



The Pregnancy Experience Among Women With HIV: A Literature Review

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Abstrak

UNAIDS data 2018 menunjukkan 36,9 juta orang hidup dengan HIV, 4400 kasus di antara orang dewasa (berusia diatas 15 tahun lebih), hampir 43% wanita. Kira-kira 24% kematian pada wanita hamil atau pasca melahirkan dikaitkan dengan HIV di Sub Sahara Afrika. Kehamilan dan pasca melahirkan adalah waktu risiko HIV yang persisten dan memiliki risiko kematian yang lebih besar sehingga diperlukan perhatian yang khusus pada ibu hamil yang terinfeksi HIV. Tujuan penelitian ini untuk mengetahui pengalaman kehamilan pada wanita yang terinfeksi HIV. Mengidentifikasi PubMed dan Proquest dari tahun 2015-2018, dengan memasukkan kata kunci "pregnant HIV" OR "pregnancy HIV" OR "HIV pregnant" OR "HIV pregnancy" AND experience*. Kriteria inklusi dan ekslusinya ditentukan menggunakan: kerangka Populasi, Exposure, Outcome dan Study (PEOS) Design, PRISMA flow diagram, ekstraksi data dan CASP dan pemetaan hasil temuan. Dari 378 artikel diseleksi kemudian didapatkan 7 artikel dengan design kualitatif mengemukakan tentang pengungkapan status HIV yang masih disembunyikan karena ketidakberanian, kekerasan dan stigma di masyarakat. Kurangnya dukungan tenaga kesehatan dalam memberikan informasi dan asuhan kehamilan tentang HIV dapat mengurangi kepatuhan ART. Dukungan dari keluarga dan teman sebaya dapat mencegah penularan HIV ke bayi. Wanita hamil yang positif HIV memiliki harapan agar kehamilannya sehat dan bayinya terbebas dari HIV. Pengungkapan status HIV masih menjadi ketakutan dan kekhawatiran. Akan tetapi dukungan yang positif dari orang terdekat, masyarakat maupun dari tenaga kesehatan yang terlibat dapat memotivasi ibu hamil dengan HIV untuk meningkatkan kesehatannya.

Kata Kunci: HIV, Kehamilan HIV, Pengalaman HIV

Abstract

The 2018 UNAIDS data showed that 36.9 million people live with HIV. Of these, 4,400 cases found among adults (> 15 years old) and nearly 43% were women. In Sub-Saharan Africa, it was estimated that 24% of maternal deaths during prenatal or postnatal care were associated with HIV. Therefore, clinical attention is highly required during pregnancy and after delivery, particularly for those who are infected or at greater risk of HIV. This study aimed to determine pregnancy experience among women with HIV. PubMed and Proquest were used to search relevant articles from 2015-2018 by typing the keywords: "pregnant HIV" OR "pregnancy HIV" OR "HIV pregnant" OR "HIV pregnancy" AND "experience". The inclusion and exclusion criteria was determined through: Population, Exposure, Outcome and Study Design (PEOS) framework, PRISMA flow diagram, data extraction and CASP, and mapping the findings. Of 378 selected articles, 7 articles were found to be relevant with the study objective. Using qualitative designs, the articles discussed the disclosure of HIV status that remained hidden. This was due to lack of courage, high level of violence, negative stigma in community and lack of support from health practitioners in providing information about HIV during pregnancy. Support from family and peers can prevent HIV

transmission from pregnant women to their fetus. Pregnant women with HIV can still expect that their pregnancy will be healthy and no HIV transmission to their newborn. Disclosure of HIV status remains be fear and concern. However, positive support from family, community and health practitioners can motivate pregnant women with HIV to improve their health.

