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Mechanisms linking intimate partner violence and prevention of mother-to-child transmission of HIV: A qualitative study

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Abstract

Prevention of mother-to-child transmission (PMTCT) can virtually eliminate HIV transmission to infants, yet up to one-third of women miss PMTCT steps. Little is known about how partner dynamics such as intimate partner violence (IPV) influence pregnant and postpartum women’s adherence to PMTCT. We conducted 32 qualitative interviews with HIV-positive pregnant and postpartum women in Johannesburg who experienced IPV. Trained researchers conducted in-depth interviews over the period of May 2014 – Nov 2015 using narrative and social constructionist approaches. Interviews were transcribed verbatim and analyzed thematically and inductively using qualitative software. Twenty-six women experienced recent IPV and one-third had poor adherence to PMTCT. Women’s experience of violence influenced PMTCT behaviors through four pathways. First, fear of partner disclosure led women to hide their HIV status to
avoid a violent reaction. Despite non-disclosure, some maintained good adherence by hiding medication or moving out from their partner’s home. Second, IPV caused feelings of depression and anxiety that led to intentionally or accidentally missing medication. Five women stopped treatment altogether as a kind of passive suicidality, hoping to end the distress of IPV. Third, men’s controlling behaviors reduced access to friends and family, limiting social support needed for good adherence. In a protective pathway, women reported good adherence partly due to their mothering role. Fourth, motherhood identity was used as a coping technique, reminding women that their infant’s wellbeing depended on their own health. PMTCT is essential to prevent vertical HIV transmission, but women living with IPV face multiple pathways to non-adherence: partner non-disclosure, mental health, and partner control and isolation. Protective factors like “striving for motherhood” may lessen the relationship between IPV and PMTCT. Addressing IPV in antenatal care can support the health of mothers and infants and may enhance PMTCT coverage.

**Keywords:** South Africa; intimate partner violence; HIV; adherence; qualitative; perinatal

**Introduction**

Prevention of mother-to-child transmission (PMTCT) interventions have potential to eliminate vertical transmission of HIV from mothers to infants (Mofenson, 2010). Yet, women’s adherence to all the steps required for successful PMTCT is often low. Within 21 priority countries, an estimated 65% of eligible pregnant women access HIV treatment (WHO et al., 2013), and pooled analysis suggests that only half of women adhere to treatment postpartum (Nachega et al., 2012). Studies in sub-Saharan Africa suggest that partner relationship factors are among the most important barriers to pregnant women’s acceptance of HIV testing and other PMTCT behaviors (Bwirire et al., 2008; Medley et al., 2004; Turan et al., 2011). Intimate partner violence (IPV) may be one important predictor of adherence to HIV medication in pregnancy and postpartum, yet this association has been understudied in the literature to date (Hatcher et al., 2015).
Among non-pregnant women, IPV victimization is associated with worse HIV-related health outcomes, including higher odds of antiretroviral failure, weaker immune response, increases in opportunistic infections, and greater risk of mortality (Schafer et al., 2012; Weber et al., 2012). A meta-analysis suggested that women’s experience of IPV was associated with 55% lower odds of self-reported adherence and 36% decreased odds of viral suppression (Hatcher et al., 2015). However, of the thirteen included studies, none were based in sub-Saharan Africa or among pregnant women. Since publication of the meta-analysis, only a single study has examined the effect of IPV on adherence in pregnant women. This Zambian study showed that IPV victimization was associated with 74% lower odds of adherence in pregnancy and 89% lower odds of adherence postpartum (Hampanda, 2016). However, the quantitative methods used by this seminal paper preclude a deeper understanding of how partner violence alters PMTCT behaviors. This is a crucial dynamic to understand, particularly since many of the same countries in sub-Saharan Africa with the highest rates of mother-to-child transmission also have high prevalence of IPV (Devries et al., 2013).

South Africa is one such sub-Saharan African setting where HIV and IPV are highly prevalent. An estimated 25 – 35% of South African pregnant women report recent physical and/or sexual IPV (Groves et al., 2012; Hoque et al., 2009). Similarly, antenatal HIV prevalence across South Africa is high, with estimates in Johannesburg reaching 29% (Department of Health, 2012). South Africa has made significant strides towards reducing mother-to-child transmission from 14% in 2009 to an estimated 5% in 2012 (UNAIDS, 2013). Yet, only 54-65% of South African pregnant women and infants complete all recommended PMTCT steps (Stringer et al., 2010; Technau et al., 2014).

Recent qualitative studies have explored the underlying dynamics of IPV among small samples of women living with HIV. Among 8 women reporting violence after HIV disclosure, Colombini et al. learned that new HIV diagnosis was a trigger for violence, even in relationships with no prior history of IPV (Colombini et al., 2016). Mulranen et al. studied postpartum women
living with HIV in Swaziland, of whom 9 reported IPV following disclosure, and learned that violence resulted from acute triggers like HIV status disclosure and also from ongoing marital tensions around fertility (Mulrenan et al., 2015). In a study of pregnant and postpartum HIV-positive women in the United States, Njie-Carr et al. found that 3 women with recent violence avoided partner disclosure because they feared a violent reaction (Njie-Carr et al., 2012).

Illangesekare et al. identified mental health as a primary pathway linking IPV to non-adherence among HIV-positive women reporting lifetime partner violence, of whom 3 were currently living with IPV (Illangasekare et al., 2014). Other qualitative research has broadly explored violence and HIV medication adherence, but not among women who present with both conditions (Hatcher et al., 2014; Zunner et al., 2015). While extant qualitative offers preliminary understanding that perhaps violence and HIV behaviors are linked, samples sizes ranging from 3-9 participants rule out the analytical rigour required to understand why IPV alters adherence.

Qualitative elucidation of the mechanisms linking IPV and HIV adherence is necessary if we are to increase the proportion of women adhering to PMTCT interventions. We conducted in-depth qualitative research with 32 women living with HIV and reporting experience of IPV in Johannesburg, South Africa. The purpose of the research was to explore mechanisms linking these interconnected issues among pregnant and postpartum women.

**Theoretical framework**

This research was informed by an integrated socio-ecological, dyadic conceptual framework (Fig. 1). The socio-ecological model suggests that individual, relationship, and structural factors shape health outcomes (Heise, 1998), and is widely used in IPV research because it incorporates many complex factors that influence partner violence (WHO, 2010).

Within the ecological model, *individual* factors are the personal characteristics or behaviours that impact one’s health. Previous literature has suggested that individual factors inhibiting PMTCT uptake include depression (Nachega et al., 2012; Turan et al., 2013), substance
use (Nachega et al., 2012), internalized HIV stigma and shame (Turan et al., 2013), and costs associated with clinic attendance (Bwirire et al., 2008). Partner relationship factors are the dyadic partnership issues that frame health outcomes. Partner dynamics that worsen PMTCT behaviors include a lack of male involvement in antenatal care (Aluisio et al., 2011), non-disclosure to a partner (Gourlay et al., 2013; Myer, 2011), and threat of further violence (Antelman et al., 2001). The theory of gender and power (Connell, 1985), which postulates that unequal power dynamics limit the ability of women to exercise personal control in relationships (Amaro & Raj, 2000), provides a theoretical underpinning for the associations seen between partner factors and PMTCT uptake. Structural factors refer to the broader social or community factors that impact on health. In this sphere, previous studies have noted that PMTCT is adversely impacted by poverty (hIarlaithe et al., 2014), lack of social support (Kirsten et al., 2011), community stigma around HIV (Turan et al., 2011), and weak health systems (Bwirire et al., 2008). A socio-ecological framework recognises that similar structural factors underpin both violence and HIV (Maman et al., 2000) and that broader social and societal factors shape women’s ability to adhere to HIV medication (Hirsch, 2007) and the extent to which they experience IPV (Heise, 1998).

Methods

The goal of this qualitative research was to build understanding around why and how IPV influences PMTCT uptake and HIV-related health. This analysis is guided by formative qualitative research with pregnant women and health providers (Hatcher et al., 2014). The formative research included no women living with IPV and HIV, but rather asked participants to speculate about the links between violence and PMTCT. As an elucidation of mechanisms requires knowledge of women who actually experience these health conditions, we now present

INSERT FIGURE 1 ABOUT HERE
data from in-depth interviews with a larger sample of women \((n=32)\) living with both IPV and HIV.

Qualitative research was nested within a randomised control trial testing an intervention for IPV in pregnancy (Pallitto et al., in submission). Called Safe & Sound, the trial recruited 1680 pregnant women from four antenatal clinics in Johannesburg to take part in baseline questionnaires. In the parent trial, women reporting recent (past-year) physical and/or sexual IPV \((n=421)\) were randomised to a nurse-led empowerment counseling intervention or an enhanced control condition. This sub-study purposively selected the sample of 32 participants to take part in qualitative, in-depth interviews between May 2014–November 2015.

The methodology for this study was informed by narrative, constructionist approaches to researching IPV (Allen, 2011). The narrative element of this approach posits that discussing IPV experiences with skillful providers can be therapeutically beneficial and that the research process itself serves as a form of reflection for participants (Allen, 2011). Narrative approaches to research on violence acknowledge that women’s stories help create coherence in otherwise chaotic, uncontrollable situations (Williamson, 2010). Narrative approaches use particular techniques during the interview process, such as validation, highlighting resistance strategies, and focusing on meaning and identity (Allen, 2011). The social constructionist methodology acknowledges that researchers are part of the research interaction and that their prior knowledge should be brought to light and examined (Charmaz, 2008).

**Participant sampling and recruitment**

We conducted qualitative research with 32 participants who were purposively selected from women taking part in baseline Safe & Sound trial questionnaires. Women recruited for this sample were living with HIV and experiencing IPV. In practice, this included women participating in the trial (ie. experiencing recent IPV), as well as women who were not eligible to enroll in the trial, but who had experienced IPV in their lifetime. These lifetime history
participants had already completed a full study baseline questionnaire and agreed to be contacted about further research. Study nurses guided the selection of participants based on their impression of women’s willingness to take part in an additional interview, their knowledge of women’s experiences of IPV, and women’s HIV-positive status.

Initially, the sample size proposed for this qualitative study was 24 participants. Using the constant comparative method to understand the emerging constructs from the data (Charmaz, 2003), we found that upon completion of 18 interviews, theoretical saturation had not yet been reached. Data on our initial research question around links between violence and PMTCT lacked richness and women’s stories failed to converge around specific pathways. We thus expanded the sample to reach 32 women using theoretical sampling to include additional women with recent IPV experiences. Theoretical sampling is a technique for using preliminary analysis to guide how data are collected further (Glaser, 1992). In this case, our initial analysis suggested that links between violence and PMTCT are best explored among participants with recent violence and with some challenges adhering to PMTCT behaviors. Displaying “challenges” with PMTCT was therefore used as a selection criteria for the next 14 participants. Additional women with these characteristics allowed us to further refine emergent concepts and test out initial impressions of the data with a more targeted group of participants.

Trained nurse researchers invited women to participate through follow-up phone calls using locator information. All participants contacted for this sub-study were reachable by phone, with 7 women refusing to take part (due to living outside the province, work commitments, or not desiring to take part in additional research). Male partners were never informed about a woman's participation in the research because of the potential for an abusive partner to react violently. To protect participants and reduce the risk that partners would overhear the conversation, nurses were trained to ask “is this a safe time to speak?” before continuing. A full distress protocol included appropriate researcher responses in cases of violence disclosure, psychological distress, high emotionality, or a need for referrals. Basic elements of the distress protocol were employed
during most interviews included in this study: a calm, non-judgmental approach to inquiry; watching for signs of resistance when inquiring about violence to avoid re-traumatisation; offering tissues if participants cried; offering a break from the interview. In cases of severe distress, researchers were trained to invite participants to stop the interview, a technique that was used with one participant, and to offer supportive referrals. In the case of current suicidal thinking, researchers were trained to make a direct referral to a psychiatric ward of the nearest hospital. In this sample, no participants revealed current suicidal thinking but several participants recounted a history of suicidal ideation, for which researchers offered empathetic listening and referrals to a nearby community psychology counseling service.

Data collection

In-depth interviews were conducted face-to-face, in a private clinic room, at a convenient time for the woman. Interviews were conducted by the lead author and three other trained qualitative researchers. The trained researchers were comprised of two South African, female nurses and two non-South African, female researchers. This composition of the research team helped ensure that some of the positionality challenges associated with language and race were addressed. However, all researchers held positions of relative power compared to participants, a dynamic that was intentionally addressed through training on a humble, inquisitive approach and the ethos among the research team that participants were the ‘experts’ and researchers were the ‘learners’. While this positionality could not be completely eliminated, the rich stories presented by most participants suggests comfort in sharing their stories through the research process.

Interviews were conducted in one of three South African languages (English, Sesotho, isiZulu) and digitally recorded. A semi-structured in-depth interview guide explored three themes: the perceived relationship between IPV and HIV in women’s lives; women’s perceptions of how violence may influence PMTCT uptake; and, potential mechanisms through which IPV
may impact PMTCT-related health behaviors. Interviews lasted between 26 minutes and 1 hour 40 minutes (median 46 minutes).

Professional transcriptionists typed verbatim transcripts from the digital recordings. Each transcript was reviewed by a researcher to ensure clarity and for additional detail about tone and non-verbal cues. Interviews conducted in the local language (Sesotho or isiZulu) were translated directly to English and reviewed for translation errors by the researcher who led the interview. All data collection materials were stored in a locked file cabinet and electronic voice files and transcripts were password protected and stored on an encrypted server. At the point of transcription, the lead researcher assigned a pseudonym unrelated to the participant’s real name for ease of analysis. The data presented here note the pseudonym, age, and whether the woman was pregnant or postpartum.

Data analysis

To ensure that interviews achieved adequate depth and richness, the first 6 transcripts were reviewed jointly to establish future questions, points of clarification, and initial themes. Researchers reviewed full transcripts and created detailed 'memos' to highlight initial impressions of the data. This review process was repeated at two other time-points (upon completion of 18 interviews and 28 interviews). Both reviews led to tweaking of the interview guides, with major themes retained but sub-questions altered to enhance probing and clarity. The team developed an initial coding framework based on the preliminary review of 6 transcripts and “sensitizing concepts”, or preliminary ideas around how to examine the data (Bowen, 2006).

The coding framework was applied to all transcripts by two researchers using Dedoose qualitative analytic software. The focus of double-coding was to ensure that code application was consistent across transcripts and that code definitions were robust. Rather than assessing inter-rater reliability, the team used a series of phone calls and in-person meetings to refine codes until consensus was reached. This process led to a refined set of thematic codes that comprised broad
topics such as relationship characteristics, experience of violence, HIV diagnosis, PMTCT uptake, mental health, social support, partner HIV serostatus disclosure, and reflections on being asked about IPV in pregnancy. Next, the team established a system of fine codes that emerged inductively from the data. Fine codes were applied to a portion of transcripts by three researchers, ensuring that every transcript was double-coded. Examples of fine codes within the partner HIV disclosure section were: fear of partner response, reactive or polarized methods of disclosure, male partner denial of disclosure, concern for the child, supportive steps, displaced anger. During analysis, cases that did not fit the overall picture, called “exceptional cases”, were actively sought out. Trustworthiness of findings was ensured by the team approach to data analysis, coding discussion meetings, and by presenting initial findings to groups of colleagues and peers.

Ethical and safety considerations

All participants provided written, informed consent. The parent trial received approval from the University of the Witwatersrand Human Research Ethics Committee (M121179) and World Health Organization Ethics Research Committee (RPC471). This qualitative substudy received additional secondary analysis approval from University of the Witwatersrand (M140451).

Given the special considerations around researching violence, all portions of this study were designed to adhere to the WHO ethical and safety guidance on IPV research (WHO, 2001). The research was presented broadly so that the specific nature of the study was not made public. Only when the participant and interviewer were alone, during the informed consent process, did the researcher provide further information that the nature of the study involved HIV and IPV. All qualitative researchers were intensively trained. A 30-hour technical training alongside weekly mentorship and debriefing by senior team members ensured all researchers had the knowledge and skills required to skillfully handle disclosure of violence (Reynolds, 2007).

Results
Sample characteristics

Of the 32 participants, 26 women reported IPV in pregnancy while 6 reported a prior history of IPV (see characteristics summarized in Table 1). The majority of participants (75%) reported physical and emotional violence, with several (16%) reporting physical, sexual, and emotional violence. Twelve participants (38%) reported that they were non-adherent to HIV medication during the time of pregnancy or were not on treatment.

INSERT TABLE 1 ABOUT HERE

Links between violence and PMTCT adherence

We learned that four pathways linked women’s experience of IPV with their adherence to PMTCT interventions. The first pathway was partner disclosure, with violent relationships framing a decision to hide one’s HIV status. Some women were unable to maintain careful PMTCT behaviors without risking disclosure, so they opted to take treatment breaks or stop treatment altogether. A second pathway was mental health, as IPV resulted in depressive views that “life is not worth living” and led to missing doses of medication. A third pathway was partner control and isolation, in which men limited participant access to friends and family, which precluded the social support required for good adherence. In a final, protective pathway, good PMTCT adherence seemed linked to women’s identity as mothers, with the wellbeing of the baby framing decisions to stay attentive to medication.

Below, we present each pathway alongside illustrative quotes and case examples of participants. While it may appear that certain women ‘belong’ primarily to one single pathway, this was certainly not the case within the overall analysis. Participants often related stories that highlighted the complex relationship across the pathways.

Partner (Non) Disclosure: Hiding HIV from a partner
Of the 16 women who disclosed to partners, many experienced subsequent physical violence (n=6) and emotional violence (n=7) that they directly linked to the disclosure act. Participants recalled incidents of violence that started or worsened immediately following HIV testing. Lulama, who was 30 years old and pregnant with her second child, made a direct link between her HIV status and physical and emotional violence from her partner. The partner consistently blamed Lulama for “giving” him HIV, and would use threats of further physical violence to show his disdain for her status. Thuto, a 25-year-old postpartum participant, explained that the violence in her relationship started when she tested HIV-positive during her first pregnancy. Thereafter, a severe episode of physical violence in her third pregnancy was directly related to her HIV status: “He came back from the shebeen [local bar] and said I was a slut, and that’s why I came with this disease.”

Not all women experienced physical violence after disclosing their HIV status. A tension occurred in Leah’s relationship that demonstrates the blurred lines between violence and partner support around HIV. As a 33-year-old pregnant participant, Leah’s husband was broadly supportive of her taking medication, because Leah had carefully convinced him that PMTCT can prevent HIV in their infant. Leah’s partner would even remind her of her treatment time. Yet, alongside this instrumental support, he was emotionally abusive and would remind her that HIV would lead to her death by stating, “You will die, your children will be alone.”

In this context of violent or psychologically harmful reactions, it is perhaps not surprising that 16 women opted to keep their HIV status a secret. Participants described this choice as a reasoned response to a dangerous situation. Six participants feared that their partners would react to disclosure with physical violence. For Simphiwe, a 33-year-old woman who had been with her partner for five years, a history of physical violence led her to keep HIV a secret. Another participant, Kandi, feared physical violence because her partner explicitly stated that he would hurt her should she test HIV-positive.
Fears of partner reaction led some women to be partially non-adherent to their HIV medications. One 32-year-old postpartum participant, Nomsa, described her fear that the father of her first child might murder her or the child as a response to HIV disclosure. Nomsa kept her status hidden by pretending the medication was for pregnancy, rather than for HIV, but admitted it was challenging to keep taking the pills after giving birth. Another participant, Thembi, was 26 years-old and postpartum when she recounted how she chose not to start HIV medication in pregnancy because she was frightened that her partner would be physically violent when she asked him to use a condom. Her (incorrect) understanding of treatment came from antenatal staff who often say that HIV medication must be accompanied by consistent condom use. Since Thembi knew she could not safely use condoms, she chose to avoid HIV medication altogether. Her non-uptake of treatment meant that her infant acquired HIV during the course of the study.

The act of hiding medication and withholding one’s status from partners requires considerable foresight and care. Lulama, 30 years and pregnant during the interview, strategically took medication at a time when her husband was away from the house. At 34 years and pregnant, Ayanda changed the container of her HIV medication so that it would appear to be other routine medication. Other women like Mpefe also had to carefully navigate clinic visits and medication:

“My boyfriend doesn’t know about this. I just kept it to myself. So my treatments, when I would come and take my treatments here by the clinic, then I would hide it by my place. Even when I drink my tablets I would hide them. – Mpefe, 25 years, Pregnant

When Mpefe noticed her partner was nearby, she would forgo treatment altogether. Eventually, Mpefe decided to move out so that she could easily take her treatment without worry that her boyfriend might see.

Similarly, Zama (25 years and pregnant) found it easier to adhere to medication once she moved out from her partner’s place. Before she would wait until he fell asleep to take her daily prescription: “It was a little bit tricky because I had to hide the medication. And then at times he
would be in the same bedroom where I hide it, so I can’t take it.” For Sonja, the original response to disclosure was threats of violence and forced eviction from the household. In this context, Sonja, 23-years-old and pregnant, carefully avoided taking medication in front of her partner, worrying that simply seeing the medicine might trigger a violent reaction. One day, her partner snuck up on her in the bathroom and caught her taking the treatment. While the response was not physical violence, her partner disappeared and returned home in an agitated state after a bout of drinking.

A subtler rationale for hiding medication from violent partners was to withhold information from a person who had caused so much pain. For two women, this appeared to be a resistance strategy for proving to themselves that their own health was not within the realm of things men could control. Simphiwe professed that she made up her mind immediately after testing HIV positive, since “he was violent, hitting me and all that stuff. So I decided I’m not going to tell him.” Similarly, Zinhile explained “If he was a proper person, then I would tell him that I’m HIV positive, let’s go to the hospital together to test. But if he is going to put me at risk, why should I say that?” Zinhile met her partner’s lack of care by stubbornly refusing to share anything about HIV with him:

I didn’t want him to know I have gone to the clinic. I didn’t even want him to know what I was doing in my life, in my future, because he didn’t want to be close... I didn’t even want him to see me taking the tablets, because he didn’t want to know, he didn’t want me. – Zinhle, 38 years, Postpartum

Mental health: Poor adherence as a result of depression and anxiety

Several women related stories of non-adherent periods, many of which resulted from depressive episodes that followed phases of violence. At 24 years, Thuto had recently delivered her fourth child, and explained the tendency to feel despondent particularly after extremely violent episodes or when her husband refused to buy food for the family. Thuto sometimes struggled with staying
adherent, and explained that she had given up hope: “Sometimes, when I’m stressed, I feel that its better I also died… I’ve just lost hope.” Zama expressed a concern that her infant would test HIV-positive, since she herself had experienced adherence struggles. Similar to several other participants, Zama disclosed a desire to “end everything” as a method to reduce the distress she was feeling about the violent relationship:

> When I was three months pregnant, that is when it started changing to being physical [violence]. At times I would just feel like ending everything. the stress and all that... I am very much worried about my baby being positive, especially with the fact that I was not able to take my medication as frequently as I was supposed to. –Zama, 25 years, Pregnant

Ayanda’s partner had been physically abusive the night before the interview. She described the physical violence alongside the overwhelming nature of coping with frequent abusive episodes and anticipating the arrival of a new baby. The stress related to the violence was a concern because Ayanda realised how episodes of IPV took priority over remembering to take her medication:

> You know what bothers me sometimes? That when he makes this thing [violence], I may forget to drink my medication. Then maybe I will just default [not comply with HIV visits and medications]. And what worries me is that I will default when I’m breastfeeding the child. –Ayanda, 34 years, Pregnant

This notion of “forgetting” to take medication is perhaps more linked to how women are able to cope with various life challenges. When violence is more of a concern, or more ‘top of mind’, than HIV-related concerns, women may forgo the steps required for good HIV care. This finding denotes how subtle mental health considerations, like being too cognitively overwhelmed by the violence, may influence PMTCT uptake.

Six women described periods of stopping treatment altogether due to depressive and suicidal feelings. The underlying emotion of stopping treatment for these women was a desire to
end their lives. One participant, Dova, named it a “death wish” and recounted the overwhelming feelings of hopelessness and failure that had led her to stop taking HIV treatment:

There was a time when I was really, really down, so I stopped taking my medication. I completely just stopped and I sort of had this death wish in me that if only this thing would, if HIV would work like really for us then it would just kill me. I stopped for three to four months without taking my medication. – Dova, 32 years, Pregnant

Another participant, Dintle, had tried to commit suicide by drinking poison several weeks prior to the interview. Her husband had been extremely violent, hitting her in front of the neighbours, withholding food, and publicly shaming her. She explained in subtle terms (such as “stress” and “feeling bad”) how her recent suicidal experience and anxiety symptoms would cause her to forgo treatment for periods of time:

Participant (P): Sometimes I forget to take my treatment. It happened two months ago. I had pills, but I just forgot dates to go fetch my treatment.

Researcher (R): What led you to forget?

P: Stress, I am always thinking.

I: What were you thinking?

P: I was thinking about the time he threatened me. I just end up thinking about too many things. By the time I remember it is too late, my days have passed. – Dintle, 30 years, Postpartum

For Dintle, stopping treatment was a by-product of experiencing intense episodes of violence and concomitant mental health challenges. This suggests that in cases of severe depression, HIV treatment non-adherence can be both a mode of self-harm and a result of being overwhelmed at times of high distress.
Isolation and partner control: The hidden nature of IPV and HIV

In this sample, there were only a few examples of partners directly controlling the health of women through barring access to clinics or medication. At 38 years and postpartum, Zinhle feared blame associated with having HIV, but not necessarily a violent reprisal. Even still, the controlling behaviors her partner exhibited against the backdrop of physical and sexual violence meant that Zinhle would surreptitiously visit the clinic.

Yet, partner control did not always lead to poor adherence. For example, Kagiso’s partner was suspicious when she went to the clinic, assuming she was cheating on him. At times, he would physically abuse her when she came home from the clinic, assuming she was unfaithful during her times away from home, but she described a stubborn dedication to continue seeking medical treatment:

*Sometimes when I go to the clinic he say hey you are not going to the clinic. He asked me too many questions...* But I refuse. *I tell him I can’t stop going to clinic because this is my life! I have children. I have to live to take care of my babies.*

*Sometimes when I come back to the house he beats me, accusing that I’m not coming from the clinic.* –Kagiso, 28 years, Postpartum

For many women, violent partners did not actively bar access to clinics, but indirectly used isolation as a type of partner control. One example is found in Lulama’s story about how returning from a normal day would often result in questions and threats: “He is always looking at what I do and wants to know what I get up to. He controls my life, he says I should always be at home.” The outcome of these controlling behaviors was often immense isolation and mental health challenges for Lulama, who was 30 years and pregnant at time of interview.

For several participants, the feeling of isolation was pervasive, leaving them troubled and continually ruminating over difficult thoughts. Dova illustrated this by describing how thoughts of the violence were “stuck in her mind” and left her isolated and alone:
It is just basically stuck there in my mind - all these things that have been happening. When you are alone, you just sit and think about it and I don't have anyone. Sometimes I don't sleep the whole night I am thinking and thinking. – Dova, 32 years, Pregnant

Another implicit trait of the partner control and isolation pathway is the hidden nature of both HIV and violence. Both HIV and IPV are stigmatised, which leads to a worsened ability among women to find support for either condition. Several women spoke of staying silent with their families about the violence in their relationships. As 30-year-old, pregnant Lulama noted, “whatever we fight about I keep to myself most of the time.” For Neo, it was easier to pretend that things were fine than to disclose to her friends that she lived in a violent relationship: It’s hard to tell people I’ve got a problem, I’m not living a good life, with a partner that I’m worried, we’re always fighting, things like that. You just pretend, like now pretending that I’m ok but I’m not ok. – Neo, 28 years, Pospartum

Motherhood as a coping strategy: protective pathway

Despite immense challenges with HIV, violence, and pregnancy, many women in this sample exhibited unique coping strategies for adhering to treatment. For some women (n=8), the concept of motherhood was a source of resilience and helped them stick with HIV medications. At 32 years and postpartum, Nomsa struggled to find clothing and food for her children, but continually reminded herself that treatment was an essential part of being able to care for her children: “I’m drinking my tablets. I’m just telling myself that I must help myself and get help. I know I need to work for my kids rather than die.”

Zama did have trouble with adhering to treatment, and considered suicide during phases when the physical violence was particularly bad. Yet, at 25 years and pregnant, the reminder of her new baby would often be enough to return her to thoughts of living and trying to provide for her baby: “Maybe after a fight, I will be crying, stressed and then I would be like, okay, let me
just do this [commit suicide], then I would think, ‘No, but let us give this baby a chance.’” It is important to note that Zama exhibited these methods of “resilience” by focusing on her baby’s wellbeing even as she struggled with suicidality and isolation. Her story illustrates the complex relationship within multiple pathways, and shows that IPV’s influence can manifest in complicated ways.

Grace used the idea of caring for her children as a way to “move on with life” and leave her violent partner:

> Like in future I was thinking like to move on with my life. Do something for my life and for my kids! That’s what I want now because I’m done with living in the painful relationship. – Grace, 27 years, Postpartum

Zethu’s baby similarly helped her keep “priorities straight.” As a 21-year-old pregnant woman, she boldly stated that HIV treatment was more important than her husband, and expressed how non-adherence was simply going to harm herself: “I’m doing it [PMTCT] for my baby. I don’t want to stress myself so that I leave the tablets - it’s better to leave that husband and continue with my tablet.” Beyond Zethu’s commitment to protecting her baby, it appeared that taking care of her own HIV could be a subtle way to “leave that husband” and regain control over her own life.

Not every participant was able to use the notion of motherhood to feel more confident around HIV treatment. For example, Dova felt that the stress related to the violent relationship was making her a worse mother – a notion that she illustrated by describing how her suicidal thoughts were linked to potential infanticide:

> I have suicidal thoughts because I don’t have anyone. The only people I have are my kids. And the worst part is with these suicidal thoughts I am always saying, if I had to kill myself, I wouldn’t leave my kids behind. I would take them with. If there is a method whereby I would kill me and my kids, I would do it. So it is just, it is not well. I am not even a good mother these days. – Dova, 32 years, Pregnant
Dova’s story reflects upon multiple pathways of mental health and isolation, suggesting again that pathways may have a dynamic relationship and do not necessarily stand alone as distinct situations.

**Discussion**

This is the first study, to our knowledge, to explore the relationship between violence and HIV adherence within a relatively robust qualitative sample of 32 pregnant and postpartum women reporting both HIV and IPV. It highlights that women living with HIV and IPV have unique challenges to maintaining healthy adherence behaviors around the time of pregnancy. Four key pathways emerged that link IPV to PMTCT: partner non-disclosure, poor mental health, isolation due to partner control, and motherhood.

As shown in Figure 2, pathways from IPV to PMTCT outcomes tend to intersect and collide. Rather than falling into distinct categories, participants often presented stories that fell within multiple pathways. The pathways seemed to be comprised of both positive and negative aspects of responding to IPV. So while mental health and partner control/isolation seemed to worsen HIV outcomes for women, pathways of motherhood and partner non-disclosure highlighted unique resilience strategies used by women. This nuanced understanding of the IPV–HIV adherence relationship can help contextualize recent conflicting evidence from sub-Saharan Africa. Whereas one study with pregnant women in Zambia showed that violence worsens HIV adherence (Hampanda, 2016), another in Kenya among female sex workers suggests that history of IPV actually improved odds of HIV-related health (Wilson et al., 2016). It is possible that while experience of IPV may hinder women’s ability to take HIV medication, it could alternately (or simultaneously) spur women towards persevering with HIV treatment.

While *motherhood* was a protective element and a resilience strategy for some participants, this finding contains critical contradictions. Our findings reflect that women’s sense of self around the time of pregnancy can be grounded in the infant relationship (Bhandari et al.,
2012), and that striving for motherhood may be an active coping strategy (Burnett et al., 2015; Foster et al., 2015). Motherhood can represent an important “turning point” when women start to consider leaving a violent relationship for the sake of the infant (Semaan et al., 2013: 74). However, there is a less positive aspect to the motherhood identity, as it necessarily expects that mothers will be the nurturing caretaker and sacrifice her own needs for that of her child (Hays, 1998). When, in the context of IPV, women may not be fully able to protect their infants from psychological and physical harm, they may be held responsible for failure to protect the child, even as they themselves require protection (Lapierre, 2008). The shame associated with both IPV and HIV may be compounded with the shame of being a ‘bad mother’, which could only worsen mental and physical health outcomes.

The pathway of partner non-disclosure seems to reveal both negative aspects of IPV as well as resilience strategies used by women. This tension between women being both constrained by the violence while also being agentic in their response has been highlighted in previous IPV literature (Campbell & Mannell, 2016; Turan et al., 2016). In our sample, partner non-disclosure made it challenging for some women to take treatment openly and consistently (Awiti Ujjii et al., 2011). Yet, for others, non-disclosure was an important safety strategy. Women in this sample made strategic choices to stay safe from violent reprisals by placing medication in other containers, taking it at times when partners would be away, and by moving out from home altogether. Importantly, non-disclosure was also a method for regaining control over chaotic lives. It is important to note that this ‘agentic’ finding around non-disclosure strategies may have emerged partly because of our narrative approach to data collection. Constructing meaning through narratives is a particularly useful approach to violence research, as it restores agency and power among a group that is often considered the “helpless victim” (Boonzaier & van Schalkwyk, 2011: 278). Notwithstanding the methodological considerations of this conclusion, the strong evidence from nine women in our cohort suggests that women do use important strategies to avoid partner disclosure while staying faithful to HIV medication adherence.
Pathways of partner control and mental health offered ‘negative’ influence on PMTCT behaviors. For several women, relationship control led to an inability to attend the clinic or take medication when desired (Lichtenstein, 2006). More often, however, partner control manifested as a sense of isolation and inability to define one’s own choices about health, movement outside the home, or taking care of the infant. The isolation caused by severe partner control meant that women had little access to social resources to help them (Liang et al., 2005). Isolation also contributed towards the mental health pathway, with women reporting increased anxiety and distress due to being alone.

