



Published in final edited form as:

*Matern Child Health J.* 2020 December ; 24(12): 1454–1463. doi:10.1007/s10995-020-02995-3.

## “This is my life we are talking about”: Adaptive Strategies for HIV Care Retention and Treatment Adherence among Postpartum Women Living with HIV in Cape Town, South Africa

Alison Z. Weber<sup>1,\*</sup>, Jennifer A. Pellowski<sup>1,2</sup>, Kirsty Brittain<sup>3,4</sup>, Abigail Harrison<sup>1,2</sup>, Tamsin K. Phillips<sup>3,4</sup>, Allison Zerbe<sup>5</sup>, Elaine J. Abrams<sup>5,6,7</sup>, Landon Myer<sup>3,4</sup>

<sup>1</sup>Department of Behavioral and Social Sciences, Brown University School of Public Health, Providence, RI, USA

<sup>2</sup>International Health Institute, Brown University School of Public Health, Providence, RI, USA

<sup>3</sup>Division of Epidemiology and Biostatistics, School of Public Health and Family Medicine, University of Cape Town, Cape Town, South Africa

<sup>4</sup>Centre for Infectious Diseases Epidemiology and Research, School of Public Health and Family Medicine, University of Cape Town, Cape Town, South Africa

<sup>5</sup>ICAP at Columbia University, Mailman School of Public Health, New York, New York, USA

<sup>6</sup>Vagelos College of Physicians and Surgeons, Columbia University, New York, New York, USA

<sup>7</sup>Department of Epidemiology, Mailman School of Public Health, Columbia, University, New York, New York, USA

### Abstract

**Introduction**—Retaining postpartum women living with HIV in ongoing care is critical for the health of the mother-child dyad but low adherence to antiretroviral therapy (ART) and retention in HIV care are a global concern. This issue is particularly salient in South Africa, where approximately 50% of women fall out of the care cascade by 6 months postpartum. The purpose of this secondary analysis is to understand the strategies that women use to navigate HIV care during the postpartum period.

**Methods**—This study was conducted in Gugulethu, in Cape Town, South Africa. In-depth interviews were conducted with 21 study participants at 18-months postpartum. Participants were interviewed about their perceptions and experiences of their postpartum HIV care, and barriers and facilitators to their adherence and retention.

**Results**—All participants reported using care navigation strategies across a spectrum of individual, interpersonal and structural levels to remain retained in care and adherent to ART. Participants expressed the importance of individual empowerment and knowledge of treatment

\*Corresponding author: Alison Z. Weber, School of Public Health, Brown University, 121 South Main Street, Box G-S121-3, Providence, RI, 02912, Phone: (860) 428-9371, alison\_weber@brown.edu.

#### DISCLOSURE STATEMENT

The authors declare that they have no conflict of interest.

benefits for their HIV care. Interpersonal relationships were discussed as a pathway to access both psychosocial and tangible support. Participants described overcoming structural barriers to care through creative problem solving and identified opportunities for care delivery improvement.

**Discussion**—Participants described a wide range of overlapping and interconnected care navigation strategies. Consistent with the assets model, participants discussed their own capacity and that of their communities to engage in lifelong HIV care. Better understanding of potentially successful individual care navigation strategies should guide future intervention work.

Trial registration: [ClinicalTrials.gov NCT01933477](https://clinicaltrials.gov/ct2/show/study/NCT01933477).

## Keywords

HIV; care navigation; health behavior; postpartum; asset model

---

## INTRODUCTION

Retaining pregnant and postpartum women in the HIV care cascade is critical for the mother-child dyad to optimize maternal health and reduce mother-to-child HIV transmission (MTCT). World Health Organization (WHO) guidelines recommend lifelong triple-drug antiretroviral therapy (ART) for all pregnant and breastfeeding women living with HIV, (World Health Organization, 2016) but suboptimal levels of retention in HIV care and adherence to ART during the postpartum period have been reported in many settings. (Abrams, 2016; Haas et al., 2016; Miller et al., 2017) Within the context of universal ART during pregnancy and breastfeeding, studies from South Africa, Kenya, and Malawi have reported a variety of challenges in postpartum retention in care and ART adherence. (Clouse et al., 2014; Helova et al., 2016; Katirayi et al., 2016)

Despite these reported gaps in postpartum care retention and adherence, there are women who are retained in care and adherent to ART medications in all contexts. Facilitators of postpartum care engagement include: patient knowledge, older age and higher education level, desire to remain healthy and protect her child, and involvement of partners and family members in care. (Hodgson et al., 2014) On a health services level, provider engagement, counseling, support groups and integration of maternal and child health services are enablers of engagement in care. (Colvin et al., 2014; Hodgson et al., 2014; Myer et al., 2018) Care navigation models seek to support a patient across the care continuum, including accessing and understanding care, seeking follow-up or continuing care, and adherence to treatment programs. (Robinson-White et al., 2010) A standard definition of care navigation does not exist; however, in the context of HIV care this model can encompass all aspects of the care cascade, from initial diagnosis and linkage to care to retention and ART adherence. (Gardner et al., 2011; Genberg et al., 2016) Several studies have investigated the impact of peer navigation programs or peer-based interventions with some data suggesting that there are positive effects of peer support on linkage and retention in care and ART adherence. (Genberg et al., 2016; Steward et al., 2018) In this analysis, we consider care navigation factors to include individual, interpersonal and structural supports that facilitate retention in care and behavioral adherence to ART.