Keywords: HIV, HIV pregnancy, HIV experience

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INTRODUCTION

According to the data UNAIDS 2018 showed 36.9 million people are living with HIV, about 5.000 cases per day are new cases in adults and children. About 66% of cases are in Sub Saharan Africa (SSA). Five hundred cases under the age of 15 years and around 4.400 cases over the age of 15 years, nearly 43% were women, 33% of young children (15–24 years) and about 19% of young women (15–24 years). East and South Africa are still ranked first for the number of adults and children living with HIV as many as 19.600.000 cases and as many as 800.000 new cases of HIV infection (1). In data Indonesia 2018 showed 46,659 cases of people living with HIV positive. Of 1,805,993 pregnant tested for HIV, there were 5,074 (0.28%) pregnant who tested positive for HIV (2)

HIV and pregnancy-related complications are the two main causes of global death for women of reproductive age (3). HIV-infected women have a high risk of worsening the condition of pregnancy and the postpartum period (4). Pregnant with HIV will increase about eight times higher mortality than pregnant who are not infected with HIV. Based on these estimates, approximately 24% of deaths occur in pregnant or postpartum women associated with HIV in SSA (5).

Despite the expansion of quality Prevention of Mother-to-Child Transmission of HIV (PMTCT)

services and widespread use of Option B+ (*Antiretroviral Therapy/ART*), most countries in sub-Saharan Africa have not yet reached the UNAIDS target for pregnant and postnatal (6). Pregnant who are infected with HIV need adequate prophylactic steps from prenatal, childbirth and post-natal care so that they require greater attention among health professionals (7) of which 187 infants were exposed and uninfected, 19 seroconverted, and 12 were still inconclusive in July 2015. Therefore, the overall vertical HIV transmission rate in the period was 8.7%. Most (71.6%.

Pregnancy experience is different for everyone, through this period is believed to be a motivation for women infected with HIV as a belief that the role of motherhood is stronger so that it requires support from the people involved so that the burden of HIV becomes lighter (8). The purpose of this review literature is to summarize the findings of pregnancy experiences in women infected with HIV.

MATERIALS AND METHODS

The article is searched through the PubMed and Proquest database, entering terms according to purpose, using the Boolean operator to combine the same performing keywords for the two “*pregnant HIV*” OR “*pregnancy HIV*” “*HIV pregnant*” OR “*HIV pregnancy*” AND *experience** databases. inclusion at the time of the search

was free full-text, data published in 2015 - 2018 and in English amounted to 378 articles. The inclusion and exclusion criteria used Population, Exposure, Outcome and Study Design (PEOS), whose population was all women who had been pregnant positively HIV, the result is the experience of pregnancy with a design study that is relevant to the experience of pregnancy in HIV.

RESULTS AND DISCUSSION

Based on the results of the literature review, one study explained that 85,7% of women were infected with HIV through unprotected (unprotected) sexual relations with men (10). The seven articles reviewed were mostly done in East Africa (4 articles), South Africa (1 article), the United States of America (1 article) and the United Kingdom (1 article). The major themes gained in the experience of pregnant women with HIV are 1) Disclosure of HIV status, 2)

Pregnancy support and care for HIV women, and 3) Pregnancy expectations for HIV women.

Disclosure of HIV Status

Almost all participants conceal their HIV status from professional staff as well as partners/family and friends. Lack of disclosure about HIV status due to lack of courage and stigma, especially diaspora in the African community, domestic violence, poor relations and fears of being abandoned by a partner (11–13,16) and discrimination in society (13,15,16) if they reveal HIV status. Throughout pregnancy and breastfeeding participants are haunted by a fear of death before revealing their status, some participants experience rejection by a partner especially if the partner is tested negative (12), however, it is different for women who have revealed their HIV status to their family, especially to their partners, they get support especially in treatment (11,14).