Our findings certainly support extant literature by suggesting that IPV leads to emotional trauma, anxiety, suicidal ideation, and depression among women, including in antenatal care (Ellsberg et al., 2008; Mahenge et al., 2013) and that poor mental health has onward impact on HIV medication adherence (Sumari-de Boer et al., 2012). We add to this evidence base by highlighting the complex underpinnings behind the IPV-mental health connection. On the more manageable side of the spectrum, women in violent relationships have stress and emotional concerns that take priority over the daily regimen of medication. For other women, on the more extreme side, a sense of hopelessness and being overwhelmed due to the extreme distress of violence led to the potential for self-harming behavior. In the six cases of women who described suicidal ideation, several used the act of stopping treatment as part of thoughts of ending their own lives. Others have noted that women’s vulnerability to abuse may create a self-image of being damaged, inhibiting self-care and access to regular health services (Leenerts, 1999; Rothenberg & Paskey, 1995). Our findings go beyond this literature by noting that HIV medication – due to its very necessity for good health – can be used in a self-harming manner through intentional treatment interruptions.

Limitations
The findings of this study should be viewed in light of several limitations. All participants were visiting antenatal care, limiting our ability to understand these dynamics among women who avoid healthcare in pregnancy. Similarly, participants in this sample all reported IPV victimization (a majority with recent violent episodes), limiting a comparison to women living without IPV. Purposive selection of participants preclude our ability to generalize these data to the entire parent trial cohort, a limitation of most qualitative research. The urban Johannesburg setting has distinctions from other sub-Saharan African health settings, which makes it challenging to compare findings. Our narrative, social constructionist approach to interviews intentionally focused on techniques like validation, highlighting resistance, and locating identity within participant stories. Therefore, our interpretations are likely to differ from that of a ‘neutral observer’, as utilized within a more positivist research paradigm. Nevertheless, this study provides initial impressions of violence among HIV-positive pregnant/postpartum women in a sample that is larger than the extant literature.

**Implications for intervention, research & policy**

Several intervention strategies emerge from these data. With appropriate training, supervision, and tools, health workers in antenatal settings could be the first point of contact for pregnant, abused women. The ‘window of opportunity’ in antenatal care, when women are repeatedly visiting the clinic, can ensure that violence and HIV considerations are jointly addressed—particularly through onwards referral to services that specialise in addressing violence. The current method of group-based PMTCT messaging should be refined towards an individually-tailored approach that truly addresses the concerns, confusions, and daily lives of pregnant and postpartum women. Open, honest discussions at this phase in a woman’s life may have benefits for staying safe while adhering to crucial PMTCT interventions. The notion of ‘striving for motherhood’ can also be harnessed during this time, to help women prioritize their own health and safety as another form of commitment to the infant. It is clear that the intertwined issues of
mental health and disclosure need to be incorporated into PMTCT services, and this can be
achieved by training antenatal staff to implement brief mental health interventions or through
referrals. Social support in the form of skillfully-facilitated peer support groups could assist
women with the isolation pathway that is so pervasive in abusive partnerships.

These qualitative findings suggest several avenues for further research. Given the
potential positive and negative ways that violence may impact HIV adherence, future quantitative
research should extend beyond simplistic analytic techniques. To date, the literature has been
limited to bivariate association between violence and HIV adherence. Simple regression
techniques may fail to account for important meditational pathways between IPV and adherence.
In one recent study, for example, the direct association between IPV and HIV adherence was non-
significant, yet when mediated by mental health there was a strong negative path association
(Malow et al., 2013). Specific pathways identified in this research should be explored and
confirmed in a larger, quantitative sample using techniques that recognize the interrelated nature
of pathways, such as structural equation modeling.

PMTCT policy could also benefit from these qualitative findings. Current South African
PMTCT guidelines discuss the “benefits” of partner HIV disclosure and prompt health workers to
“encourage” disclosure and “support…partner notification” (South African Department of Health, 2014: 37). However, no mention is made of the safety dilemmas that mothers may face in
disclosing to a violent partner. We learned that partner non-disclosure is a strategic way to stay
safe in a violent relationship, and that some women can manage to safely continue treatment
without their partners finding out. Given that 25-35% of South African women experience IPV in
pregnancy (Dunkle et al., 2004; Groves et al., 2012), the omission of strategic non-disclosure in
current guidelines is likely to burden health workers, who are currently unskilled at discussing
partner dynamics.

Conclusion
IPV and HIV are strongly linked in the lives of childbearing women in many settings globally, and violence leads to adherence challenges that place maternal and infant health at risk. These intersecting issues deserve increased attention if we are to ensure elimination of vertical HIV transmission and protect the health of mothers globally. Current policy and intervention is sorely lacking, with little evidence that health workers and policy makers are alert to the considerations of violence within PMTCT programming. Pregnant and postpartum women will greatly benefit from antenatal care that recognizes the realities of living in violent relationships and emboldens women to prioritize their own health, as well as the health of their infants, during this critical phase.