Postpartum women who are receiving HIV care can identify key factors that support them in navigating their HIV care and can also identify areas for improvement.(Morgan & Ziglio, 2007) Since few studies have investigated the strategies that postpartum women living with HIV use to navigate their care, there is a need to explore how this population remains retained in care and adherent to ART. An asset-based approach seeks to identify what is working to strengthen health, and where there is opportunity to build on areas of success.

In the context of a randomized controlled trial (RCT) of the impact of integrated maternal ART and child health services during the postpartum period in Cape Town, South Africa, the purpose of this secondary analysis is to understand experiences of engagement in care among women living with HIV. during the postpartum period. We analyzed in-depth interviews to understand the strategies that women use to navigate HIV care during the postpartum period. By coupling the care navigation framework with the assets model of health promotion, this analysis seeks to inform ongoing research and future interventions in postpartum HIV care retention and adherence.

## **METHODS**

### **Study Setting**

The Maternal-Child Health Antiretroviral Therapy (MCH-ART) study was conducted in Gugulethu in Cape Town, South Africa. Gugulethu is a former township community characterized by high rates of poverty and antenatal HIV infection. Participants were recruited from the Gugulethu Midwife Obstetric Unit (MOU), a public sector clinic that sees more than 4000 women each year for antenatal, obstetric and early postpartum care. Under the local standard of care, all women receive integrated MCH and ART services during pregnancy but are transferred out of the MCH clinic immediately postpartum to attend general adult ART services. Infants are separately referred to routine child health services, as is the norm in many low- and middle-income countries.

### **Participants and MCH-ART Intervention**

The MCH-ART study evaluated the impact of integrating maternal ART and child health services postpartum.(Myer et al., 2016, 2018) Immediately after delivery, participants were randomized to receive one of two postpartum models of care: the MCH-ART intervention or the local standard of care. The intervention condition kept postpartum women and their infants in the MCH clinic to receive integrated concurrent and co-located maternal ART and pediatric care until cessation of breastfeeding. The study found that the MCH-ART intervention was associated with significantly higher levels of retention in care and viral suppression, compared to the local standard of care.(Myer et al., 2018) Participants in the intervention condition may have benefitted from a delayed transition to general ART services, in that the women may have passed through the most vulnerable part of the early postpartum period prior to changing care providers. However, women across both trial arms ultimately navigated the postpartum care transition by 12 months postpartum.(Pellowski et al., 2019) This postpartum care transition, in which women transfer from MCH clinics to adult ART services, represents a high-risk time for care disengagement.(Phillips et al., 2015) At the time of transfer, MOU staff assist patients by providing a referral letter to attend an

adult ART clinic. Although the patient can elect to attend a clinic of her choice, the referral is typically for a clinic close to the patient's residence. As a service-level intervention, the trial did not include individual counseling or change the quality of service provided to women in each of the conditions.

Participants from the control and intervention arms of the MCH-ART study were randomly selected for this qualitative sub-study. Participants were sampled independent of retention or HIV viral load, nor did it re-assess and these were not remeasured for this sub study. Of the 47 women selected for the sub-study, 26 women were able to be reached (55%), and 21 women completed the interview. The remainder of the 47 selected participants were unable to be contacted for this study. Interviews were conducted from November 2016 to May 2017 (approximately 18 months postpartum), after the intervention was completed and all women were referred into standard of care HIV services. This sub-study and its procedures were approved by the Human Research Ethics Committee of the University of Cape Town Faculty of Health Sciences and the Institutional Review Board of Columbia University Medical Center, and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. (World Medical Association, 2013) All participants provided written informed consent.

### Data Collection

To better understand the care retention and treatment adherence experiences of postpartum women living with HIV, the MCH-ART sub-study conducted semi-structured interviews with participants. The study also collected demographic and clinical information. The interview guide included reflections on the transfer process postpartum, experiences within the adult HIV care clinics, and perceptions about barriers and facilitators to HIV care retention postpartum. For example, the interview guide asked: "What are the kinds of things that you think make it hard for mothers to continue to go to HIV clinic appointments after having their baby? What kinds of things have you experienced *personally* that make it hard to keep going to your appointments? (Probes: family, work, childcare, other responsibilities?)"

Two female bilingual (English and isiXhosa) research team members conducted the qualitative interviews. They were trained on the semi-structured interview guide, received supervision from the research team, and took field notes during and after the interviews as needed. The sub-study assessed for thematic saturation for these domains, and interviews with new participants ended once saturation was reached. This study did not set out to concentrate explicitly on care navigation techniques; rather, these emergent themes resulted from the participants' own remarks during interviews. Throughout the course of the sub-study, the research team collaborated to identify emergent themes to be explored in remaining interviews, evaluate thematic saturation, and discuss any questions or issues. Interviews lasted approximately 1 hour for each participant. Participants received a R100 grocery voucher and cash reimbursement ( $\pm$  R20) for travel costs.

