



Reproductive decision-making of Black women living with HIV: A systematic review

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Abstract

Background: Black women living with HIV account for a higher proportion of new HIV diagnoses than other groups. These women experience restricted access to reproductive services and inadequate support from healthcare providers because their position in society is based on their sexual health and social identity in the context of this stigmatizing chronic disease. By recognizing the analytical relevance of intersectionality, the reproductive decision-making of Black women can be explored as a social phenomenon of society with varied positionality.

Objective: The purpose of this review was to synthesize the evidence about the reproductive decision-making of Black women living with HIV in high-income countries from the beginning of the HIV epidemic to the present.

Methods: This systematic review was guided by the JBI evidence synthesis recommendations. Searches were completed in seven databases from 1985 to 2021, and the review protocol was registered with PROSPERO (CRD420180919).

Results: Of 3503 records, 22 studies were chosen for synthesis, including 19 observational and three qualitative designs. Nearly, all studies originated from the United States; the earliest was reported in 1995. Few studies provided detailed sociodemographic data or subgroup analysis focused on race or ethnicity. Influencing factors for reproductive decision-making were organized into the following seven categories: ethnicity, race, and pregnancy; religion and spirituality; attitudes and beliefs about antiretroviral therapy; supportive people; motherhood and fulfillment; reproductive planning; and health and wellness.

Conclusion: No major differences were identified in the reproductive decision-making of Black women living with HIV. Even though Black women were the largest group of women living with HIV, no studies reported a subgroup analysis, and few studies detailed sociodemographic information specific to Black women. In the future, institutional review boards should require a subgroup analysis for Black women when they are included as participants in larger studies of women living with HIV.

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Keywords

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Introduction

Women living with HIV encounter different challenges than men in their daily lives because of their role in reproductive health. For most women, motherhood is an important social identity¹ that gives meaning to life.² Reproductive decision-making for women has been described as passive,³ implicit,⁴ automatic,⁵ or something that just happens.⁶ However, the decision to have a child is heavily influenced by societal norms and community expectations. Hadley⁷ suggested the pronatal norm is firmly rooted in sociocultural structures, where motherhood is an inevitable decision for women. As such, motherhood is considered part of the normal course of heterosexual life.^{3,8–10}

Decisions about pregnancy for women living with HIV are often complex. 11 For instance, HIV impacts maternal mortality during pregnancy by increasing the risk of complications and the potential for adverse perinatal outcomes, such as postpartum hemorrhage and puerperal sepsis. In general, pregnant women are also more susceptible to infections. 12–14 At the same time, women living with HIV have to cope with stigma and discrimination from their families, social networks, and the larger community, 15 mostly because misinformation and prejudice persist in healthcare institutions. 16–18 Consequently, women living with HIV and contemplating pregnancy have additional concerns about their baby being born with HIV, their health during the pregnancy, and their potential death before their child becomes an adult. 14,19

Because of increased access to safe contraceptive methods, nearly, $80\%^{20}$ of women living with HIV of childbearing age have the choice to avoid pregnancy. Furthermore, more effective antiretroviral therapies can maintain an undetectable viral load, so women living with HIV can choose pregnancy and have a less than a 1% risk of mother-to-child transmission. The availability and access to effective antiretroviral therapies in high-income countries allows women living with HIV to have safe and successful pregnancies. For this reason, these women require guidance from their healthcare providers about reproductive health that is tailored to their reality of living with HIV.

Healthcare providers generally avoid managing the sexual health of patients during primary care visits.²⁴ In the case of women living with HIV, psychosocial aspects of clinical care are rarely addressed by providers during conversations about reproductive desires and sexual health needs.^{25–29} Furthermore, women living with HIV report

reproductive coercion from healthcare institutions,³⁰ being advised to avoid pregnancy,^{31,32} be sterilized,^{32–34} or have an elective abortion.^{32,35,36} Despite decades of work to develop women-centered approaches to care for women living with HIV,^{37,38} stigma remains a major problem in most healthcare settings.^{39,40} This situation is even more complex since women living with HIV have to concurrently manage family pressures and community expectations when engaging in reproductive decision-making.^{41,42}

Background

The HIV epidemic disproportionately affects some populations of women more than others as evidenced by differences in race, ethnicity, sexual orientation, and socioeconomic characteristics.⁴³ For example, Black women account for a higher proportion of new HIV diagnoses than other races. 44,45 In the United States, Black women living with HIV represent about 13% of the female population but account for 55% of female HIV diagnoses. 46 Similarly, Black women of African ethnicity in the United Kingdom represent 66% of female HIV diagnoses; White women represent only 21% of diagnoses. 47 In addition to managing their HIV infection, Black women must also navigate issues related to racism and discrimination, ⁴⁸ which contribute to their heightened feeling of stigma.⁴⁹ Therefore, Black women living with HIV are more likely to experience depression, posttraumatic stress disorder, and substance abuse.⁵⁰

Healthcare experiences are shaped by interconnected and interdependent social conditions.⁵¹ For decades, discrimination has caused an inequitable distribution of healthcare resources⁵² that continues to disadvantage Black women living with HIV.53 Because they encounter restricted access to reproductive services and inadequate support from healthcare providers when making reproductive decisions, 48 these women often access healthcare later or with less frequency for pregnancy-related care. For Black women, race also intersects with other social characteristics that generate oppression with power gradients. 54,55 As such, oppression has resulted in involuntary sterilization of Black women living with HIV.56,57 In addition, gendered racism has relegated Black women to the background of HIV research, specifically in relation to reproductive decision-making.⁵⁸ As a result, the research literature perpetuates the privilege of being a White, heterosexual, educated, and upper-middle-class woman.

