

STIGMA, PSYCHOLOGICAL DISTRESS, AND HEALTH-RELATED QUALITY OF LIFE
AMONG PERSONS LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS/ACQUIRED
IMMUNE DEFICIENCY SYNDROME (HIV/AIDS) IN THE UNITED STATES

By

JACOB JOHN VAN DEN BERG

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL
OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2009

© 2009 Jacob J. van den Berg

To my Mother and Father who taught me the value of perseverance, no matter the obstacle

ACKNOWLEDGMENTS

It is with great enthusiasm and pride that I thank the many people who have supported me throughout my entire dissertation process. I must first acknowledge all the encouragement that I received from my family and friends despite the significant personal challenges that they have encountered over the years. In particular, I would like to thank my father, Jacobus F. van den Berg, mother, Marie A. van den Berg, brother, Erik J. van den Berg, sister-in-law, Lisa van den Berg, and nephew, Alexander J. van den Berg for understanding that I would not be available to them as often as they would have liked while I was working on my dissertation. I know that you did not always understand what I was doing, or why I was still in school instead of having a "real" job, but I hope you know I missed you all and that it finally paid off in the end. I would also like to especially thank my life partner, Christopher S. Chambers, who despite many late-night conversations of me wanting to give up on this project listened patiently and calmly reassured me that I would make it through by casting away all of my fears and doubts. Your insights and advice on how I should approach the topic of stigma and discrimination from a sociological perspective were invaluable to me. I could not have completed this project without the unwavering love and support of my best friend, Denise M. Bonilla, who has always been there for me no matter what and whose wisdom I have always cherished. I greatly value your superior writing and editing skills, as well as your assistance with recruiting participants for this study. I would like to thank my dear friend, Erin P. Moore, who always knows how to cheer me up and continues to be the eternal optimist in my life.

I am also extremely grateful for the guidance of my dissertation committee at the University of Florida. I especially would like to express my warmest gratitude to my dissertation chairperson, Dr. Carolyn M. Tucker, who gave me lots of constructive feedback and put forth a great deal of energy into developing this research endeavor into an "excellent" project. I must

also thank my other dissertation committee members, Dr. Bonnie Moradi, Dr. Julie Graber, and Dr. Constance Shehan, for their flexibility and patience with me. I appreciated the combination of your expertise and unique perspectives. I would like to particularly thank Dr. Catherine Zimmer at the University of North Carolina at Chapel Hill for her guidance and wisdom on my dissertation. You were always there to listen to me no matter what and were able to understand exactly what I was trying to say. I would also like to acknowledge Dr. Kathleen J. Sikkema, Dr. Rae Jean Proescholdbell, and Dr. Baishakhi B. Taylor at Duke University who read early versions of my dissertation and gave me helpful feedback and support along the way. Last, but not least, I would like to thank all of the individuals who participated in this research and for whom I would have not been able to complete this project without their assistance. I hope and pray that the information collected from this study will directly benefit all persons living with human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) to experience happier and more fulfilled lives. As I embark on the next chapter of my professional career, I will take with me all the lessons that I have learned in graduate school and the knowledge that I have acquired from completing this dissertation project.

TABLE OF CONTENTS

	<u>page</u>
ACKNOWLEDGMENTS	4
LIST OF TABLES	9
LIST OF FIGURES	10
LIST OF ABBREVIATIONS	11
ABSTRACT	13
CHAPTER	
1 INTRODUCTION	15
The Acquired Immune Deficiency Syndrome (AIDS) Epidemic in the United States (US)	15
Calls for Action to Address the AIDS Epidemic in the US	16
The Concept of Stigma	18
The Concept of Discrimination	19
Interrelated Components of Stigma	20
Representations of Stigma and Discrimination	21
Why Stigmatization and Discrimination May Occur	24
How Stigmatization and Discrimination Are Likely Maintained	26
Human Immunodeficiency Virus (HIV)/AIDS-Related Stigma and Discrimination	27
Defining HIV/AIDS-Related Stigma	29
Conceptual Frameworks for Understanding HIV/AIDS-Related Stigma	29
Psychological Distress	33
Health-Related Quality of Life	34
Social Support	34
Perceived Patient-Centered Cultural Sensitivity in Health Care Experienced	36
Perceived Discrimination in Health Care and Demographic Characteristics	37
Statement of the Problem	38
Purpose of the Present Study	38
Hypotheses and Exploratory Research Questions	39
2 REVIEW OF THE LITERATURE	41
Dimensions of HIV/AIDS-Related Stigma	42
Assessing HIV/AIDS-Related Stigma	44
Impact of HIV/AIDS-Related Stigma on Psychological Distress	45
Impact of HIV/AIDS-Related Stigma on Health-Related Quality of Life	48
Patient-Health Care Provider Relationship for Persons Living with HIV/AIDS (PLWHA)	50

	Patient-Centered Culturally Sensitive Health Care	51
	Social Support, HIV/AIDS-Related Stigma, and Psychological Distress	53
	Social Support, HIV/AIDS-Related Stigma, and Health-Related Quality of Life	54
	Demographic Characteristics and HIV/AIDS-Related Stigma.....	55
	Summary of Literature Review	56
	Model of Hypothesized Relationships.....	57
3	METHOD	59
	Participants	59
	Procedure	61
	Participant Recruitment.....	61
	Data Collection.....	62
	Instruments	64
	Demographic and Medical Information Variables	64
	HIV/AIDS-Related Stigma Measures.....	64
	Psychological Distress.....	67
	Social Support.....	68
	Health-Related Quality of Life	69
	Social Discrimination	70
	Patient-Centered Culturally Sensitive Health Care	71
	Social Desirability	72
4	RESULTS.....	76
	Preliminary Analyses.....	76
	Descriptive Statistics for the Major Investigated Variables	77
	Results of Preliminary Pearson Correlations.....	79
	Results of Analyses to Test Hypotheses 1 and 2	82
	Hypothesis 1	82
	Hypothesis 2	83
	Results of Analyses to Test Exploratory Research Questions 1, 2, and 3	83
	Exploratory Research Question 1	83
	Exploratory Research Question 2.....	87
	Exploratory Research Question 3	90
5	DISCUSSION.....	103
	Summary and Interpretation of Findings.....	103
	Correlations Among Investigated Variables of Interest.....	104
	Correlations Among Investigated Variables of Interest and Demographic Variables ..	108
	Hypotheses 1 and 2.....	114
	Hypothesis 1	114
	Hypothesis 2	115
	Exploratory Research Questions 1, 2, & 3	115
	Exploratory Research Question 1	115
	Exploratory Research Question 2.....	116

Exploratory Research Question 3	117
Limitations and Directions for Future Research.....	117
Sampling Limitations	118
Survey Limitations	118
Research Design Limitations.....	119
Conclusions.....	120
Implications for Public Health Educators, Health Care Professionals, and Policymakers...	120

APPENDIX

A INFORMED CONSENT	125
B DEMOGRAPHIC AND MEDICAL INFORMATION QUESTIONNAIRE.....	126
C ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) STIGMA MEASURE (ASM).....	133
D MENTAL HEALTH INVENTORY (MHI).....	137
E MEDICAL OUTCOMES STUDY SOCIAL SUPPORT SURVEY (MOSS-SSS)	143
F WORLD HEALTH ORGANIZATION QUALITY OF LIFE-BREF (WHOQOL-BREF).145	
G EXPERIENCES OF SOCIAL DISCRIMINATION (ESD).....	148
H HUMAN IMMUNODEFICIENCY VIRUS (HIV) STIGMA SCALE-REVISED (HSS- R)	151
I HIV STIGMA SCALE (HSS).....	153
J MARLOWE-CROWNE SOCIAL DESIRABILITY SCALE – SHORT FORM C (M-CSDS-SFC)	154
K TUCKER-CULTURALLY SENSITIVE HEALTHCARE INVENTORY-PATIENT FORM (T-CSHI-PF).....	155
L DEBRIEFING FORM	163
M RECRUITMENT FLYER	164
REFERENCES	165
BIOGRAPHICAL SKETCH	180

LIST OF TABLES

<u>Table</u>	<u>page</u>
3-1 Demographic characteristics of the final participant sample.....	74
3-2 Medical characteristics of the final participant sample.....	75
4-1 Descriptive data for the major variables of interest.....	92
4-2 Pearson correlations for the major investigated variables including social desirability....	93
4-3 Partial correlations to test hypothesis 1 and hypothesis 2 controlling for age, gender, race, and sexual orientation.....	94
4-4 Moderating effect of social support (centered) on the relation between stigma (centered) and psychological distress to examine research question 1.....	95
4-4 Moderating effect of social support (centered) on the relation between stigma (centered) and psychological distress to examine research question 1 (continued).....	96
4-5 Moderating effect of social support (centered) and cultural sensitivity (centered) on the relation between stigma (centered) and quality of life to examine research question 2.....	97
4-5 Moderating effect of social support (centered) and cultural sensitivity (centered) on the relation between stigma (centered) and quality of life to examine research question 2 (continued).....	98
4-5 Moderating effect of social support (centered) and cultural sensitivity (centered) on the relation between stigma (centered) and quality of life to examine research question 2 (continued).....	99
4-6 Multiple linear regression analysis with stigma and demographic variables to examine research question 3.....	100

LIST OF FIGURES

<u>Figure</u>		<u>page</u>
2-1	The patient-centered culturally sensitive health care (PC-CSHC) model	57
2-2	Hypothesized relationships among variables of interest.....	58
4-1	Plot of regression lines showing how the significant interaction between social support (centered) and stigma (centered) influenced psychological distress.....	101
4-2	Plot of regression lines showing how the significant interaction between cultural sensitivity (centered) and stigma (centered) influenced quality of life.....	102

LIST OF ABBREVIATIONS

AB	Assessment Battery
AIDS	Acquired Immune Deficiency Syndrome
ANCOVA	Analysis of Covariance
ASM	AIDS Stigma Measure
CD4	Cluster Designation 4 (T helper cells are responsible for coordinating much of the immune response. HIV's preferred targets are cells that have a docking molecule called "cluster designation 4" on their cells).
CDC	Centers for Disease Control and Prevention
DMIS	Demographic and Medical Information Questionnaire
ESD	Experiences of Social Discrimination
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HSS-P	HIV Stigma Scale - Perceived
HSS-R	HIV Stigma Scale - Revised
IHS	Internalized HIV Stigma
IDU	Injection Drug Use
IP	Internet Protocol
MCSDS-SFC	Marlowe-Crowne Social Desirability Scale-Short Form C
MHI	Mental Health Inventory
MOS-SSS	Medical Outcomes Study-Social Support Survey
MTM	Male-to-Male
PC-CSHC	Patient-Centered Culturally Sensitive Healthcare

PLWHA	Persons Living with HIV/AIDS
T-CSHI-PF	Tucker-Culturally Sensitive Healthcare Inventory-Patient Form
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
US	United States
WHO	World Health Organization
WHOQOL-BREF	World Health Organization Quality of Life-BREF

Abstract of Dissertation Presented to the Graduate School
of the University of Florida in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy

STIGMA, PSYCHOLOGICAL DISTRESS, AND HEALTH-RELATED QUALITY OF LIFE
AMONG PERSONS LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS/ACQUIRED
IMMUNE DEFICIENCY SYNDROME (HIV/AIDS) IN THE UNITED STATES

By

Jacob John van den Berg

December 2009

Chair: Carolyn M. Tucker
Major: Counseling Psychology

The purpose of the present study was to investigate the associations between human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS)-related stigma and both psychological distress and health-related quality of life among persons living with HIV/AIDS (PLWHA) in the United States. In addition, whether these associations are moderated by social support and perceived patient-centered cultural sensitivity in health care experienced was examined.

Participants were 193 self-identified PLWHA recruited through HIV/AIDS Internet listservs and groups, and through snowball sampling techniques. Participants anonymously completed a security protected online survey that included instruments to measure the following variables of interest: (a) demographic and medical characteristics, (b) HIV/AIDS-related stigma, (c) psychological distress, (d) social support, (e) health-related quality of life, (f) experiences of social discrimination, (g) perceived patient-centered cultural sensitivity in health care experienced, and (h) social desirability.

Consistent with hypotheses, results indicated that level of experiences of social discrimination was related positively and significantly to HIV/AIDS-related stigma. In addition,

level of perceived patient-centered cultural sensitivity in health care experienced was related negatively and significantly to HIV/AIDS-related stigma.

Exploratory research questions revealed that social support significantly moderated the relationship between HIV/AIDS-related stigma and psychological distress, such that the strength of the association between HIV/AIDS-related stigma and psychological distress was lessened for PLWHA who reported higher levels of social support. Furthermore, perceived patient-centered cultural sensitivity in health care experienced was shown to have a significant moderating effect on the relationship between HIV/AIDS-related stigma and health-related quality of life, such that the strength of the association between HIV/AIDS-related stigma and health-related quality of life was lessened for PLWHA who reported higher levels of perceived patient-centered cultural sensitivity in health care experienced. Significant differences in HIV/AIDS-related stigma scores in association with gender and race but not sexual orientation were also found in the present study. Specifically, women had higher levels of HIV/AIDS-related stigma scores than men and African Americans/Blacks and other races had higher levels of HIV/AIDS-related stigma scores than Caucasian Americans/Whites. However, HIV/AIDS-related stigma scores did not differ significantly for heterosexuals, bisexuals, and gays/lesbians.

CHAPTER 1 INTRODUCTION

The Acquired Immune Deficiency Syndrome (AIDS) Epidemic in the United States (US)

The Centers for Disease Control and Prevention (CDC) in the United States (US) reported that at the end of 2003 between 1,039,000 and 1,185,000 adults and children were currently living with human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS), and that about 24-27% of these individuals were undiagnosed and unaware of their serostatus.¹ By the end of 2005, it was estimated that 341,524 males, 126,964 females, and 6,726 children (<13 years of age at diagnosis) were all living with HIV or AIDS in this country.² In particular, Americans 40-44 years old (101,027) and non-Hispanic Blacks (224,815) accounted for the highest numbers of persons living with HIV or AIDS (PLWHA). Furthermore, male-to-male (MTM) sexual contact continued to be the number one mode of transmission followed by high risk heterosexual contact, injection drug use (IDU), and MTM sexual contact and IDU combined (CDC, 2007).

Although the number of PLWHA is high in the US, current empirical data documenting the experience of PLWHA, remain limited. In particular, research on stigma and discrimination is greatly warranted as they have been identified as major barriers to satisfactory health care and quality of life among PLWHA (Deacon, 2006). Despite some recent attempts to elucidate the processes by which stigma and discrimination impacts the health and well-being of PLWHA (e.g., Busza, 2001; Deacon, 2006; Link & Phelan, 2001), pleas for dealing with stigma and discrimination have been made over the last 20 years by researchers, social activists, and public health officials around the world. In the next section, a discussion of the nature and content of

¹ These are the most recent statistics reported by the CDC to date.

² CDC notes that these estimates of the number of persons living with HIV/AIDS were for 33 states and US dependent areas with confidential name-based HIV infection reporting.

these pleas/concerns and how the present study best addresses a gap in current HIV/AIDS-related stigma research is presented.

Calls for Action to Address the AIDS Epidemic in the US

Calls for combating the deleterious effects of HIV/AIDS-related stigma and discrimination have been made since the mid-1980s. In a statement given to the United Nations General Assembly in 1987, the Founding Director of the World Health Organization's Global Programme on AIDS (known today as the Joint United Nations Programme on HIV/AIDS or UNAIDS), Jonathan Mann, identified three phases of the AIDS epidemic³ in any community. According to Mann (1987), the first phase is characterized by the silent and unnoticeable spread of HIV throughout communities over many years without being widely perceived or understood. The second phase includes, after some unspecified amount of time, the development of AIDS-related illnesses (i.e., Kaposi's sarcoma and pneumocystis carinii pneumonia) that arises as a direct result of HIV infection. The third and final phase is marked by the social, cultural, economic, and political responses to AIDS, including the stigmatization and discrimination of PLWHA (Mann, 1987).

Although this proclamation by Mann was an early identification of the potential harmful consequences of HIV/AIDS-related stigma and discrimination, very little was done to address this problem over the next decade. In fact, it took approximately 13 years before public health officials and researchers attempted to contend with this enduring predicament and for it to be seen as a continuing challenge to fighting the AIDS pandemic.⁴ In 2000, the Executive Director of UNAIDS, Peter Piot stated in an address to the agency's Programme Coordinating Board that, "effectively addressing stigma removes what still stands as a roadblock to concerted action,

³ The CDC's official definition of an epidemic is: "The occurrence of more cases of disease than expected in a given area or among a specific group of people over a particular period of time."

⁴ A pandemic is a very extensive epidemic, like a plague, that is prevalent in a country, continent, or the world.

whether at the local community, national or global level" (Piot, 2000, p. 2) A couple of years later, the theme for the 2002-2003 World AIDS Campaign focused solely on that of HIV/AIDS-related stigma and discrimination, demonstrating the resurgence and urgency of this topic. Secretary General of the United Nations, Kofi Annan in his message on World AIDS Day in 2003 captured the importance of contending with HIV/AIDS-related stigma and discrimination by proclaiming that,

...No progress will be achieved by being timid, refusing to face unpleasant facts, or prejudging our fellow human beings – still less by stigmatizing people living with HIV/AIDS. Let no one imagine that we can protect ourselves by building barriers between 'us' and 'them.' In the ruthless world of AIDS, there is no us and them. And in that world, silence is death...Join me in tearing down the walls of silence, stigma and discrimination that surround the epidemic. Join me, because the fight against HIV/AIDS begins with you (Annan, 2003, p. 1).

It is this fear and ignorance of difference that creates a separation between individuals or groups (commonly referred to as the "us" versus "them" dichotomy) that continues to prevent further progress from being made in the fight against HIV/AIDS. Thus, understanding HIV/AIDS-related stigma and discrimination, why it occurs, and how to prevent it from happening is vital to stopping the spread of HIV and improving the lives of those infected and affected by this disease.

In order to fully comprehend how and why HIV/AIDS-related stigma and discrimination arises in any community, it is first important to explore the general concepts of stigma and discrimination. In the next section, the ways in which stigma and discrimination have been defined and conceptualized in the empirical literature and popular discourse is presented. Second, an illustration of stigma and discrimination from American Literature and some historical representations of stigma and discrimination over time are discussed. Third, an identification of how HIV/AIDS-related stigma and discrimination has been described in the extant literature as the epidemic has evolved in the US is provided. Fourth, the reasons why

stigmatization and discrimination may occur among PLWHA today are explored. Fifth, two conceptual frameworks for understanding HIV/AIDS-related stigma and discrimination are identified.

The Concept of Stigma

In both popular discourse and the empirical literature, stigma is typically understood to be a "mark of disgrace." This understanding of stigma can be traced back to Erving Goffman's (1963) explanation of stigma in his landmark book entitled, *Stigma: Notes on the Management of Spoiled Identity*, as an "attribute that is deeply discredited" and that reduces the bearer "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p.3). Building upon Goffman's definition, some authors also refer to an interrelated aspect of stigma like rejection and stereotyping (Link & Phelan, 2001).

Over the last three decades, several other conceptualizations of stigma have been identified in the extant literature. For example, Jones, Farina, Hastorf, Markus, Miller, and Scott (1984) argued that stigma can be seen as a relationship between an "attribute and a stereotype to produce a definition of stigma as a mark that links a person to undesirable characteristics" (Jones et al., 1984, p. 5). Similarly, Stafford and Scott (1986) noted that stigma is "a characteristic of persons that is contrary to a norm of a social unit" where a norm is defined as "a shared belief that a person ought to behave in a certain way at a certain time" (Stafford & Scott, 1986, p. 80). In the same way, Crocker, Major, and Steele (1998) indicated that "stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context" (Crocker et al., 1998, p. 505).

Although each of these conceptualizations has a slightly different emphasis in their explanation of stigma, they are all focused on the social classification of the individual. In other words, these definitions center on others' perceptions of the individual and the social

consequences that result from such perceptions at the micro-level. Thus, stigma is a trait, characteristic or state of being that is viewed as fundamental to the person and discrimination is the result of others' treatment of the person due to that stigmatized classification⁵. Persons who hold negative attitudes or who enact stigmatizing or discriminatory behavior have been referred to as perpetrators of stigma and discrimination (Herek & Capitano, 1999; Sayce, 1998). In contrast, those with or associated with the condition (e.g., HIV) or the behavior (e.g., promiscuous sex) are considered the targets of stigma and discrimination.

The Concept of Discrimination

Discrimination has been defined as "overt negative and unequal treatment of the members of a social group or stratum solely because of their membership in that group or stratum" (Anderson & Taylor, 2006, p.278). For instance, person or group X labeling and stereotyping of person or group Y leads person or group X to engage in some form of overt discrimination directed at person or group Y, such as refusing to rent her or him an apartment, rejecting her or his job application, or declining her or his membership into an organization. In addition, the experience of discrimination is commonly based upon a devalued status position in such social categories as age, race, ethnicity, gender, religion, sexual orientation, disability, health status, national origin, and political affiliation.

Besides the discrimination that is enacted by one person or group against another person or group, there is also structural discrimination (Link, 2001). One example of structural discrimination would be institutional racism where on-going and regular organizational practices work to the disadvantage of racial minority groups even in the absence of individual prejudice or discrimination. When hiring, employers who are more often than not male, heterosexual, white,

⁵ I conceptualize discrimination as the by-product of stigma. In other words, discrimination is the end result of stigma.

and affluent tend to rely on the personal hiring recommendations of colleagues or acquaintances that are similar in terms of their characteristics for hiring decisions. Thus, persons of color applying for employment having been excluded from these private social networks tend to be at a greater disadvantage for job opportunities than their white counterparts (Fernandez, Castilla, & Moore, 2000; Fernandez & Weinberg, 1997; Royster, 2003). In deed, similar kinds of structural discrimination are present for other stigmatized groups as well.

Interrelated Components of Stigma

In their conceptualization, Link and Phelan (2001) extended the definition of stigma originally proposed by Goffman and others to include the convergence of five interrelated components – labeling, stereotyping, separation, status loss, and discrimination – that are used to establish a power differential between non-stigmatized and stigmatized individuals. First, they articulated that in most societies people typically distinguish and label human differences that matter socially. For example, currently in the US issues of race and gender are particularly salient areas in which naming difference is considered socially significant, and as such these are common themes in the latest race for the presidency. Second, they argued that a stereotype is formed as a result of linking a person or group to a set of undesirable characteristics. For instance, a common stereotype held in American society is that men have stronger mathematical abilities than women. Third, they contended that after social labeling and stereotyping occurs, a separation of "us" from "them" eventually develops. That is, in many societies there are individuals who are a part of the in-group ("us") and those that are set apart into the out-group ("them"). Fourth, they asserted that after the first three interrelated components (i.e., labeling, stereotyping, and separation) have been established, a justification is then formed by non-stigmatized individuals for devaluing, rejecting, and excluding stigmatized persons who, in turn, experience status loss and discrimination (the last two interrelated components) as a

consequence. For example, people perceived to be Arab experience racial profiling at airports under the rationale that these persons must be terrorists.

While some authors have challenged and expanded upon these varied definitions and conceptualizations of stigma and discrimination, most scholars and researchers investigating this topic today agree that the existence and prevalence of stigma and discrimination throughout history is clearly evident (Heatherton, Kleck, Hebl, & Hull, 2000). In the next section, a vivid representation of stigma and discrimination from American literature and history are offered to highlight the experience of these concepts. In addition, a connection is made between these examples and Link and Phelan's (2001) conceptualization of stigma and discrimination.

Representations of Stigma and Discrimination

Perhaps one of the most notable examples of the depiction of stigma and discrimination from American Literature is the story of Hester Prynne in Nathaniel Hawthorne's (1850) novel, *The Scarlet Letter*. In this book, Hester is forced to wear a prominent scarlet letter "A" on her clothes over her bosom as a mark to symbolize her crime of adultery and having a child out of wedlock. In addition to displaying the scarlet letter, she also experiences public shaming in the form of verbal and physical abuse for her sin of having a secret affair with the town minister. In fact, the first part of her sentencing is to stand on a scaffold for public viewing for three hours in the middle of the towns square for all to chastise her.

In the mid-1600s Puritan society of Boston, Massachusetts portrayed by Hawthorne, Hester is especially castigated by the women of the colony. Hawthorne vividly illustrates their smugly pious attitude towards Hester when he writes that some of the women thought she should be, "scalded with a hot iron applied to her forehead," branding her as an immoral woman. Despite Hester's apparent humility and refusal to strike back at the community, she actually resents and inwardly rebels against the viciousness of her persecutors by saying nothing and

internalizing her feelings. Ultimately, she becomes a living symbol of sin to the townspeople, who view her not as an individual but as the embodiment of evil in the world.

Although banished by this society to live her life forever as a social outcast, Hester's skill in needlework is highly sought after by the same community members most appalled by her past immoral behavior. However, they deem their desire for her work as almost charity, as if they are doing her a favor in having her sew outfits for them. Even though she is asked by the townspeople to create clothing to be worn at official ceremonies and by the fashionable women of the town, she is never allowed to make garments for weddings because it is believed that she might contaminate the sacredness of marriage were she to do so.

In essence, the character of Hester is meant to be understood as the embodiment of "the sinner." Through the town's treatment of her, we are given a critical look at the effect of public scorn on human nature. Hester goes from being a radiant beauty before her condemnation to a dreary and uninspired person throughout the course of the novel. She is seen by the townspeople as having fallen from grace, a culprit who deserves the ignominy of her sins. Hester contends with her recognition of the letter's symbolism just as the community members struggle with their moral choices. The irony is that the Puritans stigmatize her with the mark of her sin and, in so doing, reduce her to a dull, lifeless woman whose characteristic color is gray and whose vitality and femininity are suppressed.

Hawthorne's description of stigma and the process of discrimination are consistent with Link and Phelan's (2001) conceptualization presented earlier. First, Hester is labeled as an adulterer for having a clandestine affair and illegitimate child (Labeling). Second, stereotypes about her are formed by the townspeople immediately after her actions have been discovered (Stereotyping). Third, a separation between her and the community members is seen through her

sentence forcing her to exist on the fringes of society (Separation). Fourth, although she is allowed to make some clothes for the townspeople, she is restricted from making anything related to a wedding (Status Loss and Discrimination).

Besides Hawthorne's vivid illustration of stigma and discrimination, literature abounds with many others. For example, Dickens' *Oliver Twist* powerfully depicts stigma and discrimination attached to poverty in the eighteenth century. Shaw's *Pygmalion*, written in the early twentieth century, deals with the stigma connected to social class in Victorian England. The American writer Theodore Dreiser portrays the fate of single women in the nineteenth century in his novel, *Jennie Gerhardt*. Finally, stigma that engulfs a whole family is a theme that Steinbeck forcefully explores in the twentieth-century novel, *The Grapes of Wrath*.

In addition to literary depictions of stigma and discrimination, we can also find historical representations of these concepts. It is these historical examples that confirm the existence of stigma and discrimination. During the Second World War in Nazi Germany, the Nazis devised a classification system for concentration camp prisoners in order to quickly identify the reasons why persons had been imprisoned at the camp. Primarily represented as inverted triangles sewn on jackets and shirts of the prisoners, these mandatory badges had specific meaning indicated by their color and shape. For instance, male prisoners in concentration camps who were sent there because of their sexuality were forced to display an upside-down pink triangle on their prison uniforms as a badge to denote their homosexuality or bisexuality (Plant, 1988). Similarly, Jews were required to wear the Star of David represented as two superimposed yellow triangles, women jailed for "anti-social behavior" (e.g., lesbians, prostitutes, or women who used birth control) had to display a reversed black triangle, and political prisoners (e.g., social democrats, anarchists) had to wear an upturned red triangle on their garments. Also customary in the

classification system were combinations of triangles put together as a way to signify multiple identities. For example, it would be common to see prisoners with at least two and as many as six markings of categorization. Furthermore, some groups had to put letter insignia (i.e., "P" for Poles or "B" for Belgians) on their triangles to designate their country of origin (Plant, 1988).

Long before the classification system for prisoners was devised by the Nazis, historians have documented what has been noted as the origin of the term "stigma" in Ancient Greece (Dovidio, Major, & Crocker, 2000). In an effort to ensure that their valuable property would be safe and runaway slaves would be returned to their owners, the Greeks tattooed their slaves with a pointed instrument. Such a device pricked the skin and made a mark called a "stigma;" coming from the Greek word "stig," which means "to prick" (Harvey, 2001). Centuries later this process of branding or marking one's slaves in order to denote them as property would be carried over to American society and the treatment of African slaves.

Although these examples provide a context for how stigmatization and discrimination had occurred and been discussed in the past, it is less clear as to why stigmatization and discrimination continues to occur today. In the next section, the process by which stigmatization and discrimination may take place is identified. In addition, an exploration of how stigmatization and discrimination are likely maintained in most societies and a brief review of the literature on HIV/AIDS-related stigmatization and discrimination in the US is presented.

Why Stigmatization and Discrimination May Occur

Link and Phelan (2001) provided a rationale as to why stigmatization and discrimination may surface. In most societies, they contended, a status hierarchy emerges in order to enforce order and control. When a person is connected to an unfavorable trait (e.g., a life threatening illness, physical handicap, or homosexuality), it diminishes his or her position in the eyes of the stigmatizer. In most cases, a downward placement of a person on a status hierarchy is an almost

immediate outcome of successfully applying negative labels and stereotypes to that individual. Once the stigmatized persons' position has been reduced on that social hierarchy, discrimination and social inequalities are likely to be produced by the stigmatizer and experienced by the stigmatized. Thus, a lower position on the status hierarchy can have a cascade of negative effects on all manner of opportunities (e.g., access to jobs, housing, education, and healthcare) for the stigmatized person.

In many countries, stigmatization is often used as a way to marginalize, exclude, and exercise control over persons who are considered aberrant or deviant according to the established social norms of a given society. When the general public perceives something as unavoidable and unchangeable (like HIV or AIDS), stigma and discrimination are likely to develop as a common reaction to that perceived threatening agent. Even though certain marginalized groups experienced societal rejection prior to the development of HIV/AIDS based upon other stigmatized attributes (e.g., race, sexual orientation, and social class), the disease serves to further alienate and ostracize those persons. In this way, many societies continue to relinquish themselves from the responsibility of caring for and looking after such stigmatized populations (UNAIDS, 2000).

Fundamentally, stigmatization and discrimination are ways to keep order over a person or a group of individuals who are deemed to be a threatening force for the purposes of controlling these "uncontrollable" persons. However, understanding why stigmatization and discrimination occur is only one piece of the puzzle required to eradicate these problems from society. Hence, it can be argued that another important part of erasing stigmatization and discrimination from humanity is to understand how these problems are generally maintained in any society.

How Stigmatization and Discrimination Are Likely Maintained

Once a cultural stereotype is instituted, it can impact stigmatized persons in significant ways that do not involve obvious forms of discriminatory behavior on the part of people in the immediate presence of the stigmatized person. One way to explain how stigmatization and discrimination are maintained in most societies is through a combination of labeling theory and conflict theory. According to labeling theory (Becker, 1963), people or groups are able to impose a label of "deviant" on certain other members of society that are viewed as "outsiders" to that society. Labeling theory specifically focuses attention on the process by which individuals are marked as deviant rather than on the nature of their behavior. In this way, a person's reaction to another individual or group, not the action itself, produces deviance as a result of the labeling process.

Emerging from studies of social change and order, conflict theory has become one of the main schools of thought used in sociological study. Borrowing from the social theories of Karl Marx, this body of work asserts that conflict, not equilibrium and order, defines existing social arrangements. This conflict, or competition for dominance, occurs among opposing social status groups (e.g., gender, race, class, etc.), ultimately resulting in the domination of subordinate groups through power, authority, and coercion. Dominant groups maintain their status position by creating and enforcing the social rules for success and opportunity; ensuring that the powerful continue to hold a monopoly on social power, privilege, and authority (Anderson & Taylor, 2006).