Interviews were conducted in a private office and lasted approximately 45-60 minutes. Only interviewers and participants were present during interviews. Interviews were recorded using a handheld audio recorder with interview records saved on encrypted computers. Interviews

were subsequently translated into English and transcribed. The transcripts were quality checked by an independent isiXhosa-speaking research assistant to verify accuracy of both the translation and transcription. Transcripts were not returned to participants for comment or correction as part of this study. After transcription and verification was complete, the audio files were destroyed to protect participant's identifying information. Additional details regarding the methodology for the sub-study have previously been reported.(Pellowski et al., 2019)

### Data Analysis

An initial thematic coding structure was developed based on the interview guide questions, which included concepts that were likely to arise during the interviews. Two members of the study team (AZW, JP) reviewed a portion of the transcripts (33%, 7 of 21 transcripts) to define thematic codes and verify consistency in coding approaches. They independently reviewed the remainder of the transcripts, meeting regularly to discuss code evolution. They used a grounded theory approach (Glaser & Strauss, 2009; Strauss & Corbin, 1991) with constant comparative analysis to identify new codes and emergent themes. During this inductive process, they looked for patterns in the data as well as irregularities or exceptional narratives for further analysis. Through this process, emergent themes were added to the codebook on an ongoing basis, and previously coded transcripts were re-reviewed for instances of the new themes. De-identified transcripts were imported into NVivo 12, Version 12.2 (©QSR International, 1999-2018) for coding and thematic analysis, using the final coding structure. The full analysis team critically reviewed the initial results, which yielded additional queries and validity checks on the findings. As part of this study, participants did not provide feedback on the findings. Findings were verified through quality checking the themes with the raw data and confirming the accuracy of the interpretations with the full analysis team. This study followed the COREQ guidelines for reporting of qualitative methods and findings.(Tong et al., 2007)

## RESULTS

Participants in this sub-sample (n=21) had an average age of 27 years (SD  $\pm$  5.3 years; Table 1). Few participants had matriculated high school, and few were primiparous. Some participants were married or cohabiting, and approximately half were newly diagnosed with HIV during their recent pregnancy. Of the participants interviewed, 50% were retained in ART care and virally suppressed at 12 months postpartum. When compared to the full MCH-ART sample (n=471), there were no appreciable differences across demographic characteristics. Although the MCH-ART study design transitioned participants into care at different timepoints postpartum, all participants ultimately entered the standard of care model. The interview participants described a broad range of postpartum treatment experiences. The women interviewed attended different HIV clinics, with some feeling supported by the clinics while others did not. The participants also reported disparate levels of social support from friends and family. Despite this variability in the participants' lived experiences, participants from both study arms discussed common care navigation experiences. Participants reported a broad range of barriers, including: difficulty in securing reliable childcare during clinic visits, inflexible appointment scheduling, long wait times in

clinics and pharmacies, difficulty maintaining their privacy while seeking treatment, and discrimination and judgement resulting from stigma regarding their HIV status.

The remainder of the results section focuses on findings related to care retention and treatment adherence strategies. An emergent theme from this sub-study was care navigation, which comprised the following sub-themes: (1) the importance of individual empowerment and self-motivation for retention and adherence, (2) accessing support through interpersonal relationships, and (3) overcoming structural barriers through creative care navigation.

### **1) Sub-Theme 1. “Nothing could stop me from taking my treatment”: The importance of individual empowerment and self-motivation for retention and adherence.**

Many participants identified individual empowerment and self-motivation as facilitators of retention and adherence. While participants acknowledged a variety of external barriers that could interfere with maintaining their HIV care postpartum, including difficulty in securing reliable childcare and long pharmacy wait times, they asserted their commitment to taking their treatment.

**I:** What are kinds of things [that] make it hard for mothers to continue to go to HIV clinic appointments after having their baby?

**P:** Nothing could stop me from taking my treatment. (28 years old)

Participants described their own motivations for taking their treatment as long-term, lifelong commitments that extended well beyond pregnancy and the early postpartum period. Participants described wanting to see their children grow up, staying healthy, and living longer as motivating factors.

**I:** Did you see a need to continue taking your ART once you stopped breastfeeding?

**P:** Yes, this is my life we are talking about. (38 years old)

Furthermore, participants identified knowledge as a key component of their individual motivation and commitment to their ongoing care. Participants described that understanding the benefits of treatment adherence, both for their own health and that of their families, helped to motivate them to take responsibility for their care.

**I:** What motivates a person to stay on their treatment of ARVs?

**P:** I don't want to get sick because if you stop it...your CD4 count...you get different diseases. I am taking care of my life. (25 years old)

Participants also felt that learning about their ART treatment regimens helped them to take ownership of their care by ensuring they received the appropriate treatment from the pharmacy.

**P:** What is important is to know your ART. They do [make] mistakes sometimes of mixing the treatment. It is important to know your ART because human error does happen. (29 years old)

Overall, many participants identified their personal engagement, knowledge and commitment to their treatment as a necessary element of their continued engagement in care postpartum.

