

# The Experiences of HIV Status Disclosure among Pregnant and Postpartum Women: A Systematic Review of Qualitative Evidence

Ira Rahmawati<sup>1</sup> and Ratna Dewi<sup>2</sup>

<sup>1</sup>Poltekkes Kemenkes Malang, Kota Malang, Jawa Timur 65119, Indonesia

<sup>2</sup>Department of Nursing, Esa Unggul University, Arjuna Utara no. 9, West Jakarta, Indonesia

**Keywords:** HIV/AIDS, Disclosure, Experience, Pregnant Women, Postpartum Women, PMTCT, Systematic Review.

**Abstract:** Disclosure of HIV status among HIV-positive pregnant and postpartum women may significantly improve their uptake and adherence in the prevention of mother-to-child transmission of HIV programs. However, many women choose not to disclose their status because of several factors. This review aimed to understand the experiences of HIV-positive women on HIV-status disclosure during pregnancy and postpartum period. Five databases were searched to identify relevant qualitative studies published in English language from 2000 to 2017. A three-step search strategy was utilized in this review. An initial limited search of CINAHL and PubMed was undertaken followed by analysis of the text words contained in the title and abstract, and the index terms used to describe article. A second search using all identified keywords and index terms was conducted across all included databases. Thirdly, the reference list of all identified articles was searched for additional studies. Studies that met inclusion criteria were considered, which include qualitative studies, participants of the study were HIV positive pregnant or postpartum women and studies that aimed to understand the experiences of HIV-positive women on HIV-status disclosure in the context of pregnancy and post-partum period. Qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in this review using the standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). Data extraction was also conducted using the JBI-QARI. Three qualitative studies were included in this review. Twenty themes were extracted, which were then aggregated into six categories and three synthesized findings. The six categories namely reasons for disclosure and non-disclosure HIV-positive status to the partner, family, and friends, positive and negative experiences of disclosure and pattern of disclosure. The reasons for disclosure and non-disclosure of HIV-positive status among women during pregnancy and the postpartum period are different depending on to whom they disclose. Some of the women experienced negative outcomes of disclosure such as violence, which may negatively influence their decision to disclose in the future. Lastly, HIV-positive women need continuing support and counselling to cope with the outcomes of disclosure practice.

## 1 INTRODUCTION

About 2.6 million children under the age of 15 were living with HIV globally in 2015, with 150,000 children were newly infected in 2015 (The Joint United Nations Program on HIV/AIDS [UNAIDS], 2015). Mother-to-child transmission of HIV is correlated with 90% of HIV infection in children at the age of 0-6 years old (Sendo, Cherie, & Erku 2013). The transmission of HIV from an HIV-positive mother to her child can occur during pregnancy, delivery and breastfeeding. Prevention of mother-to-child transmission (PMTCT) of HIV

programmes which involve the use of antiretroviral drugs for the HIV-positive pregnant and breastfeeding women and a short course of antiretroviral drugs for the infant have been reported to reduce the rate of HIV transmission among children to nearly zero (World Health Organization [WHO], 2013; Sendo, Cherie, & Erku, 2013). However, the success of the PMTCT program is dependent upon disclosure of HIV-seropositive to partners, families and others in the community (Tam, Amzel, & Phelps, 2015).

Disclosure of HIV status is essential for preventing HIV transmission and early intervention. In the context of pregnancy and perinatal particularly,

disclosure of HIV status by women to their sexual partners is crucial for the prevention of HIV from mother to child during pregnancy, birth and through breast-feeding (Rujumba et al., 2012; Visser, Neufeld, de Villiers, Makin, & Forsyth, 2008). Indeed, several studies revealed that women who had disclosed to their partners were found to be more likely to bottle-feed their infants and more likely to participate in PMTCT programmes than women who had not disclosed (Farquhar et al., 2001; Rujumba et al., 2012). However, disclosure of HIV status remains a challenge for pregnant and postpartum women (Tam, Amzel, & Phelps, 2015). Studies have documented that the rate of HIV-status disclosure is low, especially among women in developing countries, which ranged from 16.7% to 86%, with the lowest rate of HIV serostatus disclosure occurred among women in antenatal care (Medley, Garcia-Moreno, McGill, & Maman, 2004).

HIV-related stigma, fear of partner violence, loss of financial support and blame for bringing the HIV infection into family prevent many women from disclosing their HIV-status (Bwirire et al., 2008; Rujumba et al., 2012). Studies have revealed that non-disclosure of the HIV status may contribute to non-adherence to ART, as women do not want to be seen taking the ART drugs (Madiba & Letsoalo, 2013). Another study reported that pregnant women choose to deliver at home to prevent stigma that may arise following disclosure to the health care providers (Ujiji et al., 2011). Lastly, feeding counselling and post-delivery infant prophylaxis may be less likely to occur in the context of non-disclosure (Kasenga, Hurtig, & Emmelin, 2010).

