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

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4 A.M. Hatcher^{a, b, c,}

5 H. Stöckl^d

6 N. Christofides^a

7 N. Woollett^b

8 C.C. Pallitto^e

9 C. Garcia-Moreno^e

10 J.M. Turan^f

11
12 ^a Wits School of Public Health, Faculty of Health Sciences, University of the Witwatersrand,
13 Johannesburg, South Africa

14 ^b Wits Reproductive Health & HIV Institute, University of the Witwatersrand, Johannesburg,
15 South Africa

16 ^c Division of HIV/AIDS, University of California San Francisco, San Francisco, United States

17 ^d Department of Global Health and Development, London School of Hygiene and Tropical
18 Medicine, London, England, United Kingdom

19 ^e Department of Reproductive Health and Research, World Health Organization, Geneva,
20 Switzerland

21 ^f Department of Health Care Organization and Policy, School of Public Health, University of
22 Alabama at Birmingham, Birmingham, AL, United States

23
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25
26 **Abstract**

27 Prevention of mother-to-child transmission (PMTCT) can virtually eliminate HIV transmission to
28 infants, yet up to one-third of women miss PMTCT steps. Little is known about how partner
29 dynamics such as intimate partner violence (IPV) influence pregnant and postpartum women's
30 adherence to PMTCT. We conducted 32 qualitative interviews with HIV-positive pregnant and
31 postpartum women in Johannesburg who experienced IPV. Trained researchers conducted in-
32 depth interviews over the period of May 2014 – Nov 2015 using narrative and social
33 constructionist approaches. Interviews were transcribed verbatim and analyzed thematically and
34 inductively using qualitative software. Twenty-six women experienced recent IPV and one-third
35 had poor adherence to PMTCT. Women's experience of violence influenced PMTCT behaviors
36 through four pathways. First, fear of partner disclosure led women to hide their HIV status to

37 avoid a violent reaction. Despite non-disclosure, some maintained good adherence by hiding
38 medication or moving out from their partner's home. Second, IPV caused feelings of depression
39 and anxiety that led to intentionally or accidentally missing medication. Five women stopped
40 treatment altogether as a kind of passive suicidality, hoping to end the distress of IPV. Third,
41 men's controlling behaviors reduced access to friends and family, limiting social support needed
42 for good adherence. In a protective pathway, women reported good adherence partly due to their
43 mothering role. Fourth, motherhood identity was used as a coping technique, reminding women
44 that their infant's wellbeing depended on their own health. PMTCT is essential to prevent vertical
45 HIV transmission, but women living with IPV face multiple pathways to non-adherence: partner
46 non-disclosure, mental health, and partner control and isolation. Protective factors like "striving
47 for motherhood" may lessen the relationship between IPV and PMTCT. Addressing IPV in
48 antenatal care can support the health of mothers and infants and may enhance PMTCT coverage.

49
50 **Keywords:** South Africa; intimate partner violence; HIV; adherence; qualitative; perinatal

51 52 **Introduction**

53 Prevention of mother-to-child transmission (PMTCT) interventions have potential to eliminate
54 vertical transmission of HIV from mothers to infants (Mofenson, 2010). Yet, women's adherence
55 to all the steps required for successful PMTCT is often low. Within 21 priority countries, an
56 estimated 65% of eligible pregnant women access HIV treatment (WHO et al., 2013), and pooled
57 analysis suggests that only half of women adhere to treatment postpartum (Nachega et al., 2012).
58 Studies in sub-Saharan Africa suggest that partner relationship factors are among the most
59 important barriers to pregnant women's acceptance of HIV testing and other PMTCT behaviors
60 (Bwirire et al., 2008; Medley et al., 2004; Turan et al., 2011). Intimate partner violence (IPV)
61 may be one important predictor of adherence to HIV medication in pregnancy and postpartum,
62 yet this association has been understudied in the literature to date (Hatcher et al., 2015).

