NATIONAL 2016 RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Pregnant, HIV+, and Lost to Care

Grace Appert, RN, MSN, C-PNP
Clinical Services Coordinator, Family Program
Jolene Bastas, LMSW
Director, Family Program
The Brooklyn Hospital Center, PATH Center

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Outline

Learning objectives

National HIV/AIDS strategy goals

Epidemiology of HIV in pregnancy

Emerging issues in caring for HIV+ pregnant women

Case studies including approaches to engaging and retaining HIV+ pregnant women in HIV and OB care

Topics in caring for HIV + women and HIV exposed infants post delivery

Question and answer

Discussion

Learning Objectives

At the end of this presentation, the learner should be able to:

- Identify emerging issues in caring for HIV+ pregnant women
- Identify strategies to engage HIV+ pregnant women into care
- Identify stakeholders and develop collaborative models to retain HIV+ pregnant women in HIV and OB care
- Identify issues and approaches to retaining HIV positive women and their newborn infants in care after delivery

National HIV/AIDS Strategy

Reducing new HIV infections

- Step 1.A: Intensify HIV prevention efforts in communities where HIV is most heavily concentrated
- Step 1.B: Expand efforts to prevent HIV infection using combination of effective evidence-based approaches
- Step 1.C: Educate all Americans with easily accessible, scientifically accurate information about HIV risks, prevention, and transmission

Increasing access to care and improving health outcomes for people living with HIV

Reducing HIV-related health disparities

Achieving a more coordinated national response to the HIV epidemic

(White House Office of National AIDS Policy, 2010)

Epidemiology of HIV in Pregnancy and Perinatal Transmission of HIV

8,500 women living with HIV give birth annually in the US

Most children living with HIV or AIDS in the US were infected through perinatal transmission

- 1,999 children (ages 0-12) living with perinatal HIV at the end of 2013
- 9,131 adults and adolescents (ages 13+) living with perinatal HIV at the end of 2013

Perinatal HIV infections have declined by more than 90% since the early 1990s

With correct precautions, the risk of transmitting HIV perinatally can be 1% or less

(HIV among pregnant women, infants, and children, 2016)

Emerging Issues in Care of HIV+ Pregnant Women

High rates of psychosocial barriers to care

More women are newly identified as HIV+ during pregnancy due to changes in testing recommendations[1]

More women with perinatally acquired HIV are reaching childbearing age, and have higher rates of pregnancy[2]

1.(Pregnant women, infants and children. An opt-out approach to HIV screening, 2016)
2.(Brady et al., 2010)

Stakeholders

Pregnant	Labor and Delivery	Post Partum

MEDICAL: HIV Primary Care Provider, Nursing Team, Medical Case Management, Nutrition, Mental Health, OB, Laboratory, Pharmacist, and Home Nursing Services

PSYCHOSOCIAL: Partner, Friends, Family, Community Case Management/Support Services, Transportation Services, Housing Services

OTHER: Peer Outreach Staff, New York City Department of Health (Surveillance and Field Services Units), New York State AIDS Institute

MEDICAL: Inpatient OB, Inpatient Infectious Disease, Inpatient Nursing Staff, Inpatient Pharmacy, Inpatient Nursery or Neonatal Intensive Care Unit

PSYCHOSOCIAL: New York's Administration for Children's Services (ACS)

MEDICAL: Pediatric Primary Care

Psychosocial Barriers

HIV is significantly associated with social and economic inequity[1]

Lower socioeconomic status has been linked to higher rates of HIV infection

- Women with lower social standing and more life stress have riskier sexual practices[2]
- Homeless individuals are significantly more likely to be infected with HIV compared to those with stable housing[3]

HIV infection often negatively impacts socioeconomic status

- Some research shows that up to 45% of people living with HIV are unemployed[4]

1. (Perry, 1998)
2. (Ickovics et al., 2002)
3. (Culhane, Gollub, Kuhn, & Shpaner, 2001)
4. (Rabkin, McElhiney, Ferrando, Van Gorp, & Lin, 2004)

Psychosocial Barriers for Women Infected with HIV

Growing prevalence of HIV in women

Disproportionate minority representation in women living with HIV

Women living with HIV have been found to:

- Have lower rates of testing before diagnosis[1]
- Delay entry to care[2]
- Delay starting antiretroviral therapy (ART)[3]
- Experience more visits to the emergency room[3]
- Face higher rates of poverty and unemployment[4]

1. (Aziz & Smith, 2011)
2. (Mugavera et. al, 2007)
3. (Mocroft, Gill, Davidson, & Phillips, 2000)
4. (Chu & Diaz, 1993)

