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“I want to be around for her so I got to do it, I don’t have a choice”: Exploring the role of motherhood in healthcare engagement for women living with HIV in the United States

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2019

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An abstract of  
a thesis submitted to the Faculty of the  
Rollins School of Public Health of Emory  
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2021

# **“I want to be around for her so I got to do it, I don’t have a choice”: Exploring the role of motherhood in healthcare engagement for women living with HIV in the United States**

By Celeste Ellison

**Objective:** Women are a key population affected by the HIV epidemic. Many women living with HIV are mothers who are faced with managing their healthcare and wellness needs along with those of their children and other family members. The purpose of this study is to explore challenges and facilitators to health and healthcare engagement for mothers living with HIV in the United States.

**Methods:** This study was a secondary analysis of 76 qualitative interviews conducted with women who participated in the Women’s Adherence and Visit Engagement (WAVE) study, a sub-study embedded within The Women’s Interagency HIV Study (WIHS). The data excerpts used in this analysis were originally coded using the sub-codes *motherhood*, *social support*, and *adherence/medication*. Thematic analysis of the interview excerpts was conducted to identify sub-themes that emerged from the originally coded data.

**Results:** Of the 76 women who participated in the study, the majority of the women identified as Black (N=46) and 52 women (68%) reported having 1 or more children. Commonly discussed facilitators of engagement in HIV care were: children as sources of strength and motivation, children as logistical support (appointment and medication reminders), and support from fellow mothers and parents living with HIV. The women discussed how children and HIV community support increased their healthcare utilization, improved medication adherence, and led to the prioritization of their health, not only for themselves but for the sake of their children. HIV stigma and family-related stress and responsibilities emerged as challenges faced by the mothers participating in the study. Several participants reflected on the physical and emotional challenges of balancing motherhood responsibilities and an HIV diagnosis.

**Conclusion:** These findings highlight the various ways in which motherhood and its complex and unique characteristics impact engagement in health and healthcare for women living with HIV. Future public health practice models and interventions should consider the intersectional nature of motherhood among women living with HIV, include parent-child support groups, and mandate HIV-stigma trainings for clinical providers, to better inform the development and improvement of comprehensive and appropriate interventions, programs, and clinical practice guidelines for mothers living with HIV.

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## **Chapter 1: Review of the Literature**

### **HIV in the United States**

There are approximately 1.1 million people living with Human Immunodeficiency Virus (HIV) in the United States (Centers for Disease Control and Prevention, 2018). Although the HIV epidemic in the United States impacts many, some populations are more impacted than other groups. For example, minority groups, specifically Black and Latino populations, have higher rates of HIV infection than their White counterparts (Centers for Disease Control and Prevention, 2020a; Centers for Disease Control and Prevention, 2016). These key populations are at a higher risk of HIV infection due to economic and social barriers such as poverty, stigma, and a lack of access to quality healthcare (Centers for Disease Control and Prevention, 2016). In addition to racial disparities, there are geographical disparities as the Southern United States has the highest HIV diagnosis rate when compared to other regions in the country (Centers for Disease Control and Prevention, 2016).

### **Women living with HIV**

Women are a key population affected by the HIV epidemic, as they represent 24% of people living with HIV in the United States (Centers for Disease Control and Prevention, 2018). Black women in particular are disproportionately affected by HIV, accounting for 58% of diagnoses in 2018, when only making up 13% of the female population in the United States (Centers for Disease Control and Prevention, 2018). A study conducted by Geter et al. (2018b) found that there are significant racial disparities in viral load suppression among Black and Latina women in comparison to White women, whereby virologic suppression was less prevalent. The findings from this study suggest that social and structural barriers limit access to

HIV prevention, treatment, and care that is needed for proper HIV-self-management. Lastly, many women living with HIV are faced with challenges such as inadequate linkage to quality healthcare, medication non-adherence, and stigma, which in turn may result in emotional distress (Dyer et al., 2012). It is important to note that there is a need to address these shortfalls in order to improve and understand the needs of women living with HIV, especially women of color.

### **Mothers living with HIV**

According to the Centers for Disease Control and Prevention (2018), the majority of women living with HIV are of child-bearing age, specifically ages 25-44 years old. A recent study found that approximately 5,000 women living with HIV give birth annually in the United States (Nesheim et al., 2018). Women living with HIV are often times mothers who have to balance their own healthcare needs along with the needs of their families, specifically those of their children (DeMarco et al., 2002). Some studies have shown that mothers living with HIV are more likely to delay or not receive treatment resulting in increased stress levels and other health risks which can further hinder their overall well-being (Davie et al., 2013). However, there is also literature that suggests that motherhood can encourage women living with HIV to take the necessary steps to improve their health, not only for their own well-being but for their children as well (Liamputtong, 2013). Although the majority of HIV diagnoses are among women ages 25-44, it is important to note that women 45 years and older accounted for 36% of new diagnoses in 2018 (Centers for Disease Control and Prevention, 2018). Mothers and grandmothers beyond the child-bearing age (25-44 years old) are still caregivers to children and sometimes even other adults who are living with HIV (Emlet & Poindexter, 2004). Similar to mothers living with HIV, grandmothers living with HIV are faced with multiple responsibilities, including managing their HIV care (Poindexter & Linsk, 1999).

## Facilitators to healthcare engagement

Existing literature has found that motherhood, family, and social support can serve as facilitators to engagement in health and healthcare by mothers living with HIV. Motherhood in the context of HIV can encourage women to take the necessary steps to maintaining and improving their health, in order to be healthy for their children. (Liamputtong, 2013). Studies have also shown that perceived social support by family members is a facilitator to medication adherence (Edwards, 2006).

### *Motherhood as a motivator*

Traditionally and historically, motherhood has been recognized as a transformative and emotional social identity for women, including women living with HIV, who have desires for motherhood as well (Buregyeya et al., 2017). Research has found that the desire to have a healthy baby was a motivator for starting and adhering to antiretroviral therapy among women living with HIV when they became aware of their pregnancy status (Buregyeya et al., 2017). Research indicates that women living with HIV express desires for motherhood regardless of their positive HIV diagnosis (Fletcher et al., 2016; Kennedy et al. 2013). Two research studies conducted in the Southern United States identified that motherhood was perceived as a motivator for healthcare engagement and medication adherence (Boehme et al., 2014; Fletcher et al., 2016). A mixed-methods study conducted among mothers living with HIV in rural Alabama found that the main motivator of adherence to HIV medication regimens and clinic visits was increasing their life expectancy for themselves and their children (Boehme et al., 2014). Although many women refer to their children as their primary motivator, they also prioritize their own needs. For example, a study conducted by Fletcher et al. (2016) in South Carolina found that women held

positive views and aspirations for pregnancy and motherhood as it was a means to foster a sense of normalcy, a second chance at life, and a desire for a socially valued identity.