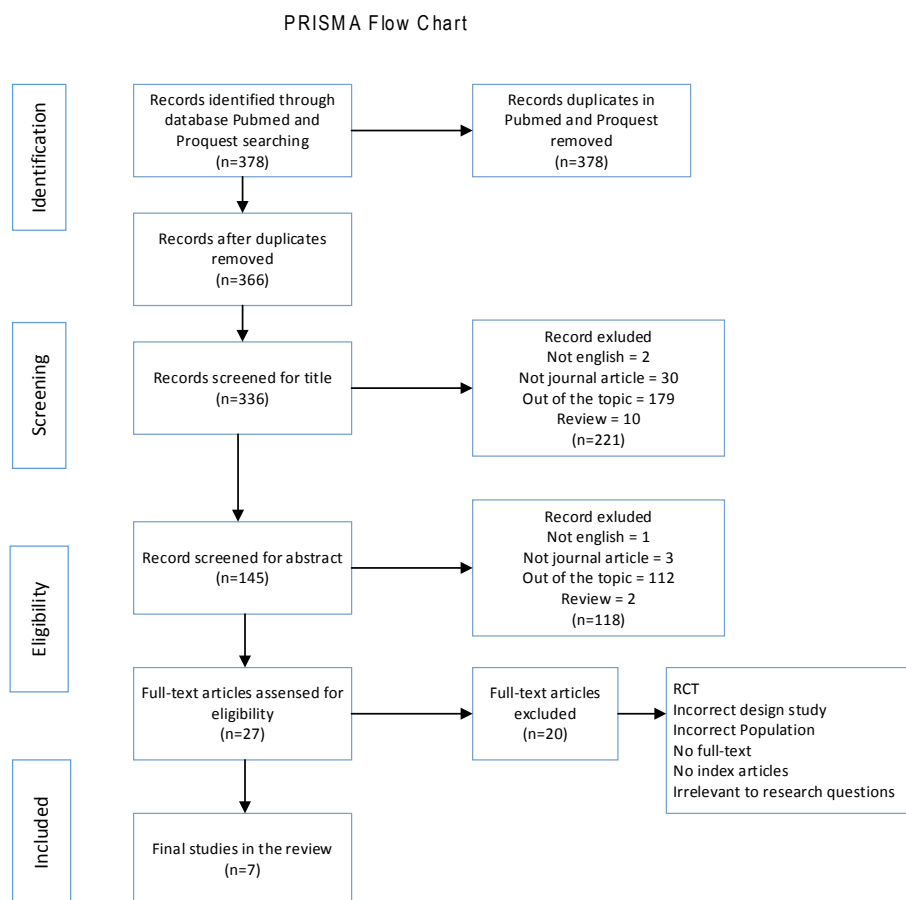


Fig. 1 PRISMA Flow Chart

Table 1 . Extraction Data

No	Title/Autor/Year/Country	Country	Research Type	Result
1.	<i>Facilitators and barriers to uptake and adherence to lifelong antiretroviral therapy among HIV infected pregnant women in Uganda: a qualitative study</i> /Buregyeya et al/2017	Urganda, East Africa	Qualitative study In-depth interviews with 57 HIV women	a. Stigma, fear of being seen with antiretroviral drugs, fear of being abandoned and violence by partners, length of treatment and side effects, lack of health workers in providing IEC and HIV-related care are barriers to lifelong HIV treatment adherence. b. Support of spouse / family and peers. c. The hopes and desires of mothers to have healthy children and want to live longer
2.	<i>'I wanted to safeguard the baby': a qualitative study to understand the experiences of Option B+ for pregnant women and the potential implications for 'test-and-treat' in four sub-Saharan African settings</i> / McLean et al/2016	Malawi, Tanzania and Uganda, East Africa	Qualitative study In-depth interviews with 22 HIV women and 15 health workers	a. The lack of support and services of Ante Natal Care (ANC) further impedes the ability especially in young mothers who are first pregnant b. There is still a hierarchy of power and little two-way communication because of the rush of health workers
3.	<i>"Out of All of this Mess, I Got a Blessing": Perceptions and Experiences of Reproduction and Motherhood in African American Women Living With HIV</i> /Fletcher et al/2016	South Carolina south United States	Qualitative study In-depth interviews with 42 HIV women	a. Expectations in pregnancy and the role of motherhood through changes in health behavior to minimize the risk of transmission to the baby b. Support service providers in offering good advice and respecting patient autonomy when counseling HIV-infected women.
4.	<i>Perceptions and decision-making with regard to pregnancy among HIV positive women in rural Maputo Province, Mozambique - a qualitative study</i> / Cuinhane et al/2018	Mozambique, East Africa	A Qualitative study of a grounded theory approach semi-structure interviews and FGDs with 59 HIV women and health nurses	a. Stigma, discrimination and fear will be left by the couple b. Pregnancy with HIV is a disease that will spread to babies c. Need support from the husband for treatment, support for health workers for counseling and therapy, especially ART adherence during pregnancy and breastfeeding d. Women do not have the power to make decisions about pregnancy e. Barriers to adherence to treatment are related to transport costs and side effects of ART
5.	<i>Psychosocial challenges facing women living with HIV during the perinatal period in rural Uganda</i> / Ashaba et al/2017	Urganda, East Africa	Qualitative studi Semi-structured interviews with 20 HIV women	a. Disclosure of HIV status, gender inequality, stigma and discrimination, get negative treatment by health workers every time they visit the hospital b. There is no support from partners and often gets violence, economic hardships so as to prevent and interfere with their ability to follow HIV-related treatment and care
6.	<i>The lived experiences of rural women diagnosed with the human immunodeficiency virus in the antenatal period</i> / Fords et al/2017	South Africa	Qualitative study of phenomenological approach semi-structured interviews with 10 HIV women	a. Stigma, cruelty by partners, and isolation during pregnancy and breastfeeding b. Support, and the role of mothers give them enthusiasm for treatment compliance and provide hope for their children free of HIV
7.	<i>'We have beaten HIV a bit': a qualitative study of experiences of peer support during pregnancy with an HIV Mentor Mother project in England</i> / McLeish and Redshaw /2016	England	Qualitative study In-depth and semi structured interviews with 12 HIV women	a. Stigma, fear and isolation but they have the desire to protect their families from HIV b. Difficult to access information and antenatal care by health workers because health workers do not have much time to provide comprehensive care c. Peer support programs (mother mentors) and mothers provide strength during pregnancy and make a good impact by strengthening medical advice to avoid mother-to-child HIV transmission.