Intersectionality

Black women living with HIV are positioned in society in relation to their sexual health, and their social identity is often contextualized by a stigmatizing chronic disease.⁵⁹ However, their social identity also includes multiple sources of oppression, such as race, ethnicity, gender, income, education, health status, and other factors^{60,61} related to "racialized and gendered subjects" marginalized by power structures.⁵⁹ Intersectionality offers a lens to see where this "power comes and collides, where it interlocks and intersects."62 Within the narrow context of reproductive justice, 63 power structures can oppress decision-making⁶⁴ and marginalize people living with HIV.⁶⁵ For these reasons, intersectionality has analytical relevance for sensitive topics, such as reproductive health, 66,67 that can be synthesized from the literature to identify the social experiences resulting in marginalization⁶⁸ and the positional variability within and between groups⁶⁹ causing health inequities.⁷⁰

Rationale for the review

The majority of reproductive decision-making literature focuses on women living with HIV without reporting the experiences of Black women living with HIV in high-income countries, such as Canada, 71 the United Kingdom, 72 and the United States. 73 Although the experiences of Black women included in this review are described by their shared social context of living with HIV, 69 the intersection of their different social identities are largely unknown in the reproductive health literature. As such, the findings of this study may guide new areas of research, improve clinical practice, inform health policy, and advance the theoretical development of reproductive decision-making.

Objectives

The purpose of this review was to synthesize the evidence about the reproductive decision-making of Black women living with HIV in high-income countries from the beginning of the HIV epidemic to the present. The principal objective was to describe the factors that influence reproductive decision-making of Black women living with HIV. Key questions guiding this review included the following: (a) Since the beginning of the HIV epidemic, how has the evidence for reproductive decision-making of Black women living with HIV evolved? (b) In studies reporting data for women of different races and ethnicities, how do influencing factors compare in subgroup analyses? (c) What is the relationship between Black women living with HIV and their reproductive intentions across cultures and countries? (d) What are the barriers and facilitators for reproductive decision-making? and (e) How has the advancement of antiretroviral therapy impacted decisions about pregnancy?

Methods

This systematic review of the scientific literature was guided by the Joanna Briggs Institute evidence synthesis recommendations. The reporting criteria followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement, and the protocol guiding this review was registered with PROSPERO (CRD42018091971), the International Prospective Register of Systematic Reviews.

Research studies with quantitative, qualitative, and mixed-methods designs published in peer-reviewed scientific journals that addressed reproductive decisions in women living with HIV were included in this review. Studies reporting any type of literature review were excluded, except when the review included a meta-synthesis or meta-analysis reporting data specific to Black women living with HIV. Review papers and graduate dissertations and theses were excluded, but their reference lists were assessed for studies meeting the inclusion criteria. Editorials and commentaries, guidelines, reports, and narrative policy papers were also excluded from the review. Randomized control trials focused exclusively on the efficacy of antiretroviral drugs and epidemiological studies not focused on the reproductive decision-making process were excluded as well.

For this study, high-income countries were determined by membership in the Organization for Economic Co-operation and Development (OECD).⁴² The 35 member countries of the OECD⁷⁸ have similar compliance with international laws, adherence to human rights conventions, and adoption of evidence-based clinical practice guidelines for HIV/AIDS.^{79–81} Their health systems are mostly uniform in structure, provide a higher complexity of services, and offer access to good quality services across the population. Evidence of disparities between health systems in higherand lower-income countries is represented by the differences in maternal and infant mortality and morbidity rates.⁸²

Publication language for the reviewed studies was limited to English and Spanish. Age was not limited, but an upper demarcation of 55 years was set for reproductive age when assessing data that included age groups from later years.

Information sources

Multiple electronic databases were searched from January 1985 to August 2021, including CINAHL, Embase, MEDLINE (through PubMed), Scopus, Social Sciences Citation Index, Cochrane Library, and PsycINFO. The publication date range was chosen so all studies for the entire HIV epidemic would be included.

Search strategy

The keywords for this review were guided by systematic reviews in related areas and defined by the research team

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Table I. Search strategy example.

CINAHL RESULTS

(Decision making OR attitudes OR beliefs OR meaning OR behavior OR behavior) AND (AIDS OR HIV OR seropositive OR serodiscordant) AND (pregnancy OR pregnant OR reproduction OR reproductive OR family planning OR contraception) NOT (screening or testing)

Narrow by subject geographic: Mexico & Central / South America, Asia, Middle East, Australia & New Zealand, continental Europe, the United States, the

United Kingdom and Ireland, Europe

Narrow by subject age: middle-aged: 45-64 years,

adult: 19-44 years

Narrow by language: English, Spanish Search modes: Boolean/Phrase Narrow by sex: female

Narrow by date from January 01, 2017 to August 30,

2021

after consultation with a reference librarian. Specifically, the keywords were HIV, AIDS, pregnancy, reproduction, and decision-making. In addition to the keywords, Boolean operators were tailored for each database search. The search was not limited by race or ethnicity since most studies were expected to include data on Black women living with HIV. A hand search for references from documents such as systematic reviews focused on HIV and women was also completed during this process. The example search strategy is provided in Table 1.

Selection process

The selection process was divided into two phases. First, records (n = 1602) were identified from a previous systematic review83 about the reproductive decision-making of women living with HIV. Next, new records (n=2145)were identified through an updated search of the above databases for studies published between January 1, 2017, and July 31, 2021. All records from the searches were then merged for an initial screening that followed an established study selection process⁸⁴ with three review layers (title, abstract, and article). All record titles were independently screened by four paired teams of experienced reviewers to identify the studies that met inclusion criteria. The abstracts for the included titles were then reviewed, where each paired team assessed a different group of abstracts than the titles in the previous step. Finally, the paired teams screened the full text of the remaining reports, strictly applying the inclusion and exclusion criteria. During each round, a third reviewer checked the work of each paired team for discrepancies and errors. If there was disagreement between paired reviewers, the report was advanced to the next phase of the review process to limit deselection bias. The primary investigator checked the level of agreement between paired reviewers for the title and abstract phases; the predetermined 95% agreement was achieved in each round. The 2020 PRISMA flow diagram⁷⁶ details the results of the screening process.

Data collection

Data extraction for each study focused on the results and conclusion sections. All figures and tables were reviewed for data specific to Black women living with HIV. General data related to the review objectives were independently extracted line-by-line from the articles by two review authors (AH-Z and JL-M) and recorded in an Excel spread-sheet with a separate tab for each study. The review authors then organized the data by aim, setting, participants, study design, interview data (direct quotes), numerical data, and key findings. Data items of interest were assessments, measurements, experiences, and characteristics related to reproductive decision-making.