Linked with conflict theory, labeling theory can explain how those with the power to label someone as deviant and to impose sanctions exert greater power in determining deviance. Undeniably, once the stamp of deviance is applied to any individual or group, it is extremely difficult for the labeled person to recover a non-deviant identity. For example, when someone is

diagnosed as being mentally ill by a mental health professional, a label in the form of a diagnosis is placed on that person that is oftentimes difficult to remove after it has been made. Moreover, during the socialization process in most cultures, children learn at an early age what it means to be mentally ill (Angermeyer & Matschinger, 1996). Once established, people's conceptions become a lay theory of what it means to have a mental illness (Furnham & Bower, 1992). Consequently, most individuals form negative preconceived notions that if he or she is mentally ill, others will reject him or her. Negative beliefs about mental illness have an especially poignant relevance for a person who develops mental illness because the possibility of devaluation and discrimination then becomes personally relevant. Presumably, if this conception of mental illness becomes a part of an individual's worldview, it could potentially have dire psychological consequences for that person.

Although these theories may explain why stigmatization and discrimination continues to be maintained today, it is important to also identify what we already know about how PLWHA have experienced stigma and discrimination in the US. In the next section, a historical context for the emergence of HIV/AIDS-related stigma and discrimination is provided. In addition, a definition of HIV/AIDS-related stigma and discrimination by some of the leading scholars (e.g., Herek, Widamin, & Capitanio) in the field is presented.

Human Immunodeficiency Virus (HIV)/AIDS-Related Stigma and Discrimination

Since the beginning of the HIV/AIDS epidemic, PLWHA and the social groups (e.g., homosexuals, injection drug users, and racial or ethnic minorities) to which they are often associated have been stigmatized and discriminated against worldwide (Herek & Capitanio, 1993; Herek & Glunt, 1988; Herek, Capitanio, & Widamin, 2002; Mann, Tarantola, & Netter, 1992). In the early 1980's, the disease was predominately found among White gay men in Los Angeles and New York City (Herek & Capitanio, 1999). Given its strong connection with the

gay community, HIV/AIDS as it is known today, was originally referred to as "gay cancer," "gay plague," "gay disease," or "gay-related immune deficiency." Consequently, the American public originally believed that HIV-infected individuals should be quarantined or tattooed to mark their HIV serostatus (Blendon & Donelan, 1988; Singer, Rogers, & Corcoran, 1987; Stipp & Kerr, 1989).

As noted earlier, stigma has often been revealed in most societies through discrimination and physical violence against members of a stigmatized group. For PLWHA, discrimination can occur in many different forms, including but not limited to, being fired from one's job, not being offered housing opportunities, or inaccessibility of healthcare. Physical violence might consist of hitting, beating up, stabbing, or even killing someone because of their HIV serostatus. Moreover, some individuals may also express negative attitudes toward PLWHA in subtle or indirect ways. Such statements as, "I don't like that person because they seem to be sick all of the time" or "I'm scared to be around him/her because I don't want to catch what he/she has," are prime examples of such implicit attitudes (Herek, 2002, Herek et al., 2002, Zierler, Cunningham, Andersen, Shapiro, Nakazon, Morton et al. 2000).

However, people may also be more direct in their expressions of discomfort and avoidance of PLWHA. For example, some individuals may still have the false assumption that HIV/AIDS is only a "homosexual disease" and that if they avoid all gay persons they will be safe from harm. Others have conveyed more hostile forms of discrimination, such as Fred Phelps, a Baptist minister who was well-known for preaching at gay pride parades and the funerals of persons who have died of AIDS-related illnesses with slogans and banners proclaiming, "God hates fags," "AIDS cure fags," "Fags die, God laughs." Furthermore, some people may support policies to alienate PLWHA from the rest of the population (Herek & Capitanio, 1997).

Defining HIV/AIDS-Related Stigma

In recent years, Herek, Widamin, and Capitanio (2005) defined AIDS-related stigma⁶ as the "social devaluing of people perceived to have AIDS or HIV, as well as the individuals, groups, and communities with which they are associated" (Herek et al., 2005, p.16). In their work, these authors indicated that AIDS-related stigma not only effects people perceived to have HIV or AIDS but also impacts the social groups to which these individuals are typically affiliated. Thus, the experience of stigma not only affects PLWHA but anyone or anything viewed as an extension of them. This is evident in the different reactions that result from knowledge of how one may have contracted HIV. For instance, a gay man with the disease will be viewed less sympathetically than a heterosexual woman who is presumed to have contracted HIV from her unfaithful partner. Ultimately, the assumption may be that the gay man deserved what he got, whereas the heterosexual woman is a victim of her unfortunate circumstance (Herek & Capitanio, 1999). Two conceptual frameworks for understanding HIV/AIDS-related stigma that may also explain this divergent response are presented below.

Conceptual Frameworks for Understanding HIV/AIDS-Related Stigma

As previously discussed, Goffman (1963) is widely credited for conceptualizing and creating a framework for the study of stigma. In his analysis, he contended that stigma is generally manifested by the public's perception of, or attitudes towards, a person for possessing an "undesirable difference" that is inconsistent with what that particular society believes constitutes a "normal" individual. Thus, someone who is deemed to be a "blemished person" because of a particular defect (i.e., physically handicapped) is seen as less than "normal" (i.e., able-bodied persons) in the eyes of that society. Once that "difference" has been identified,

⁶While some authors only refer to either HIV stigma or AIDS stigma, I refer to it as HIV/AIDS-related stigma to explicitly include both aspects (HIV and AIDS) of the disease.

according to Goffman, it is maintained by the rules and sanctions of a society, resulting in a kind of "spoiled identity" for the stigmatized person.

Based upon his work with people suffering from mental illness, possessing physical deformities, or practicing what were thought to be socially deviant behaviors, Goffman asserted that stigma typically falls into three distinct categories: (a) abominations of the body, (b) blemishes of individual character, and (c) tribal stigma. Abominations of the body refer to physical defects that an individual might possess, such as a person without arms, legs, or hands. Blemishes of individual character include those people who were seen as having traits, such as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty inferred from a known record of a mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicide attempts, and radical political behavior. Finally, tribal stigma of race, nation, and religion is believed to be transmitted through lineages and equally contaminates all members of a family (Goffman, 1963).

According to Goffman, diseases associated with the highest degree of stigma share four common attributes: (a) the person with the disease is seen as responsible for having it, (b) the disease is progressive and incurable, (c) the disease is not well understood among the general public, and (d) the symptoms of the disease cannot be concealed easily. Applying this conceptualization of stigma to HIV/AIDS, Herek (1999) argued that HIV infection fits the profile of a condition that carries a high level of stigmatization such as that articulated by Goffman.

Herek explained that HIV-positive individuals are often blamed for their condition because there is a societal belief that contraction of the virus could have been avoided if better moral decisions had been made on the part of the infected person. He also noted that, even

though HIV is currently treatable today through such medical advancements as highly active antiretroviral therapy (HAART), it is still a progressive and incurable disease. Furthermore, Herek suggested that HIV transmission continues to be poorly understood by some people in the general public, causing them to feel threatened by the mere presence of the disease. Lastly, he stated that, although asymptomatic HIV infection can often be masked, symptoms of HIV-related illnesses cannot.

Although Goffman's analysis is still regarded as foundational on the management of stigma, it should be viewed in light of some limitations. First and foremost, Goffman's assessment of stigma is narrowly focused on static individual factors that do not take into account a constantly evolving social process. Second, his concentration on spoiled identity is formulated on the experience of 1960s Western society. In other words, his conceptualization of stigma must be viewed within a historical and cultural context. Equally, Herek has been critiqued by some contemporary scholars (e.g., Fine & Asch, 1988; Link & Phelan, 2001; Sayce, 1998) who have noted that his examination of HIV/AIDS-related stigma and discrimination tends to also lean towards a highly individualistic and Westernized rendering of the subject. Such critiques rely upon the work of the French social philosopher, Michel Foucault whose post-modernist approach to the study of social life, emphasized the ambiguous, complex and constantly shifting nature of social relationships and meanings, whereas Goffman's work emerged from a US context and emphasized the stability of socially constructed meanings obtained through interactions of stigmatized and non-stigmatized persons. Foucault was particularly interested in what he coined as the "regimes of power" embedded in different knowledge systems, and the forms of control exercised by such systems over individual, as well as social bodies (Foucault, 1977, p.33). Two influential books by Foucault entitled, *Discipline*

and Punish and *The History of Sexuality, Volume I: An introduction*, placed emphasis on what he defined as a new regime of knowledge and power that characterized modern European societies during the late-nineteenth and early twentieth centuries (Foucault 1977, 1978). Within this new regime conceptualized by Foucault, physical violence or coercion increasingly gave way to what he explained as "subjectification" or social control exercised not through physical force, but through the production of conforming subjects and docile bodies. In his critical analysis of knowledge and power, he highlighted how the social production of difference (what Goffman might have defined as deviance or deviant behavior) is linked to established systems of knowledge and power. In essence, he argued that the so-called "unnatural" is necessary for the definition of the "natural," the "abnormal" exists only to define what is "normal" (Foucault 1977, 1978).

While Goffman's examination of stigma does not directly mention dynamics of social power, and Foucault's analysis of power seems altogether unconcerned with a detailed analysis of stigma, when read together their bodies of work offer a compelling case for the role of culturally constituted stigmatization (i.e., the production of negatively valued difference) in service to specific power relations, and central to both establishing and maintaining social order. Within such a combined framework, the construction of HIV/AIDS-related stigma involves marking the difference between PLWHA and those who remain seronegative. This distinction between categories of people becomes embedded in social arrangements affirmed by the very same power dynamics that brought the system into existence. Thus, HIV/AIDS-related stigma may function quite literally at the point of intersection between culture, power, and difference.

Although Goffman and Foucault's conceptualization of stigma are both useful frameworks for understanding how and why HIV/AIDS-related stigma exists, it is also important to

investigate the impact of HIV/AIDS-related stigma on psychological distress and health-related quality of life as this examination may help to uncover some of the psychological and physical challenges faced by PLWHA. Identifying protective factors, such as social support and perceived patient-centered cultural sensitivity in health care experienced, that could assist in reducing the negative experience of HIV/AIDS-related stigma is critical. In the next section, concepts of psychological distress, health-related quality of life, social support, and perceived patient-centered cultural sensitivity in health care experienced are introduced. In addition, literature to support the inclusion of selected demographic variables (e.g., age, gender, race, sexual orientation, and social class) in the present study is provided.

Psychological Distress

Psychological distress typically refers to the experience of negative affective states, such as depression, anxiety, and loss of emotional and behavioral control (Manning & Wells, 1992). In the past, research that was originally conducted on psychological distress among PLWHA tended to focus on the psychological impact of learning that an individual was HIV-positive and with respect to disease progression (Chesney & Folkman, 1994). Previous studies have explored the relationship between HIV/AIDS-related stigma and psychological distress. For instance, Silver, Bauman, Camacho, and Hudis (2003) found in a US sample of 220 low-income, mostly ethnically diverse women with late-stage HIV/AIDS that perceived stigma was significantly and positively related to psychological distress. Similarly, Miles, Burchinal, Holditch-Davis, Wasilewski, and Christian (1997) found a significant positive association between enacted stigma and psychological distress in a sample of 54 HIV-positive mothers who were receiving treatment at infectious disease clinics in the southeastern US. In both of these studies, HIV/AIDS-related stigma was measured along one dimension of stigma (e.g., perceived or enacted). However, to the author's knowledge, there have not been any empirical studies to date

that have examined the multiple forms of HIV/AIDS-related stigma (e.g., perceived, internalized, or enacted) and their relationships to psychological distress.

Health-Related Quality of Life

Health-related quality of life is a multidimensional construct generally defined as a subjective evaluation of one's life across a number of dimensions including physical functioning, social functioning, pain, and energy (Nordenfelt, 1994). Research efforts investigating health-related quality of life for PLWHA have traditionally centered on the evaluation of the effectiveness of medical and pharmacological treatments for HIV infection (Lubek & Fries, 1993). Yet, there is a growing recognition (i.e., Aranda-Naranjo, 2004; Clayson, Wild, Quarterman, Duprat-Lomon, Kubin, & Coons, 2006) in the extant literature that for PLWHA health-related quality of life is an important outcome in and of itself.

Preliminary findings from international research conducted among community samples of PLWHA residing in Ecuador suggest a negative association between HIV/AIDS-related stigma and health-related quality of life. For instance, Ayarza and Reyes (2002) identified the traumatic impact that stigmatization had on the health-related quality of life among their sample of 42 HIV-positive Ecuadorians. Castle, Cornu, Dua, Herrera, Nadkarni, Ouedraogo et al. (2002) and Ortega, Gonzales, and Liwanag (2002) reported finding that access to services that offer peer social support often ends self-isolation and reduces stigma, and thus enhances health-related quality of life. Thus, understanding the impact of HIV/AIDS-related stigma on health-related quality of life among a US population is an area rife for fruitful discovery that was explored in the present study.

Social Support

Social support can be defined as the degree to which a person's basic social needs are gratified through interaction with others, such as family members, friends, and co-workers

(Thoits, 1995). Basic social needs often include affection, esteem or approval, belonging, identity, and security. These needs may be met by either the provision of what has been referred to as "socio-emotional aid" (e.g., affection, sympathy and understanding, acceptance, and esteem from significant others) or the offering of "instrumental aid" (e.g., advice, information, help with family or work responsibilities, or financial support). Instrumental and socio-emotional aid share a reciprocal relationship in that practical help from others assures the individual that he or she is cared about (House & Kahn, 1985). Social support is often considered to be an important resource for people coping with the challenges of chronic illness and disability and is thought to be a potential avenue for intervention with PLWHA in order to address stigmatization.

Some researchers have noted that social support may improve one's health by enhancing access to resources and improving health-related behaviors. For instance, Turner and Turner (1999) suggested that integration into supportive networks helps to improve mental and physical health by reducing levels of stress or by buffering individuals from stressors that typically diminish health and well-being. Other researchers have found that connection to social supports reduces health risk behaviors and increases emotional bonding through the provision of information and advice, and positive peer influence (Ennett, Bailey, & Federman, 1999; Litwak & Messeri, 1989; Resnick, Bearman, Blum, Bauman, Harris, Jones et al., 1997).

Recently, Swendemen, Rotheram-Borus, Comulada, Weiss, and Ramos (2006) suggested that social support may assist in decreasing the experience of HIV/AIDS-related stigma, which in turn, might reduce the experience of psychological distress among PLWHA. In previous health-related research, social support has been identified as a moderator of the relationship between stress and health outcomes and stress and depressed mood (Petersen, Folkman, & Bakeman, 1996; Winefield, Winefield, & Tiggemann, 1992). Thus, social support in the present study was

explored as a potential moderator between HIV/AIDS-related stigma and psychological distress, as well as between HIV/AIDS-related stigma and health-related quality of life.

Perceived Patient-Centered Cultural Sensitivity in Health Care Experienced

Perceived patient-centered cultural sensitivity in health care experienced has been described as “cultural competence plus” and has the following specific characteristics: (a) it emphasizes displaying patient-desired modifiable provider and staff behaviors and attitudes, implementing healthcare center policies, and displaying physical healthcare center environment characteristics that culturally diverse patients identify as indicators of respect for their culture and that enable these patients to feel comfortable with, trusting of and respected by their health care providers and office staff; (b) it conceptualizes the patient-provider relationship as a partnership that emerges from patient-centeredness; and (c) it is patient empowerment oriented (Tucker, Mirsu-Paun, van den Berg, Ferdinand, Jones, Curry et al., 2007).

Among HIV-positive individuals, prior research has documented that the quality of and satisfaction with the patient-provider relationship is positively associated with medication adherence and positive health outcomes. A qualitative study conducted by Roberts (2002) with 28 HIV-positive patients recruited from an urban public health clinic in San Francisco, California suggested that poor patient-physician relationships impeded antiretroviral medication adherence. In a similar vein, a separate study found that patients with HIV/AIDS who were not being treated with antiretroviral medications had more negative perceptions of their health care experience and health care providers than those who were being treated with antiretroviral medications (Kalichman, Graham, Luke, & Austin, 2002).

Forty-six women living with HIV in the southeastern US participating in a focus group study identified several aspects of their encounters with health care providers (e.g., health care workers' lack of knowledge, providers' fears, and provider insensitivity) that were considered by

participants to be barriers to seeking HIV/AIDS-related services (Sowell, Seals, Moneyham, Demi, Cohen, & Brakes, 1997). Moreover, a study of HIV-positive persons new to primary HIV care in the northeastern US found that patients' perceptions of their physicians were positively associated with satisfaction of their health care providers (Sullivan, Stein, Savetesky, & Samet, 2000).

In an effort to understand what additional factors might assist in reducing or lessening the burden of HIV/AIDS-related stigma encountered by PLWHA, the present study explored whether patient-centered cultural sensitivity in health care experienced may serve as a moderator between HIV/AIDS-related stigma and health-related quality of life, given that some prior research has documented that the quality of and satisfaction with the patient-provider relationship positively influences medication adherence and positive health outcomes (Apollo, Golub, Wainberg, & Indyk, 2006; Bird, Bogart, & Delahanty, 2004).

Perceived Discrimination in Health Care and Demographic Characteristics

Several health-related studies have found that a significant percentage of individuals report experiencing discrimination based on their race, social class, gender, age, and sexual orientation, when obtaining health care. For example, Bird and Bogart (2001) reported that 63% of participants perceived discrimination in their interactions with health care providers based on their race and 58.9% of participants reported perceived discrimination based on their social class, among a sample of 76 African American adults living in the northwestern US. Dailey, Kasl, and Jones (2008) found a positive association between gender discrimination and non-adherence to mammography guidelines in a sample 1,451 African American and White women who obtained an index screening mammography at one of five urban hospitals in Connecticut. In a study among 810 patients living with diabetes in California or Wisconsin, Piette, Bibbins-Domingo, and Schillinger (2006) found that 7% of their sample reported experiencing age discrimination,

which was linked to negative health outcomes. Stein and Bonuk (2001) found that 17% of the 575 gay and lesbian persons residing in the New York metropolitan area who participated in their study reported avoiding or delaying seeking care as a result of their health care providers' hostile responses to their sexual orientation. In the present study, there was an exploration of whether significant differences in HIV/AIDS-related stigma exist in association with age, gender, race, sexual orientation, and social class.

Statement of the Problem

Despite significant pleas from researchers, social activists, and public health officials for a body of work that addresses the impact of HIV/AIDS-related stigma and discrimination on PLWHA (Annan, 2003; Mann, 1987; Piot, 2000), few recent empirical studies on stigma and discrimination have been conducted in the US. Current research that documents the lived experience of PLWHA is urgently needed as stigma and discrimination have been noted as major barriers to satisfactory health care and quality of life among PLWHA (Deacon, 2006). Investigating HIV/AIDS-related stigma's impact on psychological distress and health-related quality of life is imperative as this examination may provide some insights into the physical health and psychological challenges faced by PLWHA. In order to identify potential protective factors against HIV/AIDS-related stigma, it was also important to explore whether social support would moderate the relationship between HIV/AIDS-related stigma and psychological distress, and whether social support and perceived patient-centered cultural sensitivity in health care experienced would moderate the relationship between HIV/AIDS-related stigma and health-related quality of life.

Purpose of the Present Study

The purpose of the present study was to investigate the associations between HIV/AIDS-related stigma (including measures of perceived stigma, enacted stigma, and internalized stigma)

and both psychological distress and health-related quality of life among PLWHA. In addition, whether these associations are moderated by social support and perceived patient-centered cultural sensitivity in health care experienced was examined.

To accomplish these objectives, there was first an exploration of the relationship between the experiences of social discrimination and HIV/AIDS-related stigma. Second, there was an examination of the relationship between perceived patient-centered cultural sensitivity in health care experienced and HIV/AIDS-related stigma. Third, there was an exploration of whether social support would moderate the relationship between HIV/AIDS-related stigma and psychological distress. Fourth, there was an investigation of whether social support and perceived patient-centered cultural sensitivity in health care experienced would moderate the relationship between HIV/AIDS-related stigma and health-related quality of life. Fifth, there was an exploration of whether there are significant differences in HIV/AIDS-related stigma in association with selected demographic variables (i.e., age, gender, race, sexual orientation, and social class). In the next section, the two hypotheses that were tested and the three exploratory research questions that were investigated in the present study are identified.

Hypotheses and Exploratory Research Questions

Hypotheses

On the basis of prior literature, the following two hypotheses were investigated in the present study:

- **Hypothesis 1:** Experiences of social discrimination will be related *positively* to HIV/AIDS-related stigma. That is, as experiences of social discrimination increase, HIV/AIDS-related stigma will also increase.
- **Hypothesis 2:** Perceived patient-centered cultural sensitivity in health care experienced will be related *negatively* to HIV/AIDS-related stigma. That is, as perceived patient-centered cultural sensitivity in health care experienced increases, HIV/AIDS-related stigma will decrease.

Exploratory Research Questions

The following three exploratory research questions were also examined in the present study:

- **Exploratory Research Question 1:** Does social support *moderate* the relationship between HIV/AIDS-related stigma and psychological distress?
- **Exploratory Research Question 2:** Does social support and perceived patient-centered cultural sensitivity in health care experienced *moderate* the relationship between HIV/AIDS-related stigma and health-related quality of life?
- **Exploratory Research Question 3:** Are there significant differences in HIV/AIDS-related stigma in association with demographic characteristics (e.g., age, gender, race, sexual orientation, and social class)?

CHAPTER 2 REVIEW OF THE LITERATURE

This chapter presents an overview of the existing literature on human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS)-related stigma and its potential impact on psychological distress and health-related quality of life among persons living with HIV/AIDS (PLWHA) in the United States (US). First, a discussion of the dimensions of HIV/AIDS-related stigma (e.g., enacted, perceived, and internalized) that have been typically investigated separately in previous research studies is highlighted. Second, the possibility of layered stigma as an additional dimension of HIV/AIDS-related stigma is discussed. Third, a rationale for including multiple measures of HIV/AIDS-related stigma in the present study is stated. Fourth, empirical literature on the impact of HIV/AIDS-related stigma on psychological distress and health-related quality of life is presented. Fifth, the influence of the patient-provider relationship for PLWHA is examined within the context of understanding how this relationship might help to reduce or lessen the burden of HIV/AIDS-related stigma. Sixth, a literature-based, testable, and formative model for patient-centered culturally sensitive health care that includes health care provider behaviors and attitudes, office staff behaviors and attitudes, and center policies and physical environment characteristics of the health care clinic is identified to explain how perceived patient-centered cultural sensitivity in health care experienced may serve as a moderator between HIV/AIDS-related stigma and health-related quality of life. Seventh, the role of social support in possibly serving as a moderator between HIV/AIDS-related stigma and psychological distress, as well as between HIV/AIDS-related stigma and health-related quality of life is discussed.

Dimensions of HIV/AIDS-Related Stigma

Much of the previous research on HIV/AIDS-related stigma uses a broad or vague understanding of the concept of stigma (Link & Phelan, 2001). In addition, some scholars (e.g., Deacon, 2006) have critiqued work in this area, claiming that there is not a common theoretical perspective on stigma that unites both individual and social factors of this complex phenomenon. Recently, Nyblade (2006) identified and described three dimensions or forms of HIV/AIDS-related stigma, which are as follows: (a) enacted stigma, (b) perceived or felt stigma, and (c) internalized stigma. These dimensions capture both individual and social features of stigma. Hence, it can be argued that the inclusion of these three dimensions may provide a more comprehensive assessment of HIV/AIDS-related stigma as opposed to focusing solely on one of these dimensions as commonly occurs.

In the HIV/AIDS-related stigma literature, enacted stigma typically refers to the actual experiences of stigma and discrimination, whereas felt or perceived stigma tends to be a person's fear or anticipation of discrimination and rejection, and internal sense of shame (Jacoby, 1994). Perceived stigma may lead people to shape their behaviors to avoid enacted stigma, but in so doing they may also limit opportunities for support and treatment or otherwise disrupt their lives (Scambler, 1998). On the other hand, internalized stigma appears to involve the devaluation, shame, secrecy, and withdrawal triggered by applying negative stereotypes to oneself (Corrigan, 1998).

A fourth form of HIV/AIDS-related stigma that has been discussed in the extant literature but not empirically tested is the concept of layered stigma¹. For example, Crawford (1996) and Novick (1997) suggested that various stigmata may layer onto HIV stigma and result in

¹ Some authors (e.g., Grossman, 1991; Nyblade, 2006; Herek et al., 2005) have referred to layered stigma as “compound stigma,” “double stigma,” and “symbolic stigma.”

differential expression toward unpopular groups (e.g., gay men, sex workers, and injection drug users) often associated with increased risk or rates of HIV infection. Similarly, Herek and Capitanio (1999) argued that layered stigma may occur when a person who is infected with HIV additionally has to deal with the negative association of being part of a social group that is also highly stigmatized.

In this conceptualization of layered stigma, an HIV-infected gay man who is also African American, low-income, and an injection drug user, for example, has to deal with not only the stigma related to his HIV serostatus but also with the stigma associated with his race, socioeconomic status, HIV status, substance use, and sexual orientation. Thus, obtaining empirical data on layered stigma would contribute substantially to our understanding of how PLWHA may negotiate their multiple identities and the impact of their experience of layered stigma on their psychological distress and health-related quality of life.

In the present study, there were two ways in which the occurrence of layered stigma was assessed. The first way was to include a reliable and valid measure [e.g., the Experiences of Social Discrimination (ESD)] that evaluates three dimensions of social discrimination: (a) homophobia, (b) racism, and (c) financial hardship. The second way to capture the possible existence of layered stigma was to test for differences in HIV/AIDS-related stigma in relation to participant demographic characteristics. Hence, there was an examination of whether there were any significant differences in HIV/AIDS-related stigma in association with age, gender, race, sexual orientation, and social class, given that these particular variables have been examined in previous research on discrimination in the health care setting.

In the next section, a discussion of the measures of HIV/AIDS-stigma that have been used in past research studies and the rationale for including multiple measures of HIV/AIDS-related stigma in the present study are identified.

Assessing HIV/AIDS-Related Stigma

Over the last decade, several measures of HIV/AIDS-related stigma that assess one dimension of stigma (e.g., perceived, enacted, or internalized) or other aspects related to stigma (e.g., disclosure concerns, negative self-image, and concern with public attitudes) have been identified in the extant literature (Berger, Ferrans, & Lashley, 2001; Bunn, Solomon, Miller, & Forehand, 2007; Lee, Kochman, & Sikkema, 2002; Sowell et al., 1997; Sowell, Lowenstein, Moneyham, Demi, Mizuno, & Seals, 1997). While many of these instruments claim to evaluate the negative impact of HIV/AIDS-related stigma on the lives of PLWHA, it can be argued that these instruments fail to adequately assess the multiple dimensions or forms of stigma identified by Nyblade (2006) that contribute to a fuller understanding of the experience of HIV/AIDS-related stigma among PLWHA because they only focus on one dimension of stigma.

In the present study, all three dimensions of HIV/AIDS-related stigma (e.g., perceived, enacted, and internalized) were assessed using the AIDS Stigma Measure (ASM), which is further discussed in the measures section. Given that the ASM is a fairly new measure, other more traditionally used measures of each dimension of stigma [i.e., HIV Stigma Scale-Revised (HSS-R) and HIV Stigma Scale-Perceived (HSS-P)] were also included in the present study. Gathering data on a new measure that evaluates the three dimensions of stigma in one assessment tool could provide a more powerful and comprehensive assessment of HIV/AIDS-related stigma than just focusing solely on one form of stigma, as has been done in previous research. In addition, obtaining validity data (i.e., construct, concurrent) for this new stigma measure could significantly contribute to its potential usage by other investigators interested in

conducting HIV/AIDS-related stigma work. In the next section, a review of the extant literature on the impact of HIV/AIDS-related stigma on psychological distress is discussed.

Impact of HIV/AIDS-Related Stigma on Psychological Distress

Psychological distress typically refers to the experience of negative affective states, such as depression, anxiety, and loss of emotional and behavioral control (Manning & Wells, 1992). In the US, several research studies involving PLWHA have documented the association between at least one of the three different dimensions of HIV/AIDS-related stigma (e.g., enacted, perceived, and internalized) and depression, as well as anxiety, alienation, and poor psychological functioning (Clark, Linder, Armistead, & Austin, 2003; Crandall & Coleman, 1992; Lee, Kochman, & Sikkema, 2002; Lichtenstein, Laska, & Clair, 2002; Vanable, Carey, Blair, & Littlewood, 2006). In addition, previous US empirical studies among PLWHA have found a significant positive relationship between one of the dimensions of HIV/AIDS-related stigma and psychological distress (Miles, Burchinal, Holditch-Davis, Wasilewski, & Christian, 1997; Silver, Bauman, Camacho, & Hudis, 2003).

In one of the earliest studies on AIDS-related stigmatization, Crandall and Coleman (1992) found in sample of 48 US men and women who were either diagnosed with AIDS or AIDS-related complex,² or were diagnosed as being HIV-positive that those participants who felt stigmatized by others also experienced higher levels of depression, anxiety, and alienation. Moreover, these authors showed that feelings of depression, anxiety, and alienation were independent of HIV diagnostic severity but were associated with disruptions in social relationships. Lichtenstein and colleagues (2002) study on chronic sorrow with a diverse sample of 21 HIV-positive men and women living in Birmingham, Alabama showed that half of their

² AIDS-related complex was a term that was originally used among health professionals to refer to people with HIV infection who had only mild symptoms of illness such as swollen lymph glands. The term is rarely used today.

participants were clinically depressed. In particular, these authors noted that stigma and the social isolation that results from having a "discredited identity" were especially challenging for the African American infected mothers in the study, who reported greater levels of depression. Similarly, Clark et al. (2003) found that higher perceptions of AIDS-related stigma among their sample of 98 HIV-infected African American women with children were associated with poorer psychological functioning. These authors operationalized psychological functioning as the extent to which the experience of AIDS-related stigma was perceived to cause psychological distress.

Prior research that has specifically investigated the concept of internalized HIV stigma (IHS) among PLWHA found that higher levels of IHS may be related to several different factors. Lee et al. (2002) in a sample of 268 HIV-positive men and women living in Milwaukee and Madison, Wisconsin or New York City showed that being recently diagnosed with HIV, having family members who were less accepting of their illness, being less likely to have ever attended an HIV support group, knowing fewer PLWHA, and worrying about spreading their infection to others all contributed to higher levels of IHS. After controlling for the possible confounding effects of demographic characteristics, health status, level of grief, styles of coping with illness, and social support, these authors also found that IHS accounted for a significant and unique proportion of the variance in levels of depression, anxiety, and hopelessness.

Among a sample of 221 HIV-positive men and women who were outpatients at a university-based infectious disease clinic in central New York State, Vanable et al. (2006) found that study participants who reported more frequent stigma-related experiences that focused on mistreatment (e.g., "How often have you been treated badly by people because of your HIV/AIDS illness?") and social avoidance (e.g., "How often do others avoid you after they learn of your HIV/AIDS status?") since first being diagnosed with HIV were more likely to experience

depressed mood than those participants who reported less frequent stigma-related experiences. Furthermore, these authors noted that participants who reported psychiatric treatment within the previous year also endorsed more frequent stigma-related experiences.

As noted earlier, some previous research has explored the relationship between one of the dimensions of HIV/AIDS-related stigma (e.g., perceived, enacted, and internalized) and psychological distress. For example, Silver and colleagues (2003) found in a US sample of 220 low-income, mostly ethnically diverse women with late-stage HIV/AIDS that perceived stigma was significantly and positively related to psychological distress. Similarly, Miles et al. (1997) found a significant positive association between enacted stigma and psychological distress in a sample of 54 HIV-positive mothers who were receiving treatment at infectious disease clinics in the southeastern US.

While results from each of these studies demonstrate the positive relationship between HIV/AIDS-related stigma and psychological distress, it is important to consider these studies in light of two limitations. First, all of the authors of these studies defined stigma as only one of the three dimensions (e.g., perceived, enacted, and internalized) of HIV/AIDS-related stigma as previously discussed. Second, standardized HIV/AIDS-related stigma measures (i.e., *HIV Stigma Scale*) were not used in these studies; rather, separate items (i.e., “I feel stigmatized as a result of my health status” or “Do you think that HIV/AIDS is a disease that your immediate family would not want others to know about?”) of stigma were created by the investigators to measure stigma. Thus, there are no known empirical studies to date to the author’s knowledge that have conducted a standardized global assessment³ of HIV/AIDS-related stigma and its potential

³ When I refer to global assessment here I am specifically talking about examining multiple forms or dimensions of HIV/AIDS-related stigma (e.g., perceived, enacted, and internalized) in a general population of PLWHA.

negative psychological impact on PLWHA. In the next section, a discussion of the impact of HIV/AIDS-related stigma on health-related quality of life is presented.