Psychosocial Influences on HIV Care and Health Outcomes

Psychosocial barriers negatively impact engagement in HIV care and health outcomes

HIV positive diagnosis and poverty, homelessness, low level of education, substance abuse, or mental health diagnoses have all been associated with:

- Decreased engagement in HIV care
- Poor ART medication adherence
- Higher instances of morbidity and mortality

(Ickovics et al., 2002)

Case Study

K.B.* is a 45 y/o female patient HIV+ since 2004, followed by another HIV Center, presents for initial OB visit in 12/2015 at about 22 weeks gestation. Per K.B., only takes ART when pregnant, currently taking Stribild

- Last HIV visit 4/4/15: VL 2030, CD4 702/38%

Mental health history:

- Bipolar Disorder and Depression with multiple hospital admissions and no psychiatric care x 1 year

Psychosocial history:

- Crack cocaine abuse x 27 years with use during current pregnancy, daily tobacco and marijuana use
- Living in a shelter

*For the purpose of this presentation, all initials have been falsified to protect patient confidentiality

Interim History

Initial OB visit 12/2015

K.B. outreached to assess for transfer of HIV care to same hospital where K.B. is receiving OB care for improved coordination. K.B. refuses.

For next 6 weeks K.B. scheduled for multiple OB visits, outreached by phone, and offered peer escort to OB appointments

- Despite these interventions, K.B. did not return to care

Plan determined that next step is to involve New York City Department of Health (NYCDOH)

NYCDOH Involvement

2/2016: Contact NYCDOH Field Services Unit and report case.

- Request assistance for reengagement in care

Field Services Unit attempts to outreach and reengage patient for 1 month

Field Service Unit completes home visit in 3/2016 and checks their database and informs PATH that patient had not received HIV or OB care at any facility in New York since initial OB appointment

- K.B. refuses to speak with NYCDOH Field Service Unit staff member
- K.B. refuses assistance or escort for reengagement in HIV or OB medical care
- Case closed by NYCDOH Field Service Unit

AIDS Institute Involvement

Contact NYSDOH AIDS Institute (AI) for consultation. AI recommends offering nominal incentives for engagement in care (i.e. transportation and Target gift cards)

After extensive outreach and supportive counseling over the phone, K.B. agrees to return for OB care with the promise of incentives

- Peer outreach staff meet K.B. at her home and accompany her to all medical visits from that time forward

3/2016: K.B. returns to care first visit since 12/2015. K.B. transfers HIV care to our clinic after one year without HIV care at any facility, is started on Isentress and Truvada. K.B. completes OB visit, is scheduled for cesarean section in mid March

- VL 1200 from 3/2016 despite K.B.'s admission of limited adherence to Stribild between 12/2015-3/2016
- K.B. refuses admission to OB department for monitoring and direct observation of therapy (DOT) until scheduled cesarean section
- K.B. refuses referral for home nursing services

Labor and Delivery

K.B. returns to hospital in labor. Completes 4 hours of IV Zidovudine prior to cesarean section.

Baby Girl born 3/2016 via cesarean section. Baby girl with positive cocaine test.

Per consultation with UCSF Perinatal Hotline, baby girl begins presumptive positive treatment with:

- Zidovudine 4mg/kg/dose PO every 12 hours
- Lamivudine 2mg/kg/dose PO every 12 hours
- Nevirapine 6mg/kg/dose PO every 12 hours

Presumptive positive treatment continued until 1 month PCR result known with plan to change to mono-PEP with Zidovudine pending negative result

New York's Administration for Children's Services (ACS) alerted at time of birth due to positive cocaine test

Follow-up

Baby girl removed from K.B.'s custody

Placed under custody of biological father

Baby girl referred for home nursing services for oversight of completion of post-exposure prophylaxis (PEP)

Baby girl completes PEP without issue

- Birth, 2 week, 1 month, 2 month and 4 month PCR tests negative
- Per NYSDOH AI Guidelines, baby girl is effectively HIV negative

Continued ACS involvement and advocacy

Lessons Learned for NYC Providers

Contact the NYCDOH Surveillance Unit directly when in need of outreach and reengagement services. Phone number: 212-442-3388

- Remain diligent with follow-up with Surveillance Unit. The referral agency must contact Surveillance Unit to learn of updates regarding referred cases. The Surveillance Unit will not contact the referral agency.