Risk of bias assessment

The studies included in the full-text review were independently reviewed by two review authors (AH-Z and JL-M) using established tools for risk and methodological quality assessment, specifically the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies⁸⁵ and the Critical Appraisal Skills Program for qualitative studies.⁸⁶ Any uncertainty or disagreement was discussed by the same two to achieve consensus followed by an independent review (PAP) of the decision.

Data synthesis

Once assessment was completed for each study, the data were organized in an Excel spreadsheet. Although a metaanalysis of the numerical data extracted from the studies was originally planned, this analysis was not possible because the studies lacked homogeneous data and had too many variations in observational study designs. Thus, a qualitative descriptive analysis was instead completed for the abstracted data. Results were then synthesized based on the research question, and findings were organized into defined decision-making influence categories⁸³ women living with HIV but with minor modifications for this review. Organizing the findings in this manner highlighted the multiple similarities and contrasted the few differences. Selective reporting within studies was possible because of the lack of subgroup analysis for race and ethnicity.

Ethical considerations

For this review, ethics approval was not necessary since there were no human participants. All searches were

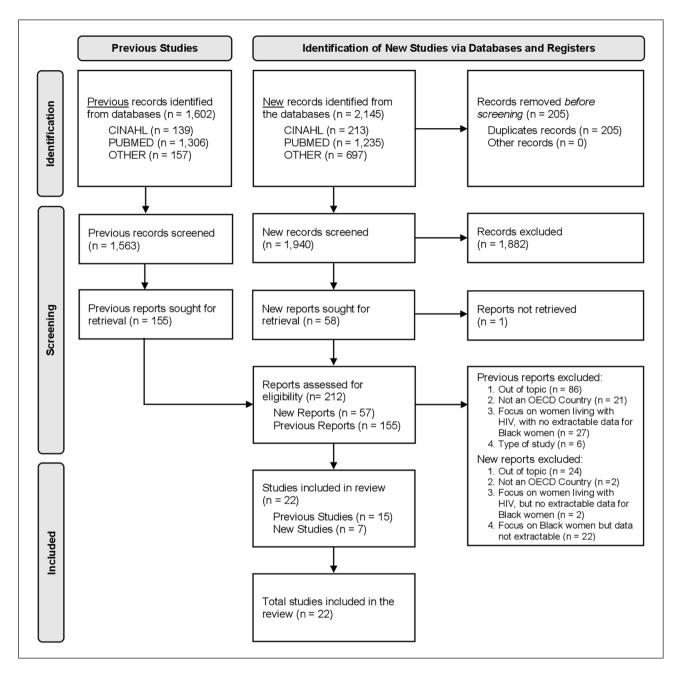


Figure 1. PRISMA 2020 flow diagram. Reference: Page et al.⁸⁷

For more information: http://www.prisma-statement.org/.

conducted in publicly accessible databases. However, the studies included in the review were evaluated for appropriate ethical standards for research involving human participants, and they all reported approval by an ethics committee or institutional review board.

Results

After removing duplicate records, 3503 records were identified through the systematic database searches. The records included 1563 studies from a previous review⁸³ and 1940

from the current review. A full-text screening of 212 studies was completed, and 190 studies were excluded for various reasons. Of the final studies (n=22) included in this review, most studies (n=15) reported groups of women living with HIV and had extractable data relevant to the review criteria; only a few studies (n=4) focused on Black women. All reviewed studies met the minimum risk and methodological assessment for quality. Results of the screening process are reported as a PRISMA flow diagram in Figure 1.

In terms of the publication years of the included studies, six were published between 1995 and 2000, six were

published between 2001 and 2010, two were published between 2011 and 2015, and the remaining and eight were published after 2015. As summarized in Table 2, most studies (n=18) were conducted in the United States, and the remainder were in Canada, France, and the United Kingdom. The studies were predominantly quantitative (n=19) with observational designs (cross-sectional), but there were a few qualitative (n=3) designs (descriptive, focus group, and phenomenology). Most studies included participants from urban settings who were mostly Black women of African ethnicity. The mean age of the women was 31.6 years. Most studies did not report information about education level (n=8) or route of HIV infection (n=7). For those studies that did report this information, most women had completed high school, and the route of infection was most often a sexual route.

No major differences were identified by race or ethnicity from previously reported categories of factors influencing the reproductive decision-making of women living with HIV. However, there were minor differences in some factors across categories related to mental health, religion, and relationships. For this reason, synthesis results were organized and reported by previously reported categories. Specifically, the seven categories were ethnicity, race, and pregnancy; religion and spirituality; attitudes and beliefs about antiretroviral therapy; supportive people; motherhood and fulfillment; reproductive planning; and health and wellness.

Ethnicity, race, and pregnancy

In earlier research from the United States, race was not related to planning or terminating a pregnancy.⁹¹ For example, Kline et al.88 reported 29.2% of Black women became pregnant after an HIV-positive diagnosis, which was similar to the 28.4% of White women who did. Regarding ethnicity, Hispanic women were more likely, at 42.3%, to become pregnant. In another study, 97 statistically significant predictors regarding the desire for childbearing were younger age, not currently on an HIV medication, higher current CD4 cell count, and a relationship duration of less than 2 years; race was not associated with a desire for children. Similarly, more recent studies reported the desire to become pregnant was unrelated to ethnicity. 101,108 For women living with HIV, being a Black non-Hispanic woman was not significantly associated with the desire to have children (adjusted odds ratio (AOR)=0.93, 95% confidence interval (CI) (0.31, 2.78)). 108

In other settings, Black women born in Africa but living in France were more likely than other groups to desire children. The desire to have children was two to six times higher among women born in sub-Saharan (odds ratio (OR)=2.38, 95% CI (1.28, 4.43)) and North Africa (OR 5.73, 95% CI (1.74, 18.85)) than among women born in Europe. Similarly, Loutfy et al. Performed a univariate

analysis of women living with HIV (n=490) and found Black women of African ethnicity (n=219) were more likely to have children and African ethnicity was a significant predictor (p<0.0001) of fertility intention in their multivariable model. Finally, a study from the United Kingdom reported no statistically significant differences in the effect of HIV diagnosis on fertility intentions by ethnicity (p=0.08) although Black women with African ethnicity were slightly more likely to report no change in fertility intentions. 100

Religion and spirituality

Religion and spirituality were important concepts for Black women living with HIV who were considering pregnancy. Faith not only helped the women cope with everyday stresses related to their HIV-positive status, but also helped them manage daily living. Black women often underscored their ruminations about the risks of vertical transmission with the belief that God would protect their baby. From their perspective, God had the power to heal and the power to decide the pregnancy outcome even when they contemplated an elective abortion.

