Published in final edited form as:
J Acquir Immune Defic Syndr. 2014 September 01; 67(1): e12–e18. doi:10.1097/QAI.0000000000000263.

“What they wanted was to give birth; nothing else”: Barriers to retention in Option B+ HIV care among postpartum women in South Africa

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Abstract

Background: Women initiating antiretroviral therapy (ART) during pregnancy have high rates of dropout, particularly after delivery. We aimed to identify challenges to postpartum retention in care under Option B+, which expands ART access to all HIV-positive pregnant women regardless of CD4 count.

Methodology: We performed two semi-structured interviews (SSI, n=50) and one focus group discussion (FGD, n=8) with HIV-positive women at Witkoppen Health and Welfare Centre, a primary care facility in Johannesburg, South Africa, that is one of the only clinics offering Option B+ in South Africa.

Results: Fifty women completed the SSI before delivery, and 48 (96%) completed the second SSI within 3 months of delivery. Median age was 28 years (IQR: 26–34), most women worked (62%) or had worked in the prior year (18%). Postpartum women attending HIV care perceived that barriers to HIV-care postdelivery among other women included the belief that mothers care more about the baby’s health than their own (29.2%, 14/48), women were “ignorant” or “irresponsible” (16.7%, 8/48), negative clinic staff treatment (12.5%, 6/48), and denial or lack of disclosure of HIV status (10.4% each, 5/48). Experienced barriers included lack of money (18.0%, 9/50), work conflict (6.0%, 3/50) and negative staff treatment (6.0%, 3/50). During the FGD, three main themes emerged: conflict with work commitment, negative treatment from health care workers and lack of disclosure related to stigma.

Conclusions: We identified a complex set of interconnected barriers to retaining postpartum women in HIV care under Option B+, including structural, personal and societal barriers. The importance of postpartum HIV care for the mother’s own health must be embraced by health care workers and public health programs.

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Conflicts of interest: The authors declare no conflicts of interest.

Keywords

HIV/AIDS; antiretroviral therapy (ART); Option B+; pregnant women; retention in care; loss to follow-up

Background

In 2012, the World Health Organization (WHO) outlined Option B+, which seeks to initiate all HIV-positive pregnant women on lifelong highly active antiretroviral therapy (ART) regardless of CD4 count.[1] The rationale for this policy is to streamline prevention of mother-to-child transmission (PMTCT) goals with additional efforts to improve maternal survival and reduce HIV transmission to uninfected partners.[2,3] While a number of African countries (including Malawi, Uganda and Zimbabwe) have adopted Option B+, other countries (including South Africa) opted for Option B, in which ART is initiated lifelong in pregnant women with CD4 ≤350 cells/μl or through the end of breastfeeding for women with CD4 >350 cells/μl.[4]

The gains sought by expanding ART access through Option B+ will depend on the proportion of women who adhere to treatment and are retained in care. While overall retention in ART care is suboptimal,[5,6] studies suggest that women who initiate ART while pregnant have poorer retention in HIV care than men and non-pregnant women.[7–10] Early experiences from Malawi show that women who initiated ART through Option B+ were five times more likely to be lost to follow-up than women who initiated because of low CD4 count.[11] Postpartum attrition is of particular concern,[12,13] with up to 50% of women dropping out of care after delivery.[13]

Among HIV-positive adults in sub-Saharan Africa, denial of infection, stigma, lack of family and/or community support, transport limitations and lengthy queues at healthcare facilities are cited barriers to retention in care.[14–19] Pregnant and postpartum women may face their own unique and additional barriers throughout the PMTCT care cascade, such as inadequate partner support, child care concerns, anxiety about infant HIV diagnosis,[20–23] lack of motivation to adhere to lifelong medication after a healthy delivery,[24] and extended travel to a rural home soon after delivery to stay with family.[8,20] Postpartum women are unique in that they transition from receiving care for themselves and the baby simultaneously while the infant is in utero, to receiving separate infant and maternal care after delivery, which may be provided in different settings. Thus, postpartum women may have unique motivations for continuing or ceasing care and it is necessary to understand their specific reasons in order to develop effective interventions. The understanding of factors associated with loss to HIV care among postpartum women is limited, particularly within the context of Option B+.