Impact of HIV/AIDS-Related Stigma on Health-Related Quality of Life

Health-related quality of life is a multidimensional construct generally defined as a subjective evaluation of one's life across a number of dimensions including physical functioning, social functioning, pain, and energy (Nordenfelt, 1994). Research on adaptation to terminal or chronic illnesses highlight the importance of a number of personal and environmental characteristics that influence health-related quality of life. These characteristics include self-esteem, quality of social and family relationships, role functioning, financial resources, and communication patterns (Servellen & Aguirre, 1995).

An increasing number of empirical studies have focused on assessing health-related quality of life among PLWHA (Howland, Storm, Crawford, Ma, Gortmaker, & Oleske, 2007; Jia, Uphold, Wu, Chen, & Duncan, 2005; Uphold, Holmes, Reid, Findley, & Parada, 2007). Early investigations of health-related quality of life among PLWHA focused on assessment methodology issues (e.g., Kaplan, Anderson, Wu, Mathews, Kozin, & Orenstein, 1989). However, more recent studies have sought to identify predictors of health-related quality of life and to develop interventions by which it can be improved for PLWHA (Hughes, Jelsma, MacLean, Darder, & Tinise, 2004; Roth & Robbins, 2004; Sikkema, Hansen, Meade, Kochman, & Lee, 2005).

To the author's knowledge, no published empirical studies in the US have explored the relationship between HIV/AIDS-related stigma and health-related quality of life (Emlet, 2007). The authors of a few unpublished international studies that were presented at the 2002 XIV

International AIDS Conference in Barcelona, Spain⁴ reported some preliminary findings that suggest a negative association between HIV/AIDS-related stigma and health-related quality of life. For example, Ayarza and Reyes (2002) described the traumatic effect that stigmatization had on the health-related quality of life among PLWHA in Ecuador. Castle, Cornu, Dua, Herrera, Nadkarni, Ouedraogo et al. (2002) and Ortega, Gonzales, and Liwanag (2002) reported finding that access to services that offer peer social support ends self-isolation and reduces stigma, and thus enhances health-related quality of life.

Orlando, Guaraldi, Murri, Wu, Nardini, Beghetto et al. (2002) found a significant negative correlation between lipodystrophy (a disturbance in the way one's body produces, uses, or stores fat) and lower health-related quality of life among 175 AIDS patients living in Italy. Although these investigators did not measure HIV/AIDS-related stigma directly, they reported that lower role functioning as measured by their health-related quality of life scale was attributable to perceived stigma. These unpublished international studies illustrate the need for additional research to investigate the relationship between HIV/AIDS-related stigma and health-related quality of life among PLWHA in the US.

In considering the impact of HIV/AIDS-related stigma on psychological distress and health-related quality of life, it is also important to take into account what variables might influence how HIV/AIDS-related stigma is experienced by PLWHA. For example, it is quite possible that protective factors, such as the patient-health care provider relationship or social support, could help to decrease or lessen the burden of HIV/AIDS-related stigma. In the next section, a discussion of the existing literature on the patient-provider relationship experienced by PLWHA is provided.

⁴ Findings from these studies were collected by the current author during his trip to the 2002 XIV International AIDS Conference in Barcelona, Spain to present his research. However, study abstracts are also available online through the US National Institutes of Health's website.

Patient-Health Care Provider Relationship for Persons Living with HIV/AIDS (PLWHA)

In recent years, the patient-health care provider relationship has gained considerable attention in the HIV/AIDS literature on medication adherence and health outcomes among PLWHA (Apollo, Golub, Wainberg, & Indyk, 2006; Bird, Bogart, & Delahanty, 2004). Beach, Keruly, and Moore (2006) found in a sample of 1,723 HIV-infected persons that the quality of the patient-provider relationship was directly related to the health outcomes of these patients. In their study, these authors showed that participants who reported that their physicians displayed “patient-centered communication” (defined by these authors as understanding each patient as a unique human being) were more likely to receive highly active antiretroviral therapy (HAART), be adherent to HAART, and have undetectable serum HIV RNA. These patients also noted higher quality of life, missed fewer appointments, held more positive beliefs about HAART therapy, had less social stress, and were less likely to use illicit substances.

Earlier HIV/AIDS-related research that was conducted on satisfaction with the patient-provider relationship among PLWHA found a number of common factors that appear to influence whether the patient values the relationship. First, the nature of the relationship (e.g., sharing a personal connection) seems to be more important than the type of health care provider (i.e., physician or nurse) for impacting patient’s positive ratings of the relationship (Stone, Weissman, & Cleary, 1995). Second, knowledge of the health care provider, especially as it relates to information regarding current medications or treatment options for HIV or AIDS, has been noted as an important factor in provider-patient relationship satisfaction (Sullivan, Stein, Savetsky, & Samet, 2000). Third, practice styles of the health care provider that denote such characteristics as caring, follow-through, and taking time with patients is believed to contribute to satisfaction with the relationship by patients (Bakken, Holzemer, Brown, Powell-Cope, Turner, Inouye, et al. 2000).

Although prior research has documented that the quality of and satisfaction with the patient-provider relationship positively influences medication adherence and health outcomes, no empirical studies to the author's knowledge have investigated whether the patient-provider relationship may help to minimize the experience of HIV/AIDS-related stigma among PLWHA. In addition, it is quite possible that other contributing factors to the health care experience may assist in reducing or lessening the burden of HIV/AIDS-related stigma encountered by PLWHA. In the next section, a literature-based, testable, and formative model for patient-centered culturally sensitive health care that includes health care provider behaviors and attitudes, office staff behaviors and attitudes, and center policies and physical environment characteristics in the health care clinic is presented.

Patient-Centered Culturally Sensitive Health Care

Extending the relationship beyond the patient and provider (e.g., doctors, nurses) to improve a patient's health-promoting behaviors (i.e., recommended healthy eating), health care behaviors (i.e., treatment adherence), and health-related outcomes and statuses (i.e., blood pressure), Tucker, Herman, Ferdinand, Bailey, Lopez, Beato, et al. (2007) proposed a literature-based, testable, and formative model for patient-centered culturally sensitive health care (PC-CSHC) that also includes office staff members (e.g., front desk staff) behaviors and physical environmental characteristics (e.g., waiting room area) and policies (e.g., stated and publicly displayed statement regarding the order in which patients are seen) of the health care clinic. In their work, these authors specifically argued for the promotion of PC-CSHC environments with the ultimate goal of reducing the health disparities that currently exist between minority and majority individuals in the US.

According to Tucker et al., their model consists of a PC-CSHC intervention program that includes the following three subcomponents: (a) training health care providers and office staff

members to engage in behaviors and display attitudes that enable patients to feel comfortable with, trusting of, and respected by their health care providers and staff members and that enable them to feel that they and their cultures are respected (i.e., inquiring about and respecting cultural beliefs of patients); (b) changing the health care clinic physical environment and clinic policies in ways that culturally diverse patients report as making them feel a sense of comfort and belonging in the clinic and involving health care administrators and providers in making these changes (i.e., displaying culturally diverse artwork and informational materials and posting a statement regarding the order in which patients are seen); and (c) training and empowering patients to engage in health-promoting lifestyles and to motivate and inspire desired behaviors and attitudes from providers and office staff members (i.e., giving negative and positive feedback to their health care provider or front desk staff member in a constructive manner) and desired changes in the health care environment (i.e., requesting that an indoor child's play area be created in the clinic waiting area).

It is explained by Tucker et al. that with the implementation of the PC-CSHC intervention program participating patients' levels of perceived PC-CSHC and perceived interpersonal control (e.g., psychological empowerment) are impacted, which in turn, influence patients' engagement in health-promoting behaviors and health care satisfaction. It is also suggested in the PC-CSHC model that patient health care satisfaction directly effects patient treatment adherence; but is not directly associated with patient health outcomes and statuses. Rather, these authors postulated that health outcomes and statuses are influenced separately by patients' health-promoting lifestyles and treatment adherence. The PC-CSHC model is illustrated in Figure 2-1 at the end of this chapter.

In the present study, exploring the potential association between HIV/AIDS-related stigma and perceived patient-centered cultural sensitivity in health care experienced is critical to understanding the health care needs and challenges often faced by PLWHA. Furthermore, since perceived patient-centered cultural sensitivity in health care experienced may also contribute to the relation between HIV/AIDS-related stigma and health-related quality of life, it would be important to see if perceived patient-centered cultural sensitivity in healthcare experienced may also serve as a moderator between HIV/AIDS-related stigma and health-related quality of life. It is also essential to consider what additional protective factors (e.g., social support) might assist in lessening or reducing the experience of HIV/AIDS-related stigma among PLWHA. In the next section, the existing literature on the role of social support in possibly serving as a moderator between HIV/AIDS-related stigma and psychological distress is discussed.

Social Support, HIV/AIDS-Related Stigma, and Psychological Distress

Social support from significant others, family members, and friends is widely believed to buffer the impact of a variety of stressful life events including chronic illness (Cohen & Willis, 1985). Decreases in the experience of psychological distress among PLWHA have been linked to social support (Hudson, Lee, Miramontes, & Portillo, 2001). In addition, social support is considered to be an important factor in HIV illness progression (Golub, Astemborski, Hoover, Anthony, Vlahov, & Strathdee, 2003), adherence to medication regimens (Ammassari, Trotta, Murri, Castelli, Narciso, Noto et al., 2002), physical functioning (Vogl, Rosenfeld, Breitbart, Thaler, Passik, McDonald et al., 1999), and spirituality (Tuck, McCain, & Elswick, 2001).

Recently, it has been suggested that social support may assist in decreasing the experience of HIV/AIDS-related stigma, which in turn, might reduce the experience of psychological distress among PLWHA (Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). In previous health-related research, social support has been identified as a moderator of the

relationship between stress and health outcomes (Winefield, Winefield, & Tiggemann, 1992) and stress and depressed mood (Petersen, Folkman, & Bakeman, 1996). However, to the author's knowledge social support has not yet been explored as a potential moderator of the relationship between HIV/AIDS-related stigma and psychological distress.

While social support may serve as a moderator of the relationship between HIV/AIDS-related stigma and psychological distress, it is also quite possible that social support may moderate the relationship between HIV/AIDS-related stigma and health-related quality of life. In the next section, the role of social support in possibly serving as a moderator between HIV/AIDS-related stigma and health-related quality of life is explored.

Social Support, HIV/AIDS-Related Stigma, and Health-Related Quality of Life

Reduced levels of health-related quality of life among PLWHA may be associated with a number of factors. These include multiple AIDS-related losses and bereavement (Hansen, Tarakeshwar, Ghebremichael, Zhang, Kochman, & Sikkema, 2006), the need to make significant changes in sexual behavior (Uphold, Holmes, Reid, Findley, & Parada, 2007), relationship and social support disruption (Burgoyne & Renwick, 2004), and limited employment opportunities (Stangl, Wamai, Mermin, Awor, & Bunnell, 2007). However, it is less clear what the associations are between social support, HIV/AIDS-related stigma, and health-related quality of life.

To date, few empirical studies have investigated the relationship between social support, HIV/AIDS-related stigma, and health-related quality of life. The only known study that has indirectly looked at the relationships among these variables was conducted by Heckman, Somlai, Sikkema, Kelly, and Franzoi in 1997. The purpose of the study was to identify psychosocial predictors of general health-related quality of life among 275 men and women living with HIV who reside in Wisconsin. In this community sample, the specified researchers found that

participants who reported higher levels of health-related quality of life also reported increased physical well-being, greater levels of social support, frequent use of active coping strategies, and fewer experienced incidents of stigma and discrimination.

While these results do provide some empirical evidence for associations among social support, HIV/AIDS-related stigma, and health-related quality of life, additional research is desperately needed to further examine these associations. Understanding the role of social support in possibly moderating the relationship between HIV/AIDS-related stigma and health-related quality of life is essential for several reasons. First, as life expectancy among PLWHA continues to increase, it is important to recognize protective factors (i.e., social support) that may guard against HIV/AIDS-related stigma. Second, health-related quality of life may influence such factors as medical decision making, willingness to pursue or accept medical treatment, and disease course and progression (Reidy & Taggart, 1992). Third, if health-related quality of life is related to social support, then intervention programs focused on reducing HIV/AIDS-related stigma that foster such variables as social support may in turn improve health-related quality of life among PLWHA.

Demographic Characteristics and HIV/AIDS-Related Stigma

Prior research has investigated the relationship between various demographic characteristics (e.g., gender, race, sexual orientation, social class, and age) and HIV/AIDS-related stigma. Carr and Gramling (2004) and Lekas, Siegel, and Schrimshaw (2004) found significant positive associations between gender and HIV/AIDS-related stigma in their community samples of HIV-positive persons living throughout the US. In addition, Sandelowski, Lambe, and Barroso (2004) conducted a metasynthesis (systematic integrations in findings) of qualitative studies on stigma among women with HIV. These authors reviewed 93 qualitative

studies that included 1,780 US HIV-positive women and reported that perceived and enacted stigma were pervasive in these women's lives, in part due to the fact that they were women.

Significant positive associations between race and HIV/AIDS-related stigma and sexual orientation and HIV/AIDS-related stigma have also been noted by some researchers. Among their sample of 202 HIV-positive persons residing in two large US cities, Sayles, Hays, Sarkisian, Mahajan, Spritzer, and Cunningham (2008) found that participants who reported higher overall internalized stigma scores also self-identified as racial/ethnic minorities and heterosexual. It has also been suggested that HIV-positive African American and Latina heterosexual women living in poverty experience increased stigma due to associations with gender, race/ethnicity, social class, and sexual orientation (Bunting, 1996).

Emlet (2007) examined relationships between age, HIV-related stigma, and patterns of disclosure of HIV status. In his study with 88 persons living with HIV, who ranged in age from 20-71 years old, Emlet found that differences in HIV-related stigma scores by age were not statistically significant. However, Emlet noted that results from his study should be interpreted with caution given that all of his participants were drawn from the same AIDS-service organization in the Pacific Northwest of the US.

Summary of Literature Review

In sum, research that extends the existing literature on HIV/AIDS-related stigma and its potential impact on psychological distress and health-related quality of life of PLWHA is clearly needed. In the present study, investigating multiple dimensions of HIV/AIDS-related stigma (e.g., perceived, enacted, and internalized) may provide us with a fuller understanding of this complex phenomenon. In addition, empirically investigating the existence of a fourth form of stigma (e.g., layered stigma) could offer some insights into the multidimensional nature of HIV/AIDS-related stigma. Identifying protective factors (e.g., perceived patient-centered cultural

sensitivity in health care experienced and social support) that moderate the relationship between HIV/AIDS-related stigma and psychological distress, as well as between HIV/AIDS-related stigma and health-related quality of life could also have important implications for helping PLWHA cope with the burden of HIV/AIDS-related stigma. In the next section, a model of all the hypothesized relationships is presented.

Model of Hypothesized Relationships

In the present study, based upon all of the existing empirical literature previously identified in this chapter, the hypothesized relationships between the following variables were examined: (a) HIV/AIDS-related stigma, (b) psychological distress, (c) social support, (d) health-related quality of life, (e) experiences of social discrimination, and (f) perceived patient-centered cultural sensitivity in health care experienced. The nature of these hypothesized relationships is presented below in Figure 2.1.

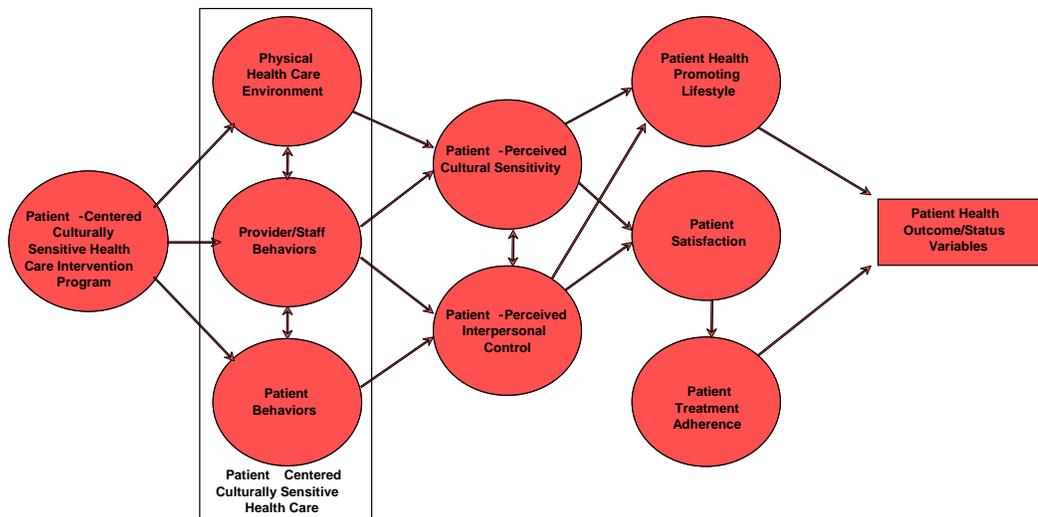


Figure 2-1. The patient-centered culturally sensitive health care (PC-CSHC) model

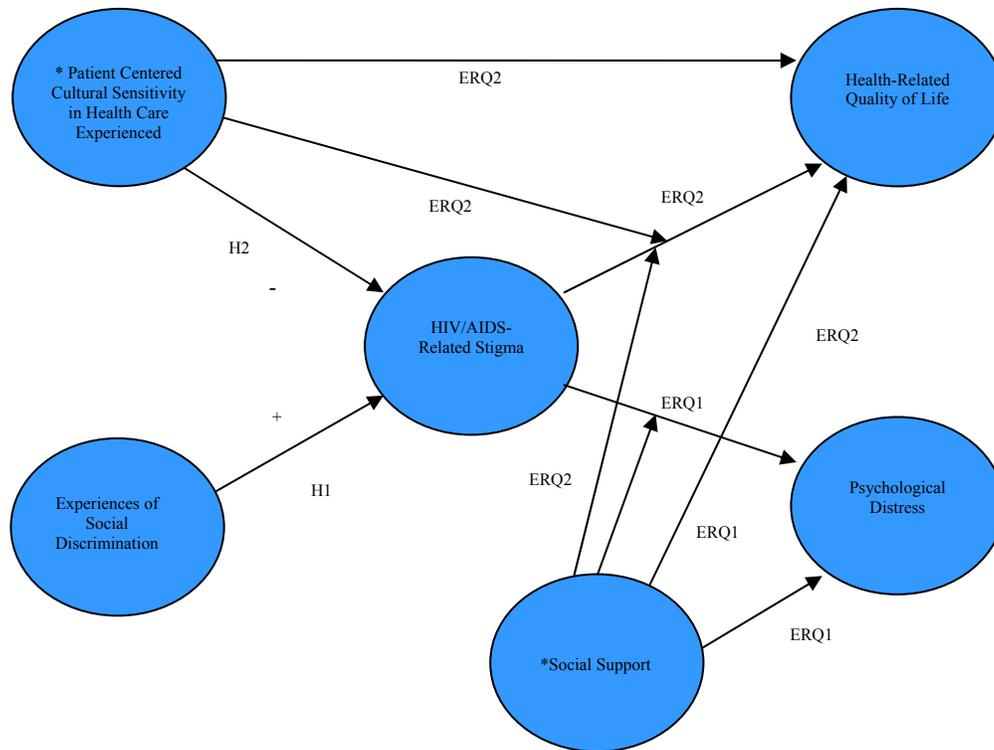


Figure 2-2. Hypothesized relationships among variables of interest.

***Note:** In the model, social support is indicated as a moderator of the relationship between HIV/AIDS-related stigma and psychological distress, as well as between HIV/AIDS-related stigma and health-related quality of life; Perceived patient-centered cultural sensitivity in health care experienced is indicated as a moderator of the relationship between HIV/AIDS-related stigma and health-related quality of life.

H = Hypothesis; ERQ = Exploratory Research Question.

CHAPTER 3 METHOD

This chapter describes the methodology that was used in the present study. First, information on a power analysis that was calculated prior to study implementation in order to determine an appropriate sample size to achieve adequate power is discussed. Second, participant inclusion criteria are identified. Third, demographic and medical characteristics of the final participant sample are presented. Fourth, participant recruitment efforts and the data collection process are described. Fifth, the survey instruments that were used to measure the variables of interest are provided (i.e., the assessment battery for this study).

Participants

Based upon a power analysis calculation¹ (with power = 80%, alpha = .025, and β = .64), it was determined that at least 158 participants was needed in the present study to achieve adequate power. In order to obtain 158 participants, over 200 self-identified persons living with human immunodeficiency virus or acquired immune deficiency syndrome (PLWHA) were recruited. Inclusion criteria were that study participants must: (a) be at least 18 years of age or older, (b) be diagnosed with HIV or AIDS, (c) have the ability to read and understand English, and (d) live in the United States (US).

Data were collected from a total of 212 participants. Given that the focus of the present study was on PLWHA in the US, two individuals who indicated living outside of the US and 15 persons with large amounts of missing data were excluded from all of the data analyses. Two participants whose validity data suggested the possibility of random responding (determined as

¹ The power analysis was calculated by using nQuery Advisor version 5.0 (Elashoff, 2002).

incorrectly answering three or more validity items²) were also not included. As such, the final participant sample consisted of 193 PLWHA (123 men, 70 women).

The demographic characteristics of the final participant sample are presented in Table 3-1. Participants ranged in age from 18 to 74 years ($M = 39.80$, $SD = 12.26$, median = 40). Approximately 41% of the sample identified as Caucasian American/White, 40% identified as African American/Black, 8% identified as Hispanic/Latina/o, 6% identified as Asian American/Pacific Islander, 1% identified as American Indian/Native American, and 4% identified as multiracial or other. In terms of sexual orientation, 46% of the sample identified as exclusively heterosexual, 34% identified as exclusively gay/lesbian, 8% identified as bisexual, 8% identified as mostly gay/lesbian, and 4% identified as mostly heterosexual. About 59% of the participants reported being single, 19% reported being in a committed relationship, 13% reported being married, 5% reported being divorced, 3% reported being widowed, and 1% reported being separated. With respect to social class, 25% of the sample identified as lower class, 34% identified as working class, 32% identified as middle class, 6% identified as upper-middle class, and 3% identified as upper class. Approximately 92% of the sample indicated that they had disclosed their HIV status to someone else.

With regard to their medical history, descriptive statistics for the final participant sample are presented in Table 3-2. The mean years since being diagnosed with HIV infection for the entire sample was 8.34 ($SD = 5.36$, median = 8). Approximately 47% of the participants indicated that they believed they contracted HIV through male-to-male sexual contact, 34% indicated high risk heterosexual contact, 7% indicated injection drug use, 6% indicated that they did not know how they contracted HIV, 4% indicated high risk heterosexual contact and

² A total of five validity items were randomly embedded in the measures of the study survey. Further explanation of these items is provided in the subsection of data collection in the procedure section of this chapter.

injection drug use combined, and 2% indicated other ways of transmission.³ Approximately 78% of participants reported currently being asymptomatic, 11% reported currently being symptomatic, and 11% reported currently having AIDS. Regarding treatment, 71% of participants indicated that they had used Highly Active Antiretroviral Therapy (HAART) in the past, 58% indicated that they are currently using HAART, and 51% indicated that they were currently taking other HIV/AIDS-related medications (i.e., Atripla, Kaletra, Norvir, Truvada, etc.).

Procedure

Participant Recruitment

Participants were recruited through HIV/AIDS Internet listservs and groups, and through snowball sampling techniques. Specifically, advertisements soliciting participants for a study on the “life experiences of PLWHA” were sent to a variety of online listservs that focus on HIV/AIDS-related issues and that have a combined focus on HIV/AIDS and racial/ethnic minorities. This study was also advertised through various on-line groups including AOL, Google, Craigslist, Livejournal, Facebook, MySpace, and Yahoo. In addition, recruitment flyers (please refer to Appendix M for a copy) advertising this research was posted in various community-based organizations (CBO) and clinics that primarily serve low-income populations, racial/ethnic minorities, and PLWHA. Snowball sampling techniques included encouraging members of the online listservs and groups, representatives of the CBO and clinics, and study participants to forward or give the survey web address to friends and relatives eligible to participate in this study.

³ Additional modes of transmission identified by participants included blood transfusion, childbirth, low risk heterosexual contact, and being raped.

Data Collection

A security protected online survey housed by SurveyMonkey.com was used to collect data from potential participants. Some research has suggested that this method of obtaining data has several advantages. First, data collected via the Internet may result in better representation of individuals who are less open about their HIV serostatus (Elford, Bolding, Davis, Sherr, & Hart, 2006) as it provides participants with anonymity so that they do not have to disclose their serostatus to researchers in person (Ross, Tikkanen, & Mansson, 2000). Second, it will likely result in a more representative sample of diverse populations with regard to demographic characteristics (Bowen, Williams, & Horvath, 2004; Hirshfield, Remien, Humberston, Walavalkar, & Chiasson, 2004). Third, online recruitment may increase the likelihood of recruiting large numbers of PLWHA (Birnbaum, 2004; Rhodes, Bowie, & Hergenrather, 2003).

The study advertisements directed participants to a security protected online survey. Data was collected over a three month period. The informed consent (please refer to Appendix A for a copy), which includes information pertaining to the purpose of the study, confidentiality of responses, and contact information of the researchers, was shown to participants once they connected to the online survey website. The participants were then instructed to click a link that served as an indication that they were voluntarily agreeing to participate in this study. Next, participants were taken directly to the online survey.

The survey measures, which are described in greater detail in the section on instruments, were counterbalanced to reduce order effects (please refer to Appendices B-K for survey measures). Additionally, a validity item was embedded in some of the measures. These validity items directed participants to respond in a particular manner. For instance, an item asked participants to select the option for “Strongly Agree” or “Not At All Agree.” There were a total of five validity items randomly placed throughout the entire survey. The purpose of these items

was to identify random responding, and to ensure that all participants were reading and understanding the questions.

At the completion of the online survey, which took approximately 45 minutes or less⁴, all participants received a thank you note and debriefing message (please refer to Appendix L for a copy). Two websites and a toll-free national hotline number were provided for participants interested in contacting counseling services and/or receiving information about HIV or AIDS. Participants were encouraged to forward or give the survey web address to friends and relatives eligible to participate in this study.

No identifying information (e.g., name, birth date, social security numbers, etc.) was collected by the survey instruments. SurveyMonkey.com (the server that was used to collect and house the data throughout the end of data collection) was designed with a 128-bit encryption algorithm, which means that the data was encrypted on the computer where the participant was accessing the survey, and that the data was also encrypted in transmission from their computer to the main server. In this way, SurveyMonkey.com does not capture Internet Protocol (IP) addresses along with the submission of completed surveys. The collected survey data was stored on highly secure and firewalled servers, which can only be accessed by the Principal Investigator (PI) via password-protected and encrypted file transfer protocols. At the end of data collection, the survey and corresponding data were removed from SurveyMonkey.com and stored locally on a highly secured and firewalled computer, which can only be accessed by the PI via password protected and encrypted file transfer protocols. However, participants were provided with a simplified version of these security procedures in that they were told on the informed consent

⁴ Two volunteer undergraduates and two volunteer HIV-positive patients took the online survey to provide initial feedback on their experience of taking the survey (i.e., perceived clarity of questions, whether or not the format was user-friendly, etc.) and to time how long it took these volunteers to complete the entire survey. The average time for survey completion by the volunteers was 37 minutes.

that no record of their web address would be maintained and that all of their responses would be completely anonymous (please refer to Appendix A). All study procedures were reviewed and approved by the Institutional Review Board of the University of Florida.

Instruments

Participants anonymously completed an Assessment Battery (AB) through a security protected online survey. The AB consisted of the instruments used to measure the variables of interest, which are as follows: (a) demographic and medical information variables, (b) HIV/AIDS-related stigma, (c) psychological distress, (d) social support, (e) health-related quality of life, (f) social discrimination, and (g) perceived patient-centered cultural sensitivity in health care experienced. The following measures were included in the AB⁵.

Demographic and Medical Information Variables

Demographic and medical information questionnaire (DMIQ). The DMIQ assessed the selected demographic (e.g., age, gender, race, sexual orientation, relationship status, social class) and medical characteristics (e.g., current HIV/AIDS disease status, usage of HAART or other HIV/AIDS-related medications) of the participants. Please refer to Appendix B for a copy of the DMIQ.

HIV/AIDS-Related Stigma Measures

AIDS stigma measure (ASM; Ramirez-Valles, 2007). The ASM is a newly developed 44-item, 4-point Likert-type scale (1 = “Strongly Disagree” to 4 = “Strongly Agree”) that assesses HIV/AIDS-related stigma along three dimensions: (a) perceived stigma, (b) experience of stigmatization, and (c) internalized stigma. Item ratings are averaged to yield an overall score, with higher scores indicating more intense experiences of HIV/AIDS-related stigma. Sample

⁵ Full names of measures (i.e., *AIDS stigma measure*) have been provided here for the reader. However, in the actual online survey, full names of measures were removed.

items include the following: “Many people would not want to be friends with someone with HIV/AIDS” (Perceived Stigma Subscale); “People treat me differently when they find out I have HIV/AIDS” (Experiences of Stigmatization Subscale); and “I sometimes feel ashamed of having HIV/AIDS” (Internalized Stigma Subscale). According to Ramirez-Valles (2007), preliminary analyses with this measure indicate good reliabilities for each of the subscales ($\alpha = 0.96, 0.81, 0.88, 0.93$, respectfully). In the present study, Cronbach’s alpha calculated for the subscales that were combined into a total score was 0.98. In addition, other measures of stigma (i.e., HIV Stigma Scale-Revised and HIV Stigma Scale-Perceived) were included in the AB to obtain validity data on the newer developed ASM measure. Only total scores from the ASM were used to assess HIV/AIDS-related stigma. Please refer to Appendix C for a copy of the ASM.

HIV stigma scale-revised (HSS-R; Bunn, Solomon, Miller, & Forehand, 2007). The HIV Stigma Scale (HSS) was originally developed by Berger, Ferrans, and Lashley (2001) from the literature on stigma and psychosocial aspects of living with HIV/AIDS to measure PLWHA’s perceptions of stigma. Recently, Bunn et al. (2007) revised HSS (referred to here in as the HSS-R) by reducing the number of items and retaining the original four factors but renaming one of the subscales. These four factors are as follows: (a) Enacted Stigma (formerly called Personalized Stigma), (b) Disclosure Concerns, (c) Negative Self-Image, and (d) Concern With Public Attitudes. The HSS-R is a 32-item, 4-point Likert-type scale (1 = “Strongly Disagree” to 4 = “Strongly Agree”) measuring how stigmatized PLWHA feel across its four dimensions of stigma described above. Subscale scores are computed by summing the responses to the items associated with that subscale (after reverse-coding two of the items), while a generalized stigma score is calculated based on the sum of the responses to all items. Higher scores indicated more intense perceptions of stigma. Sample items for each of the subscales are as follows: “I have lost

friends by telling them that I have HIV/AIDS” (Enacted Stigma); “I worry people who know I have HIV/AIDS will tell others” (Disclosure Concerns); “Having HIV/AIDS is disgusting to me” (Negative Self-Image); and “Most people believe a person who has HIV/AIDS is dirty” (Concern With Public Attitudes). Cronbach’s alphas for the subscales reported by Bunn et al. ranged from 0.90 to 0.97, and the Cronbach’s alpha for the overall scale was reported as 0.95. These data indicate that the HSS-R has very good internal consistency. These authors also noted high correlations between the HSS-R and other psychosocial measures (e.g., Stigma Consciousness Questionnaire, Discrimination Scale, and Rosenberg’s Self-Esteem Scale), which demonstrates its validity. With the present sample, Cronbach’s alpha was 0.96 for HSS-R items. Please refer to Appendix H for a copy of the HSS-R.

