An Approach to Creating a Safety Net for Individual Patients and for Programmatic Improvements

1. Problem statement and background:

Pregnant women living with HIV (WLH) are a vulnerable population that require enhanced, coordinated medical and psychosocial care over an extended period (up to 2 years) after giving birth. In addition to routine postpartum care, care for WLH needs to address prevention of perinatal HIV transmission (e.g., avoiding breast feeding, completing infant HIV testing protocols, contraception) and establishing or re-establishing linkages to longitudinal HIV care for the mother. The national Fetal Infant Mortality Review (FIMR) HIV project has documented challenges WLH experience postpartum and has highlighted delays in maternal HIV care postpartum and postnatal perinatal HIV transmissions related to incomplete infant testing and antiretroviral prophylaxis or breastfeeding [FIMR/HIV National Resource Center Webinar March 2014, Available at http://www.fimrhiv.org]. Multiple studies in low, moderate and high resource settings, including the U.S., have documented decreased adherence to antiretroviral treatment and decreased retention in HIV care among WLH postpartum. A recent U.S. study in Philadelphia showed that only 38% of WLH engaged in HIV care within 90 days postpartum. However, the finding that retention in HIV care before 90 days postpartum was significantly correlated with improved long term retention in HIV care and with HIV viral suppression at 1 year postpartum provide a call to action to actively support women to engage in HIV care after giving birth. [Adams JS et al. Clinical Infect Dis 2015;61(12):1880-7, http://www.ncbi.nlm.nih.gov/pubmed/?term=26265499]

2. Optimizing individual care plans for mother and baby:

To anticipate and address women's needs, planning for postpartum care should start during pregnancy. Novel, intensive case management plans may be required for the most challenging situations, but all WLH should receive supportive services to enhance retention in HIV care postpartum. Stigma continues to be a major barrier to engaging in care for many women, and it needs to be addressed at every point along the pregnancy care continuum. The table below summarizes action steps to begin to address the need for improved postpartum retention in care for WLH across obstetric (OB), HIV, and pediatric care settings.

Summary of goals, timing, actions, and responsible team members involved in designing a safety net for HIV postpartum care

What?	When	How?	Who?	Comments
Create a medical safety net	Antepartum and BEFORE discharge from L&D	Schedule early f/u appointments prior to delivery: OB: within 1-2 weeks rather than at 6 weeks Pediatric: within 2 weeks HIV: within 2-4 weeks	Ambulatory OB and HIV team Prior to delivery or by discharging team	Develop a community of professional HIV perinatal networks and patient/family-centered and trauma-informed care (rather than system centered care) All providers should work to communicate across specialties regarding HIV RNA results and supporting adherence Go "all the way", even if it is beyond the standard of care. Think outside the box. If necessary to achieve viral suppression, admit to hospital or extend hospitalization to enhance ART adherence
Perform depression screening during pregnancy and after delivery	Antepartum, BEFORE discharge from L&D, and at 6 weeks and 6 months postpartum	Use validated screening tool, e.g., Patient Health Questionnaire (PHQ-9)	Health care team member in OB and in HIV program (at 6 months)	Promote as routine part of care for all pregnant and postpartum women and share information among healthcare providers and provide follow up and treatment when indicated.
Assess for substance use issues during pregnancy and after delivery	Antepartum and as indicated	Use validated screening tool	Health care team member in OB and in HIV program	Promote as routine part of care for all pregnant and postpartum women and share among healthcare providers