We conducted a study to identify challenges to retention in care during the postpartum period faced by HIV-positive women initiating ART at a primary health clinic offering Option B+ in South Africa.

Methods

Study site, participants and procedures

Participants were recruited from the antenatal clinic at Witkoppen Health and Welfare Centre (WHWC), a high-volume primary health clinic in Johannesburg, South Africa, and one of few clinics in South Africa offering Option B+. WHWC primarily serves a population living in formal and informal settlements around northern Johannesburg, areas characterized by substantial poverty and high HIV/TB burden. Run as a non-governmental organization, WHWC receives public and private funding. Clients pay a R40 fee per visit (about US $4.00), but this fee is waived for the majority of clients due to inability to pay. HIV testing and care are integrated with antenatal care (ANC) services. As is standard in South Africa, clients deliver at local government hospitals, and following delivery, mothers and infants return to WHWC for postnatal care (PNC) for 10 weeks, including a 6-week visit for infant HIV testing. Following PNC, the mother continues HIV care on-site in the general HIV clinic.

To obtain comprehensive information on barriers to care, we used a mixed-methods approach and performed semi-structured interviews (SSI) and a focus group discussion (FGD) as part of a pre/post pilot study testing a text message intervention to improve retention in care. SSIs allowed for structured, semistructured and open-ended questions, while the FGD featured a guided discussion that permitted a broader range of responses; there was no overlap between the women participating in the SSI and FGD. Using convenience sampling, pregnant women ≥18 years were invited during routine care at WHWC to participate in the SSI if they were HIV-positive, at least 36 weeks pregnant, possessed a working cell phone, were willing to accept calls and messages from study staff, and able to read a short text message. Participating women were interviewed in a private setting at WHWC between May-October, 2013, in English, isiZulu or seSotho. Interviews occurred in-person at enrollment with a local research assistant and either in-person or by phone (if participant was unavailable for a study visit) at the first scheduled postpartum visit. The enrollment SSI included questions related to demographics, cell phone and internet use, upcoming travel intentions, and personal concerns regarding clinic attendance or breastfeeding; the postpartum SSI collected information on acceptability of the intervention, adherence, breastfeeding, and factors that may prevent other women from attending the clinic. Experienced and perceived barriers to care were identified through two questions: “Besides moving out of the area, what factors do you think might cause you to stop attending this clinic in the future?” (enrollment SSI), and “Sometimes women who are HIV-positive and have new babies stop coming to the clinic for their regular HIV check-ups. Why do you think women might stop coming to the clinic?” (follow-up SSI). Verbatim responses were recorded on paper forms, translated and entered in an electronic database (REDCap, Nashville, TN).[25]

For the FGD, eight HIV-positive women on ART who delivered in the past year were recruited during routine postpartum care. No demographics or patient data were recorded. The FGD explored a variety of themes relevant to postpartum, HIV-positive women, including challenges and attitudes regarding ART and adherence, issues of disclosure and partner support, barriers to clinic attendance, and acceptability of the Option B+ program. The FGD was conducted in English and isiZulu, alternating seamlessly as the participants wished, and led by the local project manager with assistance from an American researcher resident in South Africa (SS). The audio recording was transcribed and translated into English.

Analysis

Patient characteristics at enrollment in the pilot study were analyzed using SAS, version 9.2 (SAS, Inc., Cary, NC), and are presented using proportions for categorical variables and medians and interquartile ranges (IQR) for continuous variables. For responses to open-ended questions in the SSIs, we created a list of categorical themes that emerged over multiple readings and calculated proportions for the response categories. The sum of the proportions could exceed 100% as women were allowed provide multiple responses. We classified responses as “experienced” if in response to the first question about personal experiences or “perceived” if about the possible experiences and attitudes of others. The FGD transcript was read for key themes and illustrative quotes but did not contribute to the quantitative analysis.

Ethical approval

This study was approved by the institutional review boards of the University of North Carolina at Chapel Hill and the University of the Witwatersrand, Johannesburg, South Africa. All participants provided written informed consent for SSI or FGD participation and for audio recording of the FGD. To maintain participant confidentiality throughout the fieldwork and analysis, unique study identification numbers were used in lieu of personal identifiers.

