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INVITED COMMENTARY

Adherence to HIV Care After Pregnancy Among Women in Sub-Saharan Africa: Falling Off the Cliff of the Treatment Cascade

Christina Psaros · Jocelyn E. Remmert · David R. Bangsberg · Steven A. Safren · Jennifer A. Smit

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Abstract Increased access to testing and treatment means HIV can be managed as a chronic illness, though successful management requires continued engagement with the health care system. Most of the global HIV burden is in sub-Saharan Africa where rates of new infections are consistently higher in women versus men. Pregnancy is often the point at which an HIV diagnosis is made. While preventing mother to child transmission (PMTCT) interventions significantly reduce the rate of vertical transmission of HIV, women must administer ARVs to their infants, adhere to breastfeeding recommendations, and test their infants for HIV after childbirth. Some women will be expected to remain on the ARVs initiated during pregnancy, while others are expected to engage in routine testing so treatment can be reinitiated when appropriate. The postpartum period presents many barriers to sustained treatment adherence and engagement in care. While some studies have examined adherence to postpartum PMTCT guidelines, few have focused on continued engagement in care by the mother, and very few examine adherence beyond the 6-week postpartum visit. Here, we attempt to identify gaps in the research literature and make recommendations on how to address barriers to ongoing postpartum HIV care.

C. Psaros (✉) · J. E. Remmert · D. R. Bangsberg · S. A. Safren
Massachusetts General Hospital, One Bowdoin Square, 7th Floor, Boston, MA 02140, USA
e-mail: cpsaros@mgh.harvard.edu

C. Psaros · D. R. Bangsberg · S. A. Safren
Harvard Medical School, Boston, MA, USA

D. R. Bangsberg
Harvard School of Public Health, Boston, MA, USA

J. A. Smit
Maternal, Adolescent and Child Health Research, Department of Obstetrics and Gynaecology, Faculty of Health Sciences, University of Witwatersrand, Durban, South Africa

J. A. Smit
School of Pharmacy and Pharmacology, Faculty of Health Sciences, University of KwaZulu-Natal, Durban, South Africa

Introduction

In many settings, increased access to testing and treatment means that HIV can be managed as a chronic illness. However, successful management of HIV over time requires continued engagement with the health care system. For example, individuals must become aware of their HIV status through testing, undergo routine laboratory monitoring to inform decisions about when to start and the effectiveness of treatment, and then adhere to the treatment program prescribed to them. This process is often referred to as the HIV treatment cascade [1].

Sub-Saharan Africa bears a substantial degree of HIV disease burden, with well over 23 million people living with HIV at the end of 2012 [2]. Rates of new infections are consistently higher in women (particularly those of reproductive age) than in men [2, 3, 4•]. As a result of routine screening protocols, pregnancy is often the point at which an HIV diagnosis is made [5–7]. With intervention (preventing mother to child transmission, or PMTCT), the rate of vertical transmission of HIV is estimated at 1.4–5.9 %, with an average of 3.5 % [8].

The PMTCT cascade involves a series of complex steps to which women must adhere in order to minimize the risk of vertical transmission. After diagnosis, decisions about when to initiate ARVs are based on country-specific guidelines. The WHO revised its recommendations in 2010 to suggest the initiation of lifelong therapy for women with a CD4 count at

or below 350 cells/mm^3 [9]. For women who do not meet this criterion, the WHO recommends ARV prophylaxis beginning at 14 weeks of pregnancy through the duration of breastfeeding. Various iterations of these guidelines, such as "Option B+," have been adopted throughout the region [10].

After pregnancy, women are expected to administer ARVs to their infants, adhere to breastfeeding recommendations, and test their infants for HIV. With respect to their own treatment, some women will be advised to remain on ARVs while others will be expected to engage in routine CD4 testing so that treatment can be reinitiated when appropriate; both require continued engagement with the health care system. The postpartum period is different than pregnancy across multiple factors which may represent barriers to continued HIV care. Depending on the setting, women may be expected to transfer care to another clinic upon delivery [11]. In some cases, the worry around delivering a healthy infant has passed, leading to changes in motivation for remaining on treatment or in care [12]. Furthermore, caring for a newborn is time intensive and potentially overwhelming, leaving little time for self-care. Some women struggle financially and do not have the support of their families or partners [13]. Despite the fact that the HIV/AIDS epidemic recently entered its fourth decade, stigma remains prevalent and may also compromise a woman's ability to remain in care after pregnancy [14–17].

While some studies have examined adherence to postpartum PMTCT guidelines [18••], few focus on continued engagement in care by the mother, and very few examine adherence beyond the 6-week postpartum visit. Thus, the goal of this paper is to identify gaps in the research literature requiring further study and to make recommendations on how to address barriers to ongoing postpartum HIV care.

