Postpartum Care for Women Living With HIV (WLWH) and Their Newborns: How Health Home Care Managers Can Provide Support to Facilitate Improved Health Outcomes

August 15, 2018
Webinar Series for Health Home Care Managers

- **Part 1**: Preconception, Contraception, Conception/Pregnancy Counseling and Care for Women Living With HIV (WLWH) & the Prevention of Mother-to-Child Transmission (PMTCT) of HIV

- **Part 2**: Postpartum Care for WLWH, Care of HIV-Exposed but Uninfected Newborns & Breastfeeding Recommendations to PMTCT for both WLWH and Women at High Risk for Acquiring HIV

- **Part 3**: Post Exposure Prophylaxis (PEP) and Pre-Exposure Prophylaxis (PrEP) & Care of Women at Risk for HIV
Objectives for Health Home Care Managers (1)

- Synthesize key information from Part-1 of this webinar series
- Identify medical and supportive care planning needs specific to WLWH as part of hospital admission and postpartum hospital discharge
- Explain the importance and rationale for contextualizing postpartum care as the “fourth trimester”
- Describe what birth spacing means and why it’s important for the health of women and children
Objectives for Health Home Care Managers (2)

• Identify challenges experienced by WLWH that interfere with postpartum retention in care
• Understand breastfeeding recommendations for WLWH and for women at high risk for HIV acquisition
• Recognize the complexities experienced by WLWH regarding infant feeding including stigma, disclosure, and self-worth
• Identify the core components of care recommended for HIV-exposed newborns
Brief Recap from Part 1: Preconception, Contraception, Conception, Pregnancy & MTCT Prevention for WLWH

• Preconception Goals (1):
  – Prevent unintended pregnancy
  – Prevent HIV transmission to partner
  – Optimize maternal and paternal health
  – Improve maternal and fetal outcomes
Brief Recap from Part 1: Preconception, Contraception, Conception, Pregnancy & MTCT Prevention for WLWH

- Preconception Goals (2):
  - Prevent perinatal HIV transmission through multiple interventions, including initiating antiretroviral therapy (ART) for maternal health and prevention of mother-to-child transmission (MTCT) through rapid, sustained maternal viral load suppression (VLS)
Preconception Counseling and Optimizing Health for WLWH (1)

• Active, ongoing assessment of a woman’s pregnancy intention
• Discussion of contraceptive options
  – prevention of *unintended* pregnancies, and
  – spacing and timing of *intended* pregnancies
Preconception Counseling and Optimizing Health for WLWH (2)

- Emphasize, as indicated
  - health promotion
  - risk reduction
  - behavioral change
- Identify and address medical, supportive and psychosocial needs
- ART adherence/VLS (engagement and retention in care, including GYN care)
- HIV disclosure/partner services
- STI screening and treatment
- PEP/PrEP for serodiscordant couples
- Exercise/physical activity
- Healthy BMI
- Vaccinations
- Folic acid
- Tobacco/alcohol/substance use treatment/cessation
- Mental health services
- Housing
- Transportation
- Food
- Social support
Brief Recap from Part 1: Preconception, **Contraception**, Conception, Pregnancy & MTCT Prevention for WLWH

**• Contraception Guidance (1):**
  - HIV infection does not preclude the use of any contraceptive method; however, drug-drug interactions between hormonal contraceptives (e.g., pill, patch, ring, injection, implant) and antiretroviral (ARV) medications should be considered
  - Drug-drug interactions may include lower contraceptive efficacy
  - WLWH should discuss their options with a provider

Brief Recap from Part 1: Preconception, Contraception, Conception, Pregnancy & MTCT Prevention for WLWH

• Contraception Guidance (2):
  – Dual protection/safer sex practices should be promoted, including the use of condoms, to prevent HIV/STI acquisition/transmission
  – Access to reproductive services with autonomous decision-making is critical

Brief Recap from Part 1: Preconception, Contraception, Conception, Pregnancy & MTCT Prevention for WLWH

• Conception Guidance (1):
  – Assisted insemination at home or at provider’s office with a partner’s semen during the peri-ovulatory period
    • peak fertility: 2 to 3 days before and day of ovulation
  – Donor sperm
  – Peri-ovulatory intercourse
  – PrEP for the partner without HIV
  – ART and VLS for the partner living with HIV
  (Undetectable=Untransmittable; U=U)
Brief Recap from Part 1: Preconception, Contraception, Conception, Pregnancy & MTCT Prevention for WLWH

• Conception Guidance (2):
  – Partners living with HIV infection should attain maximum viral load suppression before attempting conception

  - Minimize risk of HIV sexual transmission
  - Minimize risk of HIV transmission to newborn
Brief Recap from Part 1: Preconception, Contraception, Conception, Pregnancy & MTCT Prevention for WLWH

- Pregnancy and MTCT Prevention Guidance (1):
  - Early is key!
    - Early identification of pregnancy
    - Early collaboration with experienced HIV provider
    - Early prenatal care