What?	When	How?	Who?	Comments
Assess factors affecting women's needs for more intensive follow up postpartum	Antepartum or BEFORE discharge from L&D	Use safety net assessment tool	Health care team member in OB or HIV program	See safety net assessment tool, described below and attached
Reach out using Navigation (Peer, CBO, CM)	Antepartum, At discharge, and Postpartum	Contact perinatal service coordinator re regional options	Community case manager, peer, or other navigator	Prioritize navigation to first visits or new sites of care
Assess desires/preferences and understanding about infant feeding, e.g., not breastfeeding	Antepartum and Postpartum	Understand cultural beliefs, knowledge, experiences Support women to formula feed Obtain expert consultation to work with women who have a strong desire to breastfeed	Health care team member in OB and/or HIV program WIC program	Active assessment to identify individual needs Provide care to enable and support women to formula feed Involve partner Link to resources www.hiveonline.org
Assess reproductive desires	Antepartum and Postpartum	Understand cultural beliefs, knowledge, experiences, preferences Describe options	MD, Nurse, or Social Worker in OB and/or HIV program	Help women make plans and appointments to obtain appropriate contraception postpartum
Address postpartum insurance transitions	Third trimester delivery or early postpartum, not later than 6 weeks postpartum	Before Medicaid expires, enroll in Ryan White, ACA, or other patient financial assistance programs	Nurse or Social Worker or Community Case Manager	Coordinate between medical or community Case Manager

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

The safety net assessment tool, on page 6 of this guidance, provides a checklist that is designed to assist clinical providers and members of the multidisciplinary healthcare team to recognize and identify factors associated with postpartum loss to follow up early in the pregnancy and to implement appropriate supportive services promoting engagement and retention in HIV care. In providing care to optimize care plans for mother and baby, providers should begin using the tool during pregnancy and continue postpartum in obstetric, HIV, and pediatric care settings. The tool will assist you in considering the level of services women need to support ongoing retention in HIV care postpartum.

Routine postpartum follow-up support: Suggested for postpartum women established in care who:

- Were established in HIV care prior to pregnancy and are going back to their previous HIV care provider after their pregnancy
- Are in systems where the OB provider can readily communicate with the HIV provider
- Have undetectable HIV RNA during pregnancy or by delivery

Enhanced postpartum follow-up support: Suggested for women with issues that will respond to intervention through case management, patient navigation, or other support services:

- Newly diagnosed during pregnancy
- Intermittent adherence to antiretroviral therapy
- Detectable HIV RNA at delivery
- Lack of disclosure
- Concerns about formula feeding, desire to breast feed

Intensive case management and patient navigation: Suggested for women with ongoing barriers to care that are difficult to address and may not respond to usual levels of case management and navigation.

- Consider for women with active mental illnesses that are not adequately managed, active substance abuse, or homelessness when these issues are posing barriers to effective treatment and retention in care.
- Mothers with perinatally acquired HIV infection

Using local data to inform and focus your efforts:

While there are shared themes in postpartum retention in care, each region and perinatal care environment will have unique issues that impact the care cascade for perinatal HIV prevention and the HIV care continuum. Systematically categorizing, analyzing, and sharing weak points in your local care environment is critical for targeting improvements.

One model to identify local systems issues impacting HIV transmission is the Fetal and Infant Mortality Review (FIMR-HIV) process. (http://fimrhiv.org/) This is an action-oriented community process that involves data gathering, case review of perinatal HIV transmissions or near-misses, community action, and changes to community systems designed to improve service systems and community resources for women living with HIV and their infants. In addition to correct identification of local systems issues, the process facilitates local and regional partnerships and collaboration. Further information about the model and data from the national project are available at the website above.

Another resource for local perinatal HIV data is your state health department. All state health departments perform longitudinal HIV surveillance and report their data to the U.S. Centers for Disease Control and Prevention. The main limitation of state surveillance data is that it may only focus on new HIV diagnoses and may not be include real-time data about the number of women living with HIV who are delivering in your state. At the same time, health department staff are usually knowledgeable about statewide care networks and resources.

You may need to create a local, regional, or statewide quality improvement (QI) team to help address problems in postpartum retention in HIV care. Stakeholder groups to consider including in quality improvement efforts include Ryan White HIV Care providers, Maternal-Fetal Medicine quality improvement groups, state health department representatives, and community based agencies serving women (including AIDS Service Organizations). A basic initial QI project would start with efforts to clarify a statement of the problem or weak-points in postpartum retention in your area (using the attached structured guidance and assessment tool, key informant interviews with women who recently had to navigate the system, and analysis of any existing data about perinatal transmissions or individuals lost to postpartum care).