Existing Data

Much of the literature on engagement in perinatal HIV care in sub-Saharan Africa has focused on maternal attrition during pregnancy [19–25, 26•, 27–29]. One review found the pooled estimate of women lost to follow up during pregnancy in sub-Saharan Africa was 49.08 % [26•]. Several barriers to engagement in PMTCT during pregnancy have been identified, including lack of male partner support [20, 21, 24, 27, 28, 30, 31], structural barriers [20, 21, 24, 31], the mother being too sick to visit the clinic [24, 29], and fear of stigma [20, 21, 27, 31]. Facilitators to staying in pregnancy PMTCT include participation in community-based interventions, such access to "mentor mothers," peer educators/counselors, and partner incorporation into counseling [19, 20, 23, 32]. The strong desire to deliver a healthy baby has also been associated with engagement in PMTCT [33].

The majority of the research on maternal retention in HIV care during the postpartum period has concentrated on attrition of either mother-infant pairs or infants alone [22, 25, 26•, 34–36]. Mother-infant attrition rate during the overall postpartum period, ranging from 72 h post delivery to 5 years, is approximately 50 % [12, 36], with some studies finding attrition rates as high as 81 % from prenatal enrollment to the 6-month follow-up [22]. Infant attrition rate alone within 3 months of delivery is approximately 33 %, with the greatest percentage lost to follow-up during the first week of life [25, 26•, 34]. Another study of 479 infants conducted in Zimbabwe documented an attrition rate of 43 % at 5 years after delivery, with mortality rates at 53 per 1000 infants born [36]. Barriers to retention are similar during this time period as in pregnancy, including lack of partner support around HIV status [12, 35], lack of overall support system, including lack of community or family support [13, 17, 37, 38], and structural barriers such as geographic relocation away from a clinic, and poverty [35]. Another barrier among mother-infant pairs or infants only were markers of perceived better health, for example, higher maternal CD4 counts, not being prescribed ART post delivery, and maternal perceptions that their infants were not "sick" [12]. Facilitators to continued engagement in care among mother-infant pairs and infants alone included entering PMTCT programs during the first trimester (as opposed to later in the pregnancy) [34], maternal participation in a support group [12], and tracking of defaulters with phone calls [26•].

Few studies have focused on continued maternal engagement alone beyond the acute postpartum period [17, 39–42]. In a recent study, less than half of pregnant woman who were tested for HIV (regardless of the outcome of the test) stayed in care up to 6 months postpartum [39]. A study based in South Africa asked pregnant mothers about possible barriers to retention after delivery, and then asked participants who returned to care postpartum what possible barriers other woman may have experienced with respect to returning to care. These barriers included the perception that the mother cares more about the baby's health than her own, negative treatment by staff at clinic, lack of financial resources, and denial or lack of disclosure of mother's HIV status [42]. Two studies were identified as focusing solely on maternal retention to care during the postpartum period in sub-Saharan Africa: one was a mixed methods study that assessed mothers in Uganda [41], and one was a qualitative study of mothers who dropped out of care and mothers who did not in Malawi [17]. In the Ugandan study, 38 % of mothers enrolled after delivery adhered to a 6-week visit [41]. Barriers to retention were younger age and cessation of ART post delivery [41], and facilitators were past successful PMTCT experiences and social support from partners [17, 41]. Thematic barriers in the Malawi study were fear of involuntary HIV disclosure and lack of partner support around HIV status [17].

Gaps and Recommendations

Our understanding of maternal retention to HIV care during the postpartum period is extremely limited based on available data. Information about care beyond the 6-week postpartum visit is especially lacking. Because infants will receive their PCR test around this time, women may be motivated to attend visits through this time period. The need to return to work, concerns about stigma, lack of partner and/or family support, being no longer motivated by the need to deliver a healthy baby, and lack of time and resources may make additional visits unlikely. There is little consensus on barriers to care, which could inform the development and implementation of interventions. Furthermore, WHO guidelines have not been universally adapted across all countries, and various options for ongoing ART may differentially impact postpartum engagement in care.

Women eligible to start lifetime therapy during pregnancy (per country-specific guidelines) but are unable to be retained in care may experience treatment interruptions, which can lead to virologic rebound, drug resistance, and disease progression [43, 44]. These women may not present to care again until necessitated by illness or until a subsequent pregnancy, both of which may have implications for effective initiation of subsequent PMTCT services. For women who are ineligible for lifetime treatment after pregnancy, continued engagement with care is required to initiate treatment when needed. Existing data shows that women who are ineligible for lifetime treatment and/or have a higher CD4 count may be more likely to fall out of care during the postpartum period [40, 41]. The prevailing view that PMTCT is not for the mother [33, 45•] may contribute to this phenomenon.

Systematic research to enhance adherence to PMTCT and postpartum care engagement are needed. Low-cost reminder phone calls or text messages may facilitate retention of care. When available, programs that offer support and have the potential to circumvent barriers to care, such as stigma, partner based, and structural barriers should be offered; these may include support groups and the use of individual support, such as a "mentor mother." Figure 1 depicts the transition to postpartum HIV care, what remains unknown, and the roles of possible interventions.

