



Decision-making of motherhood among Pregnant women with HIV: A systematic review

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DOI: 10.48047/ecb/2023.12.si4.1658

ABSTRACT

Women living with HIV lack evidence-based information about reproductive options while managing pressures from family, clinicians, and communities to give up the idea of having children. As the reproduction intentions of Women living with HIV are not well understood, stigmatizing behaviors force them to hide their disease to avoid rejection by their family, partner, and social networks. Compliance with social norms, fear of stigma, and discrimination influence their experience. The purpose of this study was to synthesize the evidence to explain the reproductive decision-making process for Women living with HIV.

A systematic review with research synthesis was conducted through searches in 10 electronic databases (CINAHL, EMBASE, MEDLINE, Scopus, Social Science Citation Index, Web of Science, Google Scholar). Studies published in journals from 2013 to 2023 with data about reproductive decision-making among Women living with HIV were eligible for inclusion. The study authors screened papers for eligibility and included 8 papers in the analysis.

Women living with HIV encounter reproductive decision-making with knowledge deficits and limited social support. An integrated approach to holistic care with comprehensive multidisciplinary counseling is needed to support Women living with HIV. Clinicians could benefit from professional development to learn how to be authentically present for Women living with HIV, including engaging in conversations, demonstrating compassion, and understanding situations. Evidence-based clinical practice guidelines need to be tailored for the family planning and sexual health needs of Women living with HIV.

Keywords: Motherhood, pregnant, HIV, Women, Decision making

INTRODUCTION

Globally there are nearly 40 million people living with HIV, more than half are women (*UNAIDS Data 2019* / *UNAIDS*, n.d.). In 2018, 82% of pregnant women living with HIV (WLH) had access to antiretroviral treatment to prevent mother-to-child transmission, with higher rates in developed countries (*Miles To Go Closing Gaps Breaking Barriers Righting Injustices*, N.D.). The wider

treatment coverage and improved adherence among WLH has rapidly reduced AIDS-related deaths among women (Rodriguez et al., 2017). Increased access to highly active anti-retroviral therapy (HAART) shifted HIV from an acute illness to a chronic disease (Kabapy et al., 2020) for women in terms of life expectancy, quality of life, and the opportunity for motherhood (Teeraananchai et al., 2017)

Motherhood is an important role that gives meaning to life for many women; however, decisions about pregnancy and childbearing are often complex as HIV impacts many aspects of daily living (Leyva-Moral et al., 2017). The factors influencing reproductive decision-making include concerns about the baby being born with HIV and the longevity of life for the mother (Mazzeo et al., 2012). Pregnancy with HIV brings increased risk for complications including maternal infection and adverse perinatal outcomes. Following the introduction of HAART, however, mother-to-child transmission was reduced to less than 1% in developed countries. (Joseph Davey et al., 2020) The knowledge transfer of this evidence into clinical practice, within communities, and throughout the general public has been slow. (Leyva-Moral et al., 2018)

Childbearing (CB) is a source of concern for women living with HIV/AIDS (WLHA), because of the risk of HIV transmission to children and sexual partners (Sofolahan & Airhihenbuwa, 2012). Women living with HIV must consider many factors when making childbearing decisions, including support from partners and healthcare providers (*HIV and Women – Having Children - Better Health Channel*, n.d.)

As the HIV/AIDS epidemic enters its third decade, the reproductive choices available to Women living with HIV are evolving. The initial recommendations of the CDC in 1985 and the American College of Obstetrics and Gynecology in 1987 discouraged Women living with HIV from getting pregnant (Duff et al., 2018). In 1994, the American Society for Reproductive Medicine encouraged physicians to discuss other options such as assisted reproductive technology [6]. Unfortunately, some of the recommended assisted reproductive technologies are not widely accessible to WLHA in resource-constrained settings (Jain & Singh, 2022). However, given that many women believe that a woman's identity is affirmed by her motherhood status, many WLHA in these settings make plans to have children with partners whose HIV statuses are sometimes unknown. By doing so, WLHA are at an increased risk for infection with other STIs or reinfection with a different strain of HIV by engaging in unprotected sexual practices to become pregnant (Sofolahan-Oladeinde & Airhihenbuwa, 2014)