HIV stigma scale-perceived (HSS-P; Wight, Aneshensal, Murphy, Miller-Martinez, & Beals, 2006). The HSS-P measure (referred to simply as the HIV Stigma Scale in the Wight et al. article) was developed based upon Sowell, Seals, Moneyham, Demi, Cohen, and Brake’s (1997) study of women with HIV living in rural communities for seven of the items, and two additional items were derived from separate qualitative interviews. Wight et al. reported that from these two sources, they developed the HSS-P, a 9-item, 4-point Likert-type scale (1 = “Strongly Disagree” to 4 = “Strongly Agree”) to assess perceptions of HIV stigma. Item ratings were averaged to yield an overall score, with higher scores indicating more intense experiences of perceived stigma. Sample items include, “Feel blamed by others,” “Feel people avoid you,” and “Fear your family will reject you.” With regard to validity, Wight et al. reported that perceived stigma items were related positively to scores on personal stigma scales in samples of persons living with HIV, and reported Cronbach’s alpha for this scale was 0.84. In the present sample, Cronbach’s alpha for HSS-P items was 0.86. Please refer to the Appendix I for a copy of the HSS-P.

Psychological Distress

Mental health inventory (MHI); Veit & Ware, 1983). The MHI is a 38-item, 6-point Likert-type scale (1 = “Extremely happy, could not have been more satisfied or pleased”/ “Always”/ “All of the time” / “Extremely so, to the point where I could not take care of things”/ “Yes, constantly” to 6 = “Very dissatisfied, unhappy most of the time”/ “Never”/ “Not bothered at all” / “No, never”) developed as part of the National Health Insurance study to determine the degree of psychological distress and psychological well-being among participants. Items are positively scored on a 0-100 scale. A summary score, called the “Mental Health Index”, denotes overall mental wellness. There are also higher order subscales that measure psychological distress and psychological well-being, and five lower order subscales that measure anxiety, depression, loss of behavioral and emotional control, positive affect, and emotional ties. For the Mental Health Index and the psychological well-being subscales, higher scores signify a healthier mental state. For the psychological distress subscales, higher scores indicate a poorer mental state. Sample items include: “During the past month, how much of the time have you been a very nervous person?” (Anxiety Subscale); “During the past month, how much of the time did you feel depressed?” (Depression Subscale); “During the past month, how much of the time have you felt emotionally stable? (Behavioral/Emotional Control Subscale); “During the past month, how much of the time have you felt calm and peaceful? (Positive Affect Subscale); and “During the past month, how much of the time have you felt loved and wanted? (Emotional Ties Subscale).

Veit and Ware (1983) demonstrated both reliability and validity of this measure in their original work with 5,089 participants living in 6 communities representing the four US census regions. Cronbach’s alpha was reported by these authors to range from 0.83 to 0.91 for scales based on the five lower order factors and from 0.92 to 0.96 for scales based on the two higher

order factors and the Mental Health Index. In a sample of 119 PLWHA in Hong Kong, Mak, Cheung, Law, Woo, Li, & Chung (2007), reported Cronbach's alphas of 0.91 for psychological distress and 0.93 for psychological well-being subscales. In the present study, only total scores on the psychological distress subscale from the MHI was used to assess psychological distress. Alpha for psychological distress subscale scores was 0.96. Please refer to Appendix D for a copy of the MHI.

Social Support

Medical outcomes study social support survey (MOS-SSS; Sherbourne & Stewart, 1991). The MOS-SSS is a 22-item, 5-point Likert-type (1 = "None of the Time" to 5 = "All of the Time") that evaluates social support. This instrument was originally developed for participants in the Medical Outcomes Study (MOS), a two-year study of patients with chronic conditions, such as diabetes, hypertension, coronary heart disease, and/or depression (for a complete review, please refer to Tarlov, Ware, Greenfield, Nelson, Perrin, & Zubkoff, 1989). Participants first identify approximately how many close friends and relatives they have and rate their social support system over four domains, including: (a) tangible support, (b) affectionate support, (c) positive social interaction, and (d) emotional/informational support. Item ratings are summed to form a total score, with higher ratings indicating greater levels of social support. Sample items include the following: "Someone to help you if you were confined to a bed?" (Tangible Support Subscale); "Someone who shows you love and affection" (Affectionate Support Subscale); "Someone to get together with for relaxation" (Positive Social Interaction Subscale); and "Someone to confide in or talk to about yourself or your problems?" (Emotional/Informational Support Subscale). In terms of validity, social support scores were correlated negatively with mental health scores in Sherbourne and Stewart's original study with 2,987 patients. These authors also reported Cronbach's alpha ranging across subscales from 0.91

to 0.97. In a sample of 152 adults dually diagnosed with severe mental illness and substance use disorder, Meade (2006) noted a Cronbach's alpha of 0.90 for the entire measure. In the present study, Cronbach's alpha calculated for the subscales that were combined into a total score was 0.92. Only total scores from the MOS-SSS were used to assess social support. Please refer to Appendix E for a copy of the MOS-SSS.

Health-Related Quality of Life

The world health organization quality of life-bref (WHOQOL-BREF; WHO, 1998).

The WHOQOL-BREF is a 26-item, 5 point Likert-type scale (1 = "Very Poor"/ "Very Dissatisfied" / "Not at all"/ "Never" to 5 = "Very Good"/ "Very Satisfied" / "An Extreme Amount" / "Always") that assesses health-related quality of life across four domains. The four domains are: (a) physical health and level of independence (seven items assessing areas such as presence of pain and discomfort, dependence on substances or treatments, energy and fatigue; mobility, sleep and rest of daily living, and perceived working capacity), (b) psychological well being (eight items assessing areas such as affect, both positive and negative self-concept, higher cognitive functions; body image and spirituality), (c) social relationships (three items assessing areas such as social contacts, family support and ability to look after family; sexual activity), and (d) environment (eight items assessing areas such as freedom, quality of home environment, physical safety and security and financial status, involvement in recreational activity, health and social care, quality and accessibility). Two additional items that are examined separately include one which asks about the individual's overall perception of quality of life and the other which asks about the individual's overall perception of his or her health. The domain scores are scaled in a positive direction (i.e., higher scores denote higher quality of life).

The WHOQOL group (1998) reported Cronbach alpha values for each of the four domain scores ranging from 0.66 (Social Relationships Domain) to 0.84 (Physical Health Domain). In a

study assessing health-related quality of life using the WHOQOL-BREF in 224 Taiwanese patients with HIV infection, Hsiung, Fang, Chang, Chen, and Wang (2005) reported internal consistencies across the domains of this measure ranging from 0.75 and 0.86. With respect to validity, these authors also noted good correlations ($r = 0.48$) between the physical component summary of the 36-Item Short Form Health Survey (SF-36) and the physical domain of the WHOQOL-BREF, as well as between the mental component summary of the SF-36 and all four domains of the WHOQOL-BREF (r range = 0.60-0.75). In the present study, Cronbach's alpha calculated for the subscales that were combined into a total score was 0.89. Only total scores from the WHOQOL-BREF were used to assess health-related quality of life. Please refer to Appendix F for a copy of the WHOQOL-BREF.

Social Discrimination

Experiences of social discrimination (ESD; Diaz, Ayala, Bein, Henne, & Marin, 2001). The ESD measure was referred to in the Diaz et al. (2001) study as the “experiences of homophobia, racism, and poverty.” This measure was slightly adapted in the present study to capture a broader lesbian, gay, and bisexual audience, in contrast to the target group of Latino non-heterosexual males for which the measure was originally developed. The only two minor modifications that were made to the subscale on homophobia was to exclude the word “effeminate” and to replace the term “homosexual” with “sexual orientation.” The ESD is a 25-item, 4-point Likert-type scale (1 = “Never” to 4 = “Many times”) that examines three dimensions of social discrimination including: (a) homophobia, (b) racism, and (c) financial hardship. Item ratings are averaged to yield an overall score, with higher scores indicating more frequent experiences of social discrimination. Sample items from each of the subscales include the following: “As you were growing up, how often did you feel that your homosexuality hurt and embarrassed your family?” (Homophobia Subscale); “How often have you been turned down

for a job because of your race or ethnicity?” (Racism Subscale); and “In the last 12 months, how often have you had to borrow money from a friend or relative to get by financially?” (Financial Hardship Subscale). In terms of validity, with their sample of 912 Latino gay men living in New York City, Miami, and Los Angeles, Diaz, Ayala, and Bein (2004) reported that all three subscales of the ESD were generally correlated positively with psychological distress. Diaz et al. (2001) reported high levels of internal consistency for each of the subscales of the ESD: Homophobia ($\alpha = 0.75$); Racism ($\alpha = 0.82$); and Poverty ($\alpha = 0.72$). In the present study, Cronbach’s alpha calculated for the subscales that were combined into a total score was 0.88. Only total scores from the ESD were used to assess experiences of social discrimination. Please refer to Appendix G for a copy of the ESD.

Patient-Centered Culturally Sensitive Health Care

Tucker-culturally sensitive healthcare inventory-patient form (T-CSHI-PF; Tucker, Mirsu-Paun, van den Berg, Ferdinand, Jones, Curry et al., 2007). The T-CSHI-PF is a 129-item, 4-point Likert-type scale (1 = “Strongly Disagree” to 4 = “Strongly Agree”) used to measure the level of patient-centered cultural sensitivity perceived in the health care that individuals receive from their health care providers and clinic office staff members, and in their clinic physical characteristics and policies at their health care center or site. Items relate to three components: (a) provider behaviors and attitudes, (b) clinic office staff member behaviors and attitudes, and (c) clinic physical environmental characteristics and policies. Originally developed and pilot tested as three separate race/ethnicity-specific forms for African American patients, non-Hispanic White patients, and Hispanic patients (with English and Spanish forms), the newly revised version of the T-CSHI-PF combines all three of these separate race/ethnicity-specific forms and excludes items that would have been redundant in the combining process. Sample

items from each of the components include, “Is compassionate or shows that he or she cares about how I feel” (Health Care Provider Behavior and Attitudes Component), “Are skilled at working with people” (Clinic Office Staff Behaviors and Attitudes Component), “Is a comfortable and relaxing place” or “Has the policies posted regarding the order in which patients are seen” (Health Care Physical Environment Characteristics and Policies Component). Item ratings are averaged to yield an overall score, with higher scores indicating greater experiences of perceived cultural sensitivity. Discriminant validity was evidenced in the present study by the fact that social desirability was uncorrelated with T-CSHI-PF scores ($r = .13, p = .70$). With respect to the original forms, Tucker et al. reported Cronbach’s alphas for the African American and non-Hispanic White American patient forms ranging from 0.71 to 0.96 and six month test-retest and split-half reliabilities being 0.92 and 0.99, respectfully. In the present study, Cronbach’s alpha calculated for the subscales that were combined into a total score was 0.98. Only averaged total scores of the three subcomponents from the T-CSHI-PF was used to assess perceived patient-centered cultural sensitivity in health care experienced. Please refer to Appendix K for a copy of the T-CSHI-PF.

Social Desirability

Marlowe-Crowne social desirability scale – short form C (MCSDS-SFC; Crowne & Marlowe, 1960). The MCSDS-SFC, a condensed version of Marlowe and Crowne’s original measure, was included to examine social desirability. Specifically, the MCSDS-SFC assesses the tendency for individuals to think or act in ways that conform to societal norms. It is comprised of items (e.g., “No matter who I’m talking to, I’m always a good listener,” and “I have never deliberately said something to hurt someone’s feelings) that describe highly desirable, culturally approved behaviors, but have low probability of occurrence. Respondents endorse either “True” or “False” across 13 different statements. One point is scored for each response in the socially

desirable direction, with scores ranging from 0 (no social desirability) to 13 (highest social desirability). With regard to validity, Robinette (1991) reported that MCSDS-SFC scores were related positively to scores on the L (Lie) scale and the K (correction) scale of the Minnesota Multiphasic Personality Inventory (MMPI) in a sample of 481 military trainees. In their original work on the MCSDS, Marlowe and Crowne reported an internal consistency of 0.88 and a test-retest stability coefficient of 0.89. Correlations between the original and Short Form C have been noted at 0.93 (Reynolds, 1982). Recently, Courtenay-Quirk, Wolitski, Parsons, and Gomez (2006) reported a Cronbach's alpha for this measure of 0.71 in a sample of 456 HIV-positive men who have sex with men. With the present study, Cronbach's alpha for this measure was also 0.71. Please refer to Appendix J for a copy of the MCSDS-SFC.

Table 3-1. Demographic characteristics of the final participant sample

Characteristics	<i>N</i>	%
Gender		
Men	123	64
Women	70	36
Race		
Caucasian American/White	79	41
African American/Black	77	40
Hispanic/Latino/a	15	8
Asian American/Pacific Islander	11	6
Multiracial or Other	8	4
American Indian/Native American	3	1
Sexual Orientation		
Exclusively Heterosexual	89	46
Exclusively Gay/Lesbian	65	34
Bisexual	16	8
Mostly Gay/Lesbian	15	8
Mostly Heterosexual	8	4
Relationship Status		
Single	113	59
Committed Relationship	36	19
Married	26	13
Divorced	10	5
Widowed	6	3
Separated	2	1
Social Class		
Working Class	66	34
Middle Class	62	32
Lower Class	49	25
Upper-Middle Class	11	6
Upper Class	5	3
HIV Disclosure		
Yes	177	92
No	16	8

Note. *N* = 193.

Table 3-2. Medical characteristics of the final participant sample

Characteristics	<i>N</i>	%
Mode of Transmission		
Male-to-Male Sexual Contact	90	47
High Risk Heterosexual Contact	66	34
Injection Drug Use	13	7
Do Not Know	11	6
High Risk Heterosexual Contact and Injection Drug Use Combined	8	4
Other	5	2
HIV/AIDS Status		
Asymptomatic	150	78
Symptomatic	22	11
Have AIDS	21	11
Past HAART Use		
Yes	137	71
No	56	29
Current HAART Use		
Yes	112	58
No	81	42
Other HIV Medications		
Yes	98	51
No	95	49

Note: *N* = 193; HAART = Highly Active Antiretroviral Therapy; Other modes of transmission identified by participants included blood transfusion, childbirth, low risk heterosexual contact, and being raped.

CHAPTER 4 RESULTS

This chapter presents the results of the analyses addressing the hypotheses and exploratory research questions set forth in this study. The results are divided into six major parts in this chapter. First, preliminary analyses conducted prior to analyzing the descriptive data for all of the major study variables are presented. Second, the descriptive data for all of the major variables in the present study are reported. Third, the results of the preliminary Pearson product-moment correlations (hereinafter referred to simply as Pearson correlations) calculated to determine whether there were any significant correlations among the investigated variables of interest and to examine the relationship between social desirability and the other studied variables are described. Fourth, the results of the partial correlations performed to address the first and second hypotheses in this study are presented. Fifth, the results of the two hierarchical multiple regressions conducted to test the first and second exploratory research questions are described. In addition, the plot of the regression lines showing how the significant interaction between social support and human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS)-related stigma influence psychological distress and the plot of the regression lines showing how the significant interaction between perceived patient-centered cultural sensitivity in health care experienced and HIV/AIDS-related stigma influence health-related quality of life are presented. Sixth, the results of a multiple linear regression to examine the third exploratory research question are provided. All statistical analyses were performed using the Statistical Package for Social Science (SPSS) version 15.

Preliminary Analyses

Prior to conducting the analyses to address the hypotheses and exploratory research questions, the demographic characteristics (e.g., age, gender, race, social class, sexual

orientation) and variables of interest (HIV/AIDS-related stigma, psychological distress, social support, health-related quality of life, experiences of social discrimination, and perceived patient-centered cultural sensitivity in health care experienced) were examined for accuracy of data entry, missing values, and fit between their distributions and the assumptions of multivariate analyses. The assumption of normality was met by verifying that there was no significant skewness or kurtosis, and by producing and inspecting histograms and normal and detrended probability plots. Linearity and homoscedasticity were verified by producing and inspecting bivariate scatterplots. In addition, inspection of the correlation matrix revealed no bivariate correlations above 0.70 among the variables of interest, indicating that multicollinearity did not exist.

Descriptive Statistics for the Major Investigated Variables

Descriptive statistics for the present sample (see Table 4-1) were generally comparable to sample means presented in previous studies. More specifically, the present sample's mean for HIV/AIDS-related stigma as measured by the AIDS Stigma Measure (ASM) was 2.38 ($SD = 0.84$), which is similar to the mean of 2.42 ($SD = 0.92$) obtained from a sample of 643 gay and bisexual Latino men who live in either Chicago, Illinois or San Francisco, California (Ramirez-Valles, 2007). The mean psychological distress score from the Mental Health Inventory (MHI) in the present sample was 47.18 ($SD = 26.41$), which is slightly higher than scores on this measure that were previously reported ($M = 41.90$, $SD = 13.00$) in a study involving a sample of 115 persons living with HIV in the Los Angeles metropolitan area (Murphy, Marelich, Hoffman, & Steers, 2004).

The present sample had a mean score of 3.03 ($SD = 1.29$) on the Medical Outcomes Study Social Support Survey (MOS-SSS), which is similar to, though slightly lower than scores on this measure that were previously reported ($M = 3.20$, $SD = 1.06$) by Mak, Cheung, Law, Woo, Li,

and Chung (2007) in a study involving a sample of 119 HIV-positive individuals living in China. The mean health-related quality of life score as assessed by the World Health Organization Quality of Life-Bref (WHOQOL-BREF) for the present sample was 49.86 ($SD = 26.09$), which is comparable to reported scores on this measure ($M = 50.88$, $SD = 22.75$) in a study involving a sample of 224 patients with HIV infection residing in Taiwan (Hsiung, Fang, Chang, Chen, & Wang, 2005). With regard to experiences of social discrimination, Bianchi, Zea, Poppen, Reisen, and Echeverry (2004) reported a mean score of 1.90 ($SD = 0.73$) on the Experiences of Social Discrimination (ESD) measure in a study of 140 HIV-positive immigrant Latino gay men living in New York City or Washington, DC. In contrast, the mean experiences of social discrimination score on the ESD for the present sample was 1.61 ($SD = 0.65$), which is lower than that found by Bianchi and colleagues. This difference in mean scores may be a reflection of the varied sexualities, mixed gender, and ethnic diversity present in the present sample in comparison to the Bianchi et al. study, which focused entirely on immigrant Latino gay men.

In the present study, the mean perceived patient-centered cultural sensitivity in health care experienced score as measured by the Tucker-Culturally Sensitive Healthcare Inventory-Patient Form (T-CSHI-PF) was 2.67 ($SD = 0.79$), which is slightly lower than what was found by Tucker, Mirsu-Paun, van den Berg, Ferdinand, Jones, Curry et al. (2007) in their community sample of 179 African American and non-Hispanic white American patients. These authors reported means and standard deviations for all three subcomponents (e.g., provider behaviors and attitudes, clinic office staff member behaviors and attitudes, and clinic physical environmental characteristics and policies) of the T-CSHI-PF that ranged from 2.94 ($SD = 0.37$) to 3.39 ($SD = 0.50$) for the non-Hispanic white American patients and 3.11 ($SD = 0.52$) to 3.26 ($SD = 0.54$) for the African American patients in their sample.

With respect to social desirability, Proescholdbell, Roosa, and Nemeroff (2006) reported a mean score of 3.48 (no standard deviation reported) on the Marlowe-Crowne Social Desirability Scale-Short Form C (MCSDS-SFC) in a study involving 348 gay and bisexual men living in a community in the southwest. The mean score on the MCSDS-SFC reported by Proescholdbell et al. is lower than what was found in the present sample ($M = 4.03$, $SD = 0.96$) for this measure.

Results of Preliminary Pearson Correlations

Before conducting tests of the hypotheses and exploratory research questions, preliminary Pearson correlations were calculated to determine whether there were any significant correlations among the investigated variables of interest and to examine the relationship between social desirability and the other studied variables. As presented in Table 4-2, HIV/AIDS-related stigma scores (as measured by the AIDS Stigma Measure (ASM) only) were shown to have a significant positive correlation with psychological distress scores ($r = .58$, $p = .00$) and experiences of social discrimination scores ($r = .59$, $p = .00$). As level of HIV/AIDS-related stigma increased, level of psychological distress and experiences of social discrimination also increased. HIV/AIDS-related stigma scores were also shown to have a significant negative correlation with social support scores ($r = -.67$, $p = .00$), health-related quality of life scores ($r = -.61$, $p = .00$), and perceived patient-centered cultural sensitivity in health care experienced scores ($r = -.58$, $p = .00$); that is, as level of HIV/AIDS-related stigma increased, levels of social support, health-related quality of life, and perceived patient-centered cultural sensitivity in health care experienced decreased.

Psychological distress scores were shown to have a significant negative correlation with social support scores ($r = -.61$, $p = .00$), health-related quality of life scores ($r = -.55$, $p = .00$), and perceived patient-centered cultural sensitivity in health care experienced scores ($r = -.60$, $p = .00$). As level of psychological distress increased, levels of social support, health-related quality of life, and perceived patient-centered cultural sensitivity in health care experienced decreased.

Furthermore, psychological distress scores were shown to have a significant positive correlation with experiences of social discrimination scores ($r = .40, p = .00$). Thus, as level of psychological distress increased, level of experiences of social discrimination increased as well.

Social support scores were shown to have a significant positive relationship with health-related quality of life scores ($r = .59, p = .00$) and perceived patient-centered cultural sensitivity in health care experienced scores ($r = .52, p = .00$). As level of social support increased, levels of health-related quality of life and perceived patient-centered cultural sensitivity in health care experienced also increased. Moreover, social support scores were shown to have a significant negative relationship with experiences of social discrimination scores ($r = -.57, p = .00$); that is, as level of social support increased, level of experiences of social discrimination decreased.

Health-related quality of life scores were shown to have a significant positive relationship with perceived patient-centered cultural sensitivity in health care experienced scores ($r = .59, p = .00$) and a significant negative relationship with experiences of social discrimination scores ($r = -.57, p = .00$). As level of health-related quality of life increased, level of perceived patient-centered cultural sensitivity in health care experienced also increased, while level of experiences of social discrimination decreased. In addition, experiences of social discrimination scores were shown to have a significant negative relationship with perceived patient-centered cultural sensitivity in health care experienced scores ($r = -.45, p = .00$); that is, as level of experiences of social discrimination increased, level of perceived patient-centered cultural sensitivity in health care experienced decreased.

The correlation analysis also revealed that social desirability scores were not significantly correlated with any of the study variables, suggesting that participants were not responding to the instruments to assess these variables in a socially desirable manner.

Links between demographic variables and the variables of interest were also examined using Pearson correlations in order to identify potential covariates to be entered in subsequent analyses. As shown in Table 4-1, increased age showed a significant positive correlation with HIV/AIDS-related stigma scores ($r = .27, p = .00$) and significant negative correlations with social support scores ($r = -.21, p = .00$), health-related quality of life scores ($r = -.26, p = .00$), and perceived patient-centered cultural sensitivity in health care experienced scores ($r = -.16, p = .00$); that is, as age increased, level of HIV/AIDS-related stigma also increased, but levels of social support, health-related quality of life, and perceived patient-centered cultural sensitivity in health care experienced decreased.

Gender showed significant positive correlations with HIV/AIDS-related stigma scores ($r = .50, p = .00$), psychological distress scores ($r = .41, p = .00$), and experiences of social discrimination scores ($r = .17, p = .02$), as well as significant negative correlations with social support scores ($r = -.52, p = .00$), health-related quality of life scores ($r = -.54, p = .00$), and perceived patient-centered cultural sensitivity in health care experienced scores ($r = -.51, p = .00$). Women reported higher levels of HIV/AIDS-related stigma, psychological distress, and experiences of social discrimination than men. At the same time, women reported lower levels of social support, health-related quality of life, and perceived patient-centered cultural sensitivity in health care experienced.

Race showed significant positive correlations with HIV/AIDS-related stigma scores ($r = .59, p = .00$), psychological distress scores ($r = .45, p = .00$), and experiences of social discrimination scores ($r = .56, p = .00$), as well as significant negative correlations with social support scores ($r = -.61, p = .00$), health-related quality of life scores ($r = -.62, p = .00$), and perceived patient-centered cultural sensitivity in health care experienced scores ($r = -.60, p = .00$).

African Americans reported higher levels of HIV/AIDS-related stigma, psychological distress, and experiences of social discrimination than any of the other races. Furthermore, African Americans reported lower levels of social support, health-related quality of life, and perceived patient-centered cultural sensitivity in health care experienced.

Sexual orientation showed significant positive correlations with HIV/AIDS-related stigma scores ($r = .33, p = .00$) and psychological distress scores ($r = .21, p = .00$), as well as significant negative correlations with social support scores ($r = -.36, p = .00$), health-related quality of life scores ($r = -.37, p = .00$), and perceived patient-centered cultural sensitivity in health care experienced scores ($r = -.41, p = .00$). Heterosexuals reported higher levels of HIV/AIDS-related stigma and psychological distress, and they reported lower levels of social support, health-related quality of life, and perceived patient-centered cultural sensitivity in health care experienced than gay/lesbian participants. Thus, age, gender, race, and sexual orientation were included as covariates in all analyses to adjust for their links when testing hypotheses and exploratory research questions. The variables of interest in the present study were not related significantly to social class.

Results of Analyses to Test Hypotheses 1 and 2

Hypothesis 1

Hypothesis 1 stated that experiences of social discrimination would be related *positively* to HIV/AIDS-related stigma; that is, as experiences of social discrimination increase, HIV/AIDS-related stigma would also increase. To test Hypothesis 1, partial correlations, controlling for age, gender, race, and sexual orientation, were performed to explore the statistical significance and strength of the relationship between experiences of social discrimination (assessed by using total scores from the ESD) and HIV/AIDS-related stigma (assessed by using total scores from the ASM only). As presented in Table 4-3, the partial correlation of experiences of social

discrimination scores with HIV/AIDS-related stigma scores was .47 ($p = .000$). This finding is consistent with Hypothesis 1, indicating that level of experiences of social discrimination was related *positively* and *significantly* to HIV/AIDS-related stigma, even after controlling for age, gender, race, and sexual orientation.

Hypothesis 2

Hypothesis 2 stated that perceived patient-centered cultural sensitivity in health care experienced would be related *negatively* to HIV/AIDS-related stigma; that is, as perceived patient-centered cultural sensitivity in health care experienced increases, HIV/AIDS-related stigma would decrease. To test Hypothesis 2, partial correlations, controlling for age, gender, race, and sexual orientation, were performed to explore the statistical significance and strength of the relationship between the pair of variables of interest [e.g., perceived patient-centered cultural sensitivity in health care experienced (assessed by using averaged total scores of the three components - the Provider Behaviors and Attitudes, Office Staff Behaviors and Attitudes, and Center Policies and Physical Environment Characteristics - of the T-CSHI-PF) and HIV/AIDS-related stigma (assessed by using total scores from the ASM only)]. As shown in Table 4-3, the partial correlation of perceived patient-centered cultural sensitivity in health care experienced scores with HIV/AIDS-related stigma scores was $-.63$ ($p = .000$). This finding is consistent with Hypothesis 2, indicating that level of perceived patient-centered cultural sensitivity in health care experienced was related *negatively* and *significantly* to HIV/AIDS-related stigma, even after controlling for age, gender, race, and sexual orientation.

Results of Analyses to Test Exploratory Research Questions 1, 2, and 3

Exploratory Research Question 1

The first exploratory research question under investigation explored whether social support would *moderate* the relationship between HIV/AIDS-related stigma and psychological distress.

To test exploratory research question 1, as suggested by Baron and Kenny (1986) when testing for moderator effects, a hierarchical multiple regression was conducted to examine if social support (assessed by using total scores from the MOS-SSS) moderated the relationship between HIV/AIDS-related stigma (assessed by using total scores from the ASM only) and psychological distress (assessed by using psychological distress subscale scores from the MHI). In this hierarchical multiple regression, the predictor variable was HIV/AIDS-related stigma, the criterion variable was psychological distress, and the interaction term was social support X HIV/AIDS-related stigma.

Previous researchers (e.g., Frazier, Tix, & Barron, 2004; McClelland & Judd, 1993; Pedhazur & Schmelkin, 1991; Wampold & Freund, 1987) have identified statistical difficulties of detecting moderator effects and have noted that the contribution of interaction terms above and beyond main effects will be small. Given these challenges, McClelland and Judd (1993) and Pedhazur and Schmelkin (1991) have recommended the use of liberal alphas (e.g., .10) in evaluating the significance of moderator effects. Thus, in testing the first exploratory research question for the present study, alpha was set at .10.

In this hierarchical multiple regression, centered variables (i.e., mean deviation scores) were used as recommended by Aiken and West (1991) in order to reduce multicollinearity between the interaction term and the main effects when testing for moderator effects. Demographic variables that had significant relationships with psychological distress as determined by the Pearson correlations discussed earlier (e.g., gender, race, and sexual orientation) were entered together at Step 1, HIV/AIDS-related stigma was entered at Step 2, social support was entered at Step 3, and the interaction term (social support X HIV/AIDS-

related stigma) was entered at Step 4. A significant unstandardized coefficient (B) and R^2 change for the interaction term indicates a significant moderator effect.

As presented in Table 4-4, in the first model, significant effects were found for women ($\beta = .24, p < .05$), African Americans/Blacks ($\beta = .43, p < .001$), and other races ($\beta = .22, p < .05$). This finding suggests that women had higher psychological distress scores than men and African Americans/Blacks and other races had higher psychological distress scores than Caucasian Americans/Whites. However, psychological distress scores did not differ significantly for heterosexuals, bisexuals, and gays/lesbians.

In the second model, significant effects remained for women ($\beta = .17, p < .05$), African Americans/Blacks ($\beta = .20, p < .05$), and other races ($\beta = .14, p < .05$). Psychological distress scores continued to be non-significant for heterosexuals, bisexuals, and gays/lesbians. When HIV/AIDS-related stigma was entered into the model, a significant effect ($\beta = .43, p < .001$) was found. This result suggests that as HIV/AIDS-related stigma scores increased, psychological distress scores also increased substantially.

In the third model, significant effects remained for women ($\beta = .15, p < .10$), African Americans/Blacks ($\beta = .16, p < .10$), and other races ($\beta = .15, p < .05$). A significant effect was also found for gays/lesbians ($\beta = .15, p < .10$) but remained non-significant for bisexuals and heterosexuals. In addition, HIV/AIDS-related stigma was not statistically significant in the model. When social support was entered into the model, a significant effect ($\beta = -.43, p < .001$) was found. This result indicates that as social support scores increased, psychological distress scores decreased substantially.

In the fourth model, significant effects remained for women ($\beta = .16, p < .10$), other races ($\beta = .15, p < .05$), gays/lesbians ($\beta = .16, p < .05$), and social support ($\beta = -.42, p < .001$).

However, psychological distress scores did not differ for African Americans/Blacks, bisexuals, and heterosexuals. In addition, HIV/AIDS-related stigma was not statistically significant in the model. When the interaction term social support X HIV/AIDS-related stigma was entered into the model, a significant effect ($\beta = -.12, p < .05$) was found.

Inspection of R^2 change for the interaction term social support X HIV/AIDS-related stigma (R^2 change = .01, $p < .05$) revealed a significant moderator effect, indicating that social support moderated the relationship between HIV/AIDS-related stigma and psychological distress. More specifically, the interaction of social support and HIV/AIDS-related stigma was significant and accounted for 1% of the variance in psychological distress, above and beyond the variance accounted for by demographic covariates and the main effects of the interacting variables. In addition, the model as a whole was statistically significant [$F(8, 184) = 17.45, p < .001$].

The plot of the regression lines showing how the significant interaction between social support and HIV/AIDS-related stigma influenced psychological distress is presented in Figure 4-1. In the first interaction line (+2 *SD*), the simple slope was -6.51 ($p = .12$) and the intercept was 19.99. In the second interaction line (+1 *SD*), the simple slope was -0.90 ($p = .38$) and the intercept was 32.39. In the third interaction line (mean), the simple slope was 4.71 ($p = .00$) and the intercept was 44.78. In the fourth interaction line (-1 *SD*), the simple slope was 10.32 ($p = .00$) and the intercept was 57.18. In the fifth interaction line (-2 *SD*), the simple slope was 15.92 ($p = .00$) and the intercept was 69.58.

