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Stigma and Quality of Life in African American Women Living with HIV Infection Through the Lens of Intersectionality

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Stigma and Quality of Life in African American Women Living with HIV Infection through the Lens of Intersectionality

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DEDICATION

This dissertation is dedicated to the loving God, my spouse who guided and protected me throughout the completion of this journey. In tribute to my beloved parents especially my mother, who had no formal education, but who mentored me and believed in education, which continues to be a primary focus in my life. To all of the survivors and victims of HIV/AIDS, especially my family members, who left us too early without much help. To my beloved brother Alphonce Kaihura and his wife Praxeda Alphonce who left me before completing this product.

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ABSTRACT

Stigma and Quality of Life in African American Women Living with HIV Infection through the Lens of Intersectionality

Alphoncina John Kaihura

African American women (AAW) experience the trifecta of intersections: *Black, female*, and living with *HIV infection* at a disproportionately higher rate compared to other women. Yet, little is known about these intersections on the stigmatizing and quality of life (QOL) experiences of AAW living with HIV infection. The purposes of this secondary research were to describe HIVstigma and QOL, explore the association between HIVstigma and QOL, and determine the influence of social (age, education, income, and partner status) and health (CD4 count, comorbidities, and emergency department admission) contextual factors on HIVstigma and QOL in a sample of 169 AAW with HIV infection living in Cleveland, OH and the San Francisco Bay Area, CA. Results are discussed through the lens of intersectionality and Black feminism.

The sample was a middle-aged group of AA mothers who were low-income, not partnered, educated beyond high school, on public health insurance, unemployed, and lived in permanent housing.They reported a moderate level of HIV QOL and stigma. Partnered, college-educated women with less comorbidities reported better QOL, particularly for life satisfaction. Regardless of social background and health issues, women felt stigmatized by their community and healthcare professionals. HIV-QOL (disclosure of HIV, burden of HIV medications, and life satisfaction) was associated with HIV-stigma. Results of regression analyses of the social and health predictors of stigma and QOL indicate women with less comorbidities reported less personal and public stigma; and, college-educated women reported better overall QOL, better health, and less burden of taking HIV medications.

Conclusions are stigma can be a major obstacle for HIV/AIDS prevention and treatment; and, social support such as having a partner or being married, having a college education, and limited comorbidities can have a positive effect on QOL and stigma.This study addressed a gap in science by considering social and health characteristics on stigma and QOL as perceived by AAW living with HIV infection. These findings may help in the development of HIV/AIDS health education interventions and policies that are holistic, gender-appropriate, culturally acceptable, and address the unique personal, social, and health concerns of and support needed by AAW.

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CHAPTER I

INTRODUCTION

Statement of the Problem

Human immune deficiency virus (HIV) infection and acquired immune deficiency syndrome (AIDS) affect the health and social well-being of individuals, families, populations, communities, and nations around the world. It is the costliest of sexually transmitted diseases, requiring lifelong care as a chronic illness. An estimated 1.2 million people live with HIV/AIDS in the United States (US) (Center for Disease Control and Prevention [CDC], 2011; Prejean et al., 2011). Among women in the US, African American women (AAW) bear a disproportionate burden of HIV infection (De La Cruz, Davies, & Stewart, 2010). African American women comprise 14% of the U.S. general population (Rastogi, Johnson, Hoeffel, & Drewery, 2011), yet they account for 13% of all new HIV infections (CDC, 2012) in the general population. Among U.S. women, AAW account for 64% of new HIV infections, a rate that is more than 20 times that of White, non-Hispanic women (38.1 vs. 1.9 per 100,000) and almost 5 times that of Latina women (38.1 vs. 8.0 per 100,000) (CDC, 2012).According to the CDC, 87% of AAW are infected with HIV through heterosexual sex.

Women with HIV infection often have families, and they struggle to balance family obligations with their health concerns (Webel & Higgins, 2012). Many women living with HIV infection deny, conceal, and socially isolate themselves because of the consequences and fear associated with HIV-stigma (Lichenstein, Laska, & Clair, 2002; Whetten, Reig, Whetten, & Mueohy-McMillan, 2009). In addition, their quality of life (QOL) related to HIV/AIDS is diminished because of hampered prevention efforts, delaying health-seeking behavior, and interfering with self-care and adherence to HIV management and treatment (Webel et al., 2012).

African American women experience the trifecta of intersections: being Black, being female, and having HIV infection at a disproportionately higher rate compared to other American women (Collins, von Unger, & Armbrister, 2008; Weber, 2006). Yet, little is known about the intersection of race/ethnicity, gender, and HIV infection on the stigmatizing and QOL experiences of AAW. Despite availability to and utilization of health and social services and resources, the disparity and inequity in the spread of HIV and increased mortality among AAW with AIDS continue without any consistent, clear and scientifically identified understanding (Gómez, 2011). This gap in the science of women's health within the field of HIV/AIDS calls for research to have a special focus on AAW that interpret findings in a sociocultural contextualized and embodied manner in order to understand the disparities and inequities that shape the unique experiences of AAW living with HIV infection (Collins, 1986, 2000; Weber & Parra-Medina, 2003).

Purpose of the Study

Through the lens of intersectionality and Black feminism, the purposes of this secondary research were to (a) describe HIV-stigma and HIV-QOL as perceived by AAW living with HIV infection; (b) explore the association between AAW's perceptions of HIV-stigma and HIV-QOL; and (c) determine the influence of social and health contextual factors on AAW's perceptions of HIV-stigma and HIV-QOL.

Research Questions

The following research questions for this secondary analysis were addressed for a subset sample of AAW who participated in a study focused on the self-management skills of ethnically and racially diverse adult women living with HIV/AIDS in the San Francisco Bay Area, CA and Cleveland, OH (Webel et al., 2012).

1. What is the occurrence of HIV-stigma?
2. What is the occurrence of HIV-QOL?
3. Do HIV-stigma and HIV-QOL differ by social contextual factors (age, education, income, and partner status)?
4. Do HIV-stigma and HIV-QOL differ by health contextual factors (CD4 count, number of comorbidities, and emergency department admission within the past year)?
5. What is the relationship between HIV-stigma and HIV-QOL?
6. Which social (age, education, income, and partner status) and health (CD4 count, number of comorbidities, and emergency department admission within the past year) contextual factors best explain the variance in HIV-stigma and HIV-QOL?

Significance of the Study

A description of HIV-stigma and HIV-QOL as perceived by AAW living with HIV infection may help to design interventions and policies that are holistic, gender-appropriate, culturally acceptable, and address the unique social and health concerns of and support needed by AAW (Hankivsky, Cormier, & De Merich, 2009).Consequently, these interventions and policies may minimize risk, enhance prevention, promote health-seeking behavior, encourage self-care, and facilitate adherence to treatment and management. Limited studies exist that provide a contextual foundation for understanding stigma and QOL in AAW living with HIV infection. This study fills this gap by considering personal demographic characteristics, health and well-being, and social, cultural and historical contexts for understanding HIV-stigma and HIV-QOL as perceived by AAW through the lens of intersectionality and Black feminism.

Definition of the Terms

The following epistemological and ontological definitions of the major study variables guided this research.

African American: Conceptually, the U.S. Census Bureau defines Black or African American as the self-identification of a person having origins in any of the Black racial groups of Africa (Rastogi et al., 2011). In this study, the operational definition of African American woman was self-identification.

HIV Infection: Conceptually, HIV is described as a retrovirus that infects cells of the immune system, destroying or impairing their function; the most advanced stage of HIV infection is AIDS (Quinn, 2011).In this study, a positive test for antibodies to HIV in the blood was the operational definition for HIV infection.

HIV-Stigma: Conceptually, HIV-stigma refers to perceived expectation of fear because of societal attitudes and potential discrimination that a person might experience because of having HIV/AIDS (Berger, Ferrans, & Lashley, 2001). In this study, HIV-stigma was defined operationally by the HIV Stigma Scale, devised by Berger and colleagues, to measure perceived stigma in people with HIV/AIDS.

HIV-QOL: Conceptually, HIV-QOL is a complex, multilayered construct which can be a subjective, objective, or existential evaluation of one’s life along multiple dimensions at a given moment in time while living with HIV infection (Ventegodt, Merrick, & Jorgen, 2003; Clayson et al., 2006). These dimensions include physical, mental, emotional, psychological, social, role, spiritual, as well as other dimensions. In this study, HIV-QOL was defined operationally by the HIV/AIDS Targeted Quality of

Life Instrument, devised by Holmes and Shea (1997, 1998) to measure perceived QOL concerns in people with HIV/AIDS.

Intersectionality: Conceptually, intersectionality refers to the intersections among gender, race/ethnicity, cultural ideology, and other categories of differences that affect a person’s way of living, including personal, institutional and societal supports and networks, lifestyle health behaviors and practices, perceptions of self and role expectations, and physical, emotional, spiritual and psychological well-being(Schulz & Mullings, 2006). In this study, intersectionality was operationalized by considering socio-demographic characteristics and health outcomes on perceived HIV-stigma and HIV-QOL for AAW living with HIV infection, interpreted within Black feminism as conceptualized by Collins (1986, 2000).

Assumptions of the Study

The following assumptions underlie the study purpose, significance, design, and results. The study focused on perceived HIV-stigma and HIV-QOL among AAW living with HIV infection, framed within the sociocultural context of intersectionality theory and Black feminism epistemology, with the understanding that the experiences and knowledge of AAW were based on their personal accountability and were presupposed to be true. Furthermore, HIV-stigma and HIV-QOL were considered to be bound inextricably, influencing each other, but it was not presumed to know which one as a predictor explained the other one.

The remaining chapters focus on the theoretical foundations of the dissertation study, state of the science on HIV-stigma and HIV-QOL with a particular focus on AAW, study design and methodology, results of the secondary data analysis, and contextualized interpretation and discussion of the findings as perceived by AAW living with HIV infection in the San Francisco Bay Area, CA and Cleveland, OH.

CHAPTER II

THEORETICAL PERSPECTIVES

In this chapter, intersectional theory and Black feminism (Collins, 1986, 2000), social stigma theory (Goffman, 1963), and salvaging QOL theory (Wilson, Hutchinson, &Holzemer, 1997) are examined as theoretical perspectives to understand AAW's HIV-QOL and the triple stigma of being Black, being female, and having HIV infection. These grand theories describe broad, sweeping relationships among people, environment, and society. Each perspective was assessed based on guidelines proposed by Meleis (2012) for theory evaluation: definition of its central phenomenon, historical background, major assumptions, key concepts, application, and challenges for use in research. At the end of the chapter, an integrative, middle-range framework is presented as the theoretical underpinning of this study to describe HIV-QOL and HIV-stigma among AAW living with HIV infection, taking into consideration their health and social contextual factors.

Intersectionality Theory and Black Feminism

Intersectionality theory deals with relationships among multiple intersections that shape one's experiences and decisions because of being different (McCall, 2005). It is concerned with the formation of social identities: ways that gender, race, class, sexuality, etc. work in concertor intersect to create inequality, oppression, and injustice (Schulz&Mullings, 2006; Shield, 2008). These intersections are more powerful than the sum of their intersections (e.g., more than the sum of race and gender). Black feminist thought is an application within the intersectionality paradigm that places AAW at the center of analysis, focusing on consciousness awareness to effect change, resist oppression and domination, and create resilience so that AAW feel less alienated, marginalized, and misunderstood (Collins, 1986, 2000).According to Collins, Black feminism creates and validates AAW’s ways of knowing that are different from others by placing their knowledge in its proper context for better explanation, but at the same time, disputing the notion that they are a homogeneous group.

Definition

Intersectionality refers to the power interactionsamong gender, race,and other categories of difference in people’s lives, social practices,institutional arrangements, and cultural ideologies(McCall, 2005; Schulz&Mullings, 2006; Shield, 2008).

Historical Background

Intersectionality as a concept has been used in sociological circles since the late 1960s and early 1970s as part of the feminist movement that urged feminist scholarship to move beyond middle-class, educatedWhite women (hooks, 1984; Ritzer, 2007).In 1989, Crenshaw (1991) introduced the concept intersectionality in the context of feminist sociological theory as it applies to structural, political and legal discourses. Collins (2000) introduced the concept intersectionality in the 1990s as part of the discussion on Black feminism and the oppression of women within society. Today, intersectionality theory is used to apply to all people and many different intersections of group membership (Mann & Kelley, 1997).

Assumptions

Four assumptions of alternative epistemologies—ways of knowing and validating knowledge—underlie intersectionality theory and Black feminism (Collins, 1986, 2000). Each assumption stands in disagreement to the assumptions of positivism.

The first assumption: alternative epistemology is developed based on lived experience not on an objectified position (Collins, 2000). Instead of being removed from participants' issues as is the case in positivism, the researcher assumes participants are connected knowers, those who understand from personal experience.

The second assumption: alternative epistemology is developed based on the use of dialog rather than adversarial or confrontational debate (Collins 2000). The researcher does not deconstruct findings and results during data analysis and interpretation.

The third assumption: alternative epistemology is developed based onknowledge that is shaped around ethics of caring (Collins, 2000). Instead of affirming that researchers can be value-free, Collins argues all knowledge is appropriate, and therefore, can be verified by the presence of empathy and compassion. Researchers' experiences do not obligate disconnection from their thoughts and feelings.

The fourth and final assumption of alternative epistemology: knowledge is developed based on personal experiences and beliefs—things presupposed to be true (Collins, 2000).

Key Concepts

The intersectionality and Black feminism paradigm has three major concepts: (a) interlocking matrix of oppression, (b) standpoint epistemology (outsider within), and (c) resisting oppression (Collins, 2000).

The interlocking matrix of oppression concept refers to intersections of social inequality that oppress people and privilege others based on their differences in race, class, age, sexual orientation, etc. (Ritzer, 2007). Collins (2000) refers to this either/or thinking as dichotomous oppositional difference, a construct characterized by its focus on differences rather than similarities—internalization of which could lead to further oppression and stigmatization. For example, black/white or male/female descriptors relegate AAW to inferior stereotypes and rarely represent equal relationships.

The standpoint epistemology concept represents one's unique world perspectiveand refers to situations that people experience as they transition from familiarity of self to unfamiliarity of society (Collins, 1986). For example, an AAW who becomes prominent in her profession may never feel she belongs because her professional personaovershadows her true value as a person, thus, becomingan outsider within.

The resisting oppression concept is what Collins (1986) refers to as the objectification of the dominated. According to Collins, self-evaluation and self-definition are two ways to resist oppression.Actively engaging in self-awareness and self-value enhances the oppressed group's self-esteem and buffers the dehumanizing outside impacts of becoming the mythical norm or othering, and being marginalized and dominated by stereotypical societal attitudes, which could result in the psychological oppression known as the self-fulfilling prophecy.

Application

Intersectionality theory, of which Black feminism is an application, is useful for understanding how multiple contexts influence health because it focuses on contextualization, patterns of intersections of multiple social identities, and different ways of perceiving. Researchers in various disciplines have used widely this paradigm to examine disparity based on race, gender, class, and global health (Bates, Hanskivsky, & Springer, 2009), sexuality (Bowleg, 2008), HIV/AIDS (Collins et al., 2008; Doyal, 2009), politics and violence (Crenshaw, 1991), women's health (Hankivsky et al., 2009; Weber&Parra-Medina, 2003), psychology (Warner, 2008), and public health policy (Weber, 2006).

Researchers in the nursing discipline have not applied widely the intersectionality paradigm, although it is emerging as a relevant analytic framework to examine population health, health parity and equity, ethics and social justice, social identity, and moral agency (Kelly, 2009; Lambert, 2007). American nurses are predominantly White, non-Hispanic females, a homogeneity that might contribute to disparityand inequity because of the power relations that dominate nursing care encounters and influence the way nurses provide care to diverse populations (Van Herk, Smith, & Andrew, 2011).

Challenges

Intersectionality, as a method of inquiry and praxis with its focus on social identities and intersecting oppressions, provides a unique lens to study phenomena. Intersectional theorists argue most social and behavioral theories erroneously examine one variable at a time (McCall, 2005; Shield, 2008). The basic premise of intersectionality theory is variables work in groups, making it difficult to operationalize the complexity involved in defining multiple dimensions, i.e., measuring ways socially constructed groups of distinguishing characteristics intersect.For studies that use intersectionality theory, qualitative methodologies are better suited for in-depth descriptions of participants' social identities and their experiences and realities (Collins, 1986, 2000).In contrast, practical methodological guides for quantitative researchers using the intersectionality paradigm are few (Dubrow, 2008).

For the quantitative researcher, cumulation in positivism is a particular way to build knowledge (Burns & Grove, 2005).A sample may have multiple intersections of variables, yet only one variable (e.g., race, gender, or age) is the focus of analysis and interpretation, which may yield an inaccurate picture of the sample and may limit generalization of study findings. Regression analysis, including multiplicative interaction terms and their main effects, might be one way to explore cumulative effect hypotheses within the intersectionality paradigm (Dubrow, 2008). According to Dubrow, multiplicative interaction terms would be able to measure an intersection as an identity beyond the sum of its parts, given that intersectionality theory calls for the examination of more than two variables at the same time.

Social Stigma Theory

Social stigma theory as conceptualized by Goffman (1963) is the guiding paradigm for examining HIV-stigma as a construct. Stigmatizing is a process in which the broader society indicates a person is not displaying normality (Smith, 2011). HIV infection is viewed as a social epidemiology disease (Krieger, 2001). Immoral behaviors resultin illness, and the carriers of illness are blamed for their infection and for infecting other people (Deacon, 2006). When stigma intersects with gender, race, class, and medical diagnosis, it can produce identity politics and oppression, making it difficult for an individual to overcome being stigmatized, stereotyped, discriminated against and rejected based on these categorizations (Scrambler, 2009). This individual then engages in negative compensatory behavior, such as social isolation, feeling invisible, or feeling afraid to seek health advice or treatment (Whetten et al., 2008). Fear of stigma discourages people from HIV-testing and seeking treatment, increases secrecy of disclosure of one’s HIV status to sexual partners, family and friends, and contributes to negative health outcomes, such as decreased QOL and increased viral load (Alonzo &Reynolds, 1995; Holzemer et al., 2009; Kinsler, Wong, Sayles, Davis,, & Cunningham, 2007).

Definition

The word stigma originates from the Greeks, who used the term to refer to a branded mark on the skin that signifies something undesirable about the person by another person or by society (Goffman, 1963). Stigma refers to “an ontological deficit reflecting disregard against norms of shame” (Scambler, 2009, p. 451).According to Goffman, stigma is an undesired reaction from others to another person’s differentness that is perceived as spoiling normal identity.

Historical Background

Goffman’s (1963) social stigma theory is rooted in the sociological perspective and was developed in the 20thcenturyduring the time of social change.It has roots in Herbert Blumer’s symbolic interactionism—a micro-scale approach thatemphasizes society is the product of people’s everyday interactions and how people interpret or make sense of each other’s actions. Goffman reasoned if other people’s reactions influence our behaviors and identities, then we will try to control the reactions of others by manipulating what we reveal or hide about ourselves, and thus, identity is constantly remade as people interact with each other.

Assumptions

According to Goffman (1963), normals define notions of what it means to be normal or conform to the current standard of behavior or appearance within society.

Normals are those who do not bear the stigma; the stigmatized are those who bear the stigma. The major assumptions of social stigma theory are people differentiate and label human variations (differentiation and labeling); prevailing cultural beliefs tie those labeled to adverse attributes (stereotypes); labeled people are placed in distinguished groups that serve to establish a sense of disconnection (us and them); labeled people experience discrimination that leads to unequal circumstances such as loss in status (disadvantage); and, stigmatization occurs on both personal and structural levels and is dependent on social, economic, and political institutions necessary to impose discriminatory experiences on the labeled person or group (necessity of power) (Link & Phelan, 2001).

Key Concepts

Goffman (1963) defined stigma on two levels: the discredited and the discreditable. Discredited refers to stigma that has been revealed. Discreditable refers to stigma that has yet to be revealed, but may be revealed either intentionally by the person or by some factor that the person cannot control. Stigma affects not only the person’s behavior, but also the behavior of others.

Goffman (1963) categorized stigma into three major categories: (a) overt external deformation or abomination of the body (e.g., being physically disabled or obese), (b) deviation in personal trait or blemish of individual character perceived as weak (e.g., alcoholism, mental illness, unemployment, or homosexuality), and (c) tribal stigma or deviation from the prevailing norm (e.g., race, gender, religion, or nationality). Contemporary researchers identify seven clusters of stigma: physical disability,mental disability, economically disadvantaged, social deviant, physical appearance,sexual identity, and racial identity (Scambler, 2009; Smith, 2011).

Application

Structural conditions, such as socioeconomics and politics, have been examined for their impact on stigma to highlight the role of power differentiation in the perpetuation of stigma in people living with HIV infection (Maman et al., 2009).Holzemer and colleagues (2007) proposed that the environment (cultural, economic, political, legal, and policy structures), healthcare system (hospitals, clinics, home-based care, and healthcare workers), and agents(individuals, family members, colleagues, and community members) are contextual factors that influence stigma. For example, some countries have laws and policies that discriminate against people living with HIV/AIDS by denying them access to healthcare.

Challenges

Variability in the definition of the stigma construct exists in social research and is criticized for its biased meaning. According to Link and Phelan (2001), many social scientists do not belong to stigmatized groups, and those who study stigma do so from the vantage point of theories that are uninformed by the lived experiences of the people whom they study. Stigma research focuses typically on the perceptions of individuals and the consequences of such perceptions for micro-level interactions. Research examining the sources and consequences of pervasive, socially-shaped exclusion from society is less common. Research using the sociological perspective is best done through fieldwork, such as participant observation.

Goffman’s(1963) social stigma theory is a dramaturgical perspective that is separate from other sociological theories because it does not posit the cause, but instead the context of human behavior (Link & Phelan, 2001). A person’s identity is performed through roles and is a consensus between himself or herself and society. The aim is not to understand the legitimacy of society. According to Goffman, society will always stigmatize some condition and behavior because doing so provides for group solidarity by delineating outsiders from insiders.

Salvaging Quality of Life Theory

Quality of life is a complex, multilayered construct that can be a subjective, objective, or existential evaluation of one’s life along multiple dimensions at a given moment in time (Ventegodt et al., 2003).Health-related QOL (HR-QOL) focuses specifically on those elements that impact a person’s health: one’s perceived level of functioning and overall well-being in terms of physicaland mental health, social and role functioning,pain, energy, fatigue and spiritual well-being (Clayson et al., 2006). HIV/AIDS has been shown to affect all dimensions of HR-QOL (Holzemer et al., 2009; Vosvicket al., 2003).

Health-related QOL can be non-specific and specific (Wilson & Cleary, 1995). Global or non-specific HR-QOL refers to the existence of reciprocal relationships among all clinical variables and one’s subjective evaluation of overall QOL andgeneral health.Whereas, specific HR-QOL refers to the existence of a reciprocal relationship between specific clinical variables and one’s subjective evaluation of QOL and health as it relates to a particular disease or health condition.

The Salvaging QOL theory is a disease-specific theory that is derived from a grounded theory study conducted to develop an ethnically-sensitive QOL measure for persons with HIV/AIDS (Wilson, Hutchinson, &Holzemer, 1997). The theory was derived from in-depth interviews with a purposive sample of people living with late-stage HIV/AIDS and their family and significant others. In addition, focus groups with expert nurse clinicians were conducted. Sample demographics included African American, Latino, and non-Hispanic White American adult men and women, 18 years and older.

