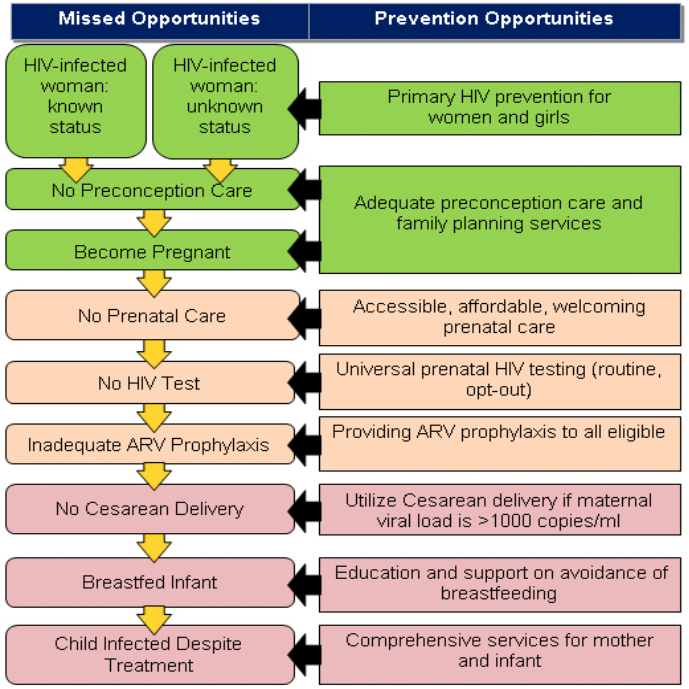
MISSED OPPORTUNITIES … PREVENTION OPPORTUNITIES

Missed Opportunity	Prevention Opportunities
HIV Infected woman: unknown status, and HIV Infected woman: known status	Primary HIV prevention services for women and girls
No Preconception care, and Become Pregnant	Adequate preconception care and family planning services
No Prenatal Care	Accessible, affordable, welcoming prenatal care
No HIV Test	Universal prenatal HIV testing (routine, opt-out)
Inadequate ARV Prophylaxis	Providing ARV prophylaxis to all eligible
No Cesarean Delivery	Utilize Cesarean delivery if maternal viral load is more than 1000 copies/ml
Breastfed Infant	Education and support on avoidance of breastfeeding
Child Infected Despite Treatment	Comprehensive services for mother and infant



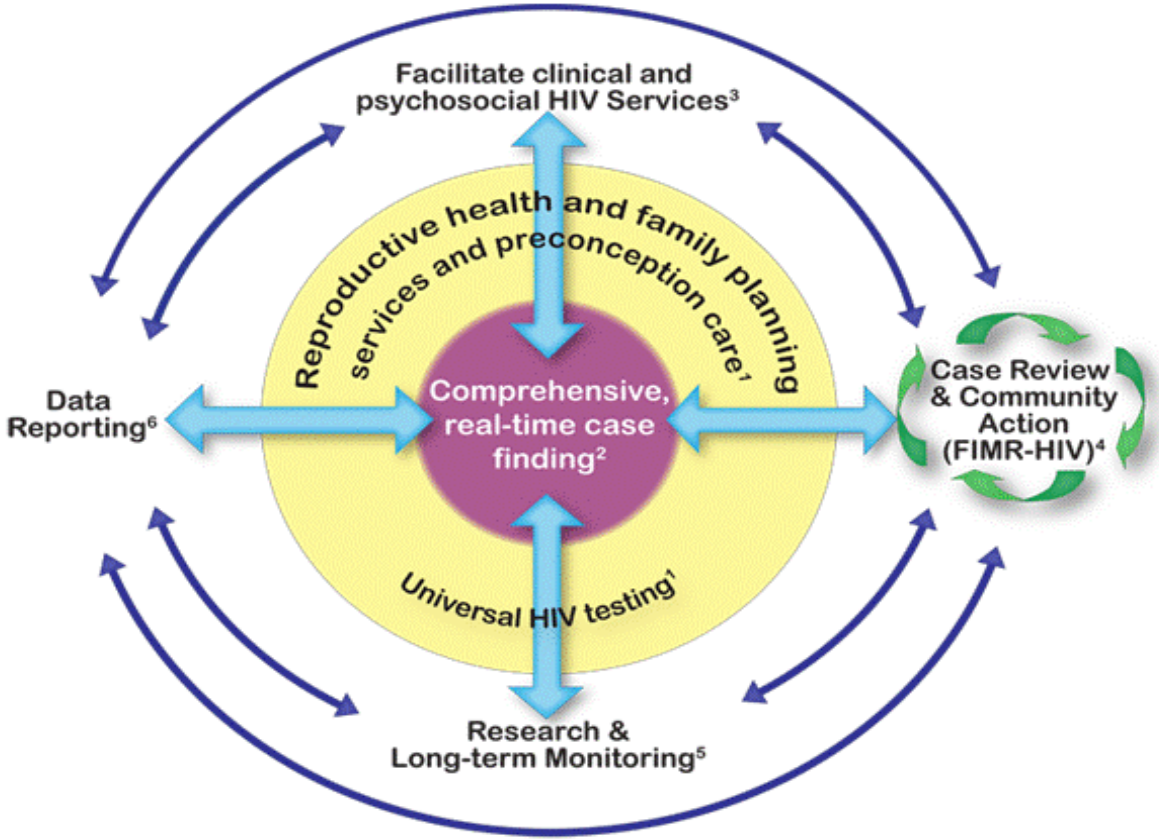
For every missed opportunity identified, a prevention opportunity was identified as well, e.g.:

BREASTING:
- Provide adequate education
- Support to the moms to avoid the potential of breastfeeding.

Retrieved from: https://www.cdc.gov/hiv/group/gender/pregnantwomen/emct.html

CDC's Framework: EMCT

(How healthcare & public health systems work together)



- Reporting of Data
- Continued Research
- Long-Term Follow-up
- Case Reviews in the Community
- Facilitating Clinical and Psychosocial HIV Services

Retrieved from: https://www.cdc.gov/hiv/group/gender/pregnantwomen/emct.html

Adaptation of CDC EMCT Initiative

- **Patient-Centered Treatment Adherence Program**
  - Designed to retain postpartum women in care and
  - Improve health outcomes along the HIV Continuum of Care
  - Facilitate comprehensive clinical care and
  - Social services for women
- **Incorporates and builds on findings …**
  - Centers for Disease Control's (CDC)
  - EMCT Stakeholders Comprehensive Care Working Group:
    - Elimination Mother to Child Transmission (EMCT)
    - Facilitated by Rutgers School of Nursing (Francois-Xavier Bagnoud Center)
    - Charged to develop strategies …

Methods: The Assessment Tool

Key Areas and Examples

1. **HIV Diagnosis and HIV Care**
   Newly Diagnosed, Detectable Viral Load
2. **Obstetric Care**
   Insufficient Prenatal Care, Preterm Delivery
3. **Social Barriers**
   Key Support Unaware of Diagnosis, Low Health Literacy
4. **System-Related**
   Insurance Loss Postnatally, Mother-Child Receiving Services diff. Jurisdictions
5. **Mental Health / Behavioral Disorders**
   Current/Previous History of Depression; Mental Diagnosis not Managed
6. **Other Factors**

Methods: Original Assessment Tool

Assessment Tool: Creating a Safety Net to Enhance Postpartum Retention In HIV Care

Pregnant women living with HIV often have reduced engagement in HIV care and lower adherence to antiretroviral medications after delivery. This checklist is designed to assist clinical providers and members of the multidisciplinary healthcare team to identify risk factors that can be associated with poor engagement and retention in HIV care in order to connect the pregnant or postpartum woman to appropriate support services. The assessment tool should be used during pregnancy and continued postpartum in obstetric, HIV, and pediatric care settings. **Check all risk factors that apply** and use the comments section to document additional information to assist in developing a plan of care.

HIV diagnosis and care	✓	Comments
New HIV diagnosis during pregnancy		
Late HIV diagnosis (in 3rd trimester/postpartum)		
Current, detectable HIV RNA (viral load)[1]		
History of detectable HIV RNA in the past year		
Lack of engagement in HIV care prior to or during pregnancy, e.g., 2 or more consecutive missed visits for HIV care		
Pregnant woman with perinatally acquired HIV infection		
Has an HIV positive child		

Methods: Our Initiative 1

1. Goal #1: Exploration
   a. Convene Advisory Group
   b. Identify Barriers
   c. Build the Intervention
      - Community Stakeholders
      - Consumers
      - Patient Care Providers
        - Medical Providers
        - Mental Health Professionals
        - Case Managers
        - Outreach Specialists

Methods: Our Initiative 2

2. <u>Goal #2: Implement Intervention</u>
   - Modify the Instrument
   - Pilot the Instrument
   - Build an Integrated and Sustainable Plan

Methods: Our Initiative 3

Fall / Winter 2020

3. Goal #3: Measure Effectiveness

- Approximately one-year follow-up
- Compare pre-intervention to post-intervention