Partnership with NYSDOH AIDS Institute for support and ongoing recommendations

Positive experience with use of peer outreach staff for escort and incentive programs

Emerging Issues in Care of HIV+ Pregnant Women

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More women with HIV acquired through perinatal transmission are reaching childbearing age[2]

1.(Pregnant women, infants and children. An opt-out approach to HIV screening, 2016)
2.(Brady et al., 2010)

Newly Diagnosed HIV+ During Pregnancy

Most perinatal HIV infections in the US can be attributed to lack of timely HIV testing and treatment of pregnant women

- In 2005 31% of the mothers of HIV-infected infants had not been tested for HIV until after delivery[1]

Changes in HIV testing recommendations over the past two decades has led to more women being diagnosed HIV positive during pregnancy[2]

1. (Pregnant women, infants and children. An opt-out approach to HIV screening, 2016)
2. (Branson et al., 2006)

History of HIV Testing Recommendations During Pregnancy

- 1995
  - USPHS recommends all pregnant women be counseled and encouraged to undergo voluntary HIV testing
- 2001
  - CDC modifies recommendations: emphasizes HIV screening as routine part of prenatal care, simplified testing process, and flexibility in obtaining consent
- 2003
  - CDC introduces Advancing HIV Prevention: New Strategies for a Changing Epidemic, with focus on prevention of mother-to-child transmission (PMTCT)
- 2006
  - CDC publishes Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings
  - Opt-out testing is established

(U.S. Department of Health and Human Services, 2015)

Challenges

Factors influencing engagement in HIV and OB care, medication adherence, and retention when newly diagnosed HIV positive during pregnancy:

- Adjustment to HIV positive diagnosis
- Lack of knowledge about vertical transmission, potential fear
- Additional burden and need for immediate treatment of HIV to control VL in addition to normal care requirements of pregnancy
- Stigmatization potentially leading to lack of support
- Need for partner notification

(Torrone, Wright, Leone, Hightow-Weidman, 2010)

Case Study

C.R. is a 23 female newly diagnosed HIV positive through routine prenatal laboratory testing at initial OB visit at 23 weeks gestation

Medical History: Herpes Simplex Virus Type 2

Psychosocial History: History of past and current sex work. Living in home with father of baby (FOB) and FOB's girlfriend. Concern for domestic violence though C.R. denies at initial visit, but C.R. repeatedly reports an unsafe living environment. 2 y/o daughter with current ACS case against C.R. for drug use. Daughter not in C.R.'s custody.

Linkage to HIV Care

Referred to HIV clinic, initial visit within 1 week of preliminary positive HIV test

Infected with multi-drug resistant HIV virus

VL 3,010 and CD4 778/37% from 3/2015

Started on Truvada, Reyataz, Norvir

- Later discovered that C.R. delayed initiation of ART for 2 weeks as initiation would “make diagnosis real”

Referred to NYCDOH for assistance with partner disclosure

Referred to in house Psychologist for assessment, and weekly therapy in house with Licensed Clinical Social Worker

Asked to follow-up every 1-2 weeks given high risk situation

Psychosocial Care

Domestic violence and safety assessment with positive results

- Refer to Safe Horizons
- Refer to Girls Educational and Mentoring Services (GEMS): Support for women engaged in sex work
- Application complete for HIV/AIDS Service Administration (HASA) through Human Resources Administration (HRA)
  - Application approved
- Moved to single room occupancy (SRO) through HASA one month after engagement in care
- Referred to Community Based Organization (CBO), CAMBA, for continued housing support

Health literacy Interventions

- Intensive education and health literacy interventions around HIV 101, initiation of ART (dosing schedule and side effects), vertical transmission, adjustment to diagnosis, and positive prognosis with engagement in care

Continued Medical Care

C.R. initiates psychotherapy, is adherent to all medications, and attends all HIV and OB visits

Medication

- Reyataz dose increased to 400mg daily in third trimester

Achieves undetectable VL within 6 weeks of initiating ART

Begins nutrition counseling bi-monthly

Starts Herpes Simplex Virus prophylaxis at 36 weeks gestation

Continued Psychosocial Care

At 36 weeks gestation, C.R. enters new relationship and one week later enters a domestic partnership

- Domestic partner lives in C.R.'s shelter

At 38 weeks gestation, C.R. reports domestic partner is verbally abusive

- Referred to legal CBOs for annulment of partnership
- Coordination with HASA to advocate for change in housing
- Arranged for immediate change in housing, but while in office, C.R. is found to be in active labor and immediately referred to OB/GYN triage

Labor and Delivery

C.R. gives birth to healthy baby boy via cesarean section in 6/2015

C.R. and baby boy transferred to family shelter at time of discharge from hospital. Shelter is a new shelter and relationship with domestic partner is annulled.

