WHO WILL CARE FOR ME?
HIV-POSITIVE MOTHERS OF COLOR, SOCIAL SUPPORT, FAMILY FACTORS, AND RETENTION IN CARE

by

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DEDICATION

To my mother Nandini Devi Dasi.
You continue to be a river of love that flows through my spirit and heart.
Thank you for all that you are…and your legacy continues!

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"What I have learned from all of the difficulties in my own life is that human beings have very thick skin. I call that skin, spirit, our highest most powerful self. Spirit is the key to everything we desire. It is our weather-proofing, our Teflon, our line of credit that assures if we just keep putting one foot in front of the other, one day; there will be a miraculous payoff." — Iyanla Vanzant

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I would like to acknowledge all 128 women who participated in the Mother's Health Study done in 1998-1999. Your efforts are not in vain and I sincerely appreciate your courage in allowing your story to influence research for HIV positive mothers.

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ABSTRACT

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Chair: Cleopatra Howard Caldwell

The purpose of the dissertation was to explore the relationship between dimensions of enacted social support, parenting stress, family factors (adaptability and cohesion), and medical appointment adherence for HIV-positive Black and Latina mothers. HIV-positive Black and Latina women demonstrate poor adherence to medical appointments and are at increased risk for dying from HIV. Chapter 2 is a literature review that examines research and intervention studies from the perspective of identifying factors important to retaining HIV positive mothers in medical treatment and care. In this chapter I also present a conceptual model that addresses potential missing frameworks, and theorizes how variables may work together to predict retention in care among HIV-positive mothers of color. Chapter 3 uses The Healthy Mother’s dataset from 1998-1999 to longitudinally investigate the direct relationship between three dimensions social support (practical, affirmational, and HIV-specific support) and adherence to medical appointments. Chapter 4 included cross-sectional analysis that examined the direct relationship between parenting stress and two dimensions of family functioning (adaptability and cohesion).

The analyses from this dissertation found that emotional support was predictive of 100% adherence to medical appointments for the sample of mothers in this study. Also, mothers who had a mental health diagnosis were two times less likely to attend medical appointments. Additionally, the results of this dissertation revealed that higher rates of family adaptability were predictive of attending 100% of medical appointments. Higher rates of family cohesion were significantly associated with not attending all medical appointments. In addition, having a partner was significantly associated with not attending 100% of medical appointments. This dissertation contributes to the literature on HIV retention in care by demonstrating through quantitative analysis that types of social support and family functioning matter and may influence mother's ability to adhere to medical appointments and stay in HIV care. The findings from this dissertation are useful to support initiatives that create more intervention programs for HIV positive mothers of color. Integrating family services and medical care and having comprehensive medical services for HIV positive mothers will help them address competing family and personal needs that may interrupt their ability to remain in care.

CHAPTER I

INTRODUCTION

Statement of the Problem

Highly active antiretroviral treatment (HAART), a combination of drug therapy cocktails that prolonged life for individuals living with the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS), was introduced in 1996 (Mahungu, Rodger, & Johnson, 2009; Mandell, 2010). The advent of antiretroviral therapy transformed HIV from a death sentence into a chronic manageable disease, and has substantially increased the quality of life for HIV-positive individuals (Adimora, Schoenbach, & Floris-Moore, 2009; Mellins, Ehrhardt, Rapkin, & Havens, 2000). Today, seventeen years later, however, not all socio-demographic groups of HIV/AIDS patients have benefited equally from this treatment (Zierler & Krieger, 1997). Globally, of the 26 million individuals who are HIV positive, only 9 million are currently benefiting from treatment (WHO, 2013). Those who remain untreated are among socially disadvantaged groups, namely ethnic minorities, women, and people of low socio-economic status (SES) (Wingood & DiClemente, 2000; Zierler & Krieger, 1997).

In the nation's capital, current HIV rates mirror those found in some of the poorest and war-torn countries, such as Rwanda and Ethiopia (Lehrer, 2012). The brunt of the HIV/AIDS epidemic, however, continues to be borne by Black men who have sex with men (MSM) and Black women (CDC, 2013a). While public health efforts are focused on the MSM community, who indisputably has escalating rates of HIV, women of color also have one of the highest rates of AIDS-related deaths, as well as the lowest HAART adherence rates and adherence to medical appointments. Nevertheless, they are less often studied in relation to issues of non-adherence and HIV retention in care (Carney, 2003; Durante et al., 2003; El-Bassel, Caldeira, Ruglass, & Gilbert, 2009).

A substantial amount of research on HIV-positive women and mothers has primarily explored patterns of behavior related to drugs and poverty as barriers to adherence (Berg, Michelson, & Safren, 2007; Gonzalez, Barinas, & O'Cleirigh, 2011; Greenfield et al., 2007; Kagee & Delport, 2010; Kalichman & Grebler, 2010; Katz, Hsu, Lingo, Woelffer, & Schwarcz, 1998; Timpson, Williams, Bowen, Atkinson, & Ross, 2010). Additionally, much of the biomedical literature refers to patients who do not adhere as “problematic”, “irresponsible”, “self-destructive”, or “misguided” (Broyles, Colbert, & Erlen, 2005; Maskovsky, 2008).

However, there are alternative paradigms that suggest that poor adherence for mothers of color may be linked to social and economic inequalities that exist within society, perpetuating poverty, racial discrimination, and inadequate access to resources (Beck, 2005; Schneider, 1998; Wallace, Gould, Fullilove, Wallace, & Fullilove, 1994; Wallace & Wallace, 2004). According to Mellins et al. (2002), HIV enters the lives of mothers already affected by a multitude of environmental and personal stressors. Circumstances such as the competing anxieties and responsibilities of daily life, family obligations, and psychiatric disorders have been recognized as critical barriers to adherence (Mellins, Ehrhardt, & Newman, 1996; Muze, 2009). Additional issues of non-adherence include struggles to keep HIV-positive individuals in continuum of treatment and care (Blashill, Perry, & Safren, 2011; Bottonari, Safren, McQuaid, Hsiao, & Roberts, 2010). The "Treatment cascade", the lack of retention in care for HIV-positive individuals, was first described by Gardner and colleagues in 2011 (Gardner, McLees, Steiner, Del Rio, & Burman, 2011). Patient data illustrate the cascade effect: Among those who are HIV positive in the United States, only 82% know they are infected; of those tested only 66% of HIV-positive people are actually linked in care; of those linked in care, only 36% actually stay in care; with 19% of HIV positive individuals achieving suppression of the virus (Gardner et al., 2011). Racial and ethnic disparities are also prevalent. Hall and colleagues (2012) found that overall 75% of persons with HIV did not have viral suppression, including 79% of Blacks, 74% of Latinos, and 70% of Whites (Hall, 2012).

Adherence and treatment success are not just contingent on taking the right pills at the right time. Another very important dynamic of successfully managing HAART medication is regularly attending medical appointments. Medical appointment attendance becomes an important link to individual adherence behaviors (Bodenlos et al., 2007; Bofill, 2010; Crawford, Sanderson, Breheny, Fleming, & Thornton, 2014; El-Sadr, Mayer, & Hodder, 2010; Gifford, White, Suarez-Almazor, & Rabeneck, 2007; Hall et al., 2012; Konkle-Parker, Amico, & Henderson, 2011). Understanding failures and challenges in medical appointment adherence is important for improving treatment success (Messer et al., 2013; Toth, Messer, & Quinlivan, 2013). This is especially true for chronic diseases that involve permanent life style changes, treatment, and care. Medical appointment attendance is fundamentally "the direct index of adherence which cuts across diverse treatment regimens", (p. 158) (McClure, Catz, & Brantley, 1999). Because managing HIV treatment can be very demanding and complex for each individual, close monitoring of disease progress and medical treatment is a critical component of successfully living with HIV. Although non-adherence is a common problem, not only among HIV patients but also among those with chronic diseases in general, most studies focus on adherence to medication rather than attendance to medical appointments (Boarts, Bogart, Tabak, Armelie, & Delahanty, 2008; Chesney et al., 2000; Dunbar-Jacob & Mortimer-Stephens, 2001; Halkitis, Wilton, Shrem, & Zade, 2005; McClure et al., 1999). Missing medical appointments can undermine the effectiveness of treatment (Lemly et al., 2007; Traeger, O'Cleirigh, Skeer, Mayer, & Safren, 2012).

HIV-positive mothers may be particularly vulnerable to missed medical appointments because they experience numerous stressors and the bulk of caregiving demands for HIV-positive children and family members (Byrd, Gerits, Moody, & Morgello, 2009; DeMarco & Lanier, 2013; Dyer, Stein, Rice, & Rotheram-Borus, 2012). The confluence of these factors creates a situation in which many HIV-positive mothers find themselves with minimal resources to take care of their families, much less manage the demands of their own illnesses (Bunting, 2001; Jones, Beach, Forehand, & Foster, 2003; Shannon & Lee, 2008). Williams (2003) reported that, for mothers, caring for their children and family members in meaningful ways overrides getting tested or addressing their own healthcare needs. Putting others first has dramatic consequences. Women often get tested too late, get sicker faster, and die sooner than their male counterparts (Durante et al., 2003). For mothers of color, the results of these pressures and choices are magnified; rates of progression from HIV to AIDS are fifteen times higher for Black and

Latina women than for their White counterparts, and Black women are twenty times more likely to die of AIDS than their White counterparts (CDC, 2013a).

Significance of Study

The current state of the HIV research focuses on maintaining HIV positive individuals in treatment and care. While advances have been made in treatment such as increased potency and decreased pill burden, the treatment cascade reveals that only one out of four HIV positive individuals are successfully navigating treatment and disparities remain among populations of color (Geng et al., 2010; Hall et al., 2012; Zuniga, 2012). HIV positive individuals engaging in a continuum of care is vital to decrease HIV viral loads and to staying healthy (Gifford et al., 2007). New data from the treatment cascade is now used to allocate resources and funds at the government level (The White House, 2010), but little is known about medical appointment attendance among HIV-positive mothers of color. Therefore, this study is the first of its kind to investigate how dimensions of social support and family dynamics may influence HIV-positive mothers' choices to attend medical appointments over time. This study contributes to the knowledge base by considering cultural and gendered perspectives such as dimensions of social support and family factors which have been identified as significant in the lives of HIV-positive mothers of color.

The theoretical premise for this dissertation is as follows: The strategies that Black and Latina mothers have used in maintaining families and social networks deserve special consideration within a framework of HIV adherence research—specifically, living with HIV may threaten the relationships and roles that provide meaning and value to their lives. Through adapting a socio-cultural representation of the stress and coping model, this dissertation will incorporate structured inequalities as a way of illuminating distinct coping mechanisms that may be salient in the lives of HIV-infected Black and Latina women, and that may impact their adherence behaviors. This dissertation will also highlight and test salient factors that may influence HIV-positive mothers of color ability to adhere to all their medical appointments.

A Note on Terminology

It is implicit that HIV-positive women do not represent one homogeneous group (Fee & Krieger, 1993). This study limits its focus to some unique subcultures among Black and Latina mothers, and the experiences that mothers within such subcultures may undergo living with HIV and AIDS. Recognizing there is no one single description of Black people (Wright, 2004) –I use the term Black "to express the collective experiences of people who are bound, not geographically, but in relation to their common experience of societal discrimination and historical oppression (pg. 2)" (Gilbert, 2003). For the purposes of this study, Latinos are defined as a diverse group of mothers from Latin America consisting of varied immigration histories, family structures, and levels of acculturation (Kelly, 2009).

The Census definition for Latinos are people who classify themselves as Spanish, Latino, or Hispanic or consider themselves Mexican, Cuban, or Puerto Rican as well as those who consider themselves of another Hispanic, Latino or Spanish origin such as Spain, South America or the Dominican Republic (Census Bureau, 2010). Using the definition of the Census Bureau in 2010, Blacks or African Americans are broadly defined for this study as people having origins of African descent (Census Bureau, 2010).

This study also recognizes HIV as a chronic life threatening disease that can vary in time, severity, and treatment management (Scandlyn, 2000). Recognizing HIV as chronic illness, because of its complex nature, implies that management requires mobilization of support systems, which may include family, health care providers, and other social services (Lanoix, 2013; Magnus et al., 2001; Pequegnat et al., 2001; Roger, Migliardi, & Mignone, 2012; Szapocznik et al., 2004). Thus, this study investigates different dynamics of social support in relationship to appointment attendance adherence- a critical component in the management of HIV.

Organization of Dissertation

The overarching goal of this research is to examine different dimensions of enacted social support, parenting stress, and family functioning, important factors which may inform patterns of adherence to medical appointments for mothers of color. In Chapter 2, I offer a literature review that provides an overview and critique of medical appointment adherence through the cultural prism of motherhood. This review responds to the need for a more in-depth analysis of the political, economic, and social factors that may affect the management of HIV/AIDS for mothers of color. The conceptual model for this study focuses primarily on structural and individual-level of analysis to understand the stress and coping process of HIV-positive mothers of color. The chapter first presents a critical review of the literature on HIV retention in care; this is followed by a discussion of an alternative framework that considers both previous and unexplored patterns of self-care among HIV-positive mothers of color, and challenges traditional assumptions concerning their non-adherence to medical appointments. This chapter then presents a model that examines retention in care for HIV-positive mothers of color.

In Chapters 3 and 4, I develop two distinct, quantitative papers that test the role of key predictors on medical appointment attendance; these include dimensions of enacted social support, parenting stress, and family factors (adaptability and cohesion). In both chapters, I use analysis from a secondary data source called the Mothers' Health Survey, which is a part of the Office of AIDS Research data set from 1998-1999.

Specifically, in Chapter 3 I test the direct or main effects of different dimension of enacted social support (practical, support, emotional support, and HIV-specific support) on HIV-positive mothers' adherence to all medical appointments after controlling for socio-demographic and mental health variables. This study also examines the influence of practical, emotional, and HIV-specific support overtime on a mother's attendance to all medical appointments.

In Chapter 4 of this dissertation, I investigate the socio-familial environment of HIV-positive mothers by examining the roles of parenting stress and family factors on HIV-positive mothers' ability to attend all their medical appointments. This is a cross-sectional study that explores the potential effects of the family environment on medical appointment attendance, which can play a significant role on HIV-positive mothers' ability to effectively adjust to and manage living with HIV (Abell, Ryan, & Kamata, 2006; Bunting, 2001; Carney, 2003; Gibson-Davis, 2008). Studying the role of family functioning and family cohesion specifically highlights the levels of bonding, support, and adaptability family members may have with each other. It also may illuminate ways in which these factors influence HIV-positive mothers' ability to manage medical appointments.

Mothers' Health Study (1998-1999)

The Mothers' Health dataset was developed early in the era of HAART treatment, and holds valuable information about understudied dimensions of enacted social support, parenting stress, and family functioning among mothers of color. The dataset was selected because it contained significant variables of interests including a broad range of demographic, socio-economic, clinical, and social indicators. This dataset was created using 128 HIV-infected mothers from inner city clinics in New York City. In order to be eligible for the study, women had to be HIV positive and mothers of children less than 18 years of age. Mother participants were initially asked to participate in a follow-up study four to five months later. One hundred and twenty-eight mothers completed the study at baseline; 113 mothers completed the study at the first follow-up; and 97 mothers completed the second follow-up, which took place eight to 18 months after the first follow-up wave. The time of the second wave varies significantly because that phase of the study was not originally planned and it was, therefore, difficult to locate and contact mother participants over the extended period of time. Comprehensive analysis of this dataset with regard to the role of these contextual factors provides a unique opportunity to understand HIV from the perspective of mothers and family systems.

Conclusion

To better understand the challenges that HIV-positive mothers of color face with managing the demands of HIV, as Bowman (2007) articulates, it is vital to address the context, choices, and roles of individuals placed in socially structured (gender, ethnic) inequalities. Many mothers of color infected with HIV come from a place of extreme deprivation, abuse, and hardship; this extreme inequality and trauma must be placed in context (Boyle, Bunting, Hodnicki, & Ferrell, 2001; Hackl, Somlai, Kelly, & Kalichman, 1997; Mellins et al., 2000). Most women are also contracting HIV within relationships and families as mothers (Antle, Wells, Goldie, DeMatteo, & King, 2001; Hackl et al., 1997; Mueller et al., 2009); therefore understanding the larger context in which these mothers live and are managing their disease may provide useful information on how they may develop better ways of coping and managing the disease. This study offers merit in identifying salient gaps, stressors, and ways of coping that may influence patterns of medical appointment attendance for mothers of color. Ultimately, this study adds to the knowledge base of HIV treatment and care for mothers, providing a more in-depth understanding of ways to assist HIV-positive mothers in their care, to benefit from their treatment, and to prolong their lives.

CHAPTER II

A REVIEW OF RETENTION IN CARE FOR HIV-POSITIVE MOTHERS OF COLOR

Scope of the Problem

HIV retention in care, broadly defined as the ability to adhere to medical appointments and remain in medical care, is currently described as the greatest challenge facing women of color in the United States (Andersen et al., 2007; CDC, 2013a; Kempf et al., 2010; Rotheram-Borus, Rice, Milburn, Stein, & Sánchez, 2010). AIDS remains a leading cause of death for Black and Latina women, yet public health efforts continue to grapple with how to effectively keep women of color engaged in HIV treatment and care (Konkle-Parker, Amico, & Henderson, 2011).

Reports of national data released from the Centers for Disease Control (2013) state that improvements in intervention efforts are greatly needed for HIV-positive individuals along the HIV care continuum—which includes testing, linkage, treatment, and reengagement. However, within this spectrum of care, nearly two-thirds of individuals are not in on-going care and only one-quarter of the diagnosed population have effectively controlled the virus (Zuniga, 2012). In response to this growing epidemic in the United States, the Office of National AIDS Policy has established the HIV Care Continuum Initiative to ensure that federal resources are implementing programs and evidence-based interventions that will improve outcomes for retention in care for HIV-positive individuals (The White House, 2010). The overall goals of this initiative, as stated by National HIV/AIDS Strategy, are to increase the number of newly diagnosed patients linked to clinical care from 65% to 85%, and to increase the proportion of Ryan White HIV/AIDS program clients who are in continuous care from 73% to 80%. The policy also has specific language to increase the proportion of HIV-diagnosed Blacks with undetectable viral loads by 20%; to increase the proportion of HIV-diagnosed Latinos with undetectable viral loads in care by 20%, and to increase the proportion of HIV-diagnosed gay and bisexual men with undetectable viral loads in care by 20% (The White House, 2010). The policy acknowledges that women of color are disproportionately infected with HIV. It also states that women are less likely to engage in HIV care than men and that gender disparities and differences need to be addressed. The policy also suggests that HIV positive mothers should be screened and tested to prevent mother to child transmission. However, the National HIV/AIDS Policy's overall goals for the Continuum in Care Initiative do not specifically address improving engagement in care for mothers or for women in general. The policy has one sentence that addresses *family-centered needs* of HIV-positive women, but does not outline a plan to respond to the needs of HIV-positive *mothers*. However, there was an initiative started by Health and Human Services to study retention in care among women, but no studies are available from this initiative at this time. Given the state of the epidemic among HIV-positive mothers, it is important to determine how research and intervention programs can be tailored to effectively meet the unique needs of this population.

The goal of this review is to identify important constructs and interventions that specifically address adherence to medical appointments for HIV-positive mothers of color. The review will offer insight into research gaps for this population and implications for appropriately addressing the needs of HIV-positive mothers of color. The current state of the literature calls for research that addresses the full range of diverse experiences among HIV-positive women, including mothers. As Stampley and colleagues (2005) assert, "the ability of women to hear, internalize, and act on prevention messages must be explored in the context of their social roles, life stages, and experiences" (p. 296). Therefore my overall research questions are as follows: *(1) what factors predict adherence to medical appointments for HIV-positive Black and Latina mothers? (2) How are research and intervention studies capturing and responding to HIV-positive mothers of color? (3) Are these interventions demonstrating improvements in adherence to medical appointments for mothers of color?*

In order to address these questions, this chapter is organized in three sections. The first section reviews the literature and identifies current knowledge and dominant themes as they relate to HIV retention in care for HIV-positive mothers. Research in this section is organized under the following rubrics: HIV Retention in Care; Motherhood; and Facilitators and Barriers of Retention in Care for Women. In the second section, I examine research and intervention studies from the perspective of identifying factors important to HIV retention in care for mothers. Also in the second section, I present my methodology for critiquing retention in care for research and intervention programs. In the third and final section of the review, I present a conceptual model that addresses potential missing frameworks, and theorizes how variables may work together to predict retention in care among HIV-positive mothers of color. I end this review with policy implications and suggestions based on my findings.

HIV Retention in Care

In order to understand retention in care among HIV-positive mothers, it is important first to understand how research has conceptualized and measured retention in care as documented in the present body of literature.

HIV retention in care is central to understanding how individuals manage HIV; it encompasses the *continuum of care* from first getting tested and diagnosed with HIV to staying in HIV care (Mugavero, Amico, et al., 2012). The goal in participating in this continuum of care process is to reach complete viral load suppression and to successfully manage HIV (Higa et al., 2012). The effectiveness of HIV treatment is significantly associated with adherence to medical appointments and treatment regimens (Bastard et al., 2012; Catz, 1997; Jones, Cook, Rodriguez, & Waldrop-Valverde, 2013; Traeger, O'Cleirigh, Skeer, Mayer, & Safren, 2012). A study conducted by Gifford et al. (2007) reveals that patients who exhibited poor adherence to medical appointments compared to those with good adherence (as measured by attending at least one clinical visit every six months) were twice as likely to die from HIV. Patient retention was also associated with decreased transmission of the virus, prevention of drug resistant strains of the virus, and lowered emergency healthcare costs and hospital visits (Poon, Dang, Davila, Hartman, & Giordano, 2013).

Operationally, patient retention is commonly measured in the literature as missed appointments, missed visit rates, or the percentage of patients who miss appointments over a defined period of time (Mugavero, Davila, Nevin, & Giordano, 2010; Mugavero, Westfall, et al., 2012). Currently, there is no “gold standard” for measuring appointment attendance (Mugavero, Westfall, et al., 2012). Research studies vary as to how they define and measure medical appointments, i.e., whether they include and account for all appointments related to care, such as blood work or follow-up, primary care visits, and nurse visits, or whether they only measure appointments with doctors related to HIV treatment and care. Hortsmann et al. (2010) point out these inconsistencies in how missed medical appointments are measured raises questions as to which appointments matter to reach viral suppression (Horstmann, Brown, Islam, Buck, & Agins, 2010). Addressing specific measurement issues is beyond the scope of this chapter; however, while the literature clearly indicates inconsistencies in *what* is measured, it consistently shows that missed medical appointments range from 25-35% (Horstmann et al., 2010). Such levels of missed treatment may certainly impact the intended treatment outcome of viral suppression as 90-95% of adherence is needed to successfully manage the virus (Bofill, Waldrop-Valverde, Metsch, Pereyra, & Kolber, 2011; Dietz et al., 2010).

Question 1: What factors are important to include for HIV positive mothers of color? In order to effectively address this question, I will examine the literature on motherhood and adherence to medical appointments for HIV positive women of color.

HIV-Positive Mothers: The Importance of Examining Motherhood

In this section, I lay the foundation for examining HIV appointment adherence from the perspective of motherhood. As Castillo and colleagues (2010) convey, the key to an effective intervention is to understand a person's cultural value system. Because the literature on motherhood is extensive, multi-faceted, and complex, I will briefly highlight important theories and frameworks as they relate specifically to women of color. I acknowledge that Black and Latina mothers, while obviously racially and ethnically different, also vary further by social class, age, region or country of origin. Nonetheless, the experiences of historical oppression, racism, and discrimination in the United States which all women of color have faced influences their core values of mothering and family roles. Therefore, these roles and identities require careful exploration in the larger HIV appointment adherence and self-care discourse.

One goal of this dissertation is to identify and investigate the fundamental causes of barriers to HIV appointment adherence for women of color. A common criticism in understanding the behavior of HIV positive women of color is that their identities are often studied in isolation and not in tandem with their lived experiences. For example, how do identities of being mother, woman of color, poor, HIV positive, wife, patient, and many others interact and help to explain their choices and behaviors in managing HIV?

The intersectionality approach considers helps to engage this research from the vantage point of considering some of the many identities of HIV positive women of color. In order to understand the relationship, for example, between class, gender, and race, Mullings (2005), suggests that the intersectionality approach allows for the examination of “multiplicative” or “interactive” effect that demonstrates the historical impact of multiple forms of oppression instead of as stratified characteristics that merely describe women of color. Exploring the multiplicative social identities and lived experiences of women helps to acknowledge and recognize their unique perspectives as mothers. The approach can also help to describe how contextual and cultural factors are interconnected and can influence individual behavior.