Attitudes and beliefs about antiretroviral therapy

Given the variety of treatment options, women living with HIV can safely attempt pregnancy. In one study, 93 understanding the benefits of zidovudine made women living with HIV more likely to consider pregnancy (n=192, p=0.0001) than those who were not knowledgeable, and no differences were found by ethnicity regarding knowledge of zidovudine. Although results were not statistically significant, in another study, a lower proportion of non-London residents, Black women from African countries, women older than 29 years, and women more recently diagnosed with HIV (<5 years) changed their decision to have children when they learned about improvements in treatments that safely facilitate pregnancy. 100

Supportive people

Healthcare providers have a key role in helping women living with HIV make informed reproductive decisions. However, when offered to women, reproductive counseling was reported as being poor and inconsistent across contexts and countries. 110,111 Insufficient information about treatment advancements and reductions in transmission risks to the fetus resulted in women perceiving even greater stigmatization from healthcare providers. 102 Furthermore, HIV status was the most important influencing factor for Black women engaged in reproductive decision-making. Black women also named significant others (husbands and partners) and other family members as the most important

Table 2. Summary of study findings in chronological order.

Kine et al. " United States Observational Petrode (design) Annaburpose Reference Annabe Cross-sectional Petrode (design) Annaburpose Annabe Cross-sectional Petrode (design) Annaburpose Annabe Cross-sectional Petrode Cros					
et al.** United States Observational Describe the profiles of women living with HIV becoming pregnant; and examine pregnant the reasons for becoming pregnant; and examine pregnant outcomes (urban) (focus groups) with HIV (the Cartes) (cross-sectional of predestand the reasons for becoming pregnant; and examine pregnancy outcomes (urban) (cross-sectional observational observatio	Author(s)	Location (context)	:) Method (design)	Aims/purpose	Key findings
(urban) (focus groups) with HIV et al. ¹⁹ United States Observational Describe the characteristics of HIV positive women living (urban) (focus groups) with HIV et al. ¹⁹ United States Observational Understand the relationship between knowledge of HIV (urban) (cross-sectional) infection and premala benefits of AZT, decisions about pregnancy channing, contraceptive use, and abortion ret al. ¹⁹ United States Observational Identify the perception of Batck women living with HIV about (urban) (cross-sectional) AZT use to reduce transmission; and examine the factors that influence their pregnancy decision and examine the factors conservational Azesss the knowledge of women living with HIV about (urban) (cross-sectional) AZT use to reduce transmission during pregnancy and to understand their reproductive perspective edecision—naking (urban) (cross-sectional) behaviors of HIV positive men and women (n/a) (cross-sectional) behaviors of HIV positive men and women (n/a) (cross-sectional) Defore the use of HART among African Americans living with HIV about (urban) (cross-sectional) behaviors of HIV positive men and women (n/b) (urban) (cross-sectional) Defore the use of HART among African Americans living with HIV about (urban) (cross-sectional) Influencing the desire to have a child among heterosexual individuals of reproductive age living with HIV (urban) (cross-sectional) Influencing the desire to have a child among heterosexual individuals of reproductive age living with HIV (urban) (cross-sectional) Hillen, and sterilization regret among women living with HIV, (urban) (cross-sectional) Hillen, and sterilization regret among women living with HIV, (urban) (cross-sectional) Hillen, and sterilization on these intentions and interventions for urban) perinacal transmission on these intentions	Kline et al. ⁸⁸	United States (urban)	Observational (cross-sectional)	Describe the profiles of women living with HIV becoming pregnant; understand the reasons for becoming pregnant; and examine pregnancy outcomes	Black women with pregnancy since HIV diagnosis (29.2%) was similar to White women (28.4%) but less than Hispanic women (42.3%). Associations between independent variables and women continuing pregnancy to term: Black (50.4%), White (37.9%), and Hispanic (41.6%). Few differences were statistically significant due to small sample size; but descriptively informative
(urban) (cross-sectiona) became pregnant, chose sterilization, and elected abortion after diagnosis (urban) (cross-sectiona) after diagnosis (urban) (cross-sectiona) after diagnosis (urban) (cross-sectiona) (dentify the perception of Black women living with HIV about (urban) (cross-sectiona) (dentify the perception of Black women living with HIV about (urban) (cross-sectiona) (dentify the perception of Black women living with HIV about (urban) (cross-sectiona) (dentify the perception of Black women living with HIV about (urban) (cross-sectiona) (dentify the perception of Black women living with HIV about (urban) (cross-sectiona) (dentify the perception of Black women living with HIV about (urban) (cross-sectiona) (dentify and attitudes about contraception and (urban) (cross-sectiona) (dentify and attitudes about contraception and (urban) (cross-sectiona) (dentify the dentify and attitudes about contraception and (urban) (cross-sectiona) (dentify and attitudes about contraception and (urban) (cross-sectiona) (dentify about dentify and attitudes about contraception and (urban) (cross-sectiona) (dentify about dentify and attitudes about contraception and (urban) (cross-sectiona) (dentify and attitudes about contraception and (urban) (cross-sectiona) (dentify about dentify and attitudes about contraception and (cross-sectiona) (dentify about dentify and attitudes about contraception and (cross-sectiona) (dentify about dentify and attitudes about contraception and (cross-sectiona) (dentify about dentify about dentify and attitudes about contraception and dentify attitudes (dentify about dentify about dentify and attitudes about contraception and dentify dentify attitudes (dentify about dentify about dentify de	Bedimo et al. ⁸⁹	United States (urban)	Qualitative (focus groups)	Explore the barriers to condom use among Black women living with HIV	Pregnancy gave women a societal status that entitled them to things they would not otherwise receive; pregnancy with HIV was a double burden, including concerns about their health, and possibility of having an infected baby
(urban) (cross-sectional) Infection and prenatal benefits of AZT, decisions about the relationship between knowledge of HIV (urban) (cross-sectional) Infection and prenatal benefits of AZT, decisions about that influence their pregatary decision and examine the factors that influence their pregatary decision and examine the factors that influence their pregatary decision and examine the factors and constructional) AZT use to reduce transmission; and examine the factors and constructional (cross-sectional) AZT use to reduce transmission during pregatary and to understand their reproductive perspective (urban) (cross-sectional) AZT use to reduce transmission during pregatary and to understand their reproductive perspective (urban) (cross-sectional) Defore the use of HAART among African Americans living with HIV od et al.? United States (n/a) (cross-sectional) Perfore the use of HAART among African Americans living with HIV at al.? United States (n/a) (cross-sectional) Influencing the desire to have a child among heterosexual influencing the desire to have a child among heterosexual individual or cross-sectional) children, and sterilization regret among women living with HIV at al.? United States (n/a) Qualitative) (descriptive) living with HIV in the context of coping (urban) (cross-sectional) aged women living with HIV in Toronto, Canada (urban) (cross-sectional) aged women living with HIV in Toronto, Canada (urban) (cross-sectional) and to assess fertility desires, intentions and actions of reproductive quality (urban) (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Bedimo et al. ⁹⁰	United States (urban)	Observational (cross-sectional)	Describe the characteristics of HIV positive women who became pregnant, chose sterilization, and elected abortion after diagnosis	Abortion among women pregnant after learning their HIV diagnosis was significantly associated with being White and non-single. Race was not associated with pregnancy after adjusting for age and sexual assault history
the risk for perinatal transmission; and examine the factors (urban) (cross-sectional) the risk for perinatal transmission; and examine the factors that influence their pregnancy decision. (urban) (cross-sectional) Assess the knowledge of women living with HIV about (cross-sectional) and cross-sectional) behaviors of HIV positive men and women (urban) (cross-sectional) behaviors of HIV positive men and women (urban) (cross-sectional) behaviors of HIV positive men and women (urban) (cross-sectional) behaviors of HIV positive men and women (urban) (cross-sectional) behaviors of HIV positive men and women (urban) (cross-sectional) before the use of HAART among African Americans living with HIV ode et al. ¹⁷ (urban) (cross-sectional) influencing the desire to have a child among heterosexual individuals of reproductive age living with HIV (urban) (cross-sectional) (influencing the desire to have a child among heterosexual individuals of ceptrations of teproductive age living with HIV (urban) (cross-sectional) (urban) (cross-sectional) (urban) (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Smits et al.91	United States (urban)	Observational (cross-sectional)	Understand the relationship between knowledge of HIV infection and prenatal benefits of AZT, decisions about pregnancy planning, contraceptive use, and abortion	Race was not significantly related to subsequent pregnancy planning or termination (women without intravenous drug use living with HIV). Neither any contraceptive nor consistent contraceptive use was significantly associated with race
