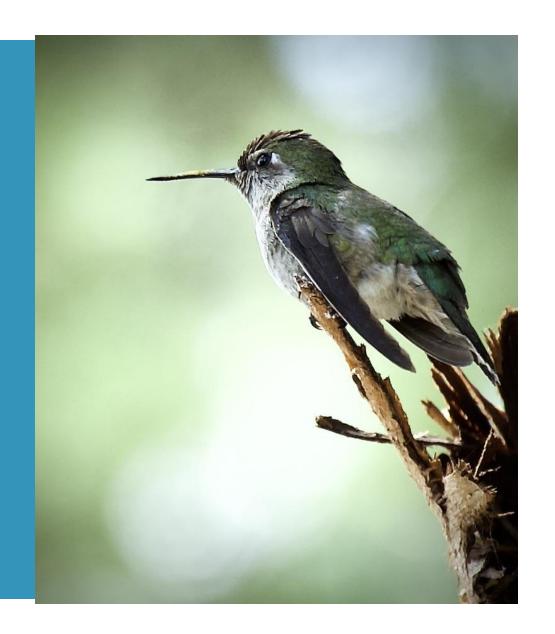
# Breastfeeding and Living with HIV

A New Paradigm in Patient Care

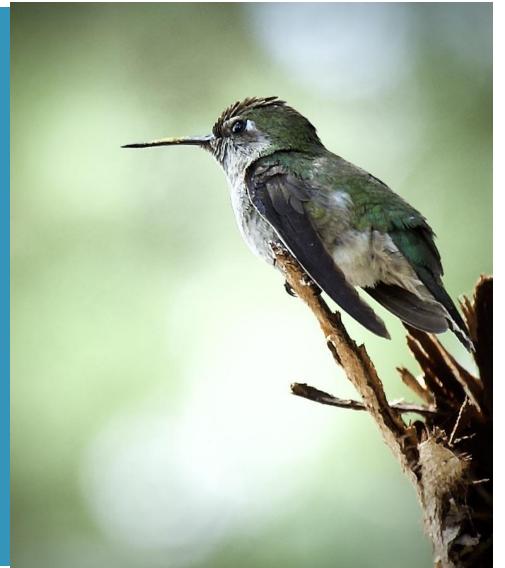
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# Disclosures

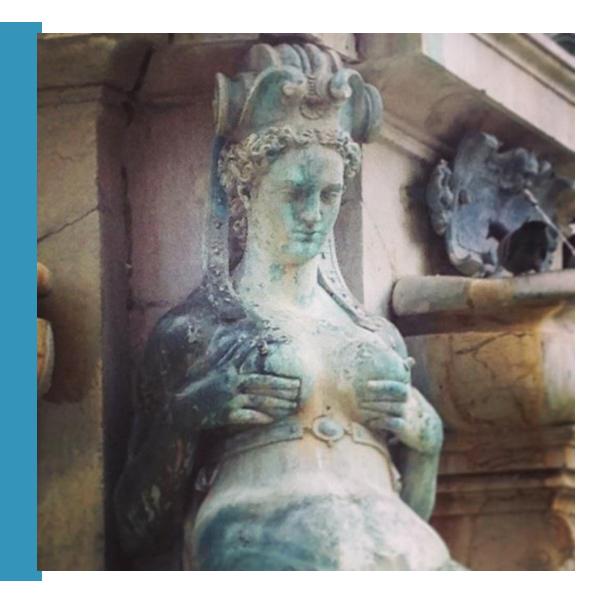


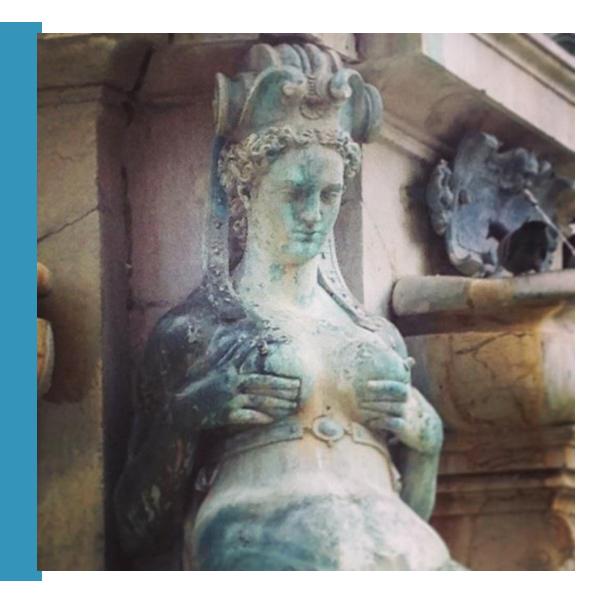
I have no relevant financial or non-financial relationships to disclose.