Across all racial and ethnic groups, mothering is largely described as a culturally constructed concept that influences all aspects of women's lives (Reichert, 2007b). Mothering also constitutes a large part of women's identities (Reichert, 2007b). A schema of theories, such as Intersectionality, Feminist Theory, Black Feminist Theory, and Historical Womanist Theory, all contribute to a deeper and broader understanding of women's roles as mothers being uniquely situated in their social, political, and economic experiences in the United States (Collins, 1998; Mullings, 1997; Rousseau, 2013). Additionally, there are overlapping experiences of race, class, and gender that influence experiences as mothers (Collins, 1987). These theories emphasize that experiences of motherhood for Black and Latina women must be understood within a broader social context. Many social and feminist theorists assert that the strategies women of color use to mitigate or maneuver their direct experiences of oppression, discrimination, and marginalization have shaped their core values, roles, and identities as mothers (Castillo, Perez, Castillo, & Gosheh, 2010; Chaney, 2011; Settles, Pratt‐Hyatt, & Buchanan, 2008; Woods-Giscombé, 2010). For example, in *Black Intimacies: A Gender Perspective on Families and Relationships*, Hill (2005) explains the importance of motherhood in the context of women of color's experiences in the United States:

> Poor women of color often have few resources or hope of fulfillment in their lives, but the oppression they experience usually does not deprive them of their procreative abilities, and pregnancy and giving birth are profoundly powerful acts. Moreover, motherhood is a significant marker of womanhood. It provides a respectable social identity, and important set of child-rearing tasks, access to kin networks, and space where authority, a

> sense of control, and self-expression can be cultivated (p. 17) (cited in Chaney, 2007).

In line with Hill's (2005) statement, Collins (1987) explains that pervasive cultural stereotypes attached to Black and Latina mothers, such as being single, promiscuous, having multiple children, and being on public assistance, have impacted perceptions of them as women and mothers. In their efforts to resist and redefine such stereotypes, communities of color instead idealized motherhood as a role defined by a strong, competent, resourceful, and dignified woman (Collins, 1987). Another perspective (Reichert, 2007a) is that of "defensive mothering" or "protective mothering" in which one role of motherhood is to ensure their families' and children's survival in an extremely hostile society.

An extension of these protective mothering practices, specifically Black mothering practices (Collins, 2006), was noted as "other mothering" or extended kin networks, where mothers protected and provided for all members in the larger community. In order for families to survive in meaningful ways under oppressive policies and discriminatory practices, family and community support became paramount.

Another growing discourse pertinent to this research concerns the consequences of cultural representations of motherhood as related to potential health risks for women of color (Geronimus, Hicken, Keene, & Bound, 2006; Kelly, 2009; Mullings, 1997; Woods-Giscombé, 2010). The constructs of *marianismo* for Latina women and *the superwoman* for Black women address issues of coping, mainly during times of adversity, while maintaining their family and gender roles. For Latina women, *marianismo* represents the iconic figure of the Virgin Mary and ideas of self-sacrifice (Kelly, 2009). It is seated in

Latino cultural values of *familismo* and *respeto*, which emphasize loyalty, respect, and sacrifice for your family first (Castillo et al., 2010). Cultural representation of *mariansmo* for Latina women exhibits the role of a mother as self-sacrificing for the wellbeing of the family. Also implicit in this construct is obedience, strength, and capability as a "good mother" or "*la mujer buena*" (Castillo et al., 2010). Sacrificing and suffering for the family is equated with respect and honor. These and other researchers have also associated the construct of *mariansmo* with depression, lack of physical activity, partner violence, and HIV/AIDS (Castillo et al., 2010; D'Alonzo, 2012; Kelly, 2009).

Similarly, in Black culture, the construct of the *superwoman* represents an idealized Black woman's ability to keep themselves and their families afloat, sometimes with few resources, and to remain vigilant and intact amongst insurmountable odds. A body of scholarly work (Chaney, 2011; Collins, 1987, 1998, 2006; Woods-Giscombé, 2010) has explored the performance of the superwoman as paramount to Black women, as it asserts their self-worth and value in a climate of racism and disenfranchisement. Theories and frameworks expanding from this superwoman construct have also been espoused in relationship to health risks (D'Alonzo, 2012; Geronimus et al., 2006; Kelly, 2009; Mullings, 2005). The framework of the "weathering hypothesis," for example, suggests that the additive effects of surviving discrimination, racism, and healthcare inequities place women at higher risk for stressors and chronic diseases (Geronimus et al., 2006). Another example, the *Sojourner Syndrome* is a framework Mullings (1995) coined in honor of Sojourner Truth, a woman, emancipated slave, and great orator who was known for making great contributions as an abolitionist while overcoming personal suffering and oppression. Mullings (1995) notes that the Sojourner Syndrome acknowledges the constraints and resilience that have characterized the Black experience in America, and thus, provide a more inclusive framework to understand intersecting forms of oppression for women and the consequent higher risks of preventable diseases among Black Americans.

These role identity studies for both Black and Latina women identify culturally mediated values of motherhood, sacrifice, and strength that are missing within the HIV medical adherence discourse. I feel that the two constructs have similarities, in that they are inherently complicated and acquire further complexity due to structural inequities and health disparities. It also translates into addressing important issues and key roles such as parenting, family functioning, and social support that offer insight into barriers and facilitators of care for Black and Latina mothers.

Question 2: How are research and intervention programs targeting the needs of mothers of color? Question (3) Are these programs effective in retaining mothers of color in HIV care?

Research and intervention programs are important to evaluate because of the implications on providing appropriate care and saving lives of women of color who are disproportionately infected and affected by HIV and AIDS. Considerable research on HIV retention in care has identified demographic variables that predict medical appointment attendance (Catz, 1997; Hall et al., 2012; Israelski, Gore-Felton, Power, Wood, & Koopman, 2001; Konkle-Parker et al., 2011; Mugavero, Amico, et al., 2012; Mugavero et al., 2010; Poon et al., 2013). These studies, using national representative samples, have shown that those of low socio-economic position (education and income), ethnic minorities, women, youth, heterosexuals, and substance abusers, are groups highly associated with poor adherence to medical appointments. Identifying correlates that predict HIV retention in care is a critical first step to creating targeted intervention programs; but such research will not provide the necessary in-depth analysis of what is needed to increase retention in care for mothers.

In this section, I use the current findings on retention in care among women and mothers of color to investigate whether research and intervention programs are actually addressing important issues such as social support and social networks, childcare or parenting responsibilities, and family dynamics as previously highlighted in the literature for HIV-positive mothers of color.

Methods

The methods I used for finding and analyzing relevant articles were searches conducted in March of 2014 that cross-referenced several databases, including PubMed, Ebscohost, ERIC, Medline, Cochrane, and Google scholar. These searches sought to identify reports published from January 1996, when antiretroviral medication became available for treating HIV, to the present. Studies were included if they met the following criteria: (a) based in the U.S., (b) focused on women or mothers, (c) included Black and/or Latina women, and (d) had a main goal or one study goal of retaining participants in HIV care or increasing appointment attendance. Selected studies also needed to include empirically tested findings and significant findings from the study. The key words I used for this analysis were: Latina, Latino, Hispanic, Black, African American, women, mothers, HIV, AIDS, HIV retention in care, retention in care, missed medical appointments, appointments, adherence to medical appointments, adherence, and interventions. Studies were excluded if they focused only on specific populations such as prison inmates or IV drug users, which are different groups than those of interest to the current study.

Research Studies

In my search, I identified two emperical studies that focused specifically on mothers of color (Boehme et al., 2014; Mellins et al., 2003); however, a burgeoning body of work addresses facilitators and barriers to retention in care for women generally, which may address prominent issues for mothers of color.

One study conducted specifically on HIV-positive mothers focusing on adherence to medical appointments and HIV medication was conducted in 2003. Using the Healthy Mother's project conducted from 1998-1999 on 128 HIV positive mothers, Mellins and colleagues (2003) found that parenting stress, any psychological disorders, number of individuals in a household, and stressful life events were significantly associated with missing medical appointments and low medication adherence.

This study was one of the first to utilize a dataset on predominately HIV-positive mothers of color with variables that included family factors and parenting factors. This study was also longitudinal, helping to capture how variables interact over time and influence medical appointment attendance. A considerable limitation of this study involves its design and duration. The three waves of data captured very small intervals of time that varied from 8 to 18 months, meaning data were only collected for a year and a half—a relatively short period of time for a longitudinal study to identify and analyze meaningful changes.

Although the Boehme et al. (2014) study does not state that it specifically focuses on mothers, it examined barriers and facilitators for medical appointments for postpartum women. Women are considered postpartum if they have delivered a baby within the last six weeks. This sample consisted of 18 new mothers, predominately Black, single, and making less than $1000/month, and receiving care from clinics in Alabama. The study consisted of both focus groups and individual interviews, with open-ended questions on barriers and motivators to attending medical appointments and remaining in care (Boehme et al., 2014) This group of mothers revealed that major motivators and barriers to care focused on childcare needs and demands of their new babies. Some women reported staying in care because their baby's health depended on their health and wellbeing. Other women reported that taking care of their baby presented major challenges in their own continuing care after returning home, i.e., the demands of keeping up with their baby's appointments, as well as their own appointments, were overwhelming. Additionally, family support was noted as both a facilitator and barrier of HIV care, i.e., whether support was available. Also, appointment reminders were noted as a helpful facilitator to care.

The Boehme et al. (2014) was the only study I could find with a sample of HIV-positive mothers that also addressed facilitators and barriers for retention in care. An insightful component of this study is that a "catch-all point" for many HIV-positive women to enter treatment is prenatal care. However, after birth, the demands of their family and new baby may pose major risks for falling out of care and not returning until symptoms worsen. Most importantly, this study highlights a critical time to address all the components in the treatment cascade. First, many women get tested in prenatal and then begin treatment to prevent transmission to their child. However retention over time remains a problem. This study addresses when a major barrier to care can occur and thus, where an intervention to keep women in care could be most effective. It also would have been useful to address mothers not only at postpartum but perhaps extending the study for mothers through their child's first year of life. Extending the study to the first year of the child's life would provide more data to analyze patterns of adherence capturing more appointments at least six months apart.

Several other qualitative studies give insight into challenges of retention in care for women (Konkle-Parker, Amico, & McKinney, 2014; Messer, Quinlivan, Parnell, & Roytburd, 2012; Messer et al., 2013; Squires et al., 2011; Toth, Messer, & Quinlivan, 2013). Squires and colleagues (2011) conducted a cross-sectional study of 700 HIV-positive women (43% Black, 28.5% Latina, and 28.5% White) with average age of 42 years. The study's objective was to identify and describe perceived attitudes and opinions about health needs of HIV-positive women in the United States. All women in the study were receiving HIV care or on HIV medication. The study data were derived from 15-minute phone survey interviews with a list questions about experiences with healthcare providers, reproductive and family planning, and emotional aspects of living with HIV. In this sample, 39% reported having children living in the home and 52% identified themselves as a caregiver. Fifty-seven percent of the sample reported being pregnant, thinking of getting pregnant, or had been pregnant. Fifty-nine percent of the sample believed that society felt they should not have any children and that their race or ethnicity had control over the type of care they would receive. Other interesting findings in the sample were that the majority of White women identified with therapy as a main source of support and coping, while Hispanic and African American women identified with social support from family and friends. A majority, 73%, also reported that HIV was a daily struggle and very difficult to manage. Most women reported feeling afraid that they would lose their children while trying to effectively manage their HIV, which may explain why they choose to seek treatment late.

Considering that many women were concerned with reproductive, childbearing, and caregiving issues, this study could have asked more in-depth questions as to why these factors were barriers in their lives. One of the main strengths of this study, however, is that it consisted of a large sample size, 700 women, across different ethnic and racial groups. This was key in identifying cultural differences, such as differences in women's sources of social support. This finding illustrates that cultural differences are critical in understanding women's experience of barriers and facilitators to care. For Black and Latina women, social support groups or therapy may not be the most effective interventions to address their issues. This study also demonstrated that reproductive and caregiving issues are of major concern for HIV-positive women, which is reflective of the literature on mothering for women of color.

A qualitative study that addressed retention in care along the HIV continuum of care (testing, engagement, treatment, and reengagement) was designed to also identify barriers and facilitators along each step of the continuum of care for women of color (Quinlivan et al., 2013). Using Self-Determination Theory, which states that people are more willing to change behaviors when they feel autonomous, competent, and protected, this study hypothesized that the core constructs of Self-Determination Theory would be present in women's experiences with retention in care. The qualitative instrument had specific questions about experience engaging in medical care and experiences with HIV care. To get comprehensive information from all participants, 11 women participated in a structured interview and 19 women participated in semi-structured phone interviews, for a final sample of 30 women. This study included an innovative approach to studying retention in care, by attempting to match or connect themes from qualitative responses of women along the continuum of care. Along the continuum of care -*entry to care* and *getting tested* was connected with fear and stigma of HIV. Retention in care was associated with competency needs such as transportation, logistical skills (e.g., how to maneuver a large health clinic), balancing personal responsibilities, and finances. Education and social support were mentioned as significant facilitators of care along each part of the spectrum of care. Alternatively, no social support and poor education by providers were mentioned as barriers. Transportation issues, lack of money, and childcare were also mentioned as significant barriers. Interestingly, this study reported that motivation was present in 92% of respondents as discussing both barriers and facilitators to care. Motivations as barriers related to family needs and responsibilities were also reported.

This study is one of the first to identify specific needs for HIV-positive women of color by directly asking them about their challenges to engaging in or remaining in care. While the needs of mothers aren't specifically addressed in this study, family obligations and support remain reoccurring themes in findings among HIV-positive women of color.

Another qualitative study (Kempf et al., 2010) examined barriers to HIV care for 39 HIV-positive women in 23 counties in rural Alabama. Using in-depth focus groups and probes, findings mirrored those of previous qualitative studies, i.e., that transportation, relationships with medical providers, social support, and relationships with children and family members influenced decisions to stay in care. The strengths of this study were its large sample size for a qualitative study (n=39) and its focus on women who had frequent no-shows to make sure it was representative of women who had issues remaining in care. Most of the women in this study were over 40 years of age, single, high school educated, unemployed, made less than $10,000, and had been living with HIV for at least 8 years. The majority of the women in the study were also African American; only 3 women participants were white.

This study is also significant because it addresses an older population of HIV-positive women and may reflect issues prevalent in the deep, rural South. Pregnancy and reproductive issues were not paramount in this study, and family and childcare were not presented as major themes but were mentioned by women during the focus groups. This could be due to the age of the participants in the focus group. Social support and family support were prominent themes.

These studies mark a first important step in analyzing issues of retention in care for HIV-positive mothers of color; they break new ground in helping to synthesize and unpack critical issues for these populations. All of these studies point to contextual issues experienced by HIV-positive women, including issues of family obligations, family support, transportation, and logistical issues for HIV care. Doctor-patient interaction, while not a focus of this study, was also recognized as paramount to seeking care and staying in care, a very critical issue but beyond the scope of this study. More quantitative research is needed to test constructs that are addressed in these qualitative studies. Further, more studies are needed that focus specifically on samples of mothers and are designed to specifically highlight their unique successes and struggles with staying in HIV care.

Intervention Studies on Retention in Care for HIV-Positive Mothers of Color

Empirical studies, both qualitative and quantitative, suggest that mothering, forms of social support, family functioning, and childcare responsibilities are critical factors for adherence to medical appointments and self-care behaviors. This section evaluates how well intervention studies are capturing and incorporating factors that can influence and predict adherence to medical appointments for this population. Evaluating research and intervention is imperative to understand the state of the literature, the quantity and quality of programs, and the effectiveness of reaching HIV-positive mothers.

One critical issue in the literature addressing intervention studies on HIV-positive mothers is that most studies on HIV-positive mothers address mothers as vectors of transmission. For example, mother-to-mother transmission, breastfeeding, and implications of HIV-positive mothers on children's health or family functioning remain the prevailing strategy to approach studying this population. This is problematic for several reason: (a) it overlooks the health of the mothers by focusing on how they can infect or disrupt others lives (b) it negates the importance of mothers' perspectives in keeping themselves healthy- a critical component of family functioning, by focusing on the mental health of other family members, and (c) it focuses predominately on biomedical outcomes such as numbers of mothers who did not infect their children with HIV. Therefore, the intervention studies discussed here are limited to those that address strategies critical to increasing medical appointment attendance for HIV-positive mothers.

Based on my selected methods, I found six intervention studies that matched most of my research criteria. Overall, my search results found no intervention studies that met all my research criteria of retention in care for an exclusive sample of HIV-positive mothers of color in the United States. There was one intervention study that focused on women. Five additional studies are included in this review because they were U.S. based, included women in the sample, included people of color in the sample, and focused on retention in care (adherence to medical appointments). Five studies were dismissed from the review because they focused on youth, transgendered women, female substance abusers, or incarcerated women, all of which represent different demographic issues. Of the studies that included women, major limitations were that the intervention studies had less than 50% inclusion of women in the sample population. In all there were six intervention studies that met my criteria for focusing on issues that may reflect the needs of HIV-positive mothers of color. The following section provides an overview for findings of the six interventions that address most of my research criteria, including how well they address family factors, social support, and parenting for HIV positive mothers of color.

Outreach Interventions

The Personal Nursing Light Model Intervention

Andersen et al. (2007) had a study sample of all women, predominately drug users, who needed HIV-related medical services. It is the only intervention study that nearly met all of my inclusion criteria for this analysis. The study’s intervention program used “hyperlinking,” a way of connecting women to all the support services they needed to remain in care, such as scheduling appointments, transportation, childcare, and substance abuse support. Nurses were trained to give informational and emotional support by encouraging women to care for themselves. Another important component of this program was that it was linked with community-based organizations and stakeholders in the community that were familiar to the women participants and that they were comfortable with helping them navigate services. Women clients who were already successfully in care were paid to provide childcare at the clinics in a “friendly home-like” environment, while the women participants went to their appointments. The demographics of this study (N=81) were: 99% of the sample were Black, 24% reported being homeless, 90% reported substance use, and 76% reported a history of mental illness.

This was a six-month intervention that assessed increase in medical appointment attendance by providing transportation. Measurements used to evaluate this intervention were the self-evaluation on depressive symptoms of the psychological stress and well-being scale. Retention in care was measured by nurses’ evaluation of the likelihood of participants’ following-up with appointments and referrals after being in the program for six months. It was also measured by a self-report of attending at least two appointments in the past six months.

At the six-month mark of the intervention, significant findings from the study showed that women were able to follow-up with appointments on their own, participants’ overall sense of wellbeing improved, and they were able to schedule follow-up appointments on their own. It would have been helpful had more analysis been done with demographics of women in the study and clinical follow-up to see whether women actually did stay in care over time. Another notable limitation is that there was no control group in the study. However, this intervention study reflected the importance of support resources coming from within women's own social network. Assuring that community members and other community stakeholders provided transportation and other forms of practical support may have influenced the success of this program. While this study did not focus specifically on mothers, family-based needs and social support were clearly critical components of this intervention program. The study also demonstrated some success in women scheduling and committing to their medical appointments. However, these results were not tested for statistical significance.

Outreach Evaluation Study

The Naar-King et al. study (2007) evaluated the effectiveness of several intervention outreach programs in improving retention for newly diagnosed HIV-infected persons in care. The study sample (N=104) included people from several outreach intervention programs in Portland, Oregon; Detroit, Michigan; Washington DC; and Los Angeles, CA. A convenience sample was selected from each outreach program. The outreach programs were reported to have focused on stigma, HIV education, and helping participants access resources, such as housing and public services. Most participants in this study had been diagnosed with HIV in the past 3 months; 15% of the sample was female, 68% identified as gay; and the average age was 31. Sixty percent of the sample was Black, 29% were Latino. Educationally, 36% had less than a high school education and 38 % had a high school diploma. Fifty-six percent of the sample was substance users.

The study used both medical extractions and self-reported measures to see whether participants attended at least one medical appointment in the past six months (Naar-King et al., 2007). Significant findings revealed that people over 30 and non-drug users were associated with improvement in medical appointment attendance. Very little detailed information was given about the outreach interventions, or the methods used to engage their population. The methods in this evaluation vary greatly and there is no way of knowing what intervention could have been more effective. The outreach method may be addressing issues of social networks by providing support and resources through outreach. The intervention program demonstrated outreach approaches to getting HIV positive individuals to enter care that may be successful. However, there were no significant findings in this study for women.

Case Management Interventions

Antiretroviral Treatment Access Studies (ARTAS I & II)

ARTAS- I

The Antiretroviral Treatment Access Study, was conducted from 2001-2003. It was a multi-site intervention trail (Atlanta, Baltimore, Miami, and Los Angeles) (Gardner et al., 2005) that explored the efficacy of case management for newly diagnosed HIV-positive individuals (N=319) found that patients who were randomly selected into case management (N=157) were also twice as likely to engage in care than the control group (N=159). This intervention included women and measured retention in care by self-reported measure of people who attended at least two visits within a 12-month period. The study took self-reported measures at both the 6-month and 12-month follow-ups. They retained 86% of the sample throughout the study period and reported no significant differences found due to attrition. The study also followed up with clinical records to make sure they were getting accurate findings. Logistic regression was used to analyze whether or not a participant went to a medical appointment visit in the last six months.

One of the strengths of this study is that it included both Latino (28%) and Black populations (86%); however, only 27% of the sample was female. The control group received an HIV resources pamphlet and information on HIV clinics. The intervention group received up to five visits in a 90-day period with a case manager. The average number of case manager appointments for each participant in the intervention group was 2-3 times.

Demographic variables significantly associated in this study with retention in care from the intervention group included age over 40, Latinos, people diagnosed with HIV within the last six months, and non-crack users. This intervention provided an opportunity for HIV-positive individuals to link to care and to get other resources and support through a case manager. Such assistance can be critical for care (Gardner et al., 2005). We do not know what type of resources they received from the caseworker; potentially, for the Latino population, more bilingual support and linking them with a culturally sensitive case manager to help them navigate the treatment could have played a role in appointment adherence. Women in this study were not associated with increased adherence to medical appointment. One plausible explanation is that, if they had barriers to attending their appointments, those same barriers could have prevented them from getting to their case manager. A noted strength of this study is that it did include a control group, however it had a small sample size of women. While this intervention was successful, it was a case study. A follow-up study was designed to test this intervention in real world settings.

ARTAS-II

To answer this question, the ARTAS-II study examined the effectiveness of the intervention in community-based settings that included 10 health departments and community based organizations, located in 11 US cities. This study also examined demographic factors, structural factors (e.g., proximity to clinic, housing); and psychosocial factors (e.g., mental health diagnosis, depression). Inclusion criteria were that participants reported finding out their HIV status within the last year. Data was collected at baseline, and follow-ups at six months, and 12 months.

Similarly to ARTAS I, the intervention used linking participants to a case manager as a liaison to HIV care. The strength-based model encourages participants to identify their personal strengths and abilities and to use these personal attributes to manage their HIV treatment. Case managers assisted participants in building personal relationships, identifying barriers to care, and helping them to identify resources and solutions.

There were 646 participants who qualified for this study; 27% of the sample was female, 70% of the sample was Black, 18% of the sample was White, and 11% of the sample was Latino. The findings from this study revealed that people age 40 and over, Latinos, people with stable housing, and participants who did not use drugs in the past 3 months were more likely to engage in care within the first six months of the intervention. Additionally, people who had at least two face-to-face meetings with the case manager were more likely to remain in care.

This intervention highlights the importance of additional forms of support to help HIV positive individuals stay engaged in care by providing case workers to help navigate and find resources for care. As data illustrates that most HIV infected individuals are vulnerable to poverty, mental health issues, unstable housing, additional support may be essential to staying in care. Further research could focus on gender specific forms of care that may better identify the needs of both men and women. One limitation of this study was the small sample size of women.

Bridge Intervention

The California Bridge intervention was an outreach program designed to identify and link HIV-positive individuals to care who had never received HIV care before (Molitor et al., 2005). The program was successful in linking 29% (N=241) of the targeted population into care. The study targeted HIV-positive people without insurance and specifically focused on recruiting Black and Latino populations. The majority of study participants were Black (75%), 5 % Latino, and 20% were white. While the majority of participants were male, 24.6% of the sample was female. Eighteen percent of the sample reported not being in HIV care over a year ago and 80% of sample reported being out of care for less than a year.

This intervention worked by sending peer Bridge workers into the community to identify people who self-reported their HIV-positive status and revealed that they were not in care. The study also used publicly funded care and treatment facilities to give referrals to people who were in need of HIV care or dropped out of care. They documented people who entered care by providing them with an identification (ID) number that they took with them to enter care and tracking this ID number for subsequent treatment.

Study results reported an average of 9 contacts with the Bridge workers. Significant findings were that women and MSM were more likely than men to engage in care than men and Blacks and Latinos were twice as likely to engage in care than Whites. The study authors also discussed plausible reasons for differences in ethnicity participation, concluding it was because the program was a peer intervention that targeted Black and Latino populations. There were no White Bridge workers in this study.

One benefit of this study was that it demonstrated the importance of ethnic differences and tailored approaches to linking HIV positive individuals to care. It provided support or social networks within the medical setting for Latinos to connect with and help them navigate care. Also, it was the one of two intervention studies that found a significant relationship between increase in retention in care among women.

Bilingual Intervention

This study targeted HIV positive Latinos, who were offered case management support with a bilingual and bicultural case worker to help participants manage medical appointments and navigate the health system (Enriquez et al., 2008). The intervention included providing HIV knowledge, liaison with healthcare providers, home-based visits to assess family needs and to provide primary care as well. This was a very small study (N=43) that consisted mainly of Latino men under the age of 40; there were 9 women in the study. Results showed that participants were twice as likely to attend medical appointments than they were before they received the interventions. They also started to schedule primary care visits and give referrals for more people who needed help. Twenty-one percent of the sample was also able to reach viral load suppression. This study is significant because few interventions focus on the needs of HIV positive Latinos. Again this study provided specific types of support for the needs of Latinos. However, a major limitation of this study was only 9 participants in the intervention were women.

