Improving postpartum retention in care for women living with HIV in the United States

Florence M. Momplaisir\textsuperscript{a}, Deborah S. Storm\textsuperscript{b}, Hervette Nkwiho\textsuperscript{a}, Olakunle Jayeola\textsuperscript{c} and John B. Jemmott\textsuperscript{d}

Research findings have consistently demonstrated that women living with HIV in the United States and globally experience declines in medication adherence and retention in care after giving birth. A number of studies have identified factors associated with postpartum retention in care, but the evidence base for interventions to address the problem and close this gap in the HIV care continuum is limited. Furthermore, the majority of studies have been conducted in low-resource or moderate-resource countries and may be less applicable or require adaptation for use in high resource countries. In the United States, up to two-thirds of women drop out of care after delivery and are unable to maintain or achieve viral suppression postpartum, at a time when maternal and pediatric health are closely linked. We conducted a critical review of the literature to identify existing gaps regarding maternal retention in the United States and conceptualize the problem through the lens of the integrated and ecological models of health behavior. This review describes existing barriers and facilitators to retention in HIV care postpartum from published studies and suggests steps that can be taken, using a multilevel approach, to improve maternal retention. We propose five core action steps related to increasing awareness of the problem of poor postpartum retention, addressing needs for improved care coordination and case management, and using novel approaches to adapt and implement peer support and technology-based interventions to improve postpartum retention and clinical outcomes of women living with HIV.

Introduction

The postpartum period is a vulnerable time in the HIV care continuum for women living with HIV (WLWH) in the United States and globally, with data demonstrating declines in medication adherence and retention in care [1–4]. Studies of interventions to improve postpartum retention in HIV care are limited. The majority of this research has been conducted in low-resource or moderate-resource countries and often addresses uptake and adherence to perinatal prevention interventions in addition to postpartum retention in care [5,6]. In a recent
review of these topics in relation to pregnant and postpartum women initiating antiretroviral therapy (ART) in sub-Saharan Africa, Myer et al. [4] examine key issues related to adherence and retention and emphasize the need for additional understanding and innovative interventions. There is a need to identify, develop or adapt, and implement culturally sensitive, women-centered interventions for improving HIV care continuum outcomes of pregnant and postpartum WLWH. Although there are some striking similarities between issues in care faced by women in sub-Saharan Africa and those faced by women in many other regions of the world, findings from interventions research may not be directly applicable to women living in the high-resource countries. This review focuses on the problem of postpartum retention in care in the United States, describing factors that prevent women from continuing HIV care after delivery, exploring interventions that have been shown to improve postpartum retention in HIV care and recommending steps that can be taken now to improve postpartum outcomes for WLWH.

**Methods**

We conducted an evolving series of searches in PubMed without a defined start date to review literature about postpartum retention in HIV care, associated factors, and intervention studies. Combinations of key words included HIV, postpartum, pregnancy, pregnant, retention, retention in care, loss to follow-up, engagement, adherence, and interventions. We examined references listed in systematic reviews on these topics and defined additional key words to explore interventions as they were identified, such as case management, care coordination, peers, support groups, mentors, mobile health, short message service (SMS), text messages, and so on. Searches were updated periodically through June 2017. We also searched 2016 and 2017 abstracts from the International Workshop on HIV & Women, the Conference on Retroviruses and Opportunistic Infections, the Ryan White Conference on HIV Care and Treatment, and International AIDS Society Conferences. Our review focuses on the United States and high-resource countries, but incorporates studies from low-resource and moderate-resource countries that contribute to our understanding of the topic.

**Poor retention in HIV care postpartum and implications for women and their family**

Although few studies have evaluated postpartum retention in the United States, available data illustrate a gap in the HIV care continuum after women give birth. A retrospective chart review of 274 WLWH (297 deliveries) at a Mississippi Medical Center with deliveries from 1999 to 2006 showed that only 37% of women had optimal postpartum follow-up, defined as at least two visits with an HIV provider in the year after delivery [7]. Presenting to antepartum care during the third trimester (vs. in the first or second trimester) and competing responsibilities, such as employment, were associated with suboptimal follow-up. A retrospective cohort analysis in Philadelphia, Pennsylvania, with deliveries from 2005 to 2013 found that only 38% of 561 WLWH (695 deliveries) had received HIV care within 3 months postpartum [2]. Only 39% of women were retained during the first year following delivery and that number had dropped to 25% at year 2. Early engagement in care was the strongest predictor of long-term retention: mothers engaged in HIV care within 90 days postpartum were 11 times more likely to be retained at 1-year postpartum compared with those who did not. Analysis of New York State surveillance data showed that 232 of 980 (24%) WLWH with a live birth between 2008 and 2010 were not retained in HIV care in the year following delivery [8]. Not being retained in HIV care in the preconception year was the strongest predictor of suboptimal care postpartum: women with low participation in HIV care during preconception were three times more likely to be lost to HIV care during the postpartum year. The gap between retention rates observed in New York, Philadelphia, and Mississippi may be influenced by differences in regional public health policies and infrastructure for the management of people living with HIV (PLWH) and pregnant WLWH. New York has strong public health programs that encompass HIV prevention, medical care, and supportive services for women of childbearing age prior to, during, and after pregnancy [9] in addition to health coverage including Medicaid reimbursement and safety net programs for the uninsured [10]. Many states in the South have not participated in Medicaid expansion under the Affordable Care Act and have restrictive income eligibility for Medicaid [11,12]. Although, by federal law, all states must provide Medicaid coverage for pregnancy-related services to pregnant women with incomes up to 133% of the federal poverty level, services expire at 60 days postpartum, which may limit access to HIV and primary care in a crucial transition period [13].