## Language



Throughout this talk I will use the terms
"woman" and "mother" and "breastfeeding."
These should be taken to include people
who do not identify as women but are
pregnant or have given birth and are feeding
their baby from their mammary glands.





# Stigma

Women \*

Race

Ethnicity

Culture

Illness

Sex

Sexualized organs

National origin

**LGBTQI** 

Economic factors

\*across the gender spectrum

## Intersectionality

### Intersectionality

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\*across the gender spectrum

Don't breastfeed.

#### New York State Department of Health (2004, 2018)

- Woman who are *HIV-positive should be counseled not to breastfeed* because of the risk of HIV transmission via breastmilk. In addition, they should be referred for appropriate HIV care.
- The HIV status of a woman should never be assumed; all pregnant women and women planning to have children should be counseled, and testing for HIV should be recommended. The risk of transmitting HIV to the infant needs to be fully explained so that women can make appropriate choices regarding getting HIV tested before and/or during pregnancy.
- At the time of delivery if a woman's HIV status is unknown, expedited testing should be
  offered. Women should know that even if they refuse testing, there is universal mandatory
  testing for their newborn. For women without prenatal HIV test results who decline HIV testing
  during delivery, hospitals in NYS are required to conduct expedited HIV testing of all newborns
  with the results available within 12 hours of testing using the Oraquick HIV test.
- Women who use IV drugs, or are involved in other high risk behavior for HIV who initially test HIV-negative during pregnancy should be retested at labor.
- Regardless of their HIV status, women who use IV drugs should be counseled against breastfeeding because of their ongoing risk of HIV infection. Transmission rates via breastfeeding are highest at the time of primary HIV infection and seroconversion. In addition to HIV risk, drugs can be transmitted via breastmilk. Counseling and assistance in stopping drug use should be provided.
- Women who are HIV-negative but are involved in high risk sexual behavior should be strongly counseled to use condoms, both to protect herself, and to prevent mother-to-child HIV transmission. Transmission rates via breastfeeding are highest at the time of primary HIV infection and seroconversion.
- Women who are counseled not to breastfeed, should be given appropriate education on the nutritional needs of their infants, and instructed on how to feed their infants with formula.

#### New York State Department of Health (2018)

- The following women should delay breastfeeding until HIV infection has been excluded:
- Women who have no documentation of a negative HIV test
- Women who have symptoms that are suggestive of acute HIV infection since their last HIV test
- Women with current or ongoing high risk factors in the absence of an HIV risk reduction plan
- Women for whom breastfeeding should be delayed may temporarily pump and discard breast milk to maintain lactation

#### New York State Department of Health (2018)

- Although the risk of MTCT (maternal to child transmission) is significantly lower
  with the use of combination ART and an undetectable viral load, neither infant
  antiretroviral prophylaxis nor suppressive maternal postpartum ART completely
  eliminates the risk of HIV transmission through breast milk
- Breastfeeding is not recommended for women in the United States with confirmed or presumed HIV infection, because *safe alternatives are available*

"Low Resource Settings"

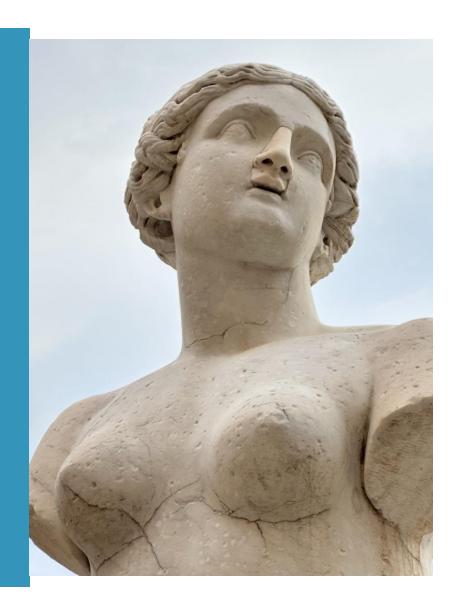
- High infant mortality
- Limited access to safe water
- Lack of affordable formula

Without ART, rates of transmission are 15-20% within 2 years

#### "Low Resource Settings"

Pre-ART studies demonstrated an increased risk of transmission with "mixed feeding," highest with introduction of table foods prior to 2 months of age.