Disclosure is defined as the willingness of an HIV-infected person to reveal their status to another person, which can be their spouse, family, health providers or friends (Adeoye-Agboola et al. 2016). It involves a process of decision-making, which is influenced by numerous factors including motivation, communication skills, psychological state and anticipated reactions (Visser et al., 2008). Disclosure of HIV status is a complex process involving multiple and continuing decisions about who to tell, how to tell and how much to tell (Makin et al., 2008; Moses & Tomlinson, 2013).

A systematic review on HIV-status disclosure among pregnant and postpartum women in sub-Saharan Africa found that individual characteristics associated with greater chances of disclosure include first pregnancy, lower level of internalized stigma, younger age and knowing someone with HIV. Other factors that positively correlated with disclosure of HIV status include characteristics of the household

such as living without extended family or co-spouses. Lastly, characteristics of the partner associated with higher disclosure rate include higher level of educations, no history of domestic violence and financial independence (Tam, Amzel, & Phelps, 2015).

Understanding women's experiences on disclosure of HIV status during pregnancy and postpartum period could provide inputs on how to improve the uptake and adherence of PMTCT programs.

To our knowledge, no systematic reviews have synthesized the experiences of HIV disclosure among HIV-positive pregnant and postpartum women. A preliminary search for systematic reviews on this topic was carried out in Cochrane Library, Joanna Briggs Institute Database of Systematic reviews & Implementation Reports, PubMed, CINAHL and PROSPERO. No existing systematic reviews were found in these databases that synthesize the experiences of HIV-positive women on HIV-status disclosure in the context of pregnancy and postpartum period. Aware of this fact, this review aims to synthesize the findings from studies that explore the experiences of HIV-positive pregnant and postpartum women on HIV-status disclosure.

## 2 METHODS

### 2.1 Inclusion Criteria

#### 2.1.1 Type of Participants

This review included studies that involve HIV-infected women who are pregnant or in the postpartum period and 18 years old and above.

#### 2.1.2 Phenomena of Interest

This review sought to understand the views and experiences of HIV-positive women on HIV-status disclosure in the context of pregnancy and postpartum period.

#### 2.1.3 Context

This review included studies that explore the HIV-positive women's experiences on HIV-status disclosure during pregnancy and in the context of vertical transmission. This review included studies that conducted in all health care settings (HIV/AIDS clinics, in-patients, out-patients, rural and urban community) and all countries. This review considered

all studies that investigate the views and experiences of HIV-positive pregnant women on HIV disclosure to the partner, family members, and friends.

#### **2.1.4 Types of Studies**

This review considered all forms of qualitative study designs such as grounded theory, phenomenology, ethnography, action research and other descriptive qualitative study published in English language.

### **2.2 Search Strategy**

The search strategy aimed to find both published and unpublished studies. A three-step search strategy following the Joanna Briggs Institute (JBI) guidelines was utilized in this review. An initial limited search of CINAHL and PubMed was undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe article. A second search using all identified keywords and index terms was conducted across all included databases. Thirdly, the reference list of all identified reports and articles was searched for additional studies. Studies published in the English language were considered in this review.

The databases searched included CINAHL, PubMed, EMBASE, PsycINFO and Scopus. The search for unpublished studies included reports and guidelines from professional organizations (UNAIDS, WHO) and ProQuest.

Initial keywords used were: experiences, views, perception, HIV, AIDS, disclosure, HIV disclosure, HIV-positive women, HIV-positive pregnant women, pregnancy and PMTCT (prevention of mother-to-child transmission of HIV).

### **2.3 Method of Review**

Qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in this review, using the standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). Any disagreement that arose between the two reviewers were resolved through discussion, or with a third reviewer.

### **2.4 Data Collection**

Qualitative data were extracted from studies included in this review using the standardized data extraction tool from JBI-QARI. The extracted data which include specific details about participants,

phenomenon of interest, study methods, and outcomes of significance to the review question and specific objectives. Information regarding the cultural and geographical settings, method of data analysis used in the primary studies and the author's conclusions were also extracted. Findings were extracted from the papers by two reviewers working independently. The two reviewers then discussed and reached consensus on the levels of credibility of the findings and the final construction of the findings were aggregated.

### **2.5 Data Synthesis**

Qualitative research findings were, where possible pooled using JBI-QARI. This involved the aggregation or synthesis of the findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to generate a single comprehensive set of synthesized findings that could be used as a basis for evidence-based practice. Where textual pooling was not possible, the findings were presented in narrative form.

## **3 RESULTS**

### **3.1 Description of Studies**

Following a comprehensive search, 316 articles were identified (Figure 1). A total of 119 duplicates were removed leaving 197 articles to be assessed. A total of 182 article were excluded on reviewing the titles and abstracts, leaving 15 articles for full text review. Of these, 12 papers were excluded for not meeting the inclusion criteria such as included multiple participants (participants were both HIV-positive and HIV-negative pregnant women or participants were HIV-positive pregnant women and their partners) and the results were not presented as qualitative findings. This left three studies eligible for critical appraisal. After assessing the quality of these papers the three papers were included in this review.

