Published in final edited form as:

AIDS Care. 2018 June ; 30(SUP2): 5–10. doi:10.1080/09540121.2018.1470308.

“I just wish that everything is in one place”: Facilitators and barriers to continuity of care among HIV-positive, postpartum women with a non-communicable disease in South Africa

Kate Clouse^{1,2}, Molebogeng Motlhatlhed³, Kemberlee Bonnet⁴, David Schlundt⁴, David M. Aronoff², Rosette Chakkalakal⁵, and Shane A. Norris³

¹Vanderbilt Institute for Global Health, Vanderbilt University, Nashville, TN, USA

²Vanderbilt University Department of Medicine, Division of Infectious Diseases, Nashville, TN, USA

³MRC/Wits Developmental Pathways for Health Research Unit, University of the Witwatersrand, Johannesburg, South Africa

⁴Vanderbilt University Department of Psychology, Nashville, TN, USA

⁵Vanderbilt University Department of Medicine, Division of General Internal Medicine and Public Health, Nashville, TN, USA

Abstract

HIV and non-communicable diseases (NCD) are co-epidemics in South Africa. Comorbid individuals must engage in lifelong care, which may require frequent encounters with the healthcare system. Postpartum HIV-positive women in South Africa are at high risk of dropping out of HIV care. We sought to explore healthcare utilization among postpartum women requiring chronic management of HIV and NCD, and identify facilitators and barriers to follow-up engagement. From August – December 2016, we enrolled 25 women in Soweto, South Africa, and conducted one-time, open-ended interviews. All participants were adult (≥ 18 years), HIV-positive, recently postpartum, and diagnosed with a NCD that required further evaluation after delivery. NCD diagnoses included chronic hypertension (12/25), gestational hypertension (4/25), and gestational diabetes (6/25); 3/25 had multiple NCDs. All participants were on antiretroviral therapy (ART). Based on analysis of coded transcripts, we developed a conceptual model that describes how maternal factors, interaction with environments, and social networks influence follow up engagement. While HIV and NCD visits usually occurred in the same clinic, visits often were on different days, and baby care visits nearly always were on different days. Barriers to follow-up included increased time commitment, transportation and logistics, unfamiliar clinic environments, and disrespectful treatment by staff. Factors facilitating patient engagement

***Corresponding author** Kate Clouse, PhD, MPH, Assistant Professor of Medicine, Vanderbilt Institute for Global Health, 2525 West End Avenue, Suite 750, Nashville, TN 37203 USA, kate.clouse@vanderbilt.edu.

Meetings:

This work was presented as an oral presentation at the AIDS Impact Conference Cape Town 2017, from November 13–15, 2017, in Cape Town, South Africa.

Conflicts of interest:

The authors declare no conflicts of interest.

included social support and partner disclosure. Women were more likely to turn to friends and family for advice regarding HIV or the NCD, rather than a health facility. Women prioritized infant care over self-care after delivery, suggesting that baby care may be an entry point for improving maternal care after delivery. Our results support advocating for better integration of services at the primary care level as a method to improve continuity of care for both women and children.

Keywords

HIV/AIDS; South Africa; pregnancy; non-communicable diseases (NCD); retention in care

Background

South Africa, with more people living with HIV than any other country in the world, has the world's largest antiretroviral therapy (ART) program (UNAIDS, 2013). This has dramatically altered the health and quality of life of people living with HIV/AIDS (Bor, Herbst, Newell, & Bärnighausen, 2013). The rapid scale-up of the national ART program has put substantial pressure on the limited resources of the public health sector.

Continuous engagement in HIV care is essential because HIV requires lifelong treatment adherence. The problem of HIV patient drop-out within the South African healthcare system is well documented (Fox & Rosen, 2015). Women who initiate ART during pregnancy may be at highest risk of dropping out of care (Bassett et al., 2009; Clouse et al., 2013; Myer et al., 2012). Since 2015, all HIV-positive pregnant are eligible to initiate lifelong ART; however, it is not enough to simply expand eligibility for national ART programs. These efforts must be coupled with strategies to improve retention in care among women and their newborns (Ghadrshenas et al., 2013).