WLWH face a number of stressors after giving birth: physiological changes, the potential for postpartum depression [14], increased child and family responsibilities [15], and anxieties associated with infant HIV testing [16]. A busy schedule and a newborn child disrupt a new mother’s medication routines, and scheduling conflicts with work and childcare are barriers to clinic visits [15]. HIV-exposed infants require follow-up care for antiretroviral prophylaxis and diagnostic HIV testing, with early ART for those who are infected. WLWH often put the needs of their children above their personal health concerns [17] which may lead to prioritization of pediatric visits over their own HIV care visits. Retention
in care is also important for managing comorbid conditions, such as hypertension [18] and mental health [14], including postpartum depression. A 2015 maternal mortality report showed that Philadelphia has a maternal mortality rate that is 50% higher than national average; the major causes of maternal mortality were linked to complications from uncontrolled cardiovascular disease, mental health conditions, and drug addiction [19]. HIV was not a major cause of death, but HIV prevalence was 16 times higher among women who died than the general population of women of childbearing age living in Philadelphia.

Retention in HIV care postpartum is crucial for women, infants, and the communities in which they live. Regular clinic visits are linked to antiretroviral adherence and viral suppression, which are essential to reduce the risk of drug resistance and disease progression. Effective ART with sustained viral suppression reduces the risk of HIV transmission to partners [20] and plays an important role in preventing perinatal HIV transmission in future pregnancies [21]. A national, prospective, multicenter French Perinatal Cohort study found no perinatal transmissions among women receiving ART before conception and among those who delivered with a viral load of less than 50 copies/ml [21].

Factors associated with poor retention in HIV care postpartum

To understand factors influencing retention in HIV care postpartum, it is helpful to put barriers and facilitators in context using guidance from behavioral health models. The integrated behavioral model [22] focuses on the constructs of attitude, subjective norm, and self-efficacy to explain behavioral intention and can be used to understand how women make decisions regarding visit attendance postpartum at the individual level. Examples of factors which are likely to influence these constructs include age, education, stigma, mental health, and drug abuse [23]. The ecological model of health behavior [22] is a multilevel model of health behavior that incorporates contextual determinants of health services use. An adaptation of these models, shown in Fig. 1, helps us understand how factors at multiple levels can affect WLWH’s health behavior regarding retention in care. In this model, three broad dimensions – interpersonal, community, and health system factors – are determinants of health behavior. Interpersonal factors include the patient–doctor relationship, relationships with partner(s), and social networks. Community level factors include neighborhood poverty but also resiliency, access to transportation, and distance to health clinics and pharmacies. Health system factors include HIV–obstetric or pediatric–maternal HIV care co-location which occurs when both HIV and obstetric care or pediatric and maternal HIV care are delivered at the same site and within the same visit. Other examples of health system factors include access to health insurance and clinic wait time.

Two recent systematic reviews identified factors related to postpartum retention in HIV care [24,25]. Although the majority of studies were conducted in low-resource countries, some themes may be similar for women in high-resource countries. Briefly, the reviews found that a commitment to pediatric health, disclosure to a spouse,
spousal involvement, access to services, and care coordination across health systems were associated with improved retention in HIV care postpartum. In the United States, qualitative studies of low-income women in the South found that strong social support from partners, family members or providers, having fewer children, better control of HIV and depression, and the desire to stay healthy to raise children facilitated retention in HIV care postpartum [15,26,27]. On the other hand, scheduling conflicts with infant care and work, limited access to transportation, and experiences of institutionalized stigma negatively impacted retention [15,26,27]. Other in-depth interviews of WLWH show that stigma affects women’s reproductive decision-making about becoming pregnant and maintaining their pregnancies [28]. In addition, women who don’t disclose their status to their partner are more likely to delay HIV care and delay initiation of ART [29], have a detectable viral load at delivery [29], factors that other studies have associated with reduced postpartum retention. WLWH in the United States are at elevated risk for intimate partner violence [30]. Studies in Africa have linked intimate partner violence to reduced medication adherence during and after pregnancy [31]. In a recent qualitative study, pregnant and postpartum women who experienced intimate partner violence described three factors that negatively impacted adherence behaviors: lack of disclosure and secrecy, depression and anxiety, and limitations in social support. Significantly, concern and desire to protect their infant’s wellbeing was a coping technique that supported adherence [32].