There are a limited number of United States based studies that focus specifically on grandmothers living with HIV. Two exceptions include qualitative studies that address the perceptions of how social support influenced medication adherence and the role of traditional social roles and responsibilities, such as motherhood and grand motherhood, on HIV self-management (Edwards, 2006; Webel & Higgins, 2012). While conducting focus groups with women living with HIV in Northeast Ohio, the most frequently reported social identity was mother and grandmother (Webel & Higgins, 2012). Similar to the studies focused on motherhood, grandchildren served as source of purpose and inspiration for managing a HIV diagnosis among grandmothers living with HIV. The notion of a socially valued identity can also be seen in this context as grandmothers want to complete the responsibilities associated with their title.

### *Family and social support*

Understanding the role of social and family support on health decision making, treatment engagement, and overall health is necessary to address the health needs of mothers living with HIV. Social support encompasses a number of aspects such as belonging to a social network, emotional support, financial support, perceived satisfaction with social networks, and instrumental support such as child care (House et al., 1998). Social support may also serve as a buffer or coping mechanism for mothers living with HIV (House et al., 1998).

According to a study conducted by Edwards (2006) in Baltimore Maryland, two facilitators of medication adherence for Black mothers living with HIV were having a supportive family and having young children in the household. The existing literature shows that mothers living with HIV who perceived their social support to be reassuring and loving were more likely to abide by their medication schedules. Additionally, children in the household were a primary source emotional and technical support as they helped with medicines and household chores (Edwards, 2006).

### **Barriers to healthcare engagement**

There are a number of existing studies that argue that stress, family related responsibilities, disclosure concerns, and HIV-related stigma impede engagement in healthcare and adherence to medication regimens for mothers living with HIV (Boehme et al., 2014; Murphy et al., 2011; Webel & Higgins, 2012;). Mothers living with HIV are faced with a multitude of responsibilities, ranging from their children's needs to their own. As a result of these competing responsibilities, women living with HIV often times delay seeking HIV care, while prioritizing the needs of their children (Stein et al., 2000).

### *HIV-related stigma*

The notion that HIV-related stigma is a barrier to HIV treatment and positive health outcomes among people living with HIV is supported across numerous studies (McDonald, 2013; Payán et al., 2017; Webel & Higgins, 2012). HIV-related stigma is defined as “the social devaluing of people perceived to have AIDS or HIV as well as the individuals, groups, and communities with which they are associated” (Herek et al., 2005). The experience of HIV-related

stigma among mothers living with HIV is exacerbated by societal norms and stereotypes. For example, mothers living with HIV are critiqued for getting pregnant and are viewed as putting innocent children at risk by giving birth (McDonald, 2013). HIV-related stigma and discrimination impact the mental and physical health of mothers living with HIV.

Webel and Higgins (2012) found that the “stigmatized patient” role was the social identity that was most detrimental to HIV self-management among mothers living with HIV. Stigma prevented women from disclosing their status, seeking out social support from family, and adhering to treatment tasks such as clinical visits and medication regimens (Webel & Higgins, 2012). In addition to their own experiences of internalized and experienced stigma, mothers also tried to protect their families from the effects of stigma by withholding their HIV status from community members (Webel & Higgins, 2012). Similar findings show that some mothers would avoid going to clinics for appointments to avoid being seen at HIV clinics (Payán et al., 2019). In addition, Payán et al. (2019) highlighted that stigma can lead to disintegration from social networks resulting in self isolation, putting women at risk for a lack of social support. There is a need for more research on how to apply this knowledge to public health models, for example with the development of inclusive social support groups, counseling services, and non-discriminatory treatment in hospitals.

### *Stress and family-related responsibilities*

Although previous studies indicated that motherhood served as a motivator for HIV care engagement, it can also serve as a source of stress (Murphy et al., 2011). Family-related responsibilities can be facilitators to healthcare engagement, or they can pose as an additional challenge for mothers living with HIV. Findings from Boehme et al. (2014) show that trying to

balance household responsibilities, including caregiving for children, and disease management could result in stress and negative mental health outcomes for mothers and grandmothers. A busy parenting schedule may be a significant challenge that mothers living with HIV face in regards to medication adherence, as it can disrupt routine medication intake schedules (Boehme et al., 2014). Additionally, the impact of family-related responsibilities poses an even greater challenge when there are multiple children in the household (Boehme et al., 2014).

It is important to acknowledge that an HIV diagnosis not only impacts the mother, as it also has an indirect effect on the whole family structure (Rotheram-Borus et al., 2005). Motherhood is a time where women can experience their children growing up, however an HIV diagnosis can give rise to a number of unexpected health challenges and events. A qualitative study conducted by Murphy et al. (2011) in California found that 60% of mothers reported that due to their HIV diagnoses they missed out on key events in their children's life such as school ceremonies, sports, and extracurricular activities. Similarly, hospitalizations, medication side effects, and fatigue were challenging factors that the women reported as having an impact on their ability to mother their children (Murphy et al. 2011). The impact of these missed events led to mental health challenges among the mothers in the study. Murphy and colleagues (2011) also found that mothers reported experiences of depression, anxiety, fear, and general emotional distress over their potential to be a good mother, as a woman living with HIV.

### *Disclosure*

Mothers living with HIV are faced with the difficult decision of deciding whether or not to disclose their status to their family, children, and friends. Previous studies have delved into the role of disclosure on medication adherence and treatment engagement (Edwards, 2006; Payán et

al., 2019). Studies have found that mothers do not want to disclose their status to their children to avoid them getting upset and imposing an emotional burden, or ensuing stigma (Armistead et al., 1999; McDonald, 2013). A qualitative study that was conducted in Australia to explore the factors considered by mothers living with HIV when deciding whether or not to disclose their status to their children (McDonald, 2013). The study found that the age of the child was the most important factors that the mothers considered. Age determined whether or not the mothers decided to disclose their status, partially disclose their status, or to not disclose to their children at all (McDonald, 2013). Additionally, the study found that mothers living with HIV carefully considered their disclosing plans to as a means to protect their children from the ramifications of others knowing her status, such as stigma (McDonald, 2013).

A recent study was conducted to analyze the impact of an HIV diagnosis and to further explore how women cope and self-manage their condition in the Dominican Republic (Payán et al. (2019). The main finding from this study was that fear of disclosure was a barrier to treatment and appropriate HIV self-management (Payán et al. 2019). Additionally, many women reported fearing rejection from family members and friends based on their status, in addition to privacy concerns (Payán et al. 2019). Results from a similar study found that misinformation regarding HIV exacerbated stereotypes which resulted in instances of nonadherence, isolation, and emotional struggles for mothers living with HIV (Edwards, 2006). It was common for mothers who had not disclosed their status to their family to not adhere to medication regimens, as they did not have the privacy to do so without being seen or questioned by others (Edwards, 2006). Non-disclosure of HIV status was found to be a barrier that is closely associated with HIV-related stigma (Payán et al., 2019).