## **2) Sub-Theme 2. “Dying are those who do not disclose their HIV status”: Accessing support through interpersonal relationships.**

Aside from individual factors, participants described the power of accessing support from their existing interpersonal relationships. The interview guide did not explicitly ask women about partner disclosure and support, but rather about support from family more broadly. Many participants described relationships with their friends and family as affirming and normalizing.

**I:** Do you get support from your family since you are taking ART?

**P:** They know it very well. I even make jokes out of it. My sister in-law knows about it because we stay in the same yard. She asks me if she needs advice about things like family planning and so on. She even makes joke about my HIV status asking me how did I find out that I am HIV positive? I would tell her that people out there knew about my HIV status before I even knew that I am HIV positive. She has no problem about it; she even reminds me to take treatment. (29 years old)

**I:** Does your family support you continuing to fetch your treatment at the clinic?

**P:** They are very supportive. Especially my step-mother. She would ask if I am still taking my pills. She would say if I don't have money to go to [name] clinic, I should borrow it from someone and she will repay that person. (22 years old)

Participants found that discussing their HIV status and treatment regimens with others provided an avenue to share knowledge about the benefits and challenges of treatment. Some participants indicated that this knowledge sharing helps them ensure they are provided with the correct treatment.

**P:** It is good to talk about it [HIV status] with friends. Example: when a friend received wrong treatment, we advise her to take it back because they might lead to drowsiness. Especial[ly] when your blood was not taken. You have to take the treatment back to the clinic. We talk about everything. We don't have a problem to talk about our illness. Dying are those who do not disclose their HIV status. (29 years old)

Beyond this psychosocial support, the participants discussed their ability to access tangible ART support through their social networks. Participants indicated that disclosing their status to friends and family allowed them more flexibility in terms of obtaining their treatment. Some participants described sending a friend or family member to collect their treatment when they were unable to do so. One participant said that openly discussing HIV treatment allowed her to share treatment with friends, thus preventing a gap in treatment.

**I:** OK. Do you take your treatment with you when you are going out for nice time?



**P:** Yes, I always keep it in my handbag. Sometimes I take my treatment during the day if I know I will go out at night. Sometimes you forget about treatment if you have to rush somewhere. You might find out that you are visiting someone who is also taking treatment but she hides it away. Most of my friends are on ART. When I forgot mine at home, I get it from my friends – visa-versa.

**I:** OK, do you share ART with friends?

**P:** Yes, we use the same kind of ART. We are open about it. The minute you hide it, the minute you are getting sick. (29 years old)

Beyond leveraging support from friends and family to remain adherent, participants described strategies that they use to navigate challenging aspects of the HIV care system.

### **3) Sub-Theme 3. “I had to get an address from that side”: Structural barriers can be overcome through creative care navigation and care delivery improvements.**

In general, participants described challenges around maintaining anonymity when receiving HIV care postpartum. Whereas attendance at the MOU is a marker of pregnancy, participants indicated that walking into an adult HIV clinic openly identifies an individual as being HIV positive. Some clinic characteristics, such as the use of separate seating areas for patients living with HIV, posed challenges that patients felt could not be overcome.

However, participants described a wide variety of creative strategies to enhance anonymity within the existing structural constraints. One participant described a strategy to keep her HIV status private in combined mother and baby general care settings. This participant reported submitting her child’s card to the clinic instead of her own. Since her patient folder was filed with her child’s folder, this provided an avenue to obtain her treatment while keeping her HIV status private.

**I:** Can you please paint me a picture [of the clinic], what do people do after they submit their cards?

**P:** It has doors where you put your card, so I would put my child’s card. Once they call us I will only show then my card inside and they would give me my treatment. My folder is always with the baby’s one. (23 years old)

Participants noted that some pharmacies used different color folders to identify patients living with HIV. Participants described hiding their folders in bags or sitting on the folders while waiting, to avoid being publicly identified as living with HIV.

**P:** When you get to the pharmacy, everybody knows that you are taking treatment for HIV because the [folder] cover says it all. It is easy to pick up patients who take ART at [name] clinic because their folders have different cover. Most of people run away because of such things. I never ran away although I was ashamed.

**I:** Do you think this plastic cover has an impact to those who happen to default their treatment?



**P:** Yes, most of them stopped their treatment. I don't use assumptions; I know what I am talking about.

**I:** Were those the mothers with newborn babies by then or did the plastic cover affect everybody?

**P:** It affected everybody because you would find people carrying big bags to hide the folders, even those who are still pregnant. (29 years old)

Folder color may also be a marker of HIV status outside of the clinic walls and may expose patients to stigma or risk once they leave the hospital. One participant described instances of treatment from being stolen upon leaving the clinic. She said that some people use the folder colors to track patients entering the pharmacy and will steal the pills once the patient leaves the hospital. Patients who have been robbed are required to file police reports in order to get a refill, a time-consuming process that deters people from returning to the clinic and contributes to gaps in adherence. In order to prevent treatment from being stolen, this participant described using money belts that hold the pills close to her body.

**P:** People steal our treatment. [...] They identify you by the folder covered with the plastic cover and they watch you when you go to the pharmacy. The minute you go out of the hospital, they rob you [for ART]. Those who stay far away put their treatment inside the money bag just to keep them safe from the thugs. (29 years old)

Several participants carefully selected their new clinic when transitioning from the MOU to adult HIV services. Participants described selecting clinics far from their homes to avoid being recognized by someone in their own communities while attending appointments and picking up ART. One participant reported falsifying her address to gain access to a clinic far away from her own neighborhood, as clinics typically accept patients who live nearby.