and United States Observational Assess the knowledge of women living with HIV about (urban) (cross-sectional) AZT use to reduce transmission during pregnancy and to understand their reproductive perspective (ross-sectional) (cross-sectional) Dehaviors of HIV positive men and women (n/a) (case-control) behaviors of HIV positive men and women (urban) (case-control) Describe factors related to reproductive decision-making (urban) (cross-sectional) Influencing the desire to have a child among heterosexual individuals of reproductive age living with HIV (urban) (cross-sectional) influencing the desire to have a child among heterosexual individuals of reproductive age living with HIV (cross-sectional) children, and sterilization regret among women living with HIV (urban) (cross-sectional) children, and sterilization regret among women living with HIV (urban) (cross-sectional) aged women living with HIV in Toronto, Canada (urban) (cross-sectional) aged women living with HIV in Toronto, Canada (urban) (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Sowell et al.º2	United States (urban)	Observational (cross-sectional)	Identify the perception of Black women living with HIV about the risk for perinatal transmission; and examine the factors that influence their pregnancy decision	HIV status is not the most important influence for the reproductive decision-making of a Black woman; they identified significant others (husbands and sex partners) and family members as those more important influences for making the decision to have a child
ral. ⁹⁴ United States Observational Observational Cross-sectional Observational Observational (urban) (cross-sectional) behaviors of HIV positive men and women (urban) (case—control) Describe factors related to reproductive decision-making HIV (ross-sectional) Describe the sociodemographic and health-related factors (urban) (cross-sectional) influencing the desire to have a child among heterosexual individuals of reproductive age living with HIV (urban) (cross-sectional) Examine the determinants of contraceptive use, desire for (urban) (cross-sectional) living with HIV in the context of coping Observational Examine the determinants of contraceptive use, desire for (urban) (cross-sectional) living with HIV in the context of coping Observational Assess fertility desires, intentions, and actions of reproductive (urban) (cross-sectional) aged women living with HIV in Toronto, Canada (urban) (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Vitiello and Smeltzer ⁹³	United States (urban)	Observational (cross-sectional)	Assess the knowledge of women living with HIV about AZT use to reduce transmission during pregnancy and to understand their reproductive perspective	There were no relationships on chi-squared analysis between knowledge about AZT to reduce prenatal transmission during pregnancy by age or by ethnicity. Women living with HIV understanding the benefits of zidovudine were more likely to consider pregnancy ($n = 192$; $p = 0.0001$) than those not knowledgeable, without differences in knowledge by ethnicity
-Rung (urban) (case—control) before the use of HAART among African Americans living with HIV (urban) (cross-sectional) individuals of reproductive age living with HIV (urban) (cross-sectional) (descriptive) living with HIV in Toronto, Canada (cross-sectional) aged women living with HIV in Toronto, Canada (cross-sectional) aged women living with HIV in Toronto, Canada (cross-sectional) aged women living with HIV in Toronto, Canada (cross-sectional) aged women living with HIV in Toronto, Canada (cross-sectional) aged women living with HIV in Toronto, Canada per intentions, and actions of reproductive (urban) (cross-sectional) aged women living with HIV in Toronto, Canada (cross-sectional) aged women living with HIV in Toronto, Canada (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Chen et al. ⁹⁴	United States (n/a)	Observational (cross-sectional)	Understand fertility and attitudes about contraception and behaviors of HIV positive men and women	All women living with HIV who desired children, 47% were Black; of the Black women 36% expected no children and 52% expected more than one child
France Observational Describe the sociodemographic and health-related factors (n/a) (cross-sectional) influencing the desire to have a child among heterosexual individuals of reproductive age living with HIV United States (n/a) Qualitative Canada Observational Assess fertility desires, intentions, and actions of reproductive (urban) (cross-sectional) aged women living with HIV in the context of coping Canada Observational Assess fertility desires, intentions, and actions of reproductive (urban) (cross-sectional) aged women living with HIV in Toronto, Canada United Kingdom Observational Explore fertility intentions among women living with HIV, (urban) (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Bedimo-Rung et al. ⁹⁵	United States (urban)	Observational (case–control)	rribe factors related to reproductive decision-making re the use of HAART among African Americans living with	Since HIV diagnosis, Black women with pregnancy 23.17% ($n = 38$); without pregnancy 26.83% ($n = 44$); surgical sterilization 21.34% ($n = 35$); and without sterilization 28.65% ($n = 47$)
United States (n/a) Qualitative Describe how spirituality impacts African American mothers (descriptive) living with HIV in the context of coping Canada Observational Assess fertility desires, intentions, and actions of reproductive (urban) (cross-sectional) aged women living with HIV in Toronto, Canada (uuban) (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Heard et al. %	France (n/a)	Observational (cross-sectional)	Describe the sociodemographic and health-related factors influencing the desire to have a child among heterosexual individuals of reproductive age living with HIV	Status variables indicated being born in Africa was associated with the desire to have children. The desire to have children was two to six times higher among women born in sub-Saharan (OR 2.38, 95% CI (1.28, 4.43)) and North Africa than Europe (OR 5.73, 95% CI (1.74-18.85))
United States (n/a) Qualitative Describe how spirituality impacts African American mothers (descriptive) living with HIV in the context of coping Canada Observational Assess fertility desires, intentions, and actions of reproductive (urban) (cross-sectional) aged women living with HIV in Toronto, Canada United Kingdom Observational Explore fertility intentions among women living with HIV, (urban) (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Stanwood et al. ⁹⁷	United States (urban)	Observational (cross-sectional)	Examine the determinants of contraceptive use, desire for children, and sterilization regret among women living with HIV	Multivariate analysis, statistically significant predictors of desire for future childbearing were younger age, not being on HIV medication, higher current CD4 cell count, and relationship duration < 2 years. No association with race
Canada Observational Assess fertility desires, intentions, and actions of reproductive (urban) (cross-sectional) aged women living with HIV in Toronto, Canada United Kingdom Observational Explore fertility intentions among women living with HIV, (urban) (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Polzer et al. ⁹⁸	United States (n/a	(descriptive)	Describe how spirituality impacts African American mothers living with HIV in the context of coping	Perceived as a benevolent authority, God controls all aspects of their lives; power to heal; protects their baby from infection; and encourages them to avoid abortion
United Kingdom Observational Explore fertility intentions among women living with HIV, (urban) (cross-sectional) and to assess the effect of treatment and interventions for perinatal transmission on these intentions	Loutfy et al. ⁹⁹	Canada (urban)	Observational (cross-sectional)	Assess fertility desires, intentions, and actions of reproductive aged women living with HIV in Toronto, Canada	Women living with HIV intending to have children were more statistically likely to be African ethnicity, in univariate analysis. HIV-positive women in 20s or 30s, African descent, living in Toronto, and already given birth, would be most likely to intend to become pregnant
	Cliffe et al. ¹⁰⁰	United Kingdom (urban)	Observational (cross-sectional)	Explore fertility intentions among women living with HIV, and to assess the effect of treatment and interventions for perinatal transmission on these intentions	There were no statistically significant differences in the effect of HIV diagnosis on fertility intentions by ethnicity (p=0.08). Black African women were slightly more likely to report no change in fertility intentions, but 35% did not want children after HIV diagnosis. A lower proportion of non-London residents, Black African women, women over 29 years old, and those diagnosed for <5 years changed their mind about not wanting children after learning the impact of improvements in treatment and interventions (not statistically significant)