Discussion for Retention in Care Research for HIV-Positive Mothers of Color

Intervention research remains scant in addressing issues of retention in care for mothers of color. The answer from the literature to my first question, i.e., what factors predict adherence to medical appointments for HIV-positive Black and Latina mothers is still inconclusive. There were studies that illustrate some barriers to care, and again parenting, social support, and family roles are prominent themes in research studies. However, there were no intervention studies that exclusively targeted sub-groups of mothers or mothers of color, although there were interventions targeting female substance users or incarcerated women.

As to the second question, i.e., how are intervention studies capturing and incorporating factors that can influence and predict adherence to medical appointments for this population? Some studies did explore women's needs, but did not address the unique cultural issues of women of color (Molitor et al., 2005). Other interventions had inappropriate or inadequate samples, too short-term research design, or different focus to effectively answer this question (Enriquez et al., 2008; Gardner et al., 2005; Naar-King et al., 2007).

The LIGHT intervention did address family-centered needs of women, such as transportation and childcare, and did find significant improvement in women keeping appointments during the six-month study period. It also addressed the critically important findings of previous research (Anderson, 2007) regarding mothers' need to feel comfortable with outreach workers. The study design used trusted community stakeholders and community members in its support and outreach efforts. Similarly, childcare to assist with appointments was provided by other mothers within the network. Thus, this intervention did address key issues in the literature identified as barriers for mothers of color. Limitations in the LIGHT intervention were that there were no Latina mothers in this study, and no follow-up on adherence beyond the six-month period of the study.

The ARTAS interventions with case management were designed to specifically identify the individual needs of clients in order to engage them in care. This model could be an effective method of engaging mothers of color in care. An essential role of this intervention was helping participants to identify their needs and to get the resources that would help them meet those needs. This individual perspective may greatly help mothers to connect with resources that address their unique needs. This model really emphasized the importance of social support and social networks in providing support for managing HIV treatment and appointment adherence.

As to the third question—"Are these interventions demonstrating an increase in adherence to medical appointments for mothers of color?"—the answer is clear: no. There were only three studies with significant findings for women. Additionally, women did not represent a large sample size for the interventions that met the selected criteria. Women most likely were represented in some of the sub categories that included significant findings, such as age and ethnicity (Latinas); however, the present body of literature does not offer much information that informs the primary question for this research: What works for HIV-positive women of color that may be applicable to improved treatment for those who are mothers.

Another limitation of the intervention studies is that most of the interventions were lacking theory to explain their models or research design. Although some of the interventions focused on social support, there was little theory to support the intervention models. For the models that addressed family factors, there was no theory to explain or support why this is important or useful for HIV retention in care. While many of the interventions focused on previous studies and research around retention-in-care, the theory was weak in support of the intervention study designs.

After reviewing the literature on research and intervention programs, I found no effective models that are tailored to address the needs of mothers of color. Therefore, there is a significant gap in meeting the needs of HIV-positive mothers of color. However, before we can begin to create more effective interventions, we must design appropriately informed models that address the real-world needs of this population.

The Need for a Model of Retention In Care for HIV-Positive Mothers of Color

In the final section of this chapter, I offer a model (see Figure 1) that considers how structural factors, social support, family factors, and parenting stress work together to influence adherence decisions to medical appointments for HIV-positive mothers. Some researchers have described many of the individual factors of HIV-positive Black and Latina women that may contribute to their high death rates (Gifford, White, Suarez-Almazor, & Rabeneck, 2007; Kagee & Delport, 2010; Merenstein et al., 2008). However, the literature is lacking models that address the historical, structural, and cultural context of these mothers. Consequently, factors, such as mothering, coping strategies, and social support that are embedded within the experiences of women of color have not been appropriately examined. For instance, although some qualitative literature has identified prominent themes that offer important insight into factors of missed medical appointments (Prosser, 2011; Wood, Tobias, & McCree, 2004)**,** many studies lack theoretical frameworks or underpinnings that may help to explain these important findings (Aspeling & Van Wyk, 2008; Berg, Michelson, & Safren, 2007; Catz, 1997; Chesney et al., 2000; Dietz et al., 2010).

Examining how systems interact and subsequently affect Black and Latina mother's lives provides a useful framework for understanding their motivations and choices to attend medical appointments. As Kuh et al. (2004) asserts, this inclusive perspective offers merit by exploring how socially patterned exposures "cumulatively and interactively influence health and disease" (p. 117). For this model I use the ecological perspective, an overarching framework that considers health behaviors of individuals by focusing on interactions with their environment and social cultural surroundings (Sallis & Owen, 2002). The ecological perspective contends that behaviors are influenced by policy, physical-environmental factors, socio-cultural factors that interact and influence health behaviors and choices (Sallis & Owen, 2002).

This dissertation examines the socio-political and cultural context in which HIV operates for Black and Latina mothers. By recognizing gaps in the HIV retention in care literature, the model makes the argument that the social context of women, i.e., social networks and family dynamics plays a vital role in the success of mothers living with HIV. In this model, I suggest that Black and Latina mothers have a unique subculture, shaped by historical events and by managing persistent effects of discrimination. Yet, there remains little explanation of how culture, politics interact for HIV-positive mothers of color and influence their ability to remain in care. Thus, this model addresses how socio-economic policies influence social networks, such as communities and neighborhoods, and how these institutions and networks, in turn affect social relationships and individual risk factors for HIV retention in care.

I suggest that the strategies that Black and Latina mothers have used in maintaining families and social networks deserve special consideration within the framework of retention in care research—specifically, that managing HIV through remaining in a continuum of care may threaten the relationships and roles which provide meaning and value to these mother's lives and compromise their adherence to medical appointments.

Overview of Conceptual Model

To address the limitations identified in this literature review, I offer a conceptual model that builds on five levels from the Schulz and Northridge (2004) Social Determinants of Health Model. These levels include: I. Fundamental (Macro) Level; II. Intermediate (Meso) Level; III. Proximate (Micro) Level; IV. Individual Level; and V. Health Outcomes. The social determinants of health perspective describe how fundamental factors are related to individual health behavior outcomes that can affect individuals differently based on race, socio-economic status (SES), and gender (Schulz & Northridge, 2004)**.** The overall model shows that structural factors influence medical appointment adherence for HIV-positive mothers of color that are mediated by family structure and perceived parenting stress and moderated by social support. This model really focuses on the individual level of parenting stress, social support, and medical appointment adherence; however it is important to address the context of how medical appointments are influenced at the individual level for mothers of color. This model contends that fundamental level factors which include *structural factors* that are the social, political, and economic forces within a society, define and shape the lives of certain populations by restricting opportunities (Gilbert, 2006). Chief among these factors are *structural violence*, an overarching framework that links racism and the denigration of cultural practices of minority groups to social and economic health inequalities (Geronimus & Thompson, 2004). *Structural factors* and *structural violence* influence the lives and decisions of HIV-positive mothers at every level of this model. This model examines the influences of *discriminatory policies* on the *socio-economic position* of HIV-positive mothers of color at the *fundamental level.* It also examines the built environment and residential segregation at the community or *meso* level. This model also asserts that *discriminatory policies* and the *socio-economic position* of mothers of color have influenced and shaped their *family structure,* which in turn affect their *social networks* at the *proximate level*. The model also predicts that *social networks* can influence the type (*affirmational, practical, emotional and HIV support*) and amount of *social support* mothers of color receive at the *proximate and individual level.* At the *individual level*, it predicts that the influences of *perceived parenting stressors* and perceived *family functioning* can directly influence decisions to adhere to medical appointments and stay in care (*retention in care). Social support* may also moderate perceived level of *parenting stress*. Although this is not a focus of the model, *mental health variables* (having a mental health diagnosis and substance abuse) and *socio-demographic variables (*partner status and age) can also have direct influences on medical appointment adherence (as indicated in the gray box in Figure 1 above). Next, I will go into a more in-depth explanation of each component of the model.

I. Fundamental (Macro) Level

Fundamental factors address how constructed social systems such as institutional discrimination[1] shape populations of colors' access to multiple resources such and jobs and educational opportunities (Schulz & Northridge, 2004). A growing body of literature (Poundstone, Strathdee, & Celentano, 2004; Rubinstein et al., 2004) explores mechanisms within and economic contexts (e.g., lack of employment, deficits) that can affect women's response to engaging and staying in HIV care. This concept is demonstrated among Black and Latino families who were affected by the economic restructuring that took place during the Reagan era of the 1980s (Sloan, 1997), and the subsequent strict incarceration policies of the Clinton administration, which marginalized communities of color and exacerbated issues of poverty. While many studies list poverty and lack of education as contributing factors to challenges in retention in care, they rarely contextualize how this manifests in communities of color (Alexander, 2010). The ways in which Black and Latina mothers experience, resist, and internalize types of discrimination are rarely explored in terms of the influence on their decisions to remain in HIV care and attend medical appointments. In the next section, I give examples of how these mechanisms can affect the lives and decisions of mothers of color.

Discriminatory Policies

The government's restructuring policies starting with the Reagan administration have played a significant role in shaping communities of color and their response to

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[1] *Institutional discrimination* – "The differences in race, ethnicity, social class, and gender, including power, privilege and resources, and the different life experiences and life opportunities that may result" (Geiger, 1999).

managing chronic diseases such as HIV (Zierler & Krieger, 1997). Specifically, the economic and drug policies of both the Reagan and Clinton administrations have led to festering neighborhoods rampant with crime and drugs—fertile ground for poverty and lack of economic opportunities (Zierler & Krieger, 1997). These policies have, in turn, influenced access to fundamental resources such as housing, education, and healthcare (Okoye, 1997; St. Pierre, 1991; Trueblood, 1999).

Both administrations also decreased programs that provided the social safety nets for families in need. Reagan's economic policy and budget cuts totaling $39 billion slashed social service programs specifically designed to help the economically and socially disadvantaged (Okoye, 1997; St. Pierre, 1991). The cuts ended federal programs such as the Comprehensive Employment and Training Act (CETA) that provided many families of color with jobs. The impact of these cuts was compounded by new defense and drug policies that targeted low income communities of color with heavy sentencing disparities (Trueblood, 1999)

Clinton aggravated these trends by initiating a "three strikes" law, a policy that mandated life sentencing for three-time offenders, regardless of the crime (Lichtenstein, 2008; Mauer, 2011; Waller & Swisher, 2008), legislation that resulted in "the largest increase in federal and state prison inmates [of] any president in American history" (Alexander, 2010, p. 202). Clinton then placed severe restrictions on welfare assistance and a permanent lifetime ban on food stamps or housing assistance for anyone with a criminal history (Brenner, 1995; Ellwood, 1994; Thomas, 1999). The ripple effect of these changes contributed to a lack of partners, especially fathers, available in the household to assist their families, often leaving mothers of color to support and provide for their families alone (Waller & Swisher, 2008)

Socio-economic Position (Education & Income)

The effects of these policies had long lasting consequences for the perpetuation of poverty, especially in communities of color (Thomas, 1999). Specifically, structural influences such as lack of economic opportunities, divestment in communities, and compromised educational systems resulted (Ellwood, 1994; Thomas, 1999)

Poverty and poor resource settings have been associated with low retention in care (Blank, Ryerson Espino, Eastwood, Matoff-Stepp, & Xavier, 2013; Bofill et al., 2011; Catz, 1997; Israelski et al., 2001; Konkle-Parker et al., 2011). Yet, as a result of these policies, many HIV-positive women are combatting recurring economic crises, job instability, and housing instability HIV-positive women articulated these challenges in one study (Blank et al, 2013) by explaining that living in poverty and lacking resources is living in a perpetual cycle from moment to moment using short-term survival skills. Often times addressing and committing to preventative health practices or committing to future medical appointments are problematic when there are daily challenges to overcome to meet basic needs. Watkins (2011) points out that a culmination of low educational attainment, fewer educational and job opportunities, high rates of incarceration, and slow responses to the needs of HIV-positive women of color have influenced their ability to remain in HIV care. This historical perspective helps to provide context as to why low socio-economic position (low income and low education) can influence retention in care.

II. Intermediate (Meso) Level

In this proposed model, the intermediated level helps to explain how external policies can influence and shape communities and how this in turn can influence the lives of families from the perspective of HIV positive mothers.

Residential Segregation and The Built Environment

The built environment is influenced by discriminatory policies described at the fundamental level. The built environment consists of conditions that further perpetuate HIV risk and restrain decisions for women of color within their neighborhood and communities. Inherent discriminatory practices and policies have restricted opportunities and in turn compounded exposure to individual risk behaviors for people of color (Adimora et al., 2009; Fullilove, 2006). One of the most prevailing examples in the literature of structural violence that has been linked to disparities in HIV is residential segregation (Poundstone et al., 2003; Lane et al., 2004). Residential segregation can be defined as the spatial isolation of groups from others based on race and ethnicity (Massey & Denton, 1993). Williams (2002) contends that residential segregation shapes socio-economic conditions for African Americans not only at the individual level but, simultaneously at the neighborhood and community level. For the purpose of this study and to address residential segregation as a community-level factor, the term "community" is operationalized as a population that is geographically focused but also exists as a discrete social entity with a collective identity and purpose (Manderson et al., 1992).

To further evaluate the association between race and HIV survival rates, Wallace (2003) noted that the historical and structural factors such as segregation and racism can create situational circumstances and behavioral outcomes that either promote or impede the proliferation the AIDS. For instance, the crippling of communities through policies such as redlining (discrimination in real estate) and benign neglect (decrease of trash removal, fire departments, and police) has created limited resources and options for individuals to seek treatment. Less access to antiretroviral medication may stem from several factors such as decisions made by clinicians regarding populations labeled as noncompliant, lack of financial or social resources to obtain expensive drugs, weakened social networks, housing instability, and drug use or mental illness (Schuman, 2000). Wallace's (2003) research illustrates an imbalance or mismatch in geographic regions with high prevalence of HIV and available HIV clinics. For example, more HIV clinics were found in affluent areas of New York and Washington DC, where the AIDS incidents are relatively low. Some researchers argue that HIV treatment has been more detrimental in communities where there are limited resources to help individuals manage medication (Deiveler, 1999; Gebo, 2003; Hutchinson, 2006). As a result, Durante et al. (2003) found that race and appointment adherence was significantly correlated with overall morbidity of low-income African American women. In fact, lack of resources and access to regimens has contributed to the rampant spread of more drug resistant strands of HIV in low-income communities (Saprano et al., 1999).

Residential segregation can also influence social interactions, limiting who people may interact with, the frequency of interactions, and on what terms people may interact with each other (Center for American Progress, 2012). The effects of persistent racial discrimination that include discriminatory housing policies have placed Black and Latina women in constrained social networks that significantly increase their risk for STIs and HIV infections. As explained by Center for America (2012) residential segregation can condense an individual's social network and, therefore, increase the "community viral load" which consists of an aggregation of individual viral loads across a community. Adimora et al. (2009) found that one of the contributors of HIV for Blacks is notably the disproportionate number of sexually transmitted infections (STIs) such as chlamydia**,** gonorrhea, and genital herpes, which can promote an environment for HIV infection. Living in an area where social resources and opportunities are limited may also limit the variability of social networks. Therefore, the rates of engaging or interacting with people who have a sexually transmitted disease increase.

Examples from the Regan and Clinton administration also demonstrate how contextual factors shape social networks and opportunities and allow for the spread of HIV spread among Black and Latina women. The targeting of Black and Latina men and disproportionate incarceration rates severely constrained the social networks of Black and Latina women by limiting their options in life partners. HIV rapidly transformed from a disease predominately contracted through intravenous drug use to a disease predominately contracted through heterosexual sex.

Sobo (1993) explains that, for Black women who felt their families were under constant assault due to poverty and the fleeting male presence, the consequences of HIV may have been outweighed by the options of being childless or without a partner or family. Decision-making for women living within the flourishing epidemic of HIV was often entangled with marginalization, relationship dynamics, and constrained choices. Viewing the spread of HIV/AIDS through a contextual lens reveals that social networks are neither random nor necessarily freely chosen. Rather, social networks are the endproducts of numerous factors, including structural dynamics, socio-economic position, geographic location, political policies, age, and gender (Berkman & Glass, 2005).

These constrained social networks that consists of high rates of HIV infection are also wrought with poverty, lower levels of educational opportunities, and lack of resources available for women to manage HIV in addition to other competing stressors and responsibilities (Center for American Progress, 2012). HIV is just one of many challenges women of color face as mothers and may not be their most pressing issue. It takes a persistent and concerted effort to find the resources, manage medications, and receive effective care.

In the following section below, I expand upon how family dynamics and social networks can influence mothers of color to attend medical appointments.

III. Proximate (Micro) Level

Proximate factors include those relevant to an individual's immediate environment, such as family and friends, as well as characteristics shaped by the interplay of these environments (Stokols, 1992). Structural barriers have not only profoundly impacted the economic resources and opportunities available to Black and Latina communities, they have also affected family structures and the roles of women as parents and family providers, as discussed earlier (Chaney, 2011; Kelly, 2009; Messer et al., 2012).

Some researchers have contended that the socio-political climate and history of discrimination and oppression has created different experiences for Black and Latina mothers, with many placed as the primary caretakers of the family. Both Black and Latina mothers have adopted very expansive social networks, which include extended families that include relationship beyond blood relatives (Chatters, Taylor, & Jayakody, 1994; Jarrett, Jefferson, & Kelly, 2010; Mellins, Ehrhardt, & Newman, 1996; Miller-Cribbs & Farber, 2008). These extended family networks remain an integral part of Black and Latina women's experiences as mothers and help to maintain families in situations of financial strain or hardship (Domínguez & Watkins, 2003).

The literature offers examples of how mothering can affect adherence to medical appointment (Boehme et al., 2013; Halkitis, Wilton, Shrem, & Zade, 2005; Kempf et al., 2010). Themes of mothering are highlighted in many qualitative works investigating women and HIV; however, these themes that are often conflated or dismissed in biomedical frameworks Due to the lack of research available in this area, I use the following examples to extrapolate how this research may relate to missed medical appointments.

Sankar (2002) conducted in-depth interviews with 15 Black women on HAART medication in Detroit, Michigan. Discourse analysis (the study of language and written documentation) helped identify narrative frameworks on how women think about adherence practices to HAART medication. Highlighted themes that contributed to non-adherence included losing control of life, diminishing feelings of status as a "full person," and fear of stigma. Most women in the study reported non-adherence as a conscious decision or moral decision because the side effects of the medication imposed on their ability to function in their families. Additionally, maintaining stability in the lives of children was revealed as a barrier to adherence, whether that meant caring for them or protecting them from involvement in managing HIV.

Moreover, qualitative studies by Wright et al. (2003) and Shambley-Ebron (2006) highlight the importance of self-care practices, mothering, and family commitments in HIV-positive African American women as factors associated with non-adherence. Women in both of these small qualitative studies (e.g., sample size of 10) reported independence and caregiving as critical to their identity and self-esteem. Characteristics of being strong and independent were noted by themes of perseverance, as women reported not letting HIV "rent space in my head" or forcing lifestyle changes (such as dealing with side effects of medication) that would impede their ability to care for their families or children. The work of these researchers illustrate salient factors related to roles of caregiving and to family relationships that offer unique challenges for Women of color but have been subsequently overlooked in the quantitative literature.

One of the many effects of discriminatory policies has been the structure of Black and Latino families and the increased responsibility on family members, primarily women, to provide resources and support within their family networks. Rarely does the literature include and/or assess in study designs the impact of family and kin networks on HIV-positive Black and Latina mothers. Narrowing the focus to the literature of social networks, social support, parenting stressors, and family functioning can provide rich context for exploring Black and Latina mother motivations to remain in HIV care.

Social Networks

Social networks are the nexus of relationships in an individual's life (Heaney & Isreal, 2002). For example, these networks may consist of interpersonal relationships with family, friends, co-workers, and members of organizations. The benefits of engaging in social networks are associated with perceived social support and health related outcomes

(Heaney & Isreal, 2002). Some studies suggest that people who engage in their social networks live longer than those who do not (Ikeda & Kawachi, 2010; Israel, 1987; Kawachi & Berkman, 2001). Social networks influence health behaviors by the transfer or exchange of resources such as social support, material goods, information, and influencing health behavioral norms both positive and negative (Ikeda & Kawachi, 2010). The structures of social networks can have many dimensions such as dyadic characteristics that include giving and receiving support (reciprocity); the level of connectedness and closeness (intensity); and the functions of each relationship (complexity); and the extent to which networks members know and interact with each other (density) (Heaney & Isreal, 2002). Research also emphasizes the distinction between ties in social networks as “strong” or “weak” which can influence the flow of resources within a network between individuals. For example, strong ties may be people who a person frequently interacts with and have significant relationships with, such as immediate family, close friends, or co-workers who help in navigating life on a day-to-day basis. Weak ties may be associates, neighbors, or friends of other people within a person’s immediate circle. Some argue that weak ties can be as important as strong ties by expanding the social network and connections to job opportunities or other types of resources. Antonucci and Akiyama (1987) illustrate this in the social convey model, which examines the structural functions of social support. It suggests a model of overlapping layers of family and friends who help to support an individual in navigating challenging situations by offering resources and support.

More work is examining this relationship among Black and Latina HIV-positive women (Hough, Magnan, Templin, & Gadelrab, 2005; Messer et al., 2012). Some research suggests because of the social stigma of HIV, women may become more isolated from their support networks and engage in care later experiencing disease progression (Hough et al., 2005; Vyavaharkar et al., 2010; Wohl et al., 2010). The burden of HIV may also strain social relationship within their social networks, which may be more economically homogenous and depend on reciprocity (Hough et al., 2005; Wohl et al., 2010). Women may also negate their health needs to maintain their social networks within their family and extended family (Watkins-Hayes, Patterson, & Armour, 2011; Watkins-Hayes, Pittman-Gay, & Beaman, 2012).

Social Support

Social support is a multidimensional construct that represents the functional aspects of the social network. Social support includes various and complex aspects, i.e., who is offering the support, how the receiver perceives the support, and what types of support are needed and/or obtained (Williams, 1988). Many studies investigating chronic diseases and adherence to medications have identified positive correlations between social support and adherence behaviors (Martin et al., 2012; Mellins, Ehrhardt, Rapkin, & Havens, 2000; Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002). The social support literature contends that people with various types of friends or family members who can provide material and psychological support during stressful times fare much better than those who do not have these supports (Cohen & Wills, 1985). Certain kinds of support, such as those derived from being involved in social networks, may be associated with improved physical health outcomes by promoting emotional benefits that provide positive chemical reactions on the neuroendocrine system or immune system in the body (Cohen & Wills, 1985). Some studies have shown that increased social support has a positive effect on health and wellbeing, regardless of the type or amount of support (Cohen & Wills, 1985; David, Eric, & Laura, 2013; Field & Schuldberg, 2011).

There is less consensus in the literature about the operational dynamics of support, i.e., how much support is needed, and what types of support work better in certain situations. However, instead of focusing on general aspects of social support in this study, I am interested in the functional aspects of social support, i.e., the type of social support and enacted levels of social support, as they relate to adherence to medical appointments.

Kahn and Antonucci (1980) explain that the function of social support is the transaction of one or more of the following: emotional support (e.g., esteem, affect, trust, concern); appraisal/affirmational support (e.g., affirmation, feedback, social comparison); informational support (e.g., advice, information); or instrumental support (e.g., aid, money, labor, or time). Social support is reciprocal in nature, involving mutual exchanges of giving and receiving (Antonucci & Kahn, 1993). HIV support also involves support that specifically relates to managing HIV, such as having someone available whom the recipient of support feels can help with navigating the challenges of HIV.

With HIV now considered a chronic disease, it is surprising that the association between social support and clinical outcomes, especially for Black and Latina women, has been poorly characterized in the literature (Feist-Price & Wright, 2003). One major issue in the literature is that most research studies are concerned with how HIV illness affects other members of the family, rather than the patient's lived experiences with HIV. Because HIV often infiltrates fragile communities that are already compromised by poverty, crime, and drug activity, it is critical that researchers understand the unique social context and social support systems, and lack thereof, within the communities most affected by HIV.   Additionally, HIV may look very different within the various communities it affects; those communities affected by HIV among men who have sex with men, for example, may need more practical social support, while those communities affected by HIV among drug users may need more informational and emotional support. Women of color, in particular, have been overlooked and/or are mischaracterized in the HIV literature as having predominantly mental health issues and severe depression. However, psychosocial issues that women can face may require that they seek specific kinds social support (Feist-Price & Wright, 2003).

Adequate social support has been found to have a substantial buffering effect for individuals coping with HIV/AIDS-related stressors, and has been found to minimize disease progression (Edwards, 2006; Gallant, 2003). As mentioned previously, Black and Latina women rely heavily on social support through social networks to mitigate economic and social barriers and to facilitate their day-to-day survival (Domínguez & Watkins, 2003; Mullings, 2005). Hurst et al. (2005), for example, concluded that family and community support and social networks in such communities are critical factors in the care and self-management, such as missed medical appointments of chronic illnesses such as HIV/AIDS (Hurst, Montgomery, Davis, Killion, & Baker, 2005). Sowell (2002) and Edwards (2006) also report that HIV-positive Black women frequently identify their children as sources of support in helping with household chores or reminding their moms to take their medications or to attend medical appointments. These studies demonstrate that social support and social networks especially within the family greatly influence HIV- positive mothers' ability to manage the disease and engage in care.

Social support studies also indicate that social interactions may have unintended negative consequences as well (Gallant, 2003). For women living with HIV/AIDS, fear that social support may decrease due to the social stigma related to the disease is common (Szapocznik et al., 2004).