Definition

Wilson and colleagues (1997) view HIV-QOL as a multifaceted concept with multipledimensions: functional status, psychological and social well-being, health perception, and HIV disease and treatmentsymptoms.

Historical Background

Wilson and colleagues (1997) were among the first nurse scientists to study HIV-QOL with specific emphasis on people living with HIV infection at a crucial time point in the HIV/AIDS epidemic.

Assumptions

The assessment of HIV-QOL is subjective because the individual is the key source of the evaluation (Wilson et al., 1997).

Key Concepts

According to Wilson and colleagues (1997), the Salvaging QOL theory posits that *living with dying* is the overarching social process for persons with HIV/AIDS,and is achieved through three-staged, progressive sub-processes: preserving (person attempts to maintain an intact and unaltered QOL); sustaining (person suspends the demise of selected dimensions of QOL); and redeeming (person comes to terms with quality of death and surrenders QOL). Preserving involves managing stigma, maintaining life functions, juggling treatments and side effects, and participating in decisions. Sustaining encompasses recasting goals and presencing of people (i.e., social support). Redeeming involves adjusting hope, calculating death, coveting time, preserving dignity, and resolving spiritual issues.

Application

The Salvaging QOL theory has not been tested or used widely since its seminal grounded theory study (Wilson et al., 1997). It was used to develop the Living with HIV Scale that measures QOL in people living with HIV/AIDS (Holzemer, Spicer, Wilson, Kemppainen, & Coleman, 1998). Even though further development and contemporaneityof the theory are needed, it was chosen as a framework to explore HIV-QOL as a construct because it has a holistic focus versus a biomedical focus. Its development was based on an ethnically diverse sample and derived from grounded theory methodology that emphasizes personal, lived experiences, making it conducive to use as a theoretical guide to design sociocultural, contextually-basedinterventions to improve HIV-QOL in diverse populations.

Challenges

Currently, people with HIV/AIDS are living longer and have better QOL than at the time the Salvaging QOL theory was developed (Wilson et al., 1997). Thirty years have passed since the beginning of the HIV/AIDS epidemic, and many medical, pharmacological and technological advances have occurred that dictate updating the theory. People living with HIV/AIDS no longer face imminent death as a definitive outcome, but will likely live with and die from the burden of other chronic diseases related to aging.

Through the Lens of Intersectionality and Black Feminism

Figure 1 is a representation of the researcher's theoretical conceptualization that underpins this study to describe HIV-stigma and HIV-QOL as perceived by AAW living with HIV infection, taking into consideration their health and social contextual factors. This conceptualization is an integrative, middle-range framework that is based on intersectionality theory and Black feminism (Collins, 1986, 2000), Goffman's (1963) social stigma theory, and the salvaging QOL theory (Wilson et al., 1997). African American women living with HIV infection are at the center of this framework.

The multilayers of the intersections of social and health contextual factors are presumed to influence AAW's perceptions of HIV-stigma and HIV-QOL, and the relationship between HIV-stigma and HIV-QOL. In this study, healthcontextual factors were CD4 count, number of comorbidities, and emergency department admissions within the past year. Social contextual factors were age, education, income, and partner status. Geography and socioeconomic status are social determinants of health (Krieger, 2001). Geography represents where AAW live, work, and socialize. Socioeconomic status is a reflection of education, income, and employment, which may influence one's health insurance status and access to andutilization of healthcare services.

Age, gender, sexual orientation, social support (partnerstatus), race, ethnicity, and culture reflect one's identity. African American women who experience simultaneously one or more of these intersections are impacted in away that defies a simplistic additive analysis. Rather than attempt tosimplify these concepts, it is crucial that we continue to integrate theircomplexity in discussions and policies to identify racist, classist,and sexist underpinnings of health inequities and disparities that negatively influence HIV-stigma and HIV-QOL for AAW living with HIV infection.

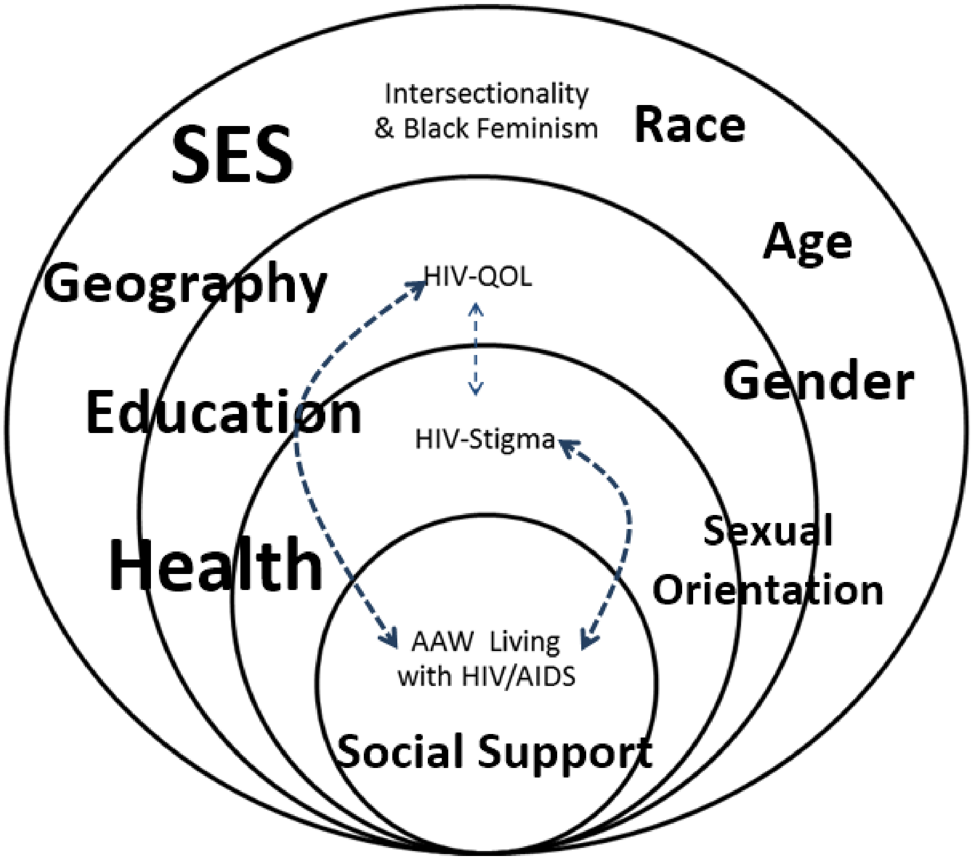

Figure 1. HIV-stigma and HIV-QOL through the Lens of Intersectionality and Black Feminism.

Discussion

The HIV/AIDS epidemic is in its third decade. The demographic profile of persons living with HIV infection continues to change (Prejean et al., 2011), with disturbing and continued increasing shifts toward ethnic and racial populations (CDC, 2011). Although people with HIV infection are living longer, existing models to design interventions to reduce HIV-stigma and improve HIV-QOL do not take into account the intersections of multiple contextual factors. In these models, the prediction of relationships is unidimensional, does not capture the complexity and multidimensionality of phenomena, and is difficult to apply at a macro-level.

The theories reviewed in this chapter focus on contextual issues, but they are global and grand, lacking specificity, but are grounded in philosophical and ethical principles. Paradoxically, these theories'limitations—ambiguity, lack of precision and operationalization, open-endedness, and multidimensionality—make them robust, comprehensive, broad, reflexive, and ideal for critically examining the multiplicity of divisions, disparities, inequalities, and inequities in healthcare research.

CHAPTER III

REVIEW OF LITERATURE

In this chapter, review of the state of the science of literature related to HIV-stigma and HIV-QOL with a particular focus on AAW living with HIV infection is presented. Additional purposes of this chapter are to present theoretical, methodological and analytic approaches used to assess HIV-stigma and HIV-QOL, and identify limitations, gaps, and contraindications in the literature about the perceptions of HIV-stigma and HIV-QOL, particularly as these issues relate to and inform the care of AAW living with HIV infection (Institute of Medicine, 2012).

Literature Review Methodology

A literature search was conducted using PubMed and Google Scholar to locate articles about HIV-stigma and HIV-QOL as perceived by racially and ethnically different men and women living with HIV infection. The search was not limited to a specific time frame, however, a majority of the articles found were published between 1995 and 2013. This period spans 18 years and is an adequate duration of time to examine tipping points of the HIV/AIDS epidemic, particularly in populations of women and ethnic and racial minorities. Studies of women with HIV/AIDS did not appear until the early 1990s. Various separate and simultaneous combinations of key terms were utilized in the search including HIV-stigma, HIV-QOL, women, and/or African American. In addition, citations listed in the included articles for this review were perused for relevant studies.

Search results indicated a literature that is sparse, particularly for perceived HIV-stigma and HIV-QOL in AAW living with HIV infection. Abstracts of the articles yielded from the search were reviewed to determine if the inclusion criteria were met:

English language, adults (18 years and older), HIV-stigma and/or HIV-QOL were assessed, and AAW were included in the sample. Based on the search parameters, 16 studies were included in the literature review: 8 studies about HIV-stigma, 3studies about HIV-QOL, and 4 studies about HIV-stigma and HIV-QOL (see Table 1 at the end of the chapter).All of the studies included participants from the US. The studies represented qualitative and quantitative designs and varying levels of evidence from descriptive and correlational cross-sectional studies to prospective, longitudinal clinical and randomized-controlled trials. The literature review is categorized into threesections: (a) HIV-stigma, (b) HIV-QOL, and (c) HIV-stigma and HIV-QOL.

HIV Stigma

HIV-stigmais posited to be the greatest obstacle to local, national, and global efforts to fight the HIV/AIDS epidemic, and in order to reduce its impact, HIV-stigma must be recognized and confronted (Scrambler, 2009). In a grounded theory study, Ingram and Hutchinson (2010) explored how stigma permeates the lives of women living with HIV and their children. Goffman's social stigma theory was the theoretical underpinning for this qualitative study. In-depth interviews were conducted with 18 HIV-positive mothers, ranging in age from 18 to 44 years. Among the participants, eight (44%) were African American, nine (50%) were Caucasian, and one (6%) was Latina. Fifty percent of participants were married or cohabiting.

The researchers did not create a theory from the data, but were able to validate propositions posed by Goffman's social stigma theory. Two major themes emerged: (a) owning HIV-stigma by admitting that the normalcy of their lives was gone due to being HIV-positive and (b) coping with HIV-stigma. The coping with HIV-stigma theme had sub-themes: passing, covering, and own and wise. Passingwas attempts to be normal by managing undisclosed discrediting information. Coveringwas attempts to draw attention away from HIV-stigma by managing social tension. Own and wise were attempts to find sympathetic others who were accepting in spite of HIV-stigma. A strength of the study was the data confirmed aspects of Goffman's social stigma theory with HIV-positive mothers who were from culturally diverse backgrounds; however, a major study limitation was the small, convenience sample.

Conducted in Birmingham, AL, Lichtenstein and colleagues (2002) also used Goffman's social stigma theory to guide their mixed methods study that explored HIV-stigma, depression, and social support in 12 men and 9 women who had been HIV-positive for at least 5 years. Participants were interviewed in-depth about HIV-stigma and social support. In addition, they were administered the Center for Epidemiologic Studies Depression scale, a self-report depression tool. The sample was home-based, symptomatic of HIV/AIDS, unemployed, and required social support. A majority of the sample were White men (*n* = 12, 52%) and AAW (*n* = 5, 24%).

Women (78%) reported more family problems than did men (45%). Women indicated a need for childcare (55%) more often than did men (0%) of men. African American women were more likely to be caregivers for children and partners with HIV infection. Women (89%) reported having no significant other compared to men (36%). African American women were less likely to be supported by families, partners, and friends (78%).In contrast, gay men reported being more actively involved in their community and having larger social networks that protected and buffered them from the impacts of HIV-stigma.

Unlike men, women feared death because of their children. Chronic sorrow was related to illness, fear of death, poverty, and social isolation especially for women with children. Themes that emerged were social isolation, loss of autonomy, loss of social support, loss of identity, discredited motherhood, and stigma related to receiving AIDS care. Social isolation was linked to HIV-stigma in 78% of women as compared to 63% of men. Women (78%) were more likely to be stigmatized as compared to men (18%). The authors believed this higher proportion of stigmatization was because women with HIV infection are associated with dirty sex and immorality within heterosexual communities, especially if they are of a different race/ethnicity and/or sexual orientation. More than half of the sample reported depressive symptomatology, with AAW having statistically significant higher depressive scores as compared to the total sample.

Study findings reflect the realities of living with HIV/AIDS, and provide evidence for the need to understand the unique and different support needed by men and women, different racial and ethnic groups, and those who are parents. As compared to men, researchers noted that women sought a source of comfort in God after receiving their HIV diagnosis. Religion/spirituality and HIV-positive status in women might be an area to explore further. Study limitations were a small, convenience sample, self-reported data, high attrition rate (4 died, 1 moved away, and 5 cancelled interviews after agreeing to participate), and participants had to be HIV-positive for at least 5 years.

In one of the few seminal studies investigating HIV-stigma in a sample of mostly AAW, Moneyham and colleagues (1996) used a semi-structured guide to conduct four focus groups to explore the perceptions of HIV-stigma in 19 HIV-seropositive women. Sixty-six percent (*n* = 12) of the sample were AAW. The urban dwelling sample was recruited from two large organizations located in the southeastern US. Over half of the small, convenience sample were unmarried and only had completed grammar school.

Four overarching themes of stigma consistent with Goffman's (1963) social stigma theory emerged: distancing, overgeneralization and stereotypes, social discomfort, and pity. Major concerns were fear of disclosure due to fear of negative responses from others, and avoidance of seeking healthcare and social services due to fear of discrimination. Findings suggest women, in particular AAW, could benefit from interventions that assist them to cope with their concerns about HIV-stigma, live with HIV infection, and care for themselves.

HIV-stigma is identified as a barrier to self-care and health-seeking behaviors. To address these barriers, Miles and colleagues (2007) examined the factors associated with HIV-stigma and emotional distress among low-income AAW living with HIV infection. The study was guided by Lazaraus and Folkman's transactional stress and coping model adapted by Thompson and colleagues (as cited in Miles, et al., 2007) for mothers with children who have chronic health conditions. The transactional stress and coping model is a framework for evaluating coping processes with stressful events.

The sample included 109participants (92 mothers and 17 grandmothers), ranging in age from 18 to 66 years, with a mean age of 36 years. Thirty-nine percent of the women were married or living with a partner, 64% of them were high school graduates, and 68% of them were unemployed. A majority of the women were receiving public assistance, and only 8% of them had annual household incomes over $15,000. The women had an average of two children for which to care. Eighty-seven percent acquired

HIV through heterosexual contact with an infected partner, and 6% acquired HIV through intravenous drug use, but a few were unaware of how they had contracted HIV.

HIV-stigma and HIV-worry were significant predictors of depression. Covariates that were statistically significant and related to higher depression were unsupportive relationships, younger age, social conflict, personal factors, perceived health, and mood state. Findings indicate a need to integrate mental health services with HIV/AIDS care to prevent and manage emotional distress associated with HIV-stigma and HIV-worry, and to help low-income AAW adapt to chronic illness. Major study limitations were HIV-symptoms were not assessed, tool to assess symptom distress had poor internal consistency reliability, self-reported data that were missing for approximately 75% of the sample, and staff were used to recruit participants, which might have biased the results.

Kinsler and colleagues (2007) evaluated prospectively the relationship between perceived HIV-stigma from healthcare providers and access to care for 223 low-income persons with HIV infection in Los Angeles County. The researchers did not identify a specific theoretical framework guiding the study; however, they cited concepts of Goffman’s social stigma theory. The sample included 46% African Americans. Female participants represented 22% of the sample. Among the sample, 25% at baseline and 20% at follow-up reported perceived HIV-stigma from a healthcare provider. Limited access to care was reported at baseline (*OR*=3.29; 95% *CI*=1.55, 7.01) and at 6-month follow up (*OR* = 2.85; 95% *CI*=1.06, 7.65).

Despite study limitations that include a small, convenience sample (23% lost to follow-up), self-reported data, low-income participants, and an underrepresentation of women, particularly AAW, findings indicate effective intervention to reduce HIV-stigma is an imperative need, and perceived HIV-stigma from healthcare providers might be a barrier to accessing healthcare and improved QOL for low-income persons living with HIV infection.

The aforementioned studies focused on HIV-stigma in the general population of people with HIV infection. Two studies focused specifically on ageism and HIV-stigma using Goffman’s social stigma theory (Emlet, 2006, 2007). Findings of these studies are consistent with the aforementioned studies that indicate HIV-stigma as being both enacted (e.g., by a healthcare professional) and felt by the person with HIV/AIDS. In the first study, which used qualitative methodology, Emlet (2006) explored dual stigma: being older and having HIV/AIDS. Twenty-five participants, 50 years and older living with HIV/AIDS, were interviewed between November 2003 and December 2004in an urban county in the Pacific Northwest. The sample included 68% males, 32% females, 60% Whites, 36% African Americans, and 4% Latinos.

Sixty-eight percent of the sample experienced both ageism and HIV-stigma, and 40% of the sample experienced rejection by younger people. Major study findings were (a) ageism (employment discrimination and internalized ageism); (b) HIV-stigma (fear of contagion, protective silence, homophobia, and violations of confidentiality); and (c) ageism and HIV-stigma (rejection, stereotyping, and separateness/being alone). The major conclusion of the study was older adults with HIV/AIDS are in double jeopardy because of HIV-stigma and ageism.

In the second study, which used quantitative methodology, Emlet (2007) described the associations between HIV-stigma and depression using descriptive, correlational analyses of the same sample (*n* = 25) described above (Emlet, 2006).

Seventy-eight percent of the sample experienced personalized stigma (rejection, fear of contagion, and separateness/being alone); 53% experienced negative self-image (feeling of other and self-deprecation); 66% reported disclosure concerns (protective silence, anticipated disclosure, unintended disclosure, and violations of confidentiality); and 60% experienced negative public attitudes (ageism, stereotyping, and homophobia).

HIV-stigma scores ranged from 54 to 141 (*M* = 94.32, *SD* = 23.12); a higher score indicates higher reports of stigma. HIV-stigma was significantly higher in African Americans as compared to Whites ($\chi^2 = 4.16$, $p = .04$). Depression scores ranged from0 to 50 (*M* = 15.76, *SD* = 13.73), with 36% (*n* = 9) of the sample having scores greater than 16, indicating depressive symptomatology. African Americans' depression scores were significantly higher than were the depression scores of Whites ($\chi^2 = 4.16$, $p = .04$). HIV-stigma was positively and significantly correlated with depression ($r = .63$, $p = .001$).

In both analyses (Emlet, 2006, 2007), study limitations were under representation of women, especially AAW, who were recruited by staff, a small convenience sample using purposive sampling in a limited geographic area, and self-reported data. The experiences of women, particularly diverse women, living with HIV/AIDS are important to capture in order to assist them to live healthier and fuller quality lives without stigma and with knowledge to cope with HIV-stigma from their sociocultural perspective.

HIV Quality of Life

Quality of life has been assessed in persons and populations who are healthy as well as those who have specific conditions and illnesses, such as HIV/AIDS. Vosvick and colleagues (2003) examined factors associated with four dimensions of QOL (physical functioning, energy/fatigue, social functioning, and role functioning) in a sample of 142 adults with HIV/AIDS. A specific theoretical framework did not guide the study; however, the researchers cited studies that addressed the dimensions of functional QOL with a focus on people with HIV/AIDS. Recruitment occurred at AIDS community research consortium hospitals. The sample consisted of 57% men and 43% women, ranging in age from 21 to 59 years. Fifty-two percent of the sample identified as White American, 26% as African American, and 52% as gay or lesbian. Among women participants, heterosexual women represented 77% of the sample.

Results indicated 40% of the sample reported moderate to severe bodily pain; 61% reported pain interfered with work; 82% reported physical functioning limitations; 68% reported limitations in vigorous activities (e.g., lifting heavy objects or running); 57% reported limitations in social activities related to health; 51% reported role functioning limitations; and 86% reported having some degree of energy. Lower CD4 count was positively associated with social and role functioning limitations ($p < .05$). There was no significant relationship between age and physical or social functioning. Findings suggest reducing pain in persons with HIV/AIDS could improve QOL. A major study limitation was the convenience sample of mostly White, non-Hispanic gay men who self-reported data.

Gielen and colleagues (2001) described the relationship between psychosocial factors and HIV-QOL in a sample of 287 HIV-positive women, recruited from community-based clinics in Baltimore, MD. The researchers did not identify a theoretical or conceptual framework that guided the study. Ninety-four percent of the sample were AAW. The mean age was 33years; 83% of the women had children; 19% of them were with HIV-positive sexual partners; 62% of them were unmarried; 55% of them did not have a high school education; and 55% of them had been intravenous drug users. Thirty-two percent of the women reported at least a one-time exchange of sex for money, food, drugs, or a place to stay.

Statistical significance was demonstrated for the association between better HIV-QOL and younger age and higher education, and for the association between presence of HIV symptoms and lower HIV-QOL. Less instrumental social support was significantly related to lower mental health functioning ($F = 8.97$, $p < .01$) and lower HIV-QOL ($F = 8.76$, $p < .001$). Sixty percent of women who reported smaller social networks reported significantly lower physical functioning ($F = 14.61$, $p < .001$) and HIV-QOL ($F = 20.05$, $p < .001$) as compared to women who reported larger social networks. Practicing more health promoting behaviors was significantly associated with better mental health functioning ($F = 12.85$, $p < .001$), physical functioning ($F = 2.84$, $p < .05$), and HIV-QOL ($F = 9.19$, $p < .001$).

Sixty-percent of the women had been physically or sexually assaulted at least once as an adult, but this characteristic was not statistically significant for HIV-QOL. Forty-one percent of the women had a history of child sexual abuse and reported significantly lower mental health functioning ($F = 15.87$, $p< .001$), physical functioning ($F = 4.18$, $p< .05$), and HIV-QOL ($F = 8.95$, $p< .01$) as compared to women who reported no history of child sexual abuse. Less instrumental social support was significantly related to lower mental health functioning ($F = 8.97$, $p< .01$) and lower HIV-QOL ($F = 8.76$, $p< .001$).

Study findings indicate more services may be needed for older HIV-positive AAW, who have lower education, less instrumental social support, smaller social networks, and more HIV symptoms. Social support and health promoting lifestyle behaviors appear to be moderating factors that could improve HIV-QOL in terms of physical and mental health functioning among HIV-positive AAW. In addition, high prevalence of history of adult violence and childhood sexual abuse suggests screening women with HIV infection for domestic violence, and social support and health-promoting behaviors appear to be protective factors for better HIV-QOL.

Study limitation was the cross-sectional design that was not guided by a theoretical or conceptual framework, restricting assertion of causality. Other study limitations were a convenience sample of predominantly low income, undereducated AAW living in an urban city who self-reported data. These limitations limit the generalization of study findings; however, the study is one of few studies in the literature that had a sample that was comprised predominantly of AAW.