**Interventions to improve retention in HIV care postpartum**

The presence of numerous, interrelated factors affecting retention in care highlights the need for conceptual models and data to inform the development of effective interventions to improve postpartum retention in care. These interventions need to address factors that contribute to this problem and should be proactive, beginning before or during pregnancy. A systematic review by Geldsetzer et al. [5] points out the weak evidence base for interventions to improve postpartum retention. Although available studies are limited, the following summary explores available data regarding care coordination and case management, peer support, and technology-based interventions to improve postpartum retention in HIV care.

**Care coordination and perinatal case management interventions**

Care coordination is the deliberate organization of patient care activities to facilitate the appropriate delivery of healthcare services [33] and has been shown to improve outcomes in various clinical populations, including PLWH. In the United States, care for WLWH and their infants is often siloed across health systems and even across specialties within the same healthcare system. Some WLWH may enter prenatal care in one clinic, deliver at a hospital not affiliated with that clinic, and obtain pediatric care at a different site, with very little communication across HIV, obstetric, and pediatric providers. These situations create challenges for providers and patients and highlight the need for interventions to coordinate care effectively across specialties and locations. Although there are no studies comparing models of care coordination in the United States, a randomized control trial of postpartum WLWH in South Africa showed that women receiving integrated maternal and pediatric care after delivery were significantly more likely to be retained and virally suppressed at 1-year postpartum compared with women receiving pediatric and maternal HIV care separately: the combined retention and viral suppression end-point for women in the maternal-pediatric care coordinated arm was 77 vs. 56% for women in the standard of care arm [34].

In Philadelphia, after determining that lack of care coordination for pregnant and postpartum women undermined efforts to reduce maternal mortality, the 2015 maternal mortality review team issued recommendations to enable better, more collaborative care coordination through increased case management staff for pregnant and postpartum women, better communication systems with support programs, and the integration of community health workers into traditional care coordination for pregnant and postpartum women [19]. Case management is an important component of care coordination. Case management for PLWH has been shown to significantly increase the use of HIV care [35], to decrease structural barriers to care by helping with transportation, housing, and food insecurity and by increasing referrals to mental health and substance abuse programs [36]. In addition to these responsibilities, perinatal case managers have the unique ability to help WLWH navigate the healthcare system and address barriers to care throughout the perinatal period. An analysis of data from 898 live births in Philadelphia from 2005 to 2013 showed that pregnant WLWH who received perinatal case management (PCM) were more likely to achieve viral suppression before delivery and be retained in HIV care at 1-year postpartum [37]. An analysis of mental health data from the same cohort showed that pregnant and postpartum women with definite or possible depression who were enrolled in PCM had similar outcomes than women without depression, suggesting that PCM support can help improve maternal HIV outcomes among women with depressive symptoms [38].
Peer support interventions

Peer support is a promising strategy for fostering postpartum retention among WLWH. In a one-year implementation study involving four centers in Uganda, 6-week postpartum retention significantly increased from 38 to 78% following introduction of peer mothers who provided support to pregnant and postpartum WLWH through home visits, counseling, and frequent reminder phone calls [39]. Another successful mentor mother program implemented in seven African countries is the mothers2mothers (m2m) peer support program. Unlike other peer mentor programs, the m2m role is professionalized: women are paid to mentor other WLWH. Mentor mothers are WLWH who recently participated in a perinatal HIV program and are willing to disclose their status and mentor other WLWH who are pregnant. They are trained in cognitive-behavioral skills to improve women’s self-efficacy and use educational modules to increase knowledge of HIV disease and promote safer sex practices [40]. The implementation of the mentor mother program has been associated with significant improvement in maternal HIV and pediatric outcomes. In Nigeria, women benefiting from a mentor mother were six times more likely to be retained in care at 6-month postpartum compared with women receiving usual care (adjusted odds ratio 5.9, 95% confidence interval 3.0–11.6) [41]. A three-arm stratified cluster randomized controlled trial conducted in Malawi found that at 24 months, retention was significantly higher with facility-based (80%) and community-based (83%) mentor mothers compared with standard of care (66%) [42]. A large cluster randomized controlled trial in KwaZulu-Natal, South Africa, showed that 63% of women had at least one postpartum visit at 6 months in the intervention arm compared with 45% in the control arm [43]. A qualitative study recently described the benefits of the HIV Mentor Mothers program developed in England as a hybrid between m2m programs in Africa and their general pregnancy volunteer peer support models [44]. Participating women and mentor mothers identified multiple positive themes including reinforcing medical advice, prioritization and problem solving, the support of a caring relationship, developing self-confidence, and others.