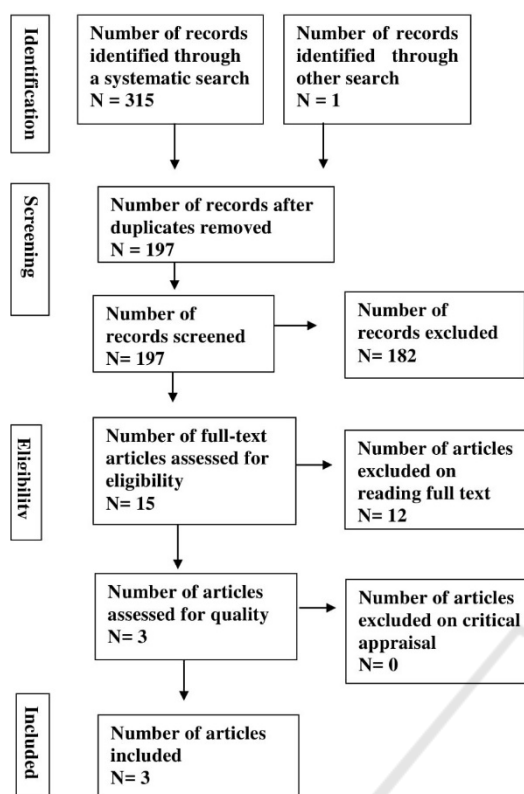


Figure 1: Flow chart of the search and study selection process.

This review included three qualitative studies conducted mainly in a South African setting. All the studies were published within the past 11 years, i.e. from 2005 to 2013. The three included studies are described below.

The study by Visser et al. was conducted in four antenatal clinics that provide health services to an urban population in Tshwane, South Africa. 293 HIV-positive pregnant women were interviewed during pregnancy (mean gestational age of 28 weeks) with open-ended questions. These women were referred by HIV counsellors from the antenatal clinics. The Interviews were conducted by trained research assistants in the participants' language: IsiZulu, Tswana or Sepedi. Content analysis from Stemler 2002, were performed and two researchers interpreted the data independently. The reasons for HIV-disclosure and non-disclosure and also the reactions after disclosure experienced by the participants are identified.

Varga, Sherman & Jones's study was conducted in the antenatal clinic of Coronation Women and Children's Hospital (CWCH) in Johannesburg, South Africa. The study carried out using a grounded theory approach, thus the data collection used a series in-

depth interview and fieldwork. A total of 31 positive mothers who have been tested for HIV for the first time during their pregnancy were interviewed at the clinic by a female interviewer in the participants' language of choice. Each participant was interviewed at least twice. The fieldwork was conducted between December 2003 and August 2003. Qualitative data from the interviews and observations were transcribed and translated. Thematic analysis was performed using QSR NUD\*IST (1997) qualitative data analysis package, and a regular meeting between the researchers was scheduled to discuss experiences and observations during data collection.

Moses & Tomlinson's study was conducted in an urban community about 20 kilometers outside Cape Town in the Western Cape province of South Africa. The study used a longitudinal ethnographic approach to trace women's experiences from late pregnancy until the end of the first year of motherhood. Hence, the fieldwork was conducted for 24 months, started in November 2008. Ten HIV-positive women were recruited via HIV counsellors during their antenatal clinic visits. Data collections used in the study are in-depth interviews with the participants, informal visits to participants' homes, infant observations and clinic-visit observations. The research team includes two researchers who conducted all the interviews and two fieldworkers who conducted the observations together with the two researchers. The interview topics evolved on the individual basis over the course of the fieldwork and thus, not all women were asked all questions. Data which include detailed field notes and interview transcriptions was analyzed using a critical interpretative phenomenological approach (IPA) with ideographic perspectives. Thus, two of the women's experiences are then chosen to be explored in more details as they highlight the range of complexity and fluidity of disclosure experiences across the group.

### 3.2 Methodological Quality

All papers assessed for quality were included in the review (Table 1). Two papers indicated the methodological approaches used which include a grounded theory and ethnographic approach. Meanwhile, the last study did not clearly indicate the methodological approach used in the study. In qualitative studies, the researchers face ethical challenges in all phases of the research, from designing to reporting. One of the ethical challenges that should be acknowledged and addressed is the researchers' potential impact on the participants and vice versa. However, all included studies did not

clearly indicate the influence of the researcher on the research and participants. Therefore, the extent to which the findings may have been influenced by the researcher is unclear.

Table 1: Assessment of methodological quality.

Citation	1	2	3	%
Q1	U	Y	U	33,3
Q2	Y	Y	Y	100
Q3	Y	Y	Y	100
Q4	Y	U	U	33,3
Q5	U	Y	Y	66,6
Q6	Y	Y	Y	100
Q7	N	N	N	0
Q8	N	Y	N	33,3
Q9	Y	Y	Y	100
Q10	Y	U	Y	66,6

\*1: Visser MJ, Neufeld S, de Villiers A, Makin JD & Forsyth BWC (2008), 2: Varga CA, Sherman GG & Jones SA (2005), 3: Moses S & Tomlinson M (2013);

\*Q1-Q10 are the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research; Y:yes, U:unclear, N:no.