## Intersectionality

An intersectional approach to understand the specific needs of mothers living with HIV will allow further exploration of the unique lived experiences considering the many integrated social identities at hand such as race, gender, economic status, being a mother, and having an HIV diagnosis. Intersectionality is a theory that proposes that multiple social identities intersect with one another at the micro-level to reflect lived experiences of stigma, oppression and inequity at the social-structural level (Bowleg, 2012). A review of the literature revealed that there is limited research focused on the intersecting identities of mothers living with HIV. One study by Caiola et al. (2014), introduced the “Motherhood and HIV: An Intersectional Approach” model and its importance for research on Black mothers living with HIV in the context of healthcare and nursing. The intersectional model acknowledges the multidimensional impact of racism, gender inequality, classism, HIV-related stigma, and motherhood among Black women living with HIV. Black mothers living with HIV have a multitude of intersecting social identities, such as gender, race, HIV status, and motherhood that disproportionately subject them to increased risk of inequities across numerous social determinants and susceptibility to poor health (Caiola et al., 2014).

Recent evidence suggests that the lack of intersectional trainings around reproductive health and HIV-related care for clinicians poses a significant barrier to care for Black women living with HIV (Fletcher et al., 2021). Using an intersectional approach, would allow for healthcare providers and public health professionals to have a more comprehensive understanding of how these social identities inform and create the experiences of mothers living with HIV to address health inequities and provide comprehensive care (Caiola et al., 2014; Fletcher et al., 2021). Intersectional research can seek to address the complexities of these

identities to develop the best approach for HIV intervention development and patient-centered approaches at an individual, clinical, and population level for mothers living with HIV (Caiola et al., 2014).

### **Study Relevance**

Although there is a fair amount of existing literature that explores the facilitators and barriers that influence HIV treatment and healthcare engagement for mothers living with HIV, many of those studies date back to 2010 and earlier. Throughout the years, dynamics surrounding the HIV epidemic have evolved. For example, there have been medical advances in HIV treatment recommendations that aid in reducing transmission to others, including mother- to-child transmission (Centers for Disease Control and Prevention, 2020b). As a result of these changes, there needs to be updated research on how the experiences of women and mothers have also evolved. There is a need for more recent literature exploring how motherhood influences engagement in HIV care and treatment, medication adherence, and other aspects of health such as mental health.

In addition to a need for more current research, another limitation is that many of the studies discussed in this literature review focused on one single state or geographic region, therefore limiting the diversity in the target populations. There is a need to examine the potential implications of this literature as it can enrich current healthcare and public health practice models for women living with HIV, especially mothers. This thesis seeks to explore the influence of motherhood on engagement in health and healthcare for women living with HIV across the United States. This thesis also seeks to examine how these factors may affect how mothers living with HIV make decisions around their medication adherence and healthcare utilization.

## Chapter 2: Manuscript

### **“I want to be around for her so I got to do it, I don’t have a choice”: Exploring the role of motherhood in healthcare engagement for women living with HIV in the United States**

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### **Contribution of the student**

In 2015, qualitative data were collected as part of the Women's Adherence and Visit Engagement Sub-Study (Project R01 MH104114 to Principal Investigator Janet Turan) of the Women's Interagency HIV Study, or WIHS ( Rice et al., 2018). I continued the exploration of the data by completion of this secondary analysis using the motherhood subcode identified in the primary study. I conducted an extensive literature review and undertook data management and analysis for this current secondary analysis. Additionally, I constructed the analytic report that was essential to completing and organizing the results section of this thesis. Lastly, I wrote the following manuscript. Dr. Hussen and Dr. Rice were instrumental in providing feedback throughout the development of this thesis.

## Abstract

### **“I want to be around for her so I got to do it, I don’t have a choice”: Exploring the role of motherhood in healthcare engagement for women living with HIV in the United States**

By Celeste Ellison

**Objective:** Women are a key population affected by the HIV epidemic. Many women living with HIV are mothers who are faced with managing their healthcare and wellness needs along with those of their children and other family members. The purpose of this study is to explore challenges and facilitators to health and healthcare engagement for mothers living with HIV in the United States.

**Methods:** This study was a secondary analysis of 76 qualitative interviews conducted with women who participated in the Women’s Adherence and Visit Engagement (WAVE) study, a sub-study embedded within The Women’s Interagency HIV Study (WIHS). The data excerpts used in this analysis were originally coded using the sub-codes *motherhood*, *social support*, and *adherence/medication*. Thematic analysis of the interview excerpts was conducted to identify sub-themes that emerged from the originally coded data.

**Results:** Of the 76 women who participated in the study, the majority of the women identified as Black (N=46) and 52 women (68%) reported having 1 or more children. Commonly discussed facilitators of engagement in HIV care were: children as sources of strength and motivation, children as logistical support (appointment and medication reminders), and support from fellow mothers and parents living with HIV. The women discussed how children and HIV community support increased their healthcare utilization, improved medication adherence, and led to the prioritization of their health, not only for themselves but for the sake of their children. HIV stigma and family-related stress and responsibilities emerged as challenges faced by the mothers participating in the study. Several participants reflected on the physical and emotional challenges of balancing motherhood responsibilities and an HIV diagnosis.

**Conclusion:** These findings highlight the various ways in which motherhood and its complex and unique characteristics impact engagement in health and healthcare for women living with HIV. Future public health practice models and interventions should consider the intersectional nature of motherhood among women living with HIV, include parent-child support groups, and mandate HIV-stigma trainings for clinical providers, to better inform the development and improvement of comprehensive and appropriate interventions, programs, and clinical practice guidelines for mothers living with HIV.

## Introduction

The Human Immunodeficiency Virus (HIV) epidemic is a public health concern affecting approximately 1.1 million people who are living with HIV in the United States (Centers for Disease Control and Prevention, 2018). The HIV epidemic has an impact on all groups of individuals; however, it is important to acknowledge that there are racial and geographical disparities in its prevalence. For example, the rate of HIV diagnosis in the southern region of the United States is significantly higher compared to other regions in the country (Centers for Disease Control and Prevention, 2016). Racial disparities also exist when examining the prevalence of HIV across racial groups. Racial and ethnic minority groups, specifically Black and Latino populations, experience higher rates of HIV infection than their White counterparts (Centers for Disease Control and Prevention, 2020a; Centers for Disease Control and Prevention, 2016). These disparities can be associated with numerous determinants of health, to include economic and social factors such as poverty, stigma, and lack of healthcare access (Centers for Disease Control and Prevention, 2016).