Rational for review

WLH lack evidence-based information about reproductive options while managing pressures from family, clinicians, and communities to give up the idea of having children (Orlando et al., 2017). Since reproduction intentions of WLH are not well understood (Warren et al., 2017), stigmatizing behaviors force women to hide their disease in order to avoid rejection by their family, partner, and social networks (Leyva-Moral et al., 2017). Compliance with social norms,

fear of stigma, and discrimination influence their experiences and guide their behaviors (Saleem et al., 2017)

Misinformation and prejudice continue in clinical practice (Fransen-Dos Santos & Guarinieri, 2017a) as WLH do not feel supported by their clinicians. They report discrimination and stigma in some cases; with the resulting fear and anxiety negatively impacting their relationships with clinicians and their confidence in the health system. WLH require comprehensive evidence-based care to safely fulfill their decisions about motherhood, whether this involves preventing or safely advancing a pregnancy (O'Brien et al., 2017).

MATERIAL AND METHODS

The electronic databases searched included (CINAHL, EMBASE, MEDLINE, Scopus, Social Science Citation Index, Web of Science, Google Scholar). The search terms relating to HIV AIDS included 'motherhood', 'women', 'HIV', 'Childbearing' and 'pregnant'. These terms were each combined with a further search term relating specifically to Decision making. These consisted of 'motherhood,' 'pregnant' and 'HIV' 'women'. Following this, reviewer independently evaluated an assigned subset of articles using previously developed data extraction forms and quality appraisal tools. Each specific item on the quality appraisal tool was openly discussed to reach consensus.

Inclusion Criteria

1. Article reported the Decision-making of motherhood among Pregnant women with HIV.
2. Full Text articles
3. Articles of any design written in English

Exclusion Criteria

1. Articles not reporting the Decision-making of motherhood among Pregnant women with HIV
2. Non peer reviewed articles

Quality Assessment

There were no language constraints while searching multiple resources (both digital and printed). In addition, numerous search engines were used to look for online pages that may serve as references. Inclusion and exclusion criteria were documented. Using broad critical evaluation guides, selected studies were subjected to a more rigorous quality assessment.

These in-depth quality ratings were utilised to investigate heterogeneity and make conclusions about meta-analysis appropriateness. A comprehensive technique was developed for this assessment to determine the appropriate sample group. The criteria for evaluating the literature were developed with P.I.C.O. in mind.

(Cronin et al., 2008) suggest that in order for nurses to achieve best practice, they must be able to implement the findings of a study which can only be achieved if they are able to read and critique that study. (J, 2010) provides a definition of a systematic review as a type of literature review which summarizes the literature in relation to a single question. It should be based on

high quality data that is rigorously and explicitly designed in order for the reader to be able to question the findings.

This is supported by (Cumpston et al., 2019) which proposes that a systematic review should answer a specific research question by identifying, appraising and synthesising all the evidence which meets a specific eligibility criterion (Pippa Hemingway, 2009) suggest a high - quality systematic review should identify all evidence, both published and unpublished. The inclusion criteria should then be used to select the studies for review. These selected studies should then be assessed for quality. From this, the findings should be synthesised making sure that there is no bias. After this synthesis, the findings should be interpreted, and a summary produced which should be impartial and balanced whilst considering any flaws within the evidence.

Data Collection Strategies

(Chapter 5: Collecting Data | Cochrane Training, n.d.) highlight that data collection is a key step in systematic reviews as this data then forms the basis of conclusions which are to be made. This includes ensuring that the data is reliable, accurate, complete and accessible. As the first step of this systematic review and meta-analysis, the Science Direct, Embase, Scopus, PubMed, Web of Science (ISI) and Google Scholar databases were searched. To identify the articles, the search terms of HIV AIDS included 'motherhood', 'women', 'HIV', 'Childbearing' and 'pregnant', and all the possible combinations of these keywords were used.

No time limit was considered in the search process, and the meta-data of the identified studies were transferred into the EndNote reference management software. In order to maximize the comprehensiveness of the search, the lists of references used within all the collected articles were manually reviewed.

Keywords used as per MeSH: HIV AIDS included 'motherhood', 'women', 'HIV', 'Childbearing' and 'pregnant'

Inclusion/exclusion criteria.