A randomized-controlled, prospective study conducted by Gore-Felton and colleagues (2006) tested a coping strategies intervention aimed at improving HIV-QOL in 166 persons living with HIV/AIDS. Lazarus and Folkman's transactional stress and coping model guided the study. Participants were recruited via newspaper advertisements at four major hospitals, a university hospital, and community clinics in the San Francisco Bay Area, CA. Men and women were equally represented in the sample. Ethnic and racial representation included 58% White, non-Hispanics, 24% African Americans, 3% Latinos, 3% Asians, and 5% other races and ethnicities. The mean age of the sample was 40 with a range of 25 to 59 years. Fifty-seven percent of participants were unemployed. There were statistically significant gender differences for education (t (57) = -4.23, $p <$ .001, Cohen's d = 1.10) and annual household income (U = 227, p < .001). Women reported less education (*M* = 12.54 years, *SD* = 2.12) than did men (*M* = 15.26 years, *SD* 2.74). As compared to men, women reported lower income (less than $20,000 per year).

Participants were randomized to two groups: control (*n* =66) or intervention (*n* = 100). The intervention consisted of building coping strategies and skills. At baseline, 82% of the intervention group reported moderate to severe cognitive dysfunction; at 3-monthfollow-up, this proportion decreased to 77%. At baseline, 76% of the intervention group reported moderate to severe distress about their health; at 3-month follow-up, the proportion decreased to 70%. Maladaptive coping strategies indicated more physical illness and less HIV-QOL were statistically significant and associated with greater depression.

A methodological limitation of the study was the mechanism used to recruit the sample. Participants were recruited through newspaper advertisements at hospitals and community clinics, which may not be representative of people living with HIV/AIDS. In addition, self-report data are often biased because of recall and social desirability (Burns & Grove, 2005; Nunally & Bernstein, 1994). Despite these study limitations and threats to external validity, findings suggest increasing adaptive coping skills could enhance HIV-QOL and overall well-being in persons living with HIV/AIDS.

HIV Stigma and HIV Quality of Life

Holzemer and colleagues (2009) explored the contribution of perceived HIV-stigma on HIV-QOL in an international sample of 726 persons living with HIV/AIDS. The researchers did not identify a theoretical or conceptual framework that guided the study. Participants were recruited from HIV-focused community clinics in 14 sites across Africa, Puerto Rico, and the southern US. The sample included 395 (55%) men and 329

(45%) women. Ethnic and racial groups represented were 30% African Americans, 28% Latinos, 21% Whites, and 15% from the African continent.

The sample had a mean score of 61.6 (*SD* = 18.1) for HIV-QOL, 39.4 (*SD* = 35.9) for HIV-symptoms, 86.5 (*SD* = 25.3) for HIV-stigma, and 23.9 (*SD* = 35.9) for depression. With the exception of HIV-QOL, higher scores equated to less than optimal indicators. General HIV symptoms as well as depressive symptomatology contributed significantly to explaining most of the variance in HIV-QOL. Participants from the African continent reported statistically significant fewer HIV-symptoms as compared to Latino participants. Statistical significance was demonstrated for the inverse association between HIV-stigma and HIV-QOL. HIV-stigma explained a statistically significant 5% increase in the variance of HIV-QOL after controlling for HIV-symptoms.

Findings suggest HIV-stigma reduction interventions have the potential to improve HIV-QOL for people living with HIV infection. The sample was a convenience sample who self-reported data. The proportion of AAW was not reported. The strengths of the study are the diverse geographic areas from which participants were recruited, and an almost equal distribution of male and female participants, enhancing the external validity of the study, even though no analyses were conducted by gender.

During a critical time when more women were being diagnosed with HIV/AIDS, Sowell and colleagues (1997) examined social (social support, maternal resources, disclosure, and family functioning) and psychological factors (stigma, emotional distress, intrusion, avoidance, and fatalism) as predictors of QOL in a sample of 264 low-income AAW with HIV infection. Similar to many of the aforementioned studies, the study was guided by Lazarus and Folkman’s transactional stress and coping model. Women were recruited from eight public health HIV/AIDS clinics that serve rural and urban areas in a southeastern U.S. state over a 13-month period between 1993 and 1994.The average age of the sample was 34years. A majority of the sample were single (74%), lived in urban areas (69%), unemployed (80%), and reported an annual income of less than $10,000 (70%).

Quality of life, anxiety, and HIV-symptoms were significantly correlated (r= .32 to .51, p <.000). Except for avoidance, other constructs of intrusive thoughts (stigma, fatalism, emotional distress, and intrusion) were positively correlated with QOL (p = <.001) and HIV symptoms (p<.001).Quality of life was predicted by stigma, fatalism, employment status, and stage of illness (R^2 = .18, p<.05). African American women who were younger, asymptomatic and working full-time reported higher QOL. Anxiety was predicted by emotional distress, intrusion, and marital status (R^2 = .50, p < .05). Single AAW, working full-time and making more than $10,000 per year reported less general anxiety. HIV symptoms were predicted by material resources, disclosure, intrusion, age, employment status, and race (R^2 = .29, p < .05). Younger and single AAW living in urban areas and working full-time reported less HIV symptoms.

Results suggest having HIV/AIDS affect QOL. Among this convenience sample of mostly unmarried, low-income unemployed AAW, stigma and other types of intrusive thoughts, anxiety, and more HIV symptoms were associated with lower QOL. Being younger, asymptomatic, working full-time and having more social and material resources had positive effects on QOL. Major study limitations were self-reported HIV symptoms and measures used to assess QOL and stigma were non-specific, global measures: they were not specific to persons with HIV/AIDS.

Vyavaharkar and colleagues (2011) examined the physical, psychological, and social dimensions of QOL in a sample of 399 women with HIV/AIDS living in rural areas in the southeastern US. Lazarus and Folkman's transactional stress and coping model was the theoretical underpinning of the study. African American women **(***n* = 340, 85%) represented a majority of the sample. The mean age was 41.5(*SD* = 9.6) with a range of 18 to 71 years. The majority of participants were unmarried (77%), 80% of them lived with children, family members or friends, 67% of them graduated from high school, 80%of them were unemployed, 69% of them received some kind of public assistance, and 27% of them had an annual income less than $10,000.More than 66% of participants were diagnosed with HIV/AIDS in or after 1996.

Statistical significance was demonstrated for the association between HIV-symptoms (frequency and bothersome) and perceived HIV-stigma (*r* = .95) and internalized stigma (*r* = .60); for the inverse association between QOL and perceived stigma, internalized stigma, and depression; and for the positive association between QOL and social support, problem-focused coping, perceived situational control, and health promoting lifestyle behaviors, which explained 55% of the variance in QOL. Sociodemographics, age (*p* = .003), race (*p*< .0001), and time of HIV diagnosis (*p* = .03), were positively correlated with QOL. African American women reported better QOL (*M* = 46.6) as compared to White, non-Hispanic and other ethnic/racial groups (*M* = 39.1).Women diagnosed with HIV/AIDS post-HAART era reported lower QOL (*M* = 44.4) as compared to women diagnosed with HIV/AIDS pre-HAART era (*M* = 47.7).

Study findings suggest efforts to reduce stigmatizing attitudes and behaviors towards women living with HIV/AIDS must continue. There is a need for improved social support networks for women, especially for those who live in rural and small towns who seek needed healthcare and support which are often limited in these areas. The results are to be received with caution because AAW from a specific geographic rural region in the US comprised the majority of the sample, limiting generalization of the findings. In addition, a global measure of QOL was used instead of a QOL measure specific to HIV/AIDS, and the cross-sectional design restricts the assertion of causality.

Using the maternal HIV self-care symptom management framework adapted from the UCSF symptom management model, Miles and colleagues (2003) designed a randomized controlled trial to determine the efficacy of a HIV self-care symptom management intervention to reduce HIV-stigma and improve HIV-QOL in 109 low-income AA mothers with young children living in a small rural town in the southeastern US. The mean age of the sample was 37 years. Participants were recruited from tertiary-care university-based infectious disease clinics and HIV-care agencies.

Women were randomized to usual care (*n* =50) or the intervention (*n* = 59). The self-care management intervention consisted of helping mothers to adjust their emotional feelings about perceived HIV-stigma and enhance their understanding of HIV as a chronic condition that requires continuous self-care practices, regular visits, and treatment adherence in order to improve HIV-QOL and health outcomes. As compared to the usual care group, the intervention group reported statistically significant fewer feelings of HIV-stigma and higher physical functioning HIV-QOL after 6 months.

Findings indicate self-care management had a positive impact on reducing perceived HIV-stigma and increasing physical functioning HIV-QOL in AAW with HIV infection. These findings are significant because research suggests HIV-stigma may be a barrier to seeking care, may isolate AAW from their social support networks, and may lead to depression and lower HIV-QOL, especially in childbearing AAW. External validity is limited by a small, convenience sample of low-income AA mothers with young children living in a rural town, self-reported data, and unclear reasons for attrition.

Discussion

After 30 years of the HIV/AIDS epidemic, little insight is available in the literature about women in general, ethnically and racially diverse women, or women who are of reproductive age. Among women, AAW bear a disproportionate burden of morbidity and mortality, despite the fact that people are living longer with HIV/AIDS and managing it as a chronic condition. Urban and rural low income, undereducated AAW living with HIV/AIDS reported lower HIV-QOL, fewer social support resources, and smaller social networks as compared to other populations living with HIV/AIDS. Men and women, and younger and older persons with HIV infection experienced stigma differently. As people with HIV/AIDS aged, they were often stigmatized by ageism. As compared to men, fear of HIV-stigma discouraged women from HIV-testing and increased distrust and secrecy from disclosure of one’s status to sexual partners, family, friends, and healthcare professionals.

Culture and power inequities shape the unique experiences of AAW living with HIV infection. Yet, a majority of the studies were guided primarily by non-contextual models such as Lazarus and Folkman’s transactional stress and coping model, Goffman’s social stigma theory, and various global, non-specific QOL models. In addition, many of the study samples were comprised primarily of White, non-Hispanic gay males. These limitations are gaping windows into understanding the lives of AAW living with HIV infection. Existing models used to guide the design of interventions that aim to reduce HIV-stigma and improve HIV-QOL do not take into account the intersections of multiple contextual factors: age, gender, race/ethnicity, HIV status, etc. Generalization of study findings is limited because the prediction of relationships among phenomena was unidimensional and did not capture the complexity and multidimensionality of phenomena, and the interventions tested are difficult to apply at a macro-level and diffuse to different populations.

Perceived HIV-stigma and HIV-QOL continue to be major issues undermining the risk, prevention, treatment, and management of HIV/AIDS, and often lead to depression, social rejection and isolation, feeling shame and guilt, feeling discredited and discounted by others, and diminished material and healthcare resources. Successful management of HIV/AIDS, whether it involves stress-coping interventions, self-care and health-promoting lifestyle behavioral management, educational programs, and/or cognitive-behavioral interventions, can moderate HIV-symptoms, improve overall health and HIV-QOL, moderate perceived HIV-stigma, and improve knowledge about HIV/AIDS, particularly if interventions are designed in an integrative, holistic and contextual manner that is acceptable and relevant to the target population.

Table 1:

Summary of HIV-stigma and HIV-Quality of Life (QOL) Literature with a Focus on African American Women (AAW) (*n*= 16)

Purpose	Design	Variables	Results	Limitations
HIV-STIGMA				
Lichtenstein, B, Laska, MA, & Clair, JM (2002)				
Explore HIV-stigma, depression, and social support in HIV-positive men and women **Theory**: Goffman's social stigma theory	**Design:** descriptive, cross-sectional (mixed methods) **Setting:** Birmingham, AL **Sample:** HIV infection for at least 5 years (*n* = 21), symptomatic, home-based, and unemployed Mean age: 40 years Age range: 24-58 years White men: 11 (52%) Ethiopian man: 1 (5%) White women: 3 (14%) Black South African woman: 1 (5%) AAW: 5 (24%)	**Qualitative:** in-depth interviews about **HIV-stigma** and **social support** **Quantitative:** **Depression:** Center for Epidemiologic Studies Depression (CES-D) scale	**Themes:** social isolation; loss of autonomy, identity and social support; stigma and AIDS care; and discredited motherhood Social isolation was linked to stigma in a majority of women. Women were more likely to be stigmatized than men. AAW were more affected by stigma. Men reported more social networks. AAW reported less social support. Women feared death because of the consequences on self and children. Majority of sample were depressed. AAW reported significantly higher depression.	Small convenience sample Included only those HIV+ for at least 5 years High attrition (4 died, 1 moved away, and 5 cancelled interviews after agreeing to participate) Self-report data

Purpose	Design	Variables	Results	Limitations
Moneyham, L, Seals, B, Demi, A, Sowell, R, Cohen, L, & Guillory, J (1996)				
Examine the experience of women living with HIV infection **Theory:** Goffman's social stigma theory.	**Design:** qualitative (4 focus groups using semi-structured guide) **Sample:** 19 women with HIV infection Mean age: 33 years Age range: 24-44 years AA: 12 Whites: 7 Single: 15 Married: 4 Children: 18 College: 1 Some college: 4 High school: 3 Grammar school: 11 **Setting:**2 large organizations in urban southeastern US	Lived experience of living with HIV infection and perceived HIV-stigma	Four themes: distancing, overgeneralization and stereotypes, social discomfort, and pity For a majority of participants, disclosure due to a fear of negative responses from others and avoidance to seek health care and social services due to fear of discrimination were major concerns.	Small convenience sample of low-educated women
Miles, MS, Holditch-Davis, D, Pedersen, C, Eron, JJ, & Schwartz, T (2007)				
Identify factors associated with emotional distress in AAW living with HIV infection **Theory:**	**Design:** descriptive, cross-sectional **Sample:** 109 AAW with HIV infection Mean age: 36 years Age range: 18-	**Depression:** CES-D **Mood states:** Profile of Mood States (POMS) **Social support:** MOS-Social	HIV-stigma and HIV-worry were significant predictors of depression. Factors significantly related to higher depression were unsupportive relationships, younger age, social conflict, personal factors, perceived health,	Missing data on about 75% of sample Self-report data HIV symptoms were not assessed

Purpose	Design	Variables	Results	Limitations
Lazaraus & Folkman's transactional stress and coping model adapted by Thompson et al for mothers with children who have chronic health conditions	66 years Married: 42 (39%) High school: 7 (64%) Unemployed: 75 (69%) Income >$15,000: 8% Medicaid: 74% SSI: 64% Food stamps: 56% HIV via heterosexual contact: 87% HIV via IVDU: 6% **Setting**: 1 adult infectious disease clinic based in a university tertiary care health center; and, various community agencies	Support Survey (SSS) **Social conflict:** Social Conflicts Scale **Spirituality:** Religious Well-Being Scale **HIV-QOL:** Medical Outcomes Study (MOS)-HIV Scale **HIV-stigma:** Demi HIV Stigma Scale **HIV-worry:** HIV Worry Scale **Emotion-focused coping:** investigator developed based on coping literature	and mood state.	Staff were used to recruit participants
Kinsler, JJ, Wong, MD, Sayles, JN, Davis, C & Cunningham, WE (2007)				
Examine perceived HIV-stigma from health care providers and access to care for low-income persons with HIV **Theory:** None	**Design:** prospective, longitudinal (Jan 2004-Jun 2006) **Sample:** 223 (baseline) and 171 (6 months) persons with HIV infection AAs: 102 (46%)	**HIV-stigma:** HIV Cost & Services Utilization Study Survey **Access to care:** HIV Cost & Services Utilization Study Survey	25% at baseline and 20% at follow-up reported perceived HIV-stigma from a health care provider Access to care was low both at baseline (OR=3.29; 95% CI=1.55, 7.01) and at 6-month follow up (2.85; 95% CI=1.06, 7.65)	Small convenience sample; 23% lost to follow-up Under-representation of women, particularly AAW Self-report data

Purpose	Design	Variables	Results	Limitations
identified, but cited Goffman's social stigma theory applied to people living with HIV/AIDS and other generic stigma conceptualizations based on physical and mental health conditions	Males: 178 (80%) Females: 45 (20%) H.S. or less: 74% MSM: 120 (54%) DUI: 37 (16%) Heterosexual: 66 (30%) Uninsured: 103 (46%) **Setting:** LA County			
Emlet, CA (2006)				
Explore HIV-stigma in older adults living with HIV **Theory:** Goffman's social stigma theory	**Design:** qualitative (in-depth interviews, using semi-structured guide) **Sample:** 25 older adults with HIV infection Mean age: 56 years (*SD* = 5.75) Age range: 50-72 years Males: 17(68%) Females: 8 (32%) Whites: 15 (60%) AAs: 9 (36%) Latinos: 1 (4%) People of color: 40%	-Ageism -HIV-stigma	Themes: **-Ageism:** employment discrimination; internalized ageism **-HIV-stigma:** fear of contagion; protective silence; homophobia; violations of confidentiality **-Ageism x HIV-stigma:** rejection; stereotyping; separateness/being alone -68% experienced both ageism and HIV-stigma -40% experienced rejection by younger people	Small sample using purposive sampling Limited geographic area Self-report data Used staff to recruit

Purpose	Design	Variables	Results	Limitations
	AIDS: 19 (76%) HIV: 6 (24%) High school: 15 (60%) Retired: 72% Live alone: 56% Medicaid: 60% Exposed to HIV via MSM: 36% Infected via IVDU: 4% **Setting**: Local AIDS service organizations; county public health clinics; infectious disease clinics; and medical centers in urban county in Pacific northwest			
Emlet, CA (2007)				
Examine the association between HIV-stigma and depression in older adults living with HIV **Theory:** Goffman's social stigma theory	**Design:** descriptive, correlational **Sample:** 25 older adults with HIV infection Age: 50-72 years with mean of 56 (*SD* = 5.75) Males: 17 (68%) Females: 8 (32%) Whites: 15 (60%)	**HIV-stigma:** HIV Stigma Scale **Depression:** CES-D Scale	HIV-stigma scores ranged from 54-141; *M* = 94.32 (*SD* = 23.12). Stigma was higher in AAs than Whites (χ^2 = 4.16, *p* = .04) Depression scores ranged from 0-50; *M* = 15.76 (*SD* = 13.73). Nine (36%) had depression scores greater than 16. As compared to Whites, AAs depression scores >16 (χ^2 = 4.16, *p* = .04) Stigma correlated with depression (*r* = .63, *p* = .001)	Small sample using purposive sampling Limited geographic area Self-report data Used staff to recruit

Purpose	Design	Variables	Results	Limitations
	AAs: 9 (36%) Latinos: 1 (4%) People of color: 40% AIDS: 19 (76%) HIV: 6 (24%) High school: 15 (60%) Retired: 72% Live alone: 56% Medicaid: 60% Exposed to HIV via MSM: 36% Infected via IVDU: 4%			
Ingraham, D & Hutchinson, SA (2010)				
Explore how stigma pervades the lives of HIV-positive mothers and their children. **Theory:** Goffman's social stigma theory	**Design:** qualitative (grounded theory) **Sample:** 18 mothers with HIV infection Age range: 18-44 years AAs: 8 (44%) Whites: 9 (50%) Latinas: 1 (6%) Partnered: 50% IVDU history: 6 (33%) CD4 (200-499): 9 (50%) CD4 (<200): 6 (33%) **Setting**: interviews conducted at a place chosen by participants	HIV-stigma	Findings confirmed aspects of Goffman's social stigma theory. Two major themes emerged: 1. Owning HIV-stigma 2. Coping with HIV-stigma • *Passing* oneself as normal to manage undisclosed discrediting information • *Covering* by drawing attention away from HIV-stigma in order to manage social tension • *Own and wise* by finding sympathetic others who were accepting of them in spite of their HIV-stigma	Small, convenience sample

Purpose	Design	Variables	Results	Limitations
	who were recruited from community organizations in the US			
HIV-QUALITY OF LIFE				
Vosvick, M, Koopman, C, Gore-Felton, C, Thoresen, C, Krumboltz, J, & Spiegel, D (2003)				
Examine factors associated with functional QOL (physical, energy/ fatigue, social, and role) with persons with HIV/AIDS. **Theory**: None, but cited studies that addressed the dimensions of functional QOL with a focus on people with HIV/AIDS	**Design:** prospective, longitudinal randomized-controlled trial (1996-99) **Sample:** 142 people with HIV/AIDS Age: 21-59 years Men: 81(57%) Women: 61(43%) White: 52% AA: 26% Gay men: 78% Heterosexual women: 77% **Setting**: AIDS community research consortium hospitals	**Coping style:** Brief COPE Tool **Functional QOL:** MOS-HIV Scale **Pain:** MOS-HIV Scale	-40% reported moderate to very severe bodily pain -61% reported pain interfered with work from “a little bit” to “extremely” -82% reported limitation in physical functioning -68% reported limitation in vigorous activities (e.g., lifting heavy objects or running) -85% reported having some degree of energy -57% reported limitation in their social activities due to their health -51% reported limitation in role functioning Lower CD4 T-cell count was positively associated with lower social and role functioning scores ($p < .05$) No significant relationship between age and physical or social functioning	Self-report data Sample comprised mainly of White, non-Hispanic gay men
Gielen, AC, McDonnell, KA, Wu, AW, O’Campo, P, &Faden, R (2001)				
Describe the relationship between HIV-QOL and	**Design:** cross-sectional (descriptive, correlational)	**HIV-QOL:** MOS-HIV Scale **Social**	32% reported a one-time exchange of sex for money, food, drugs or a place to stay	Cross-sectional design limits establishment of causality

Purpose	Design	Variables	Results	Limitations
violence, social support, and health-promoting behaviors. **Theory:** None	**Sample:** 287 women with HIV infection for 41 months Mean age: 33 years AA: 94% White: 5% Children: 83% Sexual partner HIV+: 19% Single: 62% Divorced/separated/widowed: 30% Married: 8% No high school/GED: 55% IVDU: 55% **Setting:** HIV clinic and outpatient pediatric clinic in Baltimore, MD	**support:** investigator developed based on literature **Health promoting behaviors:** investigator developed based on literature **Violence (adult violence history & child sexual abuse):** Investigator developed based on literature	63% reported being physically or sexually assaulted at least once as an adult, which was not significantly related to the HIV-QOL 41% reported a history of child sexual abuse and had significantly lower scores on mental health (F = 15.87, $p< .001$), physical functioning (F = 4.18, $p< .05$), and HIV-QOL (F = 8.95, $p< .01$) as compared to women who reported no history or child sexual abuse Having less instrumental social support was significantly related to lower mental health scores (F = 8.97, $p< .01$) and lower HIV-QOL (F = 8.76, $p< .001$) 60% reported less social support and had significantly lower scores for physical functioning (F= 14.61, $p< .001$) and HIV-QOL (F = 20.05, $p< .001$) as compared to women reporting larger networks Practicing more health promoting behaviors was significantly associated with higher scores in mental health (F = 12.85, $p< .001$), physical functioning (F = 2.84, $p< .05$), and HIV-QOL (F = 9.19, $p< .001$). High prevalence of history of adult violence and childhood sexual abuse	Self-report data Convenience sample of AAW in Baltimore, MD who were economically and educationally disadvantaged Not guided by a theoretical or conceptual framework