Results of the interaction analysis suggest that statistical significance in the simple slopes exists when social support is at its mean and lower as indicated above. In other words, as social support goes down, the slope of lines become more strongly positive, such that the relationship between HIV/AIDS-related stigma and psychological distress becomes stronger as social support

declines. Thus, it appears that among participants in the present study, social support is buffering the negative impact of HIV/AIDS-related stigma on psychological distress.

Exploratory Research Question 2

The second exploratory research question under investigation explored whether social support and perceived patient-centered cultural sensitivity in health care experienced would *moderate* the relationship between HIV/AIDS-related stigma and health-related quality of life. To test the second exploratory research question, a hierarchical multiple regression was conducted to examine if social support [(assessed by using total scores from the MOS-SSS) and perceived patient-centered cultural sensitivity in health care experienced (assessed by using averaged total scores of the three components - the Provider Behaviors and Attitudes, Office Staff Behaviors and Attitudes, and Center Policies and Physical Environment Characteristics - of the T-CSHI-PF) moderated the relationship between HIV/AIDS-related stigma (assessed by using total scores from the ASM) and health-related quality of life (assessed by using total scores from the WHOQOL-BREF)]. In this multiple regression, the predictor variable was HIV/AIDS-related stigma, the criterion variable was health-related quality of life, and the two interaction terms were social support X HIV/AIDS-related stigma and perceived patient-centered cultural sensitivity in health care experienced X HIV/AIDS-related stigma. In testing the second exploratory research question, alpha was again set at .10.

In this hierarchical multiple regression, centered variables were used in order to reduce multicollinearity between the interaction terms and the main effects when testing for moderator effects (Aiken & West, 1991). Demographic variables that had significant relationships with health-related quality of life as determined by the Pearson correlations discussed earlier (e.g., age, gender, race, and sexual orientation) were entered together at Step 1, HIV/AIDS-related stigma was entered at Step 2, social support was entered at Step 3, perceived patient-centered

cultural sensitivity in health care experienced was entered at Step 4, the first interaction term (social support X HIV/AIDS-related stigma) was entered at Step 5, and the second interaction term (perceived patient-centered cultural sensitivity in health care experienced) was entered at Step 6. Significant unstandardized coefficients (B) and R^2 changes for the interaction terms indicate significant moderator effects.

As presented in Table 4-5, in the first model, significant effects were found for age ($\beta = -.11, p < .10$), women ($\beta = -.18, p < .05$), and African Americans/Blacks ($\beta = -.48, p < .001$). This finding suggests that older participants had lower health-related quality of life scores than younger participants, women had lower health-related quality of life scores than men, and African Americans/Blacks had lower health-related quality of life scores than Caucasian Americans/Whites. However, health-related quality of life scores did not differ significantly for all other races and by sexual orientation.

In the second model, significant effects remained for African Americans/Blacks ($\beta = -.11, p < .10$) and were now significant for all other races ($\beta = .09, p < .10$). However, health-related quality of life scores did not differ significantly for older participants, women, and bisexual and gay/lesbian participants. When HIV/AIDS-related stigma was entered into the model, a significant effect ($\beta = -.68, p < .001$) was found. This result suggests that as HIV/AIDS-related stigma scores increased, health-related quality of life scores decreased substantially.

In the third model, the only significant effects that remained were for other races ($\beta = .08, p < .10$) and HIV/AIDS-related stigma ($\beta = -.45, p < .001$). When social support was entered into the model, a significant effect ($\beta = .29, p < .05$) was found. This result suggests that as social support scores increased, health-related quality of life scores increased as well.

In the fourth model, significant effects only remained for other races ($\beta = .08, p < .10$), HIV/AIDS-related stigma ($\beta = -.45, p < .001$), and social support ($\beta = .30, p < .05$). When perceived patient-centered cultural sensitivity in health care experienced was entered into the model, it was not statistically significant. In the fifth model, significant effects only remained for other races ($\beta = .08, p < .10$), HIV/AIDS-related stigma ($\beta = -.46, p < .05$), and social support ($\beta = .30, p < .05$). When the interaction term social support X HIV/AIDS-related stigma was entered into the equation, it was not statistically significant. Given this non-significant finding for the interaction term social support X HIV/AIDS-related stigma, it was not included in the last model.

In the sixth and final model, significant effects remained for HIV/AIDS-related stigma ($\beta = -.47, p < .001$) and social support ($\beta = .31, p < .05$). When the interaction term perceived patient-centered cultural sensitivity in health care experienced X HIV/AIDS-related stigma was entered into the model, a significant effect ($\beta = .08, p < .10$) was found.

Inspection of R^2 change for the interaction term perceived patient-centered cultural sensitivity in health care experienced X HIV/AIDS-related stigma (R^2 change = .01, $p < .10$) revealed a significant moderator effect, indicating that perceived patient-centered cultural sensitivity in health care experienced moderated the relationship between HIV/AIDS-related stigma and health-related quality of life. More specifically, the interaction of perceived patient-centered cultural sensitivity in health care experienced and HIV/AIDS-related stigma was significant and accounted for 1% of the variance in health-related quality of life, above and beyond the variance accounted for by demographic covariates and the main effects of the interacting variables. In addition, the model as a whole was statistically significant [$F(10, 182) = 46.67, p < .001$].

The plot of the regression lines showing how the significant interaction between perceived patient-centered cultural sensitivity in health care experienced and HIV/AIDS-related stigma influenced health-related quality of life is presented in Figure 4-2. In the first interaction line (+2 *SD*), the simple slope was -6.26 ($p = .09$) and the intercept was 104.14. In the second interaction line (+1 *SD*), the simple slope was -8.89 ($p = .00$) and the intercept was 82.46. In the third interaction line (mean), the simple slope was -11.53 ($p = .00$) and the intercept was 60.78. In the fourth interaction line (-2 *SD*), the simple slope was -14.17 ($p = .00$) and the intercept was 39.10. In the fifth interaction line (-1 *SD*), the simple slope was -16.81 ($p = .00$) and the intercept was 17.42, which appears only as a dash on the figure.

Results of the interaction analysis suggest that the simple slopes shown in Figure 4-2 are all negative and statistically significant. As perceived patient-centered cultural sensitivity in health care experienced goes down, the slope of lines becomes more strongly negative. For instance, the negative relationship between HIV/AIDS-related stigma and health-related quality of life becomes stronger as patient-centered cultural sensitivity in health care experienced declines. Thus, it appears that among participants in the present study, patient-centered cultural sensitivity in health care experienced is buffering the negative impact of HIV/AIDS-related stigma on health-related quality of life.

Exploratory Research Question 3

The third exploratory research question under investigation explored whether there were significant differences in HIV/AIDS-related stigma in association with the three demographic variables (e.g., gender, race, and sexual orientation) that had significant relationships to HIV/AIDS-related stigma as revealed in the hierarchical multiple regressions to test exploratory research questions 1 & 2. To examine this third exploratory research question, a multiple linear

regression with HIV/AIDS-related stigma as the criterion variable and the three demographic characteristics previously identified as the predictor variables was performed.

Results from the multiple linear regression (see Table 4-6) revealed significant effects for women ($\beta = .18, p < .05$), African Americans/Blacks ($\beta = .55, p < .001$), and other races ($\beta = .20, p < .01$). This finding suggests that women had higher levels of HIV/AIDS-related stigma scores than men and African Americans/Blacks and other races had higher levels of HIV/AIDS-related stigma scores than Caucasian Americans/Whites. However, HIV/AIDS-related stigma scores did not differ significantly for heterosexuals, bisexuals, and gays/lesbians. Inspection of R-square showed that 42% of the variance in HIV/AIDS-related stigma is accounted for by the model. In addition, the model as a whole was statistically significant [$F(5, 187) = 26.56, p < .001$]. Overall, these findings suggest that there were significant differences in HIV/AIDS-related stigma scores in association with gender and race but not for sexual orientation.

Table 4-1. Descriptive data for the major variables of interest

Variable	<i>M</i>	<i>SD</i>	Possible Range	Sample Range	α
HIV/AIDS-Related Stigma	2.38	0.84	1-4	1.00-4.00	0.98
Psychological Distress	47.18	26.41	0-100	.00-100.00	0.96
Social Support	3.03	1.29	1-5	1.32-4.74	0.92
Health-Related Quality of Life	49.86	26.09	0-100	.00-100.00	0.89
Experiences of Social Discrimination	1.61	0.65	1-4	1.00-4.00	0.88
Perceived Patient-Centered Cultural Sensitivity in Health Care Experienced	2.67	0.79	1-4	1.25-3.78	0.98
Social Desirability	4.03	0.96	0-13	1.00-9.00	0.71

Note. *N* = 193; Higher scores indicate higher levels of the construct assessed.

Table 4-2. Pearson correlations for the major investigated variables including social desirability

Variable	1	2	3	4	5	6	7	8	9	10	11
1. HIV/AIDS-Related Stigma	–										
2. Psychological Distress	.58**	–									
3. Social Support	-.67**	-.61**	–								
4. Health-Related Quality of Life	-.61**	-.55**	.59**	–							
5. Experiences of Social Discrimination	.59**	.40**	-.57**	-.57**	–						
6. Perceived Patient-Centered Cultural Sensitivity in Health Care Experienced	-.58**	-.60**	.52**	.59**	-.45**	–					
7. Social Desirability	.00	.09	.01	.04	.12	.13	–				
8. Age	.27**	.131	-.21**	-.26**	.07	.02	-.16*	–			
9. Gender	.50**	.41**	-.52**	-.54**	.17*	-.03	-.51**	.29**	–		
10. Race	.59**	.45**	-.61**	-.62**	.56**	.10	-.60**	.21**	.62**	–	
11. Sexual Orientation	.33**	.21**	-.36**	-.37**	.05	-.14	-.41**	.15*	-.50**	.37**	–

Note. $N = 193$; * $p < .05$. ** $p < .01$.

Table 4-3. Partial correlations to test hypothesis 1 and hypothesis 2 controlling for age, gender, race, and sexual orientation

Variable	1	2	3
1. HIV/AIDS-Related Stigma	–		
2. Experiences of Social Discrimination	.47***	–	
3. Perceived Patient-Centered Cultural Sensitivity in Health Care Experienced	-.63***	–	–

Note. $N = 193$; Hypothesis 1 stated that experiences of social discrimination would be related *positively* to HIV/AIDS-related stigma; Hypothesis 2 stated that perceived patient-centered cultural sensitivity in health care experienced would be related *negatively* to HIV/AIDS-related stigma.

Note. *** $p < .001$.

Table 4-4. Moderating effect of social support (centered) on the relation between stigma (centered) and psychological distress to examine research question 1

Step	Variable	<i>B</i>	β	<i>t</i>	Total <i>R</i> ²	Adjusted <i>R</i> ²	<i>R</i> ² Change	<i>F</i> Change	<i>dfs</i>
1	Women	13.28	.24	2.65**	.27	.25	.27	13.81***	5, 187
	African American/Black	23.25	.43	4.19***					
	Other Race	14.68	.22	3.08**					
	Bisexual	3.74	.06	.79					
	Gay/Lesbian	6.45	.12	1.33					
2	Women	9.13	.17	1.94*	.38	.36	.11	31.84***	1, 186
	African American/Black	10.56	.20	2.14**					
	Other Race	9.11	.14	2.01**					
	Bisexual	3.51	.05	.80					
	Gay/Lesbian	7.01	.13	1.57					
	HIV/AIDS-Related Stigma (HARS)	13.44	.43	5.64***					
3	Women	8.05	.15	1.77*	.42	.40	.04	13.14***	1, 185
	African American/Black	8.39	.16	1.74*					
	Other Race	9.92	.15	2.26**					
	Bisexual	4.54	.07	1.07					
	Gay/Lesbian	8.06	.15	1.85*					
	HARS	3.04	.10	.82					
	Social Support (SS)	-8.79	-.43	-3.63***					

Table 4-4. Moderating effect of social support (centered) on the relation between stigma (centered) and psychological distress to examine research question 1 (continued)

Step	Variable	<i>B</i>	β	<i>t</i>	Total <i>R</i> ²	Adjusted <i>R</i> ²	<i>R</i> ² Change	<i>F</i> Change	<i>dfs</i>
4	Women	8.49	.16	1.88*	.43	.41	.01	4.41**	1, 184
	African American/Black	6.34	.12	1.30					
	Other Race	9.99	.15	2.29**					
	Bisexual	5.26	.08	1.24					
	Gay/Lesbian	8.71	.16	2.02**					
	HARS	3.34	.11	.92					
	SS	-8.71	-.42	-3.63***					
	SS X HARS	-4.83	-.12	-2.10**					

Note. *N* = 193; HARS = HIV/AIDS-Related Stigma; SS = Social Support; Exploratory Research Question 1 examined whether social support would moderate the relationship between HIV/AIDS-related stigma and psychological distress; Predictor variables and the interaction term were centered in the above regression analyses.

* *p* < .10. ** *p* < .05, *** *p* < .001.

Table 4-5. Moderating effect of social support (centered) and cultural sensitivity (centered) on the relation between stigma (centered) and quality of life to examine research question 2

Step	Variable	<i>B</i>	β	<i>t</i>	Total <i>R</i> ²	Adjusted <i>R</i> ²	<i>R</i> ² Change	<i>F</i> Change	<i>dfs</i>
1	Age	-.23	-.11	-1.88*	.44	.42	.44	24.21***	6, 186
	Women	-9.76	-.18	-2.20**					
	African American/Black	-25.59	-.48	-6.22***					
	Other Race	-3.36	-.05	-.81					
	Bisexual	3.22	.05	.78					
	Gay/Lesbian	3.42	.06	.81					
2	Age	-.01	-.01	-.16	.70	.68	.26	156.58***	1, 185
	Women	-4.93	-.09	-1.49					
	African American/Black	-5.83	-.11	-1.71*					
	Other Race	6.00	.09	1.90*					
	Bisexual	3.96	.06	1.30					
	Gay/Lesbian	2.08	.04	.67					
3	HIV/AIDS-Related Stigma (HARS)	-20.99	-.68	-12.51***	.72	.70	.02	12.08**	1, 184
	Age	-.05	-.02	-.50					
	Women	-4.01	-.07	-1.25					
	African American/Black	-4.48	-.08	-1.34					
	Other Race	5.33	.08	1.73*					
	Bisexual	3.22	.05	1.09					
	Gay/Lesbian	1.45	.03	.48					
	HARS	-13.93	-.45	-5.36***					
Social Support (SS)	5.87	.29	3.48**						

Table 4-5. Moderating effect of social support (centered) and cultural sensitivity (centered) on the relation between stigma (centered) and quality of life to examine research question 2 (continued)

Step	Variable	<i>B</i>	β	<i>t</i>	Total <i>R</i> ²	Adjusted <i>R</i> ²	<i>R</i> ² Change	<i>F</i> Change	<i>dfs</i>
4	Age	-.04	-.02	-.47	.72	.70	.00	.07	1, 183
	Women	-4.03	-.07	-1.25					
	African American/Black	-4.64	-.09	-1.36					
	Other Race	5.21	.08	1.67*					
	Bisexual	3.29	.05	1.10					
	Gay/Lesbian	1.54	.03	.51					
	HARS	-14.07	-.45	-5.29***					
	SS	6.07	.30	3.26**					
	Perceived Patient-Centered Cultural Sensitivity in Health Care Experienced (PP-CCSHCE)	-.65	-.02	-.26					
5	Age	-.04	-.02	-.45	.72	.70	.00	.18	1, 182
	Women	-4.11	-.08	-1.27					
	African American/Black	-4.38	-.08	-1.27					
	Other Race	5.17	.08	1.65*					
	Bisexual	3.21	.05	1.07					
	Gay/Lesbian	1.47	.03	.48					
	HARS	-14.18	-.46	-5.29***					
	SS	6.13	.30	3.28**					
	PP-CCSHCE	-.88	-.03	-.35					
	SS X HARS	.71	.02	.43					

Table 4-5. Moderating effect of social support (centered) and cultural sensitivity (centered) on the relation between stigma (centered) and quality of life to examine research question 2 (continued)

Step	Variable	<i>B</i>	β	<i>t</i>	Total <i>R</i> ²	Adjusted <i>R</i> ²	<i>R</i> ² Change	<i>F</i> Change	<i>dfs</i>
6	Age	-.04	-.02	-.41	.72	.70	.01	3.07*	1, 182
	Women	-3.47	-.06	-1.08					
	African American/Black	-4.07	-.08	-1.20					
	Other Race	4.64	.07	1.49					
	Bisexual	3.18	.05	1.07					
	Gay/Lesbian	1.58	.03	.52					
	HARS	-14.52	-.47	-5.46***					
	SS	6.31	.31	3.40**					
	PP-CCSHCE	-1.80	-.05	-.71					
	PP-CCSHCE X HARS	4.16	.08	1.75*					

Note. *N* = 193; HARS = HIV/AIDS-Related Stigma; SS = Social Support; PP-CCSHCE = Perceived Patient-Centered Cultural Sensitivity in Health Care Experienced; In the sixth model, the interaction of SS X HARS was removed because it was non-significant in step 5. Exploratory Research Question 2 examined whether social support and perceived patient-centered cultural sensitivity in health care experienced would moderate the relationship between HIV/AIDS-related stigma and health-related quality of life; Predictor variables and the interaction term were centered in the above regression analyses.

* *p* < .10. ** *p* < .05. *** *p* < .001.

Table 4-6. Multiple linear regression analysis with stigma and demographic variables to examine research question 3

Variable	<i>B</i>	β	<i>t</i>	Total <i>R</i> ²	Adjusted <i>R</i> ²	<i>F</i>	<i>dfs</i>
Women	.31	.18	2.17*	.42	.40	26.56***	5, 187
Black	.94	.55	7.01***				
Other Race	.42	.20	3.05**				
Bisexual	.02	.01	.13				
Gay/Lesbian	-.04	-.02	-.31				

Note: *N* = 193; Dependent Variable = HIV/AIDS-Related Stigma; Exploratory Research Question 3 examined whether there were significant differences in HIV/AIDS-related stigma in association with demographic variables.

* *p* < .05. ** *p* < .01. *** *p* < .001

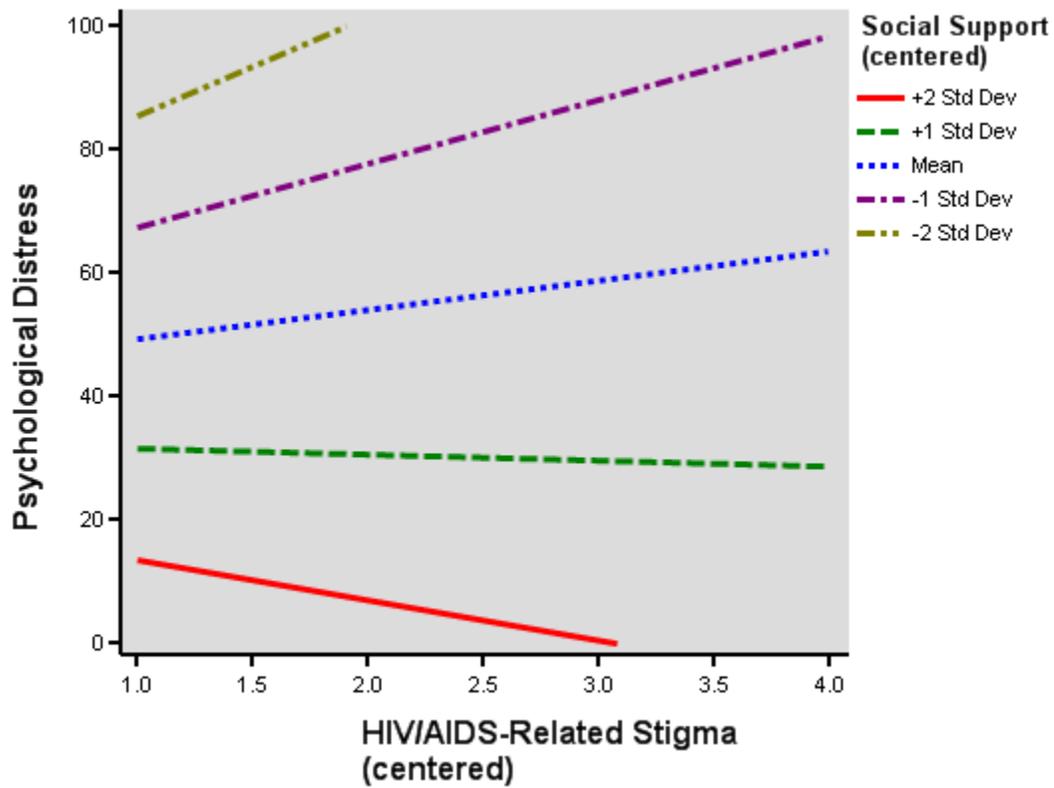


Figure 4-1. Plot of regression lines showing how the significant interaction between social support (centered) and stigma (centered) influenced psychological distress

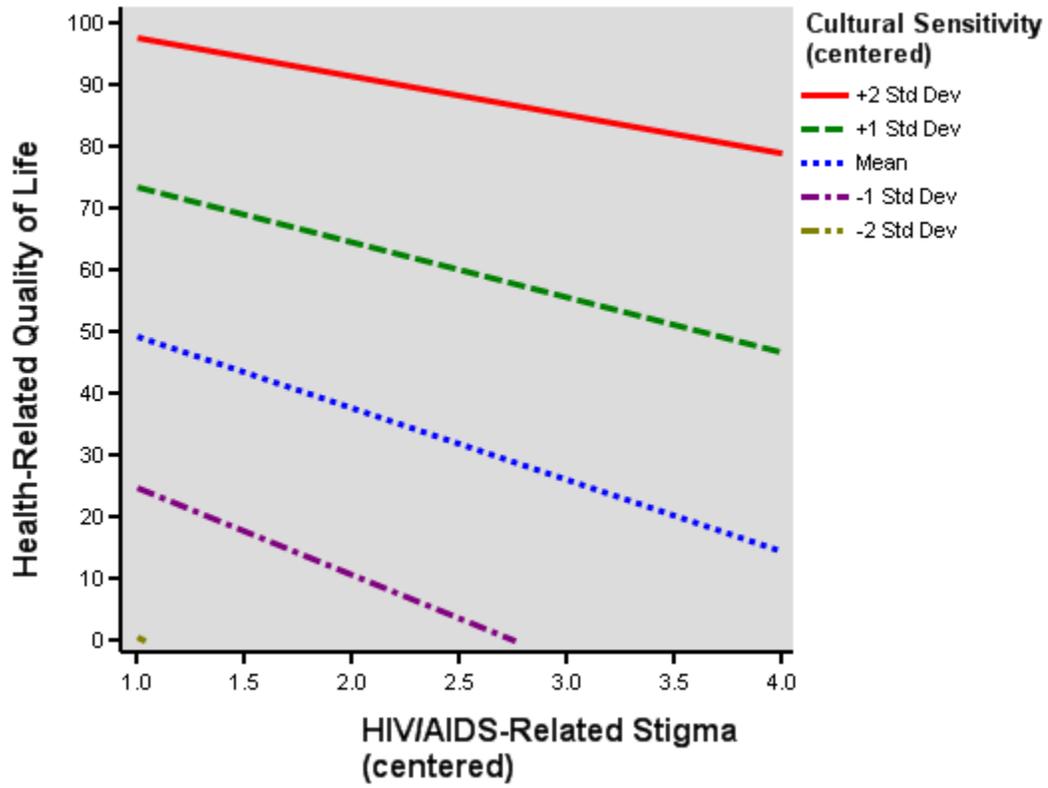


Figure 4-2. Plot of regression lines showing how the significant interaction between cultural sensitivity (centered) and stigma (centered) influenced quality of life

CHAPTER 5 DISCUSSION

The purpose of the present study was to investigate the associations between human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS)-related stigma and both psychological distress and health-related quality of life among persons living with HIV/AIDS (PLWHA) in the United States (US). In addition, whether these associations were moderated by social support and perceived patient-centered cultural sensitivity in health care experienced was examined. The present study also explored whether there were significant differences in HIV/AIDS-related stigma in association with specific demographic variables (i.e., race, gender, and sexual orientation).

This final chapter begins with a summary of the present study's findings and interpretation of the results. Second, limitations of the present study and future research directions are addressed. Third, implications of this research for public health educators, healthcare professionals, and policy makers are discussed.

Summary and Interpretation of Findings

The theoretical framework used to guide the present study was Goffman (1963) and Foucault's (1977, 1978) conceptualization of stigma. Based on this combined framework, the present study considered the social embeddedness of HIV/AIDS-related stigma and discrimination among PLWHA by examining: (a) whether having higher levels of experiences of social discrimination (i.e., homophobia, racism, and financial hardship) was associated with higher levels of HIV/AIDS-related stigma, (b) whether having higher levels of perceived patient-centered cultural sensitivity in health care experienced was associated with lower levels of HIV/AIDS-related stigma, (c) whether social support moderates the relationship between HIV/AIDS-related stigma and psychological distress, (d) whether social support and perceived

patient-centered cultural sensitivity in health care experienced moderates the relationship between HIV/AIDS-related stigma and health-related quality of life, and (e) whether there are significant differences in HIV/AIDS-related stigma in association with age, gender, race, sexual orientation, and social class. Prior to discussing the results of the hypotheses and the exploratory research questions, both expected and unexpected findings for the correlations among investigated variables of interest and demographic variables are presented.

Correlations Among Investigated Variables of Interest

The exploration of relationships among the investigated variables of interest revealed both expected and unexpected findings. Expected correlations among the investigated variables of interest are presented first with unexpected correlations to follow.

As expected, a significant positive relationship existed between HIV/AIDS-related stigma and psychological distress, which is consistent with results from previous empirical studies among PLWHA (Miles, Burchinal, Holditch-Davis, Wasilewski, & Christian, 1997; Silver, Bauman, Camacho, & Hudis, 2003). Additionally, as anticipated, HIV/AIDS-related stigma showed a significant negative relationship with social support and health-related quality of life, findings that are in line with past international research conducted among HIV-infected populations (Ayarza & Reyes, 2002; Castle, Cornu, Dua, Herrera, Nadkarni, Ouedraogo et al., 2002; Ortega, Gonzales, & Liwanag, 2002).

Consistent with other empirical studies among PLWHA (Au, Chan, Li, Chung, Po, & Yu, 2004; Siegel & Schrimshaw, 2007), psychological distress was shown to have significant negative relationships with social support and health-related quality of life. In addition, a significant positive relationship existed between social support and health-related quality of life, which is similar to findings from previous studies among HIV-positive persons (Burgoyne &

Renwick, 2004; Cowdery & Pesa, 2002; Swindells, Mohr, Justis, Berman, Squier, Wagener et al., 1999).

The unexpected findings in the present study had to do with perceived patient-centered cultural sensitivity in health care experienced and other investigated variables. The first unexpected finding was that psychological distress was shown to have a significant negative relationship with perceived patient-centered cultural sensitivity in health care experienced. While unanticipated, this finding is in line with the research of Evans, Ferrando, Rabkin, and Fishman (2000) in which an inverse association between strong, positive beliefs in health care professionals (e.g., doctors, nurses) and psychological distress was found among 173 HIV-positive gay and bisexual men. However, in the present study, other health care characteristics (e.g., office staff members' behaviors and physical environmental characteristics and policies) in addition to the patient-provider relationship that constituted the examined variable of perceived patient-centered cultural sensitivity in health care experienced was found to have a significant negative association with psychological distress.

The second unexpected finding was that social support was significantly and positively associated with perceived patient-centered cultural sensitivity in health care experienced. In a sample of 40 Native Hawaiian and 40 white persons living with HIV in Hawaii, Ka'opua and Mueller (2004) described that the Native Hawaiian participants in their sample emphasized an appreciation for health care providers who demonstrated unconditional acceptance and nonjudgmental support, suggesting that a positive relationship may exist between participants' experience with their health care provider and perceived social support. The finding from the Ka'opua and Mueller study is consistent with the first subcomponent of the patient-centered cultural sensitivity health care model - the subcomponent that stresses the importance of health

care providers and office staff members engaging in behaviors and displaying attitudes that enable patients to feel comfortable with, trusting of, and respected by their health care providers and staff members and that enable them to feel that they and their cultures are respected (Tucker et al., 2007).

The third unexpected finding was that health-related quality of life was shown to have a significant positive relationship with perceived patient-centered cultural sensitivity in health care experienced. Although unanticipated, it stands to reason that a positive relationship between health-related quality of life and perceived patient-centered cultural sensitivity in health care experienced might exist, given that patient perceived satisfaction with their health care provider has been shown to be positively associated with health-related quality of life in prior non-HIV/AIDS-related research. For instance, Ashing-Giwa, Tejero, Kim, Padilla, and Hellemann (2007) found that among 703 breast cancer survivors' satisfaction in the patient-doctor relationship and socio-ecological factors (i.e., social support, life stress, and social class) accounted for 45% of the variance in health-related quality of life. Unlike in the present study, however, in which associations between perceived patient-centered cultural sensitivity in health care experienced and health-related quality of life were investigated, the Ashing-Giwa et al. study examined associations between health-related quality of life and patient satisfaction in the patient-doctor relationship.

The fourth unexpected finding was that perceived patient-centered cultural sensitivity in health care experienced was shown to have a significant negative relationship with experiences of social discrimination. Bird, Bogart, and Delahanty (2004) examined the impact of perceived discrimination from health care providers on medication adherence among 110 persons living with HIV. Results from this study indicated a negative relationship between perceived

socioeconomic status-related discrimination and adherence, but not perceived race-related discrimination and adherence. A larger study reported lower adherence among 2,484 French persons living with HIV who experienced discrimination from sexual partners related to their HIV-positive status (Peretti-Watel, Spire, Pierret, Lert, & Obadia, 2006). Although these findings are similar to what was found in the present study, both of these studies generating these findings each measured only certain aspects of discrimination (i.e., from health care providers or sex partners) and were specifically focused on understanding how certain forms of discrimination may impact medication adherence among HIV-positive persons.

In addition to the aforementioned finding that there was an inverse relationship between experiences of social discrimination and perceived patient-centered cultural sensitivity in health care experienced, several other unanticipated results were found in the present study with respect to experiences of social discrimination and other investigated variables of interest. First, a significant positive relationship was found between psychological distress and experiences of social discrimination. Even though this finding was not expected, it is consistent with the work of Diaz, Ayala, and Bein (2004) who showed a positive association between psychological distress and poverty (defined as recent experiences of financial hardship) in a sample of 912 Latino, largely immigrant, gay men residing in New York City, Miami, or Los Angeles.

Second, social support was shown to have a significant negative relationship with experiences of social discrimination. In a similar vein, Schmitz and Crystal (2000) found an inverse association between social support and discrimination among 212 PLWHA who participated in the AIDS Community Care Alternatives Program throughout the state of New Jersey. However, the experience of discrimination under investigation in the Schmitz and Crystal study included different discrimination areas (e.g., employment, housing, and medical care) from

the social discrimination areas (e.g., homophobia, racism, and financial hardship) that were examined in the present study.

Third, health-related quality of life was shown to have a significant negative relationship with experiences of social discrimination. This finding is in line with the work of Wingood, DiClemente, Mikhail, McCree, Davies, Hardin et al. (2007) who found among their sample of 366 women living with HIV in Georgia or Alabama an inverse relationship between health-related quality of life and HIV-related discrimination. Unlike in the present study whereby experiences of social discrimination was measured using a valid and reliable measure (ESD), the Wingood and colleagues study assessed HIV-related discrimination by compiling responses from three separate items that covered the domains of access to healthcare, job loss, and needing to relocate. It is noteworthy that in the present study the experience of social discrimination was not related specifically to HIV status as was the case in the Wingood et al. study.

Correlations Among Investigated Variables of Interest and Demographic Variables

The exploration of relationships among investigated variables of interest and demographic variables also revealed both expected and unexpected findings. Expected correlations among investigated variables of interest and demographic variables are presented first with unexpected correlations to follow.