### 3.3 Findings of the Review

A meta-synthesis was carried out according to the framework provided by JBI. There were 20 findings, which were rated as unequivocal (U: 11) and credible (C: 9) (Appendix V). The findings were aggregated into six categories based on the similarity in meaning. The six categories were then meta-aggregated into three synthesized findings are illustrated in more detail in Appendix (VI).

Synthesized finding one:

The reasons for disclosure and non-disclosure of HIV-positive status among women during pregnancy and the postpartum period are different depending on to whom they disclose. Appropriate support mechanisms should be offered to help these women to deal with the outcomes of disclosure their fear and violence when it really occurs. Health worker mediated disclosure, couple counselling or collaboration with support groups for women living with HIV may be utilized to support these women.

This synthesized finding consists of three categories:

1. Reasons for disclosure and non-disclosure to the partner

The most common reason given by the HIV-positive women for disclosing to their partners was to inform them of the risk of HIV transmission. Another significant reason included a sense of responsibility given the relationship. The example of women’s expression:

*“He has the right to know as the father of the expected child. I had the responsibility to disclose” (U) (Visser et al. P.1140).*

Some women chose to not disclose the HIV status to their partners because they fear of being abandoned and blamed, and afraid that their partners will become violent towards them.

*“I do not know how to tell him. He often says he would kill me if I told him that I’m infected because he does not have HIV” (C) (Visser et al. P. 1141).*

2. Reasons for disclosure and non-disclosure to the family

HIV-positive women disclosed to the family because they need support from people they trust. These women have also disclosed their status to solicit care for their baby and to ensure breast-feeding avoidance. The following statements were example of the women’s expressions:

*“I told them [family members] exactly why [the baby] is using a bottle. As soon as I found out about my result I told them I have been tested and that I am HIV-positive so I will have to give the bottle and I am not supposed to breast-feed. After that, they stopped pressuring me. My mother [is now] supportive and helps me to make bottles and feed [the baby] properly” (C) (Varga, Sherman & Jones. 2006. P. 957).*

In contrast to the reasons for non-disclosure to the partner, a common reason for non-disclosure to the family is to protect them from the stigma:

*“My mother is sick. She had a stroke. I can’t tell her because it will affect her health” (U) (Visser et al. 2008., P. 1141).*

3. Reasons for disclosure and non-disclosure to friends

Some of these women chose to disclose to their friends, especially the close one to garner emotional support as they experienced the relationship as supportive and trusting. The following statement was expressed by one of the participants:

*“I told... when I came back from the clinic because I was so hurt and wanted someone to share the pain with me” (U) (Visser et al., 2008P.1140).*

Meanwhile, the most common reasons given by the participants for not disclosing to their friends was the lack of trusting relationship. One of the women said:

*“I am not close to them and don’t know what they will say behind my back”*

Synthesized finding two:

HIV-positive women need continued support and counselling to cope with disclosure practice as they may experience negative outcomes of disclosure that can negatively affect their lives and the wellbeing of the infant.

This synthesized finding comprises two categories:

1. Positive outcomes of disclosure

Some of the participants have reported positive responses of disclosure from their partner or family. The following statement was example of a woman's experience when disclosing the HIV-status to her mother:

*"She was very hurt, she cried but she accepted and was supportive. I felt better after telling her"* (U) (P. 1141).

An example of a women's positive experience of disclosure to her partner:

*"It was a shock at first but [now] we support each other all the way. When one is down the other lifts that one up ... [after I told him] ...we slept holding each other as though we knew death [was] coming ...our love became stronger [after I disclosed]"* (U) (Varga, Sherman & Jones, 2006, P. 957).

2. Negative outcomes of disclosure

Negative consequences of HIV-status disclosure described by some of the percipients include emotional rejection and indifferent reactions. The women's expressions describing negative outcomes of disclosure included:

*"[My husband's family] started separating out my things from the rest ... they would lay everything out for me, saying they wanted make sure I had everything [I need]. I had my own plates and cups and the would say 'here use this. Just use it and wash it right away'. They tried to be polite and caring but I could see it [my HIV status] made them uncomfortable ..."* (C) (Varga, Sherman & Jones. 2006, P. 958).

Synthesized finding three:

Disclosure of HIV status is a complex process comprising varied modes and patterns. Women may also experience disclosure as fluid rather than absolute, which means they could shift from being ready to disclose to not being ready. Therefore, counsellors or health care providers should continue to engage the HIV- positive women around how ready they feel to share their status, and keep the clients' status confidential to prevent involuntary disclosure.

One category namely disclosure patterns support this synthesized finding

Several women disclosed voluntarily to the primary target and did it in a simple and direct manner:

*"I just went home and told him"* (U) (Varga, Sherman & Jones. 2006, P. 955).