Purpose	Design	Variables	Results	Limitations
			suggests screening HIV+ women for domestic violence, and social support and health-promoting behaviors appear to be protective factors for better HIV-QOL	
Gore-Felton, C, Koopman, C, Spiegel, D, Vosvick, M, Brondino, M, Winningham, A (2006)				
Examine the effect of maladaptive coping strategies and psychological QOL on depression over time in people living with HIV/AIDS **Theory**: Lazarus & Folkman's transactional stress and coping model	**Design:** prospective, longitudinal randomized-controlled trial Control group: 66 Intervention group: 100 **Sample:** 166 persons living with HIV/AIDS Mean age: 40.3 years Age range: 25-59years No job: 57% Women reported low income < $20,000 Males: 50% Females: 50% White: 58% AA: 24% Latino: 3.0% Asian: 3.0% Other: 5% **Setting:** newspaper ads at 4 major hospitals, a university	**Coping style:** Brief COPE Tool **HIV-QOL:** MOS-HIV Scale **Depression:** CES-D Scale	Gender difference in education ($t(57)= -4.23$, $p<.001$, Cohen's $d = 1.10$); women had less education (M =12.54 years, SD =2.12) than men (M =15.26 years, SD 2.74) Gender difference in household income <$20K ($U = 227.00$, $p < .001$) 82% of intervention group reported moderate to severe cognitive dysfunction at baseline that decreased to 77% at 3-month follow-up 76% of intervention group reported moderate to severe distress about their health at baseline that decreased to 70% at 3-month follow up Maladaptive coping strategies, more physical illness, and less HIV-QOL were statistically significant and associated with greater depression	Newspaper ads as a main mechanism for recruitment Self-report data

Purpose	Design	Variables	Results	Limitations
	hospital, and community clinics in SF Bay Area, CA			
HIV-STIGMA AND QUALITY OF LIFE				
Holzemer, WL, Human, S, Arudo, J, Rosa, ME, Hamilton, MJ, Corless, I, Robin-son, L, Nicholas, PK, Wantland, DJ, Moezzi, S, Willard, S, Kirksey, K, Portillo, C, Sefcik, E, Rivero-Mendez, M, & Maryland, M (2009)				
Explore the contribution of perceived HIV-stigma on HIV-QOL in people living with HIV/AIDS. **Theory**: None	**Design:** descriptive, cross-sectional **Sample:** 726 people living with HIV/AIDS Mean age: 42.7years (*SD* = 9.5) Age range: 20-72 years Males: 395 (55%) Females: 329 (45%) AA: 230 (30%) Latino: 214 (28%) White: 163 (21%) African: 119 (15%) **Setting:** HIV-focused community clinics in 14 geographical areas: Texas (25%) Philadelphia (14%)	**HIV-QOL:** HIV/AIDS Targeted QOL Scale **HIV symptoms:** Revised Sign & Symptom Checklist for Persons with HIV Disease **HIV-stigma:** HIV Stigma Scale **Depression:** CES-D Scale	**HIV-QOL:** *M* = 61.62 (*SD* = 18.05) **HIV Symptoms:** *M* = 39.38 (*SD* = 35.89) **HIV-stigma:** *M* = 86.49 (*SD* = 25.25) **Depression:** *M* = 23.94 (*SD* = 35.89) HIV-stigma has a significant negative impact on HIV-QOL, explaining 5.3% of the variance in HIV-QOL after controlling for HIV symptoms and severity of disease HIV symptoms and depressive symptoms contribute also to HIV-QOL Participants from the African continent reported significantly fewer HIV symptoms as compared to Latino participants	Convenience sample Self-report data Gender differences were not reported Not guided by a theoretical or conceptual framework

Purpose	Design	Variables	Results	Limitations
	San Francisco (10%) Boston (9%) Salt Lake City (9%) San Diego (3%) Chicago (2%) Puerto Rico (13%) Nairobi (9%) Pretoria (6%)			
Sowell, RL, Seals, BF, Moneyham, L, Demi, A, Cohen, L, & Brake, S (1997)				
Examine the social (social support, maternal resources, disclosure, and family functioning) and psychological (stigma, emotional distress, intrusion, avoidance, and fatalism) factors as predictors of QOL in low-income AAW living with HIV/AIDS **Theory**: Lazarus & Folkman's transactional stress and coping model	**Design:** descriptive, cross-sectional **Sample:** 264 AAW with HIV/AIDS Mean age: 34 years Age range: 15-64 years Single: 195 (74%) Urban: 182 (69%) Rural: 82 (31%) Unemployed: 210 (80%) Income <$10,000: 70% **Setting:** 8 public health HIV/AIDS clinics in rural and urban areas in a southeastern state	**QOL:** MOS-SF 36 **Anxiety:** General Anxiety Subscale of the Brief Symptom Inventory **HIV symptoms:** investigator developed checklist of 18 items validated by two medical experts at CDC **Social support:** investigator developed **Material resources:** investigator developed **Disclosure:** investigator developed **Family**	QOL, anxiety, and HIV symptoms were significantly correlated (r = .32 to .51, p <.000) Except for avoidance, the other intrusive thoughts factors (fatalism, stigma, emotional distress, and intrusion) were positively correlated with QOL (p = <.001) and HIV symptoms (p <.001) QOL was predicted by stigma, fatalism, employment status, and stage of illness (R^2 = .18, p < .05) Anxiety was predicted by emotional distress, intrusion, and marital status (R^2 = .50, p < .05) HIV symptoms were predicted by material resources, disclosure, intrusion, age, employment status, and race (R^2 = .29, p < .05)	Convenience sample of low-income AAW who were single mothers Self-report data Global/non-specific measure of QOL and stigma

Purpose	Design	Variables	Results	Limitations
		functioning: Family Adaptation &Cohesion Scale (FACESII) **Stigma:** investigator developed **Emotional distress:** investigator developed **Intrusive thoughts:** Impact of Events Scale **Fatalism:** items from an unidentified scale used in another study on HIV infection		
Vyavaharkar, M, Moneyham, L, Murdangh, C, & Tavakoli, A (2011)				
Examine physical, psychological and social factors associated with QOL in rural women with HIV **Theory**: Lazarus & Folkman's transactional stress and coping model	**Design:** cross-sectional (descriptive, correlational) **Sample:** 399 rural women with HIV infection Mean age: 41.5 years (*SD* = 9.6) Age range: 18-71 years AAW: 340 (85%)	**HIV-symptoms:** HIV-symptom Distress Scale **HIV-stigma:** unnamed HIV-stigma scale, measuring perceived and internalized stigma, that was used in a study of rural women with HIV infection **Depression:**	HIV-symptoms were strongly associated with perceived (*r* = .95) and internalized (*r* = .60) HIV-stigma Perceived and internalized HIV-stigma as well as depression were negatively associated with QOL Social support, situational control, and healthy lifestyle behaviors were positive associated with QOL; these factors explained 55% of the	Cross-sectional design restricts assertion of causality Convenience sample of AAW in rural southeastern US Self-report data Global/non-specific

Purpose	Design	Variables	Results	Limitations
	White: 59 (15%) Single: 308 (77%) Married: 91 (23%) High school: 268 (67%) College: 130 (33%) Unemployed: 318 (80%) Living alone: 80 (20%) Living with others: 318 (80%) Income <$10,000: 284 (71%) Public aid: 75 (69%) **Setting**: Rural southeastern US (S. Carolina, N. Carolina, & Alabama)	CES-D Scale **Social support:** MOS-SSS **Situational control:** investigator developed **Healthy lifestyle behaviors:** Health Promoting Lifestyle Profile **QOL:** Chronic Illness QOL Ladder Scale	variance in QOL Sociodemographics—age (p = .003), race (p< .0001), and time of HIV diagnosis (p = .03)—were positively correlated with QOL Women diagnosed post-HAART era reported lower QOL (M = 44.4) as compared to women diagnosed pre-HAART era (M = 47.7)	measure of QOL
Miles, MS, Holditch-Davis, D, Eron, J, Black, BP, Pedersen, C, & Harris, DA (2003)				
Determine the efficacy of an HIV self-care symptom management intervention in reducing HIV-stigma and improving HIV-QOL in low-income AA mothers with young children	**Design:** prospective, longitudinal randomized controlled trial (1997-2000) Usual care group: n = 30 Self-care group: n = 59 **Sample:** 109 AA mothers with HIV infection	**Depression:** CES-D **Mood states:** POMS **HIV-stigma:** Demi HIV Stigma Scale **HIV-worry:** HIV Worry Scale **QOL:** MOS-HIV Scale	As compared to the usual care group, the intervention group reported less feelings of HIV-stigma and higher physical functioning HIV-QOL after 6 months	Reasons for attrition are unclear Small convenience sample of AAW in rural area Self-report data

Purpose	Design	Variables	Results	Limitations
Theory: Maternal HIV self-care symptom management framework adapted from the UCSF symptom manage-ment model	Mean age: 37 years **Setting:** southeastern US; 2 tertiary care university-based infectious disease clinics; 9 participants recruited from HIV care agencies in rural small town			

CHAPTER IV

METHODOLOGY

This chapter outlines the methodology employed to address the purposes of this secondary research: describe HIV-stigma and HIV-QOL as perceived by AAW living with HIV infection; explore the association between AAW's perceptions of HIV-stigma and HIV-QOL; and determine the influence of social and health contextual factors on AAW's perceptions of HIV-stigma and HIV-QOL. First, a description of secondary research methodology and its advantages and disadvantages are presented, followed by a description of the primary study. Finally, the methodology for the secondary study is presented: design, sample, setting, ethical considerations and protection of human subjects, data collection variables and measures, and method of data analysis.

Secondary Research

Secondary research involves accessing and analyzing previous research data that are gathered from primary research (Hulley, Cumming, Browner, Grady, & Newman, 2007). Datasets used for secondary research come from numerous sources, such as previous research, medical records, administrative or clinical databases, and government supported agencies. The three most commonly used secondary research approaches are using existing data to answer a question that is different from the original intent of the primary study; using a subset of participants from the primary study to answer new or different research questions; and using a systematic review to combine and analyze the results of multiple studies of a selected question with different statistical tests in a meta-analysis (Hulley et al., 2007). The current study used a subset of participants to answer research questions different from the original intent of the primary study.

Secondary research has advantages and disadvantages (Hulley et al., 2007). Secondary research is typically less expensive and more efficient than conducting primary research. Other secondary research advantages include a sample drawn from larger populations; study conducted by top scholars in the field; and, cleaned data archives that are readily available, accessible, and free or low-cost. Lack of control over quality of the research process and data and difficulty finding relevant data about a specific minority subgroup are disadvantages of secondary research. Other secondary research disadvantages include data can be manipulated and transformed in a way that might compromise the validity of the primary study; data might not be specific to the researcher's need and have little relevance to the context of the current analysis; and data might be incomplete, outdated and expensive to access. In addition, the researcher lacks control over the contextual relevance of the primary study (participant characteristics, cultural and historical contexts, goals of the primary study, and administrative issues and constraints related to data collection) (Switzer, Wisniewski, Belle, Dew, & Schulz, 1999).

In the current study, secondary analysis of data from the primary study has more advantages than disadvantages. The researcher was a team member of the primary study, had access to the team, helped with data collection at the San Francisco Bay Area, CA sites, and is a co-author on publications related to the main findings of the primary study (Webel et al., 2012). In addition, the researcher was granted permission without restrictions to use specific variables in the dataset for the current analysis. The dataset includes a significant proportion of AAW with HIV infection and was current, specific, and relevant to the researcher's needs.

Primary Study

The research questions for this dissertation were derived from a secondary analysis of data obtained from a prospective study conducted by Webel and colleagues (2012) that examined the self-management skills of ethnically and racially diverse adult women living with HIV/AIDS. The non-probability, convenience sample included 260 women living in Cleveland, OH (*n* = 125) and the San Francisco Bay Area, CA (*n* = 135). In the sample, there were 169 (65%) African Americans, 46 (18%) Whites, non-Hispanic, 22 (9%) Latinas, and 21 (8%) women of other or mixed races and ethnicities. The mean age was 46 years (*SD* = 9.3). A majority of the sample had children (72%), were single (59%), were unemployed (79%), had permanent housing (83%), and had a mean annual income of $12,576 (*SD* = $15,001). Eighty percent of participants were on antiretroviral therapy, 50% had an undetectable HIV viral load, and 53% had been admitted to the emergency department within the past year. Chronic comorbidities included psychiatric, cardiovascular, gynecological, hepatic, and pulmonary disorders.

Study procedures were approved by the University of California, San Francisco Committee on Human Research and University Hospital, Case Western Medical Center (Cleveland, OH) for the protection of human subjects. To further protect participants' privacy, a certificate of confidentiality was obtained from the National Institutes of Health (Webel et al., 2012). Inclusion criteria included being an adult, 21 years or older, self-identification as a biological female, confirmed HIV infection, fluent in English, and able to self-administer the survey packet. Participants were recruited from HIV/AIDS women's health clinics where flyers were posted in the waiting rooms. Data were collected by doctoral nursing students, including this researcher, who participated regularly in clinical research at the study sites and developed trust and rapport with the study population.

After explaining the study, written informed consent was obtained from each participant, who then completed a pen and paper version of the self-report survey packet that included questions about health, social factors, demographics, access to care, social capital, HIV symptom management, healthcare provider, HIV self-management, HIV medications and adherence, HIV-QOL, and HIV-stigma. Most participants completed the survey in 30 to 60 minutes. Upon completion of the survey, research assistants reviewed it for completeness and asked each participant about missing items provided she was willing to respond to those items. Each participant was provided a $25 visa gift card in appreciation for her time. Data were collected from October 2010 to February 2011.

Dissertation Study

Design

The design of this non-experimental, secondary research was cross-sectional, descriptive, and correlational. Phenomena are described for a single time point, but not over time (Burns & Grove, 2007), and relationships between phenomena were explored for associations, but not for causality (Hulley et al., 2007).

Sample

Only AAW data were used for the current analysis. African American women represented 65% (n = 169) of the primary study’s sample. This sample size was sufficient to provide statistical power of at least 80% to detect a medium effect with the significance level set at $p \leq .05$, two-tailed in order to describe differences in proportions and mean scores, detect relationships, and explain variance among variables (Cohen, 1988).

Setting

The dataset includes AAW from the urban cities of Cleveland, OH (*n* = 91) and the San Francisco Bay Area, CA (*n* = 78). The proportion of the African American population differs for each city. According to the 2010 U.S. Census, the proportion of African Americans in Cleveland is 53%, whereas in San Francisco and Oakland, the proportion of African Americans is 6% and 28%, respectively. According to the CDC (2013), the HIV infection rate per 100,000 among African American adult and adolescent females in Cleveland, OH is 14.8 and 27.3 for the San Francisco Bay Area, CA (more specifically, 21.7 for Oakland and 48.7 for San Francisco).According to the 2010 American Community Survey conducted by the U.S. Census Bureau, the median household income for Cleveland, OH is $25,977, $71,745for San Francisco, CA, and $49,190 for Oakland, CA.

Ethical Considerations and Protection of Human Subjects

See Appendix A for the memorandum of understanding for data sharing. Research involving only unidentifiable or coded private information is not human subject research and does not require review by the University of California, San Francisco Committee on Human Research (see Appendix B for the self-certification form).

Data Analysis Variables and Measures

Permission without restrictions by the principle investigator (Webel et al., 2012) of the primary study was granted to analyze the following variables for this study: HIV-stigma, HIV-QOL, age, education, income, partner status, CD4 count, number of comorbidities, and emergency department admission within the past year. All of these variables were assessed in both locations in the primary study except for HIV-stigma, which was assessed only for participants in the San Francisco Bay Area, CA. Thus, HIV-stigma data were unavailable for Cleveland, OH participants in the current analysis. The provider trust and sexual function dimensions of HIV-QOL were not assessed in the primary study, and thus, were unavailable for the current analysis.

HIV-stigma. The HIV Stigma Scale was used in the primary study to measure how people living with HIV/AIDS perceive they are treated by others (Berger et al., 2001) (see Appendix C). Based on Goffman's social stigma theory, the HIV Stigma Scale was developed in the US. Berger and colleagues define stigma as "the person with HIV's awareness of HIV-related actual or potential social disqualification (less than full social acceptance, social rejection), denial or limitation of opportunity (for example, in housing, jobs, or dental services), and negative change in social identity (how others see him/her)" (p. 520). Berger and colleagues' research is considered seminal work for studying stigma contextualized for persons living with HIV/AIDS.

Items generated for the HIV-Stigma Scale was based on a comprehensive literature review of health-related stigma and psychosocial aspects of having HIV/AIDS (Berger et al., 2001). Derived from an initial pool of 184 items, 101 items resulted from two rounds of review by content experts to establish content validity. As a result of factor analysis, the pool of items was further reduced to the current 40-item version. Using principal axis factoring, a one-factor solution emerged, indicating all of the 40 items together represent a single construct. For the total scale, Cronbach's alpha coefficient was .96, indicating high internal consistency reliability; the 2- to 3-week test-retest reliability correlation was .92, indicating temporal stability. The reliability coefficients exceed Nunnally and Berstein’s (1994) minimum criterion of .70.

Exploratory factor analysis revealed four factors: personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes toward people living with HIV (Berger et al., 2001). All four factors included only items that had at least a .50 item-factor correlation (explaining 25% of the variance), indicating factor stability (Nunnally & Berstein, 1994). The variance explained by the four-factor solution was 46%.Sixteen items belong to more than one subscale, reflecting the intercorrelation of the factors on which the subscales are based.

The personalized stigma subscale consists of 18 items that address perceived consequences of other people knowing you have HIV, such as losing friends, feeling that people are avoiding you, and regretting disclosure to other people. Cronbach’s alpha coefficient was .93 and the test-retest reliability correlation was .87 for the personalized stigma subscale (Berger et al., 2001).

The disclosure concerns subscale consists of 10 items that relate to controlling information, keeping secret your HIV status, or worrying that others who know your HIV status will tell. Cronbach’s alpha coefficient was .90 and the test-retest reliability coefficient was .90 for the disclosure concerns subscale (Berger et al., 2001).

The negative self-image subscale consists of 13 items that deal with feeling shame and guilt, unclean, not as good as others, or a bad person because of HIV. Cronbach’s alpha coefficient was .91 and the test-retest reliability coefficient was .90 for the negative self-image subscale (Berger et al., 2001).

The concern with public attitudes toward people living with HIV subscale consists of 20 items that refer to what most people think about a person with HIV, what most people with HIV can expect when others learn they have HIV, or the consequences of most people knowing a person has HIV. Cronbach's alpha coefficient was .93 and the test-retest reliability coefficient was .89 the concern with public attitudes toward people living with HIV subscale (Berger et al., 2001).

In addition to factor analysis, construct validity via convergent and divergent validity was evaluated by examining the relationship of the HIV Stigma Scale with measures of related constructs, such as self-esteem, depression, social support, social integration, and social conflict. As predicted by Berger and colleagues (2001), the HIV Stigma Scale had a moderate to strong negative correlation with the 10-item Rosenberg's self-esteem scale, a strong positive correlation with the 20-item Center for Epidemiologic Studies Depression scale, a moderate negative correlation with social support and social integration, and a moderate positive correlation with social conflict. The social support, social integration, and social conflict items were from the Multicenter AIDS Cohort Coping and Change Study.

Psychometric properties of the HIV Stigma Scale were based on a relatively large and diverse convenience sample of 318 adults, 18 years or older, with HIV infection (Berger et al., 2001). According to Comrey and Lee (1992), a sample size of 300 or more is adequate to produce stable correlations for establishing instrument reliability and validity. Participants were recruited from 60 HIV-related organizations in urban and rural settings across eight states in the US. Participants were diverse, ranging from indigent, uninsured individuals to those who were employed and had health insurance.

The sample consisted of 19% women, 21% African Americans, and 8% Latinos. African American women comprised 6% of the sample. The mean age of the sample was 37 years with a range between 19 and 82 years. Mean time since testing HIV-positive was 4.2 years with 54% of the sample reporting they had been diagnosed with AIDS. Eleven percent of the sample did not complete high school, although 29% of participants reported having completed college. The annual household income was less than $10,000for 45% of the sample, but exceeded $30,000 for 22% of the sample. The most commonly reported risk for both women (16%) and men (72%) was having sex with men. Seven percent of women and 16% of men reported using injectable drugs.

Before Berger and colleagues (2001) developed the HIV Stigma Scale, a specific HIV-stigma measure was unavailable for comparison. No HIV-stigma instrument existed as a gold standard. A strength of the HIV Stigma Scale is its psychometric properties were based on a large diverse sample, although women and in particular African American and Latina women were underrepresented. It is unclear whether the HIV-positive sample was symptomatic or asymptomatic. Even though the normative sample was a convenience sample and the scale was tested only in the US, the instrument has external validity. Since its inception, the HIV Stigma Scale, developed conceptually, has been utilized extensively by researchers and continues to demonstrate adequate validity and reliability properties across settings, populations, and countries (Galvan, Davis, Banks, & Bing, 2008; Holzemer et al., 2007; Jimenez et al., 2010).

Reading level of the HIV Stigma Scale is at the 6th grade. It is relatively long (40 items), but easy and quick to administer (10 to 15 minutes). Items are rated on a 4-point Likert-type scale: 1 = strongly disagree, 2 = disagree, 3 = agree, or 4 = strongly agree.

Scores are calculated by summing items for the total scale (40 to 160) and for each of the four subscales: personalized stigma (18 to 72), disclosure (10 to 40), negative self-image (13 to 52), and public attitudes (20 to 80). Higher scores reflect greater perceived stigma.

HIV-QOL. The HIV/AIDS Targeted QOL Instrument (HAT-QoL) was used in the primary study to measure HIV-QOL (see Appendix D). Two linked, cross-sectional studies contributed to the psychometric development of the HAT-QoL instrument. In the first study, content for item generation and content validity resulted from six group discussions with 42 HIV-positive persons (Holmes & Shea, 1997). Each person participated in only one group discussion. Participants' QOL concerns generated 83 items of which 76 items were retained.

The foci of the second study were item reduction, dimension identification, and assessment of the psychometric properties of the 76 items generated and retained from the first study in a convenience sample of 201 HIV-positive symptomatic and asymptomatic participants (Holmes & Shea, 1998). Only 18 years and older persons living with HIV infection who could read and speak English were included in the study. Participants were recruited from an urban, hospital-affiliated HIV specialty outpatient clinic, outpatient clinics of a medium-sized rural hospital, and an AIDS clinical trials unit. A majority of participants had never been hospitalized for HIV-related problems. The sample's mean age was 38 years. A majority of participants were men, Whites, non-Hispanic, and gays/bisexuals. Other than White, non-Hispanic vs. non-White, an analysis of the sample by race/ethnicity was not reported in either of the two studies.

Items were removed using methods to maximize internal consistency and to minimize item redundancy, resulting in a reduction of items from 76 to 42 (Holmes

&Shea, 1998). Principal components analysis was used to group items into nine dimensions: overall function (6 items), disclosure (5 items), health (4 items), financial (3 items), life satisfaction (4 items), sexual function (2 items), HIV mastery (2 items), medication (3 items), and provider trust (2 items). No substantial ceiling or floor effects existed, except for the provider trust dimension. Cronbach's alpha internal consistency reliability coefficients were $r \geq .70$, the minimum accepted value according to Nunnally and Bernstein (1994), for all dimensions except HIV mastery ($r = .57$), medication ($r = .51$), and sexual function ($r = .56$). Multi-trait, multi-item assessment of the degree of item convergence and discrimination indicated scaling success rates that were high (≥ 91%) for eight of nine dimensions; the HIV mastery dimension revealed a lower but modest success rate of 79%. Construct validity assessments, using self-reported HIV disease severity and sociodemographic variables, indicated expected relationships for all nine dimensions.