As anticipated, a strong positive relationship existed between HIV/AIDS-related stigma and gender, with women reporting significantly higher levels of HIV/AIDS-related stigma than men, which has been found among previous samples of PLWHA (Carr & Gramling, 2004; Lekas, Siegel, & Schrimshaw, 2006; Sandelowski, Lambe, & Barroso, 2004). Also as expected, race showed a significant positive correlation with HIV/AIDS-related stigma, with African Americans/Blacks reporting higher levels of HIV/AIDS-related stigma than any of the other races in the present study, which is similar to what was recently found by Sayles, Hays,

Sarkisian, Mahajan, Spritzer, and Cunningham (2008) among their sample of 202 HIV-positive persons residing in two large US cities. In addition, a strong positive relationship existed between HIV/AIDS-related stigma and sexual orientation, with heterosexuals reporting higher levels of HIV/AIDS-related stigma than gay/lesbian participants, which was also found in the Sayles et al. study.

Consistent with past research among late middle-aged and older adults living with HIV in the US (Heckman, Heckman, Kochman, Sikkema, Suhr, & Goodkin, 2002; Lovejoy, Heckman, Sikkema, Hansen, Kochman, Suhr et al., 2008), age showed significant negative correlations with social support and health-related quality of life in the present sample; that is, as the age of the participant increased, levels of social support and health-related quality of life decreased. A strong negative relationship existed between gender and health-related quality of life with women reporting lower levels of health-related quality of life than men, which is similar to the findings of Mrus, Williams, Tsevat, Cohn, and Wu (2005) in a study involving a sample of 202 female and 976 male patients living with HIV in the US or in Puerto Rico. Also in line with the work of Wingood et al. (2007), who examined the relationship between a participants' racial background and health outcomes among 366 African American and White women living with HIV in Georgia and Alabama, it was found in the present study that race showed a significant negative correlation with health-related quality of life, with African American women reporting lower levels of health-related quality of life than any of the other races. Additionally, a significant inverse association was found in the present study between sexual orientation and social support, with heterosexuals reporting lower levels of social support than gay/lesbian participants. In a non-probability sample of 373 HIV-positive mostly African American and Puerto Rican women in New York City who self-identified along a spectrum of sexual identities

(e.g., from “heterosexual only” to “homosexual only”), Cooperman, Simoni, and Lockhart (2003) found a significant negative relationship between sexual orientation and social support, with lesbian/bisexual women reporting significantly greater social support from friends and groups/organizations than the heterosexual women in their study.

As earlier mentioned, there were also several unexpected findings in the present study with respect to the investigated variables of interest and demographic variables. One of these unexpected findings is that age showed a significant positive correlation with HIV/AIDS-related stigma, such that as age increased levels of HIV/AIDS-related stigma also increased. This finding is inconsistent with research conducted by Emlet (2007) that specifically investigated relationships among age, HIV-related stigma, and patterns of disclosure. In his study with 88 persons living with HIV, who ranged in age from 20-71 years old, Emlet found that differences in HIV-related stigma scores by age were not statistically significant. However, due to the possibility of sampling bias, Emlet noted that results from this study should be interpreted with caution given that all of his participants were drawn from the same AIDS-service organization in the Pacific Northwest.

Another unexpected finding in the present study is the finding of an inverse association between gender and social support, such that women reported lower levels of social support than men, which is contrary to the non-statistically significant relationship that Viswanathan, Anderson, and Thomas (2005) found between gender and social support in their sample of 99 HIV-positive patients affiliated with an urban HIV/AIDS Center in the US.

In the present study, an unexpected significant positive association between gender and psychological distress was also found, with women reporting higher levels of psychological distress than men. While this finding was not expected, it is in line with the work of Sikkema,

Kochman, DiFranceisco, Kelly, and Hoffman (2003) who found among their sample of 268 HIV-infected persons that the women in their study exhibited higher levels of anxiety and traumatic stress (which they conceptualized as psychological distress) than the men. However, it is important to point out that the participants in the Sikkema and colleagues study were recently coping with a number of AIDS-related losses (according to these authors, the average number of losses was 30) that included losses of loved ones and/or friends, which likely impacted the level of anxiety and traumatic stress reported by these participants.

It was also unanticipated that gender would show a significant positive correlation with experiences of social discrimination; however, in the present study, women reported more experiences of social discrimination than men. Some prior research (e.g., Bunting, 1996; Metcalfe, Langstaff, Evans, Paterson, & Reid, 1998) conducted with HIV-positive persons have only suggested that women face more discrimination than men. This finding in the present study provides some preliminary empirical evidence for the link between gender and experiences of social discrimination among a sample of PLWHA in the US.

It is also surprising that race showed a significant negative correlation with social support in the present study. Specifically, it was found that African Americans reported lower levels of social support than any of the other races. This finding is contradictory to the previous findings of Tate, van den Berg, Hansen, Kochman, and Sikkema (2006) who observed no race-related differences in social support among their community sample of 121 African American and White gay and bisexual HIV-positive men residing in Milwaukee, Wisconsin or New York City. Race also showed a significant positive correlation with psychological distress in the present study. Specifically, it was found that African Americans reported higher levels of psychological distress than any of the other races. Heckman, Kochman, Sikkema, Kalichman, Masten, and Goodkin

(2000) also found a positive association between race and psychological distress in their study with 72 late middle-aged and older African American and White men living with HIV/AIDS in the US. However, in the Heckman et al. study, it was the White participants and not the African American participants who reported higher levels of psychological distress. In addition, race showed a significant positive correlation with experiences of social discrimination, such that African Americans reported higher levels of experiences of social discrimination than any of the other races in the present study. This result is similar to what was found in the Wingood et al. (2007) study mentioned earlier with the exception that these researchers only measured HIV-related discrimination and found that it was the White women rather than the African American women who more likely to report HIV-related discrimination.

The finding of a significant inverse association between sexual orientation and health-related quality of life was also not expected. Specifically, it was found that heterosexuals reported lower levels of health-related quality of life than gay/lesbian participants. Interestingly, to the author's knowledge, there are no current published US empirical studies that have investigated the relationship between these two particular variables. In an international study conducted in the Netherlands that specifically assessed whether differences in health-related quality of life existed between heterosexual and homosexual men and women, Sandfort, de Graaf, and Bijl (2003) found that among their sample of 7,076 participants, there was a significant negative relationship between health-related quality of life and sexual orientation. However, unlike in the present study where heterosexuals reported lower levels of health-related quality of life than those with other sexual orientations (i.e., gay, lesbian), Sandfort et al. found among their sample that homosexual men but not lesbians had lower levels of health-related quality of life.

The unexpected findings in the present study also include that sexual orientation showed a significant positive correlation with psychological distress, with heterosexual individuals reporting higher levels of psychological distress than non-heterosexually identified persons. This finding was unexpected given that Cochran and Mays (2007) had recently shown among their sample of 2,272 adults with varying sexualities that homosexuals were more likely to report psychological distress than heterosexuals. More specifically, after adjusting for possible confounding variables (e.g., demographic differences), these researchers found that women who identified as lesbian or bisexual had significantly higher levels of psychological distress in comparison to women who identified as exclusively heterosexual. In addition, gay men and homosexually experienced heterosexual men reported significantly higher levels of psychological distress in comparison to exclusively heterosexual men.

Finally, surprising significant negative correlations between several of the demographic variables (e.g., age, gender, race, and sexual orientation) and perceived patient-centered cultural sensitivity in health care experienced were found. Prior to presenting these findings, it is noteworthy that the present study is the first of its kind to investigate associations between demographic variables and perceived patient-centered cultural sensitivity in health care experienced among a sample of PLWHA. Thus, comparisons between prior research and the present study with respect to these relationships can not be made at this time. However, a summary of these specific findings are presented below.

First, age showed a significant negative correlation with perceived patient-centered cultural sensitivity in health care experienced, suggesting that older PLWHA may experience lower levels of perceived patient-centered cultural sensitivity in health care experienced in comparison to their younger counterparts. Second, gender showed a significant inverse association with

perceived patient-centered cultural sensitivity in health care experienced, indicating that women may be more likely to experience lower levels of perceived patient-centered cultural sensitivity in health care experienced than men. Third, race showed a significant negative correlation with perceived patient-centered cultural sensitivity in health care experienced, suggesting that African Americans may be more likely to experience lower levels of perceived patient-centered cultural sensitivity in health care experienced than all other races or ethnicities. Fourth, sexual orientation showed a significant inverse association with perceived patient-centered cultural sensitivity in health care experienced, indicating that heterosexuals were more likely to experience lower levels of perceived patient-centered cultural sensitivity in health care experience than all other sexual orientations. Taken together, these findings suggest that older, African American, heterosexual females may be more likely to experience lower levels of perceived patient-centered cultural sensitivity in health care experienced than their counterparts. In the next section, a discussion of the present study's results in relation to the hypotheses and exploratory research questions are presented.

Hypotheses 1 and 2

Hypothesis 1

Hypothesis 1 proposed that experiences of social discrimination (i.e., homophobia, racism, and financial hardship) would be related *positively* to HIV/AIDS-related stigma; that is, as experiences of social discrimination increase, HIV/AIDS-related stigma would also increase. This hypothesis was supported as experience of social discrimination was found to have a *positive and significant* relationship with HIV/AIDS-related stigma. This finding suggests that PLWHA who experience higher levels of social discrimination may be more likely to experience higher levels of HIV/AIDS-related stigma as well. Empirical evidence for the positive association between HIV/AIDS-related stigma and experiences of social discrimination has yet

to be documented in the extent literature. This finding also provides some preliminary support for the concept of layered stigma (that various stigmata layer onto HIV/AIDS-related stigma).

Hypothesis 2

Hypothesis 2 proposed that perceived patient-centered cultural sensitivity in health care experienced would be related *negatively* to HIV/AIDS-related stigma; that is, as perceived patient-centered cultural sensitivity in health care experienced increases, HIV/AIDS-related stigma would decrease. This hypothesis was supported as perceived patient-centered cultural sensitivity in health care experienced was found to have a *negative* and *significant* relationship to HIV/AIDS-related stigma. This finding indicates that PLWHA who experience higher levels of perceived patient-centered cultural sensitivity in health care experienced may be more likely to experience lower levels of HIV/AIDS-related stigma. It also suggests that perceived patient-centered cultural sensitivity in health care experienced may help to decrease the burden of HIV/AIDS-related stigma. However, it is important to note that the correlation between perceived patient-centered cultural sensitivity in health care experienced and HIV/AIDS-related stigma does not imply causation.

Exploratory Research Questions 1, 2, & 3

Exploratory Research Question 1

Exploratory research question 1 asked whether social support would *moderate* the relationship between HIV/AIDS-related stigma and psychological distress, such that the strength of the association between HIV/AIDS-related stigma and psychological distress would be lessened for PLWHA who reported higher levels of social support. This exploratory research question was supported as social support was found to have a significant moderating effect on the relationship between HIV/AIDS-related stigma and psychological distress. This finding is consistent with previous research involving HIV-positive persons that has explored the

moderating effect of social support (Hudson, Lee, Miramontes, & Portillo, 2001). In addition, this finding supports past research that holds that psychological health and well-being is associated with higher levels of social support (Blaney, Goodkin, Morgan, Feaster, Millon, Szapocznik et al., 1990; Hays, Turner, & Coates, 1992; Kurdek & Siesky, 1990; Leserman, Perkins, & Evans, 1992). Thus, having a strong sense of social support may help reduce the negative effects of HIV/AIDS-related stigma and psychological distress.

Exploratory Research Question 2

Exploratory research question 2 asked whether social support and perceived patient-centered cultural sensitivity in health care experienced would *moderate* the relationship between HIV/AIDS-related stigma and health-related quality of life, such that the strength of the association between HIV/AIDS-related stigma and health-related quality of life is lessened for PLWHA who report higher levels of social support and perceived patient-centered cultural sensitivity in health care experienced. This exploratory research question was partially supported as perceived patient-centered cultural sensitivity in health care experienced was found to have a significant moderating effect on the relationship between HIV/AIDS-related stigma and health-related quality of life. This finding provides some preliminary evidence for how perceived patient-centered cultural sensitivity in health care experienced may serve as a protective factor against the detrimental effects of HIV/AIDS-related stigma on health-related quality of life. Given the lack of empirical research that have investigated associations between perceived patient-centered culturally sensitive health care and the health statuses of patients (Betancourt, 2005), this finding is especially important in understanding how to reduce and eliminate health disparities that negatively impact PLWHA. While social support did not buffer the effects of HIV/AIDS-related stigma on health-related quality of life, the present study did reveal that

higher levels of social support was significantly associated with lower levels of HIV/AIDS-related stigma.

Exploratory Research Question 3

Exploratory research question 3 asked whether there were significant differences in HIV/AIDS-related stigma in association with age, gender, race/ethnicity, sexual orientation, and social class. Partial support for this exploratory research question was shown as the analyses to examine this exploratory research question revealed that three of the demographic variables (e.g., gender, race, and sexual orientation) investigated had significant relationships with HIV/AIDS-related stigma. However, when these three demographic characteristics were entered into a multiple linear regression, only gender and race remained significant. Specifically, it was found that women had higher levels of HIV/AIDS-related stigma scores than men and African Americans/Blacks and other races had higher levels of HIV/AIDS-related stigma scores than Caucasian Americans/Whites. While it was surprising that HIV/AIDS-related stigma scores did not differ significantly for heterosexuals, bisexuals, and gays/lesbians in the present study, it may be that in comparison to gender and race, sexual orientation is somewhat concealable. For instance, if an individual perceives a situation as threatening if her or his sexual orientation is revealed, she/he can act in ways that disguise her/his sexual orientation. This concealment reduces the likelihood of being discriminated against due to sexual orientation or HIV serostatus. This finding suggests that if a controllable stigma is concealable the detrimental impact of HIV/AIDS-related stigma may be attenuated.

Limitations and Directions for Future Research

Before reviewing the implications of the present study, it is necessary to describe some of its limitations. These limitations existed in the sample, survey, and research design areas of the present study.

Sampling Limitations

The present study has sample limitations that could impact its generalizability. First, the results of this study cannot be generalized to the experiences of all PLWHA in the US. The findings are limited to a modest sample size of 193 PLWHA who were self-motivated to respond to study advertisements and complete an on-line questionnaire. Nevertheless, the present study had more than adequate power (.80) with the 193 participants as determined by a power analysis calculation. Second, the majority of participants were in medically stable conditions as 78% of participants reported being asymptomatic and 58% reported current highly active antiretroviral therapy (HAART) use. Third, participants were not randomly selected to participate in the present study. Thus, these self-selection biases limit the generalizability of the present findings to those who are not accessing or utilizing supportive services, as well as other PLWHA with greater immuno-compromise. As such, the present study should be replicated with a larger and randomly selected sample size and with a greater representation of persons with medically unstable health conditions (i.e., symptomatic and AIDS diagnosis.)

Survey Limitations

While the present study controlled for order effects by randomly ordering the instruments and included five validity items to identify random responding by participants in the Assessment Battery (AB), the length of time required to complete the online survey may have impacted participants' responses. As mentioned earlier, it is estimated that it took participants approximately 45 minutes or less to complete all of the instruments in the AB, based upon feedback from volunteers who took the survey. However, the number of instruments and the length of completion time may have facilitated a fatigue factor among participants. In addition, it was not possible due to financial restrictions in the present study's budget to translate the online survey into languages other than English, such as into Spanish. The option of having Spanish

versions of the online survey may have attracted a more culturally diverse sample of research participants.

Research Design Limitations

Another major limitation of the present study includes the research design as it is cross-sectional in nature. The cross-sectional design does not allow for inferring causal relationships between predictor and criterion variables. For example, the relationship between perceived patient-centered cultural sensitivity in health care experienced and HIV/AIDS-related stigma could be explained by the influence of perceived patient-centered cultural sensitivity in health care experienced on stigma. Without longitudinal data it is impossible to determine the temporal ordering of the variables. A future longitudinal version of the present research that includes an examination of the influence of perceived patient-centered cultural sensitivity in health care experienced on HIV/AIDS-related stigma is greatly warranted.

It should also be noted that the present study relied solely on the use of self-report measures. Although a measure of social desirability (The Marlowe-Crowne Social Desirability Scale-Short Form C) was included among the instruments in the online survey to account for socially desirable responding, the mono-method approach to data collection may have been impacted by several confounding variables. For instance, participants self-reported on their physical health characteristics including HIV/AIDS serostatus (i.e., asymptomatic, symptomatic, or currently having AIDS), the number of years since first being diagnosed with HIV infection, and current HIV treatment regimens. It is quite possible that some participants in an effort to minimize their symptoms did not report their physical health characteristics honestly or were not reporting on their current health status as they were basing their answers on previous health updates. Corroborations of participant's current physical health characteristics with their medical records would have confirmed physical health characteristic data and thus increased confidence

in findings in this study related to these characteristics. Future studies would benefit from gathering data from multiple sources (e.g., medical records) and employing qualitative research methods in order to decrease mono-method bias. Additional research is needed to further explain the factors that moderate the relationships between HIV/AIDS-related stigma and psychological distress and HIV/AIDS-related stigma and health-related quality of life among PLWHA.

Conclusions

The present findings provide preliminary support for the existence of a significant positive link between experiences of social discrimination and HIV/AIDS-related stigma and a significant negative link between perceived patient-centered cultural sensitivity in health care experienced and HIV/AIDS-related stigma. In addition, the present results offer preliminary evidence that social support moderates the relationship between psychological distress and HIV/AIDS-related stigma and that perceived patient-centered cultural sensitivity in health care experienced moderates the relationship between HIV/AIDS-related stigma and health-related quality of life. However, social support was not found to moderate the relationship between HIV/AIDS-related stigma and health-related quality of life. Significant differences in HIV/AIDS-related stigma scores in association with gender and race but not sexual orientation were also found in the present study. Specifically, women had higher levels of HIV/AIDS-related stigma scores than men and African Americans/Blacks and other races had higher levels of HIV/AIDS-related stigma scores than Caucasian Americans/Whites. However, HIV/AIDS-related stigma scores did not differ significantly for heterosexuals, bisexuals, and gays/lesbians.

Implications for Public Health Educators, Health Care Professionals, and Policymakers

The findings of the present study have several implications for public health educators, health care professionals, and policymakers. Public health educators could use findings from the present study on HIV/AIDS-related stigma and discrimination in developing new or expanding

upon existing HIV/AIDS educational programs for the general public that focus on reducing misconceptions about HIV/AIDS and the persecution of PLWHA. Importantly, results of the present study document the continued existence of HIV/AIDS-related stigma and discrimination among PLWHA in the US, despite some previous research suggesting that overt expressions of stigma have declined since the 1990s (Herek, Capitano, & Widamin, 2002).

Based upon findings of the present study, effective interventions for lessening or eliminating HIV/AIDS-related stigma and discrimination at the community level are urgently needed, especially for women and racial and ethnic minority populations. Such interventions could ideally focus on increasing tolerance and empathy for PLWHA among the general population. This could take the form of positive media messages and programs that communicate the fact that PLWHA are not to blame for contracting HIV or developing AIDS and that these individuals should be accepted within society. Factual information about HIV/AIDS including modes of transmission and methods of risk reduction should also be incorporated into the content of interventions for lessening or eliminating HIV/AIDS-related stigma and discrimination.

Individual and group counseling are modalities that could be used to help PLWHA and their family members and/or friends cope with the devastating effects of HIV/AIDS-related stigma and discrimination. In particular, mental health professionals (e.g., counseling psychologists) could provide their clients who are infected or affected by HIV/AIDS with information about stigma and discrimination and allow for more intimate discussions of stigmatization and discrimination concerns during therapy. Mental health professionals ideally should also provide social support to PLWHA as the findings in the present study suggest that social support may play a significant role in helping to reduce the negative effects of HIV/AIDS-related stigma on psychological distress. In addition, social support groups for PLWHA could be

formed in order to offer a safe environment in which clients could receive social support from other PLWHA for resolving such issues as feeling excluded or shunned by others.

Mental health professionals can also play a major role in the development, implementation, and evaluation of intervention programs aimed at reducing the negative impact of HIV/AIDS-related stigma and discrimination on PLWHA. For example, counseling psychologists could develop coping skills training workshops for PLWHA that are designed to prepare these individuals for contending with psychologically stressful interactions that may arise as a result of stigmatization and discrimination. In addition, counseling psychologists could develop patient-empowerment training workshops for PLWHA to feel empowered and to learn strategies and skills for eliciting perceived patient-centered cultural sensitivity in health care experienced from health care professionals, particularly their health care providers.

Given the finding in the present study suggesting that perceived patient-centered cultural sensitivity in health care experienced may help to decrease the deleterious effect of HIV/AIDS-related stigma on health-related quality of life, health care providers (e.g., doctors, nurses) may play a critical role in improving the health-related quality of life of PLWHA. More specifically, health care providers can display behaviors and attitudes that enable their patients who are infected and affected by HIV/AIDS to feel accepted and respected rather than stigmatized and discriminated against. Counseling psychologists working in health care settings may be particularly helpful in teaching health care providers how to provide PLWHA with unbiased care through modeling of non-stigmatizing behaviors. In addition, employing PLWHA as educators of health care providers may be beneficial to practitioners in regards to issues of care management and communication with PLWHA.

Results from the present study revealed that social support did not moderate the relationship between HIV/AIDS-related stigma and health-related quality of life. One potential explanation for this finding is that study participants were in medically stable conditions (78% of participants were asymptomatic), which may have reduced the likelihood of detecting a moderating effect of social support on the relationship between HIV/AIDS-related stigma and health-related quality of life. It is also feasible that the way in which social support was measured in the present study did not capture the precise mechanisms by which social support may moderate this relationship. For instance, it is possible that receiving social support from specific individuals (e.g., friends, family members, or partners) may differentially moderate the relationship between HIV/AIDS-related stigma and health-related quality of life. This finding is certainly curious and warrants further attention in future investigations.

Empirical evidence from the present study regarding the continued negative experience of HIV/AIDS-related stigma and discrimination among highly marginalized groups (i.e., PLWHA who are racial or ethnic minorities and/or women) of PLWHA could also be used to help policymakers formulate public health initiatives to combat HIV/AIDS-related stigma and discrimination. Furthermore, evidence of this type could help to mobilize and empower PLWHA to lobby for changes in laws and policies negatively impacting them and to help raise the general public's awareness regarding the continued needs and experiences of culturally diverse and underserved PLWHA in the US, particularly those who are racial and ethnic minorities and/or women.

The present study also highlights the need for further research to examine the role of social support and perceived patient-centered cultural sensitivity in health care experienced in reducing and eliminating health disparities that negatively impact PLWHA in the US. More specifically,

future research is needed in order to enhance our understanding of how health care professionals' behaviors and attitudes, office staff members' behaviors and attitudes, and the health care physical environment and policies can negatively affect the experiences of PLWHA, and to determine effective strategies for reducing stigmatization and discrimination in the health care environment.

APPENDIX A
INFORMED CONSENT

Dear Participant,

We are conducting an online study on the experiences of persons living with HIV/AIDS (PLWHA). Our hope with this research is to contribute to the understanding of the needs and experiences of PLWHA. Participation in our study will involve completing an online survey that will take approximately 45 minutes or less. Your participation is completely voluntary and your identity will not be known to us. In addition, no record will be kept of your web address. You do not have to respond to any questions on the survey that you do not wish to answer and your responses are completely anonymous.

There are no anticipated risks to you as a participant in this study. Although some of the questions on the survey are of a personal nature, all responses are anonymous. No identifying information will ever be linked to any completed surveys. There is no compensation for completing this survey. You are free to withdraw your consent to participate and may discontinue your participation in this study at any time without any consequences.

If you have any questions about this study, please feel free to contact Mr. Jacob J. van den Berg by e-mail at jacobv@ufl.edu or by phone at (919) 684-9555 or Dr. Carolyn M. Tucker by e-mail at cmtucker@ufl.edu or by phone at (352) 273-2167. Questions or concerns about your rights as a research participant may be directed to the UFIRB office, University of Florida, Box 112250, Gainesville, Florida, 32611; phone (352) 392-0433. Please write down or print out all of this contact information for your records.

By selecting “**Next**”, you indicate that you are: (a) at least 18 years of age, (b) have been diagnosed with HIV or AIDS, and (c) have the ability to read and understand English. You are also agreeing to participate in this study and you understand your right to refuse to participate at any time.

Sincerely,

Jacob J. van den Berg, M.S.
Ph.D. Candidate in Counseling Psychology
University of Florida

Carolyn M. Tucker, Ph.D.
Distinguished Alumni Professor
Joint Professor of Psychology and Professor of Community Health and Family Medicine
Professor of Pediatrics

APPENDIX B
DEMOGRAPHIC AND MEDICAL INFORMATION QUESTIONNAIRE

Directions: Please answer each of the following below by typing in the information or clicking on the box that best describes you.

1. What is your age? _____
2. Please indicate your gender. Woman Man Transgender
3. Which best describes you? (please check all that apply):
 - African American/Black
 - Asian American/Pacific Islander
 - American Indian/Native American
 - Hispanic/Latina/o-Black
 - Hispanic/Latina/o-White
 - White/Caucasian American
 - Multiracial: If yes, please specify: _____
 - Other: If yes, please specify: _____
4. Please indicate specifically the racial or ethnic group(s) to which you belong (i.e., Cuban American, Japanese, Carribean, Chinese American, Dutch, Canadian, Italian American, etc...) _____
5. What is your preferred language to speak, read, and write? (i.e., English, Spanish, German)
6. What country are you currently residing in? _____
7. If you are currently residing in the United States, in what geographical region are you located?
 - Northeast
 - Southeast
 - Midwest
 - Northwest
 - Southwest
 - Other (please specify if the above does not describe your region well: _____)
8. What is your country of origin? _____

9. Click on the highest level of education that you have completed.
- Elementary School
 - Middle/Junior High School
 - High School
 - Some College/Technical School
 - College
 - Some Professional/Graduate School
 - Professional/Graduate School
10. Click on the highest degree that you received.
- High School Diploma
 - GED
 - Associates Degree
 - Bachelors Degree
 - Masters Degree
 - Doctoral Degree
 - Other: (please specify: _____)
11. In which country did you receive the majority of your education? _____
12. Click **one** of the following that is closest to your current income.
- \$0-\$10,000
 - \$11-\$20,000
 - \$21-\$30,000
 - \$31-\$40,000
 - \$41-\$50,000
 - \$51-\$60,000
 - \$61-\$70,000
 - \$71-\$80,000
 - Over \$80,000
13. Click **one** of the following that best describes your current social class:
- lower class
 - working class
 - middle class
 - upper middle class
 - upper class
14. What is your **current** employment status (select all that apply)?
- Employed Full Time
 - Employed Part Time
 - Disability
 - Unemployed
 - Student
 - Other (please specify: _____)

15. Which **one** of the following best describes your relationship status at this time?
- Single
 - Married
 - Committed relationship
 - Divorced
 - Separated
 - Widowed
 - Other (please specify: _____)
16. Choose the **one** best descriptor for how much you are physically attracted to members of your own gender.
- low
 - low-moderate
 - moderate
 - moderate-high
 - high
17. Choose the **one** best descriptor for how much you are physically attracted to members of the other gender.
- low
 - low-moderate
 - moderate
 - moderate-high
 - high
18. Choose the **one** best descriptor for how much you are emotionally attracted to members of your own gender.
- low
 - low-moderate
 - moderate
 - moderate-high
 - high
19. Choose the **one** best descriptor for how much you are emotionally attracted to members of the other gender.
- low
 - low-moderate
 - moderate
 - moderate-high
 - high

20. Which **one** of the following best describes your sexual orientation?
- Exclusively heterosexual
 - Mostly heterosexual
 - Bisexual
 - Mostly gay/lesbian
 - Exclusively gay/lesbian
21. Choose the **one** best descriptor to indicate if you have had sex (oral, anal, or vaginal sex) with persons of your own gender, the other gender, or both genders?
- Never had sex
 - My own gender only
 - My own gender mostly
 - Both genders equally
 - Other gender mostly
 - Other gender only
22. How connected or involved are you in the lesbian/gay/bisexual/transgender (LGBT) community?
- Very slightly or not at all
 - A little
 - Moderately
 - Quite a bit
 - Extremely
23. In general, how “open” or “out” are you about your sexual orientation to others?
- Not at all
 - A little bit
 - Somewhat
 - Mostly
 - Completely
24. Choose the **one** best descriptor for your religious affiliation.
- Catholic
 - Baptist
 - Presbyterian
 - Methodist
 - Quaker
 - Universal Unitarianism
 - Universal Fellowship of Metropolitan Community Churches
 - Christian
 - Buddhist
 - Jewish
 - Muslim
 - Bah'í
 - Other – (please specify: _____)
 - None

23. In what year did you find out that you were HIV-positive ____ or had developed AIDS? ____ (If AIDS have not developed, put "0".)
24. How do you believe that you contracted HIV?
- Male-to-male sexual contact
 - High risk heterosexual contact
 - Injection drug use
 - High risk heterosexual contact and injection drug use
 - Don't Know
 - Other (please specify: _____)
25. Which of the following best describes your current sexual activity (oral, anal, or vaginal sex)?
- Not having sex
 - Having sex, but with more than one partner
 - Having sex with just one partner, but for less than 6 months
 - Having sex with just one partner for 6 months or longer
 - Other (please specify if none of the above captures your current sexual activity)
26. Have you disclosed your HIV status to anyone?
- Yes No
27. If yes, with whom have you disclosed your HIV status? (check all that apply)
- Mother
 - Father
 - Sister(s)
 - Brother(s)
 - Uncle(s)
 - Aunt(s)
 - Grandmother(s)
 - Grandfather(s)
 - Cousin(s)
 - Children
 - Close Friend(s)
 - Other (please specify: _____)
28. Do you currently use alcohol or drugs?
- Yes No

29. Please check off **any** of the following substances that you may have used in the past year?

- Alcohol
- Marijuana (grass, pot weed)
- Inhalants (things you sniff or inhale like whippets, poppers, etc.)
- Cocaine
- Crack (rock)
- Hallucinogens (LSD, acid, mushrooms)
- Heroin, by snorting or smoking
- Angel dust (PCP)
- MDMA (ecstasy, X, E)
- Downers, Barbituates
- Tranquilizers
- Uppers, Amphetamines
- Pain medications
- Steroids

30. In the **past year**, have you:

- a. Injected illegal drugs? Yes No
- b. Shared needles? Yes No
- c. Used a needle exchange program? Yes No

31. How many of your friends have been diagnosed as HIV-positive? _____

32. How many of your friends have been diagnosed with AIDS? _____

33. Do you have children?

- Yes No (Skip to Q34)

(a) If yes, how many children do you have? _____

(b) Are any of your children HIV positive? Yes No

(c) Do any of your children take HIV medications? Yes No

34. Are you currently asymptomatic (without any HIV/AIDS-related symptoms)?

- Yes No Don't know

35. Are you currently symptomatic? (with any HIV/AIDS-related symptoms?)

- Yes No Don't know

36. Do you currently have AIDS?

- Yes No Don't know

37. Do you know your T-Helper (CD4) cell count?

- Yes No Don't know

38. If yes, in the past year has your T-Helper (CD4) cell count been between 400 and 1400?
 Yes No Don't know
39. In the past year, has your T-Helper (CD4) cell count been between 200 and 399?
 Yes No Don't know
40. In the past year, has your T-Helper (CD4) cell count been below 200?
 Yes No Don't know
41. Do you try to remember and keep up with your T-cell (CD4) count?
 Yes No Don't know
42. Do you know your viral load?
 Yes No Don't know
43. If yes, in the past year has your viral load been 100,000 or more?
 Yes No Don't know
44. In the past year, has your viral load been anywhere between 25,000 and 99,000?
 Yes No Don't know
45. In the past year, has your viral load been 25,000 or less?
 Yes No Don't know
46. In the past year, has your viral load been less than 50?
 Yes No Don't know
47. In the past year, have you been told by your health care provider (i.e., doctor) that your viral load is "undetectable"?
 Yes No Don't know
48. Do you try to remember and keep up with your viral load?
 Yes No Don't know
49. Have you ever used Highly Active Antiretroviral Therapy (HAART)?
 Yes No Don't know
50. If yes, are you currently using HAART?
 Yes No Don't know
51. Are you currently taking any other HIV/AIDS medications?
 Yes No Don't know
If yes, what medications are you currently taking? _____

APPENDIX C
ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) STIGMA MEASURE (ASM)

Directions: In this section, we want to know about other people’s attitudes and beliefs about HIV/AIDS, NOT how you feel. Please indicate your level of agreement or disagreement by clicking on the answer you choose for each statement. We will use the term “gay” to refer to gay, lesbian, bisexual, and/or transgender persons.

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
1. Many people do not want to hug, kiss, or touch someone with HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Many people believe that those with HIV/AIDS should be isolated from the rest of society.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Many people would not want to be friends with someone with HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Many people would not want to date someone with HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Many people would end the relationship if they found out their partner has HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Many people would not want to live with someone with HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Many people do not want their children around someone with HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Many people believe that if you work or volunteer in HIV/AIDS services you have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Regardless of whether or not you are currently working, please tell us your opinion of the following: <i>-Many employers would not want to have an employee who has HIV/AIDS.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Regardless of whether or not you are currently working, please tell us your opinion of the following: <i>-Many people would not want to work with someone who has HIV/AIDS.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Many people now believe that if you get HIV/AIDS, it is because you wanted it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Many people believe that those with HIV/AIDS are promiscuous or drug abusers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Many people believe that having HIV/AIDS is a punishment for being gay.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Many people believe that gay people are to blame for the spread of HIV/AIDS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Many people believe that those with HIV/AIDS are a burden to society.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Directions: The following statements refer to your own beliefs and attitudes. Please indicate how strongly you agree or disagree with the following statements by clicking on the answer you choose for each statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
1. People who have HIV/AIDS should be isolated from the rest of society.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. People who have HIV/AIDS should only date other HIV-positive people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. People who have HIV/AIDS are not sexually desirable.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. People who have HIV/AIDS are more sexually promiscuous than most people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. The promiscuity of gay people is the reason why AIDS exists.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. AIDS is a punishment from God.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Please select the answer choice “Strongly Disagree” *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***Note: Added validity item.**

Directions: Please indicate how strongly you agree or disagree with the following statements by clicking on the answer you choose for each statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
1. Some friends have grown more distant from me after they learned I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I have encountered embarrassing situations because I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. People treat me differently when they find out I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. My friends would rather not talk about my HIV status.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. My family would rather not know about my HIV status.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Changes in my appearance have negatively affected my relationships with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Some people act as though it is my fault that I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I regret having told some people that I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I have had to move away from friends and/or family because I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. People have not wanted to have sex with me because I am HIV positive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. People have not wanted to date me or get romantically involved because of my HIV status.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I have been treated with less respect because I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I sometimes feel useless because of my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. I do not tell people at work about my HIV status in order to avoid negative consequences.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I have experienced financial hardship because I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX D
MENTAL HEALTH INVENTORY (MHI)

Directions: These questions are about how you feel and how things have been with you during the past month. For each question, please click on the circle for the answer that comes closest to the way you have been feeling.

DURING THE PAST MONTH...	Extremely happy, could not have been more satisfied or pleased	Very happy most of the time	Generally satisfied, pleased	Sometimes fairly satisfied, sometimes fairly unhappy	Generally dissatisfied, unhappy	Very dissatisfied, unhappy most of the time
	1	2	3	4	5	6
1. How happy, satisfied, or pleased have you been with your personal life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Always	Very Often	Fairly Often	Sometimes	Almost Never	Never
	1	2	3	4	5	6
2. How often did you feel that there were people you were close to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How often has feeling depressed interfered with what you usually do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	All of the Time	Most of the Time	A good bit of the Time	Some of the time	A little of the Time	None of the Time
	1	2	3	4	5	6
4. How much of the time did you have difficulty reasoning and solving problems; for example, making plans, making decisions, learning new things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. How much of the time have you generally enjoyed the things you do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. How much of the time has your daily life been full of things that were interesting to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DURING THE PAST MONTH...

	All of the Time	Most of the Time	A good bit of the Time	Some of the time	A little of the Time	None of the Time
	1	2	3	4	5	6
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. How much of the time have you felt loved and wanted?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. How much of the time have you been a very nervous person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. How much of the time did you have difficulty doing activities involving concentration and thinking?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. How much of the time did you feel depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. How much of the time have you felt tense or “high-strung”?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. How much of the time have you been in firm control of your behavior, thoughts, emotions, feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. How much of the time did you become confused and start several actions at a time?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. How much of the time did you feel that you had nothing to look forward to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. How much of the time have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. How much of the time have you felt emotionally stable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. How much of the time have you felt downhearted and blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Always	Very Often	Fairly Often	Sometimes	Almost Never	Never
	1	2	3	4	5	6
18. How often have you felt like crying?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DURING THE PAST MONTH...

	All of the Time	Most of the Time	A good bit of the Time	Some of the time	A little of the Time	None of the Time
	1	2	3	4	5	6
19. How much of the time did you feel left out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Always	Very Often	Fairly Often	Sometimes	Almost Never	Never
	1	2	3	4	5	6
20. How often did you feel that others would be better off if you were dead?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	All of the Time	Most of the Time	A good bit of the Time	Some of the time	A little of the Time	None of the Time
	1	2	3	4	5	6
21. How much of the time did you forget, for example, things that happened recently, where you put things, appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. How much of the time did you feel that your love relationships, loving and being loved, were full and complete?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DURING THE PAST MONTH...

	Extremely so, to the point where I could not take care of things	Very much bothered	Bothered quite a bit	Bothered some, enough to notice	Bothered just a little	Not bothered at all
	1	2	3	4	5	6
23. How much have you been bothered by nervousness, or your “nerves”?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	All of the Time	Most of the Time	A good bit of the Time	Some of the time	A little of the Time	None of the Time
	1	2	3	4	5	6
24. How much of the time has living been a wonderful adventure for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. How much of the time have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Yes, constantly	Yes, very often	Yes, fairly often	Yes, a couple of times	Yes, once	No, never
	1	2	3	4	5	6
26. Did you ever think about taking your own life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DURING THE PAST MONTH...

	All of the Time	Most of the Time	A good bit of the Time	Some of the time	A little of the Time	None of the Time
	1	2	3	4	5	6
27. How much of the time have you felt restless, fidgety, or impatient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. How much of the time have you been moody or brooded about things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Always	Very often	Fairly often	Sometimes	Almost never	Never
	1	2	3	4	5	6
29. How often did you get rattled, upset, or flustered?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	All of the Time	Most of the Time	A good bit of the Time	Some of the time	A little of the Time	None of the Time
	1	2	3	4	5	6
30. How much of the time did you have trouble keeping your attention on any activity for long?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. How much of the time have you been anxious or worried?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. How much of the time have you been a happy person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Always	Very often	Fairly often	Sometimes	Almost never	Never
	1	2	3	4	5	6
33. How often did you find yourself having difficulty trying to calm down?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DURING THE PAST MONTH...

	All of the Time	Most of the Time	A good bit of the Time	Some of the time	A little of the Time	None of the Time
	1	2	3	4	5	6
34. How much of the time have you been in low or very low spirits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. How much of the time have you felt cheerful, lighthearted?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Extremely depressed	Very depressed	Quite depressed	Somewhat depressed	A little depressed	Not depressed at all
	1	2	3	4	5	6
36. How depressed (at its worst) have you felt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	All of the Time	Most of the Time	A good bit of the Time	Some of the time	A little of the Time	None of the Time
	1	2	3	4	5	6
37. How much of the time did you react slowly to things that were said or done?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Always	Very often	Fairly often	Sometimes	Almost never	Never
	1	2	3	4	5	6
38. How often did you feel isolated from others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX E
MEDICAL OUTCOMES STUDY SOCIAL SUPPORT SURVEY (MOSS-SSS)

Directions: Next are some questions about the support that is available to you.

1. About how many close friends do you have? _____

2. About how many close relatives do you have? _____

Directions: People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Please click on the answer you choose for each statement.

DURING THE PAST MONTH...

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
	1	2	3	4	5
1. Someone to help you if you were confined to bed.	<input type="radio"/>				
2. Someone you can count on to listen to when you need to talk.	<input type="radio"/>				
3. Someone to give you good advice about a crisis.	<input type="radio"/>				
4. Someone to take you to the doctor if you needed it.	<input type="radio"/>				
5. Someone who shows you love and affection.	<input type="radio"/>				
6. Someone to have a good time with.	<input type="radio"/>				
7. Someone to give you information to help you understand a situation.	<input type="radio"/>				
8. Someone to confide in or talk to about yourself or your problems.	<input type="radio"/>				
9. Someone who hugs you.	<input type="radio"/>				
10. Someone to get together with for relaxation.	<input type="radio"/>				
11. Someone to prepare your meals if you were unable to do it yourself.	<input type="radio"/>				
12. Someone whose advice you really want.	<input type="radio"/>				
13. Someone to do things with to help you get your mind off things.	<input type="radio"/>				
14. Someone to help with daily chores if you were sick.	<input type="radio"/>				
15. Someone to share your most private worries and fears.	<input type="radio"/>				

DURING THE PAST MONTH...

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
	1	2	3	4	5
16. Someone to turn to for suggestions about how to deal with a personal problem.	<input type="radio"/>				
17. Someone to do something enjoyable with.	<input type="radio"/>				
18. Someone who understands your problems.	<input type="radio"/>				
19. Someone to love and make you feel wanted.	<input type="radio"/>				

Open Ended Question: On the lines below, please tell us something about the support that is available to you.

APPENDIX F
WORLD HEALTH ORGANIZATION QUALITY OF LIFE-BREF (WHOQOL-BREF)

Directions: Please read each question, assess your feelings, and click on the circle for each question that gives the best answer for you.

	Very Poor	Poor	Neither poor nor good	Good	Very good
	1	2	3	4	5
1. How would you rate your quality of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
	1	2	3	4	5
2. How satisfied are you with your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

THE FOLLOWING QUESTIONS ASK ABOUT HOW MUCH YOU HAVE EXPERIENCED CERTAIN THINGS IN THE LAST TWO WEEKS.

	Not at all	A little	A moderate amount	Very much	An extreme amount
	1	2	3	4	5
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	<input type="radio"/>				
4. How much do you need any medical treatment to function in your daily life?	<input type="radio"/>				
5. How much do you enjoy life?	<input type="radio"/>				
6. To what extent do you feel your life to be meaningful?	<input type="radio"/>				
7. How well are you able to concentrate?	<input type="radio"/>				
8. How safe do you feel in your daily life?	<input type="radio"/>				
9. How healthy is your physical environment?	<input type="radio"/>				

THE FOLLOWING QUESTIONS ASK ABOUT HOW COMPLETELY YOU EXPERIENCE OR WERE ABLE TO DO CERTAIN THINGS IN THE LAST TWO WEEKS.

	Not at all	A little	A moderate amount	Very much	An extreme amount
	1	2	3	4	5
10. Do you have enough energy for everyday life?	<input type="radio"/>				
11. Are you able to accept your bodily appearance?	<input type="radio"/>				
12. Have you enough money to meet your needs?	<input type="radio"/>				
13. How available to you is the information that you need in your day-to-day life?	<input type="radio"/>				
14. To what extent do you have the opportunity for leisure activities?	<input type="radio"/>				
	Very Poor	Poor	Neither poor nor good	Good	Very good
	1	2	3	4	5
15. How well are you able to get around?	<input type="radio"/>				

THE FOLLOWING QUESTIONS ASK YOU TO SAY HOW GOOD OR SATISFIED YOU HAVE FELT ABOUT VARIOUS ASPECTS OF YOUR LIFE OVER THE LAST TWO WEEKS.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
	1	2	3	4	5
16. How satisfied are you with your sleep?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. How satisfied are you with your ability to perform your daily living activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

THE FOLLOWING QUESTIONS ASK YOU TO SAY HOW GOOD OR SATISFIED YOU HAVE FELT ABOUT VARIOUS ASPECTS OF YOUR LIFE OVER THE LAST TWO WEEKS.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
	1	2	3	4	5
18. How satisfied are you with your capacity for work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. How satisfied are you with yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. How satisfied are you with your personal relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. How satisfied are you with your sex life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. How satisfied are you with the support you get from your friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. How satisfied are you with the conditions of your living place?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. How satisfied are you with your access to health services?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. How satisfied are you with your transport?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

THE FOLLOWING QUESTION REFERS TO HOW OFTEN YOU HAVE FELT OR EXPERIENCED CERTAIN THINGS IN THE LAST TWO WEEKS:

	Never	Seldom	Quite often	Very often	Always
	1	2	3	4	5
26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?	<input type="radio"/>				

APPENDIX G
EXPERIENCES OF SOCIAL DISCRIMINATION (ESD)

Directions: In this section, we want to know about your experiences as a child and as an adult. Please indicate how often you experienced these things by clicking on the circle that best answers the question for you. If any of the questions are not applicable to you, please select “never”.

	Never	Once in a while	Sometimes	Many Times
	1	2	3	4
1. As you were growing up, how often were you made fun of because of your sexual orientation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. As you were growing up, how often were you hit or beaten up because of your sexual orientation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. As an adult, how often have you been made fun of because of your sexual orientation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. As an adult, how often have you been hit or beaten up because of your sexual orientation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. As you were growing up, how often did you hear that gays grow old alone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. As you were growing up, how often did you hear that gays are not normal?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. As you were growing up, how often did you feel that your sexual orientation hurt and embarrassed your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. As an adult, how often have you had to pretend that you are straight to be accepted?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. How often have you lost a job or career opportunity because of your sexual orientation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. How often have you had to move away from friends or family because of your sexual orientation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. How often have you been harassed by the police because of your sexual orientation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Directions: In this section, we want to know about your experiences as a child and as an adult. Please indicate how often you experienced these things by clicking on the circle that best answers the question for you. If any of the questions are not applicable to you, please select “never”.

	Never	Once in a while	Sometimes	Many Times
	1	2	3	4
1. As you were growing up, how often were you made fun of because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. As you were growing up, how often were you hit or beaten up because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. As an adult, how often have you been made fun of because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. As an adult, how often have you been hit or beaten up because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. How often have you been treated rudely or unfairly because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. As an adult, how often have you been harassed by police because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. How often have you been turned down for a job because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. How often have you been uncomfortable in predominately White spaces because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. In sexual relationships, how often do you have difficulty finding sexual partners because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. In sexual relationships, how often do you find that your partner pays more attention to your race or ethnicity than to who you are as a person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. In sexual relationships, how often have you been turned down for sex because of your race or ethnicity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Directions: In this section, we want to know about your experiences currently as an adult. Please indicate how often you experienced these things by clicking on the circle that best answers the question for you. If any of the questions are not applicable to you, please select “never”.

	Never	Once in a while	Sometimes	Many Times
	1	2	3	4
1. In the last 12 months, how often did you run out of money for your basic necessities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. In the last 12 months, how often have you had to borrow money from a friend or a relative to get by financially?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. In the last 12 months, how often have you had sex with someone in exchange for money, food, or housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. In the last 12 months, how often have you had to look for work in order to support yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Please select the answer choice “Never” *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***Note: Added validity item.**

Open Ended Question: On the lines below, please tell us something about your experiences related to your sexual orientation, race/ethnicity, or financial circumstances.

APPENDIX H
HUMAN IMMUNODEFICIENCY VIRUS (HIV) STIGMA SCALE-REVISED (HSS-R)

Directions: Please indicate how strongly you agree or disagree with the following statements by clicking on the circle that fits best for you.

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
1. In many areas of my life, no one knows that I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I feel guilty because I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Please select the answer choice “Agree.” *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. People’s attitudes about HIV/AIDS make me feel worse about myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Telling someone I have HIV/AIDS is risky.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Most people with HIV/AIDS lose their jobs when employers learn that they have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I work hard to keep my HIV/AIDS a secret.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I feel I’m not as good as others because I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I never feel ashamed of having HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. People with HIV/AIDS are treated like outcasts.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Most people believe a person who has HIV/AIDS is dirty.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Having HIV/AIDS makes me feel unclean.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Most people think that a person with HIV/AIDS is disgusting.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Having HIV/AIDS makes me feel that I’m a bad person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Most people with HIV/AIDS are rejected when others learn that they have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I am very careful who I tell that I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*Note: Added validity item.

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
17. Some people who know that I have HIV/AIDS have grown more distant.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Most people are uncomfortable around someone with HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. I never felt that I have to hide the fact that I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I worry that people may judge me when they learn that I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Having HIV/AIDS is disgusting to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. I am hurt by how people reacted to learning that I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. I worry people who know I have HIV/AIDS will tell others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. I regret having told some people that I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. People avoid touching me if they know I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. People I care about stopped calling me after learning that I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. People don't want me around their children once they know I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. People have physically backed away from me because I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. I have stopped socializing with some people due to their reactions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. I have lost friends by telling them I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. I told people close to me to keep my HIV/AIDS a secret.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. People who know that I have HIV/AIDS ignore my good points.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. People seem afraid of me because I have HIV/AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX I
HIV STIGMA SCALE (HSS)

Directions: Here are some ways that people may feel about HIV and AIDS. Thinking about having HIV/AIDS, please click on the circle for each statement that fits best for how you feel.

HOW MUCH DO YOU...

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
1. Feel blamed by others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Feel that you need to hide it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Feel ashamed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Think HIV is punishment for something.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Think other people are uncomfortable around you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Feel people avoid you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Fear you will lose your friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Fear your family will reject you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Feel that people do not want you around their children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX J
MARLOWE-CROWNE SOCIAL DESIRABILITY SCALE – SHORT FORM C
(M-CSDS-SFC)

Directions: For each of the following statements, please indicate whether you consider the statement to be “true” or “false” by clicking on the response you choose that best fits for you.

	True	False
	0	1
1. It is sometimes hard for me to go on with my work if I am not encouraged.	<input type="radio"/>	<input type="radio"/>
2. I sometimes feel resentful when I don't get my way.	<input type="radio"/>	<input type="radio"/>
3. On a few occasions, I have given up doing something because I thought too little of my ability.	<input type="radio"/>	<input type="radio"/>
4. There have been times when I felt like rebelling against people in authority even though I knew they were right.	<input type="radio"/>	<input type="radio"/>
5. No matter who I'm talking to, I'm always a good listener.	<input type="radio"/>	<input type="radio"/>
6. Please select the answer choice “True.” *	<input type="radio"/>	<input type="radio"/>
7. There have been occasions when I took advantage of someone.	<input type="radio"/>	<input type="radio"/>
8. I'm always willing to admit it when I make a mistake.	<input type="radio"/>	<input type="radio"/>
9. I sometimes try to get even rather than forgive and forget.	<input type="radio"/>	<input type="radio"/>
10. I am always courteous, even to people who are disagreeable.	<input type="radio"/>	<input type="radio"/>
11. I have never been irked (irritated) when people expressed ideas very different from my own.	<input type="radio"/>	<input type="radio"/>
12. There have been times when I was quite jealous of the good fortune of others.	<input type="radio"/>	<input type="radio"/>
13. I am sometimes irritated by people who ask favors of me.	<input type="radio"/>	<input type="radio"/>
14. I have never deliberately said something that hurt someone's feelings.	<input type="radio"/>	<input type="radio"/>

***Note: Added validity item.**

APPENDIX K
TUCKER-CULTURALLY SENSITIVE HEALTHCARE INVENTORY-PATIENT FORM (T-
CSHI-PF)

Directions: Take a moment to think about your experiences with the health care provider you see most often at your health care center or office. This provider might be a doctor, a nurse practitioner, or some other health care provider. Now please rate how strongly you agree or disagree that this provider shows each health care characteristic or behavior listed below. Please use a rating of 1, 2, 3, or 4, where 1 = “Strongly Disagree”, 2 = “Disagree”, 3 = “Agree”, and 4 = “Strongly Agree” by clicking on the answer you choose for each statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
THE HEALTH CARE PROVIDER I SEE MOST OFTEN WHEN I VISIT MY HEALTH CARE CENTER OR OFFICE:				
1. Is compassionate or shows that he or she cares about how I feel.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Is concerned about my well-being.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Is honest and direct with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Is dedicated to her or his work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Enjoys what he or she is doing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Is well educated.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Is knowledgeable about medicine.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Knows what he or she is doing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Is confident in his or her abilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Is right about why I am sick.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Responds to my requests.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Seems interested in my problem.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Is concerned about my present situation and future situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Treats all of his or her patients equally.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Examines me the same way he or she examines other patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Makes helpful and reasonable recommendations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
THE HEALTH CARE PROVIDER I SEE MOST OFTEN WHEN I VISIT MY HEALTH CARE CENTER OR OFFICE:				
17. Explains prescribed medications and procedures in ways I can understand.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Is helpful.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Treats me like a person, not just a number.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Cares more about patients than about making money.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Follows a common procedure for treating and examining all of his or her patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Correctly diagnoses and treats my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Shows that he or she is familiar with me and my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Consults with others to help me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Sends me to another health care provider when he or she cannot treat or communicate with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Is not scared to touch me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Takes my concerns seriously.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Does not question the truth or accuracy of what I am feeling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. Does not try to diagnose all my problems as psychological or “in my mind”.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. Does not talk down to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. Tries to communicate with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Tries to educate me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. Tries to connect with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. Takes all my concerns seriously even if he or she does not consider them to be serious.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. Does not embarrass me in private or public.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. Prescribes medicine only when he or she is sure of my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37. Prescribes treatments that work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
THE HEALTH CARE PROVIDER I SEE MOST OFTEN WHEN I VISIT MY HEALTH CARE CENTER OR OFFICE:				
38. Prescribes medicine only after examining me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. Reviews my record before prescribing medications or treatments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. Is available for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41. Checks out my problem as soon as I go to see her or him.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. Is consistent in her or his diagnosis and treatment of my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. Listens to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. Takes his or her time during my visit.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. Asks me questions about my symptoms.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. Examines me thoroughly and completely.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. Knows the limits of his or her skills.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. Explains the medications and procedures he or she prescribes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49. Does not make me wait long.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50. Follows up on my visits.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51. Puts on a fresh pair of gloves while I am in the examining room.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. Talks to me before making decisions about prescriptions and treatments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53. Keeps up with new research and treatments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54. Treats me with respect.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
55. Puts my mind at ease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56. Makes me feel that my visit to this health care center was informative and productive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57. Is polite and courteous.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
THE HEALTH CARE PROVIDER I SEE MOST OFTEN WHEN I VISIT MY HEALTH CARE CENTER OR OFFICE:				
58. Is willing to answer all my questions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
59. Is sensitive to my needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
60. Speaks English well enough for me to understand what he or she is saying.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
61. Lets me know about illnesses and diseases common among people of my race/ethnicity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
62. Prepares me for the next steps in treating my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
63. Shows that he or she remembers me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
64. Acts professionally.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
65. Understands my financial situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
66. Shows appreciation for me and all of his or her other patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
67. Shows care and concern for my child/children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
68. Is respectful of my religious beliefs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
69. Knows how to make me feel comfortable.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
70. Understands my culture.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
71. Has training in working with patients of my race/ethnicity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
72. Talks to me before making decisions about prescriptions and treatments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Directions: Please rate how much you agree or disagree that the front office staff members at your health care center or office show each of the following characteristics and behaviors. Please use a rating of 1, 2, 3, or 4, where 1 = “Strongly Disagree”, 2 = “Disagree”, 3 = “Agree”, and 4 = “Strongly Agree” by clicking on the answer you choose for each statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
THE FRONT OFFICE STAFF MEMBERS AT MY HEALTH CARE CENTER OR OFFICE:				
1. Are friendly and pleasant.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Are helpful.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Are polite.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Act professionally.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Are welcoming.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Are skilled at working with people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Give me a card to remind me of my next appointment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Call me the day before my appointment to confirm it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Get back with me as promised.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Appear concerned about my well-being.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Treat me with respect.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Treat me like a person, not a number.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Make fair decisions about who the health care provider is going to see next.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Do not discriminate against me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Treat all patients equally.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Do not look down on me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Do not view patients of my race/ethnicity as uneducated and unable to read.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
THE FRONT OFFICE STAFF MEMBERS AT MY HEALTH CARE CENTER OR OFFICE:				
18. Allow me to reschedule a missed appointment within a reasonable period of time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Keep my business confidential and private.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Do not grab children from their parents.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Do what the health care provider told them to do for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Work with my case even if I cannot pay the bills.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Pay attention to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Listen to my complaints.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Please select the answer choice "Disagree." *				
26. Know my name.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Admit me quickly after my initial registration of sign-in as a patient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Take care of me as I enter the waiting room.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. Get the health care provider to see me at the time of my appointment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. Work quickly to process my paperwork before and after I see the health care provider.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. Let me know if there are any changes to my record.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Give more effort to seeing patients in this health care center than to answering calls.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. Allow me to discipline my children inside this health care center [If no children, please do not rate this].	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***Note: Added validity item.**

Directions: Please rate how much you agree that the following health care center characteristics exist at your health care center or office. Please use a rating of 1, 2, 3, or 4, where 1 = “Strongly Disagree”, 2 = “Disagree”, 3 = “Agree”, and 4 = “Strongly Agree” by clicking on the answer you choose for each statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
MY HEALTH CARE CENTER OR OFFICE:				
1. Is well-maintained and clean.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Is a comfortable, relaxing place.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Is professional looking like a health care center should be.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Has affordable services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Has a program to help low-income patients receive treatments they cannot afford.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Has many doctors, nurses, and health care center staff members available to treat patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Has short waiting times to see the health care provider.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Has a short wait to get an appointment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Has procedures to make sure I am seen by the health care provider at the time of my appointment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Has a clear policy as to which patients are seen first.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Is a calm place.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Is open late for patients who work during the day.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Has brochures available about common illnesses or diseases among individuals of my race/ethnicity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Has posters and educational materials about illnesses and procedures on the wall.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Has brochures about illnesses available in English and Spanish.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Has a hotline I can call for illness information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Has receptionist areas where I can sign in and talk to the receptionist.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Disagree	Disagree	Agree	Strongly Agree
	1	2	3	4
THE FRONT OFFICE STAFF MEMBERS AT MY HEALTH CARE CENTER OR OFFICE:				
18. Has large and spacious waiting rooms.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Has plenty of safe and convenient parking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Has warm and comfortable examining rooms.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Has health care providers of my race/ethnicity on staff.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Has official interpreters for patients who do not speak English.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Has the same health care providers each time I visit.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Makes sure that patients and staff are not allowed to gossip.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Has a social worker available to speak with patients about disability and insurance problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Open-Ended Question: On the lines below, please list any additional comments or suggestions regarding the cultural sensitivity of the health care you experience.

APPENDIX L
DEBRIEFING FORM

Debriefing Information for Research Participants

Thank you for participating in our research. The goal of this study is to learn more about the experiences and needs of persons living with HIV/AIDS (PLWHA).

It is very important that you not describe the purpose or details of this study to others because they may choose to participate in this study, and if they know the details of the study before participating, their responses might be biased and thus unusable.

Counseling services and information about HIV or AIDS can be accessed online at: <http://www.thebody.com/index/hotlines/state.html> or <http://www.cdc.gov/nchhstp/>, or by calling the National AIDS Hotline at 1-800-232-4636.

Thank you again for your time and please feel free to encourage other PLWHA to participate in this study.

APPENDIX M
RECRUITMENT FLYER

RESEARCH STUDY PARTICIPATION



- **Are you 18 years of age or older?**
- **Have you been diagnosed with HIV or AIDS?**
- **Can you read and understand English?**
- **Live in the United States?**

If you said **yes** to all of these questions, we would like your assistance.

We are conducting an online research study on the needs and experiences of persons living with HIV/AIDS. This completely anonymous and confidential survey should take approximately 45 minutes or less to complete. Further details about this research project can be found in the consent form at the web address listed below. This research has been approved through the ethics board at the University of Florida. Thank you in advance for your time, and please contact Mr. van den Berg at jacobv@ufl.edu or (919) 684-9555 should you have any further questions. Also, please feel free to pass on the link below to anyone else that you feel may be interested in participating in this research study.

<https://www.surveymonkey.com/s/aspx?sm=u0S3F5SYhANvcrGeyR>
TYg_3d_3d

REFERENCES

- Aiken, L. S., & West, S. G. (1991). *Multiple regressions: Testing and interpreting interactions*. Thousand Oaks, CA: Sage.
- Ammassari, A., Trotta, M. P., Murri, R., Castelli, F., Narciso, P., Noto, P., Vecchiet, J., Monforte, A., Wu, A.W., & Antinori, A. (2002). Correlates and predictors of adherence to highly active antiretroviral therapy: Overview of published literature. *Journal of Acquired Immune Deficiency Syndromes*, *31*, 123–127.
- Anderson, M. L., & Taylor, H. F. (2006). *Sociology: Understanding a diverse society*. Thomson/Wadsworth: Belmont, CA.
- Angermeyer, M., & Matschinger, H. (1996). The effect of violent attacks by schizophrenia persons on the attitude of the public towards the mentally ill. *Social Science and Medicine*, *43*, 1721–1728.
- Annan, K. A. (2003). Message on World AIDS Day 2003. Accessed online 9/25/2007 at: <http://www.who.int/hiv/events/wad2003/wad2003/en/index.html>.
- Apollo, A., Golub, S. A., Wainberg, M. L., & Indyk, D. (2006). Patient-provider relationships, HIV, and Adherence: Requisites for a partnership. *Social Work in Health Care*, *42*, 209–224.
- Aranda-Naranjo, B. (2004). Quality of life in the HIV-positive patient: Implications and consequences. *Journal of the Association of Nurses in AIDS Care*, *15*, 20–27.
- Ashing-Giwa, K. T., Tejero, J. S., Kim, J., Padilla, G. V., & Hellemann, G. (2007). Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Quality of Life Research*, *16*, 413–428
- Au, A., Chan, I., Li, P., Chung, R., Po, L. M., & Yu, P. (2004). Stress and health-related quality of life among HIV-infected persons in Hong Kong. *AIDS and Behavior*, *8*, 119–129.
- Ayarza, R., & Reyes, B. (2002). *Changes in quality of life of people living with HIV/AIDS in Ecuador*. Abstract, XIV International AIDS Conference, July 7–12, Barcelona, Spain. Abstract Number: WePeE6460. Accessed online 3/7/07 at: <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102255301.html>
- Bakken, S., Holzemer, W. L., Brown, M., Powell-Cope, G. M., Turner, J. G., Inouye, J., Nokes, K. M., & Corless, I. B. (2000). Relationships between perception of engagement with health care provider and demographic characteristics, health status, and adherence to therapeutic regimen in persons with HIV/AIDS. *AIDS Patient Care and STDs*, *14*, 189–197.

- Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical consideration. *Journal of Personality and Social Psychology, 51*, 1173–1182.
- Beach, M. C., Keruly, J., & Moore, R. D. (2006). Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *Journal of General Internal Medicine, 6*, 661–665.
- Becker, H. S. (1963). *Outsiders*. New York: The Free Press of Glencoe.
- 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 & Health, 24*, 518–529.
- Betancourt, J. R. (2005). Racial and ethnic disparities in health care: No one suspect, no one solution. *Delaware Medical Journal, 77*, 333–334.
- Bianchi, F. T., Zea, M. C., Poppen, P. J., Reisen, C. A., & Echeverry, J. J. (2004). Coping as a mediator of the impact of sociocultural factors on health behavior among HIV-positive latino gay men. *Psychology and Health, 19*, 89–101.
- Bird, S. T., & Bogart, L. M. (2001). Perceived race-based and SES-based discrimination in interactions with health care providers. *Ethnicity and Disease, 11*, 554–563.
- Bird, S. T., Bogart, L. M., & Delahanty, D. L. (2004). Health-related correlates of perceived discrimination in HIV care. *AIDS Patient Care and STDs, 18*, 19–25.
- Birnbaum, M. H. (2004). Human research and data collection via the Internet. *Annual Review of Psychology, 55*, 803–832.
- Blaney, N., Goodkin, K., Morgan, R., Feaster, D., Millon, C., Szapocznik, J., & Eisdorfer, C. (1991). A stress-moderator model of distress in early HIV-1 infection: Concurrent analysis of life events, hardiness, and social support. *Journal of Psychosomatic Research, 35*, 297–305.
- Blendon, R. J., & Donelan, K. (1988). Discrimination against people with AIDS: The public's perspective. *New England Journal of Medicine, 319*, 1022–1026.
- Bowen, A., Williams, M., & Horvath, K. (2004). Using the internet to recruit rural MSM for HIV risk assessment: Sampling issues. *AIDS and Behavior, 8*, 311–319.
- Bunn, J. Y., Solomon, S. E., Miller, C., & Forehand, R. (2007). Measurement of Stigma in People with HIV: A Reexamination of the HIV Stigma Scale. *AIDS Education & Prevention, 19*, 198–208.