CenteringPregnancy is an innovative peer support intervention in the United States that has been shown to improve health outcomes of HIV negative pregnant women. CenteringPregnancy delivers group prenatal care to women with pregnancies of similar gestational age: groups of eight to 12 women meet for ten 90-min prenatal or postpartum visits. Prenatal care and health promotion content are delivered through patient engagement, educational modules, health assessment as well as peer support [45]. A multisite randomized controlled trial conducted at two university-affiliated prenatal clinics in the United States, among the general pregnant population, showed significant improvement in health outcomes among women assigned to CenteringPregnancy compared with usual care, with women in CenteringPregnancy having less preterm birth, better prenatal knowledge, and greater satisfaction with care. Two institutions in the United States have adapted CenteringPregnancy for WLWH by modifying educational modules to include HIV-specific materials on retention in HIV care, medication adherence, and bottle feeding instead of breastfeeding [46]. Initial data from one institution showed that CenteringPregnancy participants had a lower proportion of missed appointments (17 vs. 21%) and no preterm births when compared with the individual care group. Both groups had similar viral suppression (71%) [47].

Technology-based interventions

There is growing evidence that technology-based interventions, such as automated telephone communication systems and text messaging can change patients’ health behaviors, improve clinical outcomes, and increase healthcare utilization [48]. A recent study of standardized SMS to a vulnerable, predominantly female population in Canada found that viral load and self-reported adherence to ART improved a year after implementation of the intervention, although there was a slight decrease in clinic attendance [49]. However, only a few studies have shown that these interventions can be used to improve postpartum retention in HIV care. An unblinded, randomized controlled trial in Kenya found that text messaging significantly improved postpartum visit attendance. Thirty-eight of 194 (20%) women in the SMS group attended a maternal postpartum clinic 8-week postdelivery compared with 22 of 187 (12%) in the control group [50]. Another randomized controlled trial from Kenya compared adherence with infant prophylaxis and infant retention in primary care among 150 mother–infant pairs using phone call reminders paired with perinatal HIV prevention messages. The trial found that participants in the intervention group were significantly more likely to remain in care than those in the standard care group (79 vs. 59% at 6 weeks and 69 vs. 37% at 10 weeks) [51].

For HIV-negative pregnant women and new mothers, the ‘Text4baby’ initiative launched in 2001 by the National Healthy Mothers Healthy Babies Coalition highlights the value of technology-based interventions to promote maternal and pediatric health in the United States. Text4baby delivers gestational age-appropriate information through text messages and informs women on ways to have a healthy pregnancy [52]. A complementary mobile app for subscribers offers extended access to key information such as growth progress, medical updates, appointment reminders, and quizzes [53]. An evaluation
of this program has shown a behavioral effect of text4baby among high-exposure users, particularly with reducing alcohol consumption [54]. Such programs show promise if adapted and implemented for pregnant and postpartum WLWH.

### Proposed steps to improve postpartum retention in HIV care

Although there are limited data about interventions in the perinatal period that have been shown to improve outcomes of WLWH in the United States, waiting for additional studies to change practice should not be an option. The disproportionately elevated prevalence of HIV and pregnancy-related complications among black women point to these structural deficiencies and the urgent need for intervention. Nationally, black women account for 66% of new cases of HIV among women, they are at least three times more likely to die from pregnancy-related complications, and perinatal transmission remains 10 times higher among black compared with white women [55]. It is time to apply what has been learned to date. We propose five core action steps, summarized in Table 1, that can be applied across diverse care settings. These steps include increasing awareness of the problem of poor postpartum retention, addressing needs for improved care coordination and case management, and using novel approaches to adapt and implement peer support and technology-based interventions to improve postpartum retention and clinical outcomes of WLWH. Operational research, continuous quality improvement initiatives, and program evaluations can be used to support adaptation and implementation and generate new, and needed, evidence about effectiveness in diverse practice settings, including feasibility and acceptance by patients and healthcare providers.