For this review, a clear strategy was produced in order to identify the relevant inclusion and exclusion criteria (see table below). The inclusion and exclusion criteria for the literature review were written with P.I.Co. in mind. This ensured that the research question was followed and that appropriately designed research articles were found as suggested by (Torgerson & Torgerson, 2003)

As this review focuses on the Decision-making of motherhood among Pregnant women with HIV were deemed appropriate (Pati & Lorusso, 2017) highlight that the inclusion and exclusion criteria within a literature search is a source of potential bias therefore higher trust and credibility can be gained by the clear documentation of such exclusion and inclusion criteria. Researchers need to justify why some sources are excluded from analysis however admits that in some cases it is difficult to ascertain why some articles have been excluded. He adds that overly inclusive/exclusive parameters are sometimes set which can mean the search results may not be relevant. The inclusion criteria set by PICO

Population/Problem	Women over 18 years of age
Interest	Pregnant women with HIV
Context	Globally

Inclusion Criteria	Exclusion Criteria
Women over 18 years of age	Women under 18 years of age
Articles written in English	Articles published more than 10 years ago
Studies that examined the Decision-making of motherhood among Pregnant women with HIV	Studies without sufficient data
Studies that were original	Duplicate sources
Studies that their full text was available	Interventional studies and Case reports

In order to limit the search results to a manageable level, I excluded studies which were more than 10 years old. (Lipscomb, n.d.) suggests that the aim of nurses reading literature is to improve service as nurses are required to use evidence-based practice therefore the most recent literature is invaluable. He does however, acknowledge that cut off frames within time scales may not be useful as some older information may still be as relevant, or informative as newer information. I excluded articles which were not written in English as language bias could be prevalent due to the authors' limited understanding and with the risk of the translation being incorrect. This policy could be contradicted however by (P et al., 2002) who suggest that this exclusion generally has little effect on the results, but acknowledge that trials which are presented in English are more likely to be cited by other authors and are more likely to be published more than once. I started with basic search of key words using Boolean operators and then filtered these by adding different filters from my inclusion criteria. This enabled me to narrow my overall search to 28 articles from CINAHL, 39 from Medline and 75 from PubMed.

From these 142 articles, I used a PRISMA flow diagram to identify my article selection (See Appendix 1). Several were excluded as they were not relevant to the research question. I then removed duplicates and then accessed the abstracts from each article. I also excluded articles which did not covered meta-analysis and this left a total of six articles which met the criteria for this systematic review and were therefore included.

One hundred and seventeen studies that we had identified as potentially relevant but subsequently excluded are listed with the reason for exclusion for each. The most common reasons for exclusion were: study design (not a systemic Review); multicomponent studies with insufficient detail on Decision-making of motherhood among Pregnant women with HIV.

RESULTS

The final articles will be critiqued and analysed. The six studies included in the analysis were all qualitative studies ranging from three months to Two year. All of the studies reported the method

of random assignment with no significant difference in the characteristics of the participants. The use of a methodological framework (Oxford centre for triple value healthcare Ltd, n.d.) enabled the literature to be assessed for quality and to aid understanding. The table below is used to display an overview of each article.

Author/s Year	Sample/setting	Methodology and methods	Main findings
(Alvarez-del Arco et al., 2018)	20 WLH, between 18 and 45 years of age (Spain)	Qualitative study, design not stated. Data collection: Interviews (open ended). Dates: May and July 2013. Participants resided in Spain but represented Eastern Europe (4), Latin America (6), Spain (9), and Sub-Saharan African (1)	The findings were presented as three topics impact of HIV diagnosis, concept of motherhood, and dimensions of motherhood with four dimensions, including motherhood ideal, desire for procreation, the decision of motherhood, experience (or the lack of experience) of motherhood. The authors noted some dimensions emerged from the interview data as well as organized with the theoretical model
(Barnes, 2013)	36 WLH, mothers, from Oakland and Rochester (United States)	Grounded theory. Data collection: Interviews (in-depth). Dates: 2005 to 2009	WLH who had living children experienced longevity from fulfilling dreams of seeing their children grow up despite the unique challenges from their HIV status. The longevity offered possibilities for regaining contact with children who had been given up for adoption, were or had been in foster care, or lived with family members. WLH felt living longer offered more possibilities of becoming a mother with pregnancy, but