*"I just said it straight out, I am [HIV]-positive"* (U) (Varga, Sherman & Jones. 2006, P. 955).

In contrast, some of the women chose to disclose indirectly to avoid a conversation about death or blame of infection:

*"My sister used to dislike people [infected] with HIV. We were listening to this radio program [about people living with HIV] and I said I didn't like the way she was talking about the people they were interviewing. I said, 'don't speak badly about these people. You yourself don't know where you stand [you yourself could be infected]. Some of us have had to face this [issue of living with HIV] already'. I think she realized after that [that I am HIV-positive]"* (C) (Varga, Sherman & Jones. 2006, P. 956).

Interestingly, some of the women in these studies have experienced disclosure of HIV status as a fluid and non-linear process. This means that a dichotomy of disclosure as having either took place or not, did not always fit with women's experiences.

*"No I did not tell him ...because he lives with my friend, they live in the same yard; they talked about it over there. So when he had already heard about it over there, I said 'yes I have it, you must decide what you are going to do'. I just agreed. He came to ask me, and I told him"* (Moses & Tomlinson, 2013, P. 672).

## 4 DISCUSSION

The synthesized findings formulated in this review provide insights into factors that can influence the women's decision to disclose or not disclose their HIV-status. This review also depicts the complexity of HIV-status disclosure process experienced by the women during their pregnancy and early motherhood.

This review has identified a range of reasons and motivations for disclosure or nondisclosure of HIV status among pregnant and postpartum women. The women shared their HIV status to their partner mainly because of a sense of responsibility to their partner and to raise awareness of the risk of HIV transmission. In contrast, the women choose to

disclose to close family members or friends to seek emotional and practical supports. These women have also disclosed to their family to garner support and care for the infant as well as to ensure breast-feeding avoidance as HIV can be vertically transmitted through breast milk.

Meanwhile, the key factors identified as playing role in unwillingness to disclose included fear of violence and abandoned. Fear of abandoned was correlated with intense fear of losing financial support for the infant (Rujumba et al. 2012). Other factors that negatively associated with disclosure included previous history of domestic violence, financial dependency and living with an extended family (Tam M, Amzel A, & Phelps BR 2015). The implication here is that counsellors or health care providers should consider varying personal and social contexts in preparing women for disclosure. For example, women who are not working and highly dependent on their partner may need more counselling and help for disclosure and persuading their partner to undertake HIV testing.

Disclosure of HIV status, especially among pregnant women, has been found to be correlated with lower HIV transmission rates from mother to infants and increased maternal and infant adherence to ARV therapy (Torpey et al. 2012; Kirsten et al., 2011). These underline the importance of encouraging HIV disclosure in PMTCT programmes. However, Interventions to facilitate a safe disclosure should be provided to minimize the risk of negative outcomes from disclosure. The interventions may include strategies to increase communication and relationship building skills and working with the women to create an individualized disclosure plan (Tam M, Amzel A, & Phelps BR 2015; Walcott 2013).

This review reveals that discourse of HIV status is a complex and continues process comprising varied patterns and types. Social circumstances, cultural norms, HIV-related media and personal characteristics shaped how these women disclosed (Varga, Sherman & Jones 2006). Some women chose to disclose in a simple and direct manner, while others disclosed indirectly to avoid conversations that may lead to a discussion about death or blame for infection. Some women have experienced involuntary disclosure caused by the media that created a public association between particular perinatal health practices and HIV infection. For example advertising a particular brand of milk for HIV-pregnant women (Varga, Sherman & Jones 2006) Confidentially breach by the primary target has also been identified as a cause of involuntary disclosure in this review. Strategies should be

employed to prevent involuntary disclosure as it was frequently reported to cause negative consequences including emotional rejection and withdrawal of material supports.

Strategies that may be utilized to reduce the incidence of involuntary disclosure include a promotion or branding the PMTCT programmes as a general pregnancy health, training of the health workers and involvement of the community in HIV education. An active participation of the community in HIV education may also help to reduce HIV-related stigma, one of the significant barriers to HIV disclosure (Walcott et al. 2013; Arrey et al. 2015).

This review has also captured an interesting phenomenon, that is women may experience HIV disclosure as a non-linear and non-absolute process. This means that the women's experiences on HIV disclosure not always moving from non-disclosure to disclosure, but could change from being ready to disclose to not being ready. Therefore, an ongoing counselling should be provided for HIV-positive women to engage them around how ready they feel to disclose their status. The health workers should also understand that the non-linear and non-absolute process of disclosure may serve protective functions for these women and should be respected.