Results

Fifty women enrolled and completed the ANC interview a median of 18 days (IQR: 10–29) before delivery. All but two women (96%) also completed the postpartum interview (77.1% in person and 22.9% telephonically) a median of 14.5 days (IQR: 9–47.5) after delivery. Median time between interviews was 43 days (IQR: 27–68).

Median age was 28 years (IQR: 26–33) and most women (88.0%) reported a current partnership, with a median duration of 3 years (range 9 months−18 years) (Table 1). All women initiated ART prior to delivery: 70% during this pregnancy and 30% before (median time on ART for those with prior ART: 2.6 years [range: 2.4 months−7.0 years]). Of those newly-initiating ART, two-thirds (66.7%) had a CD4 count >350 cells/μl. Most (86.4%) women in partnerships said that their partner knew her HIV-positive status, but over half (52.3%) of women did not know their partners’ status. Few (18.0%) women were primigravida and most (67.4%) reported that their pregnancy was unplanned (Table 1). Participating women were mobile, with few (10.0%) born in Gauteng Province (the region that contains Johannesburg and the study site) and over one-third (36.0%) having moved residences at least once in the past two years. During the study, two women transferred to another facility in a different province and nine reported out-of-province travel.

Most women worked (62.0%) or had worked in the prior year (18.0%); nearly half (48.4%) were domestic workers/cleaners. The median number of hours worked per week was 40 (IQR: 25–40), earning a monthly salary of R2500 (IQR 1900–3500), approximately US $250. Nearly all (90.3%) who worked at enrollment planned to return to work within six months of delivery. The median travel time to the clinic was 30 minutes each way (IQR: 30–40) and median cost for a one-way trip to the clinic was R18 (US$1.80), (IQR: R18–20).

Barriers to HIV care

When women were asked before delivery about anticipated post-delivery barriers to their own clinic attendance, the vast majority (76.0%, 38/50) reported that "nothing" would keep them from attending, 18.0%, (9/50) reported lack of money to attend the clinic, 6.0 % (3/50) work conflicts and 6.0% poor treatment by health care staff (Table 2). When asked after delivery to identify reasons why other HIV-infected women may not return for postpartum care, the most frequently-cited barrier was the perception that the mother cares more about the baby's health than her own (29.2%, 14/48), the perception that the mother is 'ignorant" or "irresponsible" (16.7%, 8/48), staff treatment at the clinic (12.5%, 6/48) and denial or lack of disclosure of the mother's HIV status (10.4% each, 5/48). Less common responses included lack of money (8.3%, 4/48), long queues or inconvenient clinic hours (8.3%, relocation (6.3%, 3/48), and the mother's belief that she is cured (6.3%).

The following quotes illustrate the perception of SSI participants that other HIV-positive women cease HIV care after delivery because they care more about their baby's health than their own health.

> *"I think they don't care about their life … What they wanted was to give birth, nothing else"* [SSI participant 22]

> *"Most of the pregnant women take their medication only to prevent passing on the virus to the baby and do not care about their health."* [SSI participant 36]

> *"When they see that their babies are well, they don't see a need to come to the clinic anymore"* [SSI participant 3]

> *"I think most of them after giving birth to HIV-negative baby feel it is no longer important for them to come to the clinic."* [SSI participant 29]

During the FGD, three main themes regarding participants' own barriers to care emerged: conflict with work commitments, negative treatment from health care workers and lack of disclosure related to stigma. Anxiety about work commitments and possible disclosure to the employer were raised as important barriers to attendance at regular clinic visits.