- Bunting, S. M. (1996). Sources of stigma associated with women with HIV. *Advances in Nursing Science, 19*, 64–73.
- Burgoyne, R., & Renwick, R. (2004). Social support and quality of life over time among adults living with HIV in the HAART era. *Social Science & Medicine, 58*, 1353–1366.
- Busza, J. R. (2001). Promoting the positive: Responses to stigma and discrimination in Southeast Asia. *AIDS Care, 13*, 441–456.
- Carr, R. L., & Gramling, L. F. (2004). Stigma: A health barrier for women with HIV/AIDS. *The Journal of the Association of Nurses in AIDS Care, 15*, 30–39.
- Castle, C. J., Cornu, C., Dua, R., Herrera, D., Nadkarni, V., Ouedraogo, A., & Velasco, N. (2002). *Meaningful involvement of people living with HIV/AIDS: Positive and negative effects of involvement in community-based programs*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: WeOrG1292. Accessed online 3/7/07 at: <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102250124.html>
- Centers for Disease Control and Prevention [CDC] (2007). Division of HIV/AIDS Prevention. Annual Report of HIV Infection and AIDS Cases in the United States. Accessed online 2/12/07 at: <http://www.cdc.gov/hiv/topics/surveillance/basic.htm>.
- Chesney, M. A., & Folkman, S. (1994). Psychological impact of HIV disease and implications for intervention. *Psychiatric Clinics of North America, 17*, 163–182.
- Clark, H. J., Linder, G., Armistead, L., & Austin, B. J. (2003). Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African American Women. *Women & Health, 38*, 57–71.
- Clayson, D. J., Wild, D. J., Quarterman, P., Duprat-Lomon, I., Kubin, M., & Coons, S. J. (2006). A comparative review of health-related quality of life measures for use in HIV/AIDS clinical trials. *Pharmacoeconomics, 24*, 751–765.
- Cochran, S. D., & Mays, V. M. (2007). Physical health complaints among lesbians, gay men, and bisexual and homosexually experienced heterosexual individuals: Results from the California quality of life survey. *American Journal of Public Health, 97*, 2048–2055.
- Cohen, S., & Willis, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*, 310–357.
- Cooperman, N. A., Simino, J. M., & Lockhart, D. W. (2003). Abuse, social support, and depression among HIV-positive heterosexual, bisexual, and lesbian women. *Journal of Lesbian Studies, 7*, 49–66.

- Corrigan, P. W. (1998). The impact of stigma on severe mental illness. *Cognitive and Behavioral Practice, 5*, 201–222.
- Courtenay–Quirk, C., Wolitski, R. J., Parsons, J. T., & Gomez, C. A. (2006). Is HIV/AIDS stigma dividing the gay community? Perceptions of HIV-positive men who have sex with men. *AIDS Education and Prevention, 18*, 56–67.
- Cowdery, J. E., & Pesa, J. A. (2002). Assessing quality of life in women living with HIV infection. *AIDS Care, 14*, 235–245.
- Crandall, C. S., & Coleman, R. (1992). AIDS-related stigmatization and the disruption of social relationships. *Journal of Social and Personal Relationships, 9*, 163–177.
- Crawford, A. (1996). Stigma associated with AIDS: A meta-analysis. *Journal of Applied Social Psychology, 26*, 398–416.
- Crocker, J., Major, B., & Steele, C. (1998). Social stigma. In D. T. Gilbert & S. T. Fiske (Eds.), *The handbook of social psychology* (pp. 504–553). Boston, MA: McGraw-Hill.
- Crowne, D. P., & Marlowe, D. (1960). A new scale of social desirability independent of psychopathology. *Journal of Consulting Psychology, 24*, 349–354.
- Dailey, A. B., Kasl, S. V., & Jones, B. A. (2008). Does gender discrimination impact regular mammography screening? Findings from the race differences in screening mammography study. *Journal of Women's Health, 17*, 195–206.
- Deacon, H. (2006). Towards a sustainable theory of health-related stigma: Lessons from the HIV/AIDS literature. *Journal of Community & Applied Social Psychology, 16*, 418–425.
- Diaz, R. M., Ayala, G., & Bein, E. (2004). Sexual risk as an outcome of social oppression: Data from a probability sample of Latino gay men in three US cities. *Cultural Diversity and Ethnic Minority Psychology, 10*, 255–267.
- Diaz, R. M., Ayala, G., Bein, E., Henne, J., & Marin, B. V. (2001). The impact of homophobia, poverty, and racism on the mental health of gay and bisexual men: Findings from 3 US cities. *American Journal of Public Health, 91*, 927–932.
- Dovidio, J. F., Major, B., & Crocker, J. (2000). Stigma: Introduction and overview. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 1–28). New York: Guilford.
- Elashoff, J. D. (2002). *NQuery Advisor Version 5.0. User's Guide*. Los Angeles, CA: Statistical Solutions Limited.

- Elford, J., Bolding, G., Davis, M., Sherr, L., & Hart, G. (2006). The internet and HIV study: Design and methods. *BMC Public Health, 4*, 39–51.
- Emlet, C. A. (2007). Experiences of stigma in older adults living with HIV/AIDS: A mixed-methods analysis. *AIDS Patient Care and STDs, 21*, 740–752.
- Ennett, S. T., Bailey, S. L., & Federman, E. B. (1999). Social network characteristics associated with risky behaviors among runaway and homeless youth. *Journal of Health and Social Behavior, 40*, 63–78.
- Evans, S., Ferrando, S. J., Rabkin, J. G., & Fishman, B. (2000). Health locus of control, distress and utilization of protease inhibitors among HIV-positive men. *Journal of Psychosomatic Research, 49*, 157–162.
- Fernandez, R. M., Castilla, E. J., & Moore, P. (2000). Social capital at work: Networks and employment at a phone center. *The American Journal of Sociology, 105*, 1288–1356.
- Fernandez, R. M., & Weinberg, N. (1997). Sifting and sorting: Personal contacts and hiring in a retail bank. *American Sociological Review, 62*, 883–902.
- Fine, M., & Asch, A. (1988). Disability beyond stigma: Social interaction, discrimination, and activism. *Journal of Sociological Issues, 44*, 3–22.
- Foucault, M. (1977). *Discipline and punish*. New York: Pantheon.
- Foucault, M. (1978). *The history of sexuality, Vol. 1: An introduction*. New York: Random House.
- Frazier, P. A., Tix, A. P., & Barron, K. E. (2004). Testing moderator and mediator effects in counseling psychology. *Journal of Counseling Psychology, 51*, 115–134.
- Furnham, A., & Bower, P. (1992). A comparison of academic and lay theories of schizophrenia. *British Journal of Psychiatry, 161*, 201–210.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Golub, E. T., Astemborski, J. A., Hoover, D. R., Anthony, J. C., Vlahov, D., & Strathdee, S. A. (2003). Psychological distress and progression to AIDS in a cohort of injection drug users. *Journal of AIDS, 32*, 429–434.
- Grossman, A. H. (1991). Gay men and HIV/AIDS: Understanding the double stigma. *Journal of the Association of Nurses in AIDS Care, 2*, 28–32.

- Hansen, N. B., Tarakeshwar, N., Ghebremichael, M., Zhang, H., Kochman, A., & Sikkema, K. J. (2006). Longitudinal effects of coping on outcome in a randomized controlled trial of a coping group intervention for HIV-positive adults with AIDS-related bereavement. *Death Studies, 30*, 609–636
- Harvey, R. D. (2001). Individual differences in the phenomenological impact of social stigma. *Journal of Social Psychology, 141*, 174–189.
- Hawthorne, N. (1850). *The Scarlet Letter*. Boston, Massachusetts: Ticknor, Reed & Fields.
- Hays, R. B., Turner, H., & Coates, T. J. (1992). Social support, AIDS-related symptoms, and depression among gay men. *Journal of Consulting and Clinical Psychology, 60*, 463–469.
- Heatherton, T. F., Kleck, R. E., Hebl, M., & Hull, J. G. (2000). *The Social Psychology of Stigma*. New York, New York: Guilford Press.
- Heckman, T. G., Heckman, B. D., Kochman, A., Sikkema, K. J., Suhr, J., & Goodkin, K. (2002). Psychological symptoms among persons 50 years of age and older living with HIV disease. *Aging & Mental Health, 6*, 121–128.
- Heckman, T. G., Kochman, A., Sikkema, K. J., Kalichman, S., Masten, J., & Goodkin, K. (2000). Late middle-aged and older men living with HIV/AIDS: Race differences in coping, social support, and psychological distress. *Journal of the National Medical Association, 92*, 436–444.
- Heckman, T. G., Somlai, A. M., Sikkema, K. J., Kelly, J. A., & Franzoi, S. L. (1997). Psychological predictors of life satisfaction among persons living with HIV infection and AIDS. *Journal of the Association of Nurses in AIDS Care, 8*, 21–30.
- Herek, G. M. (1999). AIDS and stigma. *American Behavioral Scientist, 42*, 1102–1112.
- Herek, G. M. (2002). Heterosexuals' attitudes toward bisexual men and women in the United States. *Journal of Sex Research, 39*, 264–274.
- Herek, G. M., & Capitano, J. P. (1993). Public reactions to AIDS in the United States: A second decade of stigma. *American Journal of Public Health, 83*, 574–577.
- Herek, G. M., & Capitano, J. P. (1997). AIDS stigma and contact with persons with AIDS: Effects of personal and vicarious contact. *Journal of Applied Social Psychology, 27*, 1–36.
- Herek, G. M., & Capitano, J. P. (1999). AIDS stigma and sexual prejudice. *American Behavioral Scientist, 42*, 1130–1147.

- Herek, G. M., Capitano, J. P., & Widamin, K. F. (2002). HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999. *American Journal of Public Health, 92*, 371–377.
- Herek, G. M., & Glunt, E. K. (1988). An epidemic of stigma: Public reactions to AIDS. *American Psychologist, 43*, 886–891.
- Herek, G. M., Widaman, K. F., & Capitano, J. P. (2005). When sex equals AIDS: Symbolic stigma and heterosexual adults' inaccurate beliefs about sexual transmission of AIDS. *Social Problems, 52*, 15–37.
- Hirshfield, S., Remien R. H., Humberstone, M., Walavalkar, I., & Chiasson, M. A. (2004). Substance use and high-risk sex among men who have sex with men: a national online study in the USA. *AIDS Care, 16*, 1036–1047.
- House, J., & Kahn, R. (1985). Measures and concepts of social support. In S. Cohen & S. Syme (Eds.), *Social Support and Health*. Orlando, Florida: Academic Press.
- Howland, L. C., Storm, D. S., Crawford, S. L., Ma, Y., Gotemaker, S. L., & Oleske, J. M. (2007). Negative life events: Risk to health-related quality of life in children and youth with HIV infection. *Journal of the Association of Nurses in AIDS Care, 18*, 3–11.
- Hsiung, P. C., Fang, C. T., Chang, Y. Y., Chen, M. Y., & Wang, J. D. (2005). Comparison of WHOQOL-BREF and SF-36 in patients with HIV infection. *Quality of Life Research, 14*, 141–150.
- Hudson, A. L., Lee, K. A., Miramontes, H., & Portillo, C. J. (2001). Social interactions, perceived support, and level of distress in HIV-positive women. *Journal of the Association of Nurses Care, 12*, 68–76.
- Hughes, J., Jelsma, J., MacLean, E., Darder, M., & Tinise, X. (2004). The health-related quality of life of people living with HIV/AIDS. *Disability and Rehabilitation: An International Multidisciplinary Journal, 26*, 371–376.
- Jacoby, A. (1994). Felt versus enacted stigma: A concept revisited. Evidence from a study of people with epilepsy in remission. *Social Science & Medicine, 38*, 269–274.
- Jia, H., Uphold, C. R., Wu, S., Chen, G. J., & Duncan, P. W. (2005). Predictors of changes in health-related quality of life among men with HIV infection in the HAART era. *AIDS Patient Care and STDs, 19*, 395–405.
- Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D. T., & Scott, R. (1984). *Social stigma: The psychology of marked relationships*. New York: Freeman.

- Kalichman, S. C., Graham, J., Luke, W., & Austin, J. (2002). Perceptions of health care among persons living with HIV/AIDS who were not receiving antiretroviral medications. *AIDS Patient Care and STDs, 16*, 233–240.
- Ka'opua, L. S. I., & Mueller, C. W. (2004). Treatment adherence among Native Hawaiians living with HIV. *Social Work, 49*, 55–62.
- Kaplan, R. M., Anderson, J. P., Wu, A., Mathews, W. C., Kozin, F. L., & Orenstein, D. (1989). The quality of well-being scale: Applications in AIDS, cystic fibrosis, and arthritis. *Medical Care, 27*, 27–43.
- Kurdek, L. A., & Siesky, G. (1990). The nature and correlates of psychological adjustment in gay men with AIDS-related conditions. *Journal of Applied Social Psychology, 20*, 846–860.
- Lee, R. S., Kochman, A., & Sikkema, K. J. (2002). Internalized stigma among people living with HIV/AIDS. *AIDS and Behavior, 6*, 309–319.
- Lekas, H. M., Siegel, K., & Schrimshaw, E. W. (2006). Continuities and discontinuities in the experiences of felt and enacted stigma among women with HIV/AIDS. *Qualitative Health Research, 16*, 1165–1190.
- Leserman, J., Perkins, D. O., & Evans, D. L. (1992). Coping with the threat of AIDS: The role of social support. *American Journal of Psychiatry, 149*, 1514–1520.
- Lichtenstein, B., Laska, M. K., & Clair, J. M. (2002). Chronic sorrow in the HIV-positive patient: Issues of race, gender, and social support. *AIDS Patient Care and STDs, 16*, 27–38.
- Link, B. G. (2001). Stigma: Many mechanisms require multifaceted responses. *Epidemiologia e Psichiatria Sociale, 10*, 8–11.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363–385.
- Litwak, E., & Messeri, P. A. (1989). Organizational theory, social supports, and mortality rates: A theoretical convergence. *American Sociological Review, 54*, 49–66.
- Lovejoy, T. I., Heckman, T. G., Sikkema, K. J., Hansen, N. B., Kochman, A., Suhr, J. A., Garske, J. P., & Johnson, C. J. (2008). Patterns and correlates of sexual activity and condom use behavior in persons 50-plus years of age living with HIV/AIDS. *AIDS and Behavior, 12*, 943–956.
- Lubek, D., & Fries, J. (1992). Changes in quality of life among persons with HIV infection. *Quality of Life Research, 2*, 359–366.

- Mak, W. W. S., Cheung, R. Y. M., Law, R. W., Woo, Li, P. C. K., & Chung, R. W. Y. (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. *Social Science & Medicine*, *64*, 1549–1559.
- Mann, J. (1987). *Statement at an informal briefing on AIDS to the 42nd session of the United Nations General Assembly*, New York, 20 October.
- Mann, J. M., Tarantola, D. J. M., & Netter, T. W. (1992). *AIDS in the world*. Cambridge, MA: Harvard University Press.
- Manning, W. G., & Wells, K. B. (1992). The effects of psychological distress and psychological well-being on use of medical services. *Medical Care*, *30*, 541–553.
- McClelland, G. H., & Judd, C. M. (1993). Statistical difficulties of detecting interactions and moderator effects. *Psychological Bulletin*, *114*, 376–390.
- Meade, C. S. (2006). Sexual risk behavior among persons dually diagnosed with severe mental illness and substance use disorder. *Journal of Substance Abuse Treatment*, *30*, 147–157.
- Metcalfe, K., Langstaff, J. E., Evans, S. J., Paterson, H. M., & Reid, J. L. (1998). Meeting the needs of women living with HIV. *Public Health Nursing*, *15*, 30–34.
- Miles, M. S., Burchinal, P., Holditch-Davis, D., Wasilewski, Y., & Christian, B. (1997). Personal, family, and health-related correlates of depressive symptoms in mothers with HIV. *Journal of Family Psychology*, *11*, 23–34.
- Mrus, J. M., Williams, P. L., Tsevat, J., Cohn, S. E., & Wu, A. W. (2005). Gender differences in health-related quality of life in patients with HIV/AIDS. *Quality of Life Research*, *14*, 479–491.
- Murphy, D. A., Marelich, W. D., Hoffman, D., & Steers, D. N. (2004). Predictors of antiretroviral adherence. *AIDS Care*, *16*, 471–484.
- Nordenfelt, L. (1994). *Concepts and measurements of quality of life in health care*. Boston: Kluwer.
- Novick, A. (1997). Stigma and AIDS: Three layers of damage. *Journal of the Gay and Lesbian Medical Association*, *1*, 53–60.
- Nyblade, L. C. (2006). Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health, & Medicine*, *11*, 335–345.

- Orlando, G., Guaraldi, G., Murri, R., Wu, A., Nardini, G., Beghetto, B., Sterrantino G. K., Sbaragli, S., Borderi, M., Talo, S., Grosso, C., Erba, C., Cattelan, A. M., Antinori, A., & Esposito, R. (2002). *Does lipodystrophy affect quality of life?* Abstract. XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: ThPeB7340. Accessed online 3/7/07 at: <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102254208.html>
- Ortega, N. L., Gonzales, G., & Liwang, M. (2002). *Greater involvement of people living with HIV and AIDS: Key successful AIDS program.* Abstract, XIV International AIDS Conference, July 7–12, Barcelona, Spain. Abstract Number: WeOrG1296.
- Pedhazur, E. J., & Schmelkin, L. P. (1991). *Measurement, design, and analysis: An integrated approach.* Hillsdale, NJ: Erlbaum.
- Peretti-Watel, P., Spire, B., Pierret, J., Lert, F., & Obadia, Y. (2006). Management of HIV-related stigma and adherence to HAART: Evidence from a large representative sample of outpatients attending French hospitals. *AIDS Care, 18*, 254–261.
- Peterson, J. L., Folkman, S., & Bakeman, R. R. (1996). Stress, coping, HIV status, psychosocial resources, and depressive mood in African American gay, bisexual, and heterosexual men. *American Journal of Community Psychology, 24*, 461–487.
- Piette, J. D., Bibbins-Domingo, K., & Schillinger, D. (2006). Health care discrimination, processes of care, and diabetes patients' health status. *Patient Education and Counseling, 60*, 41-48.
- Piot, P. (2000). Report by the executive director. Programme coordinating board. Joint United Nations Programme on AIDS. Rio de Janeiro, 14–15 December.
- Plant, R. (1988). *The pink triangle: The nazi war against homosexuals.* New York, NY: Holt and Company.
- Proescholdbell, R. J., Roosa, M. W., & Nemeroff, C. J. (2006). Component measures of psychological sense of community among gay men. *Journal of Community Psychology, 34*, 9–24.
- Ramirez-Valles, J. (2007). *AIDS Stigma Measure.* Unpublished manuscript, University of Illinois–Chicago.
- Reidy, M., & Taggart, M. E. (1992). Mental health and perceived quality of life in HIV-infected persons: A heuristic view. *Canada's Mental Health, 4*, 55–78.
- Reynolds, W. M. (1982). Development of reliable and valid short forms of the Marlowe-Crowne social desirability scale. *Journal of Clinical Psychology, 38*, 119–125.

- Resnick, M. D., Bearman, P. S., Blum, R. W., Bauman, K. E., Harris, K. M., Jones, J., Tabor, J., Beuhring, T., Sieving, R. E., Shrew, M., Ireland, M., Bearinger, L. H., & Udry, J. R. (1997). Protecting adolescents from harm: Findings from the National Longitudinal Study of Adolescent Health. *Journal of the American Medical Association*, *278*, 823–832.
- Rhodes, S. D., Bowie, D. A., & Hergenrath, K. C. (2003). Collecting behavioural data using the world wide web: Considerations for researchers. *Journal of Epidemiology and Community Health*, *57*, 68–73.
- Roberts, K. J. (2002). Physician–patient relationships, patient satisfaction, and antiretroviral medication adherence among HIV-infected adults attending a public health clinic. *AIDS Patient Care and STDs*, *16*, 43–50.
- Robinette, R. L. (1991). The relationship between the Marlowe-Crowne form C and the validity scales of the MMPI. *Journal of Clinical Psychology*, *47*, 396–399.
- Ross, M. W., Tikkanen, R., & Mansson, S. A. (2000). Differences between internet samples and conventional samples of men who have sex with men: Implications for research and HIV interventions. *Social Science & Medicine*, *51*, 749–758.
- Roth, B., & Robbins, D. (2004). Mindfulness-based stress reduction and health-related quality of life: Findings from a bilingual inner-city patient population. *Psychosomatic Medicine*, *66*, 113–123.
- Royster, D. A. (2003). *Race and the invisible hand: How white networks exclude black men from blue-collar jobs*. Berkeley, CA: University of California Press.
- Sandelowski, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV-positive women. *Journal of Nursing Scholarship*, *36*, 122–128.
- Sandfort, T. G. M., de Graaf, R., & Bijl, R. V. (2003). Same-sex sexuality and quality of life: Findings from the Netherlands mental health survey and incidence study. *Archives of Sexual Behavior*, *32*, 15–22.
- Sayce, L. (1998). Stigma, discrimination and social exclusion: What's in a word? *Journal of Mental Health*, *7*, 331–343.
- Sayles, J. N., Hays, R. D., Sarkisian, C. A., Mahajan, A. P., Spritzer, K. L., & Cunningham, W. E. (2008). Development and psychometric assessment of a multidimensional measure of internalized HIV stigma in a sample of HIV-positive adults. *AIDS and Behavior*, *12*, 748–758.
- Scambler, G. (1998). Stigma and disease: Changing paradigms. *The Lancet*, *352*, 1054–1055.

- Schmitz, M. F., & Crystal, S. (2000). Social relations, coping, and psychological distress among persons with HIV/AIDS. *Journal of Applied Social Psychology, 30*, 665–685.
- Servellen, R., & Aguirre, G. (1995). Symptoms, symptom management, and psychological morbidity among persons with HIV disease. *AIDS Patient Care, 9*, 134–139.
- Sherbourne, C. D., & Stewart, A. L. (1991). The MOS Social Support Survey. *Social Science & Medicine, 32*, 705–714.
- Siegel, K., & Schrimshaw, E. W. (2007). The stress moderating role of benefit finding on psychological distress and well-being among women living with HIV/AIDS. *AIDS and Behavior, 11*, 421–433.
- Sikkema, K. J., Kochman, A., DiFranceisco, W., Kelly, J. A., & Hoffman, R. G. (2003). AIDS-related grief and coping with loss among HIV-positive men and women. *Journal of Behavioral Medicine, 26*, 165–181.
- Sikkema, K. J., Hansen, N. B., Meade, C. S., Kochman, A., & Lee, R. S. (2005). Improvements in health-related quality of life following a group intervention for coping with AIDS-bereavement among HIV-infected men and women. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care, & Rehabilitation, 14*, 991–1005.
- Silver, E. J., Bauman, L. J., Camacho, S., & Hudis, J. (2003). Factors associated with psychological distress in urban mothers with late-stage HIV/AIDS. *AIDS and Behavior, 7*, 421–431.
- Singer, E., Rogers, T. F., & Corcoran, M. (1987). The Polls: AIDS. *Public Opinion Quarterly, 51*, 580–595.
- Sowell, R., Seals, B., Moneyham, L., Demi, A., Cohen, L., & Brakes, S. (1997). The quality of life in HIV-infected women in the Southeastern U.S. *AIDS Care, 9*, 501–512.
- Sowell, R. B., Lowenstein, A., Moneyham, L., Demi, A., Mizuno, Y., & Seals, B. F. (1997). Resources, stigma, and patterns of disclosure in rural women with HIV infection. *Public Health Nursing, 14*, 302–312.
- Stafford, M. C., & Scott, R. R. (1986). Stigma deviance and social control: Some conceptual issues. In S. C. Ainsley, G. Becker, & L. M. Coleman (Eds.), *The dilemma of difference*. New York: Plenum.
- Stangl, A. L., Wamai, N., Mermin, J., Awor, A. C., & Bunnell, R. E. (2007). Trends and predictors of quality of life among HIV-infected adults taking highly active antiretroviral therapy in rural Uganda. *AIDS Care, 19*, 626–636.

- Stein, G. L., & Bonuk, K. A. (2001). Physician–patient relationships among the lesbian and gay community. *Journal of the Gay and Lesbian Medical Association*, *5*, 87–93.
- Stipp, H., & Kerr, D. (1989). Determinants of public opinion about AIDS. *Public Opinion Quarterly*, *53*, 98–106.
- Stone, V. E., Weissman, J. S., & Cleary, P. D. (1995). Satisfaction with ambulatory care of persons with AIDS: Predictors of patient ratings of quality. *Journal of General Internal Medicine*, *10*, 239–245.
- Sullivan, L. M., Stein, M. D., Savetsky, J. B., & Samet, J. H. (2000). The doctor-patient relationship and HIV-infected patients' satisfaction with primary care physicians. *Journal of General Internal Medicine*, *15*, 462–469.
- Swendeman, D., Rotheram-Borus, M. J., Comulada, S., Weiss, R., & Ramos, M. E. (2006). Predictors of HIV-related stigma among young people living with HIV. *Health Psychology*, *25*, 501–509.
- Swindells, S., Mohr, J., Justis, J. C., Berman, S., Squier, C., Wagener, M. M., & Singh, N. (1999). Quality of life in patients with human immunodeficiency virus infection: Impact of social support, coping style and hopelessness. *International Journal of STD & AIDS*, *10*, 383–391.
- Tarlov, A. R., Ware, J. E. Jr., Greenfield, S., Nelson, E. C., Perrin, E., & Zubkoff, M. (1989). The Medical Outcome Study: An application of methods for monitoring the results of medical care. *The Journal of the American Medical Association*, *262*, 925–930.
- Tate, D. C., van den Berg, J. J., Hansen, N. B., Kochman, A., & Sikkema, K. J. (2006). Race, social support, and coping strategies among HIV-positive gay and bisexual men. *Culture, Health, & Sexuality*, *8*, 235–249.
- Thoits, P. A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of Health and Social Behavior*, *35*, 53–79.
- Tuck, I., McCain, N. L., & Elswick, R. K., Jr. (2001). Spirituality and psychological factors in persons living with HIV/AIDS. *Journal of Advanced Nursing*, *33*, 776–783.
- Tucker, C. M., Herman, K. C., Ferdinand, L. A., Bailey, T. R., Lopez, M. T., Beato, C., Adams, D., & Cooper, L. L. (2007). Providing patient-centered culturally sensitive health care. *The Counseling Psychologist*, *35*, 679–705.
- Tucker, C. M., Mirsu-Paun, A., van den Berg, J. J., Ferdinand, L. A., Jones, J. D., Curry, R. W., Rooks, L. G., Walter, T. J., & Beato, C. (2007). Assessments for measuring patient-centered cultural sensitivity in community-based primary care clinics. *Journal of the National American Medical Association*, *99*, 1–11.

- Turner, R. J., & Turner, J. B. (1999). Social integration and support. In C. S. Aneshensel & J. C. Phelan (Eds.), *Handbook of the Sociology of Mental Health*. New York: Kluwer Academic/Plenum Publishers.
- UNAIDS (2000). *HIV and AIDS-related stigmatization, discrimination, and denial: Forms, contexts, and determinants*. Accessed online 7/12/2005 at: http://data.unaids.org/Publications/IRC-pub01/JC316-Uganda-India_en.pdf
- Uphold, C. R., Holmes, W., Reid, K., Findley, K., & Parada, J. P. (2007). Healthy lifestyles and health-related quality of life among men living with HIV infection. *Journal of the Association of Nurses in AIDS Care*, 18, 54–66.
- Vanable, P. A., Carey, M. P., Blair, D. C., & Littlewood, R. A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS and Behavior*, 10, 473–482.
- Veit, C. T., & Ware, J. E. (1983). The structure of psychological distress and well-being in general populations. *Journal of Consulting and Clinical Psychology*, 51, 730–742.
- Viswanathan, H., Anderson, R., & Thomas, J. T. (2005). Evaluation of an antiretroviral medication attitude scale and relationships between medication attitudes and medication nonadherence. *AIDS Patient Care and STDs*, 19, 306–316.
- Vogl, D., Rosenfeld, B., Breitbart, W., Thaler, H., Passik, S., McDonald, M., & Portenoy, R. K. (1999). Symptoms prevalence, characteristics, and distress in AIDS outpatients. *Journal of Pain Symptom Management*, 18, 253–262.
- Wampold, B. E., & Freund, R. D. (1987). Use of multiple regression in counseling psychology research: A flexible data-analytic strategy. *Journal of Counseling Psychology*, 34, 372–382.
- Wight, R. G., Aneshensel, C. S., Murphy, D. A., Miller-Martinez, D., & Beals, K. P. (2006). Perceived HIV stigma in AIDS caregiving dyads. *Social Science & Medicine*, 62, 444–456.
- Wingood, G. M., DiClemente, R. J., Mikhail, I., McCree, D. H., Davies, S. L., Hardin, J. W., Peterson, S. H., Hook, E. W., & Saag, M. (2007). HIV discrimination and the health of women living with HIV. *Women & Health*, 46, 99–112.
- Winefield, H. R., Winefield, A. H., & Tiggemann, M. (1992). Social support and psychological well-being in young adults: The multi-dimensional support scale. *Journal of Personality Assessment*, 58, 198–210.

World Health Organization Quality of Life Group (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, 28, 551–558.

Zierler, S., Cunningham, W. E., Andersen, R., Shapiro, M. F., Nakazono, T., Morton, S., Crystal, S., Stein, M., Turner, B., St. Clair, P., & Bozette, S. A. (2000). Violence victimization after HIV infection in a U.S. probability sample of adult patients in primary care. *American Journal of Public Health*, 90, 208–215.

BIOGRAPHICAL SKETCH

Jacob John van den Berg was born in Carmel, New York and raised in Mahopac, New York. Jacob graduated *summa cum laude* with a Bachelor of Arts degree in psychology from Fairleigh Dickinson University in Madison, New Jersey in 1997. After graduating from Fairleigh Dickinson, he spent approximately three years working on two National Institutes of Health-funded culturally-sensitive, community-based health promotion projects under the direction of Dr. John B. Jemmott III at Princeton University's Health Psychology Laboratory in Princeton, New Jersey. The overall purpose of these research projects was to reduce human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS)-risk and promote healthy lifestyles among inner-city African American and Latino/a adolescents living in New Jersey.

In 2002, Jacob received a Masters of Science degree in clinical psychology from Yale University in New Haven, Connecticut. During his time at Yale, he primarily worked with Dr. Kathleen J. Sikkema on a pilot study of a community-level HIV prevention intervention for adults with severe mental illness living in supportive housing programs in New Haven, Connecticut and New York City. He also worked with Dr. Sikkema on a National Institute of Mental Health-funded study that evaluated the efficacy of a secondary prevention intervention for people living with HIV infection in New York City who were also coping with traumatic stress related to sexual abuse. Continuing his work in the field of HIV/AIDS, Jacob spent the summer of 2003 at the Mailman School of Public Health at Columbia University in New York City with Dr. Maureen Miller working on a longitudinal study examining infectious disease transmission risk among African American women living in the Bedford-Stuyvesant neighborhood of Brooklyn, New York.

In collaboration with Dr. Bonnie Moradi and Dr. Franz Epting, Jacob's work in the American Psychological Association's accredited Ph.D. program in counseling psychology in the Department of Psychology at the University of Florida in Gainesville, Florida from 2002-2008 included developing a theoretically grounded measure to assess prejudice against lesbian and gay individuals and to understand the experience of internalized homophobia among lesbian and gay persons. At the University of Florida, he also worked with Dr. Carolyn M. Tucker on a National Institutes of Health-funded community-based, patient-centered, culturally sensitive healthcare project with low-income and ethnically diverse primary care patients. The ultimate goal of this research was to reduce the health disparities that currently exist between majority and minority patients living in the United States. In 2007, Jacob completed the American Psychological Association's accredited pre-doctoral psychology internship at Duke University Counseling and Psychological Services in Durham, North Carolina. Jacob's dissertation is the culmination of years of working in the field of HIV/AIDS research, education and prevention and also combines his interests in community and health psychology.