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Author(s)	Location (contex	Location (context) Method (design)	Aims/purpose	Key findings
Finger et al. ¹⁰¹	United States (urban)	Observational (cross-sectional)	Determine in a population of young women with behaviorally acquired HIV, the association between desire for pregnancy, sociodemographic variables, and sexual risk behaviors	In young women with behaviorally acquired HIV infections (n =130), 31.5% reported a desire for pregnancy in the next 6months; desire for pregnancy was unrelated to ethnicity
Fletcher et al. ¹⁰²	United States (n/a)	Qualitative (phenomenology)	Qualitative Explore perspectives of reproduction and motherhood in (phenomenology) African American women living with HIV of childbearing capacity; and the advice received from health care providers	Pregnancy fostered the sense of normalcy; motherhood was perceived to be transformative, inspirational, and purpose-filled; or a second chance. The advice of health care providers was either supportive or nonsupportive
Raziano et al. ¹⁰³	United States (urban)	Observational (cross-sectional)	Identify the factors associated with sterilization among women living with HIV	Women living with HIV (n =187), 88% Black or African American, with 41 women sterilized from which 33 were Black and eight White women. All other women (n =146) used intrauterine device, implant, injection, pill, patch, ring, condom, withdrawal, and none. Differences in sterilization by ethnicity were not significant (p =0.8)
Kaida et al. ¹⁰⁴	Canada (urban)	Observational (cross-sectional)	Measure the prevalence and correlates of effective contraceptive use among sexually active women living with HIV in Canada, and to assess the range of methods used, as well as method satisfaction and reasons for nonuse	Women living with HIV ($n=453$), with 141 (31%) African American; Black women, 66.7% ($n=94$), in the past 6 months used contraceptives, and 33.3% did not ($n=47$). Overall, 73% of women in the prior 6 months used contraceptives. Greater proportions of women who had not used contraceptives than used them were African, Caribbean, or Black (39% vs. 29%); no association between Black race and contraceptive use (OR=0.54, 95% CI (0.29, 1.03), AOR=0.56, 95% CI (0.27, 1.15).
Polansky et al. ¹⁰⁵	United States (urban)	Observational (cross-sectional)	Determine whether pregnancy happiness was positively associated with pregnancy planning and wantedness, controlling for sociodemographic factors and HIV status	Determine whether pregnancy happiness was positively Black women living with HIV had higher mean prenatal depressive symptoms ($M = 19.55$, $SD = 13.53$) than all associated with pregnancy planning and wantedness, controlling other women ($M = 15.06$, $SD = 13.24$) that was not statistically significant for sociodemographic factors and HIV status
Haddad et al. ¹⁰⁶	United States (urban)	Observational (cross-sectional)	Explore the reproductive health knowledge, attitudes, and practices among adolescents and young adults living with HIV receiving medical care at an HIV clinic in Atlanta	Women living with HIV ($n = 103$) with 92 (89.3%) Black from which 27 (29.3%) not sexually active, 26 (28.3%), used condoms, 16 (17.4%) used dual method, 13 (14.1%) used hormonal or intrauterine device, and 10 (10.9%) did not use a method at last coitus. Race not associated with increased odds of contraceptive use at last coitus
Tote et al. ¹⁰⁷	United States (urban)	Observational (cross-sectional)	Evaluate factors associated with women living with HIV method of contraceptive at last coitus defined as more effective (Tier I and 2 methods (TI/T2)) versus less effective (Tier 3 or no method (T3/none)).	Women living with HIV (n =136) with 123 (90.6%) Black or African American. From all participants, 42 used T1/T2 from which 41 (97.6%) were Black, and 94 used T3/none, from which 82 (87.23%) were Black. Differences in race and ethnicity by contraception method used were not significant (p =0.6)
Cohn et al. ¹⁰⁸	United States (urban)	Observational (cross-sectional)	Describe parenting desires among women, men who have sex with men, and men who have sex with women	In univariate analysis, factors significantly associated with parenting desires included being Black (this group included all participants) (OR=2.04, 95% CI (1.60, 2.62)). For women living with HIV, being Black non-Hispanic was not significantly associated with parenting desires with (OR=0.83, 95% CI (0.46, 1.73)). In multivariable analysis of all participants, Blacks had increased odds for considering children in the future (AOR=2.20, 95% CI (1.45, 3.34)). For women living with HIV, being Black was not significantly associated with parenting desires (AOR=0.93, 95% CI (0.31, 2.78))
Gursahaney et al. ¹⁰⁹	United States (urban)	Observational (cross-sectional)	Evaluate factors associated with self-reported condom use in a cohort of adult, predominantly African American women receiving HIV care in Atlanta	Women living with HIV (n = 187). For Black women living with HIV, 108 (73%) used condoms in last coitus. During vaginal intercourse over the past 6 months, 82 (55%) used condoms. Race was not significantly associated with condom use