Baby boy receives 6 week course of PEP with Zidovudine

Baby boy completes PCR testing at birth, 2 weeks, 1 month, 2 months, and 4 months.

- All PCR results negative
- Per NYSDOH AI Guidelines, baby boy is effectively HIV negative

Lessons Learned

Psychosocial care imperative to engagement of pregnant women with new HIV diagnoses

Intensive medical case management services, health literacy interventions, and use of referrals for supportive services help address psychosocial barriers and aid in engagement in care and medication adherence

Significance of provision of safe environment and support network for pregnant women with new HIV diagnoses that lack support elsewhere

Emerging Issues in Care of HIV+ Pregnant Women

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Perinatal HIV and Pregnancy

Due to improved management of HIV, children with perinatal HIV are surviving into adolescence, young adulthood and beyond[1]

Growing group of young women with perinatally acquired HIV entering their childbearing years

Studies have shown that women with perinatally acquired HIV express desire to have children at high rates[2]

As a result, women with perinatally infected HIV now represent a significant population of HIV positive pregnant women

1. (Phillips et al., 2011)
2. (Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006)

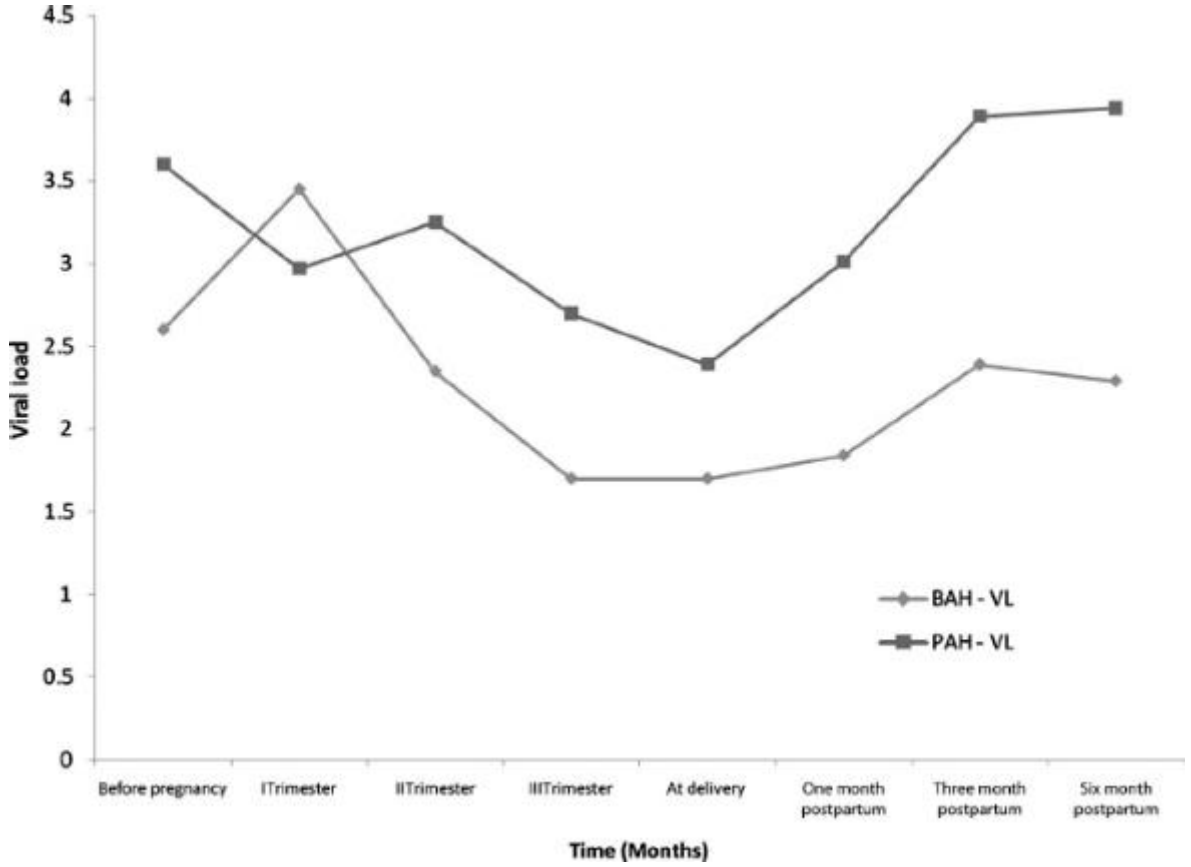
Unique Cohort

People infected with HIV through perinatal transmission face unique challenges

- Long history of treatment
- History of incomplete regimens or regimens with increased side effects
- Extensive drug resistance
- Treatment fatigue and psychosocial barriers to medication adherence
- Lower rates of viral load suppression
- Need for transition between pediatric provider and adult medical care