- Risk of MTCT of HIV can be dramatically lowered with specific strategies

- Many factors influence risk of perinatal transmission
Brief Recap from Part 1: Preconception, Contraception, Conception, Pregnancy & MTCT Prevention for WLWH

- **Pregnancy and MTCT Prevention Guidance (2):**
  - Factors which influence risk of transmission
    - mode of delivery; duration of membrane rupture; maternal plasma viral load and CD4 count; maternal ART adherence, maternal co-infections; invasive obstetrical procedures; breastfeeding; newborn ARV prophylaxis
- Maternal ART with increased frequency of VL monitoring
- Maternal rapid, sustained VLS
- Exclusive formula feeding (no breastfeeding)
- No maternal pre-mastication (pre-chewing infant/child’s food to soften, warm or cool)
- Newborn ARV prophylaxis
HIV Prevalence and Number of HIV Positive Childbearing Women in New York State by Year of Delivery, 1988-2016

Approximately 400 HIV positive women give birth each year in New York State.

78% decline in number and 72% decline in rate from 1990 to 2016.
Number of HIV Infected Infants

Transmission Rate (per 100 HIV Exposed Infants)

≈ (25%)

(11.5%)

(1.2%)

(0.5%)

(0%)

0.5

0

5

10

15

20

25

30

0

50

100

150

200

250

300

350

400

450

500

Number and Rate of Mother-to-Child HIV Transmissions by Year of Delivery, New York State, 1997-2016

* 1990 - estimate based on 1,898 exposures and an estimated 25% transmission rate

**1997 data include February-December births.
Anticipatory Planning for Inpatient and Outpatient Postpartum Care for WLWH and Their Newborns

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Facilitating Best Practices for Best Outcomes
Inpatient Postpartum Care: What WLWH Need Prior to Hospital Admission

• Ensure the following:
  – She has made an informed decision about infant feeding in the setting of HIV (exclusive formula feeding is recommended for WLWH in the U.S.)
  – She has made an informed decision about birth spacing and understands her options for immediate postpartum long-acting reversible contraception (LARC)
What is Immediate Postpartum LARC?

- LARC methods are available to women in the hospital after a delivery and before discharge
  - Intrauterine Devices (IUDs) inserted ideally within 10 minutes of the delivery of the placenta
  - Hormonal implants inserted in the upper arm prior to hospital discharge

- Discussions about immediate postpartum LARC should take place during the last few months of pregnancy so a woman can make an informed decision and her provider can make necessary arrangements
Inpatient Postpartum Care: What WLWH Need Prior to Hospital Discharge (1)

• Ensure the following:
  – She is receiving her preferred suppressive antiretroviral regimen
  – She receives a prescription for herself (ART, OI prophylaxis) and her baby (ARV prophylaxis)

❖ Ideally, she’s discharged with a relabeled bottle of her baby’s ARV medication
  ➢ Eliminates need to take Rx to outpatient pharmacy (drop off/pick up)
  ➢ Reduces likelihood of an issue with insurance coverage for baby’s Rx
  ➢ Increases the likelihood baby will receive uninterrupted ARV prophylaxis → GOAL!
Inpatient Postpartum Care: What WLWH Need **Prior** to Hospital Discharge (2)

• Ensure the following:
  – She has HIV follow-up appointments already scheduled for herself and her baby
  – She knows her HIV and Pediatric care team/s and, if new to her, has met them in the hospital
  – She knows how to contact all medical and supportive service providers (provide phone numbers)

  • **These all facilitate and promote engagement and retention in care**
Inpatient Postpartum Care: What WLWH Need Prior to Hospital Discharge (3)

• Ensure the following:
  – She has a supportive community of family and friends to whom she is able to disclose her HIV status
  – She has a supportive medical team that understands the complexity and impact of stigma
  – She has partner/s that have been tested for HIV and linked to prevention services (PrEP/PEP) or HIV treatment as appropriate
Inpatient Postpartum Care: What WLWH Need Prior to Hospital Discharge (4)

• Ensure the following:
  – She has an effective form of contraception of her choosing and is knowledgeable about birth spacing (timing, risks and benefits)
  – She has been screened (and treated) for any STIs
  – She has been screened (and treated) for cervical dysplasia/cancer, if due
Inpatient Postpartum Care: What WLWH Need **Prior** to Hospital Discharge (5)

• Ensure the following:
  – She has received mental health screening for maternal depression (and referral/treatment, if needed)
  – She has received substance use screening (and offered referral/treatment, if needed)

• If she’s been in treatment and/or on medication-assisted treatment (methadone, buprenorphine) for opioid-use disorder, a transition plan should be in place with prescheduled appointments and arrangements for Rx’s
Inpatient Postpartum Care: What WLWH Need Prior to Hospital Discharge (6)