**I:** How did you make your first appointment for the date you were given?

**P:** I was scared because I am from Gugulethu so I had to get an address from that side [from another area]. I first delayed. They ended up taking me because I said I am running out of medication. They gave me one packet and they gave me another appointment to come back to. I have been there ever since. (laughs) (28 years old)

Participants also described difficulties with long clinic and pharmacy wait times. Women described using deception as a tool to make the healthcare system fit their schedules and preferences for receiving care. Some of these techniques included lying about having another obligation in order to be seen faster, "forming stories" about running out of treatment to get a new clinic appointment date and attending clinic on the first day of the month when many other patients were obtaining social grants elsewhere rather than attending clinic appointments.

**P:** I used to lie sometimes. I used to say I am going somewhere when I was bored to spend the whole day at the clinic. [...] I used to go to the window when I get there to lie about running out of treatment. I would want them to change my clinic appointment. They provide

you with treatment when you go there to make up stories during the day. They would count the days and change the appointment for you. The clinic is quiet on the 1st day of the month. Nobody goes to the clinic on that day. People go for the social grants on that day. (29 years old)

Participants identified a variety of opportunities to improve care delivery, including delivering treatment at home rather than in-person at the pharmacy, modifying clinic settings to merge all patients into a common waiting area rather than separating patients out by illness type, providing treatment in general care clinics rather than HIV clinics, and abolishing the color-coded folders and cards that are used to identify persons living with HIV in care settings.

## DISCUSSION

All participants reported using some care navigation strategies to help them remain retained in their HIV care and adherent to their medications. Consistent with the assets model, participants discussed their capacity and that in their communities to engage in lifelong HIV care. Successful lifelong care navigation requires sustainable long-term strategies. Participants discussed a wide range of potentially successful strategies ranging from enhancing their individual empowerment to avoiding stigma and discrimination in their environments.

Importantly, participants discussed care navigation strategies as overlapping and interconnected. Indeed, none of the strategies they described were sufficient in isolation. The experience of having one's treatment stolen is illustrative: robbing patients for ART highlights contextual challenges related to illicit drug use in this community, with implications for individual motivation to secure a refill after being robbed. Similarly, women must have individual motivation to navigate their care while simultaneously avoiding stigma in their neighborhoods, workplaces and clinic settings, but clinics and pharmacies contribute to this barrier through the use of color-coded folders and refill policies. These examples point to overlapping needs for individual, interpersonal and structural navigation.

At an individual level, participants discussed the need to maintain their own motivation and empowerment in care, including needing to be knowledgeable about their ART and making a personal commitment to lifelong treatment. Participants frequently discussed their own empowerment in the context of their relationships with supportive friends and family. These relationships provided both psychosocial and tangible support to the participants. These findings are consistent with recent qualitative work that has emphasized the importance of self-efficacy and emotional support for patients' retention in care and adherence to ART. (Eshun-Wilson et al., 2019) Other in-progress studies are seeking to evaluate the impact of individual level support (via text-messaging interventions) and peer support programs on postpartum retention and adherence. (Odeny et al., 2018) As the participants underscored the importance of personal knowledge and knowledge-sharing with others, these findings support the need to continue work that teaches individuals about their treatment and care and normalizes living with HIV during the postpartum period.

On a structural level, participants identified a variety of small changes that would improve their experience of care and reduce the need to devise care navigation strategies. Women's experiences thus led us to conceptualize this process as creative care navigation, reflecting their unconventional or atypical ways of navigating care on an individual basis. These results led us to a new concept that we are conceptualizing as creative care navigation, which we are defining as unconventional or atypical ways of navigating care. For example, participants reported using a variety of strategies to cope with patient documentation systems that identified them as living with HIV, including hiding color-coded folders in bags, sitting on them in the waiting room, or using their child's clinic card to avoid experiencing stigma or discrimination in the clinic. While we do not know if such strategies are successful in maintaining a patient's privacy, these examples of creative care navigation provide avenues for further investigation. The participants also expressed a desire for common waiting rooms and suggested that clinics exclusively serving persons living with HIV may be problematic. Some participants worked around these constraints by being selective about which clinic they attended or attending a clinic far from home to avoid being recognized. Other research has reported similar instances of stigma avoidance, with patients afraid of entering healthcare settings that could expose them as persons living with HIV.(Treves-Kagan et al., 2016) Future research should investigate the prevalence of these types of patient identification systems and incorporate the expertise of clinicians and administrators to identify appropriate solutions. Implementation science tools should be utilized to facilitate uptake of any solutions identified.