Non-communicable diseases (NCD) are on the rise throughout sub-Saharan Africa. In 2015, NCDs comprised six of the top ten causes of death in South Africa (Statistics South Africa, 2017). A study of women in Soweto, South Africa, reported 50.1% obesity, 42.1% metabolic syndrome and 14.3% Type 2 diabetes (Crowther & Norris, 2012). High prevalence of hypertension has been documented in studies throughout South Africa (Alberts et al., 2005; Thorogood et al., 2007; van Rooyen et al., 2000). Data on the prevalence of gestational diabetes (GDM) are sparse throughout Africa, but range from 1.6–8.8% (Macaulay, Dunger, & Norris, 2014). To date, very little has been published on retention in NCD care, but certainly women who are diagnosed with HIV and other co-morbidities face even greater challenges accessing continuous care within South Africa's fragmented public health care system.

Postpartum HIV-positive women in South Africa are at high risk of dropping out of HIV care. Given the high prevalence of HIV and NCD in South Africa, and the added complexity of simultaneously caring for one's infant, we sought to explore healthcare utilization among postpartum women requiring chronic management of HIV and comorbid NCD. Our aim was to identify facilitators and barriers to follow-up engagement and treatment adherence.

Methods

Participant recruitment

From August–December 2016, we enrolled 25 women at the Developmental Pathways for Health Research Unit at Chris Hani Baragwanath Academic Hospital in Soweto, South Africa. All participants were adult (≥ 18 years), HIV-positive, recently postpartum (6–18 months prior to enrollment), and previously diagnosed with a NCD that required further evaluation after delivery.

Study procedures

We conducted a one-time, open-ended interview with each participant. Interviews were conducted in person by a trained interviewer in the local language chosen by the participant. Interviews were audio-recorded, transcribed, de-identified, translated into English, and formatted for data coding. All participants provided written informed consent at enrollment; study activities were approved by the ethics committees of Vanderbilt University and the University of the Witwatersrand.

Analysis

A hierarchical coding system was developed and refined using an inductive/deductive approach. The coding system was organized into major categories and then subcategorized to capture further thematic detail. Categories captured main themes of 1) personal history; 2) partner history; 3) healthcare access; 4) barriers and facilitators to care; and 5) healthcare utilization history. Based on the frequency of codes, a model was developed to highlight the specific maternal and environmental factors that influence a postpartum, comorbid woman's behavior as she interacts with her clinical and social environments. We report key quotes to illustrate each component of the model.

Results

Participant characteristics

At enrollment, median age and time since delivery was 36 years and 10.7 months. NCD diagnoses included chronic hypertension (12/25), gestational hypertension (4/25), and gestational diabetes (6/25); 3/25 had multiple NCDs. All participants were on antiretroviral therapy (ART); over one-third (9/25) were diagnosed with HIV during the most recent pregnancy. Participants reported spending the most clinic time treating their NCD (median 3.25 hours per visit, followed by 2.75 hours for HIV, and 1.5 hours for the baby's visit).

Theoretical model

Figure 1 identifies knowledge and motivation as key maternal factors that influence the mother's interaction with different types of clinics with various operational characteristics and with the mother's interpersonal social networks. How the mother uses healthcare resources to care for herself and her baby are the result of these person/environment interactions.

Maternal Factors—We identified knowledge and motivation as the two primary maternal factors influencing mothers' behaviors. The dominant themes around knowledge were understanding the importance for caring for herself and her baby, along with awareness of the need for ongoing care for HIV and comorbid conditions. Most mothers indicated an understanding for the need of continuing her own HIV care.

A person who is HIV positive cannot stop taking their ARV; they [nurses] said you have to take them forever. You should not stay and not take them because the virus will become stronger, so the ARVs make it to stop.

(Participant 12)

You have to keep on taking them...you should accept it and deal with it, and you should also talk about it. Like for me I take it as flu; I don't take it as a sickness that kills people or what. I believe that if it kills you, you are the one that cause it to kill you.

(Participant 24)

Motivation had two primary elements: the health and well-being of the mother and the health and well-being of the baby. With respect to the mother, motivation was a function of how she currently feels – specifically, feeling sick encourages attendance more than feeling well – and whether she had sufficient medication at home.

It depends on how much medication they give me, yes, if they give me medication for two months, I will go after two months...when the month ends and I can see that I have two or three [tablets] I have to run to the clinic.

(Participant 3)

I went there because I was sick; I was so weak and couldn't even eat...it was the closest clinic and I thought if I could go there, I would be able to get help.

(Participant 4)

Respondents' motivations to attend clinics themselves was also influenced by her perception of the baby's health and the baby's healthcare needs. For motivation to take the baby to the infant care clinic, the key factor was her perception of the baby's current health status. If the baby seemed healthy, some reported no need to attend the clinic; others reported a need to take the baby to clinic visits regardless of the baby's health.

No. They're [new mothers] not supposed to go to the clinic if the baby is OK and they are OK. I don't see the point of me always being at the clinic. What will I be doing there? Because the baby is healthy and I am healthy.

(Participant 4)

Why should I stop going to the clinic because the baby is healthy? But he still needs to go get his injections [immunizations] even if he is healthy, and they still need to check him...You can see a baby as being healthy on the outside but you don't know what is going on in the inside.

(Participant 3)

Timing of care also influenced the decision to attend, with nearly all participants reporting attending more visits for themselves prior to delivery. In some cases, this was due to complications or high-risk pregnancies, but other times it suggested a change in focus from the mother's healthcare to a primary interest in the baby's healthcare.

Before the baby I went a lot and after I had her went, but when I went after I had her, I was going for her.

(Participant 10)

Environmental Factors—We identified three environmental factors that influence healthcare utilization and treatment adherence: clinic type, clinic operations, and social networks. Operational factors that influenced healthcare utilization included service integration, information sharing, interpersonal interactions, and organization.

Lack of integration of HIV, NCD, and baby care was commonly noted as a barrier to care. Most women reported receiving care for HIV and the NCD in the same clinic, but a different baby clinic was common. Also, even if care was provided in the same clinic, services often were offered on different days, requiring many trips to the clinic. Distance to clinic, regardless of service integration, was a factor hindering attendance.

I just wish that everything is in one place. I shouldn't go to Tladi then the next thing I go to Bara, you see, so it should be just one place.

(Participant 17)

Sometimes you find that my date to go collect ARVs is today and tomorrow I need to go for the high blood check-up, so you see, waking up two days in a row I dread... I think if it could be the same date, I should go on the very same day and do it once.

(Participant 11)

The baby is not the same date....when I go on the 4th, he will go next month.

(Participant 16)

I don't struggle because when I go to the clinic, you find that it's the same date to take the ARVs and BP [blood pressure]; they combine them. So I go for one thing.

(Participant 12)

I was not working and my husband was not working too, so I couldn't say that I had money to catch a taxi to go to clinics that are further.

(Participant 21)

A lack of information from clinic staff was reported as a barrier to attendance of postpartum visits. Most participants reported only attending postpartum visits for the removal of her C-section stitches.

They didn't tell me to come back and I don't know how many times I was supposed to go.

(Participant 20)

After pregnancy I never went [to postpartum clinic], I just went when I went to take out my stitches.

(Participant 19)

Disrespectful treatment by clinical staff, often due to personal stigma related to HIV, was described.

When you get there, they are shouting at you as if you are a small child, that why I think people stop going to clinics.

(Participant 25)

Attitude, the way sometimes patients get treated, it's not OK for me...sometimes you find that people are afraid to ask certain things because you find that health workers can't be approached ...it's not OK the way that they deal with patients. I am not happy.

(Participant 9)

They [HIV clinic] shouldn't discriminate us who are living with this disease, because this thing of HIV-positive people being put aside in one place to take their medication, what is that? I feel it's unfair for us, because the community as whole can see that those that are there are HIV-positive and it hurts, it's so painful.

(Participant 3)

Some mothers reported being treated with more respect at infant care clinics than at non-infant care clinics, which likely facilitates attendance of infant care visits. However, HIV stigma also was noted in the infant clinic too.