As previously mentioned, after disclosing the HIV status, women experienced varying reactions. Although some women reported a supportive and strengthened partner relationship as a result of the disclosure, negative reactions were not also uncommon. Some women expressed a guilty and isolated feeling following their partner and family's reactions to the disclosure. Previous systematic reviews have reported the similar negative outcomes of HIV disclosure experienced by the women which included violence, blame abandonment and disbelief ( in order to reduce these negative outcomes, the PMTCT education should also targets the family members, partners and broader community rather than merely focus on women (Medley et al. 2004; Tam, Amzel & Phelps 2015). In cases where the women did experienced a violent reaction from their partners and family, the health workers should be ready to help with resources that can be accessed such as the involvement of the domestic violence agency.

The WHO has endorsed four approaches to prevent HIV transmission in mothers and their infants. These include the prevention of HIV transmission to potential mothers, the prevention of unintended pregnancy among HIV-positive women, the prevention of mother-to-child transmission of HIV and the provision of support, care and treatment

for mothers, and their infants, families and partners (Medley et al. 2014). The success of each element of the four PMTCT approaches will depend on disclosure of HIV status by the women to their partners and family members.

Studies have identified several strategies to facilitate a safe disclosure in the context of antenatal care. Partner's involvement in PMTCT programmes is reported to be associated with increased women's adherence to the PMTCT recommendations including ART therapy and non-breastfeeding practice (Medley et al. 2014; Tam, Amzel & Phelps 2015). Couple counselling and testing during antenatal care is one of the most favoured approaches to increase partner involvement in

PMTCT programmes. This approach will also eliminate the burden of HIV-status disclosure as the couple will be tested for HIV at the same time and thus, no one can be blamed for infecting the other (Medley et al. 2014; Tam, Amzel & Phelps 2015). Furthermore, home-based couple counselling and testing can be an alternative way to increase partner involvement and safe disclosure during ANC. Providing HIV testing and counselling at homes was reported to be feasible and acceptable to the health care workers, pregnant women and their partners (Walcott et al., 2013).

## 5 CONCLUSIONS

This review highlights the complexity of HIV disclosure experienced by HIV-positive pregnant and post-partum women. The motivations for disclosure or non-disclosure and how these women disclosed the status were moderated by several factors which include personal circumstances, social contexts, and environmental situations. The counsellors or health workers should understand the different process involved in disclosure to family and partners. This review also shows that women may experience disclosure as a fluid and non-linear process and therefore, it important that the health workers continually explore the women's readiness to share their status with the others.

## REFERENCES

- Adeoye-Agboola, D. I., Evans, H., Hewson, D., & Pappas, Y., (2016), Factors influencing HIV disclosure among people living with HIV/AIDS in Nigeria: a systematic review using narrative synthesis and meta-analysis, *Public Health*, vol. 136, pp. 13-28, doi: 10.1016/j.puhe.2016.02.021.
- Arrey, AE, Bilsen, J., Lacor, P., Deschepper, R., (2015), "It's My Secret": Fear of Disclosure among SubSaharan African Migrant Women Living with HIV/AIDS in Belgium, *PLoS ONE*, vol.10, no. 3, :e0119653.
- Bwirire, L. D., Fitzgerald, M., Zachariah, R., Chikafa, V., Massaquoi, M., Moens, M., Schouten, E. J., (2008), Reasons for loss to follow-up among mothers registered in a prevention-of-mother-to-child transmission program in rural Malawi, *Transactions of the Royal Society of Tropical Medicine and Hygiene*, vol. 102, no. 12, 1195-1200. doi: 10.1016/j.trstmh.2008.04.002.
- Farquhar, C., Mbori-Ngacha, D. A., Bosire, R. K., Nduati, R. W., Kreiss, J. K., & John, G. C., (2001), Partner notification by HIV-1 seropositive pregnant women: Association with infant feeding decisions, *AIDS*, vol. 15, no. 6, 815-817. doi: 10.1097/00002030-200104130-00027.
- Kasenga, F., Hurtig, A.-K., & Emmelin, M., (2010), HIV-positive women's experiences of a PMTCT programme in rural Malawi, *Midwifery*, vol. 26, no. 1, pp. 27-37. doi: <http://dx.doi.org/10.1016/j.midw.2008.04.007>.
- Madiba, S., & Letsoalo, R., (2013), HIV Disclosure to Partners and Family among Women Enrolled in Prevention of Mother to Child Transmission of HIV Program: Implications for Infant Feeding in Poor Resourced Communities in South Africa, *Global Journal of Health Science*, 5(4), 1-13. doi: 10.5539/gjhs.v5n4p1
- Makin, J. D., Forsyth, B. W., Visser, M. J., Sikkema, K. J., Neufeld, S., & Jeffery, B., (2008), Factors affecting disclosure in South African HIV-positive pregnant women. *AIDS Patient Care STDS*, vol. 22, no. 11, pp. 907-916. doi: 10.1089/apc.2007.0194
- Medley, A., Garcia-Moreno, C., McGill, S., & Maman, S., (2004), Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: Implications for prevention of mother-to-child transmission programmes. *Bulletin of the World Health Organization*, vol. 82, no. 4, pp. 299-307.
- Moses, S., & Tomlinson, M., (2013), The fluidity of disclosure: A longitudinal exploration of women's experience and understanding of HIV disclosure in the context of pregnancy and early motherhood. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, vol. 25, no. 6, pp. 667-675, doi: 10.1080/09540121.2012.736606.
- Rujumba, J., Neema, S., Byamugisha, R., Tylleskär, T., Tumwine, J. K., & Heggenhougen, H. K., (2012). "Telling my husband I have HIV is too heavy to come out of my mouth": pregnant women's disclosure experiences and support needs following antenatal HIV testing in eastern Uganda. *Journal of the International AIDS Society*, vol. 15, no. 2, p. 17429. doi: 10.7448/IAS.15.2.17429.
- Sendo, E. G., Cherie, A., & Erku, T. A., (2013), Disclosure experience to partner and its effect on intention to utilize prevention of mother to child transmission