### Increase awareness of poor postpartum retention and begin addressing barriers to postpartum care during pregnancy

Improved postpartum retention begins with increasing providers’ and patients’ awareness of the risk of reduced retention in HIV care after delivery, the factors that contribute to this problem, and the importance and benefits of interconception care and long-term retention in HIV care for WLWH. Effective patient–provider communication established during pregnancy allows healthcare providers to assess women’s plans regarding care engagement postpartum in a nonjudgmental manner and make plans to support effective transitions in care. In the postpartum period, limited communication and a poor patient–provider interaction can lead to reduction in care engagement [25]. Patients cared for by compassionate providers who use a patient-centered

### Table 1. Suggested steps to improve retention in HIV care postpartum.

| Areas of need                                                                 | Suggested action steps                                                                                                                                                                                                 |
|-------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Increase provider and patient awareness of poor postpartum retention and take steps to support women as early as possible during pregnancy | Supportive, nonjudgmental communication, Stigma reduction, Webinars/resources for healthcare workers on trauma informed care and other approaches, Assess and identify barriers to care, Anticipatory guidance and problem solving during pregnancy to reduce barriers, Support effective transition in care from pregnancy to postpartum, Begin to link with community-based organizations and other resources based on patient needs |
| Improve care coordination using existing resources                           | Refine existing care coordination resources to understand and address unique needs of pregnant/postpartum WLWH, Organize plans and procedures for communication across disciplines and care settings, Consider delivery of colocated HIV-obstetric care prenatally and maternal HIV-pediatric care postpartum, Quality improvement activities to follow mother–infant pairs postpartum, Investing in health information exchange of electronic health records to overcome fragmentation of prenatal/postnatal, HIV, primary, and pediatric care |
| Involve PCM in the care of pregnant WLWH                                    | Develop standards for PCM, Apply PCM standards in community and clinic-based case management programs, Identify and adapt peer support interventions to pregnant/postpartum WLWH, Implement peer support resources to address gaps in the HIV care continuum |
| Implement peer support interventions                                         | Adapt evidence-based technology interventions for pregnant and postpartum WLWH, Use technology to link WLWH with CBOs and outside resources to meet women’s parenting, nutrition, housing, family planning, and other needs |
| Using technology-based interventions to engage WLWH                          |                                                                                                                                                                                                                         |

PCM, perinatal case management; WLWH, women living with HIV.
Identified barriers to retention need to be addressed and minimized as much as possible during pregnancy while women have frequent medical visits for prenatal care. In Zambia, Bengtson et al. [58] developed a risk score for use after delivery to identify WLWH likely to be lost to follow-up care. A group of clinicians who are members of the United States Centers for Disease Control and Prevention Elimination of Perinatal HIV Transmission Stakeholders Comprehensive Care Working Group have developed structured guidance and postpartum safety net assessment tools to help providers recognize and address patient-specific barriers to postpartum retention during pregnancy in the United States [59,60]. These resources are based on available evidence about factors associated with reduced postpartum retention and factors impacting women’s retention in care that can be targeted for individual intervention. The tools can be useful for continuing education, development of continuous quality improvement initiatives [61], in addition to patient assessment and case management. Preliminary experience with use of assessment checklist in several clinical settings has been positive, but formal evaluation is still needed.

**Improve care coordination using existing resources**

Care coordination has been a consistent part of services in Ryan White HIV/AIDS Program clinics and has been championed as an enabling factor to improve access to care and reduce unmet social needs [62]. We argue that care coordination should be refined to address special needs of pregnant and postpartum WLWH and that some level of care coordination needs to be developed in clinics without these services, when possible, with the help of local health departments or community-based organizations. Plans and procedures for communication across care settings developed early during pregnancy can be used to overcome care silos. Examples include sharing of clinical information between primary, HIV, obstetric, and pediatric healthcare providers at entry in prenatal care and during the third trimester to plan for the postpartum transition. Delivery of HIV and obstetric care in the same clinic session (i.e., colocated care), during pregnancy, and maternal HIV-pediatric care co-location postpartum can facilitate communication and the management of patients’ competing childcare responsibilities that hinder attendance to medical visits. Clinics without colocated care can engage in quality improvement activities to actively follow mother-infant pairs postpartum and can consult with their Department of Public Health for women who are hard to reach [63].

Investing in health information exchange across electronic health records can also help overcome the fragmentation of prenatal, postpartum, HIV, primary, and pediatric care. Lack of timely access to prenatal records regarding HIV RNA levels can affect clinical decisions during labor regarding intravenous zidovudine, cesarian delivery, and type of infant antiretroviral prophylaxis. Reviewing and implementing procedures for effective communication of medical record information across care settings can be used to optimize care, close gaps in transitions, and facilitate follow-up between care settings, including support for postpartum retention.

**Develop and standardize the role of perinatal case management**

Based on work done in Philadelphia, the involvement of PCM benefits WLWH by improving perinatal HIV care continuum outcomes [37]. However, PCM is not available in majority of cities in the United States, and the PCM role is not standardized among clinics where it is applied. Some departments of public health, including Philadelphia, have created PCM standards that require a thorough psychosocial and clinical needs assessment and have provided clear guidance for the frequency of contact needed with clients, including at least one home visit during pregnancy and postpartum. PCM standards can be used by community and clinic-based general case management programs to better meet the needs of pregnant and postpartum WLWH. Research is needed to evaluate the impact of the adaptation and use of PCM standards in different care settings and geographic areas.

**Implement peer support interventions**

Peer support interventions, like m2m, that have been shown to be effective in improving retention in care for pregnant and postpartum WLWH in resource-limited settings, should be modified, tested through rigorous research, and implemented to serve the needs of rural and urban women in the United States. In the interim, identifying and implementing available peer support resources can be crucial in addressing gaps in the HIV care continuum. Peers can also address important psychosocial barriers to retention, such as stigma, disclosure, and help increase self-efficacy. They are well positioned to help WLWH address traumatic experiences and provide reassurance to women (when appropriate) who are anxious about transmitting HIV to their infant. This can specially be the case for first time pregnancies. Guidance for the implementation of peer interventions need be to developed to include the frequency of contact, support with conflict resolution, training, and the integration of peers in the healthcare team.

**Using technology-based interventions to increase retention in care postpartum**

Although few studies in the United States have been conducted to determine the effects of technology-based interventions on postpartum retention, emerging
evidence in other populations suggests that these interventions could be applied with success for pregnant or postpartum WLWH. Based on available data, it seems appropriate to develop strategies for use of phone reminders or text messaging to improve postpartum retention in care. As confidentiality is an important consideration for all patients, procedures to assure privacy and avoid inadvertent disclosure of diagnosis are particularly important. Input from WLWH and individual patients need to be considered to determine the preferred mode of communication and type of information to include in messages. Technology should also be used to link WLWH with community-based organizations and outside resources to meet women’s needs related to parenting skills, nutrition, housing, employment, mental health, and family planning.

Conclusion

The current review is aimed at drawing attention to available interventions and steps that can be taken now to address the problem of reduced retention in care among postpartum WLWH in the United States, in addition to highlighting key areas for further research and clinical development. The needs of WLWH during the perinatal period are multifaceted. A multidisciplinary approach is required to improve postpartum retention, with interventions that help to reduce barriers and strengthen facilitators to care beginning during or before pregnancy whenever possible. Baseline data provide important insights about existing issues and setting priorities for action within clinical programs or jurisdictions. Healthcare providers, public health programs, researchers, and policy makers have important roles to play in operational research, continuous quality improvement initiatives, and program evaluations of proposed interventions to promote effective care transitions after WLWH give birth. A number of clinical trials are ongoing in Africa and other international settings, but there is an urgent need for data about the effectiveness of relevant interventions in high-resource countries where research and evaluation are often challenged by small program size, but can be strengthened through collaborations. It is also time to support an integrated approach to address the specialized needs of childbearing women as part of clinical and community-based HIV care and retention programs that address factors with negative impacts on retention in care such as poor social support and untreated mental health. Going forward, innovative approaches with appropriate implementation, adaptation, and evaluation of interventions developed in low-resource to high-resource settings will be needed to improve postpartum retention in care for WLWH in the United States and in countries around the world.

Acknowledgements

The authors would like to thank Mary Jo Hoyt, MSN, and other members of the Centers for Disease Control and Prevention Elimination of Perinatal HIV Transmission Stakeholders Working Group for coordinating meetings among authors and contributing their expertise to this project.

The work was partially funded by the Harold Amos Medical Faculty Development Program of the Robert Wood Johnson Foundation.

Conflicts of interest

There are no conflicts of interest.