3. Opportunities for improvement:

Patient and provider outreach and education about postpartum retention in care are a new area of focus. Even though awareness may not fix the problem, if may be a first step towards improvement. And since the mechanics of educating obstetricians, pediatricians, and HIV care providers is complex, the project in and of itself may prove to be a local challenge. Likewise, care coordination across medical, case management/psychosocial disciplines, and public health requires motivation and local leadership. We hope you will share your resources and successes with us so they can be included in this guide.

Pregnant women living with HIV 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 recognize factors associated with postpartum loss to follow up early in the pregnancy and to implement appropriate supportive services promoting engagement and retention in HIV care. Begin using the assessment tool during pregnancy and continue postpartum in obstetric, HIV, and pediatric care settings. **Check all that factors that apply** and use Comments for planning care**.**

HIV diagnosis and care	✓	**Comments**
New HIV diagnosis during pregnancy		
Late HIV diagnosis (in 3rd trimester/postpartum)		
Detectable HIV RNA (viral load)[1]		
History of detectable HIV RNA in the past year		
Lack of HIV care engagement 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		
Obstetric Care	✓	**Comments**
Missed prenatal care appointments		
Infant feeding concerns, wants to breastfeed		
Pre-term delivery		
OB, HIV &/or Pediatric care not co-located		
Social and System	✓	**Comments**
Partner/family/key support network unaware of HIV diagnosis		
Lack of social support network		
Non-English speaking		
Undocumented legal status		
Low health literacy		

Social and System	✓	Comments
Lack of transportation		
Unstable housing/homeless		
Intimate partner violence		
History of involvement with child protective services		
Recently incarcerated (mother or partner)		
Exchanging sex for money or drugs		
Inability to pay med copays or out of pocket expenses, underinsurance		
Medicaid during pregnancy only, loses coverage postpartum		
Mother/Child receiving services in different jurisdictions and or funding sources, i.e., across state or county lines		
Mental Health/Behavioral Disorder		
Current or previous history of depression		
Psychological and/or mental illness NOT adequately managed		
Current or recent past history of substance abuse/alcohol abuse		
Developmental delay(s) or intellectual disability		

[1]Does not refer to transient low level increases in HIV RNA (isolated blips to less than 400 copies/mL)

Routine postpartum follow-up support: Suggested for postpartum women established in care who:

- Were established in HIV care prior to pregnancy and are going back to their previous HIV care provider after their pregnancy
- Are in systems where the OB provider can readily communicate with the HIV provider
- Have undetectable HIV RNA during pregnancy or by delivery

Make follow up appointments prior to delivery. Schedule OB follow up visits at 2 to 6 weeks postpartum. Schedule follow up visit with long term HIV provider within 2-4 weeks post-partum, before the woman is discharged from OB care. Confirm that HIV provider appointment kept, preferably through outreach to the provider.

Enhanced postpartum follow-up support: Suggested for women with issues that will respond to intervention through case management, patient navigation, or other support services:

- Newly diagnosed during pregnancy
- Intermittent adherence to antiretroviral therapy
- Detectable HIV RNA at delivery
- Lack of disclosure
- Concerns about formula feeding, desire to breast feed

Intensive case management and patient navigation: Suggested for women with ongoing barriers to care that are difficult to address and may not respond to usual levels of case management and navigation.

- Consider for any active mental illnesses that are not adequately managed, active substance abuse, or homelessness.
- Mothers with perinatally acquired HIV infection

More time, effort, and resources will be required to care for these challenging situations. Interventions may require outreach through home/community visits, strong/intensive communication with community agencies. Providers may need to use novel interventions and to think “outside the box”.