Broadly, participants differentiated the concepts of public and private disclosure of their HIV status. While women obtained support by disclosing their HIV status and ART use to friends and family, they simultaneously desired privacy and anonymity in public clinic and pharmacy settings. In a setting where HIV is highly stigmatized, understanding both the fear of broad disclosure and the power of controlled and selective disclosure for postpartum women living with HIV can enhance future intervention work. These findings add to the growing body of literature around issues of disclosure among pregnant and postpartum women living with HIV.(Brittain et al., 2018, 2019; Watt et al., 2018) Future work should build on these findings to more deeply understand the nuances around HIV disclosure for postpartum women living with HIV. In particular, future work should seek to disentangle partner versus family disclosure and support as they relate to care navigation. Participants also expressed a desire for treatment to be delivered at home to avoid long clinic and pharmacy wait times. Women reported working around these constraints by attending clinic on the first day of the month to avoid long wait times or asking friends to pick up treatment for them. Future research should evaluate the feasibility, cost-effectiveness, efficacy, and acceptability of home treatment delivery in South Africa for postpartum women living with HIV. Future work should also incorporate the expertise of a wide variety of stakeholders, including clinicians, community care organizations, and National Health Insurance officials, as these perspectives may yield key insights for clinic and pharmacy care navigation.

Future research should more explicitly focus on understanding care navigation strategies. Although this study was initially undertaken to better understand the results of the MCH-ART trial, participants spontaneously discussed the ways that they are working to remain retained in care and adherent to medications during the postpartum period. As researchers,

we should take their eagerness to discuss postpartum care navigation as feedback to direct future research. The strategies identified by these participants can be further evaluated through a more systematic assets model approach to engagement in care. Explicitly seeking out experiences from women who have been able to attend appointments and have high adherence levels in the late postpartum period may provide further insights that can be structurally extended to broader populations, with implications for future intervention work, healthcare settings and public policy.

### Strengths and Weaknesses

The MCH-ART sub study identified several emergent sub-themes around care navigation.. A strength of our study is that these participants returned to complete a second interview with study staff, and likely developed rapport with the interview team over the course of the interviews. These relationships between the participants and interviewers may have facilitated open dialogue around retention in care. The participants spontaneously discussed nearly all of the individual and contextual adherence and retention factors that have been reported in the broader literature, with the exception of education level, age and religion. (Hodgson et al., 2014) The consistency between our findings and broader literature suggests that these participants were able to shed light on a wide variety of lived experiences. Future work can build on these emergent findings to more deeply understand the strategies that women are using to successfully navigate their care. As this study did not assess data saturation for this emergent theme, future work should ensure that data saturation is achieved to provide a comprehensive discussion of care navigation strategies within the study population. For instance, the interview guide was not designed to interrogate experiences of support from partners versus from families more broadly. Future work should elucidate this nuance around family versus partner support.

Some of the participants who were randomly selected could not be reached for this interview. As such, the women participating may differ from the participants who could not. For example, women who completed the interview may have been more motivated to discuss their postpartum experiences. Women who we were able to reach for this study may have been differentially retained in care; however, we are unable to evaluate retention in care for this study. There may be variation among women in terms of how deeply they were able to reflect on issues around their postpartum retention and adherence, given that this may be relatively unimportant within the context of other major life events. However, those participants who did complete the 18-month postpartum interviews provided rich insights into late postpartum experiences, filling a gap in the current literature that largely focuses on the immediate postpartum period.(Psaros et al., 2015)

### CONCLUSIONS

As research focused on postpartum care retention and treatment adherence among women living with HIV continues to evolve, studies should strive to understand what works for women within their local contexts. Successful lifelong care navigation requires sustainable long-term strategies. The participants in this study described a wide range of care navigation strategies in the late postpartum period, ranging from enhancing their individual

empowerment to avoiding stigma and discrimination in their environments. These strategies are described as overlapping and interconnected; none of the strategies were sufficient in isolation. Better understanding of these potentially successful care navigation strategies should guide future work, leveraging the wisdom of women who have experienced the postpartum care transition to improve maternal engagement in care.

## ACKNOWLEDGEMENTS

This study was supported by the President's Emergency Plan for AIDS Relief (PEPFAR) through the National Institute of Child Health and Development (R01HD074558, M-PIs: Abrams and Myer). Support for data analysis and manuscript preparation was provided by the National Institute of Mental Health (K01MH112443, PI: Pellowski). The funders did not have any role in the development, execution, or writing of this manuscript. We would like to thank our participants who took the time to speak with us regarding their experiences postpartum. We would also like to thank the study staff, particularly Zanele Rini and Nolundi Shumane for their dedication to this sub-study.