Women in the United States are significantly impacted by the HIV epidemic, as they make up 24% of people living with HIV (Centers for Disease Control and Prevention, 2018). More specifically, Black women are disproportionately affected by the HIV epidemic. In 2018 Black women accounted for 58% of the diagnoses among women in the United States, while only accounting for 13% of the female population (Centers for Disease Control and Prevention, 2018). The literature suggests that women living with HIV are faced with multiple barriers that impact their health and HIV treatment plan, such as inadequate linkage to quality healthcare, medication adherence challenges, and HIV-related stigma (Dyer et al., 2012).

Research has found that the majority of women living with HIV are of child bearing age, ranging from 25-44 years of age (Centers for Disease Control and Prevention, 2018). A recent study has found that approximately 5,000 women living with HIV give birth annually in the United States (Nesheim et al., 2018). Therefore, many women living with HIV are mothers, and are faced with multiple responsibilities such as balancing their own healthcare needs along with caring for their family (DeMarco et al., 2002). Additionally, it is important to recognize that women 45 years and older accounted for 36% of new diagnoses in 2018 (Centers for Disease Control and Prevention, 2018). Although research on grandmothers is limited, demographically we would expect that women living with HIV are likely to be not only mothers, but also grandmothers or caregivers who are also faced with many family responsibilities, in addition to the management of their HIV care and treatment (Poindexter & Linsk, 1999). Research has shown that motherhood, and grandmotherhood, can have both helpful and detrimental effects on HIV care engagement.

Existing literature has found that children and other family social support can be facilitators to engagement in health and healthcare for mothers living with HIV (Buregyeya et al., 2017; Boehme et al., 2014; Liamputtong, 2013). Following the confirmation of pregnancy, research has found that the desire to have a healthy baby was a motivator for starting and adhering to antiretroviral therapy among women living with HIV (Buregyeya et al., 2017). For mothers living with HIV, children were seen as motivation to adhere to medication schedules and clinic visits in order to improve their quality of life and increase life expectancy, not only for themselves but for their children as well (Boehme et al., 2014; Liamputtong, 2013). In addition to children being motivators, they also have a more technical role in supporting healthcare engagement, such as providing medication and appointment reminders (Edwards, 2006).

Similarly, another study found that grandchildren were a source of inspiration and purpose for managing grandmothers' HIV diagnosis and fulfilling the grandmother role and its associated responsibilities (Edwards, 2006; Webel and Higgins, 2012). In some cases, children are also described as a source of technical support as they assisted with medication reminders, household chores, and appointment reminders (Edwards, 2006).

Research has also explored the ways in which mothers living with HIV are faced with various challenges that hinder their overall health and healthcare engagement. Studies have found that children and motherhood could also be factors that result in delayed or a lack of treatment due to increased stress levels and family-related responsibilities, including prioritizing the needs of their children (Davies et al., 2013; Stein et al., 2000). Mothers living with HIV are often times balancing their own healthcare needs, disclosure fears, stigma, and other family related stressors which can result in poor medication adherence and treatment maintenance (Webel and Higgins, 2012; Murphy et al., 2011). In addition to physical health consequences, mothers living with HIV can experience mental health challenges such as depression, fear, and emotional distress around their potential to be a good mother (Murphy et al., 2011). In some cases, mothers living with HIV do not seek appropriate treatment nor practice HIV self-management because they have not disclosed their status to their children or family (Payán et al. 2019). Therefore, fear of disclosing one's HIV status to their family is closely related to HIV-related stigma (Payán et al. 2019). Stigma has been found to impede healthcare engagement as it prevents women from seeking social support, attending clinic visits, and adhering to medication schedules (Webel and Higgins, 2012).

Mothers living with HIV are a unique population with many intersecting social identities to include race, gender, economic status, the motherhood role, and an HIV diagnosis.



Intersectionality is a theory that proposes that multiple social identities intersect at the micro-level to reflect lived experiences of stigma, oppression or inequity at the social-structural level (Bowleg, 2012). The complexities of these intersecting identities collectively influence how mothers living with HIV are able to engage in health and healthcare (Caiola et al., 2014). Using an intersectional approach would allow for a comprehensive understanding of the unique needs of mothers living with HIV. There is a need to understand how the social identities of mothers living with HIV shape and inform one another to understand the potential pathways to improving access to quality healthcare and patient-centered approaches at an individual and population level.

Although there is a fair amount of existing literature that explores facilitators and barriers to healthcare engagement for mothers living with HIV, many of those studies date back to 2010 and earlier. Throughout the years, dynamics surrounding the HIV epidemic have evolved. For example, there have been medical advances and HIV treatment recommendations that aid in reducing transmission to others, including mother- to- child transmission (Centers for Disease Control and Prevention, 2020b). As a result of these changes, there needs to be updated research on how the experiences of women and mothers may have also evolved. There is a need for more recent literature exploring how motherhood influences engagement in HIV care and treatment, medication adherence, and other aspects of health such as mental health. Another limitation is that many of the studies discussed in this literature review focused on one single state or geographic region. Lastly, there is a need to examine the potential implications of this literature as it can enrich current healthcare and public health practice models for mothers living with HIV. The current study seeks to address these gaps by examining the challenges and facilitating

factors to healthcare engagement for mothers living with HIV in a multisite cohort across the United States.

## Methods

### *Study Design*

The Women's Interagency HIV Study (WIHS) is a longitudinal prospective cohort study aiming to understand the impact of HIV disease progression, treatment use, and outcomes among women living with HIV in the United States (Adimora et al., 2018). Embedded within the WIHS are a number of sub-studies, including the Women's Adherence and Visit Engagement (WAVE) study. The WAVE study examined the perceptions of intersectional stigma and its effect on HIV treatment adherence and health service utilization among women living with HIV (Rice et al., 2018). The current secondary qualitative analysis examines how motherhood influences engagement in HIV care and treatment, medication adherence, and other aspects of health, such as mental health among women living with HIV using in-depth interviews conducted during the WAVE study.

### *Participant Characteristics and Settings*

Study participants were recruited from WIHS site locations in Birmingham, Alabama (University of Alabama at Birmingham); Jackson, Mississippi (University of Mississippi Medical Center); Atlanta, Georgia (Emory University); and San Francisco, California (University of California, San Francisco). Participant recruitment occurred during routine, semi-annual core WIHS visits. During recruitment, staff verbally provided the women with the research study description and consent forms. In order to be eligible for the study, participants had to meet the following inclusion criteria: identified as women living with HIV, at least 18 years of age, English speaking, and able to provide consent.