63 Among non-pregnant women, IPV victimization is associated with worse HIV-related
64 health outcomes, including higher odds of antiretroviral failure, weaker immune response,
65 increases in opportunistic infections, and greater risk of mortality (Schafer et al., 2012; Weber et
66 al., 2012). A meta-analysis suggested that women’s experience of IPV was associated with 55%
67 lower odds of self-reported adherence and 36% decreased odds of viral suppression (Hatcher et
68 al., 2015). However, of the thirteen included studies, none were based in sub-Saharan Africa or
69 among pregnant women. Since publication of the meta-analysis, only a single study has examined
70 the effect of IPV on adherence in pregnant women. This Zambian study showed that IPV
71 victimization was associated with 74% lower odds of adherence in pregnancy and 89% lower
72 odds of adherence postpartum (Hampana, 2016). . However, the quantitative methods used by
73 this seminal paper preclude a deeper understanding of *how* partner violence alters PMTCT
74 behaviors. This is a crucial dynamic to understand, particularly since many of the same countries
75 in sub-Saharan Africa with the highest rates of mother-to-child transmission also have high
76 prevalence of IPV (Devries et al., 2013).

77 South Africa is one such sub-Saharan African setting where HIV and IPV are highly
78 prevalent. An estimated 25 – 35% of South African pregnant women report recent physical and/or
79 sexual IPV (Groves et al., 2012; Hoque et al., 2009). Similarly, antenatal HIV prevalence across
80 South Africa is high, with estimates in Johannesburg reaching 29% (Department of Health, 2012).
81 South Africa has made significant strides towards reducing mother-to-child transmission from
82 14% in 2009 to an estimated 5% in 2012 (UNAIDS, 2013). Yet, only 54-65% of South African
83 pregnant women and infants complete all recommended PMTCT steps (Stringer et al., 2010;
84 Technau et al., 2014).

85 Recent qualitative studies have explored the underlying dynamics of IPV among small
86 samples of women living with HIV. Among 8 women reporting violence after HIV disclosure,
87 Colombini *et al.* learned that new HIV diagnosis was a trigger for violence, even in relationships
88 with no prior history of IPV (Colombini et al., 2016). Mulranen *et al.* studied postpartum women

89 living with HIV in Swaziland, of whom 9 reported IPV following disclosure, and learned that
90 violence resulted from acute triggers like HIV status disclosure and also from ongoing marital
91 tensions around fertility (Mulrenan et al., 2015). In a study of pregnant and postpartum HIV-
92 positive women in the United States, Njie-Carr *et al.* found that 3 women with recent violence
93 avoided partner disclosure because they feared a violent reaction (Njie-Carr et al., 2012).
94 Illangsekare *et al.* identified mental health as a primary pathway linking IPV to non-adherence
95 among HIV-positive women reporting lifetime partner violence, of whom 3 were currently living
96 with IPV (Illangsekare et al., 2014). Other qualitative research has broadly explored violence
97 and HIV medication adherence, but not among women who present with both conditions (Hatcher
98 et al., 2014; Zunner et al., 2015). While extant qualitative offers preliminary understanding that
99 perhaps violence and HIV behaviors are linked, samples sizes ranging from 3-9 participants rule
100 out the analytical rigour required to understand *why* IPV alters adherence.

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

106

107 ***Theoretical framework***

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

112 Within the ecological model, *individual* factors are the personal characteristics or
113 behaviours that impact one's health. Previous literature has suggested that individual factors
114 inhibiting PMTCT uptake include depression (Nachega et al., 2012; Turan et al., 2013), substance

115 use (Nachega et al., 2012), internalized HIV stigma and shame (Turan et al., 2013), and costs
116 associated with clinic attendance (Bwirire et al., 2008). *Partner relationship* factors are the
117 dyadic partnership issues that frame health outcomes. Partner dynamics that worsen PMTCT
118 behaviors include a lack of male involvement in antenatal care (Aluisio et al., 2011), non-
119 disclosure to a partner (Gourlay et al., 2013; Myer, 2011), and threat of further violence
120 (Antelman et al., 2001). The theory of gender and power (Connell, 1985), which postulates that
121 unequal power dynamics limit the ability of women to exercise personal control in relationships
122 (Amaro & Raj, 2000), provides a theoretical underpinning for the associations seen between
123 partner factors and PMTCT uptake. *Structural* factors refer to the broader social or community
124 factors that impact on health. In this sphere, previous studies have noted that PMTCT is adversely
125 impacted by poverty (hIarlaithe et al., 2014), lack of social support (Kirsten et al., 2011),
126 community stigma around HIV (Turan et al., 2011), and weak health systems (Bwirire et al.,
127 2008). A socio-ecological framework recognises that similar structural factors underpin both
128 violence and HIV (Maman et al., 2000) and that broader social and societal factors shape
129 women's ability to adhere to HIV medication (Hirsch, 2007) and the extent to which they
130 experience IPV (Heise, 1998).