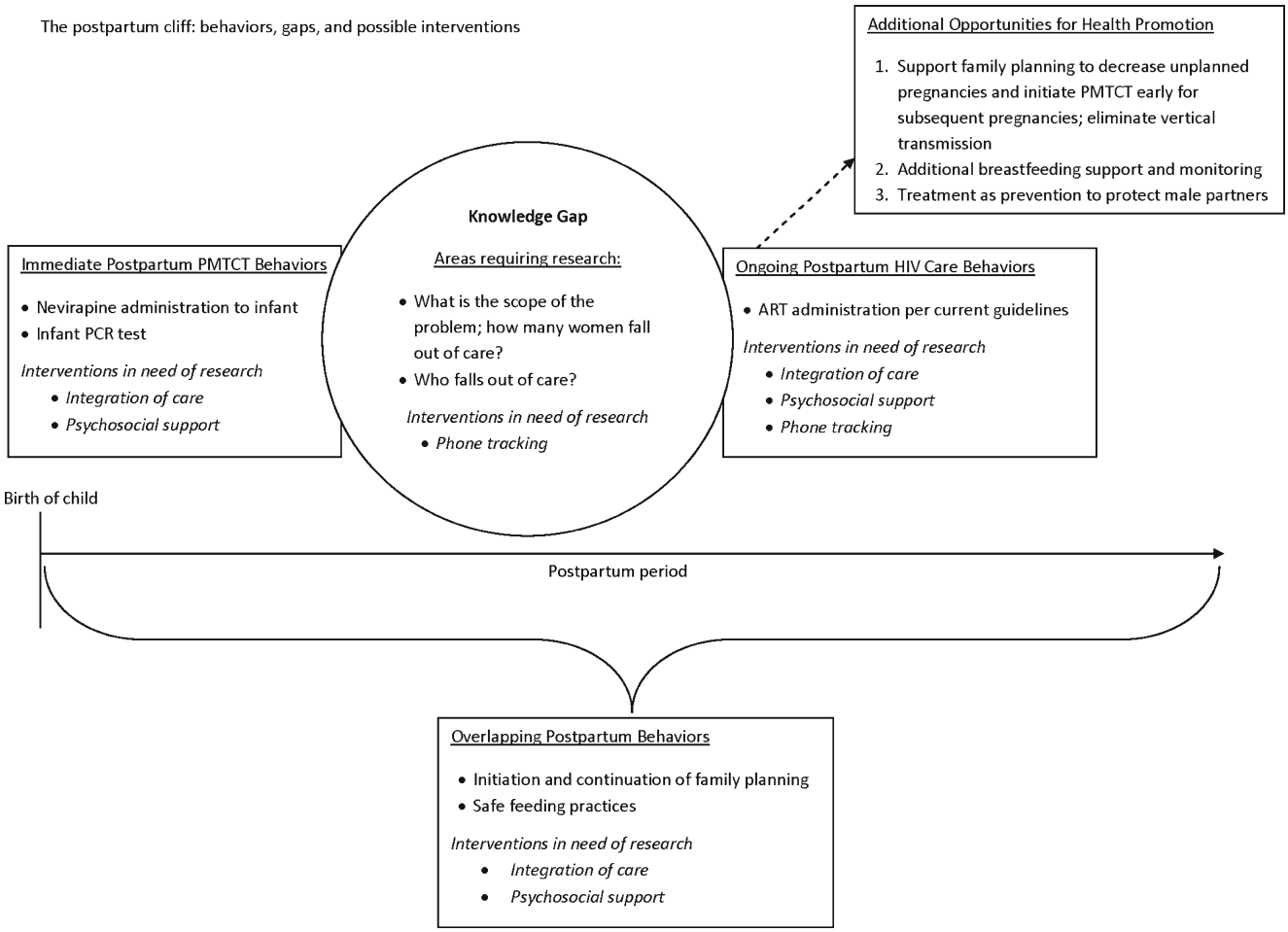

Fig. 1 The postpartum cliff: behaviors, gaps, and possible interventions

In summary, not enough is known about what happens to the care of HIV-infected mothers after the completion of the PMTCT cascade. Keeping women healthy is a worthy and important goal on its own; however, keeping women engaged in HIV care will likely have far-reaching benefits towards global calls to reduce HIV transmission. If more women are retained in HIV care after pregnancy, it may be possible to more effectively deliver family planning interventions, resulting in fewer unplanned pregnancies and initiating PMTCT earlier for subsequent pregnancies, a neglected but important strategy to prevent vertical transmission. Furthermore, helping women initiate and sustain treatment also prevents transmission to male partners. It is also important to understand the role of Option B+ in facilitating long-term retention in HIV care; such understanding could drive policy changes that support wider adoption of lifelong treatment at the time of pregnancy diagnosis. Future research efforts should determine how many women are lost to care at this important juncture and barriers to continued engagement. Scalable, effective interventions must then be developed in order to optimize the health of mothers and their children.

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Compliance with Ethics Guidelines

Conflict of Interest Christina Psaros, Steven A. Safren, and David R. Bangsberg declare grant support from NIMH.

Jocelyn E. Remmert and Jennifer A. Smit declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- • Of importance
- •• Of major importance

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