References

1. Nachega JB, Uthman OA, Anderson J, Peltzer K, Wampold S, Cotton MF, et al. Adherence to antiretroviral therapy during and after pregnancy in low-income, middle-income, and high-income countries: a systematic review and meta-analysis. AIDS 2012; 26:2039–2052.
2. Adams JW, Brady KA, Michael YL, Yehia BR, Momplaisir FM. Postpartum engagement in HIV care: an important predictor of long-term retention in care and viral suppression. Clin Infect Dis 2015; 61:1880–1887.
3. Psaros C, Remmert JE, Bangsberg DR, Saffrin SA, Smit JA. Adherence to HIV care after pregnancy among women in sub-Saharan Africa: falling off the cliff of the treatment cascade. Curr HIV/AIDS Rep 2015; 12:1–3.
4. Myer L, Phillips TK. Beyond ‘Option B+’: understanding antiretroviral therapy (ART) adherence, retention in care and engagement in ART services among pregnant and postpartum women initiating therapy in sub-Saharan Africa. J Acquir Immune Defic Syndr 2017; 75:S115–S122.
5. Geldsetzer P, Yapa HM, Vaikath M, Ogbuguji O, Fox MP, Essajee SM, et al. A systematic review of interventions to improve postpartum retention of women in PMTCT and ART care. J Int AIDS Soc 2016; 19:20679.
6. Holtz SA, Thetard R, Konopka SN, Albertini J, Amzel A, Fogg KP. A systematic review of interventions to reduce maternal mortality among HIV-infected pregnant and postpartum women. Int J MCH AIDS 2015; 4:11–24.
7. Rana AJ, Gillani FS, Flanagan TP, Nash BT, Beckwith CG. Follow-up care among HIV-infected pregnant women in Mississippi. J Womens Health 2010; 19:1863–1867.
8. Swain CA, Smith LC, Nash D, Pulver WP, Lazarini V, Anderson BJ, et al. Postpartum loss to HIV care and HIV viral suppression among previously diagnosed HIV-infected women with a live birth in New York State. PloS One 2016; 11: e0160775.
9. Birkhead GS, Pulver WP, Warren BL, Klein SJ, Parker MM, Caggana M, Smith LC. Progress in prevention of mother-to-child transmission of HIV in New York State: 1988–2008. J Public Health Manag Pract 2010; 16:481–491.
10. New York State Department of Health. HIV uninsured care programs—summary. Available at http://www.health.ny.gov/diseases/aids/general/resources/adap. [Accessed October 2017].
11. Heberlein M, Brooks T, Alker J, Artiga S, Stephens J. Getting into gear for 2014: findings from a 50-state survey of eligibility, enrollment, renewal, and cost-sharing policies in Medicaid and CHIP, 2012–2013. Menlo Park, CA: Kaiser Commission on Medicaid and the Uninsured; 2013.
12. Adimora AA, Ramirez C, Schoenbach VJ, Cohen MS. Policies and politics that promote HIV infection in the Southern United States. AIDS 2014; 28:1393.
13. The Henry J. Kaiser Family Foundation. Medicaid coverage of pregnancy and perinatal benefits: results from a state survey. April 2017. Available at https://www.kff.org/womens-health-policy/report/medicaid-coverage-of-pregnancy-and-perinatal-benefits-results-from-a-state-survey/. [Accessed October 2017].

14. Kapetanovic S, Christensen S, Karm R, Lin F, Mack WJ, Oeperskalski E, et al. Correlates of perinatal depression in HIV-infected women. AIDS Patient Care STDs 2009; 23: 101–108.

15. Boehme AK, Davies SL, Moneymah L, Shrestha S, Schumacher J, Kempf MC. A qualitative study on factors impacting HIV care adherence among postpartum HIV-infected women in the rural southeastern USA. AIDS Care 2014; 26:574–581.

16. Shannon M, Lee KA. HIV-infected mothers’ perceptions of uncertainty, stress, depression and social support during HIV viral testing of their infants. Arch Womens Ment Health 2008; 11:259–267.

17. Clouse K, Schwartz S, Van Rie A, Bassett J, Yende N, Pettitot A. ‘What they wanted was to give birth; nothing else’: barriers to retention in option B+ HIV care among postpartum women in South Africa. J Acquir Immune Defic Syndr 2014; 67:e12–e18.

18. Arab K, Spence AR, Czuzoj-Shulman N, Abenhaim HA. Mechanisms linking intimate partner violence and prevention of mother-to-child transmission of HIV: a qualitative study in South Africa. Soc Sci Med 2016; 168:130–139.

19. Kroll-Doresio AR, Crawford SL, Moore Simas TA, Rosen AK, Mattocks KM. Improving pregnancy outcomes through maternity care coordination: a systematic review. Womens Health Issues 2016; 26:87–99.

20. Myer L, Phillips T, Zerbe A, Brittain K, Le Roux SM, Remien R, et al. Integration of postnatal services improves MCH and ART outcomes: a randomized trial. CROI Abstract 24; 2017.

21. Mandelbrot L, Tubiana R, Le Chenadec J, Dollfus C, Faye A, et al. A qualitative study on factors impacting HIV care adherence among postpartum HIV-infected women in the rural southeastern USA. AIDS Care 2014; 26:574–581.

22. Glanz K, Rimer BK, Viswanath K. Health behavior: theory, research, and practice. San Francisco, CA: John Wiley & Sons; 2008.

23. Kaufman MR, Cornish F, Zimmerman RS, Johnson BT. Antiretroviral therapy for the prevention of HIV-1 transmission. N Engl J Med 2016; 375:830–839.