Disclosure of HIV status contributes to reducing HIV transmission to infants by increasing treatment compliance among HIV pregnant. Research in Nigeria suggests treatment adherence is 2,3 times greater for those who have revealed HIV status (17) and the importance of partner involvement during pregnancy (18). Research conducted by Ramlagan (2018) found a strong positive relationship between male partner involvement during pregnancy and disclosure of HIV status (18) to increase adherence to the use of HAART is consistent with research conducted by Odiachi (2018) in rural Nigeria (19). In another study, 79,5% of women had revealed their status, but were still limited to fathers or a small number of family (20), the results they receive are generally positive and support what is experienced (21) emotional adjustment to the disease, and reduced risk of HIV transmission, but women face both real and perceived barriers to disclosure. We examined patterns and predictors of HIV disclosure in a cohort of 200 women diagnosed or confirmed to have HIV during antenatal care in the Kilimanjaro region of Tanzania and followed participants to three months postpartum. Twenty women also completed qualitative in-depth interviews during pregnancy and three months postpartum. During the pregnancy period (at least 30 days post-diagnosis). In some women, they are more comfortable expressing with peers because they have a sense of trust, care and empathy (22).

Support and Antenatal Care in HIV-Positive Women

In several studies it was reported that there was no support from a husband or partner and family in treatment (11–14,16), such as a prohibition by a husband to take HIV drugs (14). and inadequate economic, preventing them from taking medication (13). Lack of support from health practitioners in providing health education and counseling especially pregnancy

care and knowledge about HIV is a barrier to their adherence to treatment (11), and officers do not have much time to care about the anxiety that pregnant experience (15). Lacking social support causes them to tend to avoid and withdraw (23). Participants consider pregnancy with HIV to be a dangerous disease and can cause death which will add to their concern if transmitting HIV to their baby (12,13,15,16).

Basically support from partners, family and peers, support from organizations, groups and service personnel was reported to be able to improve adherence to the use of ART in pregnant women (10–12,14,15) little is known about reproductive decision-making processes for African American women living with HIV. The overall goal of our study was to qualitatively explore perspectives related to reproduction and motherhood in HIV-infected African American women of childbearing capacity. HIV-infected African American women of childbearing capacity in South Carolina (N = 42, research in Malawi suggests that support contributes greatly to the treatment of Option B + (24) "container-title": "Journal of Acquired Immune Deficiency Syndromes (1999). Peer support is very important and has a positive impact on preventing HIV transmission to infants and improving the health of mothers and children, helping women in solving problems, there is a sense of caring and empathic like the *Mother Mentor Project* in the UK (15) and *Mother Support Group (MSG)* in Zimbabwe (25).