Exclusive breastfeeding was recommended for 6 months followed by abrupt weaning. Abrupt weaning was found to be associated with more viral shedding into breastmilk, so 2-4 weeks for weaning became the recommendation.



Why Breastfeed?

Breastfeeding Protects Against Maternal Disease

### Breastfeeding Protects Against Maternal Disease

- Breast cancer
- Ovarian cancer
- Endometrial cancer
- Thyroid cancer
- Osteoporosis
- Cardiovascular disease
- Hypertension
- Hyperlipidemia
- Type 2 Diabetes
- Postpartum hemorrhage

Breastfeeding Protects Against Infant Disease

### Breastfeeding Protects Against Infant Disease

- Asthma
- Otitis Media
- Cancer
- Type 1 and Type 2 Diabetes
- SIDS
- Respiratory infections including pneumonia, RSV, Pertussis
- Gastrointestinal infections
- Bacterial meningitis
- Eczema
- Obesity
- Dental caries
- Celiac disease
- NEC (premature infants)

**United States** 

2016 – one third of providers were aware that their patients [living with HIV] breastfed after being counseled not to

- How HIV is transmitted via breastmilk is not well understood
- Most studies had problems
  - Late initiation of maternal ART (third trimester or later)
  - Short duration of postpartum ART (6 months)
  - · Limited data on maternal plasma VL during breastfeeding
- Studies with these flaws show transmission rates from 0.2-3.1%

### High-Income Settings (Europe, Canada, and the US)

(Case series, observational studies)

- ART generally started in the first trimester
- Viral loads were suppressed and monitored for most, but not all
- Infant prophylaxis varied (medication, timing, duration) or was absent
- Studies were small, some with incomplete follow up
- Potential modifying factors such as mastitis, formula-supplementation for various reasons, weaning challenges were not assessed
- There were no cases of transmission related to breastfeeding identified

The PROMISE Trial (2018, 2021)

The PROMISE Trial

"Promoting Maternal-Infant Survival Everywhere"

#### The PROMISE Trial

- Randomized trial with 2 treatment arms
- Population of a locale without available ART
- 2431 dyads
- Infants were uninfected at the start
- Dyads were randomized to maternal ART or infant nevirapine prophylaxis
- Maternal viral loads and CD4 counts were measured at several points
- Infant infection was assessed at several points
- Neither baseline viral load nor CD4 count were associated with transmission
- Time-varying viral load (increased) and CD4 count (decreased) were associated with transmission in the maternal ART group but not in the infant prophylaxis group
- Dyads were followed through 18 months or cessation of breastfeeding

#### The PROMISE Trial

- Transmission rates were 0.3% at 3 months and 0.6% at 6 months
- 2 transmissions occurred with undetectable maternal viral loads at the time the infant tested positive both had detectable viral loads at delivery and later
- Other authors compared these data with the "Partner" study which identified no transmissions over 76,000 sex events between sero-discordant male partners. This study was instrumental in quantifying risk in the U=U campaign.
- If the number of breastfeeding episodes is estimated based on the typical feeding frequency of an infant by age, this is more than 3 million feeding episodes total
- The incidence rate is therefore approximately 0.053 transmissions per 100,000 feeding episodes
- While not zero, this rate is comparably low

- Other, smaller studies had results consistent with this study.
- There were very few transmissions
- Most transmissions occurred with high maternal viral loads, elevated viral load at delivery, cessation of maternal ART, medication that is no longer recommended, or late initiation of ART
- Treatment regimens varied
- Adherence was variable
- Interventions for increased viral loads varied
- No studies have systematically evaluated outcomes with initiation of ART prior to pregnancy or in the first trimester

#### Centers for Disease Control and Prevention

Mothers with HIV who want to breastfeed\* should receive patient-centered, evidence-based counseling on infant feeding options to allow for shared decision-making

Breastfeeding provides certain benefits to the breastfeeding parent and infant that are not possible with formula feeding

Providers should recommend exclusive breastfeeding for the first 6 months of life followed by the introduction of complementary foods with continued breastfeeding