These people [staff] are not the same; at the babies' side they are OK and by the older people's side they [staff] are people that are not good in how they treat and handle patients.

(Participant 4)

It [care] was so good; I think it's because it's at the babies' side.

(Participant 19)

Let them be friendly to us; the nurses that is, let them be helpful...I am a parent of a child that is maybe, like I am, HIV-positive. I shouldn't be scared to ask any questions, you see, I should be free to ask anything. Because if they are not friendly it becomes very difficult for you to ask anything.

(Participant 5)

Poor organization was also reported as challenging at HIV and metabolic clinics. Participants complained of long waits and misplaced paperwork.

You arrive and they can't find your file, and when they can't find your file, you have to stay there until they find your file...the clock strikes 12 and you have been there since five.

(Participant 19)

The staff must...be there on time, because you will be there at half-past seven then they will come at half-past eight. So I think time management should be changed.

(Participant 18)

Social Networks—Primary discussion of social support related to male partners, family, those with a shared condition, and those who provide advice. Participants reported disclosure of their HIV status to a seroconcordant partner and shared social support as a facilitator to adherence and care.

Because we [she and partner] are together in this thing, the both of us are HIV-positive, and as we are HIV-positive, we have to talk and update one another and alert each other with anything that happens.

(Participant 3)

I talk to him [partner] because we help each other, he also goes and I help him. Like he used to know my dates and I used to know his dates and we encourage each other to take medication.

(Participant 20)

For both HIV and NCD, participants reported turning to family and community for support and advice, particularly those with a shared condition. Nearly all participants reported talking to and seeking advice from partners or family members related to HIV and the NCD, but were much more likely to seek information about the baby's care from a clinic.

My cousin, the pastor's wife at the church, those are the people I talk to about it [HIV]... Like it's not a thing that you hide anymore; it's not a secret...The health of my baby, I go to the clinic and talk to the sisters [nurses] when I don't understand something.

(Participant 7)

She [family member] told me that high blood pressure can be healed and that high blood pressure reveals itself in women when they are pregnant and if you take your medication properly it will 'heal'.

(Participant 3)

That one I talk to, there is a lady that takes medication for BP, because I was not taking them like the way it was supposed to be taken, and then she told me that her father was killed by BP and it's very dangerous, so I have to take care of it...If I need advice about my baby and I can see that she is not well, I think I will go straight to the clinic.

(Participant 12)

Discussion

We found that complex, interrelated factors contribute to a woman's decision to attend postpartum, HIV, NCD, and infant care. Our conceptual model describing these influences highlights maternal factors – including maternal knowledge and motivation – and

environments, including clinic type, operations, and social networks. Our model can be seen as an adaptation of the social-ecological framework (McLeroy, Bibeau, Steckler, & Glanz, 1988), which considers factors at the individual, interpersonal, community, organizational, and policy levels. The present study helps to elucidate these factors and how they influence care among women requiring numerous healthcare visits.

South African guidelines recommend postpartum visits for the mother and child together at 3–6 days and 6 weeks postpartum to assess psychological and physical condition (Republic of South Africa Department of Health, 2015). Despite these guidelines, very few women were familiar with postpartum care or could confirm receiving it. For ongoing HIV and NCD care, participants often reported receiving care in the same clinic, but not always on the same day. Integration of mother and baby care was even less common. South Africa's Integrated Chronic Disease Management (ICDM) model calls for the integration of services for HIV and NCDs (Republic of South Africa Department of Health, n.d.), but early analyses show gaps in reaching its potential (Ameh et al., 2016, 2017). Although public clinics are free, visits on separate days incur additional transportation and opportunity costs. Financial barriers and time commitments are well-established barriers to HIV care (Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013; Merten et al., 2010) and are multiplied in the context of co-morbid conditions. Overall, women reported attending more visits for themselves during pregnancy than after, and a suggestion that after pregnancy the focus shifts to care for the baby. Based on our participant responses, this belief appears to stem from both within the woman herself and also from messages received at the healthcare facility.