In accordance with WHO guidelines, HIV-positive pregnant are required to take ART regardless of their lifetime CD4 cell count to prevent transmission to their babies (Option B+), but there are some women who do not comply with treatment for various reasons. Through an integrated family and Antenatal Care approach it has proven effective in improving services and programs for the *Prevention of Mother-to-Child Transmission of HIV (PMTCT)* (26). In line with the policy strategy undertaken by Ethiopia to

expand PMTCT services and increase treatment coverage by utilizing antenatal care visits (27).

HIV-positive women generally have better knowledge (28) because they are motivated to make themselves healthier in the hope of not wanting to spread HIV to their babies. Several studies have shown the reasons pregnant do not adhere to treatment, including stigma, fear of embarrassment seen with ART, fear of being abandoned by partners and domestic violence, forgetfulness, large tablet size, long treatment, side effects of ART, living in the countryside and the cost of transport high because they have to take drugs far away (11,16). In other studies, long distance, low household income and living in a rural environment are significant factors associated with compliance with low utilization of PMTCT services (17). Ethiopia through its strategy by increasing household welfare through economic empowerment for women and increasing access to services in particular paying more attention to rural areas (27).

Some pregnant adhere to treatment during pregnancy and breastfeeding, but leave treatment after the weaning period (16), busy taking care of the baby and other responsibilities or maybe loss or death to the baby (11). Some participants who did not disclose their HIV status to partners managed to follow ART treatment during pregnancy (16), they are motivated because treatment gives them hope of having a baby who will be born HIV negative (10–15). Disclosure of HIV status is significantly associated with improving treatment adherence, especially in HIV-positive pregnant women such as research in Nigeria (17), however, attitudes differ from studies in Saudi Arabia, more than 40% of them suggest that people living with HIV are negative and should be isolated (23).

Expectations of pregnancy in HIV positive women

According to their pregnancy experience with HIV, the hope for pregnancy at that time was

to have a healthy baby free from HIV infection. this is the main motivation for women to start ART, they want to stay healthy and live longer so they can care for children (11), so have the chance to become parents (12) and fulfill her role as a mother (10), strengthening spiritual beliefs through prayer and accepting the situation of those infected with HIV HIV (10,15). However, experience in some women, they are often afraid due to deteriorating health and the possibility of HIV transmission to infants, women think that pregnancy with HIV is a disease that can cause death (16).

At present, HIV pregnant women can have high hopes for their pregnancy, through the Option B+ PMTCT program with few side effects (29) in the United States, they were infected with HIV through PMTCT programs do care continuum from pregnancy to postpartum and provide excellent results in the long-term health, about half of HIV-positive women do 99% of vaginal delivery infants were tested for HIV result is (30) and research in Iran shows that if HIV-positive pregnant women to follow the PMTCT program, they can realistically expect to give birth to uninfected children (31) This is consistent with the expectations of all women to live longer with their children through healthy changes in behavior patterns and adherence to treatment according to the PMTCT program.

CONCLUSION AND RECOMMENDATION

Experience an HIV-positive mother's pregnancy is different from the disclosure of HIV status, support and health services received, and the expectation of pregnancy in women who are HIV positive which is a separate obstacle in pregnant women. Disclosure of status may be different for each woman, disclosure of HIV status is still a stigma, fear, anxiety, discrimination, sometimes they have to cover HIV status in order to comply with treatment. However, a good and positive support of the

partner / family, peers, community to pregnant mothers are able to provide reinforcement to adhere to the treatment that aims to stay healthy and avoid transmission to the baby. Professional officers who are involved in caring for pregnant women continuously motivate making it easier for pregnant women to access information, strengthen and expand counseling through knowledge, especially HIV in pregnancy and increasing coverage of treatment and expanding access to prevent transmission to infants. The confidence and adherence of pregnant to treatment through the role of motherhood can prevent transmission of HIV to their babies and wishes to care for children in accordance with the expectations of all pregnant women.

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