service among HIV positive pregnant women attending antenatal care in Addis Ababa, Ethiopia. *BMC Public Health*, vol. 13, pp. 765-765, doi: 10.1186/1471-2458-13-765.

Tam, M., Amzel, A., & Phelps, B. R., (2015), Disclosure of HIV serostatus among pregnant and postpartum women in sub-Saharan Africa: a systematic review, *AIDS Care*, vol. 27, no. 4, pp. 436-450. doi: 10.1080/09540121.2014.997662.

The Joint United Nations Programme on HIV/AIDS, (2015), Fact sheet 2016, Retrieved from: [http://www.unaids.org/sites/default/files/media\\_asset/UNAIDS\\_FactSheet\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf).

The World Health Organization, (2013), HIV/AIDS: Mother-to-child transmission of HIV [online]. Retrieved from: <http://www.who.int/hiv/topics/mtct/about/en/>.

Torpey K., Mandala J., Kasonde P., Bryan-Mofya G., Bweupe M., Mukundu J., et al, (2012), Analysis of HIV Early Infant Diagnosis Data to Estimate Rates of Perinatal HIV Transmission in Zambia. *PLoS ONE*. vol. 7, no. 8.

Ujiji, O. A., Ekström, A. M., Ilako, F., Indalo, D., Wamalwa, D., & Rubenson, B., (2011), Reasoning and deciding PMTCT-adherence during pregnancy among women living with HIV in Kenya, *Culture, Health and Sexuality*, vol. 13, no. 7, pp. 829-840, doi: 10.1080/13691058.2011.583682

Varga, C. A., Sherman, G. G., & Jones, S. A., (2006), HIV-disclosure in the context of vertical transmission: HIV-positive mothers in Johannesburg, South Africa. *AIDS Care*, vol. 18, no. 8, pp. 952-960. doi: 10.1080/09540120500356906.

Visser, M. J., Neufeld, S., de Villiers, A., Makin, J. D., & Forsyth, B. W. C., (2008), To tell or not to tell: South African women's disclosure of HIV status during pregnancy, *AIDS Care*, vol. 20, no. 9, pp. 1138-1145. doi: 10.1080/09540120701842779.

Walcott MM, Hatcher AM, Kwena Z, Turan JM., (2013), Facilitating HIV status disclosure for pregnant women and partners in rural Kenya: a qualitative study, *BMC Public Health*, vol. 13, no. 1, pp. 1-25.

## APPENDIX

### Extracted Findings

Extracted themes	Illustrative quotes	Level of credibility
Visser et al. (2008) Disclosing HIV status to raise risk awareness for changes in lifestyles	"I told him to inform him that we are both HIV positive and that we need to change our life styles" Visser et al. (P. 1140).	Unequivocal
Responsibility/obligation given the relationship	"He has the right to know as the father of the expected child. I had the responsibility to disclose" Visser et al. (P. 1140).	Unequivocal
Being in supportive and trusting relationships	"There is no other person but my mother I could tell, knowing that she'd help me. She understands. A mother is a mother" Visser et al. (P. 1140).	Unequivocal
Explanation of behaviour, illness and death	"I wanted them to know what killed me and ask them to look after my children when I am dead" Visser et al. (P. 1140).	Credible

Extracted themes	Illustrative quotes	Level of credibility
Fear of violence	"I don't know how to tell him, he often says he would kill me if I told him that I am infected because he does not have HIV" Visser et al. (P. 1141).	Credible
Protect others from the results	"My mother is sick. She had a stroke. I can't tell her because it will affect her health" Visser et al. (P. 1141).	Unequivocal
Lack of trusting relationships	"I am not close to them and don't know what they will say behind my back" Visser et al. (P. 1141).	Credible
Experiencing supportive and accepting reactions of HIV-status disclosure	"She was very hurt, she cried but she accepted and was supportive. I felt better after telling her" Visser et al. (P. 1141).	Unequivocal

Experiencing indifferent reaction when disclosing HIV status to the partner	“He just looked at me and turned the other way without saying a word. He acts as if I did not tell him a serious thing” Visser et al. (P. 1141).	Credible
---	--	----------