24. Hodgson I, Plummer ML, Konopka SN, Colvin CJ, Jonas E, et al. An observational study on factors affecting ART initiation, adherence, and retention for HIV-infected pregnant and postpartum women. PLoS One 2014; 9:e111421.

25. Rotheram-Borus MJ, Richter LM, van Heerden A, van Rooyen H, Momplaisir F, et al. Antiretroviral therapy (ART) for HIV-infected pregnant and postpartum women. Clin Infect Dis 2015; 61:1715–1725.

26. Clouse K, Schwartz S, Van Rie A, Bassett J, Yende N, Pettitot A. ‘What they wanted was to give birth; nothing else’: barriers to retention in option B+ HIV care among postpartum women in South Africa. J Acquir Immune Defic Syndr 2014; 67:e12–e18.
47. Villar-Loubet O, Diaz-Mendez N, Smith L, Jaramillo S, Echenique M, Potter JE. Implementing and adapting a group prenatal care program for HIV-seropositive women. 2016 National Ryan White Conference on HIV Care and Treatment; 2016.

48. Posadzki P, Mastellos N, Ryan R, Gunn LH, Felix LM, Pappas Y, et al. Automated telephone communication systems for preventive healthcare and management of long-term conditions. Cochrane Database Syst Rev 2016; 12:CD009921.

49. King E, Kinvig K, Steif J, Qiu AQ, Maan EJ, Albert AY, et al. Mobile text messaging to improve medication adherence and viral load in a vulnerable Canadian population living with human immunodeficiency virus: a repeated measures study. J Med Internet Res 2017; 19:e190.

50. Odeny TA, Bukusi EA, Cohen CR, Yuhas K, Camlin CS, McLeland RS. Texting improves testing: a randomized trial of two-way SMS to increase postpartum prevention of mother-to-child transmission retention and infant HIV testing. AIDS 2014; 28:2307–2312.

51. Kebaya L, Nduati R, Wamalwa D, Karuki N, Bashir A. PO-0260a Efficacy of mobile phone use on adherence to nevirapine prophylaxis and retention in care among the HIV-exposed infants In PMTCT: a randomised controlled trial [Abstract]. Arch Dis Child 2014; 99 (Suppl 2):A329.

52. Whittaker R, Matoff-Stepp S, Meekan J, Kendrick J, Jordan E, Stange P, et al. Text4baby: development and implementation of a national text messaging health information service. Am J Public Health 2012; 102:2207–2213.

53. Hunt S. Text4Baby App. Nurs Womens Health 2015; 19: 77–79.

54. Evans W, Nielsen PE, Szekely DR, Bihm JW, Murray EA, Snider J, et al. Dose-response effects of the text4baby mobile health program: randomized controlled trial. JMIR Mhealth Uhealth 2015; 3:e12.

55. Centers for Disease Control and Prevention fact sheet: HIV among women. Available at http://www.cdc.gov/hiv/risk/gender/women. [Accessed September 2017].

56. Beach MC, Keruly J, Moore RD. Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? J Can Intern Med 2006; 21:661–665.

57. Machttinger EL, Cuca YP, Khanna N, Rose CD, Kimberg LS. From treatment to healing: the promise of trauma-informed primary care. Womens Health Issues 2015; 25:193–197.

58. Bengtson AM, Chibwesha CJ, Westreich D, Mubiana-Mbewe M, Chi BH, Miller WC, et al. A risk score to identify HIV-infected women most likely to become lost to follow-up in the postpartum period. AIDS Care 2016; 28:1035–1045.

59. Andrews MM, Momplaisir F, Potter J, Donovan M. Promoting perinatal HIV service coordination: inside your program and beyond, session 4041. Oral Presentation at the 2016 Ryan White Conference on HIV care and treatment.

60. Elimination of Perinatal HIV Comprehensive Care Working Group. Clinical care & case management of people living with HIV resources for preconception through postpartum care. Available at http://fxbcenter.org/PerinatalHIVToolkit.html. [Accessed September 2017].

61. Ezeanolue EE, Pharr JR, Hunt A, Patel D, Jackson D. Why are children still being infected with HIV? Impact of an integrated public health and clinical practice intervention on mother-to-child HIV transmission in Las Vegas, Nevada. Ann Med Health Sci Res 2013; 5:253–259.

62. Vargas RB, Cunningham WE. Evolving trends in medical care-coordination for patients with HIV and AIDS. Curr HIV/AIDS Rep 2006; 3:149–153.

63. Brady KA, Storm DS, Naghdi A, Frederick T, Fridge J, Hoyt MJ. Perinatal HIV exposure surveillance and reporting in the United States, 2014. Public Health Rep 2017; 132:76–84.