(Mofenson & Cotton, 2013)

Pregnancy in Women with Perinatally Acquired HIV-Infection



Case Study

M.L. is a 18 y/o female with perinatal HIV, now AIDS, followed by our clinic for many years. Positive pregnancy test in 10/2014

Medical history: Perinatal HIV, AIDS, severe immunosuppression, thrombocytopenia, anemia, oral thrush, PCP pneumonia

- VL 97,730 and CD4 44/9% from 9/2014

Medications: With multi drug resistant virus

- Prescribed Stribild and Edurant, Mepron for PCP prophylaxis, and Azithromycin for MAC prophylaxis

Psychosocial history: Long history of very poor adherence to ART, HIV and sub-specialty medical appointments. Was living with mother, but mother kicked her out when she learned of M.L.'s pregnancy. Father of baby is boyfriend, HIV negative.

Interim Care

After several missed appointments, M.L. attended initial OB visit in 11/2014.

- Did not return for HIV care, missed OB follow-up.

12/2014 referred to NYCDOH Field Services Unit for assistance with reengagement in care

Returned to care end of January, 2015 and admitted to hospital for 2 weeks for treatment of presumptive PCP pneumonia

Continued in outpatient care between 2/2015-4/2015 but remained inconsistent and with high-level viremia

- Discuss consequences of lack of care with M.L. on ongoing basis including risk to own health, risk of vertical transmission, and potential for ACS involvement

Consultation and planning regarding unborn baby PEP regimen as M.L. is with past resistance to Zidovudine and Nevirapine

Third Trimester

Throughout pregnancy, M.L. reports 100% adherence to all medications, despite contradictory lab work.

- Repeat resistance testing in 4/2015 confirms that M.L. had no resistance to current ART regimen of Stribild and Edurant

Diagnosed with oral candidiasis in 4/2015, fails outpatient treatment

- Admitted to ID service between for 2 weeks in 4/2015 for IV treatment of thrush. While inpatient, draw Tenofovir level, results confirm that M.L. was taking no ART.

At discharge, M.L. accepts referral for nursing DOT services. Agrees to be seen in our clinic every 2 weeks until delivery.

After 1 month with DOT service, M.L. achieves undetectable VL in 5/2015 at around 35 weeks gestation

Labor and Delivery

M.L. gives birth to healthy baby boy in 6/2015

Per consult with AIDS Institute, hold infant discharge until birth PCR test result known

Baby boy started on PEP regimen within 12 hours of birth. Per consultation with UCSF perinatal hotline, pharmacologists, and pediatric HIV team, baby boy started on following regimen:

- Zidovudine 4mg/kg/dose PO every 12 hours x 6 weeks
- Nevirapine 12mg/dose, 3 doses in first week of life (within 48 hrs of birth, 48 hours after 1st dose, 96 hours after 2nd dose)
- Epivir 2mg/kg/dose PO every 12 hours x 2 weeks

M.L. and baby boy discharged home with nursing DOT service for administration of PEP regimen x 6 weeks

Baby boy completes birth, 2 week, 1 month, 2 month, and 4 month PCR testing, all results negative.

- Per NYSDOH AI Guidelines, baby boy is effectively HIV negative

Lessons Learned

Pre-pregnancy adherence trends and barriers often continue throughout pregnancy

Need for continued intervention around apathy towards care

Importance of intense care coordination between HIV primary care provider, inpatient infectious disease specialists, OB department, pediatric department, pharmacologists, and UCSF perinatal hotline

Success with use of nursing DOT services and continued discussion for risk of ACS involvement

Emerging Trend – PrEP

Serodiscordant couples with negative female partner are now offered pre-exposure prophylaxis (PrEP) for prevention of HIV transmission of HIV during preconception and pregnancy[1]

By preventing seroconversion during pregnancy, there is reduced risk of vertical HIV transmission[1]

It is our observation that the availability of PrEP has reduced stigma in conceiving with someone living with HIV

1. (National Institute of Health, AIDS Info, 2016)

Q&A

Discussion

Contact Information

Clinical: Grace Appert, RN, MSN, C-PNP
Clinical Services Coordinator
The Brooklyn Hospital PATH Center Family Program
Phone: 718-250-6551
Email: gappert@tbh.org
Programmatic: Jolene Bastas, LMSW
Director
The Brooklyn Hospital PATH Center Family Program
Phone: 718-826-5631
Email: jbastas@tbh.org

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