131

132 *INSERT FIGURE 1 ABOUT HERE*

133 **Methods**

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

140 data from in-depth interviews with a larger sample of women ($n=32$) living with both IPV and
141 HIV.

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

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

159

160 ***Participant sampling and recruitment***

161 We conducted qualitative research with 32 participants who were purposively selected from
162 women taking part in baseline Safe & Sound trial questionnaires. Women recruited for this
163 sample were living with HIV and experiencing IPV. In practice, this included women
164 participating in the trial (ie. experiencing recent IPV), as well as women who were not eligible to
165 enroll in the trial, but who had experienced IPV in their lifetime. These lifetime history

166 participants had already completed a full study baseline questionnaire and agreed to be contacted
167 about further research. Study nurses guided the selection of participants based on their impression
168 of women's willingness to take part in an additional interview, their knowledge of women's
169 experiences of IPV, and women's HIV-positive status.

170 Initially, the sample size proposed for this qualitative study was 24 participants. Using
171 the constant comparative method to understand the emerging constructs from the data (Charmaz,
172 2003), we found that upon completion of 18 interviews, theoretical saturation had not yet been
173 reached. Data on our initial research question around links between violence and PMTCT lacked
174 richness and women's stories failed to converge around specific pathways. We thus expanded the
175 sample to reach 32 women using theoretical sampling to include additional women with recent
176 IPV experiences. Theoretical sampling is a technique for using preliminary analysis to guide how
177 data are collected further (Glaser, 1992). In this case, our initial analysis suggested that links
178 between violence and PMTCT are best explored among participants with recent violence and
179 with some challenges adhering to PMTCT behaviors. Displaying "challenges" with PMTCT was
180 therefore used as a selection criteria for the next 14 participants. Additional women with these
181 characteristics allowed us to further refine emergent concepts and test out initial impressions of
182 the data with a more targeted group of participants.

183 Trained nurse researchers invited women to participate through follow-up phone calls
184 using locator information. All participants contacted for this sub-study were reachable by phone,
185 with 7 women refusing to take part (due to living outside the province, work commitments, or not
186 desiring to take part in additional research). Male partners were never informed about a woman's
187 participation in the research because of the potential for an abusive partner to react violently. To
188 protect participants and reduce the risk that partners would overhear the conversation, nurses
189 were trained to ask "is this a safe time to speak?" before continuing. A full distress protocol
190 included appropriate researcher responses in cases of violence disclosure, psychological distress,
191 high emotionality, or a need for referrals. Basic elements of the distress protocol were employed

192 during most interviews included in this study: a calm, non-judgmental approach to inquiry;
193 watching for signs of resistance when inquiring about violence to avoid re-traumatisation;
194 offering tissues if participants cried; offering a break from the interview. In cases of severe
195 distress, researchers were trained to invite participants to stop the interview, a technique that was
196 used with one participant, and to offer supportive referrals. In the case of current suicidal thinking,
197 researchers were trained to make a direct referral to a psychiatric ward of the nearest hospital. In
198 this sample, no participants revealed current suicidal thinking but several participants recounted a
199 history of suicidal ideation, for which researchers offered empathetic listening and referrals to a
200 nearby community psychology counseling service.

201

202 *Data collection*

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

213 Interviews were conducted in one of three South African languages (English, Sesotho,
214 isiZulu) and digitally recorded. A semi-structured in-depth interview guide explored three
215 themes: the perceived relationship between IPV and HIV in women’s lives; women’s perceptions
216 of how violence may influence PMTCT uptake; and, potential mechanisms through which IPV

217 may impact PMTCT-related health behaviors. Interviews lasted between 26 minutes and 1 hour
218 40 minutes (median 46 minutes).

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

228

229 *Data analysis*

230 To ensure that interviews achieved adequate depth and richness, the first 6 transcripts were
231 reviewed jointly to establish future questions, points of clarification, and initial themes.

232 Researchers reviewed full transcripts and created detailed 'memos' to highlight initial impressions
233 of the data. This review process was repeated at two other time-points (upon completion of 18
234 interviews and 28 interviews). Both reviews led to tweaking of the interview guides, with major
235 themes retained but sub-questions altered to enhance probing and clarity. The team developed an
236 initial coding framework based on the preliminary review of 6 transcripts and “sensitizing
237 concepts”, or preliminary ideas around how to examine the data (Bowen, 2006).