At the individual level, stress appraisal and social support may have an effect on HIV-positive Black and Latina women's adherence to medical appointments. These women's ability to manage their HIV may be inextricably linked to how they cope with competing obligations. Women's social networks may also affect the needs and demands of their caregiving and mothering experiences. Current research is in its initial stages with respect to conceptualizing and measuring all of these factors of social support, stressors, and coping for HIV-positive women; ignoring the significance and impact of social networks and relationships in women's lives grossly misrepresents mother's experiences and challenges. It also jeopardizes our understanding of medical appointment attendance behaviors.

IV. Individual Level Factors

At the individual level, this model illustrates how stressors, sources of support, and family functioning can affect medical appointment attendance for HIV-positive mothers of color. While social support and family functioning are also interpersonal factors that can fall under the micro level, this model looks at enacted level of social support and family functioning as interpreted by the mothers at the individual level and how these perceptions influence their behaviors to attend medical appointments. Explicitly, understanding the sources of stress and the social support strategies Black and

Latina women employ may provide insight into their medical appointment attendance patterns.

Aspects of Stress and Coping

In general, the literature demonstrates that HIV can lead to a tumultuous spiral of life events, such as loss or change of job, financial difficulties, and loss of children and spouses, among other devastating life stressors (Phillips, 2008). Many researchers have also used various representations of the stress and coping framework to describe how HIV and AIDS can influence psychological, social, and physical stressors for individuals infected and affected by HIV and AIDS (Mellins, Kang, Leu, Havens, & Chesney, 2003; Poundstone et al., 2004). Using The Transactional Model of Stress and Coping, developed by Lazarus and Folkman (1984), I identify key variables within the context of HIV-positive mothers' lives that may influence the way certain stressors affect their ability to consistently attend medical appointments.

The Transactional Model of Stress Appraisal and Coping (Lazarus & Folkman, 1984) identifies stress as a reaction to threats or events that exceed the resources available to adequately cope with the stressor. The model emphasizes transaction as a process between people and their environment when faced with a stressor. It further suggests four tenets of this process: A causal internal or external agent, called a stressor; cognitive evaluation of that stressor to determine whether it is threatening or benign, called appraisal; coping process used by a person while dealing with the stressful situation; and finally, the outcome of the stress reaction process.

The psychological outcomes of the stress process fall within three categories (Lazarus & Folkman, 1984): emotional, which addresses psychological states of wellbeing and somatic symptoms; functional, which includes ways in which individuals fulfill family, work, and/or social obligations; and subjective well-being, which addresses how people feel about their lives. The authors further contend that the outcome of a stressful situation depends on the antecedent variables, which can either resist or reject a potential stressor, or increase the vulnerability of an individual to succumb to that stressor. The stress resistance factor is based in an individual's personal and environmental resources, such as previous experiences, material resources, problem-solving skills, and health, to name a few.

After a situation is appraised as stressful, coping is the response made in an effort to mitigate the stressor or to create a favorable outcome. Similar to stress, coping is a process that can change, and is shaped by the context in which it occurs**.** Folkman and Moskowitz (2004) maintain that coping is strongly associated with emotional challenges, especially distress, and that it is a multidimensional and complex process sensitive to environmental, demand, resource, and personality factors. It is suggested that having someone in your life to offer support during times of difficulty helps to better manage the stressor leading to favorable outcomes. This study addresses what role social support may play in the process of managing parenting stress in relationship to retention in care as measured by medical appointment attendance.

Parenting Stress

Parenting stress is an important variable to consider when examining medical appointment attendance among HIV-positive mothers. Parenting stress refers to the perceived stress experienced when the demands of parenting exceed the personal and social resources available to respond to that demand (Quittner, Glueckauf, & Jackson, 1990). Parenting stress is also influenced by social relationships within the family. Therefore, family dynamics are critical in comprehensively examining this construct in relationship to medical appointment attendance.

The demands of parenting in and of themselves can be stressful and have direct influence on adherence to medical appointments, as they have been linked to maladaptive health behaviors (Muze, 2009). Parenting while HIV-positive, however, may be especially challenging for some Black and Latina women who may also carry additional demands and burdens within their social networks (Mellins et al., 1996). Low-income mothers living with HIV report compromised parenting skills and increased conflict with children (Murphy, Marelich, Armistead, Herbeck, & Payne, 2010). For Latina mothers in particular, length of residence in the United States was negatively associated with parenting stress (Joshi & Gutierrez, 2006). Possible separation from their family members and potentially providing for children abroad is significantly associated with parenting stress. The Mellins et al. (1996) study reveals that mothers provide resources and support for other ill family members, as well those who are affected by HIV.

Muse (2009) reported that for HIV-positive women, parenting is associated with poor physical health, and that for Black and Latina women, the stress of parenting may be compounded by experiences of racial and gender discrimination that restrict their access to the social support and resources needed to manage medical appointments and their children.

Parenting stress among Black women was associated with both lower physical functioning and lower overall emotional wellbeing (Muse, 2009). Although other studies have examined the relationship between parenting stress, social support, and health-related outcomes among HIV-infected Black women, Muse asserts that these studies have not been clear in conceptualizing how these variables interact. For example: to what extent does social support explain the relationship between parenting stress and missed medical appointments? These relationships are of critical importance to understanding treatment efficacies and dynamics, and may allow researchers to new insight as to how adherence is affected by the specific experiences of Black and Latina women.

Family Functioning

Family dynamics are rarely studied in relationship to adherence or missed medical appointments**,** yet the literature shows that families are very influential for HIV-positive mothers (Mellins et al., 2000; Mosack & Petroll, 2009). In this study, I consider the role of family processes as perceived by HIV-positive mothers on adherence to medical appointments. Family functioning can have a direct influence on a mother's decisions to attend medical appointments (Penniman, 2009). Maternal HIV can have multiple implications within the family unit and can influence the way the family functions as a unit (Penniman, 2009). A major illness in the family can cause a shift or disruption that has been associated with poor family functioning (Martin et al., 2012; Mellins et al., 2000; Murphy et al., 2002). Poor family functioning has also been associated with psychological distress for the mother as she attempts to maintain her role as a mother when compromised by HIV (Fullilove, Green, & Fullilove, 2000).

Family processes are measured with the Family Adaptability and Cohesion Scale (FACES) developed by Olsen et al, 1982. The scale measures how family structures, roles, and relationships change during times of stress. Family Cohesion subscale addresses the perceived closeness and emotional bonding among family members. The

Family Adaptability subscale measures perceptions of families' adaptation and adjustment during change or times of crisis.

The value of FACES has been heavily debated with regard to its cross-cultural applicability. It may be based on cultural values represented in the formation of family structures that may not be valid across all cultures. For example, one study describes important family qualities for Latina mothers to be solidarity, sacrificing, reciprocity, and obligation. FACES could misinterpret these as indicating too much cohesion and not enough flexibility, i.e., the family is considered enmeshed – a dysfunctional characteristic of cohesion (Kouneski, 2000). Some cultural values for Black mothers are strong discipline and authority. Additionally, identity is connected to relationships with their children and family. FACES could interpret these qualities or characteristics as having too little flexibility and rigid.

The Family Adaptability and Cohesion Scales are widely used to investigate family functioning, mainly in clinical research but also in the social sciences and medicine (Kouneski, 2000). Surprisingly, only one study to my knowledge has investigated family functioning among HIV-positive Black and Latina mothers (Mellins et al., 2000). This study found that connected and cohesive families functioned as a buffer against psychological distress for HIV-positive Black and Latina mothers. Alternatively,. this study also showed that family adaptability was associated with higher levels of stress for Black and Latina mothers and detrimental to their mental health. In the Mellins et al (2002) study adaptability was associated with psychological distress. However, it could be that the scale was not valid for this population of Black and Latina mothers.

Due to the lack of other measures for this construct, FACES may still be valuable to investigate the effects of family dynamics on missed medical appointment. In this study's model, I suggest that family cohesion and family adaptability directly influence medical appointment attendance for HIV-positive mothers.

Control Variables

Mental Health Issues and Substance Abuse

Forty to seventy percent of HIV positive individuals report substance abuse (Gonzalez, Barinas, & O'Cleirigh, 2011). Additionally substance abuse is also associated with psychiatric problems such as anxiety, depression, or other forms of mental illness (Eggleston, Strauss, Guerra, & Calhoun, 2010; Gonzalez et al., 2011). Epidemiologic studies have also demonstrated that substance abuse interferes with retention in care. HIV positive people who suffer from addiction to drugs such as crack cocaine are more likely to never engage in care (Berg et al., 2007; Greenfield et al., 2007; Haug, Sorensen, Gruber, Lollo, & Roth, 2006; Wagner et al., 2010).

HIV-positive women with psychiatric and substance abuse issues have been linked to poor retention in care (Galvan & Davis, 2012; Graff et al., 2009; Greenfield et al., 2007). Especially for HIV-positive mothers, stressors, substance use, and mental illness, have been highly correlated with low adherence to medical appointments (Abell, Ryan, & Kamata, 2006; Hackl, Somlai, Kelly, & Kalichman, 1997; Mellins et al., 2000). These relationships and their influence on medical appointment attendance, though important, will not be examined closely in the present study.

Age and Partner Status

Age and partner status are variables that are not of interest but research recognizes the importance of controlling for these effects (Gifford et al., 2007; Hall et al., 2012; Konkle-Parker et al., 2011). Studies have found that younger age is a risk factor for low adherence to medical appointments (Catz, 1997; Israelski et al., 2001; McClure, Catz, & Brantley, 1999). While many studies have controlled for partner status, some studies qualitative studies have reported that women who have a partner in the home may be more likely to focus on their care rather than their own, especially if that partner is also sick or is HIV positive (HIV Law Project, 2013; Lorece, Shalon, & Anita, 2011; Marcenko & Samost, 1999).

V. Health Outcome: Medical Appointment Attendance

Poor retention in care has been linked to progression of HIV subsequently leading to AIDS deaths. This model provides a plausible explanation of how contextual and socio-demographic factors influence retention in HIV care and contribute to progression of HIV/AIDS for mothers. Poor retention in care leads to missed opportunities for initiation or management of HIV medication. Missing medical appointments can greatly compromise the health of mothers of color and lead to a premature death from HIV and AIDS.

Limitations of the Model

There are several limitations of this model that are worth noting. First, HIV/AIDS is a complex illness; a multitude of factors can affect its treatment, including stigma, discrimination, doctor-patient-case worker interactions, gender roles, power dynamics, church and religious participation, community capacity, and resilience. Moreover, every

HIV-positive woman's life is unique, dynamic, and fluid. Attempting to generalize about a specific category of HIV-positive women and mothers to produce a representation of their lives presents a serious conceptual challenge. The model focuses on missed medical appointments and the cultural and structural experiences of HIV-positive Black and Latina mothers because these issues comprise a glaring gap in the extant literature. I recognize as well that the literature is even more scant in addressing specific issues for Latina women, who are often lumped into the categories of "women of color" or "Black women". Despite this void, it is worthwhile to mention that this study focuses specifically on the experiences of Black and Latina women and is not intended to make broad generalizations about all women of African or Hispanic descent. Future studies will be needed to explore the similarities and differences between HIV-positive African-descended and Latin-descended women from different parts of the world in terms of their retention in care and mothering roles.

Policy Implications

This study's conceptual model may lend support to policy initiatives that address the fundamental causes of poor retention in care by women of color. The model illustrates systematic inequalities such as residential segregation, lack of opportunities, and other forms of discrimination that persists in Black and Latina communities. One key policy implication of this study is that HIV/AIDS research has not addressed fully the unique experiences, factors, and circumstances facing HIV-infected mothers of color, who bear the majority of the HIV/AIDS-related burden in their families and communities (Deivler, 1999; Gant, 2004; Smith et al., 2000; Wright, 2003). More studies are needed to investigate factors that may influence missed medical appointments for HIV-positive mothers of color.

The study may also reveal salient gaps in addressing the stressors of HIV-positive Black and Latina mothers, stressors that may directly interfere with their ability to remain in care and to adhere to medical appointments. Thus, the study's model might be applied to develop specific interventions that address some of the inter- and intrapersonal stressors affecting Black and Latina mothers. Unlike drug-use and depression, these stressors may be invisible to health care providers, but they are most critical to ensuring an effective continuum of treatment and care. Specifically creating programs for healthcare providers that educate them on the variety of issues facing HIV-positive Black and Latina mothers, and that focus on culturally sensitive approaches to providing care, may be a first step. Policy initiatives focusing on resources and counseling for diverse family structures may also be helpful. Longer clinic hours or flexible hours for working families that include childcare options might also improve medical appointment attendance. Qualitative literature discussed here demonstrates that feeling valued, welcomed, and important plays a critical role in whether women follow through with care. Therefore, culturally sensitive clinics that greet and encourage patients during their visit and recognize that this is a challenging but vital step to maintaining healthy and safe.

Educational programs are also paramount to improving outcomes, as lack of education may influence comprehension of the pathology of HIV. Programs that work to confront prominent reasons for missing appointments, such as fear of medication or side effects, confusing feeling well with not being sick, or perceiving care is not necessary at all, may help to influence intentions to adhere.

More advocacy programs and/or funding for nongovernmental organizations may help women navigate resources such as food assistance, financial support, and social security and, in turn, help to alleviate some of the life stressors this study identifies as potential barriers to care. Intervention programs that focus on caregiving and caregiver burnout may be critical in this regard. Such programs may provide HIV-positive Black and Latina mothers with resources for adopting positive coping strategies, while stimulating them to focus on adherence as a tool for becoming better caregivers and mothers by taking care of themselves first. These and other approaches may help target the problem in such a way that Black and Latina mothers will believe speaks directly to their issues.

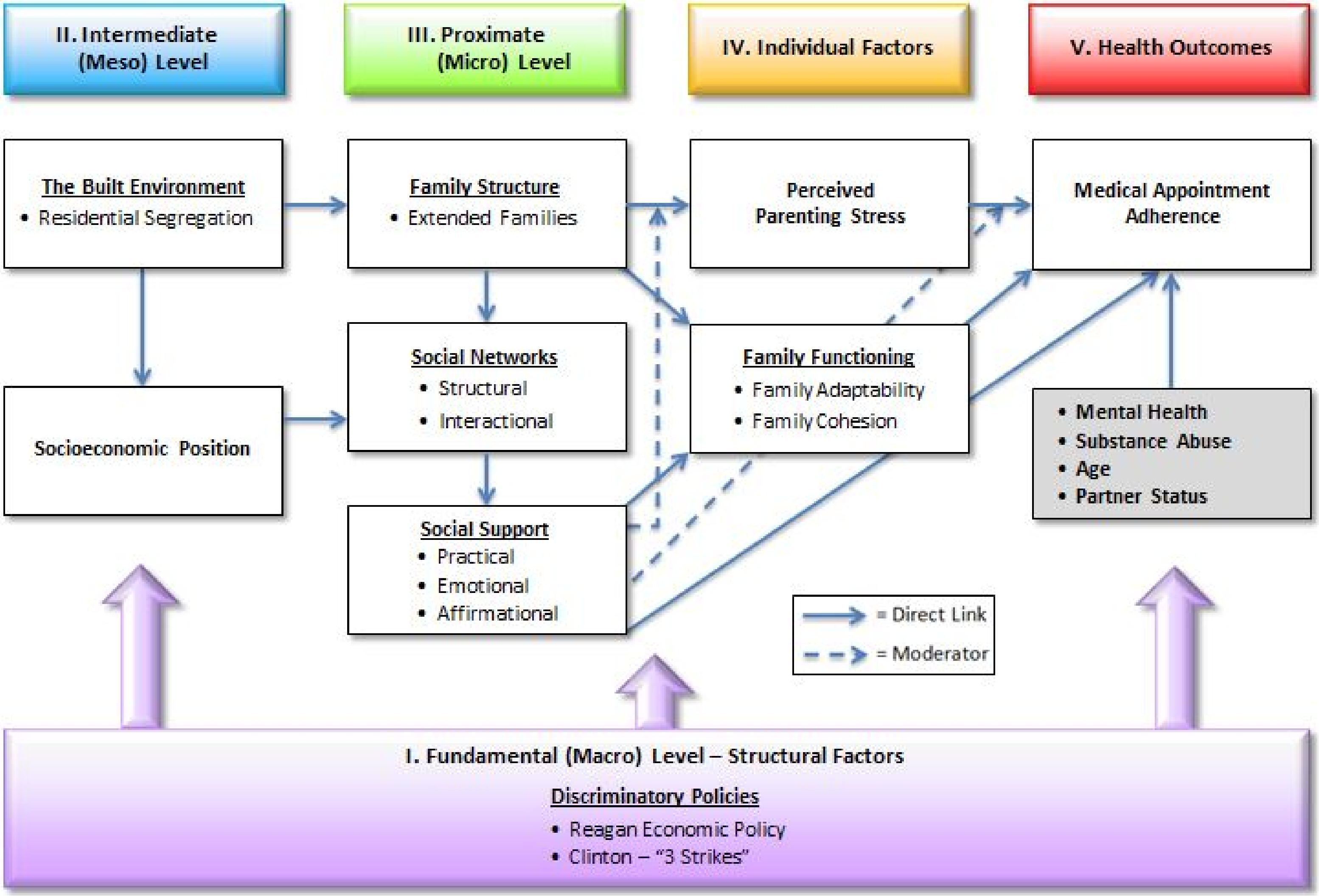

Figure 1: Conceptual Model of HIV Retention in Care for HIV-Positive Mothers of Color

CHAPTER III

MEDICAL APPOINTMENT ATTENDANCE ADHERENCE AND SOCIAL SUPPORT AMONG HIV-POSITIVE BLACK AND LATINA MOTHERS

Introduction

The vast disparities related to retention in care among HIV-positive Black and Latina mothers remains a prominent issue (Holstad, Dilorio, Kelley, Resnicow, & Sharma, 2011; Stone, 2012). For more than a decade, Black and Latina women have experienced the highest rates of new HIV infections among women; they continue to be at risk for sub-optimal adherence to medical appointments, and subsequently, to HIV treatment (Burke-Miller et al., 2006; Lopez, 2010; McClure, Catz, & Brantley, 1999; Merenstein et al., 2008; Stone, 2012; Vyavaharkar et al., 2010). Appointment adherence for HIV-positive patients is critical to successful medical treatment and provides opportunities to tailor care to reach therapeutic levels (Bofill, 2010). Yet studies show missed medical appointments in the first year for HIV-positive individuals are most prevalent among women, Blacks, patients lacking private health insurance, and substance abusers (Mugavero et al., 2009). This poses great concern, as Black and Latina women represent 64% of all HIV cases among women nationally (Centers for Disease Control, (CDC, 2013a). Even more concerning, in New York City, 93.4% of all newly reported HIV cases among women are among Black and Latina women (Black Women's Imperative, 2013).

One of the main objectives of the National HIV/AIDS Strategy (NHAS) for the United States is to reduce HIV-related disparities and optimize health outcomes for HIV-positive individuals by increasing access to care (Office of AIDS Policy, 2012). However, gaps remain in understanding the factors that are associated with low adherence to medical appointments among women of color (Geng et al., 2010; Horstmann, Brown, Islam, Buck, & Agins, 2010; Messer et al., 2013). Further, little research has addressed the underlying social factors, such as low levels of social support and family obligations, that may affect mothers' of color ability to consistently attend medical appointments (Holstad et al., 2011; Mellins, Kang, Leu, Havens, & Chesney, 2003).

Little research examines which types of support may better resonate with this population in the management of adherence to medical appointments. For example, many studies focus on perceived support (DiMatteo, 2004; Lopez, Antoni, Fekete, & Penedo, 2012; Roger, Migliardi, & Mignone, 2012). Perceived support measures the subjective judgment that if support were needed someone would be there to provide it. Enacted support measures the actual receipt of support (Mueller et al., 2009; Pequegnat et al., 2001; Xia et al., 2012). The two constructs are often conflated in the literature; however, they measure different dimensions of social support (Xia et al., 2012).

In this study, I examine the relationship between disease management, as measured by attending all medical appointments for HIV care in the last 30 days, and different dimensions of enacted support (practical support, emotional support, and HIV-specific support). To answer these questions regarding the relationship between enacted support and adherence to medical appointment attendance, I used the Healthy Mother's

Survey (formally known as Factors Mediating Adherence in HIV Positive Patients sponsored by the Office of AIDS Research) from 1998-1999. This data set consists of three waves of data: baseline (wave 1), wave 2, and wave 3 that capture the experiences of HIV-positive Black and Latina mothers.

Theoretical Rationale

According to the Stress and Coping theory by Lazarus and Folkman (1984), successfully managing perceived stressors, such as being diagnosed with HIV and AIDS, is related to numerous socio-demographic background characteristics for example age, race/ethnicity, marital or relationship status, and education. These background variables can either help to mitigate or diminish the effect of a stressor (Vyavaharkar et al., 2011). In addition, a lack of support may cause an individual to have a negative or maladaptive response to a stressor (Vyavaharkar et al., 2011). Supportive social interactions have been strongly associated with better management of HIV and better health outcomes for women (Aspeling & Van Wyk, 2008; Muze, 2009).

Social support, globally, is defined as the resources provided by others (Israel, 1987). Social support is also defined as the feeling of belonging, being valued and esteemed (Hough, Magnan, Templin, & Gadelrab, 2005). It is considered a complex, multidimensional construct that includes people who provide support, type of support, and perceived availability, enacted support, and satisfaction with support received (Israel, 1987; Vyavaharkar et al., 2011). Even though more studies are beginning to carefully differentiate between types of support, more HIV research is needed that measures support actually received ("enacted support") among HIV-positive mothers (Barrera & Baca, 1990; Frazier, Barnett, & Tix, 2003; Kelly, 2013; McDermott, Alexander, &

Goldsmith, 2000). Functionally, there are different types of enacted support: emotional support (includes affirmative interactions and affectionate interactions), instrumental or practical support (includes offering resources such as money and transportation), and informational support (includes providing advice or useful information) (Field & Schuldberg, 2011). While many studies have recognized the importance of social support, little attention has been given to which type of support may influence better adaptive responses to medical appointment attendance. This study is focused on enacted emotional, informational, and practical support.

Scholarly attention has focused on role of social support in medical appointment attendance and health outcomes (Hough et al., 2005; LeGrand, 2010). The few studies that have included HIV-positive women of color suggest that the various dimensions of social support differentially influence medical appointment attendance among racial or ethnic groups (Kempf et al., 2010; Messer et al., 2013). For example, one intervention study found that tailored messages, a form of informational or HIV-specific support, were significantly associated with attending medical appointments. This intervention was more effective among young women and men rather than adult women (Gardner et al., 2012). Other studies have found that practical support such as providing ancillary services were significant predictors of HIV-positive women's attendance of medical appointments (Andersen et al., 2007; Lo, MacGovern, & Bradford, 2002; Sherer et al., 2002). The Anderson et al. (2007) study found that women with a history of mental illness or substance abuse needed more tailored care and support, in addition to transportation, to improve medical appointment compliance.

Research clearly demonstrates both the importance of social support systems of Black and Latina women. These relationships function as key resources over the life course by providing opportunities to pool resources, especially during times of hardship (Domínguez & Watkins, 2003; Mullings, 1997; Stokes, 2012). For mothers with families, strengthened sources of social support may play a critical role in their ability to adhere to treatment regimens. Several studies also have illustrated that perceived social support has been related to decreased levels of stress and depression (Haug, Sorensen, Gruber, Lollo, & Roth, 2006; Remien et al., 2007). However, chronic illness such as HIV can burden and deplete the social networks and support systems that Black and Latina mothers rely on when enacted support is considered. As HIV progresses, a mother's inability to reciprocate support may weaken her own sources of support (Hough et al., 2005; Watkins-Hayes, 2013). Additionally, issues of stigma may leave women with no support (Roger et al., 2012).

To date few studies have attempted to characterize the types of social support HIV-infected Black and Latina mothers receive or the influence of these support types on adherence to treatment regimens. Investigating which forms of enacted support are associated with increased medical appointment adherence for Black and Latina mothers can contribute to interventions aimed at increasing medical adherence and retention in care.

Current Study

The current study seeks to examine the relationship of different types of enacted support, specifically practical support, emotional support, and HIV support, with medical appointment attendance measured at three waves of data over a period of 18 months. The time variable in this longitudinal study measures changes across waves on the outcome of interest, medical appointment adherence in the last 30 days. The wave variable accounts for the change in the odds of keeping doctor appointments between waves.

Hypotheses

Study hypotheses for the Black and Latina HIV-positive mothers in this study are as follows:

Hypothesis 1: Socio-demographic and mental health variables will be associated with greater odds of attending all medical appointments, but mental health will explain more variance in medical appointment attendance over time.

Many socio-demographic factors are associated with adherence to medical appointments for Black and Latina mothers, including poverty, education, gender, and ethnicity. These are control variables that are expected to influence the outcome of medical appointment attendance. Poverty and lack of education are key factors in late treatment engagement and consequent higher mortality for HIV-positive mothers of color (Bofill, 2010; Israelski, Gore-Felton, Power, Wood, & Koopman, 2001; McClure et al., 1999). HIV-positive women report more barriers to receiving and remaining in care than men, including higher rates of poverty and unemployment, more difficulty accessing care, and more difficulty accessing care for people other than themselves (Aziz & Smith, 2011; Bowditch et al., 2013). Overall, HIV-positive Latino and Black mothers are more likely to engage in care much later and to exhibit higher rates of AIDS-related mortality than their white counterparts (Galvan & Davis, 2012; Hall, 2012).