### *Data Collection*

Seven qualitatively trained and experienced female interviewers conducted in-depth interviews with the 76 study participants between June 2015 and December 2015. The interviews were conducted in a private room and were digitally audio-recorded. The interviewers used a semi-structured interview guide to facilitate discussion around stigma, intersectionality, discrimination, and HIV treatment engagement. The guide included questions that encouraged participants to share experiences of stigma relevant to healthcare treatment and service utilization, such as the following, “*What helps you to take your HIV medications as your doctor recommended (right time, amount)? What things might make it hard for you to take your HIV medications as your doctor recommended?*” On average, each of the interviews lasted about 73 minutes.

### *Data Management and Analysis*

After the interviews were conducted, each was transcribed verbatim prior to coding and analysis. The transcripts were deidentified and analyzed in Dedoose, a qualitative data management program (Dedoose Version 8.0.35, 2018). Seven researchers on the study team developed codes and sub-codes upon completion of data collection. To ensure consistency, reliability, and quality assurance, coding was iterative to allow for modifications and clarity across the research team. *A priori* codes such as *race, gender, intersectionality, and stigma/discrimination* were informed by reviews of the literature, intersectionality theory, and the semi-structured interview guide. Codes such as *age, image, and motherhood* were established during the iterative coding process. In order to ensure coding consistency, 12 of the transcripts were double-coded to establish a mutual understanding of coding procedure and definitions across the research team.

For this current study, a secondary analysis was performed that specifically focused on the transcript excerpts that were coded using the sub-codes, *motherhood*, *social support*, *non-disclosure*, and *adherence/medication*. Thematic analyses were conducted to inductively develop over-arching themes that emerged from the data. The themes that emerged from the data were *facilitators to engagement in health and healthcare* and *healthcare engagement challenges*. The sub-themes that emerged within the larger themes were *children as motivation and sources of strength*, *children as logistical support*, *support from fellow mothers and parents living with HIV* and *stigma* and *family-related responsibilities and stress*, respectively. An analytic report was developed to thematically organize data excerpts with its associated theme. Illustrative quotes were then selected for the final analysis and presented in the results section with the participant's demographic descriptions.

### *Ethics*

This analysis was determined to be IRB-exempt because it is secondary and all data were de-identified prior to analysis. Prior to data collection, all portions of the study were reviewed by Institutional Review Boards at the University of Alabama at Birmingham, the University of California, San Francisco, University of Mississippi Medical Center and Emory University. All participants in the study signed informed consent forms.

## Results

The following data reflect perspectives within the full sample of 76 study participants living with HIV, of which 52 (68%) reported having 1 or more children. Women who reported having 1 or more children, and women who did not shared perspectives captured by the motherhood code. The majority of participants identified as Black (n=46) while 29% of participants were Hispanic or Latina. Of the participants, 45% reported having completed at least some college education. The participant's ages ranged from 26 to 62 years of age, with a mean age of 48 years old. Participants predominately reported being heterosexual (n=63). Seventy of the participants reported being on highly active antiretroviral therapy or HAART, while 6 reported naïvely using or not using HAART at all.

Participants identified the challenges and facilitators to health and healthcare engagement related to their experiences as mothers living with HIV. Common facilitators that emerged were views of children as sources of strength and motivation, children as logistical support (medication and appointment reminders), and support from fellow mothers and parents living with HIV. The healthcare engagement challenges that emerged were stigma and family-related stress and responsibilities.

### **Theme 1: Facilitators to engagement in health and healthcare**

#### *1.1 Children as motivators and sources of strength*

Participants shared common perceptions that their children were a source of motivation and strength that influenced their healthcare engagement and decision-making. Several women described how their children-to-be served as a motivator to their engagement in HIV treatment and medication adherence throughout their pregnancy. As expectant mothers, the participants

expressed the concern they had for their children during pregnancy and the importance of taking necessary measures to ensure their health, as reflected by the following quotation:

*“... But the whole world came to coming down when [the provider] said I had [HIV] and I thought I’m going to die; he’s going to die. And they’re like no, there’s plenty of medication. We can make sure that he doesn’t get it. And I said OK so I tried it and I did it. I took the medicine every day, stopped doing drugs and all of that and now have a very healthy handsome little boy.” (White Participant, Age 42, Jackson, MS)*

One participant shared how her child-to-be was a source of love that allowed her to overcome her challenges with her HIV medication. When asked about challenges she faced with medication adherence, one participant stated:

*“Yeah, the size [ of the pill] really did kind of bug me at first but you know I was like for the love of my kid and for her not to get anything I was like, I will do it. I actually prayed when I first found out, that night when that lady gave me the news, I went straight home. I got on my knees and I prayed. I said, God, I don’t know what this is going to do to me. I am already scared because I don’t know what HIV is going to do to me but I said God please don’t let this baby, just let this baby come healthy. I don’t care if it is a boy or a girl, just let the baby come healthy, all ten fingers and ten toes, two eyes, you know.” (Black Participant, Age 31, Atlanta, GA)*

Many of the study participants shared views reflecting on experiences later on in parenthood or grandparenthood, with the notion that their children or grandchildren were a

source of strength that encouraged them to take the necessary steps to maintaining and improving their health, not only for their own well-being but for their children and grandchildren as well. The necessary steps mostly included taking scheduled medications as required. The women expressed that they wanted to be healthy in order to be around for their children. The following quotes illustrate how mothers living with HIV are motivated to take care of themselves in order to be there for their children:

*“I mean no matter what, I look at my daughter and I say, “You know what? I got to.” She’s only 13. I have to be here for her, so no matter what I’m feeling, I have to take my meds. If I don’t take nothing else, I have to take that. That one pill, I have to take that.” (Black Participant, Age 49, San Francisco, CA)*

*“I’m tired of all of it, but I’ve got a new grand baby. My first biological one and I want to be around for her so I got to do it, I don’t have a choice.” (White Participant, Age 40, Jackson, MS)*

*“Because I want to live. I have a lot to live for. I have five beautiful grandbabies and I need to be around for them. And not only for them, for myself, you know. I have a bunch of family, you know. We do family things, you know. And I’m always, I’ve always taken care of myself, always taking care of my body...” (Black Participant, Age 47, Atlanta, GA)*

When asked by the interviewer about what gives them strength, a number of participants stated that their children or grandchildren inspired the need to cope and overcome when faced with mental health difficulties:



*“I guess my son for one. I know because I know I’m living for him. I try to stay strong all the time. I will never want to let him see me depressed or down. He’ll never see me like that. So, I try not to let him see me like that so that what keep me motivated and keep me going and you know.”*

*(Black Participant, Age 31, Birmingham, AL)*

*“My daughter...when I talk to [my daughter and grandchildren] and I’m – I got to stay strong for them. I got to keep moving and then I got to stay strong for myself...”* (Black Participant, Age