OR: unadjusted odds ratio; AOR: adjusted odds ratio; IC: confidence interval.

people for consultation and guidance when making the decision to have a child. The findings underscore the importance of family in childbearing decisions for Black women living with HIV. 92

Motherhood and fulfillment

Motherhood was reported to be a vital role that gave meaning to the lives of women living with HIV. The recognition of this role may have influenced some Black women living with HIV to try to become pregnant or, at the very least, to not try too hard to prevent it. 90 Motherhood was viewed as transformative, inspirational, and purposeful. Some Black women actively sought a second chance to responsibly care for children. Motherhood post-HIV diagnosis represented and reinforced life, hope, purpose, and normalcy. By extension, pregnancy was an opportunity for "a whole new second chance at life." 102

Reproductive planning

Black women living with HIV used different birth control strategies to plan their pregnancy. During the late 1990s, abortion among women who became pregnant after their HIV diagnosis was significantly associated with being White and in a relationship. 113 In earlier studies, race was not associated with pregnancy after adjusting for age and sexual assault history. 90 Smits et al. 91 reported that not using or not consistently using contraceptives was significantly associated with race. In a later study, 103 elective sterilization was a common method to prevent pregnancies among women living with HIV. Another study reported 21% (n=35) of Black women living with HIV had surgical sterilization after learning about their HIV-positive status; 29% (n=47) were not sterilized. ⁹⁵ Finally, involuntary ⁵⁷ and nonconsensual⁵⁶ sterilizations are common among women living with HIV, but more problematic for racial and ethnic minorities.⁵⁷

Women living with HIV effectively used contraceptives to prevent unwanted pregnancies. In one study with openended responses, 73% of women living with HIV used contraceptives in the 6 months before the study. 104 Condoms were the most popular contraceptive for Black women living with HIV, and more than 70% of them used a condom during their last vaginal intercourse. However, race has not been reported as significantly associated with condom use. 109 A more recent study found 28% of Black women living with HIV used only condoms, 17% used dual methods, 14% used only hormonal contraception, and 11% did not use any method during their last vaginal intercourse. 106 Women who chose to not use contraception were significantly more likely to be Black (mostly African and Caribbean) than another race (39% vs 29%). However, there was no association between effective contraceptive use and Black women (OR 0.54, 95% CI (0.29, 1.03); OR 0.56, 95% CI (0.27, 1.15)). ¹⁰⁴ Haddad et al. ¹⁰⁶ found race was not associated with increased odds of contraceptive use during the last vaginal intercourse. Although not statistically significant, two other studies reported differences between ethnicity and contraceptive method $(p=0.06)^{107}$ and sterilization status (p=0.08). ¹⁰³

Health and wellness

When considering a successful pregnancy, Black women living with HIV feared the possibility of mother-to-child transmission because they would need to care for an infected baby. Some women believed totally avoiding pregnancy was the only way to prevent mother-to-child transmission. So For women living with HIV who became pregnant, Black women reported higher prenatal depressive symptoms than other women (M=19.55, SD=13.53 vs M=15.06, SD=13.24, p<0.24).