In addition, substance abuse, and mental health diagnosis are associated with less medical adherence (Bofill, Waldrop-Valverde, Metsch, Pereyra, & Kolber, 2011; Catz, 1997; Israelski et al., 2001; Johnson, 2002). Having mental health diagnosis is highly associated with poor medical appointment adherence (Mellins et al., 2009; Mellins et al., 2003). However, mental health diagnosis has been associated with significant effects on medication and appointment adherence for HIV populations, especially women (Mellins et al., 2002).

Hypothesis 2: After controlling for socio-demographic variables and mental health variables, the presence of any type of social support will be significantly related to greater odds of attending all medical appointments over time.

The presence of social support has been found to be beneficial for HIV-positive mothers, helping them to better cope and manage living with HIV (Gjesfjeld, Greeno, Kim, & Anderson, 2010; LeGrand, 2010; Lizy, Geetha, & Joseph, 2011; Pakenham & Rinaldis, 2001).

Hypothesis 3: After controlling for socio-demographic variables and mental health variables, *emotional support* will explain more variance in the odds of adhering to medical appointments compared to other dimensions of enacted support over time.

Informed by research on HIV-positive mothers and their retention in care, this hypothesis examines the presence of enacted social support over time and recognizes that, although global or general forms of social support may be helpful, it is important to determine which dimension of support may be most effective for women to remain in care (Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012). Current research suggests that emotional support is more strongly associated with meeting physical and psychological needs especially for persons living with HIV (Kempf et al., 2010). Qualitative studies on Black and Latina women suggest that emotional support provided by medical staff is beneficial to adherence to medical appointments by helping them to mitigate feelings of social stigma and to “feel like a normal person” (Kempf et al., 2010). Edwards’s (2006) study of HIV-positive Black mothers found that, while the mothers felt supported overall and were confident that their basic needs were met, many also indicated that they lacked emotional support and did not feel loved or cared for most of the time.

Methods

Data Collection and Sample

Participants in this study were recruited from a waiting room of a New York City infectious disease clinic (Mellins et al., 2002). Trained interviewers approached 134 women for this study. Of the 134 potential participants, five declined to participate and one woman was too cognitively impaired to participate in the study (Mellins et al., 2002). All reported that they were mothers of children under age 18. A total of 128 women agreed to participate and signed the written informed consent form; 127 were available for the baseline interview. A monetary reimbursement was offered for their time and transportation was also provided (Mellins et al., 2002). The study was approved by the New York State Psychiatric Institution Review Board in 1998. It was also approved for further analyses in 2012 and for this dissertation by the University of Michigan Institutional Review Board.

In the dataset, one hundred and twenty-seven women were accessible and completed the initial baseline interviews (wave 1). They and were asked to participate in another interview that was 4- to 5-month later (wave2) (Mellins et al., 2002). One hundred and thirteen women completed interviews for wave 2 of the data. Additionally funding was obtained to conduct a second follow-up of the study (wave 3) and the researchers were able to re-contact 97 women (Mellins et al., 2002). The Mellins et al study (2002) reports that the time between wave 2 and wave 3 was highly variable because of difficulty tracking participants. Participants were recruited anywhere from 8 months from the first follow-up to 18 months later due to high mobility of participants and illnesses (Mellins et al., 2002).

The interview was conducted in either English or Spanish for all participants in all waves of the study (Mellins et al., 2002). The adult baseline interview included variables on socio-demographic factors such as education, marital status, income, number of people in household, and public assistance (Mellins et al., 2002). Mental health variables in the model include substance use inventory, demoralization scale and mental health inventory. The major scales included stressful life events, perceived stress inventory, social support inventory, family disclosure, family functioning, medication attitudes, adherence efficacy, and health services utilization (Mellins et al., 2002). An abbreviated questionnaire was used for the first and second follow-up interviews that consisted of the same socio-demographic variables and a subset of the outcome measures that were asked in the baseline interview, including adherence to medication and medical appointments (Mellins et al., 2002).

Sample for the Current Study

According to Mellins et al. (2002), participants self-identified that they were English- or Spanish-speaking, 18 years of age or older, and were mothers of children living at home that were 18 years of age or younger. Fifty-eight percent of the women in the original study were Black and 38% were of Latina descent, and 4% percent were identified as White, non-Hispanic. The latter group was excluded because the subgroup was too small for ethnic comparisons. Only participants with complete data for all variables of interest across all three waves were included in this analysis, resulting in a sample of 91 HIV-positive mothers who self-identified as Black or African American or White Latina.

Approximately 75% of mothers at baseline (wave 1) in the study reported at least one health problem and 11% of mothers reported children with HIV. Only 14.3% of mothers in the study reported currently working and 53.6% of mothers reported currently being on public assistance. Previous studies published using this dataset found that two-thirds of the women were on anti-retroviral medication and 2% of the women reported missing anti-retroviral medication within the previous two days of the interview (Mellins, Ehrhardt, Rapkin, & Havens, 2000; Mellins et al., 2003).

Table 3.0 and 3.1 display descriptive statistics for mothers in the study at wave 1, wave 2, and wave 3. Of the 127 mothers in the study, 112 mothers had complete data at wave 1, 107 mothers had complete data for wave 2, and 91 mothers had complete data for wave 3 on variables of interest. In this sample, 40.2% of mothers self-identified as White Latina and 59.8% of mothers identified as Black. There was not too much difference across waves for *race/ethnicity* with Black mothers representing the majority of the sample across waves. In terms of *marital status* 31.3% of the sample reported never married or living with a partner, 32.1% reported married and or living with a partner, and 36.6% reported being separated, widowed or divorced. Again these ratios remained consistent across all three waves. For reported *substance abuse in the past 30 days* 14.3%

of the sample reported use in the past 30 days at baseline and this percentage was consistent across all three waves. Approximately half the mothers in the study (ranges from 49.1% at wave 1 to 47.3% at wave 3) reported a *mental health diagnosis*. For *poverty index*, the majority of mothers in the study (ranges from 71.4% at wave 1 to 67.0% at wave 3) were calculated to have a yearly income below the poverty line. The mean *age of mothers* in the study was 37 at wave 1 (SD=7.76) and this remained consistent across waves. The mean score for *practical support* was 2.60 (.69), for *emotional support* 2.62 (.76) and for *HIV support* 2.59 (.86). Scores on three dimension of support remained pretty consistent across waves.

Participant Attrition

According to Mellins et al. (2002), attrition at wave 2 was due to refusal (n=3), death (n=7), and inability to contact (n=21). Among the mothers who completed the both follow-up studies (wave 2 and wave 3), there was no significant difference in socio-demographic characteristics, rates of mental health diagnosis, substance abuse, level of psychological distress, poverty, or health status. However, mothers having more people in the household were more likely to discontinue the study (Mellins et al, 2002).

Comparing the 91 mothers who had complete data across all waves of data with mothers who had some missing data on variables of interest at wave 1 indicated that those with missing data were more likely to report substance abuse (p=0.02). However, this difference was no longer significant in wave 2 (p=.60) and wave 3 (p=.25) (see table 3.3).

Measures

Dependent Variable

Full (100%) medical appointment adherence. All mothers in the study were asked how often in the past year were they able to attend medical appointments. 1= Attend no appointment, 2= about 25% of appointments, 3= about 50% of appointments, 4=about 75% of appointments, and 5=100% of appointment. Because frequencies in the middle categories were very low, this variable was collapsed into a categorical variable 0=less than 100% of appointments attended and 1=100% of medical appointments.

Control Variables (Socio-demographic Variables and Mental Health Variables)

Socio-demographic Variables

Race/Ethnicity. A dichotomous variable was created for race/ethnicity participants were either “Black” (=2) or “White Latina” (=1). Two mothers in the study who identified as African and two mothers who identified as Caribbean included in the group described as “Black”. Although people of Caribbean and African decent are different from African Americans, there were too few African and Caribbean women in this study to do a comparison based on national origin. It was also imperative to maximum power in the analysis, since it was a very small sample. Additionally, at the time this study was conducted (1999), census data identified people of African descent as “Black, African American, or Negro.” As mentioned above, six mothers (4%) who self-identified as White were excluded from this analysis because there were not enough cases to study them as a separate comparison group.

Partner Status. Initial categories for marital status include 1= never married and not living with a partner, 2= married and living with partner, 3=separated, 4= living with partner 5=widowed, and 6=divorced. These categories were collapsed for the final analysis into 1=living with a partner with and 0= not living with a partner. The socio-economic status and race/ethnicity may affect the types of family forms identified that are different from conventional concepts of marriage and family structure (Geronimus & Thompson, 2004; Stacks, 1974). By labeling the partner status and not marital status, this study takes into account that there is a partner in the household rather than only acknowledging those that are married.

Mental Health Variables

Substance abuse in the past 30 days. A dichotomous variable for alcohol and drug abuse was used from the Clinical Diagnostic Questionnaire (Aidella, 2000) to reflect any substance abuse in the last 30 days. Mellins et al. (2000) reported sensitivity for this variable at 85% (1=yes, 0=no).

Any mental health diagnosis. This is a dichotomous measure which asks if mothers currently have any diagnosis of mental health illness (1=yes, 0=no).

Age of Mother. This is a self-reported continuous variable.

Education. Highest Grade Level completed reported (example: 1=First grade, 2=second grade…12=twelfth grade, 14=some college, 17=some graduate school).

Poverty index. The federal poverty threshold is computed and updated by the Census Bureau each year to provide an accurate picture of poverty in the United States (Bureau, 2012)**.** The Census Bureau computes poverty thresholds by using reported yearly income before taxes that accounts for family size and composition and does not include public assistance. The number is also updated each year for inflation.

For the current study, household income and household size for each participant were used to calculate a poverty measure, which was then compared to the federal poverty threshold. The ratio of the family's household income adjusted for household size, compared to the federal poverty threshold, represents the family's poverty-to-income ratio. The data used to calculate this ratio was taken from the year 1999, the year the data were collected. This ratio was used to reflect poverty status in the current study. Poverty-income ratios 1 and greater indicate that the family lives above the federal poverty line; values less than 1 indicate that the family lives below the federal poverty line.

Key Predictor Variables

Social support inventory. An abbreviated revised HIV version of the Multi-dimensional Social Support Inventory was used in this study (Bauman, 1997). This instrument was designed to measure perceived, enacted, and structural dimensions of social support, including a variable that measures HIV support. A completion of a network grid is required to examine aspects of functional support. Items that measured social networks included too much missing data and were not collected over time; thus they were not used in the current study. The Social Support Inventory includes four distinct support types: Practical, Affirmational, Emotional, and HIV-specific support. For each support type, the participant was first asked a yes/no questions about her receiving a dimension of support, then a question about the frequency of receiving such support. Only the frequency of enacted support was used in the current analysis. Because there was not enough variability in affirmational support, this item was not included in the final analysis.

The support items were rated on 4 point Likert scale ranging from (1) Frequently to (4) Rarely. The total support score was a sum of all the responses where *lower scores indicated more support* was received. This measure asks specifically about different types of support. These items were reverse scored for this analysis (1) Rarely to (4) Frequently.

For example, a question about **practical** support is:

"Over the past month, did you actually receive this type of support?"

Response: Frequently =1, Often=2, Sometimes=3, Rarely=4.

For **emotional** support, an example question is,

"Over the past month, did you actually receive this type of support?"

Response: Frequently =1, Often=2, Sometimes=3, Rarely=4.

An example question regarding **affirmational** support asked,

"Over the past month, did you actually receive this type of support?"

Response: Frequently =1, Often=2, Sometimes=3, Rarely=4.

A question eliciting **HIV support** asked,

"Over the past month, did you actually receive this type of support?"

Response: Frequently =1, Often=2, Sometimes=3, Rarely=4.

For the social support variables, composite variables were developed by combining items together for each dimension of support. For this study, the Cronbach's alphas (inter-item consistency, an estimate of reliability) were: practical support (α=.718); emotional support (α=.770); and HIV support (α=.734). This scale has good validity among Black and Latina HIV-positive mothers in other studies (Bauman & Weiss, 1994; Mellins et al., 2000; Mueller et al., 2009).

Statistical Analysis

All analyses were completed using SPSS version 22.0, which has the ability to handle longitudinal data and advanced statistical analysis. First, descriptive statistics were calculated, including means, standard deviations, and ranges for all of the main variables of interest (see Table 3.0). A total of 127 individuals in the dataset had baseline information on the variables of interest. Among the study sample, however, only 91 of those individuals had complete data on all measures of interest from baseline to second wave of follow-up data. Thus, all analyses are based on 91 cases. It should be noted that there are other ways of handling missing data. An alternate strategy may have been to use multiple imputation. In this method, missing data are replaced with simulated estimates calculated from the distribution of the data (Torres, 2011; Young & Johnson, 2013). However, criticism of this approach is that imputations are not always correct, especially if it does not include a random component; thus it may not give accurate findings either. Rughnathan (2004) explains that analyses of imputed missing data often produce estimates and standard errors that are too small and confidence intervals that are too narrow. Stochastic regression imputation would be an additional remedy for this type of bias, but was beyond the scope of this paper.

Excluding those with missing data can also produce biased results if participants included in the analysis are different from those who are excluded. In order to check for such potential biases, chi-square and t-tests were performed to test for differences between mothers with missing data and those without on the variables of interest in this study. The results, as shown in Tables 3.2, and 3.3, illustrate that there were no significant differences between mothers with missing data and those without on the variables of interests except at wave 1 with regard to substance abuse.

The next step in this analysis was to identify potentially confounding variables by performing t-tests, chi-squares, and Pearson's correlations to examine associations between all variables of interest at the bivariate level. The results of a correlation matrix for all variables are provided in Table 3.4.

Finally, Repeated Measures Logistic Regression, using a generalized linear models approach (GENLIN module in SPSS) was conducted to estimate the relationships between socio-demographic variables, mental health variables, social support variables, and 100% medical appointment attendance. The generalized linear models approach is the most appropriate for this analysis because we analyze the effects of baseline variables on a categorical outcome measured at multiple time points. A simple logistic regression model does not take account the non-independence of the data points measured over time. According to SPSS (2012) the repeated measures extension of generalized linear models (also known as generalized estimated equations) accounts for "correlated longitudinal data and clustered data. More particularly, …[they] model correlations within subjects. Data across subjects are still assumed independent." The generalized linear model also allows continuous and categorical (ordinal or nominal) data to be included in the analysis. Whereas the General Linear Model (GLM) requires the assumptions of linear responses, constant variance, and multivariate normality, the generalized linear model allows for deviations from these assumptions to be modeled.

In the current analysis, each dimension of social support (practical support, emotional support, and HIV support) was added separately to the model to determine the effect of each measure of social support on medical appointment attendance over time. Tables 3.5 and 3.6 present the results from the repeated measures logistic regression analysis. Five models were run: Model 1, which tests for hypothesis 1, examined the effect of mental health variables (substance abuse in the past 30 days, mental health diagnosis) after controlling for effects of socio-demographic measures (i.e., wave of follow-up time, partner status, race/ethnicity, education, poverty) on medical attendance across all three waves. We termed this model the “basic model” Model 2 added emotional support to the basic model; Model 3 removed the emotional support measure and added practical support to the basic model; Model 4 removed the practical support measure and added HIV support to the basic model. Models 2, 3, and 4 tested hypothesis 2. Model 5 included the basic model and all three types of support (i.e., emotional support, practical support, and HIV support), testing hypothesis 3. All models included an indicator of the wave of data collection to determine whether there was a time effect of data collection in the analyses. This hierarchical approach was conducted in order to build a model using bivariate relationships, but controlling for background factors. Thus we first tested whether ANY support variable plays a role in medical adherence (hypothesis 2). Model 5 allowed the identification of potential suppression effects as well as comparison of betas for the individual social support variables, while controlling for the others. Finally, because of the high correlation between race and education, the analysis was rerun twice, eliminating one of the two variables each time.

Results

Correlation Results

Table 3.4 presents a correlation matrix of the relationship between all variables of interest used in the model.

Demographic measures. The mother's age was unrelated to all variables, except her increased likelihood of attending 100% of medical appointments at wave 1. *Education* was highly correlated with *race/ethnicity* (r=.57, p<.01). Being black was associated with lower chance of having a *Mental health diagnosis* (r=-.23, p<.05). Living with a partner status was negatively related to 100% attendance at medical visits at wave 1 (r=.32, p<.05). Surprisingly, the *poverty index was unrelated to any other measures.*.

Mental health variables. Individuals with a mental health diagnosis were more likely to have high practical support (low scores) and more likely to have 100% attendance at waves 2 and 3. Reporting substance abuse in the last 4 weeks was not significantly related to any predictors or outcomes.

Emotional support and *practical support* were moderately correlated with each other (r=.35, p<.05 Emotional support and HIV support were moderately correlated as well (r=.55, p<.05) as were practical support and HIV support (.30, p<.05) Because attending all visits at wave 1 was positively related to age and partner status attending all visits at wave 2 was associated with lower likelihood of mental health diagnosis, and attendance at 100% of visits at wave three was associated with lower likelihood of mental health diagnosis (r=-.27, p<.05) as well as less emotional (r=.28, p<.05) and HIV support (r=.29, p<.01, these variables were included in the subsequent repeated measures regression analysis.

Table 3.5 & 3.6 summarizes the results from the repeated measures logistic regression models for all three hypotheses.

Effects of Socio-demographic and Mental Health Variables on 100% Medical Appointment Attendance (Hypothesis 1)

Model 1 represents the repeated measures logistic regression model of socio-demographic and mental health factors on 100% medical appointment attendance. First, *wave of follow-up* (time) (OR=1.43, p=0.05), *age* (OR=1.06, p=0.01), and *any mental health diagnosis* (OR 2.85, p=0.01) were all significant predictors of *100% medical appointment attendance.* Specifically, at later waves, participants were more likely to attend all medical visits. Consistent with Hypothesis 1, the older women were more likely to have *100% medical appointment attendance;* also, those with a mental health diagnosis were less likely to attend all medical visits.

Effect of Any Social Support on 100% Medical Appointment Attendance (Hypothesis 2)

Model 2 is a repeated measures logistic regression model that tested the relationship between *practical support* and *100% medical appointment attendance* while controlling for all socio-demographic and mental health variables of interest. The variables *wave follow-up (time)* (OR= 1.43, p=0.05), *age* (OR=1.07, p=0.01), and *any mental health diagnosis* (OR=2.91, p=0.01) remained significant. *Practical Support,* however was not a significant predictor of *100% medical appointment attendance* (OR=0.95, p=0.85). Model 3 represents a repeated logistic regression model controlling for all socio-demographic and mental health variables of interest and testing the effect of *emotional support*. Similarly, to Model 2 the significant socio-demographic variables *wave of follow-up (time)* (OR=1.44, p=0.04) *age of mother* (OR=1.06, p=.02) and *any* *mental health diagnosis* (OR=1.43, p=.02). Higher levels of *emotional support* (OR=1.69, p=.01) were associated with 100% medical appointment attendance **(**In Model 4 (table 3.6), represents a repeated logistic model controlling for socio-demographic and mental health variables of interest and testing the effect of *HIV support*. In this model, *wave of follow-up* (OR=1.43, p=.02) *age* (OR=1.07, p=.02), and *any mental health diagnosis* remained significant; however, *HIV support* was not significant. In Model 5, after controlling for all socio-demographic and mental health variables, all three dimensions of support were entered into the model (*practical support, emotional support, and HIV support*). Again *wave of follow-up* (time) (OR=1.44, p=.02), *age of mother* (OR=1.08, p=.01), and *any mental health diagnosis* (OR=2.90, p=.008) remained significant. Emotional support (OR=4.62, p=.07). However, no other support variables appeared to be significant. Specifically, individuals who were older, had a mental health diagnosis, and had less emotional support were more likely to attend 100% of medical visits across time.

In sum, the first model, which tests the relationship between socio-demographic variables and adherence to medical appointments, found that the longer participants were in the study the more likely they were to adhere to all medical appointments). Also, the older the participants were, the more likely they were to attend all medical appointment (OR=1.06, p=.008). In this model, mental health was a major predictor of attending all medical appointments. A person WITH a mental health diagnosis was almost three times more likely to attend all medical appointments (OR=-2.85, p=0.01). These relationships are robust and hold even after social support variables are added to the model. After adding all three dimensions of support, emotional support remained the only significant dimension of support in the model.

Discussion

This study sought to identify factors predictive of *100% full medical appointment attendance* for HIV-positive Black and Latina mothers. The goal of this study was to determine the relationship between adherence to medical appointments, socio-demographic variables and mental health variables, and the presence of different dimensions of social support over time. The first hypothesis posited that *education*, *mental health diagnosis*, and *substance use*, would be the most significant predictors of adherence to all medical appointments. The mental health variables (*any mental health diagnosis* and *substance use*) were predictive of attending all medical appointments. *Education* was not found to be a statistically significant factor in attending all medical appointments, however age was a significant socio-demographic variable.

For age, a study from the Human Resources and Social Services (HRSA, 2012) found that among more than 27,000 HIV-positive individuals, older patients were more likely to remain in care. The literature is replete with examples of how mental health influences both medical appointment attendance and adherence for HIV-positive women (Blashill, Perry, & Safren, 2011; Cook et al., 2002; Dolezal, Brackis-Cott, Spiegel, & Mellins, 2007; Gjesfjeld et al., 2010; Mellins et al., 2003; Murphy, Marelich, Armistead, Herbeck, & Payne, 2010). However, it was interesting that this study found inconsistent findings with the literature and past studies using this dataset on mental health diagnosis and attending all medical appointments. It seems antithetical that someone with a mental health diagnosis would be two times more likely to make all medical appointments.

One explanation is that during the late 1990s, when the data were collected, HIV care was often combined with mental health care (Sowell, 1999). There were many uncertainties with regard to data on HIV in the nineties including high rates of mental illnesses among people living with HIV (Valente & Saunders, 1997). HIV mental health specialists were available for people living with HIV for common psychological issues of grief, loss, socialization and adjustment to HIV, and the many debilitating conditions that could be associated with the disease (Drummond, 2002). HIV mental health specialists could also assist with coordinating and referring HIV treatment (Larkin et al., 1999). It is possible the women participants in this study that reported having a mental health diagnosis were working with an HIV psychological specialist that also assisted with HIV care. Therefore they would be more likely to make their HIV appointments.

Consistent with the literature on Black women and retention in care (Gardner et al., 2012; Konkle-Parker, Amico, & Henderson, 2011; Stone, 2012), this study, too found that, if you were not Black, you were almost two times more likely to attend all medical appointments, although this relationship did not reach significant levels in the present study. Based on the literature, one would also expect other demographic variables, such as educational level and poverty index, to be associated with attending all medical appointments. However, in this study, these variables were not predictive of missed medical appointments. Multicollinearity, a common problem in regression models could explain why some of the demographic variables in the model are not significant. There was a strong correlation between education and race/ethnicity. Models were run with and without education in the model, to account for this correlation. However, the numbers did not change without education in the model, which again demonstrates that this model is very robust. .

Guided by the literature on HIV-positive mothers and social support (Tufts, Wessell, & Kearney, 2010; Vyavaharkar et al., 2011; Wohl et al., 2010), the next set of models tested the role of different dimensions of social support on mothers' adherence to medical appointments. The dimension of support that was the only predictor of medical appointment attendance was *emotional support*; even after controlling for socio-demographic variables including mental health, *emotional support* remained a predictor of attending all medical appointments. Participants who received *emotional support* was almost twice as likely to attend all medical appointments.

Limitations

There are several limitations to consider in this study. First, the study's sample size is small. The need to find such a specific population of women, i.e., those who are both HIV-positive and mothers, and then to follow them over time resulted in a smaller sample size than desired. Although in this study every attempt was made to maintain the power of the sample, the limited sample size contributed to some large confidence intervals. Thus, the explanatory power and definitive inferences of the results, as well as the generalization of findings to larger populations, also are limited. In addition, the measurement of the outcome variable of "medical appointments,' which was defined as either attending *all* medical appointments or *not* attending all medical appointments limits the explanatory analysis of this study. However, in this sample most of the mothers who did not attend all medical appointments, reported that they attended 50 to 75% of all medical appointment.

There were also several variables we could not use such as CD4 count and Viral Load, were not used in this analysis due to lack of variability and missing data in the sample. These variables are also important to consider when addressing medical appointment attendance because studies have shown that the higher the viral load and the lower the CD4 count, the more likely individuals are to attend medical appointments due to the severity of their disease (Currier et al., 2010). Additionally, we had no comparison group of whites in the study; data were available for only six whites and the group was therefore omitted. Another issue that is important to address is the date of this sample from 1998 at the beginning of the HIV epidemic, when so much has changed in the way of advancements on HIV treatment and research. However, this dataset is still very relevant to current issues of mothers who are HIV positive. Even though the measurement of medical appointment attendance every 30 days seems short, this measurement actually reflects the medication schedule and the standard of adherence during the late 1990s at the beginning of HIV therapy. Additionally, there are still very few datasets that represent the issues of the population and include socio-demographic variables that are unique to this population.