*50, San Francisco, CA)*

Additionally, one participant discussed receiving acknowledgment and recognition of her role as a mother and consideration of her children from a medical provider in a clinical setting. She went on to describe the advice the provider shared with her in the following quote:

*“Not ever wanting to see my T-cell count drop to 43 again. Like, my doctor said do you want to live or do you want to die? You’ve got two beautiful kids. You have to make a choice. Even though I kind of slacked off this summer with my medicine, and I wasn’t taking it like I’m supposed to, I started back taking it every day like I’m supposed to...”* (Black Participant, Age

*31, Atlanta, GA)*

A participant mentioned that disclosure was a source of strength, as she wanted to be honest and transparent with her child. Additionally, two participants expressed that another reason for disclosing their HIV status to their children was to use their personal experience as a

way to educate and empower their children to practice safe sex, as stated in the following quotations:

*“I have my children, those are my only big, major concerns, that when I go, I want my kids not to feel... I don’t want them to feel like they have to pity me. I want them to empower themselves on how to stay safe.” (Black Participant, Age 62, San Francisco, CA)*

*“Yeah, but at the same time I kind of like want to arm my kids because when they go to school, they’re going to get misinformation. I educated my kids about me being positive. My girls were asking about the birds and the bees when they were two. I made sure to tell them things as they went along. I guess it was therapeutic for both of us because they got to know what’s really going on and then at the same time it’s like I have to be responsible for a whole other being. I get a chance to do this better than the way my parents did.” (Multiracial Participant, Age 40, San Francisco, CA)*

### *1.2 Children as logistical support*

Following the birth of their children and their subsequent development through early childhood, adolescence, and adulthood stages, our participants were faced with the decision of deciding whether or not they want to disclose their HIV diagnosis with their children. Many of the participants made the decision to disclose their HIV status to their children. As a result of disclosing their HIV status with their children, children were able to support and influence the participants engagement in health and healthcare. One participant shared that she disclosed her condition with her daughter at an early age:

*“I told [daughter’s name] early on...like three to four years old because [daughter’s name] use to always bring my medication to me.... She asked me one day what it was for and I said okay if she is inquisitive enough to ask I am going to be strong enough to tell her but I told it to her in terms that a kid could understand. I said look I have a germ. Mommy has a germy and this is the medicine that is used to help fight the germies. I said I have soldiers that help protect mommy and you know they fight mommy’s battles in her body but this medicine helps protect mommy’s soldiers so that the germies don’t beat mommy’s soldiers up and take over. You know, at that time I had to explain it to her like that and then as she got older...” (Black Participant, Age 31, Atlanta, GA)*

Several study participants discussed the ways in which their children provided logistical support. As children grow older and enter the later phases of the life course, they reach the age in which they can begin assisting their parents and becoming more aware of the circumstances, such as their mother’s HIV diagnosis. Participants described the ways in which their children provided and showed interest in appointment updates and reminders, as well as medication reminders. Several participants reflected upon the ways their children facilitated and provided logistical support in regard to medication reminders:

*“They make sure that I take my medication. They make sure that I eat. They don’t even live with me. My baby’s 17. She lives with her oldest sister because that’s her best friends... they make sure I eat. They call me every day. They make sure that I have my doctor’s appointments. They want to know what the doctor said and if I’m explaining things right or if I don’t remember. The*

*next time, one of them will come with me so they will be able to explain to the other ones. It's like I'm the child. I'm just trying to understand.” (Black Participant, Age 44, Birmingham, AL)*

*“My daughter, 13...She has a focus to make sure that she always has a mommy taking meds. If I don't take anything else, she'll push that little pill, or she'll shake the bottle to remind me.”*  
*(Black Participant, Age 49, San Francisco, CA)*

Many participants discussed how their children showed interest in understanding and learning about their HIV diagnosis. The participants commonly discussed ways in which their children were attentive to their appointments and provided reminders. One participant discussed how her eldest daughter is overprotective and constantly checking to make sure that she remembers her appointments, as she shared:

*“... Plus, like I told my daughter yesterday I had a doctor's appointment today. She is up at 6:00 in the morning...she texts me and asks me...What time is your appointment? I text her back...Not this dang early! After lunch. She is like...Oh, go back to sleep. Well, I'm up now...6:00 in the morning....” (Black Participant, Age 42, San Francisco, CA)*

Another participant discussed how her children have connected her to an application that will assist her with appointment reminders, as she stated:

*“...They will ask me, “Well, ma, did you ask the doctor why this happened? Did you ask the doctor?” I'm like no, I forgot. So when's the next appointment? Sometimes I forget that. As a*

*matter of fact, my baby, [name of daughter] came with me and she was the one who signed me up for the [hospital name] portal because it shows up in my emails and as text message when my next appointment is... They put like little things that I have on my keychain. Well, I have another set of keys, but these little capsules that they put my pills down in.” (Black Participant, 44, Birmingham, AL)*

### *1.3 Support from fellow mothers and parents living with HIV*

Although the interviews explored the role of social support among mothers living with HIV, they did not discuss this factor in terms of its direct impact on health and healthcare engagement. However, a few participants discussed their involvement in HIV support groups. These HIV support groups served as a place for mothers living with HIV to connect with other fellow mothers and parents living with HIV, provided them with access to resources, and connected them to other support groups and community resources:

*“We were the first 200 out of 200 women in the Bay area who are in recovery and who are positive and pregnant. I got into that support. We had support groups for pregnant women who were positive, and that was really good. So when I finally had my daughter in [housing] and with these [AIDS service organization], she did not come out positive. She was negative. I lived in [housing] for almost six months with her... (White Participant, Age 57, San Francisco, CA)*

One participant mentioned that the HIV community was a source of support for mothers living with HIV, as she states that:

*“The people within the HIV community are very supportive to each other when it comes down to parenting. Everybody has very positive, nurturing feedback with people with babies.”*

*(Multiracial Participant, Age 38, San Francisco, CA)*

## Theme 2: Healthcare engagement challenges

### 2.1 Stigma

When prompted to reflect on instances in which they felt stigmatized or discriminated against, several participants discussed feeling stigmatized as a pregnant woman living with HIV. One participant discussed her experience with a healthcare professional who displayed negative feelings about pregnancy among women living with HIV:

*“The only time that I really experienced, experienced anything as far as that goes is when I got pregnant with my daughter, I was going to a women’s clinic here in San Francisco. And, the doctor there, who I had, thought that I should terminate the pregnancy...She didn’t think I should have the baby, because of my status. And, she outright told me that..... But, as soon as she found out that I was pregnant, and because I was positive, she was, “No, you should, you should terminate the pregnancy. You shouldn’t bring a child into this world.” (Native American Participant, Age 53, San Francisco, CA)*