> *"The boss cannot understand why you are taking a day off every month…if you take off this month, if you want another off, it's a problem. So you end up not going to the clinic… We are free on Saturdays and [the clinic] is not open, so you end up not taking your medication."* [FGD participant 3]

> *"It helps to tell your boss - even if you don't tell him or her the reason why. … Like mine, when she first hired me I told her I had to go to the clinic every month to get my tablets but I didn't tell her what the tablets are for."* [FGD participant 2]

> *"It's not easy. One day she will say, 'Let me take you to my doctor…it will be quick because here [WHWC] you spend the whole day…let me make it easy…10 minutes you get the appointment and then by 11:00 you are back from the doctor's' It will be a problem if you don't tell him or her [you have HIV]."* [FGD participant 1]

The discussion above raises the issue of lack of HIV disclosure to employers and the community at large. FGD participants also shared how lack of disclosure to family and friends leads them to hide the true identity of ART medication:

> *"My family doesn't know I'm positive; it's only my partner, just the two of us. When I gave birth, my younger sister…was insisting that I must breastfeed this baby…It is very difficult to convince the family members why you are formula-feeding this particular baby…So being HIV-positive is not a problem if it's only you to worry about, but with the baby it becomes a completely different story. We hope that if we take our medication, we will give the child nevirapine, then after those 6 weeks if the baby is negative at least life can go on, you don't have to answer to a lot of people asking why you are doing A, B, C about the baby. I think, having a supportive partner…he understands, but family, I don't want to lie −1 don't think they will understand any of it."* [FGD participant 3]

> *"That's why you will end up lying and say you have high blood pressure."* [FGD participant 1]

Furthermore, women reported that pregnancy provided a legitimate "excuse" to take medication and attend the clinic, and expressed concern that when their pregnancy is over, they will not know how to explain their medication or attending the clinic.

> *"I didn't have a problem [with adherence] because even at work, I used to take my tablets. [If others asked] 'What are those tablets for?' I said it's because I'm pregnant."* [FGD participant 2]

> *"Sometimes women lie to their partners and told them that they were taking meds for pregnancy, so after birth, what will they tell their husband?"* [IDI participant 46]

Experiences with harsh treatment at the delivery hospital highlighted the discrimination women experience due to their HIV and/or immigrant status.

> *"When I entered there was a nurse in the maternity ward. I pulled out my card and she shouted at me and said, 'Why do you get pregnant while you know you have AIDS?' and there were people everywhere! [Participant begins to cry.] That's why people don't want to come to the clinic, they are scared of these things people shout at you."* [FGD participant 4]

> *"At [public hospital], they [nursing staff] were shouting. They say you foreigner, come to make a baby here."* [FGD participant 5]

> *"To me it happened but it wasn't from the nurse. It was the other mother who had just had a premature baby and she said that the hospital is crowded because of you Zimbabweans. You must go back to Zimbabwe. And it was hurtful, knowing that*

> *your child is still in your stomach and they are trying to save your child and she is saying all those things."* [FGD participant 2]

Discussion

We identified a complex set of interconnected barriers to retaining postpartum women in HIV care under Option B+, including structural barriers such as lack of money, clinic issues, work conflict and relocation, personal beliefs including that the baby's health trumps that of the mother, the mother thinking that she is cured, and societal barriers, such as stigma and fear of disclosure. A particularly troubling barrier for postpartum women - and the most common barrier identified in the SSIs - is the belief that HIV care for the mother's own health is unimportant once the infant is born, especially after the baby receives a negative HIV result. Earlier studies also documented similar lack of motivation to remain in HIV care after a healthy delivery among women participating in PMTCT programs other than Option B+.[21,24,26] The misconception of the acceptability of ceasing HIV care and ART after delivery jeopardizes the potential benefit of Option B+, as women initiating ART when they are well may see less reason to remain in care after delivery. Numerous misconceptions reported during the interviews highlight the importance of coupling ART initiation with adherence counseling during pregnancy and after delivery, and underscores the need for new interventions that address the importance of remaining in HIV care and adhering to treatment for the mother's own health and the infant's after delivery, particularly if breastfeeding.

Financial limitations are a commonly noted barrier to care[15–17,19,21,26–28] and were frequently mentioned as a barrier to women returning to care after delivery, even though most women in our study were employed prior to childbirth. Women in our study were among the working poor: working full-time with low earnings and partners with similarly low earnings. For these women, attending the clinic entails taxi fare and possible clinic fees, time off work and possibly child care. Participants explained how clinic operating hours (Monday-Friday, 8:00 am-4:00 pm) contribute to conflict with work commitments. Expanded hours on Saturday or evenings could provide additional opportunities for working clients to attend appointments. Opting to save time by attending a private health care worker through one's employer was mentioned as an alternative but still poses the potential of disclosure of the mother's HIV status to the employer and requires an employer willing to offer health care.