## REFERENCES

- Abrams E (2016, 7). Impact of Option B+ on ART uptake and retention in Swaziland: A stepped-wedge trial. AIDS 2016, Durban, South Africa. [http://programme.aids2016.org/PAGMaterial/PPT/5556\\_11745/Nontokozi%20Langwenya.pptx](http://programme.aids2016.org/PAGMaterial/PPT/5556_11745/Nontokozi%20Langwenya.pptx)
- Brittain K, Mellins CA, Remien RH, Phillips TK, Zerbe A, Abrams EJ, & Myer L (2019). Impact of HIV-Status Disclosure on HIV Viral Load in Pregnant and Postpartum Women on Antiretroviral Therapy: Journal of Acquired Immune Deficiency Syndromes, 81(4), 379–386. 10.1097/QAI.0000000000002036 [PubMed: 30939530]
- Brittain K, Mellins CA, Remien RH, Phillips T, Zerbe A, Abrams EJ, & Myer L (2018). Patterns and Predictors of HIV-Status Disclosure Among Pregnant Women in South Africa: Dimensions of Disclosure and Influence of Social and Economic Circumstances. AIDS and Behavior, 22(12), 3933–3944. 10.1007/s10461-018-2263-6 [PubMed: 30155586]
- Clouse K, Schwartz S, Van Rie A, Bassett J, Yende N, & Pettifor A (2014). “What They Wanted Was to Give Birth; Nothing Else”: Barriers to Retention in Option B+ HIV Care Among Postpartum Women in South Africa. Journal of Acquired Immune Deficiency Syndromes, 67(1), e12–e18. 10.1097/QAI.0000000000000263 [PubMed: 24977376]
- Colvin CJ, Konopka S, Chalker JC, Jonas E, Albertini J, Amzel A, & Fogg K (2014). A Systematic Review of Health System Barriers and Enablers for Antiretroviral Therapy (ART) for HIV-Infected Pregnant and Postpartum Women. PLoS ONE, 9(10), e108150. 10.1371/journal.pone.0108150 [PubMed: 25303241]
- Eshun-Wilson I, Rohwer A, Hendricks L, Oliver S, & Garner P (2019). Being HIV positive and staying on antiretroviral therapy in Africa: A qualitative systematic review and theoretical model. PLoS ONE, 14(1), e0210408. 10.1371/journal.pone.0210408 [PubMed: 30629648]
- Gardner EM, McLees MP, Steiner JF, del Rio C, & Burman WJ (2011). The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection. Clinical Infectious Diseases, 52(6), 793–800. 10.1093/cid/ciq243 [PubMed: 21367734]
- Genberg BL, Shangani S, Sabatino K, Rachlis B, Wachira J, Braitstein P, & Operario D (2016). Improving Engagement in the HIV Care Cascade: A Systematic Review of Interventions Involving People Living with HIV/AIDS as Peers. AIDS and Behavior, 20(10), 2452–2463. 10.1007/s10461-016-1307-z [PubMed: 26837630]
- Glaser BG, & Strauss AL (2009). The discovery of grounded theory: Strategies for qualitative research (4. paperback printing). Aldine.
- Haas AD, Tenthani L, Msukwa MT, Tal K, Jahn A, Gadabu OJ, Spoerri A, Chimbwandira F, van Oosterhout JJ, & Keiser O (2016). Retention in care during the first 3 years of antiretroviral therapy for women in Malawi's option B+ programme: An observational cohort study. The Lancet HIV, 3(4), e175–e182. 10.1016/S2352-3018(16)00008-4 [PubMed: 27036993]