Conclusion

Despite these limitations in the data, the results warrant further investigation on the relationship between missed medical appointments and social support among HIV-positive mothers. One of the main strengths of this study is this dataset that allows us to test variables such as enacted social support on a population of HIV positive mothers. There are no other datasets currently available to test these relationships among mothers of color. Even though this dataset is over 15 years old, not much has changed for HIV positive women of color in terms of their day-to-day issues managing and living with HIV and AIDS (Norman & Dumois, 1999; Habegger, 1999). The implications of the results are relevant, even today. Certain dimensions of enacted social support may play a role in engaging mothers to attend all medical appointments. Enacted emotional support from providers and health care professionals may encourage women to enroll in care and stay in care. Perceived feelings of being engaged, heard, understood, welcomed, and valued for HIV-positive mothers have been noted as critical factors in managing and adapting to a very stigmatizing disease (Amutah, Edwards, Irving, & Sydnor, 2012; Aspeling & Van Wyk, 2008; Bodenlos et al., 2007). Emotional support may be more effective than practical or HIV-specific support in providing the initiative to seek additional help, as well as to seek other forms to support. A qualitative study that corroborates this view by Kempf (2010) found that emotional support was particularly instrumental in encouraging women to stay engaged in care and more encouraging if offered by family members. Emotional support was mentioned as imperative to maneuvering difficult situations and remaining in care. Another prominent finding from the Kempf (2010) study was that healthcare providers who listened, encouraged, and affirmed their patients saw increased appointment retention.

While there have been significant improvements in anti-retroviral treatment for HIV-positive individuals, medical treatment is only effective if it is taken correctly and consistently. For mothers living with HIV, effective care means effective support services to assist and provide care in the midst of their parenting responsibilities. It is likely that gender may influence how social support is perceived and received. The effectiveness of support services for women is currently failing as the needs of HIV-positive women and mothers continue to be overlooked. Population-specific experimental designs are needed to address the dynamics of women and mothers grappling with HIV and to inform intervention programs. Further, engaging more cohorts of women could help to dissect and illuminate how women's complex and overlapping relationships affect their health decisions; identifying the contextual factors of women's and mothers' social and interpersonal needs is critical to providing effective care for this population.

This paper provides the first step in identifying and confirming other studies in which social support plays an important role in management of care for HIV-positive women of color. This information will help to better tailor care and effective interventions for this population. As more public health efforts focus on management of care for women of color, it would be beneficial to do more interventions studies that explore the benefits of emotional support for this population, especially in clinical settings.

Table 3.0. Descriptives for Initial Sample and Subsamples with At-Least One Missing and with No Missing Values on Study Variables (Categorical Variables)

Descriptors	**Initial Sample No Exclusions (N=121)**	**Wave 1 No Missing Data (N=112)**	**Have Missing Data (N=9)**	**Have Missing Data vs. No Missing Data**	
	Frequency (%)	**Frequency (%)**	**Frequency (%)**	***t* (*df*)**	**p-value**
Ethnicity					
White Latina	48 (39.7%)	45 (40.2%)	3 (33.3%)	.16 (1)	.49
Black	73 (60.3%)	67 (59.8%)	6 (66.7%)		
Partner Status					
Never married	38 (31.4%)	35 (31.3%)	3 (33.3%)	2.00 (2)	.37
Married or living with partner	37 (30.6%)	36 (32.1%)	1 (11.1%)		
Separated, widowed, or divorced	46 (38.0%)	41 (36.6%)	5 (55.6%)		
Substance abuse in last 30 days	20 (16.5%)	16 (14.3%)	4 (44.4%)	**5.49 (1)**	**.02**
Mental health	55 (49.1%)	52 (48.6%)	1.22 (1%)	.27	43 (47.3)

Table 3.1. Descriptives for Initial Sample and Subsamples with At-Least-One Missing and with No Missing Values in Wave 1 (Continuous and Ordinal Variables)

Descriptors	**Initial Sample No Exclusions (N=121)**	**Have No Missing Data On Study Variables (N=112)**	**Have Missing Data On Study Variables (N=9)**	***t*-Test** **Comparing Missing Data Sub-Sample With No Missing Data Subsample**	
	Mean (SD)	**Mean (SD)**	**Mean (SD)**	***t* (*df*)**	**p-value**
Age	37.93 (7.67)	37.89 (7.76)	38.33 (6.86)	.17 (119)	.87
Education (highest grade) (4=missing)	11.08 (2.53)	11.03 (2.38)	12.20 (1.10)	1.09 (115)	.28
Practical Support	2.59 (.69)	2.60 (.69)	2.44 (.73)	-.64 (119)	.52
Emotional Support	2.59 (.80)	2.62 (.76)	2.11 (1.17)	-1.30 (8.6)	.23 [b]
HIV Support	2.55 (.87)	2.59 (.86)	2.11 (.93)	-1.61(119)	.11

Table 3.2. Cross-Tabulation Analysis across Waves for the Sample

Categorical Descriptors	**Wave 1 (N=112)**	**Wave 2 (N=107)**	**Wave 2 Respondents vs. Wave 2 Drop-outs (N=107 vs. N=14)**		**Wave 3 (N=91)**	**Wave 3 Respondents vs. Wave 3 Dropouts (N=91 vs. N=30)**	
	Frequency (%)	**Frequency (%)**	***t* (*df*)**	**p-value**	**Frequency (%)**	***t* (*df*)**	**p-value**
<u>Race/Ethnicity</u>							
White Latina	45 (40.2%)	41 (38.3%)	.71 (1)	.40	35 (38.5%)	.22 (1)	.64
Black	67 (59.8%)	66 (61.7%)			56 (65.1%)		
<u>Partner Status</u>							
Never Married	35 (31.3%)	35 (32.7%)	1.03 (2)	.52	26 (28.6%)	1.62 (2)	.45
Married or Living with Partner	36 (32.1%)	31 (29.0%)			28 (30.8%)		
Separated, Widowed, or Divorced	41 (36.6%)	41 (38.3%)			37 (40.7%)		
Substance Abuse in Last 30 Days	16 (14.3%)	17 (15.9%)	.28 (1)	.60	13 (14.3%)	1.34 (1)	.25

Table continues…

Table 3.2 (continued). Cross-Tabulation Analysis across Waves for the Sample

Categorical Descriptors	**Wave 1 (N=112)**	**Wave 2 (N=107)**	**Wave 2 Respondents vs. Wave 2 Drop-outs (N=107 vs. N=14)**		**Wave 3 (N=91)**	**Wave 3 Respondents vs. Wave 3 Dropouts (N=91 vs. N=30)**	
	Frequency (%)	**Frequency (%)**	***t* (*df*)**	**p-value**	**Frequency (%)**	***t* (*df*)**	**p-value**
Poverty Index							
Above 1	32 (28.6%)	31 (29.0%)	2.90 (1)	.09	28 (30.8%)	2.97	.09
Below 1	80 (71.4%)	72 (67.3%)			61 (67.0%)		
Missing	5 (55.6%)	4 (3.7%)			2 (2.2%)		
100% Visits							
Wave 1	66 (58.9%)	59 (55.1%)	2.79 (1)	.10	53 (58.2%)	.02 (1)	.88
Wave 2		78 (73.9%)	n/a	n/a	67 (73.6%)	.29 (1)	59
Wave 3		63 (58.9%)	.03 (1)	.85	65 (71.4%)	2.63 (1)	.11
Missing Wave 3		19 (17.8%)			n/a	n/a	n/a
Missing Wave 2		n/a			3 (3.3%)		

Table 3.3. Bivariate Correlations among Study Variables for Subjects with Data at All Waves

Measure	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
1 Age of Mother	--									
2 Education [b]	.00	--								
3 Ethnicity [a] (1=Latina; 2=African/African American) [a]	.03	**.57****	--							
4 Marital Status (1=married; 2=single; 3=other) [a]	.16	.11	.18	--						
5 Poverty Index [a] (1=above; 0=below 1)	-.08	.06	.05	.16	--					
6 Substance Abuse in Last 30 days [a] (1=yes; 0=no)	.06	-.03	.22+	.21	-.13	--				
7 Mental Health Diagnosis [a] (1=yes; 0=no)	-.05	-.20+	**-.23***	.16	-.15	.07	--			
8 Practical Support [b]	.13	-.02	-.01	.21+	.04	-.02	**-.28***	--		
9 Emotional Support [b]	-.03	-.08	-.14	.17	.01	-.15	-.15	**.35****	--	
10 HIV Support [b]	.04	.13	.19+	**.23***	-.03	-.02	-.11	**.30****	**.45***	--
11 Wave 1 Attended All Visits (1=yes; 0=no) [a]	**.27***	-.04	-.09	**.32***	.01	-.03	-.14	.03	.09	.00
12 Wave 2 Attended All Visits (1=yes; 0=no)	.10	.14	.02	.22	.03	-.12	**-.24***	.04	.06	-.09
13 Wave 3 Attended All Visits (1=yes; 0=no)	.17	.06	.07	.08	.09	.08	**-.27**	.11	**.28***	**.29****

<u>Note</u>: +p<.10*p<.05; **p<.01; ***p<.001

Table 3.4. (Models 1, 2, and 3) Generalized Longitudinal Model of Socio-demographic Variables, Practical Support, Emotional Support, and HIV Support

Variables	Model 1 Basic Model			Model 2 Practical Support			Model 3 Emotional Support		
	OR	**CI (95%)**	**Wald Chi-square**	**OR**	**CI (95%)**	**Wald Chi-square**	**OR**	**CI (95%)**	**Wald Chi-square**
Wave of Follow-Up	1.44*	(1.00-2.04)	3.93	1.43*	(1.00-2.04)	3.93	1.44*	(1.00-2.06)	3.95
Age of Mother	1.06**	(1.01-1.12)	6.97	1.07**	(1.02-1.13)	7.21	1.09**	(1.02-1.23)	7.41
Partner Status	0.74	(0.49-1.13)	1.96	.745	(0.49-1.13)	1.86	1.08	(0.42-1.09)	2.56
Black (0=ref)	1.77	(0.79-3.96)	1.95	1.83	(0.79-4.01)	0.61	1.65	(0.73-3.71)	1.47
Education	1.17	(0.90-1.28)	0.65	1.07	(0.58-1.58)	0.43	1.08	(1.02-1.13)	0.91
Substance Abuse in Last 30 Days (0=ref; 0=none)	0.82	(0.27-2.47)	0.11	0.83	(0.27-2.47)	0.73	0.70	(0.22-2.22)	0.55
Mental Health Diagnosis (0=none; 1=yes)	2.85**	(1.33-6.11)	7.29	2.91**	(1.35-6.26)	0.01	2.93**	(1.22-3.63)	6.14
Poverty Index (0=below poverty level) (1=above poverty level)	0.97	(0.46-2.06)	0.01	0.97	(0.45-2.07)	0.94	0.99	(.43-2.08)	0.00
Practical Support	----	----	----	0.95	(0.57-1.57)	0.85	----	-----	-----
Emotional Support	----	----	----	-----	----	----	0.32*	(1.04-2.63)	4.60
HIV Support	----	----	----	-----	----	----	-----	----	-----

Note: +p<.10*p<.05; **p<.01; ***p<.001

Table 3.5. (Models 4 & 5) Generalized Longitudinal Model of HIV Support and All Support Measures and 100% Appointment Attendance

Variables	**Model 4 HIV Support**			**Model 5 All Support Measures**		
	OR	**CI (95%)**	**Chi-Square**	**OR**	**CI (95%)**	**Wald Chi-square**
Wave of Follow-Up	1.43*	(1.00-2.05)	3.91	1.44*	1.00-2.07	3.91
Age of Mother	1.07**	(1.02-1.12)	6.98	1.08**	1.02-1.14	7.73
Partner Status	1.07	(0.45-1.07)	2.96	0.11	0.44-1.09	2.47
Black (0=no; 1=yes)	1.94	(0.86-4.37)	1.95	1.75	0.75-4.03	1.71
Education	1.07	(0.90-1.28)	0.64	1.07	1.00-1.29	0.70
Substance Abuse in Last 30 Days (0=no; 1=yes)	0.80	(0.27-2.47)	0.16	0.69	0.22-2.22	0.47
Mental Health Diagnosis (0=no; 1=yes)	2.83*	(1.32-6.17)	7.15	2.90*	1.33-6.33	7.09
Poverty Index (0=below poverty level) (1=above poverty level)	0.97	(0.46-2.02)	0.01	0.98	0.47-2.04	0.03
Practical Support	--	--	--	0.77	0.48-1.24	1.09
Emotional Support	--	--	--	1.70*	0.94-3.05	3.08
HIV Support	0.70	(0.94-1.81)	--	0.61	0.75-1.60	0.26

Note: +p<.10*p<.05; **p<.01; ***p<.001

CHAPTER IV

HIV-POSITIVE MOTHERS OF COLOR, PARENTING STRESS, FAMILY FUNCTIONING, AND ADHERENCE TO MEDICAL APPOINTMENTS

Introduction

Poor Black and Latina mothers disproportionately represent the majority of HIV-positive women in the United States (CDC, 2013a; Stone, 2012). Black and Latina families have unique circumstance living with HIV. Studies report that HIV-positive mothers often live with other HIV infected family members, including children who may have special needs (Antle, Wells, Goldie, DeMatteo, & King, 2001; Mellins, Ehrhardt, & Newman, 1996). Additionally, the environmental context for HIV-positive low-income mothers may include a variety of stressors such as financial hardship, compromised parenting while sick, and housing instability (Kotchick et al., 1997; Lorece, Shalon, & Anita, 2011; Mellins et al., 2002; Penniman, 2009; Wood, Tobias, & McCree, 2004). This translates to a daily reality in which more than 75% of HIV-positive women have children in the household under the age of 18 years old and live with other adults experiencing crisis situations (Dyer, Stein, Rice, & Rotheram-Borus, 2012). It also means that the majority of HIV-positive mothers in the US are more likely to experience ongoing changes or disruptions in family household structures than their White counter parts and/or mothers of higher economic status (Chatters, Taylor, & Jayakody, 1994; Dyer et al., 2012; Hough, Magnan, Templin, & Gadelrab, 2005; Mellins et al., 2002; Snyder, McLaughlin, & Findeis, 2006). Additionally, the majority of HIV-positive mothers are more likely to miss medical appointments and are more likely to depend on the emergency room for medical care than men and their White counterparts (HIV Law Project, 2013; Kaiser Family Foundation (KFF), 2011). These data suggest that family dynamics and competing parenting stressors may play a significant role in the decisions that HIV-positive mothers make to initiate and to remain in HIV treatment and care.

Although getting HIV-positive individuals to remain in care is a public health priority (Arthur, Susan Louise Ryerson, Betsy, Sabrina, & Jessica, 2013; Naar-King et al., 2007; The White House, 2010), there have been few studies that have explored family dynamics and adherence to appointments among HIV-positive mothers (Penniman, 2009). The lack of research in this area warrants a family approach in examination of these issues among mothers. It also indicates a need to examine more scales that measure family dynamics and to test the validity of these scales on Black and Latina mothers.

Therefore, in this current exploratory study, I have two main goals:

(1) To investigate parenting stress and family functioning as measured by the Family Adaptability and Cohesion Sub-Scales of FACES and the Parenting Stress Scale (PSS) (Abidin, 1986) in order to determine the direct relationship between these measures and medical appointment adherence among HIV-positive mothers; and

(2) To investigate the relationship between the three primary predictors (parenting stress, family functioning, and family cohesion) and their relationship to medical appointments.

Mellins and colleagues (2002) examined parenting stress, substance use, and mental health diagnosis among HIV-positive mothers. This study is an extension of that work, examining parenting stress and family functioning among HIV-positive mothers and further investigating psychosocial and family factors that may influence medical appointment attendance.

Using data gathered in the Mother's Health Survey from 1998-1999, I examine parenting stress and family functioning among HIV-positive mothers. I also seek to verify the merits of using these measures to address critical issues reflecting the everyday family realities of HIV-positive mothers. I will use the findings from this study to inform intervention programs to effectively address the needs of this population.

Theoretical Rationale

Even though HIV infects families not only individuals, there is little research addressing how family dynamics and the demands of parenting influence HIV-positive mothers' ability to make, and keep, medical appointments. According to stress process theory, parenting while HIV-positive can be extremely stressful because: a) it is an unforeseen event, much like that of an unplanned pregnancy; and b) the mother may not have any prior experiences with managing stressors such as parenting while HIV positive (Younger, 1991). For example, Antle and colleagues (2001) explain that while people are living longer with HIV, parenting challenges subsequently may include decisions to give birth and to manage HIV while pregnant to prevent mother-to-child transmission. This study also examined the lives of HIV-positive mothers whose self-reports suggest that parenting while HIV-positive may be a new and daunting task for women who already shoulder a majority of household and caregiving responsibilities.

Another important factor is family functioning, i.e., the perceived ability of families to maintain healthy relationships and to adjust during times of stress and hardship. When key family members, such as mothers, experience a stressor, such as

HIV, there may be strain or disruption to the family dynamic. How family members respond to this extreme change can influence how HIV-positive mothers manage their disease and their decisions and abilities to attend medical appointments.

As mentioned, the two measures used in this study to explore these dynamics are the Family Adaptability and Coping Scale (FACES II) (Demi, Bakeman, Sowell, Moneyham, & Seals, 1998; Sowell, Seals, Moneyham, Demi, & et al., 1997) and the Parenting Stress Scale (Abidin, 1983; Doll, 1989). Both scales address important, yet different, aspects of managing HIV for mothers that may elicit pertinent information about mothers' adherence to medical appointments. Perceived levels of parenting stress may offer unique perspectives on stressors of HIV-positive mothers, by measuring their perceived competency levels as a parent. Similarly, measuring family adaptability and cohesion may identify the mother's perceived levels of bonding and functioning within her family that is living with HIV/AIDS. Both of these measures are important because they address valued ideals of parenting that are deemed important for Black and Latina mothers. For example, several studies have noted that a major stressor for HIV-positive mothers is ensuring that they have enough resources both physically and materially to meet their family's needs (Andersen et al., 2007; Antle et al., 2001; Aspeling & Van Wyk, 2008; Chadiha, Rafferty, & Pickard, 2003; Engler et al., 2006) The work of Mellins, Ehrhardt, and Newman (1996) was one of the first to recognize the impact of HIV on family structures and on the complex dynamics that exist within HIV families. Their work also found that mothers often experience strain and psychological stress while trying to keep their families afloat. Single mothers of color have reported that, during times of hardship and distress, support and help from family members may produce tension within the family and be perceived as more stressful than helpful (Cooper, McLanahan, Meadows, Brooks-Gunn, & Johnson, 2009; Domínguez & Watkins, 2003). Living with HIV may challenge mothers' perceived competency as a parent and/or caregiver, which may also influence their levels of parenting stress and subsequently their adherence to medical appointments.

Parenting Stress

Lazarus (1966) identified parenting stress as an extension of the stress process; it is often also defined as role strain, where the demands of parenting exceed the material and social resources available to effectively carry out that parental role (Younger, 1991). Parenting stress also has been described as "multi-faceted and complex," and categorized by its different types of stressors and demands, i.e., material (money, skills, resources), time-based (time necessary to care for children). psychological (feeling incapable), and social (parental isolation) (Nomaguchi & House, 2013).

The parenting stress scale designed by Abidin (1986) measures perceived stress in the parent-child-relationship. This measure is widely used in psychosocial and family psychology research (Younger, 1991). Abidin's (1986) work on this scale, grounded in Lazarus's (1966) theory of the stress process, emphasizes its complexity. Models include characteristics of the environment, family dynamics and relationships, and individual characteristics of the child and parent, all of which play significant roles in measuring parenting stress. Attempting to capture this dynamic process, the Parenting Stress Scale includes thee domains: a) parental stress attributed to the child's characteristics, b) parental stress attributed to the parent's characteristics, and c) parental stress attributed to stressful life events (Huang, Costeines, Kaufman, & Ayala, 2014). These scale domains attempt to account for stressors not only in the parent and child relationship, but also in the parent’s life.

Arguably, there would be variations in parenting demands and stressors across different ethnic and racial groups due to cultural differences of parenting styles and socio-economic disparities. Some studies demonstrate that poverty and income inequality make minority groups more vulnerable to high levels of parenting stress (Klebanov, Brooks-Gunn, & Duncan, 1994; Murphy, Marelich, Armistead, Herbeck, & Payne, 2010; Nomaguchi & House, 2013; Quittner, Glueckauf, & Jackson, 1990). Research also suggests that low-income Black and Latina HIV positive families may have homogenous social networks with less available material support to pull from in times of need than their White counterparts (Domínguez & Watkins, 2003; Klebanov et al., 1994). Contrarily, other studies also point out that families who value social support and parenting may experience less parenting stress because the overall family supports and values these relationships and provides the necessary resources to overcome stressors (Huang et al., 2014; Lesar, Gerber, & Semmel, 1996; Muze, 2009).

Additionally, there are noted cultural differences in parenting styles (Nomaguchi & House, 2013). For example, firm discipline, parental control, and structure are considered essential goals of Black and Latina mothers. Commonly espoused reasons for firm discipline are that Black and Latina children have to navigate oppressive environments and firm discipline protects them from acts of oppression in the form of unfair treatment by law enforcement or in their school environments. Firm discipline is necessary to keep their children alive. Also, studies have found that for Black and Latina families parenting and caregiving practices have also protected their children from participating in risky sexual behaviors (Rousseau, 2013; Stokes, 2012). However, few articles in the literature take these noted differences into account when addressing parenting stress and cultural differences in parenting styles among families of color.

Authoritative parenting styles were also shown to be strongly associated with higher levels of parenting stress. Another study found that parenting stress among Black women was associated with lower physical functioning and lower overall emotional wellbeing than their White counter parts (Ruth, 2009). It is important, therefore, to specifically test the relationship between parenting stress and adherence to medical appointments, given the evidence that this population may be especially vulnerable to higher levels of parenting stress.

Family Functioning (Family Adaptability and Cohesion)

The retention in care literature on HIV-positive individuals also gives little attention to measuring and analyzing family dynamics. Relationships are important to examine for HIV-positive mothers within the context of family for several reasons. First, family is the most proximal and fundamental social system potentially influencing behavior for mothers such as adherence to medical appointments (Bell & Pequegnat, 2012; Pequegnat & Bell, 2011). Secondly, studies have demonstrated that mothers' psychological distress and ability to adhere to medication is associated with poor cohesion and sociability within their families (Beals, Wight, Aneshensel, Murphy, & Miller-Martinez, 2006). Several studies have also found that the problem solving skills within the family are important to HIV-positive individuals' maintaining their overall sense of wellbeing and health (Beals et al., 2006; Bell & Pequegnat, 2012; Feaster et al., 2010; Pequegnat & Bell, 2011; Szapocznik et al., 2004).

Family functioning is less explored, however, in connection with how its management impacts HIV-positive mothers' attending medical appointments. It is important to understand how families function and support each other during times of crisis, especially within the context of HIV-positive mothers, who may be carrying the brunt of family responsibilities.

The FACES scales were developed from the family and marriage literature to create a comprehensive measure of family behavior and family functioning (David, 1978). Olsen (1978) defined healthy family functioning "in terms of a family unit effectively coping with cultural, environmental, psychosocial, and socio-economic stresses throughout the family life cycle" (p. 42). Measures of family functioning utilize two constructs, known as family cohesion and family adaptability. Family cohesion addresses connectedness and emotional bonding between family members. Family adaptability measures how well families adapt to change and respond to different situations that may occur in the family. Family adaptability also considers the degree to which families remain stable and the degree to which they can tolerate change.

There are several versions of the FACES scale that was developed by Olson (1989). The first FACES scale (Olsen et al, 1983) aroused much debate for its use of the circumplex model, which classifies 16 family types that fall into general categories of balanced, mid-range, or extreme. That model identified four categories for measuring family adaptability: rigid, structured, flexible, and chaotic. Structured and flexible are considered the more "balanced" levels of family adaptability, while rigid and chaotic are considered "extreme" levels. The four levels identified for family cohesion are disengaged, separated, connected, and enmeshed, with separated and connected identified as "balanced" levels of family cohesion (high scores) while disengaged and enmeshed are considered to be the "extreme" levels (low scores).

However, other studies (Cumsille & Epstein, 1994; Estrada, Miranda, & Firpo-Jimenez, 2000; Perosa & Perosa, 2001) suggest a linear relationship between family adaptability and cohesion, wherein higher levels of cohesion and adaptability display higher levels of family functioning. Wagner et al., 2010 contested the use of both the circumplex model and the curvilinear relationship in explaining/exploring family functioning among ethnic minority groups. One major methodological issue regarding development of the scale and the circumplex model is that the validation of the scale was conducted on majority, middle-class Caucasian and Lutheran families. Very few studies have focused on Black, Hispanic, or low-income populations; in those that have, the families were non-selected and not random. One study (Vega 1986) examined whether there were differences in family adaptability and cohesion between White middle-income families and low-income Mexican families. The study found no significant difference in scores based on income or race.

While the FACES scale has been translated into more than ten different languages, some researchers assert that the scale is based on Western cultural values which tend to promote individualism and independence, both of which would influence questions regarding and perceptions of balanced family functioning (Baer & Schmitz, 2007; Brittain, Taylor, & Wu, 2010; Kouneski, 2000; McFarlane, 2001; Publishing, 2013). For example, the scale may view values important to non-Western cultures, such as interdependence, as extreme or dysfunctional family functioning, or may overlook them altogether (Kouneski, 2000). Additionally, the FACES scale may not appropriately capture the differing family dynamics of various cultures. One study, for example, describes important family qualities for Latina mothers to be solidarity, sacrificing, reciprocity, and obligation (Kelly, 2009). If applied to these Latina mothers' data, the FACES scale could interpret the scores as too much cohesion and not enough flexibility. The family could be considered "enmeshed"—a dysfunctional characteristic of cohesion.