			opportunities were complicated with reconciling past reproductive experiences and poor choices
(Carlsson-Lalloo et al., 2016)	18 qualitative studies with a total of 588 WLH interviewed from wealthier countries outside the Asian and African continents	Meta-ethnography. Data collection: Interview and observational data. Dates: 1997 to 2012. Locations: USA (11), Canada (2), UK (2), Australia (1), Ireland (1), and Brazil (1). Two systematic searches (sexuality and reproduction) in CINAHL and MEDLINE. Articles assessed with Critical Appraisal Skills Programme	HIV infection is a burden in relation to sexuality and reproduction. The weight of the burden can be heavier or lighter. Conditions making the HIV burden heavier included: HIV as a barrier, feelings of fear and loss, whereas motherhood, spiritual beliefs, and supportive relationships make the HIV burden lighter
(Cuca & Rose, 2016)	20 WLH, > 18 years old, diagnosed at least 1 year prior to study; pregnant at least once since their HIV diagnosis living in San Francisco (United States)	Grounded theory with situational analysis. Data collection: Interviews (in-depth) and observations. Dates: 2009, October to 2010, February; and 2012, October and 2013, February	Reproductive choices are made in situations of chaos, instability, and stigmatization. For some women, providers are sources of stigma. Participants demonstrated resistance to stigmatization, through building supportive communities and developing trusting relationships with HIV providers
(Jean et al., 2016)	19 WLH, sexually active, ages 18 to 45, living in Southern Florida (United States)	Collaborative with thematic analysis. Data collection: Interviews (open-	Decisions to conceive are influenced by women and partners; knowledge and use of safer conception

		ended questions). Date: Unknown	practices are low. Discussion and support from partners, family and providers is limited and diminished by stigma and nondisclosure
(Toupin et al., 2019)	42 heterosexual WLH, childbearing age (mean 35 years) living in Montreal (Canada)	Qualitative study design not stated. Data collection: Semi-structured interviews. Dates: 2004 to 2005 Participants described as African (17), Haitian (12), and French Caucasian (13)	The researchers explicated the themes for decision-making of WLH at each stage of motherhood, including during conception (deciding based on the open-mindedness of providers, during pregnancy (managing transmission risks during pregnancy, making the best of medical resources, and incessant worrying about ART), and during post-partum (fearing child diagnosis, evaluating treatment during pregnancy, and reasons for continuity and change)

The first study was conducted by (Alvarez-del Arco et al., 2018) Objective was to in depth analyse elements shaping their desire for procreation and specifically investigate the impact of HIV. Methods: A qualitative study was conducted through open interviews with 20 women living with HIV between 18 and 45 years of age, from the Spanish AIDS Research Network Cohort (CoRIS). Interviews were audio-recorded and transcribed. A content analysis was performed. Results: HIV diagnosis is a turning point in women's sexual and emotional life that is experienced traumatically. HIV diagnosis is usually associated with the fear of an immediate death and the idea of social isolation. Motherhood is considered an element of compensation that helps them to cope with HIV diagnosis. All these elements make health professionals key actors: they provide information and support after HIV diagnosis. Conclusions: Barriers and drivers for procreation are similar among HIV positive women and general population. However, stigma and discrimination linked with HIV weigh in HIV positive women decision of motherhood. In this context, it is necessary to provide these women with the necessary counselling, guidance and resources to take decisions about procreation properly informed.

The second study was conducted by Barnes, 2013). Fifty-nine women living with HIV, from Oakland, California (n = 30) and Rochester, New York (n = 29), participated in an initial study on reproductive decisions (1995–2001). In the follow study (2005–2009), 51 women were living. The author completed face-to-face interviews with women (n = 36) for a follow-up rate of 70.6 %. Grounded theory qualitative methods of collaborative coding, memo writing, diagramming, and participant verification of analysis were used. The sample (n = 36) was predominantly women of color, with a mean age of 42.6 years. Half of the participants reported an annual household income of less than \$15K. The majority had a current HIV status as asymptomatic. Most participants were single, and more than half had children living with them. Participants were living with HIV an average of 14.8 years. How women with increased longevity with HIV managed their “lost mothering” opportunities, as they defined loss, was interrelated with their attitudes about how mothers should care for their children and how participants’ related HIV stigmatization may affect their children

The third study is conducted by (Carlsson-Lalloo et al., 2016) A total of 18 peer-reviewed qualitative studies were included, which comprised a total of 588 HIV-positive interviewed women. The studies originated from resource-rich countries outside the Asian and African continents. The analysis, resulting in a lines-of-argument synthesis, shows that HIV infection was a burden in relation to sexuality and reproduction. The weight of the burden could be heavier or lighter. Conditions making the HIV burden heavier were: HIV as a barrier, feelings of fear and loss, whereas motherhood, spiritual beliefs, and supportive relationships made the HIV burden lighter. The findings are important in developing optimal health care by addressing conditions making the burden of HIV infection lighter to bear. In future research there is a need to focus not only on examining how HIV-positive women's sexual and relationships manifest themselves, but also on how health care professionals should provide adequate support to the women in relation to sexuality and reproduction.