Discussion

This review synthesized the evidence about the reproductive decision-making of Black women living with HIV in high-income countries from the beginning of the HIV epidemic to the present. The categories previously identified as factors that influence the reproductive decision-making process for all women living with HIV83 were remarkably similar to those identified for Black women. However, few studies in this review specifically focused on Black women living with HIV, and most did not provide subgroup analyses by race or ethnicity. Furthermore, the studies reported limited demographic characteristics of participants that could be synthesized by race or ethnicity. Because of this limited data for analysis, synthesis for intersectionality was not possible. However, three key areas related to the findings—reproductive intention, mental health, and research inequity—have implications for policy, practice, and future research.

Reproductive intention

Although HIV status seems to have little impact on a woman's decision to have children, cultural, and contextual factors make the decision-making process more complex. 114 Regardless of race and ethnicity, motherhood after an HIV diagnosis offers women living with HIV an opportunity for normalcy, achieved through a second chance at life with a family. 115 In this review, no relationship was found between race or ethnicity and planning or ending a pregnancy in the United States, but some studies from Europe reported Black women with African ethnicity were less likely to change their fertility intentions after an HIV diagnosis than European women. This finding may be related to the positive association between African cultural values

and the importance of having children for Black women that was reported in an older study. 116 In a retrospective review of women living with HIV in Canada (n=1165), 30% of the women identified as African/Caribbean/Black, almost 25% became pregnant after their HIV diagnosis with slightly more than 60% unintended. 117 However, none of the reported data was specific to race and ethnicity. Black women living with HIV usually want to continue their pregnancy, 118 but they also need to feel their baby is protected from HIV. 119,120 For this reason, some Black women turn to their faith in God and pray for a good outcome. 119 However, involuntary 57 and nonconsensual 56 sterilizations are reported to eliminate reproductive decision-making for women living with HIV especially in the case of racial and ethnic minorities.⁵⁷ More research is needed to understand the reproductive intentions of Black women living with HIV and to support their reproductive decision-making and family planning in relation to their culture and context.

Mental health

In this review, significantly higher mean prenatal depressive symptoms were reported for Black women living with HIV than for other women. 105 Similarly, a systematic review of depression in HIV-infected African women reported a 23% mean weighted prevalence for antenatal (13 studies) and postnatal depression (10 studies); suspected depression was reported to be 43% and 31%, respectively. 121 Because symptoms in the studies were not explained by timing or etiology, depression may have been an underlying condition during the reproductive decision-making process. 122 Depressive symptoms for Black women are often missed or not clinically managed by providers. 123 For example, Black women are less likely to receive treatment for mental health problems than nearly all other racial and ethnic groups. 124 In the United States, White women are twice as likely to receive treatment for depression related to pregnancy than Black women. 125 Furthermore, most mental health research specific to pregnancy and to development of screening tools has focused on White women. More research is needed to understand mental health in all groups of women living with HIV, 126 most especially for depression experienced by Black women¹²⁷ engaging in reproductive decision-making.

Research inequity

For women living with HIV accessing health services worldwide, inadequate resources and lack of evidence-based clinical guidelines result in poor health outcomes¹²⁸ and high levels of marginalization.¹²⁹ Although Black women are disproportionately impacted by an HIV diagnosis,^{44,130} most reproductive decision-making

research focuses on White women.83 Studies that included Black women rarely reported subgroup analysis for race or ethnicity. One notable exception is a secondary data analysis¹¹² published nearly 20 years following the original data collection. 131 that examined the major influencers of Black mothers with HIV. As a result, the scientific literature has largely ignored Black women living with HIV despite their increased risk for adverse health outcomes, 132 problems with stigma and discrimination, 129 and barriers to accessing health services. Targeted funding is essential to increase the level of research and tailor clinical programs to address reproductive health. As a community, Black women living with HIV need to be prioritized as key stakeholders 133 in the development of new approaches that increase their access to women-centered care.18

Limitations

This review had several limitations. Few studies reported data that could be extracted for synthesis specific to race or ethnicity. However, to our knowledge, this is the first systematic review focused on the reproductive decisionmaking of Black women living with HIV. Although most studies were conducted in urban areas of the United States, there were similarities with the few studies conducted in other countries. The lack of sociodemographic participant data and subgroup analysis for race and ethnicity from the reviewed studies limited the depth of analysis and prevented a robust review of intersectionality. Despite these limitations, major strengths of this review were the depth and breadth of the literature search, the longevity of the literature reviewed, the rigorous methods, and the quality assessment. Finally, the including criteria for OECD member countries can be considered a weakness as the literature specific to Black women of African ethnicity from other countries was not included in this review. However, the inclusion criteria can also be considered a strength as the OECD countries are more comparable in the socioeconomic and human rights conditions for women. This limitation is an important area for further research focused on the other countries.

Conclusion

Becoming a mother can be a transformative, inspirational, and purposeful experience for all groups of women. In this review, there were few differences in the reproductive decision-making process between Black women and other groups of women living with HIV. However, the desire to have children was more pronounced for Black women from Africa living with HIV in Europe. Also, prenatal depressive symptoms were more often observed among Black women. Furthermore, religion and spirituality

helped Black women cope with their HIV infection and manage fears about vertical transmission. Unfortunately, dehumanizing behaviors and stigmatizing practices still exist in healthcare institutions.

Of the 35 OECD countries, studies from only four countries investigated the reproductive decision-making of Black women living with HIV. Despite the disproportionately larger number of Black women living with HIV, very few studies reported subgroup analysis for race or ethnicity. Therefore, institutional review boards should require subgroup analysis for Black women in larger studies of women living with HIV. Furthermore, clinical trials specifically focused on Black women are necessary to better understand the biopsychosocial factors associated with reproductive decision-making. As such, funding agencies should take a proactive role in promoting research that investigates Black women living with HIV.

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Mariela P Aguayo-Gonzalez: Data curation; Formal analysis; Writing – original draft.

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Supplemental material

Supplemental material for this article is available online.

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