In addition to poor service integration, hostile treatment by clinic staff was frequently noted. Poor treatment has been reported often as a barrier to HIV care (Bwirire et al., 2008; Ferguson et al., 2012; Gourlay et al., 2013), and our findings suggest that treatment may be particularly affected by staff stigma about HIV-positive individuals, despite the continually high prevalence of HIV. Clinic operations that separate HIV-positive patient populations support stigma and possible inadvertent disclosure. Additionally, fear of disclosure about the mother's HIV status may inhibit the baby's follow-up care as an HIV-exposed child. Participants also reported poor organization within clinics, which may increase the pressure on clinic staff, resulting in problematic patient/staff encounters.

Participants who reported disclosure to an HIV-seroconcordant partner noted an increased positive outlook on self-care and clinic visits. We found high levels of disclosure overall between participants and partners or family members, and these individuals often were consulted about HIV and the NCD. Interestingly, when asked who they talk to about their HIV or NCD, only one of the 25 participants responded clinic staff; however, when asked about talking about their baby's health, most reported talking to the clinic. This discrepancy may underscore a reluctance to talk to healthcare providers about HIV and NCD, and also may indicate a lack of counseling and patient interaction at the clinic. This also may indicate an opportunity to use baby care as a starting point to improve maternal care after delivery, offering follow-up care for chronic conditions like HIV and NCDs.

Our study is subject to a number of limitations. First, our results represent the findings from one city in South Africa. The one-time nature of our interview means that we cannot assess how attitudes, motivations, or actions may change over time. Lastly, we asked postpartum women to describe both their recent past care and their current care; past care may have been affected by recall bias.

In South Africa, as in much of sub-Saharan Africa, public health clinics are grappling with co-epidemics of HIV and non-communicable diseases. HIV-positive women struggle to achieve continuity of HIV care after delivery. Our findings suggest that adding an NCD to this mix results in multiple clinic visits with many hours spent at each. Our results support the call for better integration of HIV and NCD in primary care, with a focus on providing services on the same day. South Africa's ICDM model should especially recognize women with chronic diseases and a baby and provide differentiated support to encourage continuity of care, potentially integrating maternal and child health services at baby wellness clinics. Quality of postpartum follow-up care can also be improved through implementation of organizational and policy-level changes that will allow better care coordination, enhanced clinic organization, reduced stigmatization of HIV-positive women, improved social support, and more efficient clinic operation. Addressing these barriers to care is a necessary step to delivering high-quality care for chronic conditions like HIV and NCDs, and to ensuring healthy continuity of care for the mother and infant.

Acknowledgments

Sources of funding:

This work was supported by the National Institute of Mental Health of the National Institutes of Health under Award Number K01MH107256. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH or the US Government. S.A.N. is supported by the DST-NRF Centre of Excellence in Human Development at the University of the Witwatersrand, South Africa

REFERENCES

- Alberts M , Urdal P , Steyn K , Stensvold I , Tverdal A , Nel JH , & Steyn NP (2005). Prevalence of cardiovascular diseases and associated risk factors in a rural black population of South Africa. *Eur J Cardiovasc Prev Rehabil*, 12(4), 347–54.16079642
- Ameh S , Klipstein-Grobusch K , D'ambruoso L , Kahn K , Tollman SM , & Gómez-Olivé FX (2016). Quality of integrated chronic disease care in rural South Africa: user and provider perspectives. *Health Policy Plan*, 32(2), czw118.
- Ameh S , Klipstein-Grobusch K , Musenge E , Kahn K , Tollman S , & Gómez-Olivé FX (2017). Effectiveness of an Integrated Approach to HIV and Hypertension Care in Rural South Africa. *J Acquir Immune Defic Syndr*, 75(4), 472–479.28640065
- Bassett IV , Wang B , Chetty S , Mazibuko M , Bearnot B , Giddy J , ... Freedberg KA (2009). Loss to care and death before antiretroviral therapy in Durban, South Africa. *J Acquir Immune Defic Syndr*, 51(2), 135–9.19504725
- Bor J , Herbst AJ , Newell M-L , & Barnighausen T (2013). Increases in adult life expectancy in rural South Africa: valuing the scale-up of HIV treatment. *Science*, 339(6122), 961–5.23430655
- Bwirire LD , Fitzgerald M , Zachariah R , Chikafa V , Massaquoi M , Moens M , ... Schouten EJ (2008). Reasons for loss to follow-up among mothers registered in a prevention-of-mother-to-child transmission program in rural Malawi. *Trans R Soc Trop Med Hyg*, 102(12), 1195–200.18485431