• Ensure the following:
  – She has been screened (and offered referral with safety planning) for intrapersonal violence/trauma
  – She has a social worker, case manager, home health nurse, patient navigator, and/or other support services as needed → health home care manager - YOU!
The Fourth Trimester: Redefining Postpartum Care

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A Needed Paradigm Shift to Optimize Health for All Women and Infants
Postpartum Care: Why it Matters for ALL Women (1)

- Morbidity and Mortality
  - About half of pregnancy-related deaths occur within a week of the end of pregnancy
  - More than half of pregnancy-related deaths are preventable
- NYS ranks 30th in the nation for its maternal mortality rate
- Racial disparities are significant - NYS Black women are almost four times more likely to die in childbirth than white women

Postpartum Care: Why it Matters for ALL Women (2)

• The leading causes of pregnancy-related deaths were:
  – Embolism (29%)
  – Hemorrhage (17.7%)
  – Infection (14.5%)
  – Cardiomyopathy (11.3%)

• Critical factors identified as contributing to death
  – Patient/family (lack of knowledge about warning signs and when to seek care)
  – Provider (misdiagnosis and ineffective treatments)
  – Systems of care (lack of coordination between providers)

Postpartum Care: Why it Matters for ALL Women (3)

• Addressing maternal morbidity and mortality is paramount, and postpartum care is **vital for many other reasons too!**

Given the urgent need to reduce severe maternal morbidity and mortality, ACOG has redefined the postpartum visit to reinforce the importance of the “fourth trimester” and to propose a new paradigm for postpartum care.

https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Obstetric-Practice/Optimizing-Postpartum-Care
Postpartum → The Fourth Trimester (1)

• The weeks following birth are a critical period for a woman and her infant, setting the stage for long-term health and well-being
  – Continued monitoring of chronic diseases, gestational diabetes, preeclampsia/hypertension and other pregnancy induced health conditions

• During this period, a woman is adapting to multiple physical, social, and psychological changes
  – Recovering from childbirth
  – Adjusting to changing hormones
  – Learning to feed and care for her newborn

https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Obstetric-Practice/Optimizing-Postpartum-Care
The Fourth Trimester (2)

In addition to being a time of joy and excitement, this “fourth trimester” can present considerable challenges for women, including:

– Lack of sleep
– New onset or exacerbation of mental health disorders
– Stress
– Pain
– Lack of sexual desire
– Urinary incontinence
– Breast/bottle infant feeding difficulties

https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Obstetric-Practice/Optimizing-Postpartum-Care
Optimizing Postpartum Care and Anticipatory Guidance

• To optimize postpartum care, **anticipatory guidance should begin during pregnancy** with development of a postpartum care plan that addresses:
  – Identification of primary health care provider beyond the postpartum period (**including HIV specialist**)
  – Ongoing management of chronic health conditions (**VLS**)
  – Transition to parenthood, including challenges of parenting
  – Postpartum recovery from birth
  – Purpose and value of postpartum clinical care as well as the types of services and support available (**Health Homes!**)
  – Importance of well-woman care

https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Obstetric-Practice/Optimizing-Postpartum-Care
What is Birth Spacing?

• Birth spacing is the practice of waiting between pregnancies
• The body needs to replenish and restore between pregnancies
  – Gives the woman time to replenish vital nutrients (folate, iron)
  – Allows organs to restore back to normal
• How much time between pregnancies?
  – The length of time between giving birth to one baby and getting pregnant with the next baby should ideally be at least 18 months, but less than 5 years
Additional Benefits to Birth Spacing

- Mom can give baby lots of attention promoting baby’s development
- Mom will have more time to bond with the baby
- Children who are adequately spaced are better prepared to begin kindergarten and perform better in school
- Families have more time to bond with each child
- Parents have more time for one another
- Parents can have time to themselves
- Families can have less financial stress
What Risks are Associated with Closely Spaced Pregnancies?

- Delayed prenatal care
- Premature birth
- Low birth weight
- Placental abruption

❖ These conditions are associated with infant mortality and other complications leading to ongoing health problems:

- Developmental delay
- Asthma
- Vision and hearing loss
Live Births within 24 Months of a Previous Live Birth, NYS 2012

Note: Denominator includes birth records where any date for a previous live birth was recorded.

Birth Spacing Interval in Months Among Live Births, NYS 2012
(Interval Between Date of Previous Live Birth and Date of Subsequent Conception)

- Note: Includes only records with complete date of last live birth (both Month and Year recorded) and only singleton births. Interval calculated as date from previous live birth to date of subsequent conception (calculated using obstetrical estimate of gestational age and date of subsequent live birth).

Live Births within 24 Months of a Previous Live Birth Compared to Percent of Live Births that were Subsequent Live Births by Maternal Age, NYS 2012

Note: Subsequent Birth means the birth record has any date for a previous live birth recorded.
Live Births within 24 Months of a Previous Live Birth by Maternal Educational Attainment, NYS 2012

Maternal Educational Attainment

Note: Denominator includes birth records where any date for a previous live birth was recorded.
Counseling Pathway for Women who are Pregnant, Postpartum, or with a Child less than 2 years old

START HERE

Are you thinking of getting pregnant again soon?