The fourth study was conducted by Cucu Y, Rose C. 20 women living with HIV through in-depth interviews were examined. These women made decisions within situations of chaos, instability, and trauma, which often limited their ability to make truly informed choices about their lives and childbearing. Despite their HIV, many of the women wanted children, but experienced stigmatization related both to their HIV and to their decisions to have children. This stigmatization came from multiple sources, including health care providers, some of whom encouraged their patients to abort pregnancies because of their HIV. Participants, however, demonstrated resistance to stigmatization, through building supportive communities and developing trusting relationships with HIV providers. These results support the need for specialized HIV care for women of childbearing age.

The fifth study was conducted by Jean et al. (2016). Reviewers examined reproductive decision making, conception practices, and patient-provider communication among women living with HIV. Qualitative interviews were conducted with 19 HIV-infected sexually active women aged 18-45 in southern Florida, USA. Using thematic analysis, we found decisions to conceive were

influenced by women and partners; knowledge and use of safer conception practices were low. Discussion and support from partners, family, and providers was limited and diminished by stigma and nondisclosure. Preconception counselling discussions in HIV care should be comprehensive and initiated frequently by all health care providers.

The sixth study was conducted by Toupin et al. (2019). Semi-structured interviews were conducted with 42 African, Caucasian and Haitian HIV-positive women recruited in Montreal. All were or wished to be biological mothers. Transcripts underwent thematic analysis organised by three culturally informed models of motherhood described by the participants, which influenced decision-making and perceived risks. For women who saw motherhood as 'self-fulfilment and completeness', vertical HIV transmission was a primary concern. It threatened their identity as a 'good mother', which also meant adhering to antiretrovirals. For women who viewed motherhood as a 'social realisation' (all African or Haitian), fears of compromised fertility dominated. Not becoming pregnant threatened their social status and presumed health within their community.

DISCUSSION

Once a woman is diagnosed with HIV, life changes and identity alter. Many women living with HIV cancel motherhood plans due to knowledge deficits, misinformation, stigma, and judgment. Being a mother is defined by their feminine identity as well as social expectations defined by the cultural context. As such, women living with HIV seek to salvage their role as "good mothers" to stabilize their identity and to maintain their social value threatened by HIV. In general, people living with HIV experience a wide range of negative emotions such as stress, fear, guilt, hopelessness, and internal stigma (Herek et al., 2013). In the case of women living with HIV engaged in reproductive decision-making following broken mothering opportunities, their guilt and pain is elevated.

In consonance with available evidence, this study found a lack of knowledge about the relationship between living with HIV, sexual health, and reproductive decision-making. The women believed they should not become mothers, and their reproductive desires were broken by the force of this belief (Friedman et al., 2016). As Fransen and Guarinieri (Fransen-Dos Santos & Guarinieri, 2017b) concluded, a woman's desire to have children is not influenced by the HIV diagnosis, but their ability to act upon this desire is blocked by the stigma resulting from the negative attitudes of people in their lives. Moreover, their sexuality is modified, and the feeling of normality is lost. In this regard, WLH experience sexual problems including decreased function and diminished desire, activity, and satisfaction compared to uninfected women (Lassi et al., 2014).

Bias Assessment

A systematic review of published studies is limited by the fact that it excludes unpublished data and this may result in publication bias but till potential publication bias was not assessed using a funnel plot or other corrective analytical methods.

Limitation of the study

Social desirability bias may be a limitation of this type of study although some observations suggest that this was not substantial. Subjective measurements by an individual of their own confidence cannot be standardised by any yardstick other than the individual themselves

CONCLUSION

For women living with HIV, reproductive decision-making is a complex process based upon incomplete information and inaccurate perspectives. In developed countries, women living with HIV engage in reproductive decision-making more frequently due to advances in pharmaceuticals and better evidence-based practices while receiving limited assistance from family, friends, partners, and clinicians. Decisions regarding reproduction are individual but women are not able to make an informed decision without guidance and medical consultation. Clinicians need to be authentically present for discussions and open to the new possibilities for women living with HIV in the context of the modern person-centered health system. An integrated approach with comprehensive multidisciplinary counselling is necessary to address reproductive decision-making and sexual health as a right. Clinicians need to initiate discussions for WLH in the same way as other women.

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