Similarly, some important cultural values for Black and Latina mothers are strong discipline and authority; identity is strongly connected to relationships with children and family (Collins, 1987; Marcenko & Samost, 1999; Rousseau, 2013). The FACES scale applied to Black mothers' data could interpret these qualities or characteristics as indicative of too little flexibility /too much rigidity. One study of particular note using the FACES scale found that family cohesion had a moderately significant relationship with being HIV-positive, and that it also buffered or moderated the relationship between being HIV-positive and having suicidal thoughts (Demi, Bakeman, Sowell, Moneyham, & Seals, 1998).

Need for the Present Study

Taken as a whole, the literature offers no studies, to my knowledge, that explore the relationship between family adaptability and/or family cohesion with adherence to medical appointments for HIV-positive mothers. This study seeks to examine the relationship between stressful life events, family cohesion, and family adaptability on HIV-positive mothers' ability to adhere to their medical treatment appointment schedules. By identifying the contextual realities that exist within family relationships, researchers can begin to understand and measure the parental stressors of HIV-positive women. Reducing these family stressors may help to reduce overall distress while helping to increase successful management of HIV. Developing and using this scale is an important first step to exploring the impact of family systems on the management of HIV. This study can also help to further dissect and illuminate the validity of this scale's use with Black and Latina mothers.

Hypotheses

Hypothesis 1. Any mental health diagnosis and living below the poverty threshold will explain more of the variance in the model than the other control variables and will be adversely associated with attending all medical appointments.

Previous studies have demonstrated that mental health variables have been significantly associated with attending medical appointments (Israelski, Gore-Felton, Power, Wood, & Koopman, 2001; Mellins, Ehrhardt, Rapkin, & Havens, 2000; Mellins et al., 2002)**.** In addition, low socio-economic status has been a strong predictor of adherence to medical appointments (Geng et al., 2010; Gifford, White, Suarez-Almazor, & Rabeneck, 2007; Lemly et al., 2007). I predict that this study will replicate findings in past empirical studies.

Hypothesis 2. After controlling for socio-demographic and mental health variables, all main predictors: parenting stress, family cohesion, and family adaptability will be positively associated with medical appointment adherence.

The variables of interest (parenting stress, family cohesion, and family adaptability) have been examined in other studies in relationship to behavior and mental health outcomes for mothers. Research has demonstrated that these variables may play a salient role for adherence to medical appointments for mothers of color (Cooper et al., 2009; Mellins et al., 2000; Mellins et al., 2002; Muze, 2009).

Hypothesis 3. After controlling for socio-demographic variables, higher scores on parenting stress will be adversely associated with adherence to medical appointments.

A previous study using this dataset (Mellins et al., 2002) found that parenting stress is associated with the odds of missing pills in the last two days, a measure of adherence to recommended treatment. Similarly, parenting stress could also be associated with missing medical appointments, since both outcomes have to do with different forms of adherence. Further, lower socio-economic status, multiple children in the household, lower levels of education, employment, and being single have all been associated with higher levels of parenting stress (Muze, 2009). A disproportionate number of HIV-positive mothers of color are included in these demographic groups. It is plausible, therefore, to suggest that parenting stress may be associated with attending medical appointments, i.e., as HIV-positive mothers attempt to meet the demands of parenting, they may miss or dismiss their medical appointments.

Hypothesis 4. Higher scores of family functioning and family cohesion will be positively associated with adhering to all medical appointments.

Family functioning has been associated been associated with different forms of stressors in two studies that have looked at family functioning among HIV-positive mothers (Mellins et al., 2000; Murphy, Marelich, Stritto, Swendeman, & Witkin, 2002). These studies found that family functioning was related to stressors and depressive symptoms. Higher scores on the FACES scale were associated with lower levels of depression, more family support, and more resources to adapt to extreme changes in the family, such as managing a chronic illness. It is likely that high levels of family functioning may be associated with high levels of support for the mother increased likelihood of attending medical appointments.

Methods

Data Collection and Sample

Participants in this study were recruited from a waiting room of a New York City infectious disease clinic (Mellins et al., 2002). Trained interviewers approached 134 women for this study; of these, five declined to participate and one woman was too cognitively impaired to participate. A total of 128 women agreed to participate and signed the written informed consent form. A monetary reimbursement was offered for their time and transportation. The New York State Psychiatric Institution Review Board approved the study dataset in 1998 and approved further analysis in 2012. The further use of this dataset was also approved for this study by the University of Michigan Institutional Review Board.

In the dataset, 127 women were accessible to complete the initial baseline interviews (wave 1) and were asked to participate in another interview 4-5 months later (wave 2) (Mellins et al., 2002). Of these, 113 women completed interviews for wave 2 of the data. Additionally, funding was collected to conduct a second follow-up of the study (wave 3) and for this phase, the researchers were able to recruit 97 women from the original sample. Mellins et al. (2002) reported that, because of difficulty tracking participants, high mobility of participants, and illnesses, the time between waves 2 and 3 was high variable i.e., anywhere from 8 months after the first follow-up to 18 months later.

The interview was conducted in either English or Spanish for all participants in all waves of the study. The adult baseline interview included variables on socio-demographic factors such as education, marital status, income, number of people in household, and public assistance. Mental health variables in the model include substance use inventory, demoralization scale, and mental health inventory. The major scales included stressful life events, perceived stress inventory, social support inventory, family disclosure, family functioning, medication attitudes, adherence efficacy, and health services utilization (Mellins et al., 2002).

This study includes only baseline data. Analyses included only those without any missing data for variables for wave 1 (baseline). Thus, study participants were 110 HIV-positive mothers who self-identified as Black or African American and White Latina.

Data Description

According to Mellins et al. (2002), dataset participants self-identified that they were English- and Spanish-speaking, 18 years of age or older, and were mothers of children living at home who were 18 years of age or younger. Fifty-eight percent of the women in the study were Black; 38% were of Latina descent; and 4% percent were identified as White, non-Hispanic.

Approximately 75% of mothers in the study reported at least one health problem and 11% of mothers reported children with HIV. Only 14.3% of mothers in the study reported as currently working and 53.6% of mothers reported currently being on public assistance.

Previous studies published using this dataset (Mellins et al., 2000; Mellins, Kang, Leu, Havens, & Chesney, 2003) found that two-thirds of the women were on antiretroviral medication and 2% of the women reported missing anti-retroviral medication within the two days previous to the interview   The most common reasons given for not adhering to medical appointments were forgetting the appointment or being too fatigued to make the appointment. Other reasons reported were "too scared to go to doctors," conflicting appointments for children or other family members, and that they "could always just reschedule" the appointment.

Measures

Socio-demographic Variables

Age of mother. Age was a self-reported continuous variable.

Race/ethnicity. A dichotomous variable was created for race/ethnicity, i.e., Black or White Latina. Two mothers in the study who identified as African and two who identified as Caribbean were collapsed into Black. I acknowledge that ethnically people of Caribbean and African decent are different, but there were not enough women in this study to do a comparison based on ethnicity. It was also imperative to keep as much power in the dataset. Additionally, at the time of this study in 1999, census data identified people of African descent as "Black, African American, or Negro." Six mothers who self-identified as White were excluded from the analyses because there were not enough cases to study them as a separate comparison group.

Partner status. Initial categories for marital status include 1 = never married and not living with a partner, 2 = married and living with partner, 3 = separated, 4 = living with partner, 5 = widowed, and 6 = divorced. These categories were collapsed into two descriptive categories: 1= married and living with a partner; and 0= separated, widowed, or divorced. These categories were further collapsed for the final analysis into 1 = living with partner (4=living with partner and 1=married and living with a partner) with and 0 = not living with partner (5=widowed, 6=divorced, and 3=separated). The research acknowledges that there are different forms of family structures based on socio-economic status and race/ethnicity that may differ according to conventional concepts of marriage and family structure (Geronimus & Thompson, 2004; Stacks, 1974). Therefore, by labeling the partner status and not marital status, this study takes into account that there is a partner in the household in addition to those who may also be married.

Education. The Education variable was based on reports of Highest Grade Level completed, for example, 1 = first grade; 2 = second grade…12 = twelfth grade; 14 = some college; 17 = some graduate school.

Poverty index. The federal poverty threshold is computed and updated by the Census Bureau each year to provide an accurate picture of poverty in the United States (Bureau, 2012). The Census Bureau computes poverty thresholds by using reported yearly income before taxes that accounts for family size and composition and does not include public assistance. The yearly income is also updated each year for inflation.

For this study, household income and household size for each participant were used to calculate a poverty measure, which was then compared to the federal poverty threshold. The ratio of the family's household income adjusted for household size, compared to the federal poverty threshold, represents the family's poverty-to-income ratio. The data used to calculate this ratio was taken from the year 1999, the year the data was collected. In the current study, a dichotomous variables was create; poverty-income of 1 indicate that the family lives above the federal poverty line; poverty income of 0 indicate that the family lives below the federal poverty line.

Mental Health Variables

Substance abuse in the past 30 days. A dichotomous variable for alcohol and drug abuse derived from the Clinical Diagnostic Questionnaire (Aidella, 2000) was used in the present study to reflect any substance abuse in the last 30 days. Mellins et al. (2000) reported sensitivity for this variable at 85% 1= yes engaged in drug or alcohol abuse within the last 30 days and 0= no, have not engaged in drug or alcohol use in the last 30 days.

Any mental health diagnosis. This is a dichotomous measure that asks if mothers currently have any diagnosis of mental health illness and is scored as 1 = yes, have a mental health diagnosis; 0 = no, no current mental health diagnosis.

Family Adaptability and Cohesion Scale. The FACES II scale was used in this study to examine family adaptability and cohesion. This scale uses linear scores (as opposed to curvilinear scoring, discussed earlier) and can be used for individual self-report, couple or family version. This study used individual self-reporting. Other reasons for selecting the FACES II scale for this study was because it reportedly has better overall psychometric properties (Olsen & Watson, 1991); higher internal validity than FACES III, and higher concurrent validity, especially in measuring family flexibility.

The scale consists of 30 questions that address attitudes and perceptions of family relationships and family life (Olsen, Bell, & Portner, 1992). The scale's two dimensions are family cohesion and family adaptability. Example statements related to family functioning are, "Children have a say in their discipline," and "Family members avoid each other at home" (Olsen, Bell, & Portner, 1992). Examples of items related to family cohesion are, "Family members know each other's close friends," and "Our family does activities together." Each item is rated on a scale ranging from 1 (almost never) to 5 (almost always) (Olsen et al., 1992). Reported test reliability is 0.83, and correlations with other family functioning instruments support its validity (Lesar et al., 1996; Martin et al., 2012; Mellins et al., 2000; Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002). Reported reliability in past studies has been 0.87 and 0.88 (Beckmann et al, 1998, Mellins et al., 2000).

The items for adaptability and cohesion are summed and scored separately. In this study, a composite variable was made for both domains of the scale, i.e., family function and family adaptability. The reliability scores were 0.76 for cohesion and 0 .84 for adaptability. The higher the scores on family cohesion and family adaptability, the better the overall family functioning.

Parenting stress. The parenting stress measures stress in three domains of the parenting and childcare experience: parent, child, and life stress. Parenting stress was assessed with an abbreviated version of the scale that includes 11-items measuring only the domain of perceived parenting stress as taken from the 2nd edition of the parenting stress index (Abidin, 1983); this scale overall is noted to have well-documented psychometric properties (Mellins et al., 2003). Example questions are: " I have no doubts about my ability to handle being a parent;" "I enjoy being a parent;" and "I feel capable and on top of things when I am caring for my child." Items are scored on a five-point Likert scale, i.e., 1 = strongly agree, 2 = agree, 3 = not sure, 4 = disagree, and 5 = strongly disagree. The higher the score, the higher the level of parenting stress. In past studies, the reliability for parenting stress using this sample was reported around 0.72 (Mellins et al., 2002); however for this current study, the reliability could not be tested because the scale was already constructed and there were individual items available in the dataset to retest the reliability for this study.

Dependent Variable

Full (100%) medical appointment adherence. All mothers in the study were asked how often in the past 30 days were they able to attend medical appointments. 1= Attend no appointment, 2= about 25% of appointments, 3= about 50% of appointments, 4=about 75% of appointments, and 5=100% of appointment. Because frequencies in the middle categories were very low, this variable was collapsed into a categorical variable 0=less than 100% of appointments attended and 1=100% of medical appointments.

Statistical Analysis

All analyses were completed using SPSS version 22.0. First, descriptive statistics were calculated, including means, standard deviations, and ranges for all of the main variables of interest for data available at baseline (see Table 4.0). A total of 127 individuals in the dataset had data available at baseline, which was used for cross-sectional analysis. Among the study sample, however, only 110 of those individuals had complete data on all measures of interest for this study. Even though the sample size was considerably small, I decided not to impute any missing data for this analysis.

Arguments for not imputing contend that imputations fills data gaps with simulated estimates calculated from the distribution of the data. Because this approach uses imaginary, not real numbers, it may not give accurate findings; Rughnathan (2004), for example, asserted that analyses with imputed missing data often produce estimates and standard errors that are too small and confidence intervals that are too narrow. One notable limitation of my decision not to impute the data is that 17 participants were dropped from that analysis and I lose some power for interpreting the findings. Another limitation of not imputing the data is that exclusions can also produce biased results if participants included in the analysis are different from those excluded. In order to check for such potential biases introduced by my decision, chi-square and t-tests were performed to test any differences between missing data and variables of interest in this analysis. The results, as shown in Table 4.0, illustrate that there were no significant differences between missing data and variables of interests.

The next step in this analysis was to identify potentially confounding variables by performing t-tests, chi-squares, and Pearson's correlations to examine associations between all variables of interest and the predictor variable at the bivariate level. All variables of interest that would be included in the final analyses were examined and results of the correlation matrix are given in Table 4.1.

This study is exploratory. The first three sets of models are to test bivariate relationships and to see whether the variables are appropriate to use in the final model. The omnibus (F-test) for these models were set at $p > .10$. It is often difficult to find significance when working with a small sample size (Bower, 2009; Krzywinski & Altman, 2013; Liu, 2013). However, a researcher's inability to get the most appropriate sample size for the analysis does not mean a study is invalid (Goodman, 2008). Additionally, there are arguments against always setting a p-value to a conservative measure of .05 (Goodman, 2008; Liu, 2013); some researchers support changing the p-value to meet the power of the data. For a sample the size of the present study, for example, Lui (2013) suggests a p-value of .10 for the overall model. Therefore, to test the effect of the overall model in the present study, I used a p-value of .10 for the F-test.

To test the relationships between the predictors of interest and medical appointment attendance, I used logistic regression models that controlled for demographic variables of interest. Based on the findings of the logistic regression at the bivariate level, a final logistic regression model was built to explore the relationship between all three main predictive variables (parenting stress, family functioning, and family cohesion) and medical appointment adherence.

Results

Baseline Predictors

Table 4.2 presents a correlation matrix of the relationship between all variables of interest used in the model. There were several measures used that were significantly correlated. *Ethnicity* was strongly correlated with *education* ($r = .44, p < .01$) and weakly correlated with *substance use* ($r = .28, p < .01$). *Partner status* was weakly correlated with *stress* ($r = -.19, p < .05$). *Education* was weakly correlated with *adaptability* ($r = -.22, p < .05$). *Poverty index* was weakly correlated with *stress* ($r = -.22, p < .05$). *Adaptability* was strongly correlated with *cohesion* ($r = .56, p < .01$) and weakly *stress* ($r = -.28, p < .01$). Lastly, *cohesion* was moderately correlated with *stress* ($r = -.34, p < .01$).

Model Testing

I tested a baseline model that only contained the socio-demographic covariates. Results of the model showed significance at the .05 level ($\chi^2 (7) = 14.16, p = .05$, Nagelkerke $R^2 = .163$). The individual predictors were examined further (see Table 4.3). Results showed significant relationships between age ($OR = 1.07, p = .03$) and partner status ($OR = 0.36, p = .03$). This suggests that as age increases or if the participant was not living with a partner, they were more likely to meet all their medical appointments.

I then assessed whether parenting stress was significantly related to medical appointment attendance (after controlling for the covariates). Results of the Omnibus χ^2 test showed significance for the model when an alpha level of .10 was used ($\chi^2(8) = 14.92$, $p = .06$, Nagelkerke $R^2 = .171$). This suggested that the covariates at parenting stress significantly predicted medical appointment attendance. However, upon examining the individual variables, parenting stress was not a significant predictor, $OR = 1.03$, $p = .38$, suggesting that parenting stress was not significantly related to medical appointment attendance (see Table 4.4).

Next I ran a model to assess if family cohesion predicted medical appointment attendance after controlling for the demographics. Results of the logistic regression showed significance for the full model at the .05 level of significance ($\chi^2(8) = 17.66$, $p = .02$, Nagelkerke $\mathrm{R}^2 = .200$). The individual predictors were examined further for significance (see Table 4.5). Family cohesion was a significant predictor of medical appointment attendance at the .10 level of significance ($OR = 0.78$, $p = .07$). This suggests that as family cohesion increased, the likelihood of the participant to *not* meet all of their medical appointments also increased.

A model was next run to assess if family adaptability predicted medical appointment attendance after controlling for the demographics. Results of the logistic regression showed significance for the full model at the .10 level of significance ($\chi^2(8) = 14.61$, $p = .07$, Nagelkerke $\mathrm{R}^2 = .167$). The individual predictors were examined further for significance (see Table 4.6). Family adaptability was not a significant predictor of medical appointment attendance at the .10 level of significance ($OR = 1.10$, $p = .50$). Therefore, family adaptability was not related to medical appointment attendance.

Last, a model was conducted that examined if stress, family cohesion, and family adaptability predicted medical appointment attendance after controlling for the demographics and mental health variables. Results of the logistic regression showed significance at the .05 level for the model ($\chi^2(10) = 22.86$, $p = .01$, Nagelkerke $R^2 = .252$). The individual predictors were examined further. Both family adaptability (*OR* = 1.51, $p = .03$) and family cohesion (*OR* = 0.63, $p = .01$) were significant predictors of medical appointment attendance. This suggests that as family adaptability increased and as family cohesion *decreased*, the likelihood of attending all medical appointments increased. Results of the logistic regression are presented in Table 4.7.

Discussion

Using a sample of HIV-positive mothers in New York, this study examined the effects of socio-demographic variables, mental health variables, family functioning, and parenting stress on medical appointment attendance. This study's methodology and findings add to the literature by introducing measures that help explain the influence of family factors on HIV-positive mothers' ability to attend medical appointments

Family adaptability in this study was significantly associated with attending all medical appointments. These results support the literature that family dynamics can influence a mother's decisions to make and keep medical appointments (Dyer et al., 2012; Lizy, Geetha, & Joseph, 2011). Again, however, because of the dearth of research on medical appointment attendance for HIV- positive mothers, we must rely on general studies of medical adherence for insights. Mitrani et al.'s (2010) family intervention study to improve medical adherence among HIV-positive mothers found that better family functioning and adaptability was characterized by better parenting, fewer stressors, and less drug abuse among HIV-positive mothers. Because the intervention included the entire family's engagement in improving the mother's management of HIV, the family had better skills to adapt to living with family members with HIV, which, in turn, helped to support the HIV-positive mother's role within the family. Attending medical appointments also speaks to the degree to which HIV-positive mothers intend to manage their disease. Additionally, the decision to attend all medical appointments may also imply that the overall mental state of the mother, family support, and healthy functioning within a family unit impacts the self-care decisions of HIV-positive mothers.

Family cohesion in the present study was significantly associated with *not* attending all medical appointments. These results are counter-intuitive to research on health behaviors and family functioning, which suggests that the better the family cohesion, the better the behavioral health outcome (Demi et al., 1998; Dyer et al., 2012; Li, Liang, Ding, & Ji, 2011; Mitrani, McCabe, Robinson, Weiss-Laxer, & Feaster, 2010; Murphy et al., 2010). It is important to first note that some research (Vega et al., 1986) contends the scales used in this study may not have merit in measuring Black and Latina family dynamics because the research questions may not be tapping into what this population conceptualizes as connectedness.

However, other studies have found the FACES scale to have high reliability and validity with this population (Lesar et al., 1996; Martin et al., 2012; Mellins et al., 2000). Taking evidence for the validation of the scale used on similar populations, another perspective is that mothers are primarily concerned with making sure that their families are nurtured and connected, so they may forget their own needs or place them secondarily, hence missing medical appointments. Several studies (Boyle, Bunting, Hodnicki, & Ferrell, 2001; Glover, Garcia-Aracena, Lester, Rice, & Rothram-Borus, 2010; Wood et al., 2004) validate this explanation, demonstrating that Black and Latina mothers value their families' needs first while putting their own needs last. One study on HIV-positive Latina women entitled "I'm a Mother First" (Kelly, 2009) emphasizes the cultural identity of mothering as self-sacrificing.

A considerable amount of research also substantiates the possibility of a "family first" value for Black mothers, who report that family roles are paramount to their self-identity and are a priority at the expense of their own health (Antle et al., 2001; Bunting, 2001; Chadiha et al., 2003; Marcenko & Samost, 1999). In a qualitative study (Edwards, 2006), Black mothers reported not adhering to or attending medical appointments as both a conscious decision and a moral decision due to implications of their family knowing they were sick. Maintaining family stability by caring for family members and protecting them from the mother's disease was another theme; making sure the family is functioning well was reported as an important aspect of mothers' identity, a sign of strength, and perseverance, which were all identified as important qualities for mothers of color (Edwards, 2006). Thus, family cohesion factors as viewed by mothers of color also may create significant barriers to attending medical appointments. Family functioning, particularly family cohesion, were found to be high in the present study and that evidence supported ***not*** attending all medical appointments.

Parenting stress, surprisingly, was not found to be significantly associated with missed medical appointments. There could be problems with the measurement of parenting stress used in this study; although it was validated in a previous study for this population, it could be that more specific constructs are necessary to adequately access parenting stress among mothers of color with HIV/AIDS. Perhaps a more sensitive scale measure of parenting is needed to assess perceptions of parenting while HIV positive, where a sense of morality is more pronounced. However, the scale used was previously created in the dataset for this study, so I cannot confirm how it was constructed. Previous research for this scale, however, reported that it was valid for this population (Mellins et al., 2002).

Limitations

There are several limitations to note in this study. First, the study's sample size was very small and thus limited the study's power. The sample represents a very specific group of women, i.e., HIV-positive and mothers. Although every attempt was made in this analysis to maintain the power of the sample, the limited sample size may contribute to some large confidence intervals and limit the explanatory power of the model, as well as limiting the generalization of findings to larger populations.

In addition, the dichotomous measurement of the outcome variable "attending all medical appointments" as either attending *all* medical appointments within the last 30 days or *not* attending all medical appointments also limits the explanatory analysis of this study. However, this variable did reveal that most women who reported not attending all medical appointments nevertheless reported attending 50-75% of them. Although this dataset is old (1999), it is still relevant today; because the current the body of research does not reflect the unique demographics of women of color and there is little research focusing on HIV-positive mothers and medical appointments.

There were several variables we could only use descriptively, such as CD4 count, but could not use in the final models due to lack of variability in the sample and to missing data. These variables are important to consider in medical appointment attendance because the literature shows that the higher the viral load and the lower the CD4 count, the more likely subjects are to attend medical appointments due to the severity of their disease (Currier et al., 2010). Additionally, we had no comparison group of whites in the study; because data were available for only six whites, the group was omitted.

Despite these limitations in the data, the results of the present study add to very limited literature on medical appointment attendance of HIV-positive women. These results warrant further investigation on the relationship between missed medical appointments and family functioning among HIV-positive mothers.

Conclusion

This paper highlights very important factors surrounding having a partner and how well the relationships within a family can influence medical appointment attendance for HIV=positive mothers of color. What is interesting is that these findings were not intuitively what we would expect for populations based on theoretical models and frameworks. However, these findings should move research to further look outside of conventional wisdom and study the unique cultural implications of what these findings can mean for mothers of color. The findings of the paper demonstrate that these relationships are complex and warrant further research. Some recommendations would be to develop measures or scales that address the experiences of HIV-positive mothers and parents. Also develop scales that address the experiences of mothers of color.

It is important to understand what dynamics are in play within the family unit and what impact events such as birth, death, divorce, or other transformations within HIV-positive families may also have on the mother. HIV-positive families are very heterogeneous; the differing challenges they may experience through infertility, loss of job, and economic instability, and how families adjust to these challenges, deserve further research and discourse.

Researchers continue to stress the need for more comprehensive study designs that include family and social networks to better understand the behaviors of HIV-positive mothers. One key policy implication of this study is that HIV/AIDS research has not adequately addressed the unique experiences, factors, and circumstances facing HIV-infected Black and Latina mothers. Attention to these issues remains critical as this subpopulation continues to suffer adverse effects that also disproportionately burden their families, communities, and the nation as a whole. This study illustrated the need for further action and research and provides interesting findings to help move the research forward.

Table 4.0. Descriptive Statistics for Cross-Sectional Sample (Categorical Variables)

Descriptors	**Initial Sample No Exclusions (*n*=121)**	**Wave 1 No Missing Data (*n*=110)**	**Have Missing Data (*n*=11)**	**Have Missing Data vs. No Missing Data**	
	Frequency (%)	**Frequency (%)**	**Frequency (%)**	**Chi-square**	**p-value**
<u>Ethnicity</u>					
White Latina	48 (40%)	44 (40%)	4 (36%)	0.06 (1)	.81
Black	73 (60%)	66 (60%)	7 (64%)		
<u>Partner Status</u>					
Married or Living with Partner	37 (31%)	36 (33%)	1 (9%)	2.76 (2)	.25
Separated, Widowed, Divorced, or Never Married	84 (69%)	74 (67%)	10 (81%)		
Substance Abuse in Last 30 Days	20 (17%)	16 (15%)	4 (36%)	3.45 (1)	.06
<u>Medical Attendance Baseline</u>				0.05 (1)	.82
Attended All Visits	70 (58%)	64 (58%)	6 (55%)		

<u>Note</u>: Ethnicity/Race other than Latino or Black were omitted (*n*=6).