Our findings also highlight the stigma related to HIV infection that doggedly persists in sub-Saharan Africa more than three decades into the pandemic, despite high disease prevalence and widespread treatment availability.[14,17,24,27–29] Our findings expand on earlier research suggesting that lack of disease disclosure and fear of accidental disclosure is a substantial barrier to HIV-positive women continuing care after delivery,[12,23,30] but identify multiple facets of stigma that affect postpartum retention in care. First, the secrecy of postpartum HIV care, emerging from persistent stigma of HIV and fear of disclosure, is a major deterrent to continued HIV care and highly troubling within the context of lifelong ART under Option B+. Our findings show that from both a personal and societal level, women receive strong messages that a new mother need not seek care for herself after delivery and if she does, she may be viewed with suspicion. Pregnancy provides a socially-acceptable excuse to take ART, under the guise of pregnancy-related medication, that ends with delivery. Second, lack of male partner involvement, a known deterrent to PMTCT attendance,[12,23,31] is a formidable challenge in this setting. When the female partner is trying to hide her HIV-positive status, partner support for postpartum attendance may be difficult to achieve. Third, even when there is disclosure within the partnership, disclosure with other family members and outside society may bring additional difficulties, especially given that women lose a “valid” reason for attending clinic services once the baby is delivered and immunized. Fourth, harsh treatment from public facility staff is a common complaint that has been cited as a barrier to continuous care by women attending PMTCT services.[21,22,32] In our study, women reported hostile treatment based not only on their HIV status, but also their foreign nationality. The shared personal accounts during the FGD regarding hostile treatment at the delivery hospital suggest that traumatic experiences – including publicly outing one’s HIV status and denigrating one’s nationality – may damage the relationship between healthcare provider and patient to such an extent that the patient no longer wishes to seek care at any facility. Our findings show that stigma occurs in many forms, thus, interventions that aim to improve retention in care among postpartum women must address stigma and the pervasive secrecy of HIV at every angle: within the household, the community at large, and the health facility.

Population mobility likely contributes to patient attrition,[33] but to what extent is not fully understood. Recent immigrants from surrounding countries are common in Johannesburg clinics[34,35] and South Africa has a history of in-country population mobility that continues today.[36–38] In addition, pregnant and postpartum women often return to a rural home to receive care from family members.[8,13,20,39] Nearly all participating women had migrated into Johannesburg: 48.0% from other provinces of South Africa and 42.0% from outside of South Africa, mostly Zimbabwe. Travel around the time of delivery was frequent (22%) and explained by a participant as, *“They go far to their hometowns, so their family will help with their babies”* [SSI participant 37]. Such frequent mobility can disrupt ART adherence and regular clinic attendance. Electronic linkage of patient records nationwide across facilities could improve the continuity of patients’ care.

It is curious that 76% of respondents reported that “nothing” would cause them to cease care in the future, particularly since this response is in stark opposition to the litany of potential barriers that respondents identified about other women. The frequency of “nothing” may be due to pregnant respondents’ best intentions to remain in care or methodological reasons, such as social desirability concerns or reluctance of our interviewers to probe deeper for more meaningful responses. The striking difference in the richness of responses between the two retention questions, though, suggests that it may be easier for participants to opine about activities viewed as negative (failing to attend clinic visits) when discussing other people. Additionally, while the two interviews were conducted only about a month apart for most women, perspectives may have shifted during the course of the study as the participant transitioned from pregnancy to postpartum. Future research to explore the extent to which reported barriers to care vary between the antenatal and postpartum period is warranted.

These results should be viewed with an understanding of the strengths and limitations of our study. Our data represent the views of study participants within one clinic, selected because the clinic is one of the few providing Option B+ in South Africa. The clinic is located in an urban environment with a large population born outside South Africa. However, our results are consistent with other studies of HIV-positive women receiving PMTCT services in both rural and urban settings throughout southern Africa.[21,23,24,26] Our sample size of 50 SSI participants and eight FGD participants was small but allowed for meaningful discussion. Lastly, since participants were recruited while at clinic visits, they represent those who were engaged in care and not those who have already dropped out of care: the opinions and responses of whom are greatly valuable but difficult to assess.