238 The coding framework was applied to all transcripts by two researchers using Dedoose
239 qualitative analytic software. The focus of double-coding was to ensure that code application was
240 consistent across transcripts and that code definitions were robust. Rather than assessing inter-
241 rater reliability, the team used a series of phone calls and in-person meetings to refine codes until
242 consensus was reached. This process led to a refined set of thematic codes that comprised broad

243 topics such as relationship characteristics, experience of violence, HIV diagnosis, PMTCT uptake,
244 mental health, social support, partner HIV serostatus disclosure, and reflections on being asked
245 about IPV in pregnancy. Next, the team established a system of fine codes that emerged
246 inductively from the data. Fine codes were applied to a portion of transcripts by three researchers,
247 ensuring that every transcript was double-coded. Examples of fine codes within the partner HIV
248 disclosure section were: fear of partner response, reactive or polarized methods of disclosure,
249 male partner denial of disclosure, concern for the child, supportive steps, displaced anger. During
250 analysis, cases that did not fit the overall picture, called “exceptional cases”, were actively sought
251 out. Trustworthiness of findings was ensured by the team approach to data analysis, coding
252 discussion meetings, and by presenting initial findings to groups of colleagues and peers.

253

254 *Ethical and safety considerations*

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

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

267

268 **Results**

269 ***Sample characteristics***

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

275

276 *INSERT TABLE 1 ABOUT HERE*

277

278 ***Links between violence and PMTCT adherence***

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

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

293

294 *Partner (Non) Disclosure: Hiding HIV from a partner*

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

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

313 In this context of violent or psychologically harmful reactions, it is perhaps not surprising
314 that 16 women opted to keep their HIV status a secret. Participants described this choice as a
315 reasoned response to a dangerous situation. Six participants feared that their partners would react
316 to disclosure with physical violence. For Simphiwe, a 33-year-old woman who had been with her
317 partner for five years, a history of physical violence led her to keep HIV a secret. Another
318 participant, Kandi, feared physical violence because her partner explicitly stated that he would
319 hurt her should she test HIV-positive.

320 Fears of partner reaction led some women to be partially non-adherent to their HIV
321 medications. One 32-year-old postpartum participant, Nomsa, described her fear that the father of
322 her first child might murder her or the child as a response to HIV disclosure. Nomsa kept her
323 status hidden by pretending the medication was for pregnancy, rather than for HIV, but admitted
324 it was challenging to keep taking the pills after giving birth. Another participant, Thembi, was 26
325 years-old and postpartum when she recounted how she chose not to start HIV medication in
326 pregnancy because she was frightened that her partner would be physically violent when she
327 asked him to use a condom. Her (incorrect) understanding of treatment came from antenatal staff
328 who often say that HIV medication must be accompanied by consistent condom use. Since
329 Thembi knew she could not safely use condoms, she chose to avoid HIV medication altogether.
330 Her non-uptake of treatment meant that her infant acquired HIV during the course of the study.

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

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

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

343 Similarly, Zama (25 years and pregnant) found it easier to adhere to medication once she
344 moved out from her partner's place. Before she would wait until he fell asleep to take her daily
345 prescription: "It was a little bit tricky because I had to hide the medication. And then at times he

346 would be in the same bedroom where I hide it, so I can't take it." For Sonja, the original response
347 to disclosure was threats of violence and forced eviction from the household. In this context,
348 Sonja, 23-years-old and pregnant, carefully avoided taking medication in front of her partner,
349 worrying that simply seeing the medicine might trigger a violent reaction. One day, her partner
350 snuck up on her in the bathroom and caught her taking the treatment. While the response was not
351 physical violence, her partner disappeared and returned home in an agitated state after a bout of
352 drinking.

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

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

366

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

368 Several women related stories of non-adherent periods, many of which resulted from depressive
369 episodes that followed phases of violence. At 24 years, Thuto had recently delivered her fourth
370 child, and explained the tendency to feel despondent particularly after extremely violent episodes
371 or when her husband refused to buy food for the family. Thuto sometimes struggled with staying

372 adherent, and explained that she had given up hope: “Sometimes, when I’m stressed, I feel that
373 its better I also died... I’ve just lost hope.” Zama expressed a concern that her infant would test
374 HIV-positive, since she herself had experienced adherence struggles. Similar to several other
375 participants, Zama disclosed a desire to “end everything” as a method to reduce the distress she
376 was feeling about the violent relationship:

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

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

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

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

396 Six women described periods of stopping treatment altogether due to depressive and
397 suicidal feelings. The underlying emotion of stopping treatment for these women was a desire to

398 end their lives. One participant, Dova, named it a “death wish” and recounted the overwhelming
399 feelings of hopelessness and failure that had led her to stop taking HIV treatment:

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

405

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

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

413 *Researcher (R): What led you to forget?*

414 *P: Stress, I am always thinking.*

415 *I: What were you thinking?*

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

418 *Dintle, 30 years, Postpartum*

419 For Dintle, stopping treatment was a by-product of experiencing intense episodes of violence and
420 concomitant mental health challenges. This suggests that in cases of severe depression, HIV
421 treatment non-adherence can be both a mode of self-harm and a result of being overwhelmed at
422 times of high distress.

423

424 *Isolation and partner control: The hidden nature of IPV and HIV*

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

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

435 *Sometimes when I go to the clinic he say hey you are not going to the clinic. He*
436 *asked me too many questions... But I refuse. I tell him I can't stop going to clinic*
437 *because this is my life! I have children. I have to live to take care of my babies.*
438 *Sometimes when I come back to the house he beats me, accusing that I'm not*
439 *coming from the clinic. –Kagiso, 28 years, Postpartum*

440

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

447 For several participants, the feeling of isolation was pervasive, leaving them troubled and
448 continually ruminating over difficult thoughts. Dova illustrated this by describing how thoughts
449 of the violence were "stuck in her mind" and left her isolated and alone:

450 *It is just basically stuck there in my mind - all these things that have been*
451 *happening. When you are alone, you just sit and think about it and I don't have*
452 *anyone. Sometimes I don't sleep the whole night I am thinking and thinking. –*
453 *Dova, 32 years, Pregnant*

454 Another implicit trait of the partner control and isolation pathway is the hidden nature of
455 both HIV and violence. Both HIV and IPV are stigmatised, which leads to a worsened ability
456 among women to find support for either condition. Several women spoke of staying silent with
457 their families about the violence in their relationships. As 30-year-old, pregnant Lulama noted,
458 “whatever we fight about I keep to myself most of the time.” For Neo, it was easier to pretend
459 that things were fine than to disclose to her friends that she lived in a violent relationship:

460 *It's hard to tell people I've got a problem, I'm not living a good life, with a*
461 *partner that I'm worried, we're always fighting, things like that. You just pretend,*
462 *like now pretending that I'm ok but I'm not ok. – Neo, 28 years, Postpartum*

463
464 *Motherhood as a coping strategy: protective pathway*

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

472 Zama did have trouble with adhering to treatment, and considered suicide during phases
473 when the physical violence was particularly bad. Yet, at 25 years and pregnant, the reminder of
474 her new baby would often be enough to return her to thoughts of living and trying to provide for
475 her baby: “Maybe after a fight, I will be crying, stressed and then I would be like, okay, let me

476 just do this [commit suicide], then I would think, ‘No, but let us give this baby a chance.’” It is
477 important to note that Zama exhibited these methods of “resilience” by focusing on her baby’s
478 wellbeing even as she struggled with suicidality and isolation. Her story illustrates the complex
479 relationship within multiple pathways, and shows that IPV’s influence can manifest in
480 complicated ways.

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

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

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

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

497 *I have suicidal thoughts because I don’t have anyone. The only people I have are*
498 *my kids. And the worst part is with these suicidal thoughts I am always saying, if*
499 *I had to kill myself, I wouldn’t leave my kids behind. I would take them with. If*
500 *there is a method whereby I would kill me and my kids, I would do it. So it is just,*
501 *it is not well. I am not even a good mother these days. –Dova, 32 years, Pregnant*

502 Dova’s story reflects upon multiple pathways of mental health and isolation, suggesting again that
503 pathways may have a dynamic relationship and do not necessarily stand alone as distinct
504 situations.