Extracted themes	Illustrative quotes	Level of credibility
Varga, Sherman, Jones (2006) Voluntary direct disclosure	“I just went home and told him”, “I just said it straight out” Varga, Sherman, Jones (P. 955).	Unequivocal
Voluntary indirect disclosure	“My sister used to dislike people [infected] with HIV. We were listening to this radio program [about people living with HIV] and I said I didn’t like the way she was talking about the people they were interviewing. I said, ‘don’t speak badly about these people. You yourself don’t know where you stand [you yourself could be infected]. Some of us have had to face this [issue of living with HIV] already’. I think she realized after that [that I am HIV-positive]” Varga, Sherman, Jones (P. 956).	Credible
Involuntary disclosure of HIV status	“They show everything on TV [quoting a documentary on the nevirapine controversy] ...’mothers who are infected, they use this and that [nevirapine and infant formula]. They are infected and they get this Pelargon for free at the hospital’ 10 o’clock in the morning they are showing this thing. We were watching and [my family] asked why I use that milk [Pelargon] they show on the TV to feed the baby. Do I get it for free at the hospital like they [the HIVpositive women featured in the documentary] do? So I lied to them. I told them the hospital is selling this milk, you pay for your monthly supply. They never said anything more	Credible

Extracted themes	Illustrative quotes	Level of credibility
	about it, but I couldn’t stop wondering if now they think I am [HIV]-positive” Varga, Sherman, Jones (p. 956).	
	“I told them [family members] exactly why [the baby] is using a bottle. As soon as I found out about my result, I told them I have been tested and that I am	
Disclosing HIV-status to ensure breast feeding avoidance		Unequivocal
	HIV-positive so I will have to give the bottle and I am not supposed to breastfeed. After that, they stopped pressuring me. My mother [is now] supportive and helps me to make bottles and feed [the baby] properly” Varga, Sherman, Jones (P. 957).	
Disclosure is necessary to solicit care and support for the infant	“After I got very sick ...my boyfriend panicked. It was better to cough it up [disclose] in case things got worse. So we just told them. We needed to support in case something happens to me ...I think about [the baby’s] future, if it happens that I die. Now her future is secure [there will be someone to look after her]” Varga, Sherman, Jones (P. 957).	Unequivocal
Experiencing strengthened partner relationship after HIV disclosure	“It was a shock at first but [now] we support each other all the way. When one is down the other lifts that one up ... [after I told him] ...we slept holding each other as though we knew death [was] coming ...our love became stronger [after I	Unequivocal

Extracted themes	Illustrative quotes	Level of credibility
Feeling self-conscious, trapped and isolated following family reactions after HIV-status disclosure	disclosed]" Varga, Sherman, Jones (P. 957).  "[My husband's family] started separating out my things from the rest ... they would lay everything out for me, saying they wanted make sure I had everything [I need]. I had my own plates and cups and the would say 'here use this. Just use it and wash it right away'. They tried to be polite and caring but I could see it [my HIV status] made them uncomfortable ... on my side [of the family] they are too [heavy emphasis] supportive. They are too concerned. They are always asking me 'Are you okay? Are you getting sick?' so now I have started feeling guilty ... they are too focused on me. [I feel as though] my life is longer [my own] Varga, Sherman & Jones (P. 958).	Credible

Extracted themes	Illustrative quotes	Level of credibility
Moses & Tomlinson (2013) Experiencing HIV-status disclosure as a non-absolute and non-linear process	"I'm not gonna tell [my mother]. Maybe she's gonna find out. But my mother, I don't know but if I remember it was, maybe it was 2005 or 2006, I did tell my mother, but like in a nice way, it was like a joke. No, she said to me, 'oh you're sick but you are drinking, smoking, what about your life?' it ends there, we never talk about it again, so I don't know maybe she still remembers that or not" Moses & Tomlinson (P. 672).	Credible
Indirect disclosure	"No I did not tell him ... because he lives with my friend, they live in the same yard; they talked about it over there. So when he had already heard about it over there,	Credible

Extracted themes	Illustrative quotes	Level of credibility
Disclosing HIV status to garner emotional and practical support	I said 'yes I have it, you must decide what you are going to do'. I just agreed. He came to ask me, and I told him" "I asked him; 'what if you could go and get tested? Or maybe I am making an example: 'if I turned out positive, what would you do?' ... I was joking, I wanted to see what he was going to do" Moses & Tomlinson (P. 672).  "Pumla was very stressed...she said to me 'how are [my] children going to grow without their father?' ... as Pumla talking you could feel her frustration anger, saying that 'if only I hadn't fallen pregnant', and 'why did my boyfriend ask for another child only to find out that he's going to leave them. Who's going to look after his children?' but she is happy that her sister-in-law is supporting her at all times" Moses & Tomlinson (P. 673).  "Because if I tell him, he will leave me here with this baby, because he will say I am the one who brought this to him" Moses & Tomlinson (P. 670).	Credible
Fear of being blamed and abandoned		Unequivocal