The overall function dimension includes items about the ability to perform work, household, social, and routine daily physical activities (Holmes & Shea, 1997, 1998). The life satisfaction dimension includes items about satisfaction with social life, health, and living in general. Health dimension items address worries about CD4 count, viral load, and dying. Financial dimension items address worries about income and ability to pay bills. The medication dimension includes items about whether taking HIV medications is a burden. HIV mastery dimension items address anger and regrets about HIV risk behavior. Disclosure dimension items address worries about disclosing HIV status to family, friends, and coworkers, and whether disclosure would result in income loss if HIV status is known.

The readability of the HAT-QoL, which can be self-administered, is at the 7th grade level (Holmes & Shea, 1997, 1998). The number of positively- and negatively-directed items is distributed evenly, and the items are ordered randomly to minimize order effects. Responses are rated on a 5-point Likert-type scale: (1) all of the time, (2) a lot of the time, (3) some of the time, (4) a little of the time, or (5) none of the time. Dimension scores are transformed to a linear 0 to 100 scale. A higher score indicates better functioning and well-being.

The HAT-QoL has some psychometric issues such as suboptimal internal consistency reliability for some of its dimensions (Holmes & Shea, 1997, 1998). Another HIV-specific HR-QOL tool should have been combined with the HAT-QoL tool in order to yield a comprehensive evaluation of QOL in people living with HIV/AIDS. Tool development was not guided by a theoretical framework, nor was HIV-QOL defined conceptually. Despite these limitations, the HAT-QoL was based on QOL concerns of HIV-positive symptomatic and asymptomatic persons living in rural and urban settings.

Social and health contextual factors. A standard demographic survey was administered in the primary study to measure social and health contextual factors (see Appendix E). For the current analysis, social contextual factors included age (years), education (less than high school, high school/GED, or college), personal annual income (dollars), and partner status (partnered or not partnered). Health contextual factors includedCD4 count, number of comorbidities, and emergency department admission within the past year (yes or no).CD4 cells or T-cells are the cells that send signals to activate the body’s immune response when they detect microorganisms such as viruses or bacteria (AIDS.gov, 2010). The CD4 count is often used to determine the stages of HIV infection. A normal CD4 count can range from 500 cells/mm^3 to 1,000 cells/mm^3. The new guidelines from the U.S. Department of Health and Human Services suggest treating all individuals whether the CD4 count is 350 cells/mm^3 or above 500 cells/mm^3 (2013). According to AIDS.gov, a CD4 count of fewer than 200 cells/mm^3 is one of the qualifications for a diagnosis of AIDS.

Method of Data Analysis

Data were analyzed using SPSS Statistics for Windows software version 21 (IBM Corporation, 2012). A codebook was created to reflect coding decisions. Missing data were managed via deletion of missing cases, deletion of the variable with extensive missing cases, or substituted with the mean response of the entire sample (Burns & Grove, 2005). Reported percentages were adjusted for missing cases. Missing responses were minimal, given that missing responses were reviewed with participants upon completion of the survey in the primary study. If the response to one item in a subscale was not completed, the mean imputed value of the other completed items in the subscale was substituted for the missing item as long as at least half of the other items were completed (Munro, 2005).

Descriptive statistical analyses were computed to describe demographics, social and health contextual factors, HIV-stigma, and HIV-QOL as well as to assess study variables for violations of statistical assumptions such as skewness (lack of symmetry), kurtosis (quality of distribution), and significant floor (percentage of respondents with lowest possible score) and ceiling (percentage of respondents with highest possible score)effects. Ceiling and floor effects can limit responsiveness by not capturing increments and decrements that occur above or below a scale’s highest and lowest scores, respectively (Munro, 2005). Descriptive statistics include the median, mean, standard deviation, and range for continuous variables, and frequencies and percentages for categorical variables.

Depending on the level of data, chi-square or independent student's *t*-test analysis was computed to compare the proportion or mean score between study variables, respectively (Munro, 2005). When appropriate, the Fisher's exact chi-square statistic is reported. Pearson correlations were computed to determine associations between study variables. Cronbach's alpha for internal consistency reliability was calculated for the HIV Stigma Scale and the HAT-QoL instrument and their subscales. Nunnally and Berstein (1994) recommend an adequacy minimum criterion of .70 for reliability coefficients.

Based on the HIV-stigma and HIV-QOL through the lens of intersectionality and Black feminism integrative theoretical model presented in Chapter II, multiple regression analyses were computed to identify which social and health contextual factors best explain the variance in HIV-stigma and HIV-QOL as perceived by AAW living with HIV infection. Hierarchical regression procedures were applied separately for HIV-stigma and HIV-QOL as the dependent variable. A group of independent variables (social contextual factors: age, income, partner status, and education) as a set were entered into the regression analysis, followed by another set of grouped independent variables (health contextual factors: CD4 count, number of comorbidities, and emergency department admission), while controlling for the variance explained by the other independent variables previously entered. This technique allows for an estimate of the unique contribution of each block of independent variables to variance in the dependent variable (Munro, 2005).

Multiple linear regression analysis explores how well each independent variable, individually and in combination with other independent variables, explains the variance in the dependent variable (Burns & Grove, 2005). Dummy coding was used for independent variables that were not continuous: partner status (0 = not partnered, 1 = partnered); education (0 = high school or less education, 1 = college); and, emergency department admission (0 = no, 1 = yes).

Regression assumptions were evaluated prior to analysis (Munro, 2005). Assessment of the correlation matrix of model variables was examined for multicollinearity (highly correlated independent variables).Most researchers consider multicollinearity to exist if the correlation is greater than .65 while other researchers use a correlation of .80 or greater as an indication of multicollinearity (Burns & Grove, 2005).The assumption of normality was assessed by histograms, normal probability plots, and residual plots to check homoscedasticity (equal dispersion or homogeneity of variance of variables about the line of best fit) (Munro, 2005). If variables were not normally distributed or the relationship between them was not linear, transformation was conducted. The amount of variance (R^2) that was explained by the independent variables as well as which specific independent variable made a significantly unique contribution to the prediction of HIV-stigma and HIV-QOL, respectively, are reported. In addition, the adjusted R^2, a conservative estimate of R^2 used to correct for effect of sample size and number of independent variables, was examined for each multiple regression analysis.

For the overall study, a p-value $\leq .05$, two-tailed was considered statistically significant. Power was set at .80, unless stated otherwise (Cohen, 1988). The *p*-value was adjusted as necessary for multiple pairwise analyses to control for the experiment-wise error (Type I) using a Bonferroni correction (Munro, 2005).

CHAPTER V

RESULTS

Findings of this secondary data analysis of HIV-stigma and HIV-QOL as perceived by AAW living with HIV infection in the San Francisco Bay Area, CA and Cleveland, OH are presented in this chapter. Of note with this analysis, HIV-stigma was assessed only with participants in the San Francisco Bay Area, CA in the primary study, and thus, HIV-stigma data were unavailable for analysis with participants in Cleveland, OH. Tables of results are located at the end of the chapter.

Following a profile of the sample, sections in this chapter are arranged by the study's six research questions: (a) What is the occurrence of HIV-stigma? (b) What is the occurrence of HIV-QOL? (c) Do HIV-stigma and HIV-QOL differ by social contextual factors (age, education, income, and partner status)? (d) Do HIV-stigma and HIV-QOL differ by health contextual factors (CD4 count, number of comorbidities, and emergency department admission within the past year)? (e) What is the relationship between HIV-stigma and HIV-QOL? and (f) which social (age, education, income, and partner status) and health (CD4 count, number of comorbidities, and emergency department admission within the past year) contextual factors best explain the variance in HIV-stigma and HIV-QOL?

Profile of African American Women Living with HIV Infection

See Table 2 for the sociodemographic and health profile of AAW living with HIV infection by location: Cleveland, OH (*n* = 91, 54%) and San Francisco Bay Area, CA (*n* = 78, 46%). The mean age of the sample was 46.4 years (*SD* = 8.7) with a range from 22 to 69 years. A majority of the sample were 40 years and older (83%), not partnered

(86%), unemployed (78%), and had permanent housing (81%). The mean number of children living in the household was 1.1 (*SD* = 1.2) with a range of 0 to 4 children. Ranging from no income to $100,080, the mean annual income was $11,645 (*SD* = $14,282, *Md* = $9,654).Thirty-eight percent of the sample completed high school/GED, 25% completed college, and 37% did not complete high school.

A majority of the sample had public health insurance (95%) and had not been diagnosed with AIDS (61%). The mean years between diagnosis and treatment were 1.8 years (*SD* = 3.8) with a range of 0 to 20 years. Seventy-seven percent of the sample were on highly active antiretroviral therapy. The CD4 count ranged from 0 to 32,475 cells/mm^{3}with a mean of 830 cells/mm^3 (*SD* = 2,865, *Md* = 532). The number of comorbidities ranged from 0 to 5 with a mean of 1.4 (*SD* = 1.3, *Md* = 1). The most prevalent comorbidities were related to cardiovascular, mental health, and hepatic conditions. Over half of the sample reported no emergency department admission within the past year (57%).

The profile of AAW was relatively homogeneous between the two study sites, but they differed statistically by location for age *t*(160) = -3.104, *p* = .002, *d*= -4.18, 95% CI [-6.83, -1.52], number of children living at home *t*(103) = 3.90, *p* = .0001, *d*= 0.83, 95% CI [0.41, 1.25], number of comorbidities *t*(162 = 2.70, *p* = .008, *d*= 0.52, 95% CI [0.14, 0.90], annual income χ^2(3, N=150) = 13.28, *p* = .004, and permanent housing χ^2(1, N=167) = 12.73, *p* = .001.The sample in the San Francisco Bay Area, CA as compared to the sample in Cleveland, OH was older by 4 years, reported less mean number of children living with them (0.6 vs. 1.5), reported less mean number of comorbidities (1.1

vs. 1.7), reported higher mean annual incomes ($13,581 vs. $9,655), and reported with less frequency that they had permanent housing (69% vs. 91%).

Description of HIV Quality of Life

HIV-QOL is reported as a total score for the total sample. In addition, scores are reported on seven HIV-QOL dimensions: overall function, life satisfaction, health, financial, medication, HIV mastery, and disclosure. The overall function dimension reflects the ability to perform work, household, social, and routine daily physical activities. The life satisfaction dimension reflects satisfaction with social life, health, and living in general. The health dimension reflects worries about CD4 count and dying. The financial dimension reflects worries about income and ability to pay bills. The medication dimension reflects whether or not taking HIV medications is a burden. The HIV mastery dimension reflects anger and regrets about HIV risk behavior. The disclosure dimension reflects worries about disclosing HIV status to family, friends, and coworkers, and whether disclosure would result in loss of income if HIV status is known.

Cronbach’s alpha internal consistency reliability coefficients were adequate and ranged from .81 for the overall function dimension to .93for the life satisfaction dimension (see Table 3). Cronbach’s alpha internal consistency reliability coefficient was .94 for total HIV-QOL. Scores can range from 0 to 100, where 0 is the worst score possible and 100 is the best score possible. Mean scores ranged from a low of 43.44 (*SD* = 35.98) for the financial dimension to a high of 73.60 (*SD* = 30.23) for the medication dimension. The medication dimension included only AAW who took HIV medications in the past 4 weeks (*n* = 139). With the exception of the financial dimension (*M* = 43.44), HIV-QOL mean scores were higher than 50 (half the range of 0 to 100). If a mean score of 50 is used as average, then the HIV-QOL scores in this sample of AAW living with HIV infection suggest a moderate level of HIV-QOL.

There was no statistical difference in mean scores on HIV-QOL between the two study sites (see Table 4). Taking into consideration social contextual factors, HIV-QOL did not differ statistically by age (see Table 5) or income (see Table 6). The mean score for life satisfaction was statistically significant for partner status (see Table 7). African American women who were partnered reported more life satisfaction (*M* = 90.63, *SD* = 15.09) as compared to AAW who were not partnered (*M* = 71.26, *SD* = 28.73). Statistically significant difference exists for HIV-QOL and several of its dimensions by education (see Table 8). As compared to AAW who had a high school education or less, college-educated AAW had higher mean scores for overall function (*M* = 53.13, *SD* = 25.56 vs. *M* = 66.28, *SD* = 22.87), health (*M* = 54.95 *SD* = 33.88 vs. *M* = 79.65, *SD* = 25.99), medication adherence (*M* = 67.70, *SD* = 31.43 vs. *M* = 88.72, *SD* = 20.45), HIV mastery (*M* = 51.92, *SD* = 37.14 vs. *M* = 73.84, *SD* = 31.79), and total HIV-QOL (*M* = 55.73, *SD* = 22.83 vs. *M* = 72.56, *SD* = 21.12).

Taking into consideration health contextual factors, HIV-QOL did not differ statistically by CD4 count (see Table 9), emergency department admission within the past year (see Table 11), or number of comorbidities except for on the life satisfaction dimension (see Table 10).African American women with less comorbidities reported a higher mean score on life satisfaction (*M* = 84.51, *SD* = 24.97) as compared to AAW who reported more comorbidities (*M* = 70.08, *SD* = 28.28).

Description of HIV-Stigma

This section describes HIV-stigma for AAW living with HIV infection in the San Francisco Bay Area, CA only. Almost all of them had disclosed their HIV status to someone (87%) (see Table 12). A majority of them had disclosed their HIV status to relatives (63%), husband (55%), children (54%), and friends (54%), but not at work (19%), nor in the community (24%), at church (26%), or to neighbors (28%). Thirty-four percent of them reported they had been treated differently since disclosing their HIV status.

HIV-stigma is reported as a total score. In addition, scores are reported on four subscales: personalized stigma, disclosure concerns, negative self-image, and public attitudes toward HIV. The personalized stigma subscale reflects perceived consequences, such as losing friends, and of other people knowing HIV status. The disclosure concerns subscale reflects controlling information about one’s HIV status. The negative self-image subscale reflects feeling shame and guilt because of HIV status. The concern with public attitudes toward people living with HIV subscale reflects what most people with HIV can expect when others learn they have HIV.

Cronbach’s alpha internal consistency reliability coefficients were adequate and ranged from .87 for the disclosure concerns subscale to .95 for the personalized stigma subscale (see Table 13). Cronbach’s alpha internal consistency reliability coefficient was .96 for total HIV-stigma. Higher mean scores reflect greater perceived HIV-stigma. HIV-stigma mean scores were less than half the range of mean scores, indicating relatively moderate levels of perceived HIV-stigma. HIV-stigma did not differ statistically by social (see Tables 14 to 17) or health (see Tables 18 to 20) contextual factors.

Associations among Study Variables

HIV Stigma and HIV Quality of Life

Correlational analysis between HIV-stigma and HIV-QOL included only AAW with HIV infection living in the San Francisco Bay Area, CA. Higher mean scores reflect better HIV-QOL and greater perceived HIV-stigma. A negative or inverse correlation indicates a high HIV-QOL score was associated with a low perceived HIV-stigma score. A positive correlation indicates a high HIV-QOL score was associated with a high perceived HIV-stigma score. The association between total HIV-stigma and total HIV-QOL was not statistically significant (see Table 21).

When examining associations among HIV-stigma subscales and HIV-QOL dimensions, there was statistical significance (see Table 21). The disclosure HIV-QOL dimension was significantly correlated with HIV-stigma and all of its subscales, indicating AAW who did not worry about disclosing their HIV status was associated with lower perceived total HIV-stigma ($r = -.36$), less personalized stigma ($r = -.23$), less disclosure concerns ($r = -.33$), less negative self-image ($r = -.37$), and less worries about public attitudes toward HIV ($r = -.28$). There were also statistically significant associations between HIV mastery and personalized stigma ($r = -.23$) and negative self-image ($r = -.24$), indicating taking HIV medications was not a burden was associated with lower perceived personalized stigma and less negative self-image for AAW who reported taking medication. In addition, high life satisfaction was significantly associated with less perceived negative self-image ($r = -.23$) for AAW.

HIV Stigma and Contextual Factors

HIV-stigma was associated with several contextual factors: age (social factor) and number of comorbidities and emergency department admission (health factors) (see Table 22). Age was significantly associated with personalized stigma (*r* = -.24) and disclosure concerns (*r* = -.28), indicating that being younger was associated with higher personalized stigma and more worries about disclosure concerns for AAW. Number of comorbidities was significantly associated with personalized stigma (*r* = .34), public attitudes about HIV (*r* = .29), and total HIV-stigma (*r* = .27), indicating less comorbidities were associated with lower perceived personalized stigma, less worries regarding public attitudes about HIV, and lower perceived total HIV-stigma. Emergency department admission was significantly associated with personalized stigma (*r* = .24) and public attitudes about HIV (*r* = .24), indicating that having no emergency department admissions within the past year was associated with having lower perceived personalized stigma and less worries regarding public attitudes about HIV.

HIV Quality of Life and Contextual Factors

In the total sample of AAW, the association between perceived HIV-QOL and health contextual factors was not statistically significant, but it was statistically significant for its association with social contextual factors—partner status and education (see Table 23).Partner status was statistically significant for its association with life satisfaction (*r* = .24), indicating partnered was associated with a higher level of life satisfaction for AAW. Education was statistically significant for its association with total HIV-QOL (*r* = .31) as well as all of its dimensions: overall function (*r* = .23), life satisfaction (*r* = .18), health (*r* = .32), financial (*r* = .16), medication (*r* = .31), HIV mastery (r = .26), and disclosure (r = .17). This finding indicates that having a college-educated was associated with higher perceived HIV-QOL for AAW.

Meaning and Significance of Associations between Study Variables

None of the statistically significant coefficients in the above mentioned correlational analyses was above the absolute value of r = .37, indicating the magnitude of the relationship between variables was weak to low. According to Munro (2005), a correlation of .00 to .25 is weak or has little, if any, relationship, a correlation of .26 to .49 is low, a correlation of .40 to .69 is moderate, a correlation of .70 to .89 is high, and a correlation of .90 to 1.00 is very high. Munro states, “When studying the relationships among various aspects of human behavior, we may be happy with a correlation of .50” (p. 249).Burns and Grove (2005) consider a correlation of .10 to .30 as a weak linear relationship, a correlation of .30 to .50 as a moderate linear relationship, and a correlation greater than .50 as a strong linear relationship.

According to Burns and Grove (2005), there is a tendency in nursing research to erroneously disregard weak correlations that may have meaning within the context of other variables (Type II error). This could happen because the measurement tools were not adequately sensitive to detect fine discriminations, homogeneous scores, small sample size, and the limitations of bivariate analysis which does not provide clarity about the synergy among variables (e.g., a number of variables can be associated through weak correlations, but together they provide increased clarity about a particular phenomenon).

The coefficient of determination (r^2), a measure of the amount of variance that two variables share, often is used as a measure of the meaningfulness of r (Munro, 2005). In the above correlational analyses, the statistically significant lowest absolute correlation (*r* = .16) and the statistically significant highest absolute correlation (*r* = .37) indicate the variance shared between any two of the study variables was between 3% and 14%.

Social and Health Contextual Factors as Predictors of HIV Stigma and HIV Quality of Life

Hierarchical linear regression analyses were computed to examine the unique and combined contributions of two blocks of independent variables—social contextual factors (age, income, partner status, and education) and health contextual factors (CD4 count, number of comorbidities, and emergency department admission within the past year)—to access variability in each of the dependent variables (HIV-stigma and HIV-QOL). Social and health contextual factors were entered in two blocks—social factors first, followed by health factors.

Violations to statistical assumptions of using multiple regression analysis were examined for normality, linearity, independence, homoscedasticity, and collinearity as described by Munro (2005) and Burns and Grove (2005). The correlation matrices of model variables showed no evidence of highly correlated independent variables. A measure of collinearity, tolerance values ($1 - R^2$) were within acceptable limits (.83 to .96), indicating the variance shared with other predictors ranged from 4% to 17%. Partial plots of the dependent and independent variables revealed no evidence of curvilinear relationships. Histograms and normal probability (P-P) plots of standardized residuals (difference between actual and predicted values for the dependent variable) indicated each of the dependent variables was linear and normally distributed. Scatter plots of the relationship between standardized residuals and standardized predicted values and between standardized residuals and each of the independent variables indicated linearity and equality of variance (homoscedasticity).

Predictors of HIV Stigma

Table 24 presents the results of the regression analyses for social and health contextual factors predicting total HIV-stigma and its four dimensions (personalized stigma, disclosure concerns, negative self-image, and public attitudes toward HIV) in AAW with HIV infection living in the San Francisco Bay Area, CA only.

Total HIV-Stigma. Social factors accounted for 10% of the variance in total HIV-stigma. The difference between 0% and 10% was not statistically significant. Adding health factors to the model increased R^2 from 10% to 22%, an increase of 12%. This addition, however, was not statistically significant. In this model, social and health factors accounted for 22% of the variance, and the model was not statistically significant. None of the individual predictors contributed significantly to the variance in total HIV-stigma.

Personalized Stigma. Social factors accounted for 11% of the variance in personalized stigma. The difference between 0% and 11% was not statistically significant. Adding health factors to the model increased R^2 from 11% to 26%, an increase of 15%. This addition was statistically significant ($F = 3.254$, $p = .03$). In this model, social and health factors accounted for 26% of the variance, which was statistically significant ($F = 2.373$, $p = .04$). Number of comorbidities was the only individual predictor that contributed significantly to the variance in personalized stigma ($\beta = .33$, $t = 2.54$, $p = .01$).

Disclosure Concerns. Social factors accounted for 10% of the variance in disclosure concerns. The difference between 0% and 10% was not statistically significant. Adding health factors to the model increased R^2 from 10% to 20%, an increase of 10%. This addition, however, was also not statistically significant. In this model, social and health factors accounted for 20% of the variance, but the model was not statistically significant. None of the individual predictors contributed significantly to the variance in disclosure concerns.

Negative Self-image. Social factors accounted for 7% of the variance in negative self-image. The difference between 0% and 7% was not statistically significant. Adding health factors to the model increased R^2 from 7% to 12%, an increase of 6%. This addition, however, was not statistically significant. In this model, social and health factors accounted for 12% of the variance, and the model was not statistically significant. None of the individual predictors contributed significantly to the variance in negative self-image.

Public Attitudes about HIV. Social factors accounted for 9% of the variance in public attitudes about HIV. The difference between 0% and 9% was not statistically significant. Adding health factors to the model increased R^2 from 9% to 25%, an increase of 16%. This addition was statistically significant ($F = 3.423$, $p = .02$). In this model, social and health factors accounted for 25% of the variance, which was statistically significant ($F = 2.286$, $p = .04$). Number of comorbidities was the only individual predictor that contributed significantly to the variance in public attitudes about HIV ($\beta = .27$, $t = 2.11$, $p =.04$).

Predictors of HIV Quality of Life

Table 25 presents the results of the regression analyses for social and health factors predicting total HIV-QOL and its seven dimensions (overall function, life satisfaction, health, financial, medication, HIV mastery, and disclosure) for the total sample of AAW.

Total HIV-QOL. Social factors accounted for 13%of the variance in perceived total HIV-QOL. The difference between 0% and 13% was statistically significant (*F* = 3.813, *p* = .006). Adding health factors to the model increased R^2 from 13% to 15%, a statistically non-significant increase of 2%. In this model, social and health factors accounted for 15% of the variance, which was statistically significant (*F* = 2.587, *p* = .02).Only the predictor, education, contributed significantly to the variance in total HIV-QOL (β = .31, *t* = 3.32, *p* =.001).

Overall Function. Social factors accounted for 6% of the variance in overall function. The difference between 0% and 6% was not statistically significant. Adding health factors to the model increased R^2 from 6% to 9%, a statistically non-significant increase of 3%. In this model, social and health factors accounted for 9% of the variance. The overall model was not statistically significant. With the exception of education (β = .23, *t* = 2.33, *p* =.02), none of the individual predictors contributed significantly to the variance in overall function.

Life Satisfaction. Social factors accounted for 10% of the variance in life satisfaction. The difference between 0% and 10% was statistically significant (*F* = 3.009, *p* = .02). Adding health factors to the model increased R^2 from 10% to 12%, a statistically non-significant increase of 2%. In this model, social and health factors accounted for

12% of the variance, which was not statistically significant. Only the predictor, partner status, contributed significantly to the variance in life satisfaction (β = .21, *t* = 2.21, *p* =.03).

Health. Social factors accounted for 12% of the variance in health. The difference between 0% and 12% was statistically significant (*F* = 3.753, *p* = .007). Adding health factors to the model increased R^2 from 12% to 15%, a statistically non-significant increase of 3%. In this model, social and health factors accounted for 15% of the total variance, which was statistically significant (*F* = 2.536, *p* = .02). Only the predictor, education, contributed significantly to the variance in health (β = .33, *t* = 3.56, *p* =.001).

Financial. Social factors accounted for 5% of the variance in the financial model. The difference between 0% and 5% was not statistically significant. Adding health factors to the model increased R^2 from 5% to 8%. This 3% increase was not statistically significant. In this model, social and health factors accounted for 8% of the variance, which was not statistically significant. None of the individual predictors contributed significantly to the variance in the financial dimension of HIV-QOL.

Medication. Social factors accounted for 13% of the variance in the medication model. The difference between 0% and 13% was statistically significant (*F* = 3.836, *p* = .006). Adding health factors to the model increased R^2 from 13% to 14%, a statistically non-significant increase of 1%. In this model, social and health factors accounted for 14% of the variance, which was statistically significant (*F* = 2.382, *p* = .03). Only the predictor, education, contributed significantly to the variance in the medication model (β = .29, *t* = 3.06, *p* =.003).

HIV Mastery. Social factors accounted for 8% of the variance in HIV mastery. The difference between 0% and 8% was not statistically significant. Adding health factors to the model increased R^2 from 8% to 9%, a statistically non-significant increase of 1%. In this model, social and health factors accounted for 9% of the variance. The overall model was not statistically significant. With the exception of education ($\beta = .26$, $t = 2.72$, $p = .008$), none of the individual predictors contributed significantly to the variance in HIV mastery.

Disclosure. Social factors accounted for 6% of the variance in disclosure. The difference between 0% and 6% was not statistically significant. Adding health factors to the model increased R^2 from 6% to 8%. This 2% increase was not statistically significant. In this model, social and health factors accounted for 8% of the variance, which was not statistically significant. None of the individual predictors contributed significantly to the variance in disclosure.

Table 2

Sociodemographic and Health Profile of African American Women Living with HIV Infection (n = 169)

	Cleveland (*n* = 91)		San Francisco (*n* = 78)		Total	
Characteristic	*n*	%	*n*	%	*n*	%
*Age in Years [*M* (*SD*)]	44.6 (8.9)		48.7 (7.9)		46.4 (8.7)	
21-29	7	7.8	2	2.8	9	5.6
30-39	13	14.4	6	8.3	19	11.7
40-49	48	53.3	25	34.7	73	45.1
50-59	17	18.9	34	47.2	51	31.5
60+	5	5.6	5	6.9	10	6.2
Education						
Less than high school	38	41.8	24	30.8	62	36.7
High school/GED	31	34.1	33	42.3	64	37.9
College	22	24.2	21	26.9	43	25.4
Partner Status						
Partnered	15	16.9	9	11.5	24	14.4
Not partnered	74	83.1	69	88.5	143	85.6
*Children Live with You [*M* (*SD*)]	1.5 (1.2)		0.6 (0.9)		1.1 (1.2)	
Yes	68	91.9	55	88.7	123	90.4
No	6	8.1	7	11.3	13	9.6
*Annual Income in Dollars [*M* (*SD*)]	9,655 (8,785)		13,581 (17,957)		11,645 (14,283)	
No income	10	13.5	7	9.2	17	11.3
$1-$10,000	43	58.1	26	34.2	69	46.0
$10,001-$20,000	14	18.9	34	44.7	48	32.0
$20,001-$30,000	3	4.1	4	5.3	7	4.7
$30,001-$40,000	3	4.1	0	0.0	3	2.0
$40,001-$50,000	1	1.4	2	2.6	3	2.0
$50,001-$74,999	0	0.0	0	0.0	0	0.0
$75,000+	0	0.0	3	3.9	3	2.0

	Cleveland (*n* = 91)		San Francisco (*n* = 78)		Total	
Characteristic	*n*	%	*n*	%	*n*	%
Employed						
Yes	19	21.3	18	23.1	37	22.2
No	70	78.7	60	76.9	130	77.8
*Permanent Housing						
Yes	81	91.0	54	69.2	135	80.8
No	8	9.0	24	30.8	32	19.2
Health Insurance						
Public	79	95.2	69	94.5	148	94.9
Private	4	4.8	4	5.5	8	5.1
Diagnosed with AIDS						
Yes	37	42.0	28	35.9	65	39.2
No	51	58.0	50	64.1	101	60.8
Years between Diagnosis & Treatment [*M* (*SD*)]	1.9 (4.5)		1.8 (3.0)		1.8 (3.8)	
CD4 Count [*M* (*SD*)]	1,009 (3,954)		636 (478)		830 (2,865)	
Less than 200 cells/mm^3	17	25.8	10	16.4	27	21.3
200-499 cells/mm^3	16	24.2	15	24.6	31	24.4
500+ cells/mm^3	33	50.0	36	59.0	69	54.3
Highly Active Antiretroviral Therapy						
Yes	71	82.6	53	70.7	124	77.0
No	15	17.4	22	29.3	37	23.0
*Number of Comorbidities [*M* (*SD*)]	1.7 (1.4)		1.1 (1.1)		1.4 (1.3)	
None	20	22.5	28	35.9	48	28.7
1-2	43	48.3	41	52.6	84	50.3
3+	26	28.6	9	11.5	35	20.7
Emergency Department in Past Year						
Yes	40	46.0	31	40.3	71	43.3
No	47	54.0	46	59.7	93	56.7

Note. Percentages were adjusted for missing cases.

$^*p \leq .01$.

Table 3

Summary Statistics and Reliability Coefficients for the HAT-QoL Instrument (n = 169)

QOL Dimension	*n*	*Range*	*M*	*SD*	*r*
Overall Function	168	4-100	56.50	25.49	.81
Life Satisfaction	169	0-100	74.20	27.91	.93
Health	168	0-100	61.27	33.75	.91
Financial	169	0-100	43.44	35.98	.90
[a]Medication	139	0-100	73.60	30.23	.92
HIV Mastery	167	0-100	57.56	37.02	.91
Disclosure	166	0-100	58.07	33.28	.87
Total HIV-QOL	169	13.99-100	60.02	23.52	.94

Note. HAT-QoL: HIV/AIDS Targeted Quality of Life Instrument. Scale range = 0 to 100. A higher mean score reflects better HIV-QOL. *r* = Cronbach’s alpha internal consistency reliability coefficient. [a]Includes only women who took HIV medications in the past 4 weeks.

Table 4

Mean Scores for HIV Quality of Life by Location (n = 169)

	Cleveland (*n* = 91)		San Francisco (*n* = 78)			
QOL Dimension	*M*	*SD*	*M*	*SD*	*df*	*t*
Overall Function	60.21	23.87	52.11	26.78	166	2.073
Life Satisfaction	71.98	29.02	76.79	26.49	167	-1.118
Health	66.67	31.07	55.05	35.80	166	2.252
Financial	45.88	33.82	40.60	38.37	167	0.951
Medication	77.44	26.52	68.07	34.38	100	1.730
HIV Mastery	61.26	35.06	53.13	39.00	165	1.419
Disclosure	62.14	31.07	53.13	35.37	164	1.746
Total HIV-QOL	63.33	21.86	56.16	24.91	155	1.973

Note. Scale range = 0 to 100. A higher mean score reflects better HIV-QOL.

Table 5

Mean Scores for HIV Quality of Life by Age (n = 169)

	Younger than 40 Years (*n* = 28)		40 Years and Older (*n* = 134)			
QOL Dimension	*M*	*SD*	*M*	*SD*	*df*	*t*
Overall Function	65.18	28.93	54.89	24.24	35	1.754
Life Satisfaction	75.89	31.76	73.61	27.12	160	0.392
Health	68.53	29.44	60.10	34.85	159	1.192
Financial	52.38	37.33	41.23	35.00	160	1.515
Medication	84.55	22.46	71.50	31.36	133	1.857
HIV Mastery	66.52	35.36	57.20	36.81	158	1.225
Disclosure	58.57	32.60	58.86	33.32	157	-0.041
Total HIV-QOL	66.30	23.56	59.15	23.29	160	1.471

Note. Scale range = 0 to 100. A higher mean score reflects better HIV-QOL.

Table 6

Mean Scores for HIV Quality of Life by Income (n = 169)

	$0-$20,000 (*n* = 134)		$20,001+ (*n* = 16)			
QOL Dimension	*M*	*SD*	*M*	*SD*	*df*	*t*
Overall Function	54.17	25.92	65.89	21.15	147	-1.739
Life Satisfaction	73.20	27.39	88.67	18.85	23	-2.935
Health	59.35	33.57	65.23	36.87	147	-0.655
Financial	39.80	35.64	58.33	34.43	148	-1.972
Medication	72.39	31.18	84.62	24.45	120	-1.363
HIV Mastery	55.21	38.12	70.31	29.54	22	-1.866
Disclosure	56.87	33.44	66.56	32.65	145	-1.097
Total HIV-QOL	58.00	33.53	70.47	22.60	148	-2.012

Note. Scale range = 0 to 100. A higher mean score reflects better HIV-QOL.

Table 7

Mean Scores for HIV Quality of Life by Partner Status (n = 169)

	Not Partnered (*n* = 143)		Partnered (*n* = 24)			
QOL Dimension	*M*	*SD*	*M*	*SD*	*df*	*t*
Overall Function	56.69	24.50	55.38	31.91	28	0.192
Life Satisfaction	71.26	28.73	90.63	15.09	56	-4.959*
Health	60.39	33.46	66.15	35.69	164	-0.772
Financial	41.08	35.11	54.17	39.09	165	-1.662
Medication	71.41	30.67	85.25	26.18	135	-1.902
HIV Mastery	56.21	37.07	64.58	36.98	163	-1.024
Disclosure	56.00	33.08	70.21	31.60	162	-1.957
Total HIV-QOL	58.42	23.25	68.54	23.43	165	-1.971

Note. Scale range = 0 to 100. A higher mean score reflects better HIV-QOL.

*$p \leq .0001$.

Table 8

Mean Scores for HIV Quality of Life by Education (n = 169)

	High School or Less Education (*n* = 126)		College (*n* = 43)			
QOL Dimension	*M*	*SD*	*M*	*SD*	*df*	*t*
Overall Function	53.13	25.56	66.28	22.87	166	-2.986[*]
Life Satisfaction	71.30	28.62	82.70	24.05	167	-2.345
Health	54.95	33.88	79.65	25.99	95	-4.951[***]
Financial	40.08	34.59	53.29	38.54	167	-2.100
Medication	67.70	31.43	88.72	20.45	106	-4.631[***]
HIV Mastery	51.92	37.14	73.84	31.79	165	-3.455[**]
Disclosure	54.72	34.38	67.67	28.12	89	-2.449
Total HIV-QOL	55.73	22.83	72.56	21.12	167	-4.252[***]

Note. Scale range = 0 to 100. A higher mean score reflects better HIV-QOL.

[*] $p \leq .005$. [**] $p \leq .001$. [***] $p \leq .0001$.

Table 9

Mean Scores for HIV Quality of Life by CD4 Count (n = 169)

	[a]500+ cells/mm^3 (*n* = 69)		0-499 cells/mm^3 (*n* = 58)			
QOL Dimension	*M*	*SD*	*M*	*SD*	*df*	*t*
Overall Function	58.09	27.06	57.38	25.37	124	0.151
Life Satisfaction	75.66	26.37	70.69	29.78	125	0.998
Health	69.58	30.18	54.85	36.31	111	2.450
Financial	48.31	40.31	42.67	31.96	125	0.879
Medication	78.42	27.00	72.34	32.06	105	1.064
HIV Mastery	64.18	36.14	55.17	37.25	123	1.370
Disclosure	61.04	33.16	56.90	32.93	123	0.700
Total HIV-QOL	64.70	24.00	57.12	23.85	125	1.662

Note. Scale range = 0 to 100. A higher mean score reflects better HIV-QOL.[a]CD4 count ≥ 500 cells/mm^3 is normal.

Table 10

Mean Scores for HIV Quality of Life by Number of Comorbidities (n = 169)

	No (*n* = 48)		Yes (*n* = 119)			
QOL Dimension	*M*	*SD*	*M*	*SD*	*df*	*t*
Overall Function	58.78	30.52	55.78	23.43	68	0.607
Life Satisfaction	84.51	24.97	70.08	28.28	165	3.081*
Health	61.33	38.76	61.12	31.95	74	0.032
Financial	50.35	37.74	40.76	35.30	165	1.558
Medication	78.82	31.11	71.67	30.08	135	1.234
HIV Mastery	61.44	39.51	55.72	36.27	163	0.890
Disclosure	55.85	36.67	58.33	31.88	162	-0.406
Total HIV-QOL	63.37	25.93	58.56	22.64	165	1.191

Note. Scale range = 0 to 100. A higher mean score reflects better HIV-QOL.

*p= .002.

Table 11

Mean Scores for HIV Quality of Life by Emergency Department Admission (n = 169)

	No (*n* = 93)		Yes (*n* = 71)			
QOL Dimension	*M*	*SD*	*M*	*SD*	*df*	*t*
Overall Function	59.33	26.73	53.11	23.94	161	1.541
Life Satisfaction	77.58	26.77	69.89	29.61	162	1.739
Health	65.22	34.80	58.19	31.44	161	1.333
Financial	46.95	36.75	40.14	35.59	162	1.192
Medication	75.19	28.92	71.05	32.78	133	0.776
HIV Mastery	60.46	35.66	53.21	38.76	160	1.234
Disclosure	58.53	32.85	55.65	34.19	159	0.541
Total HIV-QOL	62.65	23.48	56.75	23.85	162	1.583

Note. Scale range = 0 to 100. A higher mean score reflects better HIV-QOL.

Table 12

Disclosure of HIV Status in African American Women Living with HIV Infection (n = 78)

	No		Yes	
Disclosed HIV Status To:	*n*	*%*	*n*	*%*
Anyone	10	12.8	68	87.2
Husband	35	44.9	43	55.1
Children	36	46.2	42	53.8
Relatives	29	37.2	49	62.8
Neighbors	56	71.8	22	28.2
Friends	36	46.2	42	53.8
Church	58	74.4	20	25.6
Work	63	80.8	15	19.2
Community	59	75.6	19	24.4
Treated differently since disclosure of HIV status	51	66.2	26	33.8

Note. Includes only the San Francisco Bay Area, CA study site.

Table 13

Summary Statistics and Reliability Coefficients for HIV Stigma Scale (n = 78)

Stigma Dimension (Scale Range)	*n*	*Range*	*M*	*SD*	*r*
Personalized Stigma (18-72)	78	12-68	37.53	12.90	.95
Disclosure Concerns (10-40)	78	10-40	25.22	7.36	.87
Negative Self-image (13-52)	78	14-45	28.41	8.45	.88
Public Attitudes about HIV (20-80)	78	20-79	44.82	13.63	.94
Total HIV-Stigma (40-160)	78	44-150	90.18	24.81	.96

Note. Includes only the San Francisco Bay Area, CA site. Higher mean score reflects greater perceived stigma. *r* = Cronbach's alpha internal consistency reliability coefficient.

Table 14

Mean Scores for HIV Stigma by Age (n = 78)

	Younger than 40 Years (*n* = 8)		40 Years and Older (*n* = 64)			
Stigma Dimension (Scale Range)	*M*	*SD*	*M*	*SD*	*df*	*t*
Personalized Stigma (18-72)	48.13	20.22	35.38	11.26	8	1.750
Disclosure Concerns (10-40)	28.25	9.79	24.63	7.02	8	1.015
Negative Self-image (13-52)	31.38	11.46	27.56	8.08	70	1.199
Public Attitudes about HIV (20-80)	52.38	19.91	43.09	12.38	8	1.288
Total HIV-Stigma (40-160)	105.00	37.61	86.98	22.50	8	1.326

Note. Includes only the San Francisco Bay Area, CA site. Higher mean score reflects greater perceived stigma.

Table 15

Mean Scores for HIV Stigma by Income (n = 78)

	$0-$20,000 (*n* = 67)		$20,001+ (*n* = 9)			
Stigma Dimension (Scale Range)	*M*	*SD*	*M*	*SD*	*df*	*t*
Personalized Stigma (18-72)	37.22	13.33	37.78	10.23	74	-0.120
Disclosure Concerns (10-40)	25.04	7.64	24.78	4.47	15	0.152
Negative Self-image (13-52)	28.30	8.35	27.22	8.89	74	-0.361
Public Attitudes about HIV (20-80)	44.16	13.66	47.56	13.21	74	-0.702
Total HIV-Stigma (40-160)	89.34	25.18	90.89	20.79	74	-0.176

Note. Includes only the San Francisco Bay Area, CA site. Higher mean score reflects greater perceived stigma.

Table 16

Mean Scores for HIV Stigma by Partner Status (n = 78)

	Not Partnered (*n* = 69)		Partnered (*n* = 9)			
Stigma Dimension (Scale Range)	*M*	*SD*	*M*	*SD*	*df*	*t*
Personalized Stigma (18-72)	37.75	12.77	35.78	14.51	76	0.430
Disclosure Concerns (10-40)	25.38	7.56	24.00	5.79	76	0.525
Negative Self-image (13-52)	28.32	8.47	29.11	8.71	76	-0.263
Public Attitudes about HIV (20-80)	44.93	13.61	44.00	14.62	76	0.191
Total HIV-Stigma (40-160)	90.43	24.80	88.22	26.30	76	0.250

Note. Includes only the San Francisco Bay Area, CA site. Higher mean score reflects greater perceived stigma.

Table 17

Mean Scores for HIV Stigma by Education (n = 78)

	High School or Less Education (n = 57)		College (n = 21)			
Stigma Dimension (Scale Range)	*M*	*SD*	*M*	*SD*	*df*	*t*
Personalized Stigma (18-72)	39.23	13.14	32.90	11.25	76	1.955
Disclosure Concerns (10-40)	25.49	7.45	24.48	7.23	76	0.538
Negative Self-image (13-52)	29.14	8.65	26.43	7.70	76	1.263
Public Attitudes about HIV (20-80)	46.37	14.01	40.62	11.87	76	1.671
Total HIV-Stigma (40-160)	92.70	25.49	83.33	21.97	76	1.491

Note. Includes only the San Francisco Bay Area, CA site. Higher mean score reflects greater perceived stigma.

Table 18

Mean Scores for HIV Stigma by CD4 Count (n = 78)

	500+ cells/mm^3 (*n* = 36)		0-499 cells/mm^3 (*n* = 25)			
Stigma Dimension (Scale Range)	*M*	*SD*	*M*	*SD*	*df*	*t*
Personalized Stigma (18-72)	38.33	12.08	39.40	12.06	59	-0.339
Disclosure Concerns (10-40)	26.06	7.80	25.20	5.85	59	0.489
Negative Self-image (13-52)	28.83	8.28	29.56	7.94	59	-0.343
Public Attitudes about HIV (20-80)	46.58	12.84	44.96	12.48	59	0.491
Total HIV-Stigma (40-160)	92.53	24.30	92.56	21.80	59	-0.005

Note. Includes only the San Francisco Bay Area, CA site. Higher mean score reflects greater perceived stigma.

Table 19

Mean Scores for HIV Stigma by Number of Comorbidities (n = 78)

	No (*n* = 28)		Yes (*n* = 50)			
Stigma Dimension (Scale Range)	*M*	*SD*	*M*	*SD*	*df*	*t*
Personalized Stigma (18-72)	32.89	14.33	40.12	11.37	76	-2.450
Disclosure Concerns (10-40)	23.96	8.33	25.92	6.75	76	-1.127
Negative Self-image (13-52)	26.43	8.97	29.52	8.01	76	-1.565
Public Attitudes about HIV (20-80)	40.79	15.88	47.08	11.77	76	-1.994
Total HIV-Stigma (40-160)	83.29	28.40	94.04	21.92	76	-1.866

Note. Includes only the San Francisco Bay Area, CA site. Higher mean score reflects greater perceived stigma.

Table 20

Mean Scores for HIV Stigma by Emergency Department Admission (n = 78)

	No (*n* = 46)		Yes (*n* = 31)			
Stigma Dimension (Scale Range)	*M*	*SD*	*M*	*SD*	*df*	*t*
Personalized Stigma (18-72)	34.87	11.87	41.26	13.77	75	-2.172
Disclosure Concerns (10-40)	24.13	7.86	26.81	6.47	75	-1.569
Negative Self-image (13-52)	27.52	8.27	29.42	8.67	75	-0.968
Public Attitudes about HIV (20-80)	41.98	13.31	48.42	13.17	75	-2.092
Total HIV-Stigma (40-160)	85.54	24.34	96.48	24.64	75	-1.925

Note. Includes only the San Francisco Bay Area, CA site. Higher mean score reflects greater perceived stigma.

Table 21

Correlations between HIV Stigma and HIV Quality of Life (n = 78)

	QOL							
Stigma	Overall Fx	Life Satisfaction	Hlth	Financial	Med.	HIV Mastery	Disclose	Total HIV-QOL
Personalized Stigma	-.06	-.20	-.08	-.20	-.02	-.23*	-.34**	-.24*
Disclosure Concerns	.05	-.19	.17	.00	.32*	-.03	-.33**	-.02
Negative Self-image	-.13	-.23*	-.12	-.16	.12	-.24*	-.37**	-.25*
Public Attitudes about HIV	.02	-.19	.03	-.11	.18	-.13	-.28*	-.11
Total HIV-Stigma	-.02	-.21	.01	-.11	.16	-.17	-.36**	-.16

Note. Includes only the San Francisco Bay Area, CA site. Fx = Function. Hlth = Health. Med. = Medication. Disclose = Disclosure.

$^{*}p < .05$. $^{**}p < .01$.

Table 22

Correlations between HIV Stigma and Contextual Factors (n = 78)

	Social Factors				Health Factors		
Stigma	Age	Education	Income	Partner Status	CD4 Count	Comorbi-dities	Emergency Admit
Personalized Stigma	-.24*	-.22	.08	-.05	.06	.34**	.24*
Disclosure Concerns	-.28*	-.06	.06	-.06	.22	.19	.18
Negative Self-image	-.22	-.14	.04	.03	.06	.21	.11
Public Attitudes about HIV	-.21	-.19	.11	-.02	.18	.29*	.24*
Total HIV-Stigma	.03	.21	.09	.14	.14	.27*	.22

Note. Includes only the San Francisco Bay Area, CA site.

$^{*}p < .05$. $^{**}p < .01$.