Preliminary Findings

- Key Areas for Improvement Identified
- The Tool was Missing:
  - Who, What and When
    - Prioritizing the Need
    - Prioritizing the Resources
    - Establishing the Timeframe
    - Clearly Identifiable: Resolution, Reoccurrence
    - Emergency/Other Contact

Initiative: Advisory Team Meetings

- Insights / Ideas:
  - Converting to an Acuity Scale
  - Time-stamped by Trimester
  - System Level:
    - Transportation Alternatives (Lyft / Uber)
  - Social Level:
    - Building Social Networks
    - Social Media
  - Patient Level: “Aha!” Moment
  - Communication with Stakeholders
    - (between and amongst)

Methods

THE PROCESS:

- Consumer Key Informant Sessions
  - English, Spanish, Haitian Creole
- Modification of the Tool
  - Iterative Process
- Field Test the Tool
  - Outreach Worker and Social Workers
- Modification of the Tool
  - Iterative Process
- Pilot the Tool

Haitian Creole Language: Key Informants

Conducted Dec 2018

- Consumer Key Informants: 2 Participants
  - Consent Forms Signed
- Participant Profile
- Participant #1: First Pregnancy
- Participant #2: >1 Child (1 y.o. to 12 y.o.)

Section 1: Personal Experiences

Participant	How many children do you have?	How long ago was your last child born?	How many children under age 18 live with you?	Do you have a primary care provider?	Is this the same provider you had before your pregnancy?	Seeing a PCP within 3 months after delivery	Do you have a pediatrician for your child?	Difficulty getting insurance for yourself after pregnancy	Difficulty getting insurance for the baby
Participant 1	1	1 Year	1	Yes	No	Yes	Yes	Yes	Yes
Participant 2	>5	1 Year	>5	Yes	No	Yes	Yes	Yes	Yes

Section 2: Life after the birth of an infant

- **Barriers cited:**
  - **Transportation**
    - **“It’s hard to travel with newborn on the bus”**
    - **“Other transportation means are too pricey”.**
  - **Lack of family/social support after birth**
    - **“Few family members helped with household chores and childcare”.**
    - **P1 did not disclose to family members and didn’t want them to be involved in her healthcare.**
  - **System-Level**
    - **Not meeting anyone from the Pediatric Screening clinic prior to delivery.**
    - **Did not remember being informed about the screening process.**

Section 3: PRIM clinic experience

- **Strengths Identified:**
  - **Participants reported overall positive experience in PRIM Clinic.**
  - **>=1 Creole-speaking staff member for interpretation during clinic visits.**
- **Opportunities for Improvement:**
  - **Participants reported not receiving material to take home.**
  - **Participants were not aware of our Group Prenatal Program.**
  - **Neither engaged in the prenatal classes with Patient Educator.**

Section 4: Remaining in Primary Care 1

- **Barriers Shared:**
  - **Immediately post-delivery: Transportation, lack of family support, lack of babysitting, conflict with availability of appointments.**
  - **Insurance coverage: Change in coverage (Medicaid to Ryan White. Case managers are not available as was in pregnancy)**
  - **Disclosure: One participant avoided an appointment, saw someone she knew at clinic.**
  - **Hospital: Unfavorable Staff Attitudes; Unwillingness to help,**
  - **Clinic PCP Providers: Satisfaction overall.**

We Wanted to Hear from Them

Suggestions for Improvement

- To improve:
  - Waiting Time …
  - Additional Staff Members Needed
    - Help with Patient Barriers
    - Help with Linkage to Resources

Enhanced Assessment Tool

POSTPARTUM RETENTION TOOL (MIAMI) (04-02-2020)

MRN **Age** **Pregnancy:** weeks days **Trimester** ☐ 1st Trimester (0–13 wks, 6 days) ☐ 2nd Trimester (14 –27 wks, 6 days) ☐ 3rd Trimester (28–40 wks, 6 days) ☐Postpartum
# of appointments attended/total (%); **Last missed appointment;**
Notes:

	OPPORTUNITIES/STRENGTHS	REFERRAL/RECOMMENDATION (Date)	OUTCOME (FOLLOW-UP)
MENTAL HEALTH Current/previous history of depression ☐ Mental health diagnosis ☐ Substance abuse/alcohol abuse ☐ Developmental delays/intellectual disability ☐ Intimate partner violence ☐			
BARRIERS TO CARE Transportation ☐ Insurance Issues ☐ Inability to pay copays/out of pocket expenses ☐ Medicaid for pregnancy only (loses coverage PP) ☐ No childcare ☐ Recent transfer to adult (from peds/adol) ☐ No or non-working phone ☐ Clinic scheduling issues (work, childcare, too far) ☐			