\*either direct feeding or with expressed milk

#### Centers for Disease Control and Prevention

- The risk of transmitting HIV through breast milk can be reduced by:
- Replacing breastfeeding with properly prepared formula or pasteurized donor human milk from a milk bank. This eliminates the risk of HIV transmission to the infant after birth.
- Achieving and maintaining viral suppression through ART during pregnancy, delivery, and after birth. This decreases risk of transmission through breastfeeding to *less than 1%*, but not zero.
- If mothers choose to breastfeed, providers should emphasize the importance of taking ART as directed and sustaining an undetectable HIV viral load. Providers should also address challenges to taking ART as directed after birth.
- Mothers with HIV who choose to breastfeed should receive close follow-up care and be supported in minimizing the risk of HIV transmission to their infants.
- There is no evidence that formula supplementation or introducing table foods when appropriate increases the risk of transmission in the setting of ART with suppressed viral load.

#### Centers for Disease Control and Prevention

- Infant prophylaxis with ART is recommended
- Extended infant ART should be considered for certain circumstances.
- Infant testing schedules are available and are risk-stratified, but the evidence is not clear, and transmissions have occurred long after weaning
- In the case of a detectable viral load in a breastfeeding parent... recommend breastfeeding be stopped temporarily or discontinued and replacement feeding\* initiated while the viral load is rechecked, causes for the viremia are assessed, and, when applicable, adherence counseling is reinforced
- Depending on the level and persistence of viremia in the breastfeeding parent, next steps may include initiating or modifying infant antiretroviral prophylaxis, permanently stopping breastfeeding, and considering the need for additional infant HIV testing
- If the repeat parental viral load is undetectable, a joint decision should be made by the parent and providers about whether breastfeeding may resume

\*stored milk, donor milk, formula, flash heated breastmilk

#### Centers for Disease Control and Prevention

- Accessing an adequate supply of formula may be difficult for some people, and there may be cost and access barriers to obtaining donor milk. For anyone with HIV who chooses replacement feeding, systems of care should ensure supportive access to clean water, safe formula, and banked human milk, if available.
- Individuals with HIV who choose to formula feed should be supported in this decision. Providers should ask about potential barriers to formula feeding and explore ways to address them

**Centers for Disease Control and Prevention** 

Engaging Child Protective Services or similar agencies is not an appropriate response to the infant feeding choices of an individual with HIV

#### **American Academy of Pediatrics**

- Pediatric health care professionals should be aware of the potential risk of HIV transmission during the antepartum, intrapartum, and postpartum periods (including while breastfeeding) for infants born to people with HIV.
- Pediatric health care professionals should be aware of the recommendation for routine, opt-out HIV testing for all pregnant people in the United States.
- For any person in labor or postpartum with undocumented HIV infection status during the index pregnancy:
  - Perform HIV testing as soon as possible, unless the person declines.
  - If HIV rapid test results are positive:
    - Infant feeding options should be discussed. If the person desires to breastfeed, human milk should be expressed and stored until a confirmatory HIV test result is available. The infant should receive formula or certified, banked donor human milk while awaiting confirmatory test results. Skin-to-skin care can be initiated to maintain milk supply.
    - Consultation with a pediatric HIV expert (ie, National Perinatal Hotline, 1-888-448-8765) is recommended to determine whether infant ARV prophylaxis is indicated. Infant prophylaxis should ideally be initiated within 6 hours of birth.
    - If HIV infection is ruled out with confirmatory testing, breastfeeding can safely be initiated.
    - If acute HIV infection is suspected, an HIV RNA polymerase chain reaction test (eg, HIV viral load test) should be obtained as part of confirmatory testing before breastfeeding is initiated.
  - If HIV rapid test results are negative, breastfeeding can be initiated.
  - If rapid HIV testing during labor is not available or the pregnant person declines testing, providers should consider potential risk factors for HIV acquisition (eg, intravenous drug use or high-risk sexual exposures) versus the benefits of initiating early breastfeeding.

#### **American Academy of Pediatrics**

- For pregnant and postpartum people with HIV:
  - Health care professionals should advise parents with HIV that the only method of infant feeding that eliminates the risk of postnatal HIV transmission to the infant is complete avoidance of breastfeeding.
  - Health care professionals should explore and address barriers to replacement feeding (with infant formula or certified, banked donor human milk), including the need for financial support.
  - Health care professionals should be prepared to counsel people with HIV who express a desire to breastfeed their infant. Counseling should include the following:
    - Explore reasons for wanting to breastfeed and provide guidance to address parental goals where possible (eg, alternative ways of bonding with the infant, approaches to avoiding HIV infection status disclosure, validating parental role regardless of infant feeding approach);
    - Educate parents regarding the potential risk of HIV transmission throughout the duration of breastfeeding and inform parents that ART and infant ARV prophylaxis significantly reduce, but do not eliminate, this risk.
  - Breastfeeding should be supported for people with HIV who strongly desire to breastfeed after comprehensive counseling if all of the following criteria are met:
    - ART was initiated early in or before pregnancy;
    - There is evidence of sustained viral suppression in the parent (HIV viral load <50 copies per mL);
    - The parent demonstrates a commitment to consistently taking their own ART and to giving infant ARV prophylaxis;
    - The parent has continuous ART access.

#### **American Academy of Pediatrics**

- Involvement of a multidisciplinary team in the counseling and management of a breastfeeding parent with HIV is recommended. For example, this team might include the pediatric providers who will care for the infant, the breastfeeding parent's HIV care and obstetric providers, lactation consultants, and a pediatric HIV expert.
- Providers should recommend the following strategies to reduce the risk of HIV transmission via breastfeeding:
  - Exclusive breastfeeding (no formula or other foods) through the first 6 months;
  - Continuous ART for the breastfeeding parent with sustained undetectable viral load throughout the duration of breastfeeding;
  - Regular assessment of viral load in the breastfeeding parent (eg, every 1–2 months);
  - Infant ARV prophylaxis in consultation with a pediatric HIV expert;
  - Gradual weaning over 2 to 4 weeks, rather than abruptly.
- Breastfeeding infants should be screened for HIV using nucleic acid testing (eg, plasma HIV RNA or DNA polymerase chain reaction) at 14 to 21 days, 1 to 2 months, and 4 to 6 months of life and then every 2 months throughout lactation and at 4 to 6 weeks and 3 and 6 months after weaning.
- Breastfeeding infants who receive extended ARV prophylaxis beyond 4 to 6 weeks of life should periodically be screened for hematologic and liver toxicity, as these complications can be associated with ARV drugs that are commonly used for infant prophylaxis (eg, a baseline complete blood count and liver enzymes can be obtained at the onset of infant prophylaxis and repeated after 2 to 4 weeks, then repeated only if abnormal or if clinically indicated).
- A decision to breastfeed by a person with HIV who is on ART and virally suppressed should not constitute grounds for a referral to child protective services agencies.
- Breastfeeding is not recommended for people with HIV who are not on ART or who do not take ART consistently, people without a sustained undetectable HIV viral load, or people newly diagnosed with HIV infection in pregnancy or postpartum. Those who choose to breastfeed despite this recommendation should receive ongoing intensive counseling and consultation with a team of experts (eg, pediatric HIV expert, social worker, ethicist, etc) to engage the person with HIV in a culturally effective manner that seeks to address both their health as well as the child's.
- Parents with HIV who are not virally suppressed on ART should avoid premastication of food for infants. This recommendation should be discussed in a culturally sensitive and nonjudgmental manner.

### Current Guidance

#### **American Academy of Pediatrics**

- For pregnant and postpartum people who do not have HIV but who are at high risk of acquiring HIV (eg, people who inject drugs or who have sexual partners living with HIV who are not virally suppressed):
  - Counseling should be provided regarding the potential risk of HIV transmission to an infant through human milk if HIV acquisition were to occur while breastfeeding.
  - Frequent HIV testing should be performed during pregnancy and breastfeeding (eg, every 3 months).
  - Education about HIV prevention should be provided and HIV preexposure prophylaxis (PrEP) should be offered.
- If acute HIV infection is suspected in a person who is breastfeeding:
  - The infant should not consume human milk from that person until HIV infection is confirmed or ruled out. Human milk can be expressed and stored until a confirmatory HIV test result is available. The infant should receive formula or certified banked donor breast milk while awaiting confirmatory test results. Skin-to-skin care can be initiated to maintain milk supply.
  - If HIV infection is ruled out, breastfeeding can resume.
  - If HIV infection is confirmed:
    - Breastfeeding should be discontinued;
    - The infant should undergo HIV testing, with follow-up testing at 4 to 6 weeks and 3 and 6 months after breastfeeding cessation if the initial test result is negative;
    - Consultation with a pediatric HIV expert (ie, National Perinatal Hotline, 1-888-448-8765) is recommended regarding decisions about postexposure ARV prophylaxis for the infant;
    - The breastfeeding parent with HIV should be promptly linked to care and receive ART, psychosocial support, and counseling on breastfeeding cessation.

### Current Guidance

#### **World Health Organization**

- Mothers known to be HIV-infected should be provided with *lifelong* antiretroviral therapy or antiretroviral prophylaxis interventions to reduce HIV transmission through breastfeeding.
- National or sub-national health authorities should decide whether health services will principally counsel mothers known to be HIV-infected to either breastfeed and take antiretrovirals, or, avoid all breastfeeding.

### Current Guidance

#### World Health Organization

In settings where national health authorities are recommending breastfeeding for HIV-infected mothers:

- Mothers known to be HIV-infected (and whose infants are HIV uninfected or of unknown HIV status) should exclusively breastfeed their infants for the first 6 months of life, introducing appropriate complementary foods thereafter, and continue breast feeding.
- Mothers living with HIV should breastfeed for at least 12 months and may continue breastfeeding for up to 24 months or longer (similar to the general population) while being fully supported for ART adherence (see the WHO Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection for interventions to optimize adherence).
- In settings where health services *provide and support lifelong ART*, including adherence counselling, and promote and support breastfeeding among women living with HIV, the *duration of breastfeeding should not be restricted*.
- Breastfeeding should then only stop once a nutritionally adequate and safe diet without breast milk can be provided.
- National and local health authorities should actively coordinate and implement services in health facilities and activities in workplaces, communities and homes to protect, promote and support breastfeeding among women living with HIV.

# Ethical Considerations

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- Autonomy
- Beneficence
- Non-maleficence
- Reproductive Justice

# Ethical Considerations

- Autonomy
- Beneficence ART
- Non-maleficence remove barriers to ART
- Reproductive Justice

### Autonomy

#### Counseling should respect patient autonomy

- Evidence-based
- Patient-centered
- Respectful
- Non-judgmental
- Shared decision-making

Breastfeeding is a human right.

Breastfeeding is a human right.

- Breastfeeding is a social and biological process wherein women must have the right of self-determination
- Breastfeeding is a maternal and child health imperative and reproductive right
- It is important to re-orient the paradigm from the current view that breastfeeding is a "lifestyle choice," to a paradigm that views breastfeeding as a reproductive health, rights and social justice issue so as to ensure the social, economic and political conditions necessary to promote success
- Women's decisions to breastfeed should not result in the loss of their economic security or any rights or privileges to which they are otherwise entitled

Labbock (2008)





"Breastfeeding is a human rights issue for both the child and the mother."

"We remind States of their obligations under relevant international human rights treaties to provide all necessary support and protection to mothers and their infants and young children to facilitate optimal feeding practices. States should take all necessary measures to protect, promote, and support breastfeeding, and end the inappropriate promotion of breast- milk substitutes and other foods intended for infants and young children up to the age of 3 years."

- Intersectionality
- Social and structural determinants of health
- Gender equity
- Culturally responsive practices

#### Counseling should support reproductive justice

- Barriers to alternative feeding
- Access to clean water
- Barriers to breastfeeding
- Healthcare costs
- Access to ART
- Social, cultural, family concerns
- Stigma
- Lack of provider comfort

### Team Components

- Infectious Disease Specialist
- Obstetrician-Gynecologist, Family Physician, Nurse-Midwife
- Pediatrician
- Breastfeeding Medicine Specialist
- Lactation Consultant (IBCLC)
- Postpartum nursing staff
- Case Manager
- Reproductive Psychiatrist
- Peer support

### Stigma

- Coercion
- Parentalism (paternalism)
- Shaming
- Undue surveillance
- Withholding information
- Imposing a value system
- Assumptions
- Exacerbating health inequity
- Oppression

## Counseling

### Counseling

- Facts
- Active listening
- Open communication
- Avoidance of stigmatizing or coercive language
- Adoption of facilitative language

Instead of: "I recommend..."

Use: "It is reasonable to consider..."

### The Future

New studies are largely still conducted in Africa.

### Questions?



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