Table 23

Correlations between HIV Quality of Life and Contextual Factors (n = 169)

	Social Factors				Health Factors		
QOL	Age	Education	Income	Partner Status	CD4 Count	Comorbi-dities	Emergency Admit
Overall Function	-.05	$.23^{**}$	.08	-.02	.15	-.04	-.12
Life Satisfaction	-.02	$.18^{*}$	.16	$.24^{**}$	.10	-.11	-.14
Health	-.10	$.32^{**}$	.00	.06	.14	.05	-.11
Financial	-.09	$.16^{*}$	.08	.13	.15	-.17	-.09
Medication	-.03	$.31^{**}$	.16	.16	.11	-.11	-.07
HIV Mastery	-.08	$.26^{**}$	.04	.08	.12	-.01	-.10
Disclosure	-.10	$.17^{*}$	-.05	.15	.12	.17	-.04
Total HIV-QOL	-.10	$.31^{**}$	.06	.15	.17	-.05	-.12

$^{*}p < .05$. $^{**}p < .01$.

Table 24

Regression Analyses for Social and Health Factors Predicting HIV Stigma (n = 78)

Variables	*B*	*SE B*	β	*t*	R^2 Change	*F* Change (*df*)
Total HIV-Stigma: $R = .47$, $R^2 = .22$, F(7,48) = 1.954, $p = .08$						
Social Factors					10%	1.427 (4,51)
Age	-0.68	0.42	-0.22	-1.62		
Income	0.00	0.00	0.15	1.15		
Partner status	0.04	10.45	0.00	0.00		
Education	-7.89	7.41	-0.14	-1.07		
Health Factors					12%	2.490 (3,48)
CD4 count	0.01	0.01	0.18	1.33		
Comorbidities	5.85	3.08	0.25	1.90		
ED admission	8.42	7.03	0.17	1.20		
Personalized Stigma: $R = .51$, $R^2 = .26$, F(7,48) = 2.373, $p = .04^{*}$						
Social Factors					11%	1.511 (4,51)
Age	-0.31	0.21	-0.19	-1.46		
Income	0.00	0.00	0.16	1.23		
Partner status	-0.58	5.31	-0.02	-0.11		
Education	-5.62	3.76	-0.20	-1.50		
Health Factors					15%	3.254 (3,48)*
CD4 count	0.03	0.00	0.10	0.80		
Comorbidities	3.97	1.56	0.33	2.54**		
ED admission	3.97	3.57	0.15	1.11		
Disclosure Concerns: $R = .45$, $R^2 = .20$, F(7,48) = 1.704, $p = .13$						
Social Factors					10%	1.382(4,51)
Age	-0.25	0.13	-0.26	-1.94		
Income	0.00	0.00	0.10	0.77		
Partner status	-1.23	3.15	-0.05	-0.39		
Education	-0.31	2.23	-0.02	-0.14		

Variables	*B*	*SE B*	β	*t*	R^2 Change	*F* Change (*df*)
Health Factors					10%	2.021(3,48)
CD4 count	0.00	0.00	0.25	1.83		
Comorbidities	1.15	0.93	0.17	1.24		
ED admission	2.40	2.12	0.16	1.14		
Negative Self-image: $R = .35$, $R^2 = .12$, F(7,48) = 0.942, $p = .48$						
Social Factors					7%	0.887(4,51)
Age	-0.20	0.15	-0.18	-1.29		
Income	0.00	0.00	0.09	0.67		
Partner status	0.95	3.78	0.04	0.25		
Education	-2.46	2.68	-0.13	-0.92		
Health Factors					6%	1.014(3,48)
CD4 count	0.00	0.00	0.09	0.61		
Comorbidities	1.66	1.11	0.21	1.50		
ED admission	1.02	2.54	0.06	0.40		
Public Attitudes about HIV: $R = .50$, $R^2 = .25$, F(7,48) = 2.286, $p = .04^{*}$						
Social Factors					9%	1.255(4,51)
Age	-0.27	0.23	-0.15	-1.18		
Income	0.00	0.00	0.17	1.32		
Partner status	1.36	5.64	0.03	0.24		
Education	-5.48	4.00	-.18	-1.37		
Health Factors					16%	3.423(3,48)*
CD4 count	.01	.00	.23	1.75		
Comorbidities	3.94	1.66	.27	2.11*		
ED admission	5.51	3.79	.20	1.45		

Note. Includes only the San Francisco Bay Area, CA site.

$^{*}p < .05$. $^{**}p \leq .01$.

Table 25

Regression Analyses for Social and Health Factors Predicting HIV Quality of Life (n = 169)

Variables	*B*	*SE B*	β	*t*	R^2 Change	*F* Change (*df*)
Total HIV-QOL: $R = .39$, $R^2 = .15$, F(7,103) = 2.587, $p = .02^*$						
Social Factors					13%	3.813 (4,106)**
Age	0.23	0.26	-0.09	-0.90		
Income	1.64	0.00	0.01	0.11		
Partner status	5.28	6.30	0.08	0.84		
Education	16.73	5.05	0.31	3.32**		
Health Factors					2%	0.959(3,103)
CD4 count	0.00	0.00	0.14	1.45		
Comorbidities	-0.04	1.76	-0.00	-0.02		
ED admission	-3.20	4.50	-0.07	-0.71		
Overall Function: $R = .30$, $R^2 = .09$, F(7,103) = 1.472, $p = .17$						
Social Factors					6%	1.697(4,106)
Age	-0.16	0.29	-0.05	-0.55		
Income	0.00	0.00	0.04	0.45		
Partner status	-6.07	7.06	-0.08	-0.86		
Education	13.17	5.66	0.23	2.33*		
Health Factors					3%	1.161 (3, 103)
CD4 count	0.00	0.00	0.15	1.55		
Comorbidities	0.04	1.97	0.00	0.02		
ED admission	-4.38	5.04	-0.09	-0.89		
Life Satisfaction: $R = .34$, $R^2 = .12$, F(7, 103) = 1.938, $p = .07$						
Social Factors					10%	3.009 (4, 106)*
Age	0.04	0.31	0.01	0.12		
Income	0.00	0.00	0.12	1.24		
Partner status	16.82	7.62	0.21	2.21*		
Education	8.60	6.10	0.14	1.41		

Variables	*B*	*SE B*	β	*t*	R^2 Change	*F* Change (*df*)
Health Factors					1%	0.560 (3, 103)
CD4 count	0.00	0.00	0.06	0.57		
Comorbidities	-1.27	2.13	-0.06	-0.60		
ED admission	-4.01	5.44	-0.07	-0.74		
Health: $R = .38$, $R^2 = .15$, F(7, 103) = 2.536, $p = .02^{*}$						
Social Factors					12%	3.753 (4, 106)**
Age	-0.45	0.37	-0.12	-1.22		
Income	-0.00	0.00	-0.04	-0.41		
Partner status	-1.12	9.06	-0.01	-0.12		
Education	25.83	7.25	0.33	3.56**		
Health Factors					2%	0.925 (3, 103)
CD4 count	0.00	0.00	0.12	1.28		
Comorbidities	2.08	2.53	0.08	0.83		
ED admission	-5.48	6.47	-0.08	-0.85		
Financial: $R = .29$, $R^2 = .08$, F(7, 103) = 1.356, $p = .23$						
Social Factors					5%	1.408 (4, 106)
Age	-0.27	0.40	-0.06	-0.66		
Income	-0.00	0.00	0.03	0.35		
Partner status	7.29	10.00	0.07	0.73		
Education	13.07	8.01	0.16	1.63		
Health Factors					3%	1.272 (3, 103)
CD4 count	0.00	0.00	0.11	1.15		
Comorbidities	-3.70	2.79	-0.13	-1.33		
ED admission	-1.51	7.14	-0.02	-0.21		
Medication: $R = .38$, $R^2 = .14$, F(7, 99) = 2.382, $p = .03^{*}$						
Social Factors					13%	3.836 (4, 102)**
Age	-0.07	0.34	-0.02	-0.21		
Income	0.00	0.00	0.10	1.07		
Partner status	9.71	8.29	0.11	1.17		
Education	20.28	6.64	0.29	3.06**		

Variables	B	$SE\ B$	β	t	R^2 Change	F Change (df)
Health Factors					1%	0.516 (3, 99)
CD4 count	0.00	0.00	0.09	0.87		
Comorbidities	-1.84	2.31	-0.08	-0.79		
ED admission	0.67	5.92	0.01	0.11		
HIV Mastery: $R = .31$, $R^2 = .09$, F(7, 103) = 1.534, $p = .16$						
Social Factors					8%	2.305 (4, 106)
Age	-0.33	0.41	-0.08	-0.81		
Income	-0.00	0.00	-0.00	-0.01		
Partner status	2.23	10.24	0.02	0.22		
Education	22.26	8.20	0.26	2.72^{**}		
Health Factors					1%	0.545 (3, 103)
CD4 count	0.00	0.00	0.10	1.06		
Comorbidities	0.74	2.86	0.03	0.26		
ED admission	-4.70	7.31	-0.06	-0.64		
Disclosure: $R = .28$, $R^2 = .08$, F(7, 103) = 1.204, $p = .31$						
Social Factors					6%	1.756 (4, 106)
Age	-0.31	0.38	-0.08	-0.82		
Income	0.00	0.00	-0.06	-0.56		
Partner status	10.39	9.30	0.11	1.12		
Education	13.64	7.45	0.18	1.83		
Health Factors					1%	0.501 (3, 103)
CD4 count	0.00	0.00	0.09	0.90		
Comorbidities	2.29	2.59	0.09	0.89		
ED admission	-2.12	6.64	-0.03	-0.32		

$^{*}p < .05$. $^{**}p \leq .01$.

CHAPTER VI

DISCUSSION

This secondary research study focused on HIV-stigma and HIV-QOL as perceived by AAW with HIV infection living in Cleveland, OH and the San Francisco Bay Area, CA. African American women experience the trifecta of intersections: Black, female, and living with HIV infection at a disproportionately higher rate compared to other American women. Yet, little is known about these intersections on the stigmatizing and QOL experiences of AAW living with HIV infection. This study addressed this gap in science by considering social and health characteristics on HIV-stigma and HIV-QOL as perceived by AAW living with HIV infection.

The aims of the study were to describe HIV-stigma and HIV-QOL, explore the association between HIV-stigma and HIV-QOL, and determine the influence of social and health contextual factors on HIV-stigma and HIV-QOL as perceived by AAW living with HIV infection. This chapter is organized into the following sections: (a) discussion of study findings, (b) limitations of the study, (c) implications for health, nursing, and policy, (d) recommendations for further research, and (e) conclusions. Study findings are discussed through the lens of intersectionality and Black feminism with the assumption that AAW have a unique background to understand their situation.

Discussion of Study Findings

Sample Characteristics

The sample was a relatively middle-aged group of AA mothers living with HIV infection. Lichtenstein and colleagues (2002) reported mothers with HIV infection fear death for themselves and their children as compared to men with HIV infection. A majority of these AA mothers were low-income, not married or partnered, educated beyond high school, on public health insurance, unemployed, and lived in permanent housing even in a more expensive urban location like the San Francisco Bay Area. Permanent housing is significant in the lives of women living with HIV infection. Temporary housing comes with many risks such as substance abuse, sexual assault, unwanted pregnancies, and lack of healthcare access and utilization, particularly for women living with HIV/AIDS (Phillips, Moneyham, &Tavakoli, 2011a; Phillips, Moneyham, Thomas, & Vyavaharkar, 2011b).

The sample's characteristics were typical of AAW living with HIV infection in the US. According to the CDC (2012), AAW with HIV infection typically have an annual income less than $10,000, have been living with HIV/AIDS since the age of 21 years, have less education, have minor children for which to care, are unemployed, and are not married or partnered. These personal, socio-demographic factors can cause chronic distress, which can have a negative impact on AAW's health and the health of their children (Lichtenstein et al., 2002; Phillips et al., 2011a, 2011b).

Thirty-nine percent of the sample was diagnosed with AIDS. Almost all of the women had comorbidities related mainly to cardiovascular, mental health, and hepatic conditions. Over half of the sample reported no emergency department admission within the past year. The literature indicates HIV/AIDS-related illness as the primary emergency department admissions are infrequent relative to all emergency department visits, however, HIV/AIDS-related illness visits utilize significantly more resources than non-HIV/AIDS-related illness visits, and utilization increases over time (Shih, Chen, Rothman, & Hsieh, 2011). Over half of the sample had a CD4 count of 500 cells/mm^3 or higher and were on highly active antiretroviral therapy. This subset sample of AAW had CD4 counts that were higher than the CD4 counts of the total sample of the primary parent study (Webel et al., 2012) as well as other studies reported in the literature of women living with HIV infection (Ingram & Hutchinson, 2010; Vosvick et al., 2003).

New guidelines from the U.S. Department of Health and Human Services recommend starting treatment when the CD4 count 350 cells/mm^3 or above 500 cells/mm^3 (AIDS.gov, 2013). Advocacy and promotion of early screening, detection and treatment in urban cities, such as Cleveland and the San Francisco Bay Area with large research university medical centers, might be probable reasons that a majority of the women in this study were on highly active antiretroviral therapy and their CD4 counts were 500 cells/mm^{3}and higher. The literature indicates the geographic location of people living with HIV infection did not affect receipt of highly active antiretroviral therapy; however, African Americans with HIV/AIDS living in rural areas are less likely to receive highly active antiretroviral therapy (Wilson et al., 2011).

Description of HIV Quality of Life

This sample of AAW living with HIV infection reported a moderate level of HIV-QOL. Most of the time, they were able to perform activities of daily living, were satisfied with their life, did not worry about dying from HIV/AIDS, did not consider taking HIV medications as a burden, did not have anger or regrets about HIV risk behavior, and did not worry about disclosing their HIV status to family, friends, and coworkers. The literature indicates women from diverse ethnic and racial backgrounds living with HIV infection have moderate to severe HIV-QOL issues, such as physical health, bodily pain, and social, physical and role functioning limitations (Vosvick et al., 2003).

The AAW in this study did worry, however, about their income and ability to pay bills a lot of the time. This finding is to be expected considering this was a sample of women with minor children who reported being unemployed, having low annual household incomes, and not being married or partnered. When differences by social contextual factors were considered, the description of HIV-QOL did not differ by age or income. Similar to this study's sample, many of the HIV-QOL studies in the literature that included women solely or along with men in the sample were of low-income socioeconomic status, regardless of race and ethnicity. Arns and colleagues (2004) reported that many people with HIV/AIDS feel they are financial burdens to their families, have more worries about finances than with health issues, and even if they work full-time, they need financial assistance.

In this study, AAW's description of HIV-QOL varied by partner status and education. Women who were married or partnered reported being significantly more satisfied with life than women who were single or not partnered. As compared to women who had a high school education or less, college-educated women were better able to perform activities of daily living, were more satisfied with their life, worried less about dying from HIV/AIDS, did not consider taking HIV medications a burden, had less anger and regrets about HIV risk behavior, were less worried about disclosing their HIV status, and were less worried about their income and ability to pay bills. Similar to this study's findings, evidence in the literature indicates the positive impact on HIV-QOL as a result of positive social support (Gielen et al., 2001; Vyavaharkar et al., 2011) and higher education (Gore-Felton et al., 2006) for women.

There were no significant differences in HIV-QOL by health contextual factors except for comorbidities. Women with less comorbidities reported being more satisfied with life as compared to women with more comorbidities. Rodriquez-Penney and colleagues (2013) found greater comorbidity burden was associated uniquely with lower HIV-QOL across the lifespan. Such results show HIV-stigma is inextricably related to HIV-QOL.

Description of HIV Stigma

A majority of the sample reported a moderate level of perceived HIV-stigma that did not differ by social or health contextual factors. Regardless of social background and health issues, this sample of AAW living with HIV infection felt stigmatized by their community and healthcare professionals. Almost all participants had disclosed their HIV status to someone in their personal social network (family and friends), but not to their community, church, or neighbors. Studies show we tend to trust and have confidence in persons in our personal social network, but not in persons outside of our personal social network, including healthcare professionals (Kinsler et al., 2007).

Over one-third of the sample reported being treated differently since disclosing their HIV status. This finding suggests why stigma can be a major obstacle for HIV/AIDS prevention and treatment, particularly for women and ethnic minority women (Ingram & Hutchinson, 2010; Lichtenstein et al., 2002). Interpersonal and healthcare discrimination related to stigma has been shown to be experienced more by women than men in the US (Phillips et al., 2011a, 2011b) as well as in other countries (Neuman, Obermeyer, & MATCH Study Group, 2013). Webel and Higgins reported HIV-stigma as a barrier for women disclosing their HIV status, seeking social support, and engaging in self-management.

Association between HIV Stigma and HIV Quality of Life

Quality of life related to worrying about disclosure of HIV status was associated with every dimension of HIV-stigma. Having worries about disclosure of HIV status was associated with higher perceived HIV-stigma in general, for AAW and specifically, AAW felt more perceived consequences if people knew their HIV status, felt they had to control information about their HIV status, had negative self-image with feelings of shame and guilt because of their HIV status, and were concerned about public attitudes toward their HIV status. Quality of life related to the burden of taking HIV medications was associated with more perceived consequences if people knew HIV status and negative self-image. In addition, having less life satisfaction QOL was associated with more negative self-image related to stigmatization for AAW.

Study findings indicate HIV-QOL related to HIV status disclosure, taking HIV medications, and life satisfaction were associated inextricably with all aspects of HIV-stigma in this sample of AAW living with HIV infection. The literature documents this inextricable relationship between HIV-stigma and HIV-QOL, regardless of health, gender, race, ethnicity, nationality, geography, and other social and demographic factors (Holzemer et al., 2009; Miles et al., 2003; Vyavaharkar et al., 2011).

Social and Health Predictors of HIV Stigma

Two models of HIV-stigma were significant: (a) personalized stigma (perceived consequences if people knew HIV status), and (b) public attitudes toward HIV status. Twenty-six percent of the variance in the personalized stigma model was explained by social (11%) and health (15%) factors. In the public attitudes toward HIV status model, 25% of the variance was explained by social (9%) and health (16%) factors. None of the combined or individual social contextual factors explained a significant proportion of variance in either model. Only the health contextual factor, number of comorbidities, explained a significant proportion of variance in both models, 11% and 7%, respectively. African American women living with HIV infection who had less comorbidities reported less perceived personalized stigma and less perceived stigma related to public attitudes toward HIV status.

This finding suggests the importance of limiting the number of and managing comorbidities in AAW living with HIV infection in terms of how they internalize stigma and how they perceive the public stigmatizes them because of their HIV infection and concomitant comorbidities. The literature is sparse regarding the type, number, and management of comorbidities as a predictor of HIV-stigma. After cardiovascular conditions, mental health conditions were the second most frequently reported comorbidities in this study of AAW living with HIV infection. Depression as a mental health comorbidity that predicts HIV-stigma has been demonstrated in various studies (Emlet, 2007; Vyavaharkar et al., 2011), particularly in AAW where depression and HIV-stigma perceptions were significantly higher than other ethnic and racial groups (Miles, et al., 2007).Depression and stigma have been shown to undermine HIV self-care management and health seeking behavior in women with HIV infection (Webel& Higgins, 2012).

Social and Health Predictors of HIV Quality of Life

Three models of HIV-QOL were significant: (a) overall HIV-QOL, (b) health-related QOL (worries about CD4 count, viral load, and dying), and (c) medication-related QOL (taking HIV medications is a burden). Fifteen percent of the variance in the overall HIV-QOL model was explained by social (13%) and health (2%) factors. In the health-related QOL model, social (12%) and health (3%) factors accounted for 15% of the total variance. In the medication-related QOL model, social (13%) and health (1%) factors accounted for 14% of the total variance.

None of the combined or individual health contextual factors explained a significant proportion of variance in any of the three HIV-QOL models. The unique contribution of the social factor, education, explained a significant proportion of variance in overall QOL, health-related QOL, and medication-related QOL, 10%, 11%, and 8% respectively, indicating AAW living with HIV infection who were college-educated reported better overall QOL, better health, and less burden about taking HIV medications. This finding suggests the importance of education to the QOL of AAW living with HIV infection (Gore-Felton et al., 2006).

Lens of Intersectionality Theory and Black Feminism

The perspectives of intersectionality theory and Black feminism (Collins, 1986, 2000) provided the lens for and guided this study (see Chapter II). Kelly (2011) describes feminist intersectionality as “a body of knowledge that is driven to by the pursuit of social justice and seeks to explain the processes by which individuals and groups in various oppressed social positions, such as gender, race, ethnicity, class, age, sexual orientation, disability status, and religion result in inequitable access to resources, which in turn results in societal inequities and social injustice” (p. E43-E44).

This sample of middle-aged AAW had multiple identities and roles (female, mother, AA, and HIV infection) that intersect and require the daily balancing of motherhood, caring for others, and managing HIV infection and comorbidities—often without personal social networks, without adequate financial support, or assistance to navigate the public healthcare insurance system of care. These social and health factors influence QOL and stigma as perceived by AAW living with HIV infection. In the model shown in Figure 1 (described in detail in Chapter II), factors that were significant predictors of HIV-QOL and HIV-stigma are denoted with an asterisk: education, health (number of comorbidities), and social support (partner/marital status). Sexual orientation was not assessed. The sample was comprised of all women who self-identified as African American, and was relatively homogenous in regards to being of low socioeconomic status regardless of geography—Cleveland, OH or the San Francisco Bay Area.

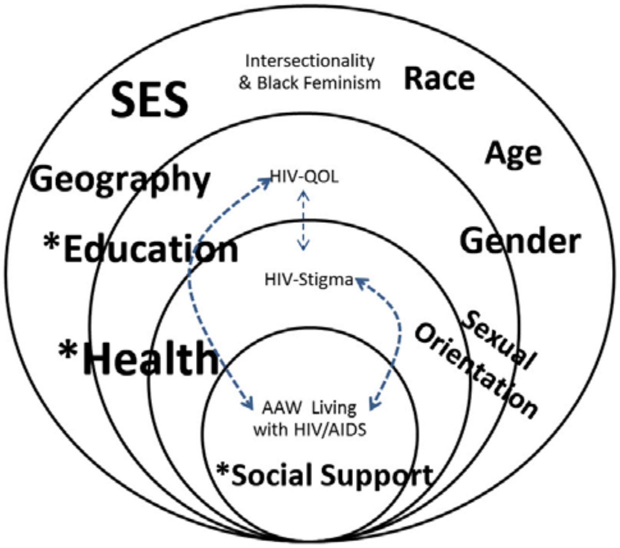

Figure 1. HIV-Stigma and HIV-QOL through the Lens of Intersectionality and Black Feminism.

Interpreted within the intersectionality and Black feminism paradigm, if the intersections of these factors are not addressed, they could have a negative impact on AAW’s QOL, health outcomes, self-management of HIV infection, adherence to complex therapeutic regimens, and perceived stigma placed upon them by society for being poor, uneducated, unmarried women of color living with HIV/AIDS. This stigmatization can lead to social, health, and power inequities and disparities for AAW, and can lead to AAW's perceiving they are controlled by society and systems that do not understand their unique lived experiences and their need for self-determination and autonomy. Study findings indicate education might be the key to empowering AAW living with HIV infection to improve their QOL, which is bound inextricably to perceived stigmatization by themselves (internal) and others (external) because of their HIV status and social place in life.

Limitations of the Study

A majority of the study limitations are shortcomings of secondary research. The convenience sample was relatively homogeneous between the two study sites, but they differed statistically by location for age, number of children living at home, number of comorbidities, annual income, and permanent housing. The sample in the San Francisco Bay Area, CA as compared to the sample in Cleveland, OH was older, had less number of children living with them, less number of comorbidities, higher annual incomes, and less permanent housing. The sample did not differ by site for the study variables. It is possible that participants differed systematically from the entire population of AAW living with HIV infection, which might have an impact on the findings and limit generalizations of the results. External validity is also limited by the setting: data collection occurred in urban cities. Study findings might have been different had data collection occurred in rural or suburban areas.