- Clouse K , Pettifor A , Maskew M , Bassett J , Van Rie A , Gay C , ... Fox MP (2013). Initiating antiretroviral therapy when presenting with higher CD4 cell counts results in reduced loss to follow-up in a resource-limited setting. *AIDS*, 27(4), 645–650.23169326
- Crowther NJ , & Norris SA (2012). The current waist circumference cut point used for the diagnosis of metabolic syndrome in sub-Saharan African women is not appropriate. *PloS One*, 7(11), e48883 10.1371/journal.pone.004888323145009
- Ferguson L , Grant AD , Watson-Jones D , Kahawita T , Ong'ech JO , & Ross DA (2012). Linking women who test HIV-positive in pregnancy-related services to long-term HIV care and treatment services: a systematic review. *Trop Med Int Health*, 17(5), 564–580.22394050
- Fox MP , & Rosen S (2015). Retention of Adult Patients on Antiretroviral Therapy in Low- and Middle-Income Countries. *J Acquir Immune Defic Syndr*, 69(1), 98–108.25942461
- Ghadrshenas A , Ben Amor Y , Chang J , Dale H , Sherman G , Vojnov L , ... Yogeve R (2013). Improved access to early infant diagnosis is a critical part of a child-centric prevention of mother-to-child transmission agenda. *AIDS*, 27 Suppl 2, S197–205.24361629
- Gourlay A , Birdthistle I , Mburu G , Iorpenda K , & Wringe A (2013). Barriers and facilitating factors to the uptake of antiretroviral drugs for prevention of mother-to-child transmission of HIV in sub-Saharan Africa: a systematic review. *J Int AIDS Soc*, 16(1), 18588.23870277
- Macaulay S , Dunger DB , & Norris SA (2014). Gestational diabetes mellitus in Africa: a systematic review. *PloS One*, 9(6), e97871.24892280
- McLeroy KR , Bibeau D , Steckler A , & Glanz K (1988). An ecological perspective on health promotion programs. *Health Educ Q*, 15(4), 351–77.3068205
- Merten S , Kenter E , McKenzie O , Musheke M , Ntalasha H , & Martin-Hilber A (2010). Patient-reported barriers and drivers of adherence to antiretrovirals in sub-Saharan Africa: a meta-ethnography. *Trop Med Int Health*, 15 Suppl 1, 16–33.20586957
- Myer L , Cornell M , Fox MP , Garone D , Wood R , Prozesky H , ... IeDEA-Southern Africa Collaboration. (2012). Loss to follow-up and mortality among pregnant and non-pregnant women initiating ART: South Africa 19th Conference on Retroviruses and Opportunistic Infections. Seattle, WA.
- Republic of South Africa Department of Health. (n.d.). Integrated Chronic Disease Management - Manual.
- Republic of South Africa Department of Health. (2015). Guidelines for Maternity Care in South Africa, 4th Edition.
- Statistics South Africa. (2017). Mortality and causes of death in South Africa, 2015: Findings from death notification. Pretoria.
- Thorogood M , Connor M , Tollman S , Lewando Hundt G , Fowkes G , & Marsh J (2007). A cross-sectional study of vascular risk factors in a rural South African population: data from the Southern African Stroke Prevention Initiative (SASPI). *BMC Public Health*, 7(1), 326.17999764
- UNAIDS. (2013). Global report: UNAIDS report on the global AIDS epidemic 2013. Geneva.
- van Rooyen JM , Kruger HS , Huisman HW , Wissing MP , Margetts BM , Venter CS , & Vorster HH (2000). An epidemiological study of hypertension and its determinants in a population in transition: the THUSA study. *J Hum Hypertens*, 14(12), 779–87.11114693

Figure 1. Conceptual model of healthcare utilization and treatment adherence among HIV-positive, postpartum women with a non-communicable disease.