Many of the participants discussed that they had received negative opinions and stigma from family members or friends about women living with HIV birthing a child into the world. Participants stated that their family members responded negatively to pregnant women living with HIV, mostly due to their lack of understanding of antiretroviral therapy (ART) and its success in preventing mother-to-child transmission. When discussing negative perceptions and stereotypes about women living with HIV, one participant stated that a common stereotype that she has heard is that women living with HIV should not have children. The participant further explained:

*“That’s what they’ve always said, because your baby will be positive. If you’re HIV positive and you’re pregnant, people are like, “You should go to prison. You’re putting this disease on an innocent child.” When I was diagnosed, the odds of the baby seroconverting and staying that way were 93%. Now it’s under 10%. It’s changed. In the 1990s and that time, other HIV positive women would look at other HIV positive women who were pregnant and look down on them, like, “You bitch. How can you do that to your child?” (Multiracial Participant, Age 51, San Francisco, CA)*

## *2.2 Family-related responsibilities and stress*

Although motherhood can serve as a motivator for HIV care engagement, it is important to acknowledge that it may be a source of stress for women living with HIV. The following quotes provide examples of how mothers living with HIV have to manage and deal with child and family-related stress:

*“... I think a lot of my stressing and the anxieties, all of those things, I think that affects my health in a big way. They say that stress is not good for somebody with the virus. That’s all I do is stress, especially behind two of my sons. Every time they call me, they just oh, man, I fall apart.” (Hispanic/ Latina Participant, Age 59, San Francisco, CA)*

One participant reflected upon her experience being a temporary caregiver to her sister’s children. The participant stated that while her sister was in the hospital she had to fill in and care for her own children and those of her sister. The following quote explains the physical impact that this family-related stress had on the participants overall health:

*“It was becoming overwhelming so I kind of took them off of his hands for a while but this was right during the time when I was diagnosed so [older niece], the older daughter, was driving me freaking crazy and she started wearing my immune system down. That is what made me to end up having to go on meds. She was wearing me down. She was stressing me out. I was 21 years old with three kids, three of my sister’s kids.” (Black Participant, Age 31, Atlanta, GA)*

In some cases, participants reported feeling stressed thinking about what would happen to their child if their condition worsened. Participants feared what would happen to their child if they were to fall ill as a result of their condition, as it could have detrimental consequences to their safety. One participant reflected on what would happen to her daughter:

*“She was 16 at the time. I kept thinking; this is going to be it. Single mom, really sick. I wanted to keep her school work going. I didn't want her to end up being mad at me and going out on the streets because mommy's sick.” (White Participant, Age 57, San Francisco, CA)*

When asked the question, “Can you tell me about a time when it was difficult to balance your responsibilities as a mother in caring for your HIV, if at all?”, little to no participants discussed feeling unable to control both responsibilities. Most of the participant responses to that question was “no”. For example, the following participant stated:

*“Well actually, no. There isn't originally really a hard time because either our daughter was little in a stroller, she went with me, or growing up a little older daycare, or she's at school and I have my appointments. That was really never an issue, not even during the summer. It was*



*always something. She has camp or just something. It's never been an issue. Thank God.'* (Black Participant, Age 49, San Francisco, CA)

## Discussion

The primary objective of this secondary qualitative analysis was to examine how motherhood (including mother-child and grandparent-child relationships) poses as a challenge or facilitator to engagement in health and healthcare by women living with HIV. This study provides insight into the various ways motherhood influences medication adherence and healthcare utilization among women living with HIV across a number of geographic regions in the United States. Among the women participating in the study, motherhood and children were found to be motivators and facilitators for engagement in HIV care, whereas stigma and family-related-stress and responsibilities emerged as the most commonly discussed challenge for maintaining and improving engagement in HIV treatment and medication adherence. These findings are consistent with prior research on mothers living with HIV in the United States (Boehme et al., 2014; Edwards, 2006; Fletcher et al., 2016; Liamputtong, 2013).

Similar to the existing literature, the participants in this secondary analysis demonstrated that women living with HIV viewed motherhood as a transformative and purpose-filled role that motivated them to prioritize their health and implement life-sustaining behaviors such as adhering to medication regimens (Boehme et al., 2014; Fletcher et al., 2016). As in other studies of mothers living with HIV (Edwards, 2006), many of the participants expressed the various ways in which their children provided logistical support such as medication and appointment reminders to facilitate and support healthcare engagement. In support of that finding, existing research has found that the presence of young children is a prominent source of technical support for women with young children and grandmothers who live in the same household as young grandchildren (Edwards, 2006). In addition to providing logistical support, many participants discussed that their children were sources of strength that influenced and increased motivation

for healthcare engagement and health-conscious decision-making (Edwards, 2006; Fletcher et al., 2016; Webel & Higgins, 2012). For example, the participants discussed that staying healthy for not only themselves, but also for their children was one of the main reasons for engaging in HIV care. Studies have found that mothers living with HIV that are emotionally influenced and supported by their children reported increased medication adherence and successful appointment management (Boehme et al., 2016). Several participants expressed that their children or grandchildren inspired them to overcome mental health challenges. The role of children as sources of coping and strength have been previously reported among mothers living with HIV (Murphy et al., 2011), therefore indicating the potential benefits of including children in support groups and future interventions for mothers living with HIV.

In addition to discussing how motherhood served as a facilitator to health and healthcare engagement, the participants discussed how HIV-related stigma and family stress and responsibilities proved to be a challenge experienced by mothers living with HIV. Although there have been medical advances in regards to HIV treatment and antiretroviral medications to reduce mother-to-child transmission, women living with HIV still experience stigma from medical providers (Centers for Disease Control and Prevention, 2020; Cuca & Rose, 2016). As the study results indicate, participants described experiences in which medical providers displayed negative opinions of pregnant women living with HIV, in some cases even recommending terminating the pregnancy. A systematic review on HIV-related stigma by healthcare providers in the United States identified the role of attitudes, beliefs, and behaviors, quality of patient care, and education and training as underlying factors that influenced provider stigma in the clinical setting (Geter et al., 2018a). Additionally, limited or no HIV-related stigma training in the past 12 months was a key factor associated with stigmatizing behaviors and

attitudes among clinical providers (Geter et al., 2018a). Although, there are existing stigma reduction programs for clinical providers and healthcare workers (Batey et al., 2016; Li et al., 2013), to our knowledge there are not any focused on maternal and reproductive health providers. However, there is a need for future stigma reduction interventions and research that focuses on acknowledging and addressing the critical role of healthcare provider stigma as a barrier to engaging in health and healthcare, specifically for mothers living with HIV, to ensure retention in care.