505

506 **Discussion**

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

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

525 While *motherhood* was a protective element and a resilience strategy for some
526 participants, this finding contains critical contradictions. Our findings reflect that women’s sense
527 of self around the time of pregnancy can be grounded in the infant relationship (Bhandari et al.,

528 2012), and that striving for motherhood may be an active coping strategy (Burnett et al., 2015;
529 Foster et al., 2015). Motherhood can represent an important “turning point” when women start to
530 consider leaving a violent relationship for the sake of the infant (Semaan et al., 2013: 74).
531 However, there is a less positive aspect to the motherhood identity, as it necessarily expects that
532 mothers will be the nurturing caretaker and sacrifice her own needs for that of her child (Hays,
533 1998). When, in the context of IPV, women may not be fully able to protect their infants from
534 psychological and physical harm, they may be held responsible for failure to protect the child,
535 even as they themselves require protection (Lapierre, 2008). The shame associated with both IPV
536 and HIV may be compounded with the shame of being a ‘bad mother’, which could only worsen
537 mental and physical health outcomes.

538 The pathway of partner non-disclosure seems to reveal both negative aspects of IPV as
539 well as resilience strategies used by women. This tension between women being both constrained
540 by the violence while also being agentic in their response has been highlighted in previous IPV
541 literature (Campbell & Mannell, 2016; Turan et al., 2016). In our sample, partner non-disclosure
542 made it challenging for some women to take treatment openly and consistently (Awiti Ujiji et al.,
543 2011). Yet, for others, non-disclosure was an important safety strategy. Women in this sample
544 made strategic choices to stay safe from violent reprisals by placing medication in other
545 containers, taking it at times when partners would be away, and by moving out from home
546 altogether. Importantly, non-disclosure was also a method for regaining control over chaotic lives.
547 It is important to note that this ‘agentic’ finding around non-disclosure strategies may have
548 emerged partly because of our narrative approach to data collection. Constructing meaning
549 through narratives is a particularly useful approach to violence research, as it restores agency and
550 power among a group that is often considered the “helpless victim” (Boonzaier & van Schalkwyk,
551 2011: 278). Notwithstanding the methodological considerations of this conclusion, the strong
552 evidence from nine women in our cohort suggests that women do use important strategies to
553 avoid partner disclosure while staying faithful to HIV medication adherence.

554 Pathways of partner control and mental health offered ‘negative’ influence on PMTCT
555 behaviors. For several women, relationship control led to an inability to attend the clinic or take
556 medication when desired (Lichtenstein, 2006). More often, however, partner control manifested
557 as a sense of isolation and inability to define one’s own choices about health, movement outside
558 the home, or taking care of the infant. The isolation caused by severe partner control meant that
559 women had little access to social resources to help them (Liang et al., 2005). Isolation also
560 contributed towards the mental health pathway, with women reporting increased anxiety and
561 distress due to being alone.

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

577

578 ***Limitations***

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

592

593 ***Implications for intervention, research & policy***

594 Several intervention strategies emerge from these data. With appropriate training, supervision,
595 and tools, health workers in antenatal settings could be the first point of contact for pregnant,
596 abused women. The ‘window of opportunity’ in antenatal care, when women are repeatedly
597 visiting the clinic, can ensure that violence and HIV considerations are jointly addressed—
598 particularly through onwards referral to services that specialise in addressing violence. The
599 current method of group-based PMTCT messaging should be refined towards an individually-
600 tailored approach that truly addresses the concerns, confusions, and daily lives of pregnant and
601 postpartum women. Open, honest discussions at this phase in a woman’s life may have benefits
602 for staying safe while adhering to crucial PMTCT interventions. The notion of ‘striving for
603 motherhood’ can also be harnessed during this time, to help women prioritize their own health
604 and safety as another form of commitment to the infant. It is clear that the intertwined issues of

605 mental health and disclosure need to be incorporated into PMTCT services, and this can be
606 achieved by training antenatal staff to implement brief mental health interventions or through
607 referrals. Social support in the form of skillfully-facilitated peer support groups could assist
608 women with the isolation pathway that is so pervasive in abusive partnerships.

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

619 PMTCT policy could also benefit from these qualitative findings. Current South African
620 PMTCT guidelines discuss the “benefits” of partner HIV disclosure and prompt health workers to
621 “encourage” disclosure and “support...partner notification” (South African Department of Health,
622 2014: 37). However, no mention is made of the safety dilemmas that mothers may face in
623 disclosing to a violent partner. We learned that partner non-disclosure is a strategic way to stay
624 safe in a violent relationship, and that some women can manage to safely continue treatment
625 without their partners finding out. Given that 25-35% of South African women experience IPV in
626 pregnancy (Dunkle et al., 2004; Groves et al., 2012), the omission of strategic non-disclosure in
627 current guidelines is likely to burden health workers, who are currently unskilled at discussing
628 partner dynamics.

629

630 **Conclusion**

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

640

641

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