In Summary

Eliminating Perinatal HIV & Postnatal Care Engagement

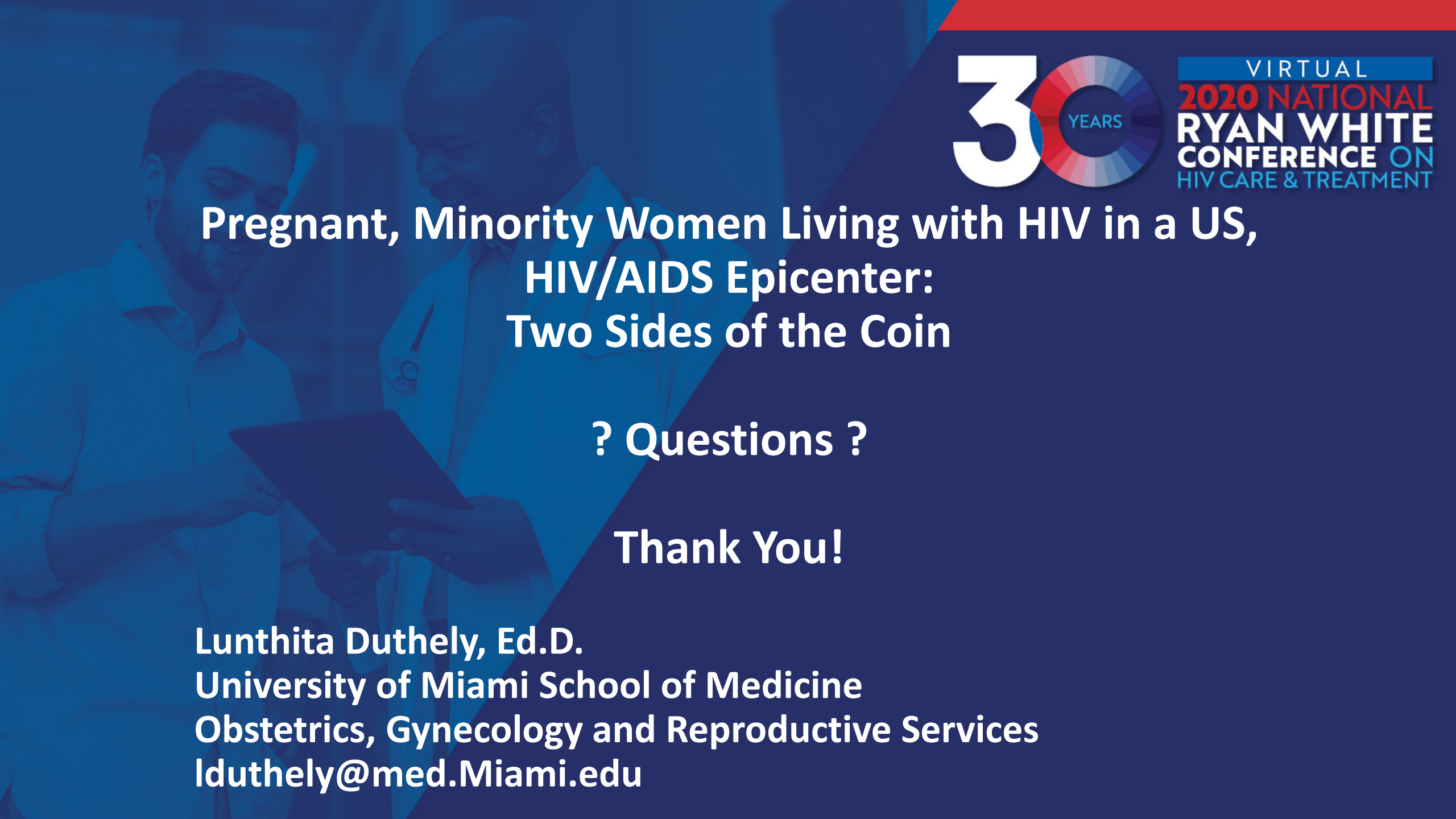
- Two Intertwined and Complex Issues
- Multi-level, Interdisciplinary, Multi-pronged Approach
- Consider all Stakeholders: Patient to Community
- Screening, Referrals, Tracking
  - Begin Prenatally
  - Continue Post-natally
- Continuous Evaluation

Acknowledgements

Patients

Providers and Staff

HRSA Ryan White Part D



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? Questions ?

Thank You!

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