Similar to stigma, participants described family-related stress and responsibilities as a challenge for maintaining health and healthcare engagement, as they had to balance their health needs and the needs of their children. This study aligns with the existing literature that discusses how motherhood may be a social role that negatively impacts HIV-self management among women living with HIV (Webel et al., 2012; Webel et al., 2013). The dual challenge of managing motherhood and an HIV diagnosis lessens the opportunity for engagement in health and healthcare, specifically in regard to medication adherence. Several participants explained the physical and emotional impact of caring for multiple children on their stress levels, anxiety, and overall immune health. A previous study found that the impact of caring for multiple children and having increased child care burden was associated with lower HAART adherence among mothers living with HIV when compared to mothers with less or no children (Merenstein et al., 2009). A formative evaluation of the Healthy MOMS intervention, a stress-reduction and social support intervention for mothers living with HIV, found that its participants highlighted the need for program components such as stress management, information on HIV-related parenting issues, and health education (Davies et al., 2009). Mothers living with HIV are best equipped to

provide insight that could be used to inform intervention development that is comprehensive and appropriate for their specific needs.

The findings of this study must be considered within the context of several methodological limitations. Due to the inherent nature of secondary data analysis, the data used in this study was not collected to answer the current research question (Cheng & Phillips, 2014). Therefore, it is important to note that the interview guide was not directly focused on motherhood, however participant responses and experiences resulted in the iterative development of the “*motherhood*” subcode. Additionally, the participants in the study consisted largely of women over childbearing age who were now mothers to older, adult children. Although, the study captured the perspectives of older mothers living with HIV, there is an increased risk of recall bias, or a discrepancy in the recollection of events pertaining to early motherhood years such as pregnancy (Althubaiti, 2016). It is also important to acknowledge the possibility of social desirability bias, which is defined as the “tendency to present oneself and one’s social context in a way that is perceived to be socially acceptable, but not wholly reflective of one’s reality” (Bergen & Labonté, 2019, p. 783). When discussing their role as mothers, some of the participants may have withheld challenges, perceptions, or experiences that could result in them being perceived as a failing mother. This limitation could account the overwhelming experiences of motherhood as facilitator, rather than a reflection of the challenges in the data. Lastly, although many of the experiences of the women in the current study characterized motherhood and children as motivators, it is important to acknowledge that these findings cannot be generalized to all mothers living with HIV in the United States, as everyone’s experience is unique.

Aside from the limitations, this study contributes to the existing motherhood and HIV literature by providing geographical and age diversity among the women participating in the study. Many existing studies focus on one single state or geographic region, while the current study explores the experiences of mothers living with HIV across the United States. The participants of this study were living in multiple cities and regions across the United States, varying from urban to rural cities. The inclusion of these participants provides greater geographical diversity and representation of mothers living with HIV in the United States. Additionally, many women in the study were above childbearing age. Including these women in the study allowed for the inclusion of the perspectives and experiences of grandmothers living with HIV, a less examined target population in HIV literature.

While this study found motherhood to be a facilitator of health and healthcare engagement for women living with HIV, further research should seek to focus on the role of motherhood and opportunities to overcome its respective challenges to HIV care engagement. Although there is a great amount of literature on motherhood as a facilitator, including these study results, there is a dearth of qualitative data exploring the challenges that accompany managing HIV, motherhood, and engagement in healthcare. Overall, the findings from this study provide insight that can inform and enhance public health practice models to better support women living with HIV, especially mothers. There is a need for HIV interventions and programs that address the specific and unique needs of mothers living with HIV.

### Chapter 3: Conclusion and public health recommendations

Mothers living with HIV exemplify “the cultural contradictions inherent in Western motherhood, whereby motherhood is both redeeming and damning” (Sandelowski & Barroso, 2003, p. 167). The existing literature on mothers living with HIV varies in depiction of the ways that the motherhood role impacts health outcomes. The findings from this study demonstrate that motherhood can act as a facilitator or challenge to engagement in health and healthcare for women living with HIV. To provide mothers living with HIV with appropriate resources, interventions, and clinical care, public health professionals must further their understanding of the complexities of motherhood in the context of HIV. The diverse experiences of the women participating in the study highlights the need for public health models to consider the intersectional nature of this population, the role of stigma, the influence of children, and the unique insight of mothers living with HIV to promote and sustain health engagement and support mothers living with HIV.

Given that healthcare provider stigma emerged as a challenge to healthcare engagement for mothers living HIV, the development and mandatory requirement of HIV-related stigma trainings for providers is critical for HIV care retention and engagement. Trainings and workshops during medical degree training and residency should focus on HIV-related stigma and its associated consequences for the health outcomes of mothers living with HIV. Additionally, courses on HIV-related stigma should be a continuing medical education requirement for healthcare providers renewing and validating their medical license, especially those who care for women living with HIV. Lastly, anti-discrimination policies should be enforced in the clinical setting to ensure continued engagement and retention in HIV treatment for mothers and pregnant women living with HIV. Mandatory HIV stigma trainings and anti-discrimination policies may

be effective in creating a supportive, non-judgmental clinical environment for mothers living with HIV, facilitating health and healthcare engagement.

It is critical that interventions and programs address the needs of mothers living with HIV, both as parents and as women living with HIV. A study found that formative research is essential for designing interventions that meet the needs of mothers living with HIV (Davies et al., 2009), therefore interventions should be informed by the insights that mothers themselves have provided while actively participating in the development of interventions. While mothers living with HIV are the true experts of their needs, it is important for public health practitioners to approach the complexities of mothers living with HIV through an intersectional lens. The use of an intersectional approach for intervention development will consider the intersection of experiences, identities, and statuses of mothers living with HIV. Having this comprehensive understanding is essential to promoting and sustaining healthy living, social support, stress management, and engagement in and health and healthcare for mothers living with HIV.

As a common facilitator to health and healthcare engagement for mothers living with HIV, it is important to consider the role of children in future interventions and public health approaches. Being that children played an important role in many of the participants engagement in health, this suggests that they could potentially enhance interventions for mothers living with HIV. For example, an intervention for parents with AIDS and their adolescent children was found to have lowered emotional distress and improved coping styles in response to illness-related challenges (Rotheram-Borus et al., 2001). Examples of future interventions and programs may include child-parent support groups, mentoring programs, clinical programs, and involvement in large-scale studies such as WIHS to provide women with an opportunity to share their experiences.



The findings of this study are meant to highlight the experiences and perceptions of motherhood among women living with HIV as it pertains to their health and healthcare engagement. The results of this study concluded that motherhood serves as a facilitator and a challenge to engagement in HIV care for women living with HIV. Further research on this topic would provide more recent insight on how to best address the health outcomes, challenges, and triumphs of mothers living with HIV. Lastly, the diverse experiences of the women participating in the study highlight the need for public health models to acknowledge the intersection of motherhood and HIV to better inform the development and improvement of comprehensive and appropriate interventions, programs, and clinical practice guidelines for mothers living with HIV.

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