In conclusion, we illuminate the complex personal, societal and structural barriers to continued HIV care facing postpartum women receiving ART through Option B+ in South Africa. While some of these barriers are true of adults in general within the same setting, the situation of the postpartum HIV-positive woman has unique characteristics which require targeted interventions and programmatic adaptations. Our findings also highlight the need for increased education and individual counseling regarding the importance of a return to HIV care for the mother's own health after delivery. As countries seek to expand ART access and eligibility through Option B+, they must ensure that the unique needs of HIV-positive, postpartum women are addressed in order to retain them in care and facilitate adherence to ART.

Acknowledgements

The authors would like to express their gratitude to the staff and clients of Witkoppen Health and Welfare Centre; without their dedication and participation, this research would not have been possible. We would also like to thank Ntombenhle Shipalana, Nokuthula Mcunu, Mantombi Ntuli, Thembisile Makhomboti and the antenatal clinic team at Witkoppen Health and Welfare Centre for assistance with this study and Clarence Potter at the North Carolina Translational and Clinical Sciences Institute for REDCap database expertise.

Source of Support:

This work was supported by USAID cooperative agreement AID-674-A-12–00033. REDCap software assistance was supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number 1UL1TR001111. The opinions expressed herein are those of the authors and do not necessarily reflect the views of USAID, NIH or Witkoppen Health and Welfare Centre.

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Table 1.

Characteristics of the semi-structured interview participants (N=50)

Age at enrollment, *median (IQR)*	28 (26–33)
Previous pregnancies (not including current), *n (%)*	
None	9 (18.0)
One	11 (22.0)
Two or more	30 (60.0)
Currently employed, *n (%)*	
Yes	31 (62.0)
No	19 (38.0)
If no, when most recently employed	
Less than 6 months ago	5 (27.8)
6 months - 1 year ago	4(22.2)
More than 1 year ago	3(16.7)
Never employed	6(33.3)
Birthplace, *n (%)*	
Gauteng Province, South Africa	5 (10.0)
Another South African province	24 (48.0)
Outside of South Africa	21 (42.0)
Number of times moved residence in the past 2 years, *n (%)*	
None	32 (64.0)
One	13 (26.0)
Two or more	5 (10.0)
Current partner, *n (%)*	
Yes	44 (88.0)
No	6(12.0)
Duration of current relationship (months), *median (IQR)*	36 (24–96)

Table 2.

Barriers to retention in care identified by semi-structured interview participants (N=50).

Reasons why respondent may cease care, reported during antenatal care (n=50)	**n**	**%**
Nothing	38	76.0%
Lack of money	9	18.0%
Work conflict	3	6.0%
Staff treatment at clinic	3	6.0%
Reasons why other women may cease care, reported during postpartum care (n=48)		
Mother cares about the baby’s health but not her own	14	29.2%
Mother is “ignorant” or “irresponsible”	8	16.7%
Staff treatment at clinic	6	12.5%
Mother’s denial of her HIV status	5	10.4%
Mother hasn’t disclosed her HIV status to others	5	10.4%
Lack of money	4	8.3%
Long queues or limited hours at clinic	4	8.3%
Mother relocates	3	6.3%
Mother thinks she is cured	3	6.3%
Don’t know	4	8.3%

Participant responses to questions: “Besides moving out of the area, what factors do you think might cause you to stop attending this clinic in the future?” (enrollment interview), and “Sometimes women who are HIV-positive and have new babies stop coming to the clinic for their regular HIV check-ups. Why do you think women might stop coming to the clinic?” (follow-up interview). The enrollment interview was conducted during antenatal care, a median of 18 days (IQR: 10–29) before delivery; the follow-up interview was conducted during postpartum care, a median of 14.5 days (IQR: 9–47.5) after delivery. Median time elapsed between interviews was 43 days (IQR: 27–68).

Multiple responses were allowed, so the total may sum to >100%.