Although data were self-reported, internal consistency reliability for the instruments, in particular the HIV-QOL measure, were adequate and better than the internal consistency reliability for the studies that initially used these measures to establish the tool’s psychometric properties. Missing data were kept to a minimum in the primary, parent study because of the face-to-face, one-on-one data collection procedure.

HIV-stigma was assessed only in the San Francisco Bay Area, CA in the primary parent study, and thus, HIV-stigma data were unavailable for analysis with participants in Cleveland, OH, which decreased the sample size from 169 to 78 for HIV-stigma data analyses. These two sample sizes, however, were sufficient to provide statistical power to describe differences, detect relationships, and explain variance in variables.

The provider trust and sexual function dimensions of HIV-QOL were not assessed in the primary, parent study, and thus, were unavailable for the current analysis. These HIV-QOL dimensions are important to assess client-provider relationships and communications (provider trust) and acknowledge women’s sexuality (sexual function) particularly within the feminist paradigm.

Phenomena were assessed to a single time point, but not over time. Longitudinal assessments over time would have allowed for changes in descriptions and perceptions of HIV-QOL and HIV-stigma in AAW living with HIV infection for a better reflection of the intersections among social and health contextual factors. Relationships between phenomena were explored for associations, but causality cannot be assumed. Examining and understanding such intersections may lend itself better to qualitative methodology than to the non-experimental, cross-sectional quantitative design that was used in this secondary research study.

Implications for Health, Nursing, and Policy

The AIDS pandemic has been around for 30 years and has claimed 36 million lives, with 35 million more people currently infected with HIV (CDC, 2013). People with

HIV infection are living longer with comorbidities, such as heart disease, that will likely kill them instead of HIV/AIDS. The focus of HIV/AIDS treatment and management needs to shift more toward health behavior and lifestyle changes as people with HIV/AIDS live longer. Interventions to improve HIV-QOL, encourage HIV disclosure, and reduce HIV-stigma in AAW living with HIV infection could help to eliminate the disparity between their hopes, anticipations, and experiences so that they can feel a sense of control over their environment and a sense of social integration and well-being.

While acknowledgement or disclosure of HIV/AIDS can create problems because of stigma and ignorance, there is value in openness to help women live healthier and fuller lives within their sociocultural context by receiving education, support, tangible and intangible resources that they need without feeling embarrassed, discredited and discounted, and without fear of being rejected and judged. The complexities that intersect with gender, race, class, social and health factors put women and other vulnerable groups at a disadvantage in initiating equitable power relationships with family, community, institutions, healthcare providers, and society.

Care must be taken to not take an overly narrowed approach to support women who live with HIV infection such that it marginalizes them from their communities. Conversely, care must be taken to not take an overly liberal approach to support women who live with HIV infection such that it supports community rights over each woman’s rights. Care must be taken to not develop policies and interventions that fail to acknowledge cultural differences by insisting that White, middle-class values be adopted by AAW, resulting paradoxically, in racism and paternalism. The public trusts nurses, who have a moral obligation to be on the frontline protecting people living with HIV infection by showing empathy and respect, and by advocating for policies that are fair, just, and place women at the center.

Recommendations for Further Research

Until the early 1990s, research on women with HIV infection was nonexistent. Then, we studied women assuming they were a homogeneous group based on their gender. Understanding the perceptions of HIV-stigma and HIV-QOL in AAW living with HIV infection through the lens of intersectionality and Black Feminist theory broadens scientists' scope to look at AAW and other populations with empathy and understanding of their lived experiences without judgment and free of morality. Study findings do not apply only to AAW in the US. The findings could also be applied to understanding Black women in other countries, such as sub-Saharan Africa, where the burden of HIV infection is even higher, where the communication patterns are different (what, how, and to whom information is delivered or censored), and where the roles, identities, and autonomy of women are vastly different as compared to women in the US.

Using a community-based participatory research approach, an area for research is to assess the linkage between HIV-stigma, HIV-QOL, and women's lives by focusing on macro- and micro-level interactions. Macro-level interventions include human rights, equitable access and delivery of HIV services, linkages to care and resources, informed consent and confidentiality, mass marketing of health education, community support and engagement, legal protection, public laws and policies, etc. Micro-level interactions include client-provider communication, tailored one-on-one health education, social networks, adherence to therapeutic regimen, etc.

A mixed-methods approach to primary data collection over time would be of importance in assessing intersectionality and its complexity of the lived experiences of women living with HIV infection that cross the boundaries of race, ethnicity, culture, country, continent, gender, sexuality, income, education, health, religion/spirituality, etc. Many of these intersections, such as sexual orientation, were not analyzed in this study because these variables were not assessed in the primary, parent study. For example, what are the consequences of these correlates (such as the paradox of disclosure) for women living with HIV infection on QOL and stigma? In-depth interviews, participant observations, and survey methodology might provide insights into the multisectorial lives of women living with HIV infection at a population level.

Within the Black feminist intersectionality paradigm, racism and health should be explored in order to identify interventions that seek to reduce the multiple dimensions of racism in order to improve health and reduce health disparities and inequities at individual and societal levels. To improve minorities' health, Williams and Mohammed (2013) recommend policies and procedures that seek to reduce institutional racism by improving neighborhood and educational quality, enhancing access to healthcare, additional income, employment opportunities, and other limited resources, addressing social factors that initiate and sustain risk behaviors, and empowering individuals and communities to take control of their lives and health.

Conclusions

Social and health factors can have negative and positive effects on how AAW living with HIV infection perceive stigma and QOL. Stigma can be a major obstacle for HIV/AIDS prevention and treatment. Moreover, social support such as having a partner or being married, having a college education, and limiting comorbidities can have a positive effect on both HIV-QOL and HIV-stigma. This study filled a gap in science by considering social and health characteristics for describing HIV-stigma and HIV-QOL as perceived by AAW within the intersectionality and Black feminism paradigm. This perspective may help in the development of HIV/AIDS health education interventions and policies that are holistic, gender-appropriate, culturally acceptable, and address the unique personal, social, and health concerns of and support needed by AAW.

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Appendix A

Memorandum of Understanding for Data Sharing

Carol Dawson-Rose, PI of the *MANAGE* study, University of California, San Francisco (UCSF), agrees to share a de-identified dataset with Catherine Waters, PI, UCSF on behalf of PhD student advisee, Alphoncina Kaihura.

Research involving only unidentifiable or coded private information is not human subject research and does not require review by UCSF Committee on Human Research (see self-certification form).

The researchers agree to the following:

(1) The data will be used only for research purposes related to preparing a doctoral dissertation and writing manuscripts for publication about stigma and quality of life in African American women living with HIV infection. Use of the following variables are allowed: HIV-stigma, HIV-QOL, and social and health demographic characteristics.

(2) The dataset will be de-identified. It will not be possible to identify any individual participant.

(3) All data will be transmitted on a password-protected server at the UCSF and stored on an encrypted hard drive on a password-protected computer using appropriate computer technology.

(4) Dr. Dawson-Rose, who is a member of Ms. Kaihura's dissertation committee, will have the right to monitor and track use of the dataset and review all manuscripts on which her name will appear prior to submission for publications that result from the dataset.

(5) The dataset will be wiped permanently using appropriate computer technology after completion of the dissertation and manuscripts.

Alphoncina Kaihura (PhD student) DATE UCSF	Carol Dawson Rose, RN, PhD (PI) DATE UCSF

Catherine Waters, RN, PhD (advisor)
DATE
UCSF

University of California, San Francisco (UCSF)
Committee on Human Research (CHR)

Self-Certification for Determining Whether Human Subjects Are Involved In Research When Obtaining Coded Private Information (Data) and/or Biological Specimens

Instructions:

1. If you need documentation for funding agencies, administrators, or collaborators, this self-certification form is provided for your use. Copies of this should be maintained in the PIs research files. Do **not** submit a copy of the form to the CHR.
2. If the following condition is met for your research, the use of coded private information (data) and/or biological specimens does not meet the definition of a *human subject* and does not require Exempt Certification or IRB review. The Determining Whether Human Subjects Are Involved in Research Decision Tree will help you make this determination.
3. More background information and CHR written guidance can be found at http://www.research.ucsf.edu/chr/Guide/chrExemptApp.asp
4. If you have questions on how to use this form contact the CHR at (415) 476-1814 or e mail: chr@ucsf.edu.

Principal Investigator:		
Name and Degree Alphoncina Kaihura (PhD Student) Catherine Waters, PhD (Advisor)	Institution Univ. of California, San Francisco	Department Community Health Systems
Mailing Address 2 Koret Way, Box 0608; San Francisco, CA 94143-0608	Phone Number (415) 502-7995	E-mail Address catherine.waters@ucsf.edu

Study/Grant Title/Award No.:

Stigma and Quality of Life in African American Women Living with HIV Infection

Condition that must be met for the coded private information (data) or biological specimens:

1. The research is not regulated by the Food and Drug Administration (FDA).
   AND
2. One or more of the following apply. Check all that apply:

☐ a. The key to decipher the code is destroyed before the researcher begins.

☑ b. PI and holder of the key enter into an agreement prohibiting the release of the key under any circumstances.

☐ c. There are IRB-approved written policies for the repository or data management that prohibit the release of the key.

☐ d. There are other legal requirements prohibiting the release of the key under any circumstances.

Principal Investigator's Certification:
I certify that the information provided in this application is complete and correct.

Catherine M. Waters
Principal Investigators Signature

February 15, 2013
Date

Appendix C

HIV Stigma Scale

A. Have you told anyone that you are HIV-positive?

____ Yes
____ No, If no, go to question 1

B. Who have you told that you are HIV-positive? (check all that apply)

____ Husband/wife/partner
____ Children
____ Relatives / other family members
____ Neighbors
____ Friends
____ Church community
____ Work colleagues
____ Other members of the community

C. After you told people that you are HIV-positive, were you treated differently?

____ Yes
____ No

This next set of questions asks about some of your experiences, feelings, and opinions as to how people with HIV feel and how they are treated. Please do your best to answer each question. For each item, circle your answer: Strongly disagree (SD), disagree (D), agree (A), or strongly agree (SA).

	Strongly Disagree (SD) 1	Disagree (D) 2	Agree (A) 3	Strongly Agree (SA) 4
1. In many areas of my life, no one knows that I have HIV.	SD	D	A	SA
2. I feel guilty because I have HIV .	SD	D	A	SA

	Strongly Disagree (SD) 1	Disagree (D) 2	Agree (A) 3	Strongly Agree (SA) 4
3. People's attitudes about HIV make me feel worse about myself.	SD	D	A	SA
4. Telling someone I have HIV is risky.	SD	D	A	SA
5. People with HIV lose their jobs when their employers find out.	SD	D	A	SA
6. I work hard to keep my HIV a secret.	SD	D	A	SA
7. I feel I am not as good a person as others because I have HIV.	SD	D	A	SA
8. I never feel ashamed of having HIV.	SD	D	A	SA
9. People with HIV are treated like outcasts.	SD	D	A	SA
10. Most people believe that a person who has HIV is dirty.	SD	D	A	SA
11. It is easier to avoid new friendships than worry about telling someone that I have HIV.	SD	D	A	SA
12. Having HIV makes me feel unclean.	SD	D	A	SA
13. Since learning I have HIV, I feel set apart and isolated from the rest of the world.	SD	D	A	SA
14. Most people think that a person with HIV is disgusting.	SD	D	A	SA

	Strongly Disagree (SD) 1	Disagree (D) 2	Agree (A) 3	Strongly Agree (SA) 4
15. Having HIV makes me feel that I'm a bad person.	SD	D	A	SA
16. Most people with HIV are rejected when others find out.	SD	D	A	SA
17. I am very careful who I tell that I have HIV.	SD	D	A	SA
18. Some people who know I have HIV have grown more distant.	SD	D	A	SA
19. Since learning I have HIV, I worry about people discriminating against me.	SD	D	A	SA
20. Most people are uncomfortable around someone with HIV.	SD	D	A	SA
21. I never feel the need to hide the fact that I have HIV.	SD	D	A	SA
22. I worry that people may judge me when they learn I have HIV.	SD	D	A	SA
23. Having HIV in my body is disgusting to me.	SD	D	A	SA

Many of the items in this next section assume that you have told other people that you have HIV, or that others know. This may not be true for you. If the item refers to something that has not actually happened to you, please imagine yourself in that situation. Then give your answer ("strongly disagree," "disagree," "agree," "strongly agree") based on how you think you would feel or how you think others would react to you.

	Strongly Disagree (SD) 1	Disagree (D) 2	Agree (A) 3	Strongly Agree (A) 4
24. I have been hurt by how people reacted to learning I have HIV.	SD	D	A	SA
25. I worry that people who know I have HIV will tell others.	SD	D	A	SA
26. I regret having told some people that I have HIV.	SD	D	A	SA
27. As a rule, telling others that I have HIV has been a mistake.	SD	D	A	SA
28. Some people avoid touching me once they know I have HIV.	SD	D	A	SA
29. People I care about stopped calling after learning I have HIV.	SD	D	A	SA
30. People have told me that getting HIV is what I deserve for how I lived my life.	SD	D	A	SA
31. Some people close to me are afraid others will reject them if it becomes known that I have HIV.	SD	D	A	SA
32. People don't want me around their children once they know I have HIV.	SD	D	A	SA
33. People have physically backed away from me when they learn I have HIV.	SD	D	A	SA
34. Some people act as though it's my fault I have HIV.	SD	D	A	SA
35. I have stopped socializing with some people because of their reactions to my having HIV.	SD	D	A	SA

	Strongly Disagree (SD) 1	Disagree (D) 2	Agree (A) 3	Strongly Agree (A) 4
36. I have lost friends by telling them I have HIV.	SD	D	A	SA
37. I have told people close to me to keep the fact that I haveHIV a secret.	SD	D	A	SA
38. People who know I have HIV tend to ignore my good points.	SD	D	A	SA
39. People seem afraid of me once they learn I have HIV.	SD	D	A	SA
40. When people learn you have HIV, they look for flaws in your character.	SD	D	A	SA

Scoring:

1. Items are scored as follows: (1) strongly disagree; (2) disagree; (3) agree; and (4) strongly agree.
2. If a response is in between two options (e.g., between SD and D), a numerical value midway between the two options is used (e.g., 1.5).
3. Reverse score items 8 and 21.
4. Each subscale's score is calculated by adding the raw values of the items belonging to each subscale.
5. Higher scores reflect greater perceived stigma.

Total Scale Score (40-160): Items 1 to 40

- **I.** **Personalized Stigma Subscale Score (18-72):** Items13, 16, 18, 24, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 38, 39, 40
- **II.** **DisclosureConcerns Subscale Score (10-40):** Items 1, 4, 6, 11, 17, 19, 21, 22, 25, 37.
- **III.** **Negative Self-image Subscale Score (13-52):** Items 2, 3, 6, 7, 8, 11, 12, 13, 15, 23, 27, 38, 39
- **IV.** **Public Attitudes about HIV Subscale Score (20-80):** Items 4, 5, 9, 10, 11, 13, 14, 16, 19, 20, 22, 27, 28, 30, 32, 33, 34, 38, 39, 40

Reference:

Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing and Health, 24*, 518-529.

Appendix D

Quality of Life

You will find some questions that ask about your <u>job/routine daily activities</u>. If you have a job, answer these questions thinking about your job. If you don't have a job, answer these questions thinking about the activities you usually do during most days of the week, such as housework, going to school, or volunteering in an organization.

1. The following questions ask about your <u>overall function</u> in the past 4 weeks:					
	All of the time 1	**A lot of the time 2**	**Some of the time 3**	**A little of the time 4**	**None of the time 5**
a. In the past 4 weeks, I've been satisfied with my physical activity.					
b. In the past 4 weeks, I've been physically limited in my ability to do routine household chores.					
c. In the past 4 weeks, pain has limited my ability to be physically active.					
d. In the past 4 weeks, I've been worried about not being able to do my job/routine daily activities as I have in the past.					
e. In the past 4 weeks, I've felt that having HIV has limited the amount of work I can do at my job/routine daily activities.					
f. In the past 4 weeks, I've been too tired to be socially active.					

2. The following questions ask about your <u>life satisfaction</u> in the past 4 weeks:					
	All of the time 1	**A lot of the time 2**	**Some of the time 3**	**A little of the time 4**	**None of the time 5**
a. In the past 4 weeks, I've enjoyed living.					
b. In the past 4 weeks, I've felt in control of my life.					
c. In the past 4 weeks, I've been satisfied with how socially active I am.					
d. In the past 4 weeks, I've been pleased with how healthy I've been.					

3. The following questions ask about your <u>health worries</u> in the past 4 weeks:					
	All of the time 1	**A lot of the time 2**	**Some of the time 3**	**A little of the time 4**	**None of the time 5**
a. In the past 4 weeks, I haven't been able to live the way I'd like to because I'm so worried about my health.					
b. In the past 4 weeks, I've been worried about my CD4 count.					
c. In the past 4 weeks, I've been worried about my viral load.					
d. In the past 4 weeks, I've been worried about when I'm going to die.					

4. The following questions ask about your financial worries in the past 4 weeks:

	All of the time 1	**A lot of the time 2**	**Some of the time 3**	**A little of the time 4**	**None of the time 5**
a. In the past 4 weeks, I've been worried about having to live on a fixed income.					
b. In the past 4 weeks, I've been worried about how to pay my bills.					
c. In the past 4 weeks, money has been too tight for me to care for myself the way I think I should.					

5. The following questions ask how you've felt about your HIV medications in the past 4 weeks:

Have you taken HIV medications in the past 4 weeks? (Please circle No or Yes)

NO →→→→→→ Go to # 6

YES →→→→→→ Continue below

	All of the time 1	**A lot of the time 2**	**Some of the time 3**	**A little of the time 4**	**None of the time 5**
a. In the past 4 weeks, taking my medicine has been a burden.					
b. In the past 4 weeks, taking my medicine has made it hard to live a normal life.					
c. In the past 4 weeks, taking my medicine has caused unpleasant side effects.					
d. In the past 4 weeks, I’ve been worried about the effects my medicine may have on my body.					

e. In the past 4 weeks, I’ve been unsure about why I’m taking medicine.					

6. The following questions ask how you've felt about <u>being HIV positive</u> in the past 4 weeks:					
	All of the time 1	**A lot of the time 2**	**Some of the time 3**	**A little of the time 4**	**None of the time 5**
a. In the past 4 weeks, I've had regrets about the way I lived my life before knowing I had HIV.					
b. In the past 4 weeks, I've been angry about my past HIV risk behavior.					

7. The following questions ask about your <u>disclosure worries</u> in the past 4 weeks:					
	All of the time 1	**A lot of the time 2**	**Some of the time 3**	**A little of the time 4**	**None of the time 5**
a. In the past 4 weeks, I've limited what I tell others about myself.					
b. In the past 4 weeks, I've been afraid to tell other people that I have HIV.					
c. In the past 4 weeks, I've been worried about my family members finding out that I have HIV.					
d. In the past 4 weeks, I've been worried about people at my job/routine daily activities finding out that I have HIV.					
e. In the past 4 weeks, I've been worried that I'll lose my source of income if other people find out that I have HIV.					

Total Scale: 29 Items

- I. **Overall Function Dimension (6 Items):** Items 1a, 1b, 1c, 1d, 1e, 1f
- II. **Life Satisfaction Dimension (4 Items):** Items 2a, 2b, 2c, 2d
- III. **Health Worries Dimension (4 Items):** Items 3a, 3b, 3c, 3d
- IV. **Financial Worries Dimension (3 Items):** Items 4a, 4b, 4c
- V. **Medication Worries Dimension (5 Items):** Items 5a, 5b, 5c, 5d, 5e
- VI. **HIV Mastery Dimension (2 Items):** Items 6a, 6b
- VII. **Disclosure Worries Dimension (5 Items):** Items 7a, 7b, 7c, 7d, 7e

Scoring:

1. Items are scored as follows: (1) all of the time; (2) a lot of the time; (3) some of the time; (4) a little of the time; and (5) none of the time.
2. Reverse score items 1a, 2a, 2b, 2c, and 2d.
3. Each dimension's score is calculated by adding the raw values of the items belonging to each dimension. If the response to one item in a dimension is not completed, the average imputed value of the other completed items in the dimension substitutes for the missing item (as long as at least half of the other items have been completed).
4. Each dimension is scored so that the final dimension score is transformed to a linear 0 to 100 scale, where 0 is the worst score possible and 100 is the best score possible.
    - a. **Overall Function:** Fx100 = (100/(30-6))*(Fx-6)
    - b. **Life Satisfaction:** LifSat100 = (100/20-4))*(LifSat-4)
    - c. **Health Worries:** Hlth100 = (100/20-4))*(Hlth-4)
    - d. **Financial Worries:** Fin100 = (100/(15-3))*(Fin-3)
    - e. **Medication Worries:** Med100 = (100/(25-5))*(Med-5)
    - f. **HIV Mastery Worries:** HIV100 = (100/(10-2))*(HIV-2)
    - g. **Disclosure Worries:** Disclose100 = (100/(25-5))*(Disclose-5)

References:

Holmes, W. C., & Shea, J. A. (1997). Performance of a new, HIV/AIDS-targeted quality of life (HAT-QoL) instrument in asymptomatic seropositive individuals. *Quality of Life Research, 6,* 561-571.

Holmes, W. C., & Shea, J. A. (1998). A new HIV/AIDS-targeted quality of life (HAT-QoL) instrument: Development, reliability and validity. *Medical Care, 36,* 138-154.

Appendix E

Social & Health Demographics

1. ____ Age in years

2. Are you:
   ___Married
   ___Single
   ___Separated
   ___Divorced
   ___Domestic Partnership
   ___Other, please list ______________________

3. What is the highest level of education you have completed? (Check one)
   ___ 11th grade or less
   ___ High school or GED
   ___ 2 years of college/AA degree/technical school training
   ___ College (BA or BS)
   ___ Master's degree
   ___ Doctorate/medical degree/law degree

4. What is your annual income?_____________

5. Do you have health insurance?
   ___ No
   ___ Yes

6. If you have health insurance, what type of health insurance do you have?
   ___Medicaid
   ___Medicare
   ___ADAP
   ___Veteran's Benefits
   ___Private, provided by work
   ___Private, not provided by work

7. Do you have any children?
   ___ No
   ___ Yes
   If yes, how many live with you? _____

8. Do you work for pay?
___ No
___ Yes

9. Do you have permanent housing?
___ No
___ Yes

10. Have you ever been told that you have AIDS?
___ No
___ Yes
If yes, what year? __________

11. After being diagnosed with HIV, how many years passed before you sought medical care? __________

12. What is your most recent CD4 or T-cell count? _____

13. What is your most recent viral load? _____

14. Do you have any other health conditions? (For example, high blood pressure, diabetes, depression, hepatitis)
____ No
____ Yes
If yes, please list the condition(s)
____
____
____
____

15. Have you ever been prescribed HAART (HIV medications)?
____ Yes
____ No

16. In the past 12 months, have you been to the Emergency Department?
____ Yes
____ No

Appendix F

Publishing Agreement

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S.AKaihura
Alphoncina John Kaihura

December 4, 2013
Date