Yes or Unsure

- Advise to wait at least 18 months before trying again
- Educate on benefits/risks of birth spacing options

NO

- Discuss how long she wants to wait
- Discuss best FP method
- Provide/Refer for FP

Do you think you can wait

NO

- Safe motherhood counseling
- Educate on LAM
- Educate on FP counseling for HIV + women

YES

- Discuss appropriate FP methods (including LARC and sterilization)
- Provide or refer for FP

UNSURE

- Discuss and address concerns
- Discuss appropriate FP methods
- Reinforce messages
What is the Goal of Contraceptive Counseling?

A. To inform women about all postpartum contraceptive options
B. To have a woman leave the hospital after delivery with a plan for contraception (or a method already in place) that she feels comfortable with
C. To allow women to make the contraceptive choices that are best for them
D. To remind women that there is not one perfect method for everyone
E. To promote optimal health for women and families
F. All of the above!
Contraception and Postpartum

• Ideally, discussions and decisions about contraception occur **DURING pregnancy**, *not* initiated postpartum
• Are a collaborative, informed decision making process
  – Online decision making tool: [https://www.bedsider.org/methods](https://www.bedsider.org/methods)
• Address timing of return to ovulation postpartum
  – Non-breastfeeding: mean return of ovulation is 39-94 days postpartum
  – Ovulation: 20-71% ovulate (can become pregnant) before first menses
The Fourth Trimester: Expectations for Care

- All women should ideally have contact with a maternal care provider **within the first 3 weeks postpartum**
- The initial assessment should be followed up with ongoing care as needed, concluding with a comprehensive postpartum visit **no later than 12 weeks after birth**
- The timing of the comprehensive postpartum visit should be individualized and woman-centered

https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Obstetric-Practice/Optimizing-Postpartum-Care
BUT…

• Currently, as many as 40% of women do **not** attend a postpartum visit
  ➢ This is also true for WLWH

• Why is this a significant problem?
  – Underutilization of postpartum care impedes management of chronic health conditions, **such as HIV**, and access to effective contraception, which increases the risk of short interval pregnancy and preterm birth

• Postpartum attendance rates are lower among populations with limited resources, which contributes to health disparities
ART Adherence Differences between Antepartum (Prenatal) and Postpartum WLWH

- Meta-analysis: 51 studies; 20,153 pregnant WLWH (14 studies in U.S.)

- Adequate adherence (≥80% ARV*)
  - Antepartum: 75.7% (71.5%-79.7%)
  - Postpartum: 53.0% (32.8%-72.7%)

- Barriers to adherence:
  - Physical, economic, emotional stresses
  - Depression (especially postpartum)
  - Alcohol, drug use
  - ARV dosing, frequency or pill burden

Protective Factors for High ART Adherence:
  - Disclosure of HIV status
  - Social support


*threshold defining good adherence varied across studies (>80%, >90%, >95% and 100%)
Postpartum “Lost to Follow-up” (1)

- Postpartum care is often fragmented among maternal and pediatric health care providers and other specialists/services, and communication across the transition from inpatient to outpatient settings AND outpatient to other outpatient settings is often inconsistent
  - most women must independently navigate the postpartum transition

Health Home Care Managers can facilitate care coordination and support retention, which supports ART adherence, which supports VLS!
Postpartum “Lost to Follow-up” (2)

“I feel fine”
“I don’t have child care”
“I’m too tired”

“My baby’s health is more important than mine”
”I had to go back to work”

“I don’t have a ride”
“I don’t have time to go”

“I don’t have anyone to help”
“I couldn’t reschedule”

“My insurance ran out”

“I don’t have any more paid leave”

“I can’t afford the copay”
Postpartum “Lost to Follow-up” (3)

“My baby’s OK, can’t I just forget about HIV for awhile?!”
Strategies to Address Postpartum “Lost to Follow-up”

- **Strategies** for increasing attendance include:
  - Discussing the importance of postpartum care during prenatal visits
  - Using peer counselors, intrapartum support staff, postpartum nurses, and discharge planners to encourage postpartum follow-up
  - Scheduling postpartum visits during prenatal care or before hospital discharge
  - Using technology (e.g., email, text, and apps) to remind women to schedule postpartum follow-up
  - Increasing access to paid sick days and paid family leave
  - Addressing barriers to care (e.g., transportation)
  - Utilizing Health Home Care Managers
Supportive Service Needs of WLWH: Addressing Barriers to (Postpartum) Care

• Supportive services should be tailored to the individual woman’s needs and can include:
  – case management
  – child care
  – respite care
  – assistance with basic life needs, such as housing, food, and transportation
  – peer counseling
  – legal and advocacy services
Levels of Support to Promote Postpartum Follow-up

- **Routine**
  - Schedule appointments prior to delivery
  - Dispense adequate ARVs for mom and baby before hospital discharge

- **Enhanced**
  - Case management
  - Patient navigators

- **Intensive**

  **Health Home Care Managers have a vital role!**
Levels of Support to Promote Postpartum Follow-up

- Routine
- Enhanced
- Intensive

**Intensive:**
- Home and community visits
- Community agency involvement
- State health department
  - Linkage and Retention Services
  - Medical Provider HIV/AIDS and Partner/Contact Report Form (Form DOH-4189)

Health Home Care Managers have a vital role!

https://commerce.health.ny.gov
Women Living with HIV or at Risk for HIV and Breastfeeding/Infant Feeding Recommendations

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Collaborative Decision-making in the Antepartum and Postpartum Period
HIV and Breastfeeding (1)

• “Avoidance of breastfeeding is the standard, strong recommendation for WLWH in the United States (U.S.)”
  – Maternal antiretroviral therapy (ART) **reduces but does not eliminate** the risk of HIV transmission via breast milk
  – Safe and affordable infant feeding alternatives are readily accessible in the U.S.
  – There is a lack of safety data on most modern ART regimens during breastfeeding
    • Potential toxicity for neonate
    • Increased risk of neonate developing ARV drug resistance should transmission occur
HIV and Breastfeeding (2)

- Viral load in human breast milk differs from viral load in blood (plasma)
- ART does not adequately reduce cell-associated HIV virus in human breast milk
- Breast infections/inflammations (e.g., mastitis) significantly increase the amount of virus in breast milk
- Infants ingest large volumes of breast milk daily for many months (very high, prolonged exposure)

HIV and Breastfeeding (3)

• At this time, Undetectable = Untransmittable does **not** extend to breastfeeding, blood transfusions, transplants, and the sharing of syringes or preparatory paraphernalia/items (but **DOES** apply to sexual transmission!)

• Maternal pre-mastication (maternal pre-chewing of infant/child’s food to soften, warm or cool) should be avoided; pediatric HIV transmission has been attributed to pre-mastication
Factors that Increase Risk of Acquiring HIV Infection in Women

- New diagnosis of a sexually transmitted infection (STI) in self and/or partner(s)
- Partner is known to be living with HIV with an unknown viral load (VL) or detectable VL
- Partner(s) with unknown HIV status
- Male partner who also has sex with other men
- Injection drug use, self and/or partner(s)
- Engagement in transactional sex (e.g., trade sex for shelter)

https://www.hivguidelines.org/perinatal-hiv-care/preventing-mtct/#tab_4
Women at High Risk for HIV Infection and Breastfeeding

• 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

https://www.hivguidelines.org/perinatal-hiv-care/preventing-mtct/#tab_4
Risk Reduction Planning for Women at High Risk for HIV Acquisition Who Desire to Breastfeed

• A risk reduction plan is essential for women who have high risk factors but wish to breastfeed
• An HIV risk reduction plan may include:
  – Pre-exposure prophylaxis (PrEP)
  – Regular HIV/STI testing
  – Access to condoms and consistent use of safer sex practices
  – Access to mental health services and substance use treatment
  – Access to syringe exchange programs

https://www.hivguidelines.org/perinatal-hiv-care/preventing-mtct/#tab_4
Acute HIV Infection (AHI)

• Early stage of HIV infection that extends approximately 1 to 4 weeks from initial infection until the body produces enough HIV antibodies to be detected by an HIV antibody test

• Highly infectious period because the virus is multiplying rapidly

• Rapidly increasing HIV viral load allows detection of virus before HIV antibodies are present
  – importance of fourth generation HIV tests (antigen/antibody combination)

https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/7/acute-hiv-infection
Symptoms of AHI

- “Flu”- or “mono-like” illness
- Fever
- Muscle aches
- Fatigue
- Headache
- Sore throat
- Nausea/vomiting/diarrhea
- Rash
- Weight loss
- Joint pain
- Abnormal laboratory findings

https://www.hivguidelines.org/hiv-testing-acute-infection/acute-hiv/#tab_1
https://www.hivguidelines.org/hiv-testing-acute-infection/acute-hiv/#tab_1_0
AHI and Pregnant and Breastfeeding Women

• Clinicians should include acute HIV infection in the differential diagnosis for any pregnant or breastfeeding woman not known to be HIV-positive presenting with a rash and/or flu or mono-like illness or other symptoms compatible with acute HIV infection.

→ This is critical because risk of MTCT is dramatically increased in the presence of AHI.

https://www.hivguidelines.org/perinatal-hiv-care/hiv-testing-pregnancy-and-delivery/#tab_2
Supporting WLWH with Avoidance of Breastfeeding (1)

- Recognize that women may face social, familial, and personal pressures to consider breastfeeding despite the recommendation to avoid it.

- Understand this may be particularly problematic for women from cultures where breastfeeding is important and anticipated, as they may fear that formula feeding would reveal their HIV status.

It is critical to address these, and other possible barriers to formula feeding during the antenatal period.
Supporting WLWH with Avoidance of Breastfeeding (2)

• Engage in open-ended conversations
  – “In the U.S., we recommend that women with HIV not breastfeed. Please share with me your thoughts about this.”
• Validate her desire to breastfeed, if present
• Seek to understand her motivation (e.g., HIV disclosure concern, cultural norm/expectation, natural and desirous way to connect with infant)
Supporting WLWH with Avoidance of Breastfeeding (3)

- Inquire if partner and/or family are aware of woman’s HIV status
- If not, explore with woman barriers to disclosure
- Complete a domestic violence screen
- Develop a disclosure plan
- Offer resources to assist with disclosure
  - NYSDOH PartNer Assistance Program (PNAP)
  - NYCDOHMH Contact Notification Assistance Program (CNAP)
    - staff can notify potentially exposed partners anonymously and help those who want to tell their partners on their own
Supporting WLWH with Avoidance of Breastfeeding (4)

• Ensure she understands the transmission risks so she may make an informed, conscious decision regarding feeding

• Emphasize she maintain communication with providers about her thoughts, feelings and choices rather than avoid sharing information out of fear

• Provide non-judgmental, compassionate care
Supporting WLWH with Avoidance of Breastfeeding (5)

• Acknowledge the benefits of breastfeeding, especially in regions of the world where water quality is poor and formula isn’t a safe option

• Honor the grief, loss and emotional difficulty she may be experiencing by giving up breastfeeding
Supporting WLWH with Avoidance of Breastfeeding (6)

• Provide instruction on ways she may bond with her baby while bottle feeding including skin-to-skin contact

• Offer her resources for support (e.g., partner services, counseling/Mental Health, appropriate support groups, Women, Infant and Children Supplemental Nutrition Program)
Breastfeeding in the Context of HIV: The Bottom Line

- Although the risk of MTCT 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.

- **Women need and deserve support!** (support/assistance with disclosure, reducing stigma, creative strategizing, informal or formal counseling, validation and affirmation, and non-judgmental compassionate care)

Care of the HIV-exposed Newborn
HIV-exposed Newborns

• All babies born to WLWH are considered HIV-exposed
• HIV-exposed is not the same as having HIV infection
• HIV-exposed babies need special testing to determine if they acquired HIV infection from perinatal exposure
HIV Testing of the Newborn

- HIV testing is one of 50 required tests the NYSDOH Wadsworth Center tests on all newborns born in NYS

- The Newborn Screening (NBS) test is a heal stick done prior to the newborn being discharged from the birth facility

- The NBS HIV test detects if the mother has HIV antibodies indicating the mother is HIV-positive and that the newborn has been exposed to HIV
Care of the HIV-exposed Newborn (1)

• Exclusive formula feeding
  – prevent MTCT
• ARV prophylaxis
  – prevent MTCT
• HIV testing
  – determine HIV status

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Care of the HIV-exposed Newborn (2)

• Coordinated care with Pediatrician and Pediatric HIV/Infectious Diseases Specialist
  – facilitate healthcare
• Co-located clinic for mom and baby
  – promote family-centered care and ease of appointments
• Supportive services, as needed
  – provide enhanced support (e.g., visiting/home nursing services, Special Supplemental Nutrition Program for Women, Infants and Children – WIC, etc.)
Care of the HIV-exposed Newborn: ARV Prophylaxis

- All HIV-exposed newborns should receive ARV prophylaxis for prevention of MTCT initiated as soon as possible after birth, and within 12 hours.

- Consultation with an experienced pediatric HIV care provider as soon as possible, preferably before labor, helps ensure the most effective regimen is chosen for infant ARV prophylaxis.
  - This is particularly crucial when the woman: 1) is diagnosed with HIV infection during labor, or 2) did not have prenatal care or antenatal ART prior to presenting in labor, or 3) has unsuppressed virus, or 4) has ART-resistant virus.

https://www.hivguidelines.org/perinatal-hiv-care/care-of-hiv-exposed-infant/#tab_1
Care of the HIV-exposed Newborn: HIV Testing (1)

- All NYS birth facilities and pediatricians caring for HIV-exposed infants are encouraged to use the Pediatric HIV Testing Service at the NYSDOH Wadsworth Center.

- HIV qualitative RNA testing (nucleic acid test or NAT) is performed for early detection of HIV infection in infants.
  - Testing should be performed at the following ages:
    - Within 48 hours of birth (before hospital discharge)
    - At 2 weeks of age
    - At 4 to 6 weeks of age
    - At 4 to 6 months of age
Care of the HIV-exposed Newborn: HIV Testing (2)

- Two to four specimens per infant may be necessary to determine the infant’s HIV infection status
  - Criteria to definitely “exclude” HIV (to say the infant is not infected) requires:
    - One negative test at ≥4 weeks of age, and
    - One negative test at ≥ 4 months of age

Care of the HIV-exposed Newborn: HIV Testing (3)

• If a newborn/infant has a Positive HIV NAT result, a repeat test using a new blood sample should be submitted as quickly as possible for confirmatory testing.

• Two independent positive NAT results definitively diagnose pediatric HIV infection in HIV-exposed infants and subsequent testing is not necessary.

HIV-Positive Newborn

• Steps following confirmed HIV-positive diagnosis:
  – Consult with a Pediatric HIV/Infectious Diseases expert
  – Discontinue perinatal ARV prophylaxis, if still being administered
    • Prophylaxis (prevention dosing) in the setting of infection may cause ARV drug resistance and is sub therapeutic
  – Initiate combination ART (treatment dosing)
  – Assess mother/family for needed emotional support and refer for therapeutic services as needed (e.g., supportive counseling/mental health)
  – Ensure newborn formally linked and engaged in HIV care
Role of Health Home Care Managers (1)

- Facilitate **navigation, linkage, engagement** and **retention in care** throughout all phases:
  - pre-pregnancy, pregnancy and postpartum/newborn
    - Primary care/HIV care
    - OB/GYN care
    - Primary Pediatric and Pediatric HIV/ID specialty care
    - Mental health treatment (be aware of postpartum depression)
    - Substance use treatment
    - Housing
    - Other identified medical and supportive service needs
Role of Health Home Care Managers (2)

- Collaborate with mother and her health care providers to ensure:
  - She has a contraceptive plan postpartum
  - She has the ability to access reproductive services (e.g., convenient clinic location, reliable transportation, family planning insurance coverage)
  - She is up to date with her gynecological care (pap/colposcopy, STI screening, mammography, etc.)
Role of Health Home Care Managers (3)

- Stay connected with her after delivery of her child
- Ensure she is attending her postpartum and contraceptive appointments
- Ensure she is engaged with her HIV provider
- Ensure she is taking her ART as prescribed and has sustained VLS
  - And if she is not achieving the above goals…
    - Work with her to identify her barriers
    - Creatively strategize together on how to eliminate/reduce the barriers
Role of Health Home Care Managers (4)

- Ensure newborn engaged in general pediatric care and pediatric infectious diseases care, if needed
  - Verify HIV testing is being completed according to the recommended schedule
- Ensure mother has ready access to ARV prophylaxis for newborn so no interruption in therapy after hospital discharge
  - Be aware/help coordinate discharge planning with birth facility, pharmacy and insurance
  - Verify newborn receiving ARV prophylaxis as prescribed with good adherence
Role of Health Home Care Managers (5)

• Engage in supportive, non-judgmental discussions regarding infant feeding
  – Provide emotional support over loss of breastfeeding
  – Ensure mother/baby enrolled in WIC and receiving adequate amounts of infant formula
  – Offer assistance with HIV disclosure if disclosure is identified as a barrier to avoidance of breastfeeding
  – Mitigate stigma whenever and wherever possible

• Continue to provide reassurance and support
Role of Health Home Care Managers (6)

Don’t give up on her!
(or on yourself – make sure you get support too)
Resources and References
Webinar Presenters: Contact Information

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Resources for Newborn/Pediatric HIV Testing in NYS, Wadsworth Center

• Newborn Screening Program
  – https://www.wadsworth.org/programs/newborn/screening
  – (518) 473-7552

• Pediatric HIV Testing Service
  – https://www.wadsworth.org/programs/id/bloodborne-viruses/clinical-testing/pediatric-hiv
  – (518) 486-9605
Resources for Linkage and Retention in Care

• New York State Department of Health:
  – Perinatal HIV Prevention Program
  – (518) 486-6048

• New York City Department of Health and Mental Hygiene:
  – Field Services Unit
  – (347) 396-7601
Resources on AHI and Breastfeeding

• NYSDOH
  – Testing for Acute HIV During Pregnancy
    • https://www.hivguidelines.org/perinatal-hiv-care/hiv-testing-pregnancy-and-delivery/#tab_2
  – Postpartum Management and Breastfeeding
    • https://www.hivguidelines.org/perinatal-hiv-care/preventing-mtct/#tab_4

• US Department of Health and Human Services Federal Guidelines
  – Special Populations: Acute HIV Infection
  – Postpartum Management and Breastfeeding
Postpartum/Birth Spacing Resources


- [https://www.bedsider.org/methods](https://www.bedsider.org/methods)
National Perinatal HIV Hotline Resource

#(888) 448-8765

• 24 hours a day, 7 days a week, 365 days a year
• Clinician Consultation Center (CCC) provides free, confidential, and timely expert perinatal HIV and HIV-exposed infant consultation to clinicians of all experience levels and training backgrounds
• Advice is based on Federal treatment guidelines, current medical literature, and clinical best practices
Resources on Preconception, Contraception and Conception for WLWH

New York State Department of Health AIDS Institute

* HIV  * HCV  * STIs  * SUBSTANCE USE  * LGBT

- HIV Testing and Acute HIV
- ART
- Primary HIV Care
- Perinatal HIV Care
- PrEP
- PEP
- Hepatitis Care
- STIs
- Substance Use

https://www.hivguidelines.org/
Resources on Preconception, Contraception and Conception for WLWH

U.S. Department of Health and Human Services

Recommendations for the Use of Antiretroviral Drugs in Pregnant Women with HIV Infection and Interventions to Reduce Perinatal HIV Transmission in the United States

- Introduction
- Maternal HIV Testing and Identification of Perinatal HIV Exposure
- Counseling and Management of Women Living with HIV Who Breastfeed
- Preconception Counseling and Care for Women of Childbearing Age Living with HIV
- Antepartum Care
- Intrapartum Care
- Postpartum Follow-Up of Women Living with HIV Infection
- Management of Infants Born to Women with HIV Infection
- Appendix A: Review of Clinical Trials of Antiretroviral Interventions to Prevent Perinatal HIV Transmission
- Appendix B: Supplement: Safety and Toxicity of Individual Antiretroviral Agents in Pregnancy

Resources on Preconception, Contraception and Conception for WLWH

Contraceptive Counseling and Resources

• https://www.cdc.gov/mmwr/volumes/65/rr/rr6503a1.htm

HIV Among Pregnant Women

• https://www.cdc.gov/hiv/group/gender/pregnantwomen/index.html
• https://www.acog.org/About-ACOG/ACOG-Departments/HIV
Additional Resources for People Living with HIV

https://www.health.ny.gov/diseases/aids/general/about/hlthcare.htm
Additional Resources for People Living with HIV

https://www.health.ny.gov/diseases/aids/general/about/comm_support_services.htm
Additional Resources for People Living with HIV

Partner Services & Retention in Care:

- **PNAP**
  - [https://www.health.ny.gov/diseases/aids/general/about/field_services.htm](https://www.health.ny.gov/diseases/aids/general/about/field_services.htm)
  - [https://www.health.ny.gov/diseases/communicable/std/partner_services/](https://www.health.ny.gov/diseases/communicable/std/partner_services/)
  - [https://www.health.ny.gov/diseases/aids/providers/regulations/partner_services/](https://www.health.ny.gov/diseases/aids/providers/regulations/partner_services/)
  - [https://www.health.ny.gov/diseases/aids/providers/regulations/reporting_and_notification/question_answer.htm](https://www.health.ny.gov/diseases/aids/providers/regulations/reporting_and_notification/question_answer.htm)

- **CNAP**
  - [https://www1.nyc.gov/site/doh/health/health-topics/aids-hiv-partner-notification-law.page](https://www1.nyc.gov/site/doh/health/health-topics/aids-hiv-partner-notification-law.page)
  - [https://www1.nyc.gov/site/doh/health/health-topics/aids-hiv-contact-notification-assistance-program.page](https://www1.nyc.gov/site/doh/health/health-topics/aids-hiv-contact-notification-assistance-program.page)

- **Retention in Care**
Additional Resources

**HIV/AIDS Warmline**
800-933-3413
HIV treatment, ARV decisions, complications, and co-morbidities

**Perinatal HIV Hotline 888-448-8765**
Pregnant women with HIV or at-risk for HIV & their infants

**Hepatitis C Warmline**
844-HEP-INFO
844-437-4636
HCV testing, staging, monitoring, treatment

**PrePline**
855-HIV-PrEP
Pre-exposure prophylaxis for persons at risk for HIV

**Substance Use Warmline 855-300-3595**
Substance use evaluation and management

**PEPline**
888-448-4911
Occupational & non-occupational exposure management
Additional Resources

New York State Clinical Education Initiative:
Tele-mentoring with Project ECHO™
HIV/STD/HCV/PrEP/PEP Inquiries
(technical assistance, and additional clinical tools available)

Resource Center of Excellence
# 1-866-637-2342 (toll free) or # 585-612-1343
support@ceitraining.org
Additional Resources

NYC Mental Health and Substance Use Services:
NYC WELL Hotline (24 hours a day/ 7 days a week by phone, text and online chat)
# 1-888-NYC-WELL (# 1-888-692-9355)

NYS Office of Alcohol and Substance Use Services:
Agency Main Number and General Information
# 518-473-3460
Referrals can be obtained by calling OASAS HOPEline
# 1-877-846-7369

NYS Office of Mental Health:
# 1-800-597-848
Patient Educational Resources

• Birth Control: https://www.bedsider.org/

• Planning for Pregnancy: https://www.cdc.gov/preconception/planning.html

• HIV and Pregnancy: https://www.acog.org/Patients/FAQs/HIV-and-Pregnancy