Table 4.1. Descriptive Statistics for Initial Sample and Subsamples with At Least One Missing and with No Missing Values in Wave 1 (Continuous and Ordinal Variables)

Descriptors	**Initial Sample No exclusions (*n*=121)**	**Have No Missing Data on study variables (*n*=110)**	**Have Missing Data On study variables (*n*=11)**	***t*-Test Comparing Missing Data Subsample with No Missing Data Subsample**	
	***M* (*SD*)**	***M* (*SD*)**	***M* (*SD*)**	***t* (*df*)**	***p***
Age	37.93 (7.67)	37.78 (7.73)	39.36 (7.26)	0.65 (119)	.52
Education (highest grade)	11.08 (2.53)	11.05 (2.40)	11.57 (1.51)	0.57 (115)	.57
Income (*n*=116)	$983.28 ($555.59)	$994.49 ($567.21)	$777.67 ($367.89)	-0.92 (114)	.36
Poverty Index (*n*=116)	0.82 (0.41)	0.83 (0.42)	0.76 (0.24)	-0.36 (114)	.72
AdaptFaces (*n*=119)	22.81 (5.34)	22.91(5.21)	21.56 (7.00)	-0.73 (117)	.47
Adaptability Original (*n*=119)	27.47 (5.79)	27.46 (5.86)	27.56 (5.13)	0.05 (117)	.96
CohesFaces (*n*=119)	20.09 (4.99)	20.21 (4.81)	18.67 (6.98)	-0.89 (119)	.37
Cohesion Original (*n*=119)	13.06 (7.42)	13.40 (7.24)	8.89 (8.72)	-1.77 (117)	.08
Stressful Life Events Score	14.19 (10.14)	14.29 (10.39)	13.18 (7.49)	-0.35 (119)	.73

Note. Ethnicity/Race other than Latino or Black were omitted (*n*=6)

Table 4.2. Correlation Matrix between Continuous and Ordinal Variables

Descriptor	**Age**	**Black**	**Partner Status**	**Education**	**Poverty Index**	**Substance Use**	**Adaptability**	**Cohesion**	**Stress**	**Attendance**
Age	--									
Black (0=no; 1= yes)	.09	--								
Partner Status (0=not living together; 1= living together)	.16	.10	--							
Education	.06	.44**	.05	--						
Poverty Index	.14	.10	-.01	.01	--					
Substance Use	-.04	.28**	.15	-.06	-.03	--				
Adaptability	-.11	-.02	.06	-.22*	.09	.05	--			
Cohesion	.01	-.13	.13	-.01	.07	-.13	.56**	--		
Parenting Stress	.00	-.07	-.19*	-.16	-.22*	.17	-.28**	-.34**	--	
Medical visit attendance	.14	-.02	.24*	-.05	.00	.04	.11	-.08	.05	--

Note. * $p < .05$; ** $p < .01$

Table 4.3. Logistic Regression of 100% Medical Appointment Attendance and Socio-demographic Variables at Baseline

Variables	***OR***	***SE***	**Wald χ^2**	***p***	**CI (95%)**
Age	1.07	0.03	4.90**	.03	(1.01, 1.13)
Black (0=no; 1=yes)	0.74	0.51	0.34	.56	(0.27, 2.02)
Partner Status (0=not living together; 1=living together)	0.36	0.47	4.76**	.03	(0.14, 0.90)
Poverty Index (binary) (1=above poverty; 0=below poverty)	0.96	0.47	0.03	.87	(0.37, 2.32)
Substance Abuse in Last 30 days (0=no; 1=yes)	0.76	0.66	0.17	.69	(0.21, 2.81)
Mental Health Diagnosis (0=no; 1=yes)	1.58	0.44	1.10	.30	(0.67, 3.70)

Note: Omnibus χ^2 (7) = 14.16, p = .048. Nagelkerke R^2 =. 163; * $p < .01$, ** $p < .05$

Table 4.4. Logistic Regression of 100% Medical Appointment Attendance on Parenting Stress at Baseline

Variables	***OR***	***SE***	**Wald χ^2**	***p***	**CI (95%)**
Age	1.06	0.03	4.37**	.04	(1.00 -1.13)
Black (0=no, 1=yes)	0.74	0.51	0.34	.56	(0.27 - 2.01)
Education (highest grade)	0.98	0.10	0.05	.81	(0.80 -1.19)
Partner Status (0=not living together; 1=living together)	0.32	0.49	5.31**	.02	(0.12 -0.84)
Poverty Index (binary) (1=above poverty; 0=below poverty)	1.01	0.48	0.00	.98	(0.39-2.57)
Substance Abuse in Last 30 days (0=no; 1=yes)	0.85	0.67	0.06	.81	(0.23-3.16)
Mental Health Diagnosis (0=no; 1=yes)	1.70	0.44	1.41	.24	(0.71-4.06)
Parenting Stress	1.03	0.04	0.76	.38	(0.96-1.110)

Note: Omnibus χ^2 (8) = 14.92, p = .061. Nagelkerke R^2 =. 171; * p < .01, ** p< .05

Table 4.5. Logistic Regression of 100% Medical Appointment Attendance on Family Cohesion at Baseline

Variables	***OR***	***SE***	**Wald χ^2**	***p***	**CI (95%)**
Age	1.08	0.03	5.88*	.02	(1.02-1.15)
Black (0=no, 1=yes)	0.61	0.53	0.88	.35	(0.22-1.71)
Education (highest grade)	0.97	0.10	0.06	.80	(0.79-1.19)
Partner Status (0=not living together; 1=living together)	0.29	0.49	6.03**	.01	(0.01-0.78)
Poverty Index (binary) (1=above poverty; 0=below poverty)	0.94	0.48	0.02	.90	(0.37-2.38)
Substance Abuse in Last 30 days (0=no; 1=yes)	0.83	0.70	0.08	.77	(0.23-3.02)
Mental Health Diagnosis (0=no; 1=yes)	1.90	0.455	2.00	.16	(0.78-4.64)
Family Cohesion	0.78	.137	3.32	.07	(0.57-1.02)

Note: Omnibus χ^2 (8) = 17.66, p = .024. Nagelkerke R^2 =. 200; * $p < .01$, ** $p < .05$

Table 4.6. Logistic Regression of 100% Medical Appointment Attendance on Family Adaptability at Baseline

Variables	***OR***	***SE***	**Wald χ^2**	***p***	**CI (95%)**
Age	1.07	0.03	4.68**	.03	(1.01-1.13)
Black (0=no; 1=yes)	0.74	0.51	0.34	.56	(0.27-2.02)
Education (highest grade)	0.98	0.10	0.03	.85	(0.80-1.20)
Partner Status (0=not living together; 1=living together)	0.36	0.47	4.55**	.03	(0.14-0.92)
Poverty Index (binary) (1=above poverty; 0=below poverty)	0.91	0.47	0.04	.83	(0.36-2.28)
Substance Abuse in Last 30 days (0=no; 1=yes)	0.77	0.67	0.15	.70	(0.21-2.88)
Mental Health Diagnosis (0=no; 1=yes)	1.50	0.44	0.86	.35	(0.63-3.56)
Family Adaptability	1.10	0.14	0.45	.50	(0.84-1.44)

Note: Omnibus χ^2 (8) = 14.61, p = .067. Nagelkerke R^2 =. 167; * $p < .01$, ** $p < .05$

Table 4.7. Logistic Regression of 100% Medical Appointment Attendance on Parenting Stress, Family Cohesion, and Family Adaptability

Variables	***OR***	***SE***	**Wald χ^2**	***p***	**CI (95%)**
Age	1.08	0.03	5.19**	.02	(1.01-1.15)
Black (0=no; 1=yes)	0.51	055	1.52	.23	(0.17-1.48)
Education (highest grade)	1.06	0.11	0.26	.61	(0.85-1.33)
Partner Status (0=not living together; 1=living together)	0.25	0.53	6.73*	.01	(0.91-0.72)
Poverty Index (binary) (1=above poverty; 0=below poverty)	0.95	0.50	0.01	.92	(0.36-2.53)
Substance Abuse in Last 30 days (0=no; 1=yes)	1.02	0.67	0.00	.98	(0.26-3.91)
Mental Health Diagnosis (0=no; 1=yes)	1.94	0.47	2.01	.16	(0.77-4.88)
Parenting Stress	1.03	0.04	0.56	.45	(0.95-1.12)
Family Cohesion	0.63	0.18	6.15*	.01	(0.44-0.91)
Family Adaptability	1.51	0.19	4.70**	.03	(1.04-2.91)

Note: Omnibus χ^2 (10) = 22.86, p = .011. Nagelkerke R^2 =. 252; * $p < .01$, ** $p < .05$

CHAPTER V

CONCLUSION

Current research aims to better understand and increase HIV-positive individuals' ability to seek and remain in treatment and care. However, HIV-positive Black and Latina mothers have been an overlooked population; little research has sought to understand their unique motivations and barriers to remaining in care. In this chapter, I summarize my findings from Chapters 2-4, discuss the broader implications of this work, and suggest future directions for research.

In Chapter 2, by conducting a systematic literature review of current research and intervention programs that focused on HIV-positive mothers of color, I demonstrated that while initiatives are addressing HIV retention in care, currently there are few published studies that focus on HIV-positive mothers of color. Broader themes in that chapter revealed that caregiving responsibilities, social networks, and social support were not only salient aspects of mothers' roles and identity, they also influenced decisions to remain in HIV care. While research studies have identified contextual factors such as family obligations and family functioning, intervention programs have not reflected this work. Few studies focused on women, with even fewer studies focusing on mothers of color, thus leaving many questions regarding what works for this population. In the final section of Chapter 2, I offered a conceptual explanation of retention in care from the perspective of HIV-positive mothers of color. This model considered both previously examined and unexplored patterns of adherence to medical appointments among Black and Latina mothers. It used both the Social Determinants of Health model and the Stress and Coping Model to explain how uniquely situated contextual factors of HIV-positive mothers of color can shape their behaviors and influence decisions to remain in care. It also demonstrated at the individual level how family factors and levels of social support may moderate decisions to remain in care.

Chapter 3 addressed the lack of quantitative research by empirically testing the relationship between three forms of enacted social support and medical appointment adherence for HIV-positive mothers of color over time. By using a hierarchal approach in Chapter 3, this work also showed that certain types of support may explain more variance and have a greater influence on women's decisions to remain in care. While practical support and HIV support were noted as important for HIV-positive individuals, this study found that after controlling for socio-demographic and mental health variables, enacted emotional support was a significant predictor of attending all medical appointments for this sample. Enacted emotional support (expressing of care, concern, empathy, or worthiness) may be tapping into socio-cultural experiences that best resonate with HIV-positive Black and Latina mothers. Having explored themes of mothering in Chapter 2, a sense of value, esteem, and the ethics of personal responsibility were found to be central to Black and Latina women's identity and self-worth, and they are often expressed through the act of mothering (Chaney, 2011; Collins, 1987; Kelly, 2009). Enacted emotional support may be capturing a need to be visible and to feel worthy despite these women's roles of mothering perhaps being compromised by living with HIV. This work helps to support and expand health behavior models--especially the stress and coping model—by illustrating that enacted forms of support may matter for HIV-positive women. This work also informs other individual level behavior change models by showing that sustained behavior change over time can be influenced by types of support that resonate with certain populations. These findings could translate into health care models for retention in care that focus on tailored care that better responds to different HIV populations.

Chapter 4 tested other salient themes found in the literature for HIV-positive mothers that addressed family functioning and parenting stress. By testing the direct relationship between parenting stress and two dimensions of family functioning (i.e., family adaptability and family cohesion), this study found that parenting stress was not associated with attending all medical appointments. Also, both dimensions of family functioning were associated with medical appointment adherence for this sample of HIV-positive mothers. However, higher scores of family cohesion were significantly associated with not attending all medical appointments. These findings raise several questions concerning the motivations of HIV-positive Black and Latina mothers. It is plausible that HIV-positive mothers may be focusing more on holding the family together, another esteemed function of mothering, over personal care and management of HIV. Again, the relationship between partner status and adherence to medical appointments suggests that racial and gendered identities of mothering may be influencing HIV-positive mothers' decisions to attend medical appointments. Contrarily, it is possible that the FACES scale used to measure family functioning may not be tapping into the experiences of Black and Latina women.

While this study was interested primarily in family functioning and social support, some interesting findings emerged among the socio-demographic and mental health variables used in this study. As demonstrated by these two quantitative studies, a mental health diagnosis, age, and partner status were significantly associated with attending all medical appointments for this sample of women. Mental health was also found to be significant in Chapter 3, which explored social support, but it was not significant in Chapter 4, which explored family functioning in relationship to attending all medical appointments. However, as demonstrated by other studies, having a mental health diagnosis strongly predicted medical appointment attendance. The finding of increase in age as a predictor of attending all medical appointments for HIV-positive mothers is consistent with studies that found younger age to be a risk factor for HIV-positive individuals' missing medical appointments (Catz, 1997; Israelski et al., 2001; McClure, Catz, & Brantley, 1999). However, Malone et al. (1998) offered an additional perspective; their qualitative study with focus groups of older HIV-positive women found themes such as meaning and hope in the coping of older HIV-positive women. These women used spirituality and faith as an anchor to cope, and reported having a good sense of control over their lives, all of which help with managing HIV. While there are no studies to my knowledge that directly predict age and adherence to medical appointments, a study on HIV-positive Latina women, acculturation, and coping styles found that acculturation was a mediating factor for poor health behaviors such as substance abuse and non-adherence (Sánchez, Rice, Stein, Milburn, & Rotheram-Borus, 2010). While studies on acculturation have found that younger people try to acculturate into society by adopting maladaptive health behaviors (Rotheram-Borus, Rice, Milburn, Stein, & Sánchez, 2010), other researchers have reported that older people may use their cultural heritage as a protective factor. This could possibly explain the finding of age as a predictor for adhering to medical appointments for Latina women (Abraído-Lanza, Armbrister, Flórez, & Aguirre, 2006). More work is warranted in this area to better elucidate these findings for mothers of color, especially Latina women.

While partner status was not significant in Chapter 3, which tested adherence to medical appointments and social support, it was significant in Chapter 4, which investigated the relationship between family functioning and adherence to medical appointments. There are also interesting findings in the literature that suggest why having a partner would be a factor in decreased adherence to all medical appointments for HIV-positive women. While there is a plethora of literature that reports that being married or having a partner increases overall health, wellbeing, and social support (Jim, Fernando, & Peek, 2012; Kawachi & Berkman, 2001; Kiecolt-Glaser & Newton, 2001), these findings are not consistent for women (Henretta, 2007; Umberson, 1992). Some studies show that women in general will prioritize care for their spouse and take on a caregiving role that may have adverse health consequences (Bunting, 2001; Chadiha, Rafferty, & Pickard, 2003). A study that investigated HIV-positive women who were married or had a partner found that Black women became the providers and caregivers for the families, and sometimes, for their husbands who were also HIV positive (Lorece, Shalon, & Anita, 2011). These researchers found that HIV-positive women put their spouse's health and wellbeing over their own, especially if their spouse was also HIV positive; they invested in making sure their spouse attended appointments and had support at the expense of their own health. These findings have direct implications for the findings in the present study, i.e., that women with partners may be caring for their spouses and other members in their family at the expense of their own health, and with consequences to their attending all necessary medical appointments.

Placing these findings within the larger context of mothering and motivations to adherence to medical appointments, missing appointments may be perceived as a necessary sacrifice and reflection of being a *good* mother who cares for family first. HIV-positive mothers may not want to be perceived as a burden; attaining ethnically mediated roles of being strong and self-sacrificing may be a maladaptive coping strategy for managing HIV and meeting the family needs.

Management of treatment for HIV positive women, specifically mothers of color, has not drastically changed since HIV treatment became available in 1996 (Drummond, 2001). In the late 1990s, women of color were dramatically and disproportionately becoming infected with HIV, and this pattern is similar to the current state of the epidemic for women of color (Murphy et al., 1999). Many scholars grappled with the complex web of issues mothers of color faced regarding their decisions to take or adhere to antiretroviral zidovudine (AZT), one of the first available drugs to manage and reduce the viral load of HIV (Drummond, 2001). This drug was documented to significantly reduce the transmission of HIV from mother to child during pregnancy and the baby's first six weeks of life. However, many HIV positive mothers refused this drug or had significant challenges adhering to it. Many of the barriers identified by scholars in the mid-90s for mothers of color adhering to antiretroviral medication continue to be challenges in the current millennium. For example, several studies in the mid-1990s identified competing household responsibilities, poor treatment of women by healthcare establishments, lack of effective liaison of women to care, and social support, just to name a few (Habegger, 1997; Mok & Cooper, 1997; Norman & Dumois, 1999; Papp & Star, 1997). These challenges persist for women today.

HIV positive women continue to lag in becoming a priority in medical treatment and research and there are few datasets available to investigate retention in care among HIV positive mothers. Therefore, the 17-year old dataset used for this research is still relevant today because of the lack of progress in this area of HIV research. Also, there has not been much data collection specifically designed to examine the needs of mothers of color and retention in care. Research on the challenges of HIV positive mothers has been done internationally in countries such as in Africa and Asia; however, this research is not often transferable to fostering an understanding of domestic challenges in the United States. This limitation of existing research also makes a case for why the use of the older data specific to the U.S. context are still advantageous to current issues regarding HIV positive mothers of color.

Public Health Implications and Recommendations

Inadequately studying and addressing issues of retention in care among HIV-positive mothers of color can have far reaching public health consequences. Mothers of color who die of AIDS are leaving children and families behind at their most productive years. This can result in orphaned children, major family disruptions, and poverty. Also HIV-positive mothers not retained in care have higher rates of hospitalization and use of emergency care, contributing to the economic burden of HIV in the United States which is currently estimated at $6.7 billion in direct medical costs (CDC, 2012).

More intervention studies are needed that focus on the unique experiences of mothers and how they manage their care. One interpretation of this dissertation is that mothers may always put their children's and family's needs first before their own, even if it kills them. Therefore, integrating care with family services would be a way to capture and help to retain women in care. For example, if mothers are assisting their partners, HIV clinics should provide the option of making appointments for couples where they can both receive care and attend each other's appointments together. They should also have the option of making their appointments at the same time to support each other. If mothers are attending to their children first, and many HIV-positive mothers use public assistance, then it would be valuable to have HIV services and care available with Maternal and Child Health Care. There may not be a need to provide separate HIV offices, but offering combined care would relieve mothers of making multiple visits. They would also be getting care for themselves in a family environment that helps them to focus on themselves while noting they have also met the needs of attending to their family and children. If programs provide a way for women to attend to their family and still receive care, they would alleviate a barrier for women, while freeing up the mental space for them to focus on themselves and their self-care needs.

Providing comprehensive care in one healthcare clinic, where women could get all their needs met, not just HIV care, would also be valuable for this population. Such a facility would allow women to get all their obstetrical, gynecological, and mental health needs met, to pick up medication (in-house pharmacy), and to receive child care. This would help to relieve the burden of multiple trips and multiple appointments and services. An essential element presently missing in care is treating the whole person and providing care that is inclusive of their needs. Such care would provide an opportunity for them to build relationships and networks by having all their care centrally located.

The healthcare expenditures associated with HIV/AIDS are costing the United States roughly $12.1 billion annually (CDC, 2012). Furthermore, approximately 30 percent of annual healthcare costs spent in the United States are deemed unnecessary (Robin Wood Johnson Foundation, 2013). Many HIV related healthcare costs stem from lack of proper treatment or non-adherence to medical appointments or regimens (Pappas et al., 2014).

A model of care that is being supported by the U.S. government is called Patient Centered Medical Home (PCMH), which consists of certified centers that provide comprehensive medical care in one facility (Pappas et al., 2014). Primary care health centers can be financially rewarded under the Affordable Care Act if they convert to certified PCMH centers (Pappas et al., 2014). An example of some of the Affordable Care Act provisions are to create plans with options for states to establish health homes for Medicaid beneficiaries with chronic conditions such as HIV/AIDS and award grants to states for establishing programs to educate providers on topics, including medical homes (Sitapati, 2012). A cost analysis conducted on PCMH centers suggest that they are more expensive to run than the average primary care facility, costing an average $40,000 extra per year (Farmer et al., 2014). However, it is the expectation that PCMH centers will save tremendously in overall healthcare costs by providing better quality of care and improving patient services by reducing the number of unnecessary medical expenses (Farmer et al., 2014; Spatz et al. 2014).

For chronic diseases such as HIV and AIDS, PCMH offers a very promising outlook for many of the challenges that mothers of color face with managing such a challenging chronic disease. For example, the Absolute Care center in Atlanta is making strides in quality of care for HIV patients. One of the center's primary goals is to make patients feel comfortable seeking care for HIV treatment. The facility achieves this by not labeling the center as an infectious disease or HIV center. This helps to reduce the stigma associated with getting treatment. This center offers all forms of care for patients—including urgent emergency care, education and support, chiropractic care, massage, laboratory work, pharmacy, mental health services, smoking cessation, social work, and nutrition assessment among many other services. This center helps patients to feel important and valued by getting the care they need and the services offered at the center are covered by Medicaid, Medicare, the Ryan White Care Act Fund, or the Affordable Care Act. Additionally, with their "one-stop-shopping" they are eliminating the costs that would be incurred by their clients if they had to go to multiple facilities to seek comprehensive care. By attending one facility that houses all their care needs, the patients are building relationships with people who have time to provide the appropriate care instead of being shuffled through a disconnected system.

Although the data for this dissertation did not allow for testing variables at the macro level, structural interventions are also needed to address HIV prevention, care, and appointment adherence. Structural interventions are most effective because they change the environment in which people choose to engage in health-related behaviors (Adimora & Auerbach, 2010). In the case of HIV/AIDS, these conditions consist of systemic resources, policies, and better social conditions to enhance HIV/AIDS prevention and living with HIV. Some of the most effective policy initiatives would be to provide better educational opportunities for students, early educational programs, and more vocational and skill programs to help increase the chances of getting jobs and participating in the workforce. Added to that list would be policies to support the creation of non-traditional high school programs that can meet the needs of diverse populations who work or have other family obligations. These structural policies can help to increase individuals' socio-economic position and decrease criminal activity by providing greater education and employment options.

As mentioned previously, higher incarceration rates also contribute to constrained social networks plagued with high rates of HIV in communities of color. Legislation that addresses racial disparities in sentencing is a critical first step to addressing high incarceration rates. Some examples are initiating national policies that terminate the three-strike law, reducing mandatory sentences for crack, and initiating alternative correctional programs instead of resorting to jail-time for minor crimes of first time offenders. Also, government programs can be established that provide rewards such as tax breaks or other incentives to businesses that hire past offenders.

Shifting national priorities to invest in educational and job opportunities and decrease spending in the prison system will not only help to mitigate issues related to HIV management and spread of HIV, but also will address a host of other health and social conditions. According to the VERA Institute of Justice (2013), the United States spent over $33.5 billion on the prison system in 2013. Some states such as California, New York, and Michigan spent four times more on their prisoners than on education and often cut the education budget to maintain overcrowded prisons. Investing in education and skills training for underserved populations not only saves the American economy money, it can also boost the economy by developing a more skilled work force and decreasing spending on healthcare costs and prisons.

Future Research Directions

This dissertation adds to the scant body of knowledge on HIV positive women of color by investigating the potential influences of different dimensions of enacted social support, parenting stress, and family functioning on medical appointment adherence for Black and Latina HIV-positive mothers. This dissertation complements and supports qualitative studies on HIV-positive mothers and retention in care by demonstrating that interpersonal relationships that often use social support are influenced by family dynamics and may play a pertinent role in how HIV-positive mothers of color manage their appointments and care. This quantitative study helps to establish systematic, evidence-based research that documents the unique needs of HIV-positive mothers of color.

While this study identified important linkages between variables that may be pertinent to mothers living with HIV, these relationships are merely associations, and they do not verify causation. More work is needed with better measures that address these relationships for mothers of color. Larger sample sizes and more comparison samples would be helpful to further test these relationships such as race and mothers and single women. Also, considering variations within ethnically diverse populations from the Caribbean and continental Africans living in the United States would add more depth and generalizability to the findings. Additionally, there is a need to explore diverse family and parenting types. For example, how does parenting impact HIV-positive fathers' ability to remain in care? More studies are needed comparing *women* of color with *mothers* of color to see whether there are differences and whether these differences are intergenerational or are related to household structure.

The next logical steps would be to collect a diverse sample (socio-economic status, age, race, ethnicity, parenting status) and study this population for five years to get a grasp of HIV management and adherence to medical appointments over time for women of color. A larger more diverse population of women of color over time would help to tell a more comprehensive story of the challenges and successes of HIV positive women of color and mothers of color.

Overall, this dissertation provides evidence for HIV retention in care initiatives that focus more on HIV-positive women of color and which explore the needs of mothers. This works illustrates that the unique needs of mothers of color matter with regard to adherence and retention in care. This dissertation also assists in advancing the research in this field to include many more variables and to explore the complex relationships that this population warrants.

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