- Helova A, Akama E, Bukusi EA, Musoke P, Nalwa WZ, Odeny TA, Onono M, Spangler SA, Turan JM, Wanga I, & Abuogi LL (2016). Health facility challenges to the provision of Option B+ in western Kenya: A qualitative study. *Health Policy and Planning*, *czw122*. 10.1093/heapol/czw122
- Hodgson I, Plummer ML, Konopka SN, Colvin CJ, Jonas E, Albertini J, Amzel A, & Fogg KP (2014). A Systematic Review of Individual and Contextual Factors Affecting ART Initiation, Adherence, and Retention for HIV-Infected Pregnant and Postpartum Women. *PLoS ONE*, *9*(11), e111421. 10.1371/journal.pone.0111421 [PubMed: 25372479]
- Katirayi L, Namadingo H, Phiri M, Bobrow EA, Ahimbisibwe A, Berhan AY, Buono N, Moland KM, & Tylleskär T (2016). HIV-positive pregnant and postpartum women's perspectives about Option B+ in Malawi: A qualitative study. *Journal of the International AIDS Society*, *19*(1), 20919. 10.7448/IAS.19.1.20919 [PubMed: 27312984]
- Miller K, Muyindike W, Matthews LT, Kanyesigye M, & Siedner MJ (2017). Program Implementation of Option B+ at a President's Emergency Plan for AIDS Relief-Supported HIV Clinic Improves Clinical Indicators But Not Retention in Care in Mbarara, Uganda. *AIDS Patient Care and STDs*, *31*(8), 335–341. 10.1089/apc.2017.0034 [PubMed: 28650703]
- Morgan A, & Ziglio E (2007). Revitalising the evidence base for public health: An assets model. *Promotion & Education*, *14*(2\_suppl), 17–22. 10.1177/10253823070140020701x [PubMed: 17526320]
- Myer L, Phillips TK, Zerbe A, Brittain K, Lesosky M, Hsiao N-Y, Remien RH, Mellins CA, McIntyre JA, & Abrams EJ (2018). Integration of postpartum healthcare services for HIV-infected women and their infants in South Africa: A randomised controlled trial. *PLoS Medicine*, *15*(3). 10.1371/journal.pmed.1002547
- Myer L, Phillips TK, Zerbe A, Ronan A, Hsiao N-Y, Mellins CA, Remien RH, Le Roux SM, Brittain K, Ciaranello A, Petro G, McIntyre JA, & Abrams EJ (2016). Optimizing Antiretroviral Therapy (ART) for Maternal and Child Health (MCH): Rationale and Design of the MCH-ART Study. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *72*, S189–S196. 10.1097/QAI.0000000000001056 [PubMed: 27355508]
- Odeny TA, Onono M, Owuor K, Helova A, Wanga I, Bukusi EA, Turan JM, & Abuogi LL (2018). Maximizing adherence and retention for women living with HIV and their infants in Kenya (MOTIVATE! study): Study protocol for a randomized controlled trial. *Trials*, *19*(1), 77. 10.1186/s13063-018-2464-3 [PubMed: 29378622]
- Pellowski JA, Weber AZ, Phillips TK, Brittain K, Zerbe A, Abrams EJ, & Myer L (2019). "You must leave but I didn't want to leave": Qualitative evaluation of the integration of ART into postnatal maternal and child health services in Cape Town, South Africa. *AIDS Care*, 1–6. 10.1080/09540121.2019.1659913
- Phillips T, McNairy ML, Zerbe A, Myer L, & Abrams EJ (2015). Implementation and Operational Research: Postpartum Transfer of Care Among HIV-Infected Women Initiating Antiretroviral Therapy During Pregnancy. *Journal of Acquired Immune Deficiency Syndromes*, *70*(3), e102–e109. 10.1097/QAI.0000000000000771 [PubMed: 26470033]
- Pсарos C, Rimmert JE, Bangsberg DR, Safren SA, & Smit JA (2015). Adherence to HIV Care After Pregnancy Among Women in Sub-Saharan Africa: Falling Off the Cliff of the Treatment Cascade. *Current HIV/AIDS Reports*, *12*(1), 1–5. 10.1007/s11904-014-0252-6 [PubMed: 25620530]
- Robinson-White S, Conroy B, Slavish KH, & Rosenzweig M (2010). Patient Navigation in Breast Cancer: A Systematic Review. *Cancer Nursing*, *33*(2), 127–140. 10.1097/NCC.0b013e3181c40401 [PubMed: 20142736]
- Steward WT, Sumitani J, Moran ME, Ratlhagana M-J, Morris JL, Isidoro L, Gilvydis JM, Tumbo J, Grignon J, Barnhart S, & Lippman SA (2018). Engaging HIV-positive clients in care: Acceptability and mechanisms of action of a peer navigation program in South Africa. *AIDS Care*, *30*(3), 330–337. 10.1080/09540121.2017.1363362 [PubMed: 28814110]
- Strauss AL, & Corbin JM (1991). *Basics of qualitative research: Grounded theory procedures and techniques* (3. printing). Sage.
- Tong A, Sainsbury P, & Craig J (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. 10.1093/intqhc/mzm042 [PubMed: 17872937]



- Treves-Kagan S, Steward WT, Ntswane L, Haller R, Gilvydis JM, Gulati H, Barnhart S, & Lippman SA (2016). Why increasing availability of ART is not enough: A rapid, community-based study on how HIV-related stigma impacts engagement to care in rural South Africa. *BMC Public Health*, 16(1), 87. 10.1186/s12889-016-2753-2 [PubMed: 26823077]
- Watt MH, Knippler ET, Knettel BA, Sikkema KJ, Ciya N, Myer L, & Joska JA (2018). HIV Disclosure Among Pregnant Women Initiating ART in Cape Town, South Africa: Qualitative Perspectives During the Pregnancy and Postpartum Periods. *AIDS and Behavior*, 22(12), 3945–3956. 10.1007/s10461-018-2272-5 [PubMed: 30196332]
- World Health Organization. (2016). Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach. (2nd edition). <http://www.deslibris.ca/ID/10089566>
- World Medical Association. (2013). World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. *JAMA*, 310(20), 2191. 10.1001/jama.2013.281053 [PubMed: 24141714]



**SIGNIFICANCE**

Suboptimal levels of retention in HIV care and adherence to ART during the postpartum period have been reported in many settings. Facilitators of postpartum care engagement have been described; however, few studies have investigated the strategies that postpartum women living with HIV use to navigate their care. This analysis presents emergent themes around postpartum HIV care navigation during the late postpartum period, filling a gap in the current literature which largely focuses on pregnancy or the immediate postpartum period. Experiences from women who have experienced the postpartum HIV care transition provides insights that can be leveraged during future intervention design.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 1:**

Characteristics of the qualitative sub-sample vs. the full sample of the MCH-ART randomized controlled trial participants

	Sub-Sample (n=21)	Full Sample (n=471)	Test Statistic (p-value)
Mean age (SD), years	27.9 (5.3)	28.6 (5.4)	0.551
Completed secondary/any tertiary education	3 (14)	114 (25)	0.311
Primiparous	2 (10)	85 (19)	0.394
Married/cohabitating	9 (43)	184 (41)	0.858
Newly diagnosed HIV+ in this pregnancy	10 (48)	258 (57)	0.380
Composite endpoint of women's retention in ART care and VS <sup>a</sup> at 12 months postpartum	10 (50)	262 (67)	0.117

<sup>a</sup>VS (viral suppression) is defined as VL (viral load) < 50 copies/ml based on VL testing at the MCH-ART trial measurement visit.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript