

## ABSTRACT

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WITH HIV/AIDS BELIEFS AMONG  
AFRICAN AMERICANS

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This dissertation describes a qualitative study of 15 African American, HIV-positive individuals who were clients in a day treatment program at an HIV clinic in the Washington, DC, area. Data were collected through semistructured interviews; grounded theory methodology was used to generate a theory of how the participants gave meaning to HIV. The theoretical model included Personal Context, Support and Education, Socio-cultural Meaning, and Personal Meaning, all of which related to the formation of a global meaning regarding HIV. The emergent theoretical model and its components are presented, and the implications of the study for research, practice, and advocacy are discussed.

THE INTERSECTION OF HIV INFECTION WITH HIV/AIDS BELIEFS AMONG  
AFRICAN AMERICANS

By

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## Dedication

This dissertation is dedicated to all those who are living with (not dying from) HIV,  
particularly my study participants,  
my own clients,  
and the other clients of the Whitman-Walker Clinic.

## Acknowledgements

First, I would like to thank my amazing research team members, who played a large and crucial role in the analysis, theory-building, and interpretation of this study. To Amy, Bronwyn, Kate, Kristin, Lynn, Stephanie, and Sueleidy: I could not have done this without you. Thank you for being as passionate about the project as I was. You are all extraordinary women.

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## Chapter 1

### Introduction

African Americans are disproportionately affected by HIV/AIDS in the United States, with rates substantially higher than among Hispanics or Whites (Centers for Disease Control and Prevention [CDC], 2007). African Americans account for approximately 49% of AIDS cases in the United States, despite numbering only 13% of the total population. Thomas and Quinn (1993) stated that the spread of HIV/AIDS has “highlighted the complex relationship between social class, gender and race in a society where health care facilities are impoverished, access to care is inadequate and prevention technology is devalued” (p. 326). Furthermore, they asserted that the response of the African American community to AIDS must be examined within a socio-political context, taking into account African Americans’ history and treatment in the United States. Please note that when citing specific sources in discussing these issues, I adopt the language of the authors I am referencing (e.g., the use of African American or Black, and the use of HIV or AIDS).

African Americans’ responses to HIV/AIDS have consisted largely of mistrust of Whites and/or the United States government, as reported in anecdotal accounts and reports from popular media (Thomas & Quinn, 1993). Community-based organizations have reported that African Americans mistrust government reports on the disease, believe that HIV is a man-made virus, and believe AIDS is a form of genocide (Thomas & Quinn). African Americans’ distrust is not necessarily limited to HIV—Thomas and Quinn have asserted that African Americans experience pervasive distrust of the public health system and public health authorities, likely fueled by the Tuskegee Syphilis Study.

The study, conducted by the United States Public Health Service beginning in 1932, denied available syphilis treatment to African American men for 25 years so that researchers could continue their study of the course of the disease. Despite the availability of treatment after 1947, researchers continued to observe untreated participants as they went blind, became insane, and eventually died (Bird & Bogart, 2005).

Thomas and Quinn (1991) asserted that the legacy of the Tuskegee study has contributed to African Americans' beliefs that genocide is possible and that public health authorities cannot be trusted. They described beliefs regarding AIDS as a form of genocide as a "legitimate attitudinal barrier" (p. 1503) rooted in the history of the Tuskegee study. In other words, African Americans' beliefs about HIV/AIDS are formed in a historical context, which includes an unethical study in which little regard was shown for the lives of African American men.

After reports appeared in the popular media about such beliefs, empirical investigations examined the prevalence, correlates, and implications of these beliefs. It appears evident that some African Americans do possess beliefs about large-scale discrimination in regard to HIV/AIDS. Estimates of their prevalence vary widely because different beliefs were assessed in each study. For example, Parsons et al. (1999) assessed agreement with the statement that the government is not telling the whole truth about AIDS, with which 70% of participants agreed. Klonoff and Landrine (1999) assessed African Americans' belief that the government deliberately created AIDS to kill Black people, which 27% of their participants endorsed. Overall, results demonstrated that

endorsement of mild or “benign” beliefs is more common than endorsement of more “malicious” beliefs (e.g., Parsons et al.).

Furthermore, African Americans’ beliefs about large-scale discrimination regarding HIV/AIDS are significantly more prevalent than Caucasian Americans’, regardless of the nature of the beliefs, e.g., benign or malicious. Significant racial differences were found in the endorsement of statements that the government and the medical community know more than they are willing to say (Dusenbury et al., 1994), that the government deliberately put AIDS into African American communities (Goertzel, 1994), that the government is using AIDS to kill off minorities (Herek & Capitanio, 1994), that AIDS was created deliberately to eliminate undesirable people (Dusenbury et al.), and that the virus that causes AIDS was deliberately created in a laboratory in order to infect Black people (Crocker et al., 1999). Overall, African Americans are more likely than Caucasians to endorse beliefs regarding large-scale discrimination regarding HIV/AIDS.

The literature also suggests explanations for this discrepancy. Klonoff and Landrine (1999) found that lower levels of acculturation (i.e., stronger immersion in Black culture) and experiences of racism predicted endorsement of these beliefs. Crocker et al. (1999) found that when system blame (i.e., the tendency to attribute problems to prejudice and discrimination) was entered into a regression equation with other relevant variables (race, income, and other psych-social variables), system blame was the only predictor of endorsing large-scale discrimination beliefs about HIV/AIDS. Their results support the theoretical argument that these beliefs have arisen from the cultural history and experiences of African Americans in the United States, rather than from personality

characteristics or defects (Crocker et al.). Results consistently showed that endorsements of beliefs about large-scale discrimination regarding HIV/AIDS are unrelated to income or to education (Goertzel, 1994; Parsons et al., 1999); specifically, several researchers found that once race was entered into their regression equations, income and education were no longer predictors of these beliefs (Herek & Capitano, 1994; Klonoff & Landrine; Crocker et al.).

Finally, potential impact of discriminatory beliefs about AIDS and the government and medical community has been explored as well. Bogart and Bird (2003) found that belief in government conspiracies was related to a greater number of sexual partners in the last three months and a lower perceived quality of condoms. Bogart and Thorburn (2005) found that HIV/AIDS conspiracy beliefs were related to condom use only in men. For men, the beliefs were correlated with more negative attitudes about condom use and a lower likelihood of using condoms consistently.

Thus, existing literature regarding large-scale discriminatory beliefs about HIV/AIDS among African Americans clearly has demonstrated pervasiveness of these beliefs and even has explored several implications of these beliefs (e.g., risky sexual behavior, variable condom use; Bogart & Bird, 2003; Bogart & Thorburn, 2005). However, the only empirical analysis of such beliefs to date has been achieved through quantitative measures (i.e., statements constructed by the researchers) that did not allow for discovery of beliefs generated by the participants themselves. The nature of African Americans' beliefs about HIV/AIDS has not been explored exhaustively. In addition, literature has not focused on examining the prevalence or implications of these beliefs among African American individuals who are HIV-positive. Research findings regarding

medication adherence and coping with chronic illness suggest potential implications for these beliefs among African Americans who are living with HIV/AIDS. The purposes of the current study were to conduct in-depth research that uncovered, in a more exhaustive fashion, the nature of African Americans' beliefs about HIV/AIDS, and to explore the relationship between the beliefs and HIV-positive status among African Americans.

The study utilized grounded theory, a qualitative methodology whose primary goal is theory development (Glaser & Strauss, 1967). Theory development was important in achieving the purposes of the study, which included identifying the relationship between people's beliefs and experiences. In particular, the study was conducted from a constructivist standpoint (Charmaz, 2000), which allowed me to explore participants' subjective experience and acknowledged that the results would reflect one temporally bound reality as opposed to a universal truth. The first step in theory development is identifying research questions that give researchers the flexibility and freedom to explore a phenomenon in depth (Strauss & Corbin, 1990). I developed research questions that were based on existing literature but allowed room for the discovery of novel concepts.

I constructed a semi-structured interview protocol based on my research questions and interviewed HIV-positive African Americans who were clients of the Whitman-Walker Clinic, a non-profit community-based health organization in Washington, DC that serves individuals who are HIV-positive. The interviews were tape recorded and were later transcribed and analyzed by me and seven undergraduate research team members. Our grounded theory analysis involved the identification of concepts (points or ideas discussed by the participants) and categories (higher-order, more abstract concepts that encompassed the initial concepts we had identified). Characteristics of the categories also

were described and a preliminary theory was developed, representing how the participants made sense or meaning of HIV. We discovered that participants developed personal and socio-cultural meanings about HIV and that those constructs combined to form an overall meaning of HIV for each individual.

## Chapter 2

### Review of the Literature

A review of the literature pertaining to African Americans' beliefs about HIV/AIDS is presented in this chapter. First, the status of HIV/AIDS among African Americans, including risk factors for HIV infection, is discussed. Second, African Americans' beliefs are defined and explained in relation to the current study. Third, empirical literature examining the topic is reviewed and summarized. Finally, the statement of the problem, purpose and framework of the current study, and research questions are identified.

#### *HIV/AIDS Prevalence among African Americans*

African Americans are disproportionately affected by HIV/AIDS in the United States at all stages of the disease (i.e., from infection to death). African Americans comprise approximately 13% of the United States population according to the 2000 census. In the 33 states with confidential, name-based HIV reporting (i.e., those states in which data could be collected), African Americans comprised 49% of the new HIV/AIDS diagnoses in 2005. Similarly, African Americans accounted for 50% of the estimated AIDS cases diagnosed in the United States (the 50 states and the District of Columbia), and accounted for 44% of the people who are living with AIDS in the United States. Since the beginning of the AIDS epidemic, African Americans have accounted for 42% of the estimated AIDS cases diagnosed in the United States (Centers for Disease Control and Prevention, 2007).

The effect of HIV/AIDS upon African Americans is significant when compared with other racial/ethnic groups. According to the Centers for Disease Control and

Prevention (CDC; 2007), “The rate of AIDS diagnoses for African American adults and adolescents was 10 times the rate for whites and nearly three times the rate for Hispanics [in 2005]” (p. 2). Broken down by gender, the rate of AIDS diagnoses for African American women was over 23 times the rate for white women, and the rate of AIDS diagnoses for African American men was eight times the rate of that for white men. In addition, a smaller proportion of African Americans were alive after 9 years compared with American Indians and Alaska Natives, Hispanics, whites, and Asians and Pacific Islanders (based upon those who were diagnosed with AIDS from 1997-2004; CDC).

According to the CDC (2007), “Race and ethnicity, by themselves, are not risk factors for HIV infection” (p. 3). Data from 2005 indicated that of all African American men living with HIV/AIDS, the primary mode of transmission was sexual contact with other men, followed by injection drug use and high-risk sexual contact with women. For African American women living with HIV/AIDS, the primary mode of transmission was high-risk sexual contact with men, followed by injection drug use. Thus, the primary risk factors for HIV/AIDS among African Americans include sexual risk factors and substance use (CDC). At the same time, research indicates that Black and White men who have sex with men (MSM) have comparable risk behaviors (Millett, Peterson, Wolitski, & Stall, 2006), and African Americans in general report less risky sexual behaviors than their White counterparts (e.g., reported condom use is higher among Blacks than among other racial and ethnic groups; Blankenship, Smoyer, Bray, & Mattocks, 2005). African Americans reported (in a 2002 study) less lifetime and past year use of illicit drugs other than marijuana, and only slightly more use in the past month, than White adults (Blankenship et al.). In addition, White adolescents have been found to



be more likely to use illicit drugs than their African American counterparts, and to begin using drugs—both legal, e.g., tobacco, alcohol, and illegal—at younger ages. All of this suggests that race differences in HIV/AIDS are likely related to structural, social, and contextual factors that determine health, rather than to individual risk factors (Blankenship et al.).

When such factors are considered, it becomes clear that the disproportionate effect of HIV/AIDS upon African Americans is related to marginalized social status. The United States is a racially and economically segregated country in which poverty is disproportionately concentrated in African American and Hispanic communities (Fullilove, 2006). According to Anderson and colleagues, such a structure has led to large numbers of lower-income African Americans in central cities, particularly in impoverished neighborhoods, with ongoing racial discrimination posing difficulties for movement out of such areas. When affordable housing is not available to low income families, most financial resources are spent on housing costs, leaving other needs such as medical care unmet. Some implications are that African Americans may not have access to HIV/AIDS testing and treatment (Anderson, St. Charles, Fullilove, Scrimshaw, & Fielding, 2003). This is particularly significant in light of the fact that most African Americans who are aware of their HIV-positive status are likely to engage in safer sex practices, whereas those who are unaware of their status are less likely to do so (Fullilove).

Living in such poverty is a stressor on those who experience it, and on the community as a whole. As Fullilove (2006) pointed out, “Crime tends to flourish, particularly drug-related offenses” (p. 18). Injection drug use (IDU) accounts for more

than 19% of new African American HIV infections in the United States (CDC, 2007). If African Americans' reported rates of drug use are no higher than Whites', why would IDU pose a more significant threat to them? According to Blankenship et al. (2005), African Americans are disproportionately incarcerated for drug offenses, particularly since the country's so-called war on drugs: "While the number of White state prison inmates sentenced for drug offenses increased 306% between 1985 and 1995, the number of African American state prison inmates sentenced for drug offenses increased 707% in the same time period" (p. 143).

How does incarceration relate to HIV risk? Research supports the fact that HIV risk behaviors take place in at least one of the nation's largest state prison systems (Fullilove, 2006). Because having sex as a prisoner (either with another prisoner or with a member of the correctional staff) is illegal, as is injection drug use, HIV risk reduction interventions such as access to condoms and needle exchange are unavailable to most or all prisoners (Fullilove). Blankenship et al. (2005) noted that sex and drug use appear to decrease overall among prisoners (i.e., people engage in much less sexual behavior and drug use when they are in prison than when they are outside of it), but when they do occur, the behaviors are conducted in a riskier manner than they are outside of prison. Studies indicate that there is little difference in risk behaviors of African American prisoners versus Whites, suggesting that the disparity in HIV/AIDS is due to incidence of incarceration, not to differences in risk behavior while incarcerated (Fullilove).

African Americans' disproportionate incarceration leads to further consequences after their imprisonment. Fullilove (2006) points out that prisons are a major factor in the continuing rates of poverty and social disadvantage in the African American community.

It is usually difficult for ex-prisoners to secure jobs, which also means difficulty in securing healthcare (Blankenship et al., 2005). They often are ineligible for housing assistance or subsidies and are at high risk of becoming homeless (Fullilove). Ex-prisoners therefore often reside in economically disadvantaged communities (which often is where they came from; Fullilove), thus closing a circle characterized by racism and economic disadvantage and perpetuating such a cycle.

#### *African Americans' Response to HIV/AIDS*

Anecdotal accounts have suggested that African Americans' responses to HIV/AIDS have consisted of mistrust of Whites and/or the United States government (Thomas & Quinn, 1993). For example, community-based organizations have reported that African Americans mistrust government reports regarding HIV/AIDS, believe that HIV is a man-made virus, and believe that AIDS is a form of genocide (Thomas & Quinn, 1993). A 1992 *New York Times* article ("AIDS Plot," 1992) described results from polls indicating that many African Americans believe that HIV was deliberately created in a laboratory in order to infect Black people and that AZT (a medication used for HIV/AIDS treatment) is a plot to poison them. Media sources such as PBS programs, the *Los Angeles Sentinel*, and *Essence* magazine examined HIV/AIDS as a potential form of genocide, exploring the idea that African Americans were potentially infected by the disease intentionally in order to eliminate that population (Thomas & Quinn, 1993).

Several theorists (e.g., Bird & Bogart, 2005; Thomas & Quinn, 1991) have explained these beliefs in terms of the cultural history of African Americans in the United States. Thomas and Quinn (1991) asserted that the history of slavery and racism in the United States has contributed to the current social environment, in which the American

dream of opportunity and equality has failed to be realized by the majority of the African American population; their consequent anger and despair in the face of persistent inequality have contributed to the development of their beliefs about Whites and/or the United States government. These theorists also point specifically to the history of African Americans' experiences of institutional health care discrimination in particular in explaining what they call "conspiracy beliefs" about HIV/AIDS.

Thomas and Quinn (1991) asserted that African Americans' beliefs about HIV/AIDS stem from an overall distrust of the public health system and public health authorities, most likely due in large part to the Tuskegee Syphilis Study. Conducted by the United States Public Health Service, the study (which began in 1932) denied available syphilis treatment to African American men for 25 years so that researchers could continue their study of the course of the disease. Treatment became available in 1947, but researchers withheld treatment from African American men so that they could continue to observe the course of the disease. Researchers observed participants as they went blind, became insane, and eventually died (Bird & Bogart, 2005). According to historian James Jones, the ultimate reason why the study continued for 40 years was the lack of sense of responsibility and lack of ethical concern among the small group of men who controlled the study. The experiment was still being conducted when the story broke in the news because an employee at the United States Public Health Service had come forward after struggling with "moral concerns" (Thomas & Quinn, 1991). An official in the Center for Disease Control publicly stated that the experiment was "almost like genocide...a literal death sentence was passed on some of those people" (Thomas & Quinn, 1991).

Thomas and Quinn (1991) asserted that the Tuskegee study has fostered beliefs among African Americans that public health authorities cannot be trusted and that genocide is possible. African Americans' endorsement of "conspiracy beliefs" is related to their history of racist experiences in the United States, particularly to the Tuskegee Syphilis Study (Thomas & Quinn, 1993). The following section explains how such beliefs are conceptualized in the current study.

#### *Defining HIV/AIDS Beliefs*

In order to understand the focus of the current study, it is important to define the beliefs to which the study refers. Beliefs of interest in the current study and included in the review of previous research are "beliefs about large-scale discrimination, by the government and health care system, against a group (in this case, African Americans)" (Bird & Bogart, 2005, p. 110). While the popular media as well as some academic authors have referred to these beliefs as "conspiracy beliefs" (e.g., Crocker, Luhtanen, Broadnax, & Blaine, 1999), the broader definition explicated above is used in the current study for several reasons. First, given the very small body of literature on this topic, it allowed the literature to be searched broadly for the study of these types of beliefs, regardless of the terminology used by the authors. Furthermore, the phrase "conspiracy beliefs" might imply some psychological or intellectual malady, while the theory on the topic actually utilizes a historical and cultural explanation for the phenomenon. As Thomas and Quinn (1991) explain, a risk of drawing attention to the disproportionate number of AIDS cases among African Americans is that the epidemic could be attributed to some innate weakness of this population and could be used to further justify neglect or

deprivation. I assert that studying so-called “conspiracy beliefs” might create the same effect.

When discussing specific research, I adjust my language to adopt the language of the authors I am referencing. I applied the same principle for the use of the words Black and White, as well as the use of HIV or AIDS. This research topic has been examined from multiple fields (i.e., psychology, sociology, political science), contributing to difficulties in finding uniform terminology within this literature. The research included in this review includes studies that focused on HIV/AIDS beliefs specifically as well as studies that covered a broader range of beliefs but included HIV/AIDS beliefs. In all cases, the beliefs refer to those concerning large-scale discrimination by the government or public health care system. This empirical research is reviewed chronologically so that the reader may understand the development of the research area over time.

#### *Empirical Research Involving African Americans’ HIV/AIDS Beliefs*

The first research study documenting these types of beliefs tapped into the prevalence of distrustful HIV/AIDS beliefs by African Americans within a study that more generally examined AIDS-related attitudes in the United States (Herek & Glunt, 1991). The purpose of the study was to understand American’s attitudes related to the AIDS epidemic, including dimensions along which attitudes are organized. The researchers conducted a national telephone survey using random digit dialing (RDD) techniques with a random sample of English-speaking adults from the pool of all American households with telephones. In total, 960 interviews were obtained, with a response rate of 47 percent. The interviews contained four main areas of inquiry: knowledge/opinion about whether AIDS could be transmitted through each of 12

different routes, level of agreement with AIDS policy items, a short form of the Attitudes Toward Gay Men Scale (ATG); and demographic information.

Herek and Glunt (1991) report several results that are relevant to the current study. First, Black respondents agreed significantly more than Whites that the government is not telling the whole story about AIDS. Second, Blacks were somewhat more likely than Whites (51% versus 41%) to agree that the AIDS epidemic is being used to promote hatred of minority groups, though the authors note that the difference was not statistically significant. Finally, the belief that AIDS could be spread by casual contact was predicted by distrust for Blacks but not for Whites. Overall, the results, and the way in which they were reported (e.g., statistical significance unclear), do not offer strong evidence for significant mistrustful beliefs about HIV/AIDS held by Blacks, especially as compared to Whites. However, the findings did shed light on this phenomenon and spawned further research.

The area was next touched upon by Goertzel (1994), who approached the topic by studying conspiracy theories through the lens of political psychology. This author conducted a study with the purpose of determining the prevalence of conspiracy beliefs in general, and of testing possible psychological or sociological correlates of belief in conspiracies. Goertzel's (1994) study consisted of a telephone survey, which was given to 348 randomly selected residents of counties in southeastern New Jersey. The survey included three items that addressed beliefs about HIV/AIDS: "The AIDS virus was created deliberately in a government laboratory," "The government deliberately spread the AIDS virus in the homosexual community," and "The government deliberately spread

the AIDS virus in the Black community.” There was a total of 10 survey items assessing a variety of beliefs.

Once all responses were recorded, very few (6.2%) of the respondents thought that none of the conspiracies was at least probably true, while 21% thought that two were true, and 19% thought that three were true. Overall, belief in conspiracies was not significantly correlated with gender, educational level, or occupational category. There was a correlation ( $r = .44$ ) between conspiracy beliefs and minority status. Overall, African American respondents were more likely than White or Hispanic respondents to believe in the conspiracies which specifically affected their community. In particular, 31% believed that the government deliberately put AIDS into African American communities. This study presented stronger evidence of these beliefs, at least in one geographic area.

Dusenbury, Diaz, Epstein, Botvin, and Caton’s (1994) study regarding attitudes toward AIDS and AIDS education was conducted with multi-ethnic parents in New York City, therefore exploring this phenomenon in a different geographical area than that examined by Goertzel (1994). In order to obtain a multi-ethnic sample, the researchers used a random digit dialing procedure of residential telephone numbers in New York City. Prior to creating and conducting the telephone interviews, the researchers conducted discussions with three focus groups of parents, one group for each population they wanted to target (African American, Caucasian, and Latino). The interview items were developed based on these focus groups, and were organized into six general areas; the areas relevant to the current review are Beliefs About the Origins of AIDS and Views About the Level of Public Disclosure. The beliefs area included items such as “AIDS was



created deliberately by government scientists to eliminate undesirable groups of people.” The origins area included, “The medical community, that is, doctors and researchers, know more about AIDS than they are willing to say.” As part of their analysis, the researchers compared responses by racial group on these items.

In general, the analyses compared the Caucasian group of parents to the African American parents and to the Latino parents (i.e., African American and Latino parents were not compared to one another; Dusenbury et al., 1994). African American parents were more likely than Caucasian parents to believe that AIDS was deliberately created to eliminate undesirable groups of people (29% versus 9%), that AIDS had been created in the laboratory but had spread to the public by accident (27% versus 14%), that the medical community knows more about AIDS than they are willing to say (63% versus 38%), and that the government knows more about AIDS than they are willing to say (60% versus 38). Statistical significance of the differences between racial groups on the interview items was not reported, which is clearly a limitation of the study and the interpretation of its results. One strength of the study, however, lies in the fact that the researchers conducted focus groups prior to constructing the telephone interviews, providing more empirical reasoning for the inclusion of certain measurement items than in some of the other articles reviewed here.

Herek and Capitanio (1994) were perhaps the first researchers to focus a study solely on investigating trust in relation to perceptions of AIDS. The authors considered three manifestations of mistrust, measuring each with one item assessing participants’ level of mistrust in these areas: disbelief of medical authorities concerning the safety of casual social contact, the belief that AIDS is part of a genocidal conspiracy, and the belief

that information about AIDS is being deliberately withheld from the public. The researchers also assessed beliefs about HIV transmission; AIDS-related behavior change, which assessed whether participants had made any changes in their own sexual behavior because of AIDS); AIDS-related stigma, which examined participants' opinions about people with AIDS; sources of information, where participants personally had received any information about AIDS (participants were asked about each of 11 possible sources); and demographics.

Results revealed that more than one-third of the respondents gave at least one response that indicated a lack of trust (Herek & Capitanio, 1994). Overall distrust was higher among African Americans than among Whites. However, the authors did not state whether or not the difference was statistically significant. More than one in four Blacks (27%) expressed distrust of scientists and doctors who say AIDS is not spread by casual contact, compared to 14% of Whites. Twenty percent of African Americans interviewed believed that the government is using AIDS to kill off minority groups, compared to 4% of Whites. Finally, 43% of Blacks and 37% of Whites believed that information about AIDS is being withheld from the public. Fifty-five percent of Whites and 35% of Blacks did not give any distrustful responses to any of the three items.

To further assess the relationship between race and trust, the researchers conducted additional analyses (Herek & Capitanio, 1994). Race predicted mistrust above and beyond income and education. None of the three distrust items was associated with exposure to information about AIDS, in that no particular source of information was significantly correlated with any of the trust items. Distrust of doctors was correlated with overestimating risks of contracting the disease. Distrust of doctors also was correlated

with having stigmatizing beliefs about people with AIDS. The authors conclude that lack of trust is widespread and is unrelated to access to information. The study points to African American race, above and beyond correlates such as income and education, as related to mistrust with regard to AIDS.

Klonoff and Landrine (1999) studied HIV/AIDS beliefs of African Americans exclusively. Subjects were sampled from ten randomly selected middle- and working-class census tracts in San Bernardino County, California. The primary survey item posed to the participants was, “HIV/AIDS is a man-made virus that the federal government made to kill and wipe out Black people. How much do you agree with the above statement?” The responses were: totally disagree—32.7%, disagree somewhat—18%, neither agree nor disagree—22.7%, agree somewhat—12.2%, totally agree—14.3%.

The authors also examined predictors of agreement with the survey item about HIV/AIDS being a man-made virus (Klonoff & Landrine, 1999). Predictors included acculturation (i.e., low or no immersion in Black culture; with low-acculturated individuals who were more immersed in Black culture more likely to endorse the survey item), gender (with men more likely to endorse the survey item), and racist experiences. Education, income, and age were not predictive of agreement with that item. Women’s agreement was most predicted by low levels of acculturation, while men’s agreement was most predicted by high experiences of racist events. This study offered the first empirical examination of potential correlates of trust or mistrust in relation to HIV/AIDS.

Parsons, Simmons, Shinhoster, and Kilburn (1999) analyzed conspiracy theories among Blacks in one southern state, collecting data through a survey of church parishioners. A Likert scale was used to measure beliefs in 11 conspiracy theories. Two

of the 11 items were related to AIDS; one asked if the government was telling the truth about AIDS; the other asked if AIDS was intended to wipe Blacks off the face of the earth. Both items were taken from previous research. In regard to beliefs about HIV/AIDS, almost 70% of participants reported that the government is not telling the whole truth about AIDS. One of the least endorsed items of all 11 of the conspiracy theories was AIDS as a form of genocide, and that belief was held by 27.8% of participants.

The 11 items grouped into two distinct factors: “malicious intent,” the belief in a more active conspiracy by the government, including the AIDS as a form of genocide item; and “benign neglect,” belief that the government does not address specific social problems, the factor that included the item that the government was not telling the truth about AIDS (Parsons et al., 1999). Overall, beliefs in the benign neglect theories were more prevalent than beliefs of malicious intent. Age, gender, and education were not contributors to belief in conspiracy theories. These findings show, once again, that these beliefs appear unrelated to those demographics but are, rather, related primarily to race. The factor analysis in this study also helped to reveal the nature and complexity of these beliefs (e.g., benign neglect versus malicious intent).

The next study undertaken in this area moved beyond the prevalence and correlates of these beliefs and tested theories related to racial differences. Crocker et al. (1999) hypothesized that the beliefs would be related to system blame, a tendency to make external attributions for the problems facing one’s racial group, which may be an attempt to cope with the threat to the self that the situation of inequality poses. Participants were recruited primarily from the psychology department’s subject pool at a

large, predominantly White, Northeastern university. Belief in government conspiracies against Blacks was assessed with a 13-item scale developed for the study; two items were related to AIDS. Black students scored significantly higher on the belief in conspiracies index than did White students. Moreover, results revealed a significant effect of race on each individual item. The results also were compared to the *New York Times*/CBS News survey (DeParle, 1990). Results demonstrated that belief in conspiracies is at least as widespread, and perhaps more so, among relatively advantaged college students as compared to the general population.

Next, Crocker, et al. (1999) sought to examine explanations for the racial divide. Black students were higher than White students in system blame, meaning that they were more likely to attribute problems in the Black community to prejudice and discrimination. Initially, family income (but not parents' education or participant's sex) was a significant predictor of belief in conspiracies, but once race was added to the model, none of the other demographic variables were significantly related to belief in conspiracies. When all predictor variables were considered together, system blame was the only variable to predict belief in United States government. Rather than attribute the wide disparities in the outcomes experienced by Black and White Americans as some deficit in Blacks themselves, many Black Americans appear to attribute these disparities to problems associated with the power held by White Americans, namely prejudice and discrimination.

Bogart and Bird (2003) also began to explore some of the implications of conspiracy beliefs about HIV/AIDS among African American adults. The researchers conducted a cross-sectional, anonymous telephone survey with a national sample of

African American adults. During the interviews, participants were asked to report the extent to which they agreed or disagreed with nine statements regarding belief in HIV/AIDS conspiracy theories, most of which were adapted from prior research. Six items measured belief in conspiracies about the government and three items assessed belief in conspiracies about new treatments for HIV; scoring was on a 5-point scale.

Scores on the HIV/AIDS government conspiracy scale averaged around the midpoint ( $M = 2.94$ ), and scores on the HIV/AIDS treatment scale were slightly lower ( $M = 2.20$ ; Bogart & Bird, 2003). The two scales were significantly, moderately correlated. Greater endorsement of an HIV/AIDS government conspiracy was significantly related to greater number of partners in the last three months and to lower perceived quality of condoms as a method of birth control. Belief in a treatment conspiracy was significantly related to more positive attitudes about using condoms in the next three months and to greater intentions to use condoms during the next engagement in sexual intercourse (i.e., participants presumably wanted to avoid contracting the disease so that they could avoid treatment).

Bogart and Thorburn (2005) conducted a similar study. The research examined endorsements of HIV/AIDS conspiracy beliefs and the relationship of those beliefs to condom attitudes and condom use among African Americans. The study was an anonymous telephone survey of African American adults. Endorsement of HIV/AIDS beliefs and the relationship of beliefs with condom attitudes and condom use were the focus of analyses and results. Total scores on the HIV/AIDS conspiracy beliefs scale averaged around the midpoint (2.34 on a 5-point Likert scale), with men reporting significantly stronger conspiracy beliefs than women. HIV/AIDS conspiracy beliefs were

not significantly related to condom attitudes or use in the overall sample or with women only, but were significantly associated among men. Men who held stronger HIV/AIDS conspiracy beliefs had more negative attitudes about condoms and were less likely to use condoms consistently. The correlations were significant among males, so the researchers then tested whether men's attitudes about condoms mediated the relationship between endorsement of conspiracy beliefs and condom use. Results indicated that the relationship between HIV/AIDS conspiracy beliefs and condom use was reduced to nonsignificance when condom attitudes were included in the model, suggesting that condom attitudes could be considered a mediator. The relationship between sexual attitudes and behavior with endorsement of these beliefs suggests, as do the results of all of the reviewed studies, that these beliefs represent an important research topic.

#### *Summary of the Empirical Literature*

Examining the reviewed studies together makes clear, first of all, that many African Americans possess beliefs about large-scale discrimination in regard to HIV/AIDS. While estimates of the prevalence vary in terms of level of endorsement and type of belief (e.g., 70% of participants agreed with the statement that the government is not telling the whole truth about AIDS [Parsons et al., 1999], while 27% of participants believed that the government deliberately created AIDS to kill Black people [Klonoff & Landrine, 1999]), the phenomenon has been pervasive throughout these disparate studies that have emerged from multiple fields of study. Overall, results demonstrated that endorsement of mild or "benign" beliefs is more common than endorsement of more "malicious" beliefs (e.g., Parsons et al.).

Furthermore, African Americans' beliefs about large-scale discrimination regarding HIV/AIDS are significantly more prevalent than Caucasian Americans', regardless of the nature of the beliefs, e.g., benign or malicious (e.g., Dusenbury et al., 1994; Herek & Capitanio, 1994; Crocker et al., 1999). The literature also suggests explanations for this discrepancy. Klonoff and Landrine (1999) found that lower levels of acculturation (i.e., stronger immersion in black culture) and experiences of racism predicted endorsement of these beliefs. Crocker et al. found that when system blame (the tendency to attribute problems to prejudice and discrimination) was entered into a regression equation with other relevant variables (race, income, and other psych-social variables), system blame was the only predictor of endorsing large-scale discrimination beliefs about HIV/AIDS; their results support the theoretical argument that these beliefs have arisen from cultural history and experiences of African Americans in the United States, rather than from personality characteristics or defects (Crocker et al.). Results consistently showed that endorsements of beliefs about large-scale discrimination regarding HIV/AIDS are unrelated to income or to education (Goertzel, 1994; Parsons et al., 1999); specifically, several researchers found that once race was entered into their regression equations, income and education were no longer predictors of these beliefs (Herek & Capitanio; Klonoff & Landrine; Crocker et al.).

Finally, some implications of large-scale discriminatory beliefs about HIV/AIDS and the government and medical community have been explored as well. Bogart and Bird (2003) found that belief in government conspiracies was related to a greater number of sexual partners in the last three months and a lower perceived quality of condoms. Bogart and Thorburn (2005) found that HIV/AIDS conspiracy beliefs were related to condom



use only in men. For men, the beliefs were correlated with more negative attitudes about condom use and a lower likelihood of using condoms consistently.

### Statement of the Problem

Existing literature regarding beliefs about large-scale discrimination with regard to HIV/AIDS among African Americans clearly has demonstrated pervasiveness of these beliefs and even has explored several implications of these beliefs (e.g., risky sexual behavior, variable condom use; Bogart & Bird, 2003; Bogart & Thorburn, 2005). However, researchers have yet to study the nature of the beliefs exhaustively. Although several authors conducted focus groups prior to their quantitative analyses in order to inform the construction of their measures (e.g., Dusenbury et al., 1994; Herek & Capitanio, 1994), all of the previous research reviewed for the current study relied solely on asking participants about their agreement with statements constructed by the researchers (e.g., Goertzel, 1994; Herek & Glunt, 1991; Klonoff & Landrine, 1999; Parsons et al., 1999). Thus, the only empirical analysis of such beliefs to date has been achieved through quantitative measures that did not allow for discovery of beliefs generated by the participants themselves. Such methods raise the question of whether African Americans' beliefs about HIV/AIDS have been fully explored or uncovered.

Second, previous research has studied African Americans generally. The literature has not focused on examining the prevalence or implications of these beliefs among African American individuals who are HIV-positive. Several bodies of literature inform why such an exploration is important. In particular, research findings regarding medication adherence and coping with chronic illness suggest potential implications for these beliefs among African Americans who are living with HIV/AIDS.

*Medication adherence.* The health belief model (Becker et al., 1977) is the most widely used model for explaining people's health-related actions or behaviors, including medication adherence (Barclay et al., 2007). According to the health belief model, a patient's decision to be adherent or nonadherent to medication is derived from the patient's assessment of the relative costs and benefits of the treatment. If perceived costs outweigh the perceived benefits, patients are less likely to adhere to their medication regimen (Lacro et al., 2002; Osterberg & Blaschke, 2005). Thus, among other factors, attitudes and beliefs about medication are posited to play a role in medication adherence.

Substantial empirical support exists for the health belief model. Janz and Becker (1984) critically reviewed 29 investigations concerning the health belief model. A significance ratio was utilized to examine the efficacy of the model; the authors constructed a ratio that divided the number of positive, statistically significant findings for dimensions of the model by the total number of studies reporting significance levels for those dimensions. Results indicated considerable support for the model. Since then, many subsequent empirical investigations have found support for the model (e.g., Juniper, Oman, & Hamm, 2004; Sapp & Jensen, 1998; Winfield & Whaley, 2002), including at least one study that found support for the model among HIV-positive adults (Barclay et al., 2007). Thus, strong empirical evidence exists to support the theory that attitudes and beliefs about medication play a role in medication adherence, including adherence among HIV-positive individuals.

Based on research discussed in the current review, it is clear that some African Americans have negative views about HIV medications (e.g., Bogart & Bird, 2003). Bogart and Bird found that African Americans endorsed beliefs that people who take new

medicines for HIV are human guinea pigs for the government (43% of the sample agreed or strongly agreed), that the medicine that doctors prescribe to treat HIV is poison (9.3%), and that the medicine used to treat HIV causes people to get AIDS (9.1%). The health belief model suggests that such beliefs would contribute to nonadherence among African Americans with HIV.

Why is medication adherence important, particularly among individuals who are HIV-positive? In general, poor adherence to medication regimens accounts for substantial worsening of disease and death and also increases health care costs (Osterberg & Blaschke, 2005). It jeopardizes the outcome of treatment for every medical and psychiatric condition (Lacro et al., 2002). This is especially true for individuals who take medications for HIV (Osterberg & Blaschke). Barclay et al. (2007) pointed out that while the introduction of highly active antiretroviral therapy (HAART) has transformed HIV treatment and prognosis by substantially reducing morbidity and mortality from HIV/AIDS, early optimism was offset by the evidence that even occasional nonadherence can greatly diminish the benefits of treatment. Patterson et al. (2000) found that adherence greater than 95% is needed to achieve successful biological and clinical outcomes, and that suboptimal adherence is associated with clinically significant health-related setbacks. Nonadherence to HAART also has been described as a public health concern because it results in the development and spread of drug-resistant strains of HIV (Ickovics & Meade, 2002). Several authors (e.g., Ickovics & Meade, 2002) have cited the importance of identifying risk factors related to medication adherence generally and regarding HIV specifically. Thus, examining the beliefs under investigation in the current

study as they relate to individuals who are HIV-positive could identify a risk factor for medication adherence.

*Illness representations and coping.* Another model that informs the potential relationship between living with HIV/AIDS and the beliefs under investigation in the current study is the common sense model of illness representations (Leventhal, Meyer, & Nerenz, 1980). The model addresses how cognitive factors influence coping and subsequent outcomes related to illness by identifying factors involved in the processing of information related to one's disease or illness, describing how the information is integrated to form a "lay" view of the illness, and outlining how the lay view guides coping behaviors and outcomes. The model suggests that individuals create mental representations of their illness based on the sources available to them, and that such representations lead to engaging in coping strategies and adopting ways to manage illness (Hagger & Orbell, 2003). The cognitive factors, or illness representations, have been found to consist of several distinct (though somewhat overlapping) dimensions. One such dimension is known as the cause dimension, which represents one's beliefs regarding the causes of one's illness (Hagger & Orbell, 2003). Beliefs about causes that have been identified include psychological reasons (e.g., stress, personality, depression, workaholic, lack of rest), environmental reasons (e.g., chemicals, pollution, sprayed food, use of medication, and malnutrition), and fate (Heijmans & de Ridder, 1998). As stated above, the model posits that such beliefs impact coping, and there is empirical support for that relationship. For example, a strong belief in external causes of illness has been associated with more social support-seeking and more behavioral-avoidant coping (Heijmans & de Ridder, 1998).

As I discussed earlier, African Americans' responses to HIV/AIDS have included the formation of beliefs about its cause. My review of the literature showed that some African Americans have endorsed beliefs that AIDS could be spread through casual contact (Herek & Glunt, 1991), that the AIDS virus was created deliberately in a government laboratory (Goertzel, 1994), that HIV is a man-made virus, and that the medicine used to treat HIV causes people to get AIDS (Bogart & Bird, 2003). The illness representation model (Leventhal et al., 1980) suggests that if African Americans who are living with HIV hold such beliefs, such beliefs likely influence how those individuals cope with their illness. It is well documented in psychological literature that coping styles relate to individuals' ability to establish and maintain psychological well-being during chronic stressful events (e.g., illness; Folkman & Moskowitz, 2004). Clearly, African Americans' beliefs about large-scale discrimination regarding HIV/AIDS have potentially important implications for people with HIV, and this intersection is thus deserving of empirical study. However, I did not uncover any existing research addressing that intersection.

#### *Purpose of the Study*

Available literature suggests that some African Americans hold beliefs about large-scale discrimination against them with regard to HIV/AIDS. However, research regarding the nature of such beliefs has not been exhaustive. In addition, I was unable to find any existing theoretical or empirical literature directly addressing how African Americans' beliefs about HIV (as defined in my literature review) might relate to what it is like for them to live with the disease. Available literature suggests that such beliefs

may be related to medication adherence or to coping styles among individuals who are living with HIV.

The purpose of the current study was to conduct in-depth research that uncovered the nature of African Americans' beliefs about HIV/AIDS, and to explore the implications of such beliefs among those who are actually living with it. In order to accomplish that goal, I needed a methodology that would allow me to uncover aspects of the beliefs and their relationship to living with HIV that have not yet been hypothesized in the literature. Since little is known about the intersection between African Americans' beliefs about HIV/AIDS and their experiences of living with the illness and no existing theoretical literature fully explains their connection, it also was desirable for me to use a methodological approach that would allow me to construct a theoretical framework for articulating that relationship.

#### *Framework of the Current Study*

The current study utilized grounded theory, a qualitative methodology whose primary goal is theory development (Glaser & Strauss, 1967). Strauss and Corbin (1990) noted that qualitative methods can be used to uncover and understand what lies behind a phenomenon about which little is known and can provide details of phenomena that are difficult to convey with quantitative methods. They also noted that some areas of study naturally lend themselves to qualitative research. They stated that research attempting to uncover the nature of people's experiences with illness is particularly well-suited to qualitative research. Thus, such an approach allowed me to achieve my research goals of describing details of a phenomenon (African Americans' beliefs about HIV/AIDS),

discussing African Americans' experiences in living with HIV/AIDS, and articulating the relationship between those beliefs and experiences.

Grounded theory was selected as the specific qualitative methodology utilized in the current study for several reasons. It was chosen primarily because it allows researchers to discover categories and relationships among them, fosters the identification of connections between events, and emphasizes theory development (Charmaz, 2000; Strauss & Corbin, 1990, 1994). Once again, these characteristics were optimal in providing me the opportunity to achieve the goals of the current study. Employing a research method that led to theory development allowed me to articulate the relationship between HIV-positive African Americans' beliefs and experiences. In addition, grounded theory focuses on giving participants a voice, which was important given my review of how the population studied in the current research has been marginalized. Grounded theory also has been used extensively in studies of chronic illness in the past (e.g., Charmaz, 1990). An additional reason that grounded theory was chosen was my personal familiarity with the method; I had previously worked on a research study that utilized grounded theory and had learned about the method and analysis.

Even within grounded theory, several different philosophical stances have been taken. Charmaz (2000) suggested that grounded theory may be conceptualized on a continuum of objectivist to constructionist. She asserted that most grounded theorists write as if their data have an objective status and reflect reality, suggesting that one universal truth and a true, testable, verifiable theory could be found. In contrast, constructivist grounded theorists distinguish between real and true; they do not seek one universal truth, but rather attempt to discover what participants define as real and how

those definitions of reality impact them. Charmaz asserted that data are narrative constructions, and as such, they are reconstructions of participants' experiences—data are not the experiences themselves. She asserts that researchers may place an emphasis on meaning without assuming the existence of a unidimensional external reality. Thus, the goal of the analysis is to seek meaning. She explains that constructivist grounded theory “assumes that people create and maintain meaningful worlds through dialectical processes of conferring meaning on their realities and acting within them” (p. 521). In studying such a process, she recommends examining beliefs and ideologies as well as situations and structures.

A constructivist approach was assumed for the current study in relation to my goals of understanding people's beliefs and how they relate to their lived experiences—that is, how they confer meaning on their realities, and act within them. The decision to adopt a constructivist approach also was a philosophical one. I agree with Charmaz (2000) that, in general, research produces one temporally bound reality, as opposed to a universal truth. In addition, constructivist grounded theory recognizes that the concepts, categories, and theoretical level of analysis emerge from the researcher's interactions with the participants and the data. I conducted my study from a constructivist perspective because I wanted to work within a framework that shared my philosophical underpinnings and incorporated them into the analysis. This is accomplished in part through attention to detail, which sensitizes researchers to multiple realities and viewpoints. Charmaz also recommended using grounded theory methods as flexible strategies that are emergent and interactive rather than as guidelines or rules that are didactic and prescriptive. In so doing, grounded theory can be used to advance



“knowledge of subjective experience and expand its representation while neither remaining external from it nor accepting objectivist assumptions and procedures” (p. 521).

### *Research Questions*

In order to formulate a grounded theory, research questions are needed that give researchers the flexibility and freedom to explore a phenomenon in depth (Strauss & Corbin, 1990). The underlying assumption is that not all of the concepts pertaining to the phenomenon being studied have been identified. Thus, the research questions need to allow room for the discovery of new concepts related to the phenomenon under investigation. I constructed research questions for the current study with those goals in mind. The questions related clearly to the literature review and to my hypotheses about how HIV-positive African Americans’ beliefs and experiences might interact, while also remaining broad enough to capture potential new concepts.

Research Question 1: What do HIV-positive African Americans believe about HIV/AIDS, and what are their sources of information?

Research Question 1a: What do HIV-positive African Americans believe about how or why people get or have HIV/AIDS?

Research Question 1b: What do HIV-positive African Americans believe about the role of the government in HIV/AIDS?

Research Question 1c: What do HIV-positive African Americans believe about the role of medications and health care institutions in HIV/AIDS?

Research Question 1d: What have HIV-positive African Americans heard about HIV/AIDS that they do *not* believe?

Research Question 1e: What sources do HIV-positive African Americans believe regarding information about HIV/AIDS, and what sources do they not believe?

These research questions were designed to investigate the nature of participants' beliefs, in keeping with the first goal of the study.

Research Question 2: How do HIV-positive African Americans' beliefs about HIV/AIDS relate to their experiences of living with HIV/AIDS?

This was the primary research question of the study; it related directly to the goal of exploring the relationship between African Americans' beliefs about HIV/AIDS and their experiences of living with the disease.

Research Question 3: How have HIV-positive African Americans' beliefs about HIV/AIDS changed over time?

This question was included because previous research has shown that individuals' appraisals of their illnesses (including HIV) sometimes change over time, which suggests that education and support may influence coping (e.g., Moskowitz & Wrubel, 2005).

## Chapter 3

### Method

#### *Recruitment*

Recruitment of participants took place at the Austin Center, one of two outpatient day treatment centers that are part of Whitman-Walker Clinic, a non-profit, community-based health organization serving the Washington, DC metropolitan region. The mission of Whitman-Walker Clinic is to provide or facilitate the delivery of high quality, comprehensive, accessible health care and community services for gay, lesbian, bisexual, and transgender people and people living with HIV/AIDS. Whitman-Walker Clinic spans several locations in the Washington, DC metropolitan region. The Austin Center is located in Northwest Washington, DC, near the Columbia Heights neighborhood.

The Austin Center provides day treatment services for people living with HIV/AIDS. The center provides a supportive community where clients receive medical/nursing care, counseling, socialization, and other services. Depending on personal needs, clients attend daily groups that address addictions (recovery, relapse prevention, and harm reduction techniques), health education (focusing on adherence issues and maximizing wellness), mental health, skills building (including independent living skills, e.g., cooking, budgeting, communication, assertiveness, and stress reduction), and general support. In addition, two nutritionally balanced meals are provided each day, and field trips are frequently planned for the clients, as well. Many of the clients were long-term clients of the program or the clinic as a whole, and most clients knew each other quite well, resulting in a culture of support and education.

The Austin Center was appropriate as a place of recruitment for the current study in that it consisted of a large group of African American clients who were gathered in one place, readily available to participate; nearly 100% of Austin Center clients are African American, and clients attend the program each weekday from morning through mid-afternoon. With cooperation from the clinical director of the program, the primary researcher arranged to attend the program's daily community meetings in order to recruit participants.

I explained to clients that I had been an intern at the clinic, was a graduate student at the University of Maryland, and was conducting a research study as part of my academic requirements. I explained that the purpose of the study was to learn about African Americans' beliefs about HIV/AIDS. Clients also were informed that those who participated in the study would receive a \$10.00 grocery card for their participation. Clients were informed that refusal to participate in any part of the study, i.e., choosing not to answer an interview question, would not jeopardize the grocery card reward.

My only absolute criteria for recruitment were African American race/ethnicity and HIV-positive status, which all of the clients met; therefore, everyone to whom I spoke was eligible to participate. I visited the center every day for approximately two weeks, simultaneously recruiting and interviewing participants during that time period. Each time I recruited at the daily meetings, clients were invited to approach me at the end of the meeting if they would like to schedule an interview appointment. I was available to schedule two to three appointments per day for approximately two weeks and was able to accommodate nearly every volunteer. On several occasions, the scheduled participant was unavailable on the scheduled date and an additional volunteer—at times, a client who

had not initially fit into the interview schedule—was available and was interviewed on that date.

### *Theoretical Sampling*

In outlining the procedures of grounded theory, Corbin and Strauss (1990) stated that representativeness of concepts, not of persons, is crucial. It is by theoretical sampling that such representativeness is achieved. Theoretical sampling is a process by which data analysis occurs concurrently with sampling (Fassinger, 2005). Theoretical sampling is used to develop emerging categories and to refine ideas (Charmaz, 2000), and is thought by most researchers to be completed at the point of “saturation”—that is, when new data fit into the categories already devised (Charmaz).

Some researchers accomplish theoretical sampling by returning to previous participants or by interviewing additional participants as data analysis proceeds, a strategy that Charmaz (2000) asserted is not necessary. Charmaz asserted that theoretical sampling also includes returning to existing data to sample scenes, events, or documents. In addition, Fassinger (2005) noted that in the interest of time constraints (e.g., limited time in which to conduct interviews), she chooses a demographically diverse sample within her population of interest, with the assumption that will provide the widest range of experience possible within that group. She also conducts interviews that are sufficiently lengthy to allow for collection of data that has both breadth and depth. She noted that when she engages in such practices, returning to interviewees is rarely necessary given the relatively large and diverse data sets she has collected.

Given my time and geographical constraints, I was guided by Charmaz’s (2000) assertions and Fassinger’s (2005) practices in selecting my interview sample. Thus, the

primary goal of recruitment was to select participants who were diverse (e.g., in terms of gender, sexual orientation, or HIV-related demographics) in order to capture the maximum variability possible in the sample with regard to the initial data collected. I ceased data collection when I had a demographically diverse group of participants and I had begun to hear similar concepts discussed during the interviews.

### *Interviews*

Each interview was held in office space at the Austin Center. All interviews were audiotaped on two separate tape recorders, to guard against losing data due to technical difficulties. After completing their interviews, participants were given their \$10.00 grocery card rewards (one per participant) for their participation, as well as contact information for the faculty researcher and the telephone number for Whitman-Walker's crisis hotline (see Appendix A). A field notes form (see Appendix B) was completed by the interviewer (myself) immediately following each interview, documenting the length of the interview, general themes that emerged, comments on the rapport between interviewer and participant, and any other relevant information (e.g., interruptions, technical difficulties).

Interviews were to be considered pilot interviews until the interview protocol and process were deemed effective. The purpose of conducting pilot interviews was to assess the efficacy of the field notes form and of the interview protocol. In particular, the relevancy of the questions and whether any questions might be missing were explored. Ultimately, only one interview was considered a pilot interview, because it was determined based on the interviewee's feedback and the interviewer's own perceptions that there was no need for any modifications of the interview protocol or procedures, and

that the interviewer had sufficient practice and was ready to complete interviews that could be used for analysis. The willingness of the participants to answer the questions and to trust the researcher also was explored; for further discussion, see the following section.

### *The Interviewer*

I personally conducted all of the interviews. I am a female, European American, counseling psychology doctoral candidate, and at the time of the interviews, was 26 years old. Given that the participants were all African Americans and that the background of the current study suggests that African Americans may be mistrusting of the government and medical institutions, which they appear to associate with White people and values, a discussion of my decision to conduct the interviews myself is warranted.

Initially, I was inclined to conduct the interviews myself simply because I am the primary researcher and am passionate about the project. In consultation with several faculty members who are experienced in conducting qualitative research, a number of other advantages to my conducting the interviews were identified. As a fourth year student, I possessed advanced clinical skills that would likely be useful in conducting the type of semi-structured interview for which my study called, and that would likely surpass the skills of someone with less experience whom I might have trained to conduct interviews for me. I also had prior experience conducting semi-structured interviews for a grounded theory study. In addition, I had a relatively long-term relationship with the Whitman-Walker Clinic and some of its clients, having been an intern there for two years. I hypothesized that my relationship with the clinic was likely to enhance participants' trust in me. Staff members at all levels of Whitman-Walker Clinic attempt to

foster a culture of trust within and between staff and clients. Indeed, the mission of the clinic is built around the idea that these individuals need health care providers whom they can trust. At the Austin Center in particular, many clients had long term relationships with the clinic (refer to Chapter 4 for a detailed discussion regarding participants' perception of and relationship with the clinic). Even more specifically, I was known well by one Austin Center client because I had a therapeutic relationship with that client in the past; that client had expressed trust in me, and I expected that the client would inform other potential participants that I was trustworthy. In short, consensus among committee members was that my relationship with the clinic was likely to outweigh perceptions about my race.

I also turned to existing literature on cross-race interviewing (i.e., race-of-interviewer effects). Initial research regarding cross-race interviewing found that race of interviewer was associated with bias “only when social distance is high and when an interview question is highly threatening” (Williams, 1964, p. 338). More recently, Davis (1997) noted that “characteristic of the traditional role-playing behavior meant to appease and accommodate Whites, African-Americans out of a sense of fear or intimidation are expected to conceal their true political beliefs and place self-imposed limits on their freedom of expression in response to the White interviewer” (p. 309). On the other hand, Rhodes (1994) and Hall (2004) have asserted that racial matching (i.e., choosing an interviewer who is the same race as the participants) runs the risk of portraying the research topic as solely an ethnic-minority issue, and thus marginalizing the issue. Rhodes also has noted that racial matching suggests an assumption of a single truth. Such an assumption is antithetical to the constructivist paradigm in which I placed the current



study. Hall herself is White and conducted interviews with South Asian women. She has stated that a White feminist researcher is likely to be viewed as an outsider by ethnic minority interviewees, but that there are pros and cons to such a dynamic. For example, an ethnic-majority interviewer/researcher is likely to hold structural power over ethnic-minority participants; however, ethnic-minority participants may hold personal power (i.e., refusing an interview, withholding information). Furthermore, “in some interview situations the researcher’s ethnicity, gender and/or class may not necessarily be the focus upon which the minority ethnic participant relates to the majority-ethnic interviewer” (Hall, p. 139).

Ultimately, I interpreted the literature to be favorable toward the idea of my conducting the research interviews. I decided that conducting the interviews myself would allow me to obtain skillfully conducted interviews that were consistent with the constructivist stance of the overall study. Rather than simply rely on assumptions, I also decided to solicit feedback about the interview process from my participants at the close of the interviews.

Only two participants offered substantive feedback (i.e., more than a word or phrase) about the interview process, and both sets of feedback were positive. The first of the two participants essentially noted that any risk regarding trusting me was worth it for the good of himself and the cause:

If...I’m not doing any harm nowhere, I don’t care what you think about me, I got to think about myself. If there’s anything along the way that I can help you with, I’ll help you, but if not, I don’t have time to focus on that, because I’m not doing anything to you...anything that I might be able to share that may help somebody else somewhere down the line, well, I’m pretty much willing to do that, you know?...This thing isn’t something to play with, you know. Hopefully one day, we’ll find a cure.

I commented to the same participant that I hoped my connection to the clinic would help people to trust me. He responded that, “Yeah, that made a difference too, when you did say something about, you worked over there for awhile, you know, that made a difference too. Because, I mean, like, I’ve actually been to the point where someone would come in, and I wouldn’t say nothing, anything to them.” The feedback from the second participant who offered it also involved a reaction to me:

The only thing I would like to say is I’m glad you came and I took part in it [the study] because it gave me to express my feelings and somebody else could hear how I feel about things instead of, because, you know, because sometimes you try and address it here and somebody feels another way...but I like the way I can express these words...So, it was a positive experience.

### *Participants*

Sixteen participants were recruited and interviewed. Since one interview was considered a pilot interview, the total number of participants included in the analysis was 15. Ten of the participants were male and five were female, which reflected the greater ratio of men to women in the program as a whole. Ten of the participants identified as heterosexual, two participants identified as gay, two identified as bisexual, and one identified as both bisexual and gay. Nine of the participants were currently in relationships, while six were not. Three of the participants discussed having been divorced, and two participants had lost partners through death. Eleven participants had children: five had two children, four had one child, and two had three children; four participants had no children. The age range of the sample was 36-60; the average age of the participants was 52. Eight participants had completed some college, four had completed high school, two had completed some high school, and one had completed eighth grade. All participants’ source of income was disability—either Supplemental

Security Income (SSI) or Social Security Disability Income (SSDI). The participants' average self-reported income was \$693 per month. One participant did not know his income and therefore was excluded from that calculation. When asked about identification with a particular religion or spirituality, eight participants identified as Baptist (with one specifically identifying as an "open minded Baptist"), three claimed no religious identification, one identified as Catholic, one as Christian, one as Lutheran, and one as spiritual. The participants were reported being diagnosed with HIV between the mid-1980s and 2002. Eight of the participants also were diagnosed with AIDS, all during the 1980s and 1990s.

### *Instruments*

*Interview protocol.* The research questions posed by the current study were explored through the use of a semi-structured interview protocol (see Appendix C) developed by the primary researcher. The interview protocol included questions that were designed to assess the nature of the participants' beliefs, connection between beliefs and the experience of living with HIV, changes in beliefs over time, and experiences at Whitman-Walker Clinic. The question regarding the nature of participants' beliefs included prompts regarding the sources of the beliefs. The question regarding the connection between beliefs and the experience of living with HIV included prompts about treatment-seeking and about coping. The question regarding changes in beliefs over time included a prompt about how the changes came about. The question regarding experiences with Whitman Walker Clinic included prompts regarding how participants heard about the clinic, services used, and initial and current impressions of the clinic. An additional question in the protocol also allowed participants to add additional comments

that the interviewer's questions did not address. The efficacy of the protocol was explored during a pilot interview, and the initial protocol was deemed effective (i.e., no changes were made to the protocol between the pilot interview and the analyzed interviews).

*Demographics.* Demographics were measured by questions created by the primary researcher (see Appendix D). Personal, HIV/AIDS-related, and clinic-related demographics were assessed. The questions were contained in a form such that I could record participants' responses for quick reference at a later point; the forms were not given to the participants themselves. The questions were asked as part of the interviews (the protocol included prompts which directed me to turn to the demographic questions), with participants having the opportunity to discuss their responses at length.

*Field notes form.* A field notes form (see Appendix B; c.f. Richie et al., 1997) was completed by the interviewer immediately following each interview. The field notes form documented the length of the interview, general themes that emerged, comments on the rapport between interviewer and participant, and additional information that the interviewer judged to be relevant (e.g., interruptions, technical difficulties).

### *Research Team*

Corbin and Strauss (1990) noted that, "A grounded theorist need not work alone" (p. 11). They asserted that discussions among multiple researchers often lead to new insights and increased theoretical sensitivity. They also noted that involving others in one's analysis helps to prevent personal bias. My personal belief, from a more constructivist perspective, is that rather than prevent bias completely, teamwork tends to introduce multiple biases. Such biases do not necessarily cancel each other out, but the

multiple perspectives from which team members approach the work may add depth to the emergent theory.

Data for the current study were transcribed and analyzed by me and by seven undergraduate research team members from the College of the Holy Cross, my alma mater. Holy Cross is an undergraduate, Jesuit, liberal arts institution in Worcester, Massachusetts. I chose to work with a research team for the reasons noted above, and chose to work with Holy Cross students in particular for reasons of convenience. I was familiar enough with Holy Cross to have ideas regarding how to recruit students there, and my desire was to hold team meetings in a place near my home or work. I also felt that leading a research team at my alma mater would give me a chance to mentor students about whom I had a vested interest. I posted fliers in the Holy Cross building that houses the psychology, sociology, and anthropology departments (see Appendix E). Nine students expressed interest in participating; I interviewed all of them and invited seven of them to participate in the research team.

All interviewees whom I invited to the team accepted, resulting in our eight-person (including me) team. All eight of us were female. All of the team members except me were age 20-22. Five of the team members were psychology majors, one was a double major in psychology and sociology, and one was a sociology major. Four of us identified as Caucasian or White, three identified as Hispanic or Latina, and one identified as Haitian-American. All of us identified our sexual orientation as heterosexual/straight. All members of the team were HIV-negative. Some team members had previous experiences with people who were HIV-positive. As I discussed earlier, I worked as a psychotherapy intern at the Whitman-Walker Clinic for two years; I have

continued to work as a therapist to HIV-positive individuals since then. Regarding the other team members' professional or educational experiences, two team members traveled to Kenya on an educational trip to learn about individuals with HIV/AIDS during their membership on the research team; two team members volunteered at a local HIV/AIDS organization and had been heavily involved there during the course of their college careers, and an additional team member began interning at the same organization during her course of participation in the current study. In addition, two team members identified personal experiences that affected their outlook on HIV/AIDS: one had two uncles who were HIV-positive, one of whom died as a consequence of substance abuse; and the other had been tested for HIV herself and found the experience scary, which she reported helped her relate to the participants' experiences.

The team members held a discussion regarding our personal biases related to the research project. One common theme was that team members' own race/ethnicity and/or experience (or lack thereof) related to HIV/AIDS contributed in unique ways to each of us feeling very responsible to take action in the fight against HIV/AIDS, and in particular, to tell our participants' stories as accurately as we could. We discussed our experiences of feeling similar or different from the participants, and how those feelings affected us. Ultimately, we agreed as a team that it felt beneficial to have worked with team members who each were "insiders" in some ways and "outsiders" in others, as related to the research topic and participants.

### *Transcription*

All audiotaping was successful and no data were lost, with the exception of a small amount of inaudible content from some interviews (i.e., transcribers' inability to

understand a statement or partial statement from an audiotaped interview). Members of the research team transcribed the audiotaped interviews. After each tape was transcribed, I checked each transcript by reading it along with the audiotape to check for and correct any errors.

### *Data Analysis*

All research questions were addressed through grounded theory analysis of interview data. Data were analyzed by our eight-member research team. Data analysis also was overseen by the chair of the dissertation committee, the primary researcher's advisor. In its essence, the process of grounded theory is about constant comparison (Corbin & Strauss, 1990)—comparison of concepts to other concepts, concepts to categories, categories to other categories, participants to other participants, and points in time to other points in time (Charmaz, 2000). The first level of data to be understood and compared is the conceptual level. In grounded theory, concepts are the basic unit of analysis (Corbin & Strauss). Line-by-line coding sharpens attention to such concepts, which facilitate comparisons, which informs the overall theory. Instead of confining data to preconceived standardized codes, the researchers' interpretation of the data shapes emergent codes (Charmaz).

Grounded theory has been criticized for “fracturing the data”—that is, critics assert that the separation of data (such as transcripts) into codes and categories might limit understanding by obscuring the participants' experience in its fullness (e.g., Conrad, as cited in Charmaz, 2000). Although Charmaz asserted that it is possible not to “lose the forest for the trees” even through line-by-line coding, my personal experience with grounded theory had taught me that breaking up data into very minute pieces could

obscure the context of the participants' statements. Thus, with a desire to preserve the constructivist goal of understanding participants' lived experiences, I explained my concerns to the research team, and we decided to code slightly larger chunks of data than is described as preferable by Charmaz. The goal was that once the data were sorted by code number and were no longer visible in the context of an entire transcript, the context could still be fairly easily understood. We preserved the complexity of the data by frequently coding sections of the transcripts with more than one concept label.

At our initial research team meeting, we created a provisional code list (see Appendix F) by reviewing one transcript and labeling each small section of the transcript (i.e., one thought or point discussed by the participant) with a concept (e.g., "realization regarding diagnosis"). Between meetings, team members coded three additional transcripts (two members to each transcript), using the provisional code list and noting concepts that were missing or problematic. At the following meeting, we discussed members' findings and amended the code list, resulting in a second working list (see Appendix G). Between meetings, team members coded three additional transcripts, and at the following meeting, the list was amended further. At that point, relatively few changes were made. We decided that the code list was relatively final and that we would code all previously coded and uncoded transcripts using the updated list (i.e., transcripts that already had been provisionally coded were recoded with the new list; see Appendix H). Using the "final" list (I place the term final in quotes because while we considered it complete for the time being, we were always open to amending if necessary), all transcripts were coded independently by two team members each. Transcripts were then each checked in pairs by the two people who had coded them. The pairs came to



consensus on their coding and/or presented problems to the team for final decision-making. It should be noted that it was permissible to apply as many codes as were applicable to each block of text. Throughout that process, our code list remained unchanged, suggesting that we had saturated the concepts (i.e., the addition of the previously uncoded transcripts did not result in the addition of further concepts to the code list).

In addition to relying on concepts as the basic units of analysis, grounded theory relies on the construction of categories (Corbin & Strauss, 1990). This allows researchers to compare concepts to one another, to compare concepts to categories, and to compare categories to one another. After all of our transcripts were coded and the code list was complete, we created a provisional list of categories by identifying and naming higher-order, more abstract concepts and listing which codes/concepts were related to which categories (Strauss & Corbin, 1990). It was permissible for concepts to be related to more than one category. We amended the list several times, changing the names of the categories as well as the concepts they encompassed, based on further analysis of the concepts and how they related to one another and to the categories.

Further analysis of the data and the comparisons explained above were accomplished through a process of propertizing and dimensionalizing outlined by Strauss and Corbin (1990). Properties are characteristics of categories, and dimensions are the possible locations of properties along continua. For example, properties of color might include shade, intensity and brightness. Shade might be dimensionalized as varying from dark to light, intensity might vary from weak to intense, and brightness might vary from dark to light. In addition to simply creating properties and dimensions of each category,

we identified where each participant was located across each dimension. Charmaz (2000) criticized such processes as being potentially too formulaic. However, it was helpful to utilize a process that provided guidelines for examining the characteristics of our categories, particularly because all members of the research team except for me were new to qualitative research. At the same time, we tried to remain constructivist by not relying exclusively on traditional dimensions as outlined by Strauss and Corbin. I encouraged team members to describe categories in any way that was helpful, and as a result, we occasionally described or depicted characteristics of the categories in ways other than dimensions (e.g., lists or graphs).

To organize the data from a logistic standpoint, we created a database that allowed us to list each concept along with its transcript number and code numbers. In order to sort the data, we listed each block of text as many times as it was coded—for example, if Text #1 were given three codes—say 6, 12, and 32—then the text appeared first in Row #1 with Code #6, then in Row #2 with Code #12, and finally in Row #3 with Code #32. This allowed us to sort the data by code number and still be able to see each block of text that was coded with each number. Since blocks of text were repeated in the database, they were also given what we called a “blurb” number, so that the database also could essentially be sorted back into the order of the actual transcripts. This enhanced our ability to gain more context for any concept we read (i.e., if I did not understand the meaning of a concept by itself, I could sort the database by “blurb” number in order to see it in the context of its own transcript rather than in a list of other concepts that shared its code number).

Thus, members of the research team created properties and dimensions of categories by sorting the database by code numbers and reading the content of all code numbers that fell into the category in question. The goal was to identify characteristics of the category that appeared across the codes that it encompassed, though in some cases, characteristics were found primarily within one code. We first practiced identifying properties and dimensions together as a team. Then each member of the team claimed responsibility for one or more categories and completed the process for “their” categories. This allowed us to develop in-depth knowledge of the categories that we were responsible for; thus, each category was very well understood by at least one member of the team. (Please see Appendix I for a working draft of our category list, including who was responsible for each category.)

Throughout the next several meetings, we presented our work to one another, including thoughts and written statements regarding themes within the categories. We continued to amend category titles and content as we engaged in the process of constantly comparing our broader, more thematic work to our raw transcript data. Once our properties and dimensions were complete, we engaged in another comparison (sometimes viewed as a form of auditing), in which we checked one another’s work and again compared our broader, more thematic work to our raw data. We returned to original transcripts and checked that participants were properly placed along the dimensions we had created. If participants were placed incorrectly, we edited their placements; we conducted the process during meeting time so we could consult with one another in our decision-making. If participants had not been placed at all along a dimension, we added them when we had enough data from their transcripts to do so.

Once our analysis was complete, we turned to discussion about the overall themes that existed within the raw data and the products of our analyses (i.e., the categories, properties, and dimensions). We agreed upon what we thought was the primary point of participants' interviews. As another form of auditing, half of our team created a working theoretical model that encompassed the constructs that had emerged as a result of our analyses, and we presented it to the other half of the team for review. During the team's final review and discussion, and even during the early stages of the writing process, we continued to refine the model, categories, properties, and dimensions. During the writing process, I constantly returned to the raw data, which continued to direct our final product. Sometimes my conceptualization of the theory guided my search for quotations, and at other times, the quotations continued to guide the theory. Even during that final stage, I continued to use the team in an auditing role, consulting with them to come to consensus about the results. Ultimately, we arrived at a complete and final list of categories and their properties and dimensions (see Appendix J), as well as an emergent theory (described in the next chapter).

## Chapter 4

### Results

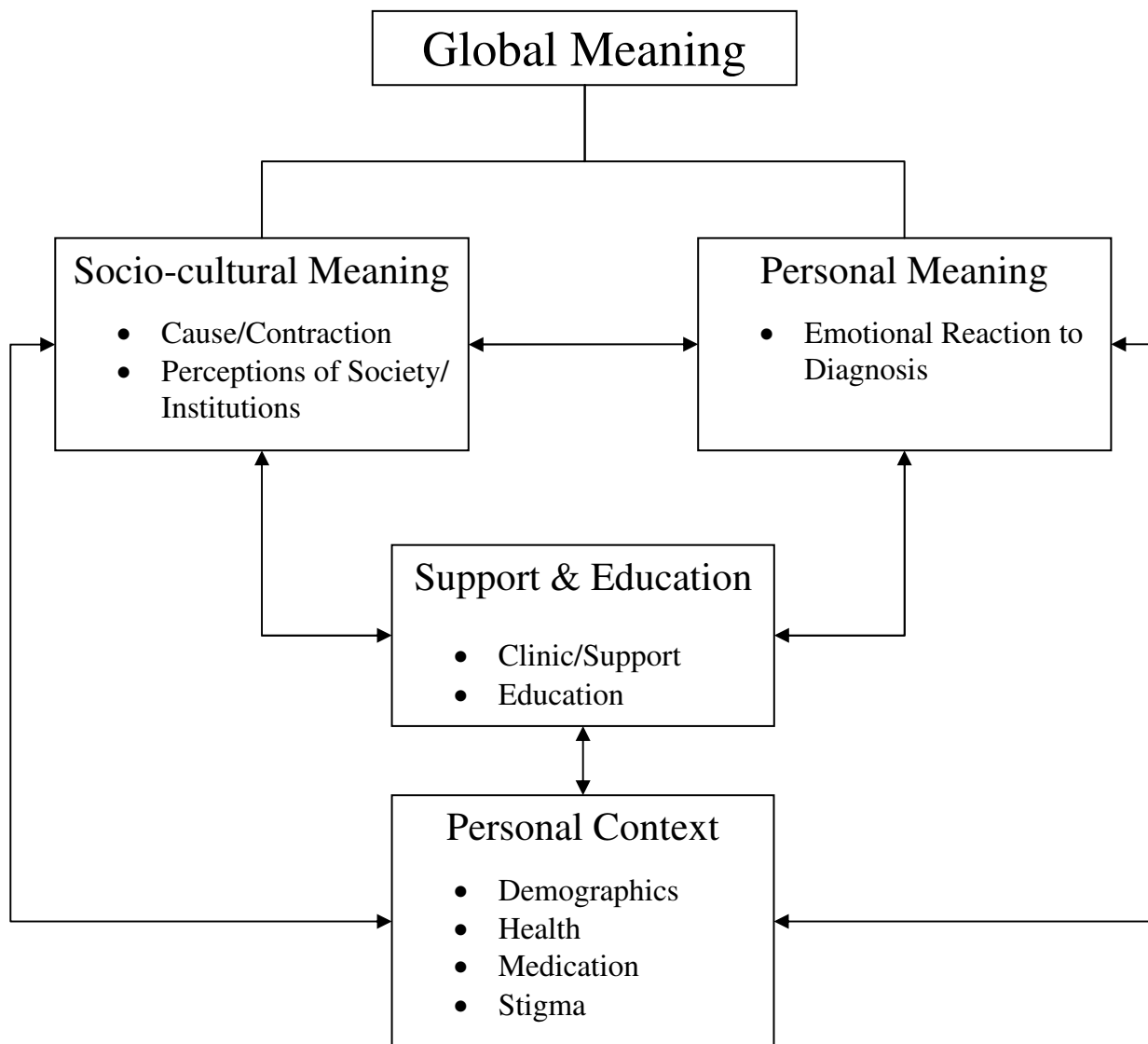
The purpose of the current study was to articulate a theory reflecting the intersection between African Americans' beliefs about HIV/AIDS and their experiences in living with HIV/AIDS. As detailed in Chapter 3, the process began with interviews of African American people who are living with HIV/AIDS. The interviews were transcribed and coded by concept. Analysis, discussion, and auditing by me and the members of my research team resulted in an emergent theory.

#### *Overview of the Emergent Theory*

The emergent, grounded theory, represented in Figure 1, reflects how our African American, HIV-positive participants constructed meanings of HIV/AIDS for themselves. The theory reflects that our participants found overall meaning by making sense of HIV/AIDS personally, making sense of HIV/AIDS socio-culturally, and integrating both forms of meaning. Such meaning relates directly and indirectly to their experiences (or lack thereof) of education and support, and to their personal contexts. Each component of the model interacts with the others in a bi-directional way, reflecting that all components are capable of affecting one another. As such, individuals' personal context, experiences of support and education, socio-cultural understanding of HIV/AIDS, and personal understanding of HIV/AIDS all relate to the overall meaning that they create for themselves with regard to HIV/AIDS.

*Personal context.* Personal context takes into account individuals' personal demographics (e.g., gender, sexual orientation, religious affiliation), physical and mental health, experiences and reactions to medication, and experiences and perceptions of

Figure 1. Making Sense of HIV.



stigma. Physical and mental health includes HIV and AIDS status, other medical diagnoses, experiences of symptoms and illness, history of substance abuse, and other mental health diagnoses and concerns. Experiences with medication include number of medications taken, side effects, and adherence. Stigma includes ease of disclosing HIV status, perceptions of stigma experienced by others, and perceptions of stigma experienced personally.

*Support and education.* This piece of the model reflects the level and type of support and education received, including structural and program support, personal support, and lack thereof. Also reflected is individuals' involvement in educating others. Specifically, support includes clinic-related experiences, such as attitudes regarding Whitman-Walker Clinic generally, length of time at the clinic, reactions/perceptions of other clients, and responses to the gay community. Support also includes the perceived role of doctors, reliance on or trust in doctors, who may or may not be affiliated with the clinic, as well as other sources of support unrelated to the clinic or to medical care (e.g., friends, family). Education includes sources of education received and what sources are believed, the role of education in coping, beliefs about what education is needed by others or at large, and involvement in educating others.

*Socio-cultural meaning.* Socio-cultural meaning includes individuals' perceptions about the cause or origin of HIV, and perceptions about institutions' and/or society's role in HIV (e.g., whether HIV/AIDS is prioritized, funded, or ignored). Perceptions about the cause or origin of HIV include whether theories have been heard or believed that are other than scientific, and what those theories are. Perceptions of institutions and society

at large include perceptions of the government, religious institutions, and medical institutions (particularly pharmaceutical companies), and society in general.

*Personal meaning.* Personal meaning consists of individuals' emotional reaction to their HIV diagnosis and their perceptions of their own role in contracting HIV. Individuals' emotional reaction includes ways of coping, past and current reactions to diagnosis, and sense of control.

*Global meaning.* The global meaning of HIV for HIV-positive, African American individuals consists of the socio-cultural meaning they have constructed, the personal meaning they have constructed, and the interaction between the two. Each component of the model is related, implying that the global meaning is influenced not only by the socio-cultural and personal meanings that individuals create, but also by support, education, and personal context. In turn, the meaning that people create influences support, education, and personal context. The global meaning encompasses what we found to be the pinnacle or culmination of individuals' personal stories.

#### *Profile of the Participants' Stories*

What meaning have these individuals made of HIV, personally and socio-culturally? From what contexts have they emerged, and what sort of support have they experienced? In this section, I provide an overall profile of the participants by summarizing the characteristics that they displayed, using the notation discussed above.

Before I begin to discuss participants' stories, allow me to explain how I define and explicate the experiences of the participants. Charmaz (2000) recommends that stories of participants analyzed through grounded theory be explicated in narrative fashion. In order to do so clearly, I use a notation system that has been adopted by other



grounded theory authors in the past (e.g., Noonan et al., 2004; Richie et al., 1997).

Wording or phrasing such as *most*, *the majority*, *many*, *usually*, *generally*, *typically*, and *the participants* indicate responses from 9 or more of the participants. Words and phrases such as *some*, *several*, and *a number of* indicate responses from 5-8 participants. Finally, the phrase “a few” indicates responses from 4 participants or fewer. In addition, more specific wording (e.g., *all*, *half*, *three participants*) also is used.

Overall, the participants are positive, determined individuals whose stories are of perseverance through multiple barriers. Many have been diagnosed not only with HIV but with other physical disorders (e.g., Hepatitis C, diabetes), and have histories of substance abuse. Some participants have a diagnosed mental illness. Participants have experienced side effects from their medications, and some continue to experience side effects.

Initially, they reacted to their diagnoses with fear and/or a belief that they were going to die. Most had a specific memory of when they were diagnosed, including a few people who reported the exact day. Eventually participants sought out support, and received it. While personal support came from different sources (friends, family, support groups, church), most participants received some form of it. Participants also turned to the clinic, particularly to their day treatment program, for support and education. Not all participants were eager to seek out such support; some wanted to keep their HIV status a secret and feared that their affiliation with the clinic would expose them, through being seen entering or leaving the clinic, for example. Some heterosexual participants also were wary of the clinic’s gay community.

While some participants intensely feared stigmatization, especially having heard others' experiences of stigma, participants did not actually experience much stigma themselves. Participants began to regard the clinic as their primary source of information. Those who initially were uncomfortable with the gay community at the clinic came to accept it. Participants reported overwhelmingly positive attitudes about the clinic; even those who had initial problems or reservations discussed ways in which the clinic has been helpful or beneficial. Most participants received their medical care through the clinic, and doctors were discussed by many participants. Participants reported that they trusted and relied on their doctors and that their doctors were a major source of information for them. Participants developed positive views about medication, and most reported adhering to their medication always or almost always (e.g., reported having missed one dose).

Through all of their experiences, participants acquired an evolving sense of the meaning of HIV, both in their own lives and in a broader sense. Most participants identified that HIV particularly affects Blacks. They expressed concern for the government only seeking profit-enhancing action and expressed disappointment in the way government money is spent. They wish for the government to become more involved with HIV/AIDS prevention and elimination. Many have heard theories about the origins of HIV that are other than medical, but most do not believe any of them. While participants still remember when they were diagnosed, their reactions have changed. They have made meaning of HIV that casts them as active players who can live with their disease. Particularly in light of their disappointment in the government, they have seen a need to take action themselves—for example, by living life to the fullest, taking control,

keeping busy, and educating others. Overall, despite having faced disappointment and a lack of control in many ways, participants explicitly or implicitly conveyed that they are positive, determined individuals whose overall sense of HIV in their lives and in the world drives them to persist through personal and structural barriers. Perhaps most importantly, participants' understanding of HIV continues to evolve. As they continue to live with the disease, all of the components of the model continue to affect one another. Summarized one participant, "Everyday I hear something different, even today it be something totally different, it's not the same all the time about HIV."

#### *Explication of the Emergent Theory*

The following sections describe the components of the emerging theory in greater detail. I also attempt to portray, through narrative and excerpts from the interviews, how the components of the model fit together, and how "global meaning" was manifested within our participants. The next sections detail the four primary components of the theory—*Personal Context*, *Support and Education*, *Socio-cultural Meaning*, and *Personal Meaning*, the key categories that compose those components, and the overarching component of the theory, *Global Meaning*.

#### *Personal Context*

Personal context includes participants' personal demographics, physical and mental health, experiences and reactions to medication, and experiences and perceptions of stigma.

*Demographics.* As dictated by the purpose of the study, participants were African American individuals. Most of the participants were male. Most were heterosexual, though some were gay or bisexual. Most participants held a high school degree and/or

some college credits. At the time of the study, participants all received income from disability (either SSI or SSDI). Most participants had at least one child. However, most participants reported not currently being in a relationship.

Some participants discussed their relationship status being directly or indirectly related to their HIV status or their general health. Three participants discussed having made a conscious choice not to date. For example, one bisexual male participant commented, “I’m not doing anything. You don’t want to go out and hurt people, you don’t want to do that. I am not taking the chance.” Two participants chose to remain single in relation to their sobriety. For example, a heterosexual female participant stated:

Don’t want to be [in a relationship]. No, I feel like I need to—My main focus is on my health and my recovery. And from what I can see from people that are in relationships, they are totally stressed all the time. I can be miserable all by myself.

One heterosexual male participant’s wife died of AIDS six months after he was married, leaving him to raise their three children alone. Two participants who were in relationships during the time of our interviews were actually dating fellow clients. Thus, participants’ relationship status clearly was related to their HIV status, at least for some. One participant summarized the fact the two can be related, though people might feel differently about how:

You know, we talk about relationships. And everybody here talks about, I hear somebody say I rather be in a relationship with somebody that’s not HIV and very vividly I always will oppose, but that is just what they felt. But for any reason for the type that I am and type of person, if I start a relationship I want it to be with someone that’s HIV because that way it breaks down the wall, the pain, and all that, to be deceptive or to be deceived, so you know it tears down, tears down all that. So that way you can be open, and that way, you know, two people that’s at the same bridge will help each other across.

A similar pattern was found regarding participants' religious affiliations—that is, some participants reported their personal religious experiences as either hurtful/damaging or helpful/supportive with regard to their HIV status. Some of the participants were Baptist, a few did not identify with a particular religion, and one participant each was Catholic, Christian, Lutheran, or spiritual. Only one participant talked about his personal experience with religious institutions being on the hurtful side. He stated that he did not identify with a particular religion or spirituality, that “I used to, but I’ve lost it I guess, over the last few recent years. I used to be a Seventh Day Adventist, but I found my church to be growing prejudiced instead of growing broad-minded so I got very disappointed and left.” He was actually the only participant to report having felt personally rejected by his religion or church. While many participants had overall negative views of religious institutions, which I discuss as part of the *Socio-cultural Meaning* part of the model, other participants who discussed their own religions reported them to be personally accepting, and for some, a source of support. (One can begin to see how the parts of the model overlap and influence one another; religion as a source of support is discussed further as part of the *Support and Education* portion of the theoretical model.) While views and experiences related to religion are further discussed elsewhere, the current examples highlight how individuals' personal demographics—relationship status, religion, and more—interact with the other parts of the theoretical model.

*Physical and mental health.* In keeping with the purpose of the study, all participants were HIV-positive. The date of participants' HIV diagnoses encompassed about a 20-year time span, from the mid-1980s to 2002. However, most participants were

diagnosed during the latter of those two decades, from 1992 to 2002. Eight of the participants also had been diagnosed with AIDS. Of the participants who were diagnosed with AIDS, a few were diagnosed with both HIV and AIDS at the same time. Only a few participants discussed how they contracted HIV, or how they were diagnosed. A few participants noted similar patterns of first noticing that they were sick or had physical symptoms, then seeking treatment, which eventually led to HIV testing and diagnosis.

Some participants discussed physical symptoms either related or unrelated to their HIV status. Six participants discussed the physical symptoms or illness they experienced in direct relation to their HIV status. Most participants also mentioned having been diagnosed with other illnesses or conditions in addition to HIV. These included diabetes, Hepatitis C, high blood pressure, hypertension, joint disease/arthritis, kidney problems, and stroke. One participant explained her experience with both HIV symptoms and other health-related issues:

I know people who have had HIV for six or seven years who have never been ill. They never had pneumonia. I've had three types of pneumonia. I was in the hospital for months. I been plump all my life. The smallest I ever been in my life was a size 18. When I got sick I was wearing 11 or 12, I never been that small in my life. None of my friends knew who I was. You know, so when they see me now they say, 'You look good. You look good as hell, girl! You know, real good!' Because I was so sick, I couldn't even walk. So it was really tough for me. I think the hardest part that I have now is that I'm a diabetic. Cause I take insulin four times a day.

In addition to physical health issues, participants discussed mental health issues. Most participants were former substance abusers and were in recovery. Drugs of choice included alcohol, cocaine, and heroin; a few participants indicated that they used drugs but did not specify their drug of choice. Similar to other facets of participants' personal context, a few participants' substance use related directly to their HIV status. At least one

participant reported using drugs as a way to cope with finding out about his HIV diagnosis, while at least one other participant discussed her recovery being a direct result of having been diagnosed: “When I got out of college, I started using cocaine...But when I found out I had HIV, I stopped because I didn’t want to die. I didn’t need no program, I just stopped.” The same participant also stated, “I’d love to get high. But then I’d die.”

Participants discussed other mental health issues in addition to substance use and recovery. Some participants reported having been diagnosed with a mental illness; these included bipolar depression, unipolar depression, anxiety, and schizophrenia. A few participants also discussed feeling under stress, a topic that is further discussed as part of one’s emotional reaction to diagnosis, in the *Personal Meaning* section of the theoretical model.

*Medication.* Participants not only experienced symptoms related to their physical and mental health diagnoses, but also experienced symptoms in relation to their HIV medications. Most of the participants experienced side effects from their medications in the past, and about half of the participants were experiencing side effects during the time of their interviews. Most participants reported that they were taking three medications. A few participants were taking the new one-a-day medication, and there was a lot of talk about that at the clinic when I visited. Most of the participants believed their medications to be important and beneficial and adhered to them always or almost always. A few participants reported that they had missed one dose, and one participant stated that he is adherent “95% of the time.” The voices of the participants convey their medication-related thoughts and behaviors the best:

At first, I was too sick, too weak, to even think about it, I think I missed some. If it wasn’t for my sister, I don’t think I would have taken my medication, but I had

a sister that pushed me, said, “You got to take this before leaving.” And I was saying if I got sick one more time—I had the PCP pneumonia, went into the hospital... And they kept me in the hospital for about three weeks. I mean, they made me take my—I hated medicine. I didn’t like medicine before I got my HIV. I didn’t like Tylenol, aspirin, or none of that stuff. So the doctor started feeding it through my veins with the medication and two weeks, I was feeling alright. They took blood from me to see how my CD count was doing. I just got tired of hospitals, I said, “I’m not coming back here.” So, when I went home, didn’t nobody have to tell me to take my medicine or nothing. I did that all myself. And from then on, I’ve been doing okay.

Sometimes I get that feeling, that everyday I was going there, I was going there like every day in the beginning—my therapy—I would go every day, I mean, I had to take my medicine in front of the doctor or whatever at the clinic everyday. I was tired. But I kept going, because I knew these people were trying to help me... I am just amazed they have these different types of medicine now that we can take, one time there wasn’t... Things are getting a little better, you know?

One participant summed up his opinion succinctly: “Well, if you don’t take the treatments, and take the stuff, you’re going to die. Yeah. You might hang on for awhile, but you’re going to die.”

In contrast, a few participants were wary of certain medications or regimens. One participant was actually worried about stopping her medication. She stated:

Actually, they wanted me to take a year drug holiday, and I refused. My medicine making me sick now, what is it going to do in a year. So I said no, I don’t think so. Not going to experiment on me. Mm-mm. So I refused that... My CD4 count... well, it’s very good, and to take the drug holiday would determine to them, you know, if I really, really need the medication. But I don’t want them to experiment on me with that. You’re not going to experiment on me with medication. When I came my CD4 count was 2. So from 2 to 1,035 within four years is excellent. But you’re not going to experiment on me and get it back down.

For the most part, however, participants had largely positive views about their medications, despite having experienced side effects. Such views are very connected with the other components of the model, particularly support and education, and are discussed further in that section.



*Stigma.* Another construct that provides context regarding participants' personal experiences and how they approach and think about HIV is that of stigma. Some participants discussed stigma that they had feared or heard about from others, as well as stigma (or lack thereof) that they had experienced themselves. In addition, most participants discussed what it was like to disclose their HIV status to others.

A few participants talked about stigma that they heard others talk about or expected, such as that people would not sit next to them on the bus, that people would assume they were gay, that they might be given special plates and utensils that would be cleaned with bleach, and that they would not be accepted. The following excerpts highlight such beliefs.

I heard it from people I know, you know, if you contact it, automatically they would think that you had sex with somebody of the same sex.

When I first came here, I wouldn't sit outside, because I didn't want anybody to know, if they see Whitman Walker, they know I have the virus, you know, or that it's a lot of gay people, and all those types of things, you know, but then after being here, it's a situation where, you know, gay people, everybody, people that weren't gay, uh, you know, I mean, just that everybody was getting it, and people got it in so many different types of ways, not necessarily through sex, that it didn't discriminate.

I wouldn't even go sit in the front, you know, for a long time, you know. It took me awhile to go out there, and I found that to be true of a lot of other people that first came...I wouldn't go out there—it says Whitman-Walker up there, I knew people knew Whitman-Walker. I called it the AIDS clinic, you know. So, you know, I wouldn't go out there. The air conditioning could be off, and everything else, and it could be 100 [degrees], and the breeze could be blowing out there, I wouldn't go sit out there, I'd sit there and sweat. (laughter)

Clearly, a few participants were concerned about how they would be viewed. Some participants discussed how they actually were treated; a few felt accepted, while one did feel stigmatized. The person who experienced stigma explained that it was difficult to find people to live with (i.e., to share housing). One participant reported that people think

she's lying when she tells them that she has HIV because she looks good and does not fit a stereotype. The others each reported that they felt accepted at church, that family didn't treat them differently, and that they have been treated "fine," respectively. The following excerpt summarizes one participant's experience in moving from fear of stigma to the reality of how people treated her.

I had to get past the—I guess, getting past, you know, things about how people were going to accept me when they found out, because I had heard when I was first diagnosed, you know I started coming here and listened to people talk about—this is before I disclosed my status to my family—And I heard people talking about how their families kind of disowned them, and how they set them apart, they, if they came to the house, they would have to eat out of paper plates and plastic forks and knives and so forth, and just that kind of stuff, and if they sat on something, they'd walk behind them, wiping it down with some kind of sanitary or bleach, you know, just the whole thing, so in the beginning, you know, before, I think I told my family, I called them and I wrote them and told—well, I think it was about a year later before I went home, and actually was around them, and you know, they didn't treat me any different.

As the above excerpt suggests, participants also think about how, when, and whether to disclose their HIV status to others. Such disclosure (or lack thereof) may take place in a personal relationship, as mentioned by the participant discussed earlier who preferred the idea of entering a relationship with another HIV-positive person, or in a more public relationship, such as disclosing to students or strangers in order to educate them about the disease (which also is discussed further in *Education and Support*). Most participants talked about the relative ease or difficulty of disclosing their status. Those who discussed their feelings from the past mentioned fear and avoidance (similar to the excerpts directly above), while the few who discussed their current feelings conveyed that they are open and find it easy to disclose, or at least preferable to hiding it:

You know, so I've been through enough to share shit with people. So when I think about it, you know, people say, "Well how easy is it for you to disclose your

status?” and I say, “It’s very easy for me!” Because when I tell people I have it, then I break the stigma of what they used to say about it.

As far as society and stuff, I used to be afraid of being accepted and stuff like that. But for me, it’s much more stressful to try and hide it or deny it—well, I won’t say deny it, but suppress it or anything than it is to let people know what you choose to let them know about you, what you choose to let them know about your prognosis and everything. After I put it out there, that’s on them. Once I have accepted it, I’m okay.

One participant summarized the issue of stigma as related to HIV/AIDS succinctly:

A lot of people have a lot of like really rough, tough diseases, that they don’t bear prejudice and stigma about it, you know, but people with AIDS do, and that only hurts, that doesn’t help them fight AIDS.

### *Support and Education*

This portion of the model reflects the level, type, and sources of support and education received, including structural and program support, personal support, and lack thereof. Also reflected is individuals’ involvement in educating others.

*Clinic/Support.* Participants’ experiences at Whitman-Walker Clinic and the concept of support were grouped together because so many participants described the clinic as a primary source of support. More broadly, this category was grouped in the theoretical model with the category Education, because participants discussed education as a form of support.

Most participants acknowledged receiving support from one or more sources. A few participants each cited family, friends, the workplace, and church or retreats as sources of support. A few participants also mentioned staff at the Austin Center or the clinic as a whole as sources of support. Additionally, some participants utilized support groups, both outside the clinic (e.g., Alcoholics Anonymous) and within the clinic. A few

participants also received structural support from the clinic, such as housing or financial assistance.

Participants' length of time affiliated with the clinic ranged across a continuum from just a few months to over 11 years, and was spread relatively evenly across that time span. They had heard about the clinic from a host of sources, including case managers or other professionals, friends, group homes, shelters, hospitals, nursing homes, and advertisement; such sources were the origin of information about the clinic for a few people each. One participant described finding out about the clinic from her sister:

Actually, it was my baby sister...When I first found out that I had AIDS, my baby sister lives in Oklahoma, and she searched through the clinic with me to go to. And she got in contact with Whitman-Walker. And two days later I got me a case manager. And my case manager asked if I wanted to do something, because I was very depressed. And she asked me did I want to learn more about my disease...and I said yes. And I've been here [at the Austin Center] ever since.

In addition to the Austin Center, the day treatment program from which participants were recruited, most of the participants also utilized Whitman-Walker's medical, case management, dental, and food bank services. In addition, some had utilized the pharmacy and legal services, and a few had received individual psychotherapy.

A few participants were initially hesitant about the gay community at the clinic. One person said that she was initially "weirded out" and another mentioned that he was uneducated. Another had this to say:

Uh, my expectations, first I was afraid, you know, I mean, that what I heard about it was for gay and lesbians...or what I thought on what would be conceived if somebody saw me coming out of here, the clinic, if they would have thought I was gay or in a gay relationship. Then after awhile, after coming to the Austin Center and being around gays, lesbians, straights, you know what I mean, it's a well-rounded group of all individuals, of all different walks of life. I began to relax, and you know, began to be unafraid to ask questions, you know, listen more, and that's it.

Participants' overall attitudes about the clinic were overwhelmingly positive. In fact, only two participants had anything negative to say, and both of their critiques were based more on the past than on the present. One participant, who had been at the clinic for three years, had this to say:

When I first went over there it was chaotic, you know, some of the doctors didn't show up, some of the nurses didn't show up for work - I forget which ones, so that was putting a lot of strain on everybody else. I was over there to see a case manager to get time with them but that's when I noticed, I noticed clients that say, "I'm around here to see Doctor so-and-so" and Doctor so-and-so is not here so Doctor so-and-so's going to see you but Doctor so-and-so got a full load themselves so, but now when I go over there, you know, I'm not sitting out, waiting that long and, you know, once I see my doctor, I'm seeing him for like maybe 15 to 20 minutes, not unless he go see something on the test or if I'm in there if maybe there's something going on with me, but he's about 15-20 minutes at the most.

The only other participant who had anything negative to say about the clinic was a heterosexual female participant who reported initially not liking the clinic because of the predominance of people who were male and/or gay:

I didn't like the clinic because it was mostly males here. There were a couple of females here but they were much older than I. So I went through a lot when I first got here; being very young and I was...I didn't get along with a lot of people here because I was too blunt. So I had a hard time fitting in.

She reported that while she initially had a difficult time fitting in, "after fighting, I worked things out."

Participants' positive reviews of the clinic included that the clinic is helpful, enjoyable, a model of teaching, a good source of learning, well-rounded, and safe. Additionally, some participants reported that the group meetings are helpful, that the employees and doctors are helpful, and that the people in general are friendly and wonderful. One participant reported that he enjoys the activities, such as traveling, cooking, and socializing. Several participants discussed the positive influence of other

clients. For example: “Coming here and finding out that a lot people had the same problems—everybody had the same problems that I had, I was able to begin to deal with it.” Additionally, one participant reported that the clinic has restored his faith in “mankind” (sic). Said one participant, “They should have more programs like this, I love it!” Some participants were very specific about referring to the clinic as a source of support:

Because one time we didn't have all this clinics and stuff you hardly have somewhere you can go and then people had problems with insurance, getting insurance and help. There wasn't that many clinics around. For people, it still—a lot of people probably still don't know today where to go. But I think Whitman-Walker is great. As far as I am concerned, for me. You know what I'm saying? Because I came in on a lot of good support people there. Oh my goodness, I'm never going to forget them. One after another, like teamwork. I didn't have any problems with getting HIV support at all.

Most participants, many of whom received their medical care through the clinic, also discussed the role of doctors. Two participants discussed a lack of support from doctors in the past; one participant felt that in the past, doctors ignored the epidemic and didn't try to help people, and the other participant had a negative experience with his first doctor:

Now the first doctor that I had...I didn't get along with, you know, because he had some backwards views about people living with HIV dating and having sex and all that so yeah, you know, I was glad when he left. Every doctor after that has been wonderful, so my trust level has really—is very, very high.

Similar to that participant, some others discussed having a great deal of trust in their doctors. One participant noted that she does everything her doctor says and that “you have to trust in your doctor or you'll die.” One participant discussed how he tests doctors to find out whether they are supportive:

Sometimes I will ask a dumb question just for—just to see what they would do. And when he said, “Who's supposed to be stupid, me or you?”—And that day I

respected him. You know what I mean? You got to throw some old hook, lines, and sinkers out there to see who, if these care providers, if they have your best intentions at heart... You know, test, they ain't feeling you, leave them alone until you find the right one then, until you feel comfortable. And it's true; you must feel comfortable talking to whoever your health care provider is.

Some other participants also mentioned looking to doctors for decision-making, and believing that doctors are trying to help. Most participants also mentioned that their doctors are their main source of information, which is discussed in the following section.

*Education.* This category encompassed participants' sources of education, the effects of education (e.g., helps with coping), and beliefs and behaviors regarding education of others. As I mentioned above, most participants cited their doctor as their primary source of education. For example, "Up until I had [the clinic] I didn't have a real close working relationship with a doctor. But now that I do, I learn a lot of stuff through her." Additionally, two participants mentioned not only using their doctors as a source of information, but verifying other sources of information with their doctors. One participant explained, "[I] ask my primary care attendant, or I don't just ask one person. I ask my primary care attendant and I ask the doctors here at the Austin Center. If they all say the same thing then I believe it."

In addition to doctors, participants reported turning to a number of other sources for information about HIV/AIDS. Nine participants mentioned that they utilize the clinic in general as a resource, eight said that they watch television or videos, six read newspapers, five read magazines on the topic (e.g., *POZ*), five attended groups, four searched the Internet, three read books or other literature, three turned to the CDC or the National Institutes of Health (NIH), two attended seminars, and one listened to the radio. The following are excerpts about sources of information in participants' own words:

Well, I'm like this here, if, you know, I was, if I read it or hear it from somebody somewhere I would go to like on the Internet, to the CDC, or places like that, you know, and see if what was said was true or not. You know, email somebody at the CDC and ask them, "Well, I heard this and this and what's this and this? Email me back or mail me the information." So that's what I do, I don't believe in, you know, I do investigation, that's what I wanted to say, before I believe or disbelieve something.

We have seminars where I'm staying; I'm in a group home right now. We do seminars. And I heard on the radio. And then Whitman-Walker. They have pamphlets over there, that you can pick up and take home with you. Actually, most everywhere got pamphlets; clinics and stuff have pamphlets that you can take home. And groups, support groups, and AA groups. All those places have stuff, but it's up to you to pick them up and read them. They don't cost you nothing.

An additional, specific source of information that about half of the participants mentioned was other people (i.e., laypeople). Six participants reported not believing information that they received from other people, while only two participants mentioned believing what others told them about HIV/AIDS. One person noted, "I'm not sure who it is I *don't* believe...I think I could basically disbelieve the average person on the street right off the bat." Two participants mentioned the term "ear hustling," which they explained meant listening to or overhearing others' conversations—for example, "if I'm on the bus and some people talking." Both of those participants mentioned disbelieving what they heard from others, and sometimes noticing erroneous information being passed on. One participant went so far as to correct it:

Anytime another person that's HIV-positive that's not fully informed gives another person wrong information I kind of say, well you know, if I see them get off [the bus], that may not be my stop, but I will get off with them. And kind of get where, "The information you probably gave this individual is wrong, it's not right, without your doctor's permission it's not right." You know, stuff like that, I try to give—hear wrong advice, and try to give right...



Clearly at least a few participants were wary of information they heard from others and even worked informally to prevent the spread of misinformation. (Formal educating of others also is discussed below.)

Perhaps more significant to the participants than where they received their education was how it affected them. Some participants explicitly mentioned that education impacted their ability to cope, and the way they viewed their disease:

The more information I have about it, the better my self-esteem is. I have very high self esteem. Everyone that knows me knows I have very high self esteem because at one time I didn't. One time I wanted to kill myself because I didn't know anything about the disease...so now the doctors are, hell, they're getting paid to do this. I mean big money. So if I can get it free, I'm going. I have an electric chair that's out front, that's parked right around the corner, somebody tell me about a group, I'm out there.

The more you educate yourself, you know, you won't fall at the wayside. If you just go to the doctor, and educate yourself, just take the medication, you don't know what the numbers mean, you don't know how much of the virus is in your system, then therefore, you're not going to...you're just...how should I say it? You're just going along with the program. But when you educate yourself...It gives you a sense of—it gives you power. It gives you a sense of power, power over the virus. Yeah, it gives you power.

Half of the participants also discussed their involvement in educating others, and the impact that it had on them. One participant stated, “You know, I try to go out and do my little part, as far as trying to share my experience and things with other people, and maybe somebody will, you know, listen.” A few participants explicitly stated that educating others made them feel good about themselves. For example:

Just being able to—helping others. Help educate others who don't know much about the virus. If they are living with the virus, helping them, if I can, to come out of their denial or their fear and everything. Mainly to help them educate themselves about the virus, so they would know more about the virus. I mean, this thing is going to be with you for the rest of your life, therefore, you know...I get a good feeling—that's not the right word—but I feel good when I can help others help themselves. You know?

It makes sense that participants were involved in educating others in light of how necessary they thought it was. In particular, six participants discussed the need for education among children or teens. Their beliefs about the need for education intersected with their beliefs about who is affected by HIV, which is located in the *Socio-cultural Meaning* part of the theoretical model. That portion of the model is outlined next.

#### *Socio-cultural Meaning*

In essence, socio-cultural meaning refers to how participants made sense of HIV within the context of broader society. Our research team found that participants had developed beliefs about the origins or cause of HIV, as well as beliefs about the roles that the government, religious institutions, medical institutions/pharmaceutical companies, and society at large play with respect to HIV/AIDS. Participants also held perceptions about who is most affected by HIV, and how that related to other concepts that are part of the theoretical model, such as education. Participants made it very evident that HIV/AIDS was not an issue that existed in isolation. Rather, participants observed and formed opinions about how HIV/AIDS came about, and how it is dealt with (or not) at a societal level.

*Cause/Contraction.* When asked about why or how people get or have HIV or AIDS, all of the participants first spoke about medical causes, and all of them displayed at least a somewhat accurate understanding of the medical causes of HIV. Most of the participants were quite accurate and thorough in discussing how HIV is contracted. The following excerpt is a typical example.

You usually get it through blood contact, contact with blood, but several ways I guess people can get it through: breast milk; injections—just about any type of needle injection, if it's not clean; unsafe sex, from a partner; and the use of

unsterile needles. That's pretty much the ways. Contact from blood, that's basically the main way of getting it.

At the same time, most of the participants also had heard about other theories regarding the cause and contraction of HIV. These theories included that HIV is a gay disease, that casual contact such as kissing or sharing a toilet seat could cause HIV, that a monkey or a plant played a role in the origin of HIV, that HIV originated from an experiment gone bad, that HIV is "man"-made (sic), and that HIV is a government conspiracy. Most of the participants acknowledged these theories as rumors:

You know, I've heard all kinds of, like, rumors, you know, at first, about where it came from, like somebody saying it was a monkey, it came from a monkey, somebody saying it was a plant, some kind of plant, some kind of experiments that went bad, so you know, I've heard a lot of different things.

Some participants verbalized disagreement with the theories:

I don't believe there is a government conspiracy. It is not a government conspiracy...Some Black Americans be saying that, and I say, look, it's a myth, it is not a government conspiracy, it's a problem of the world...The government didn't do that, that is something nature designed.

Six participants mentioned the theories about casual contact, but none believed those theories themselves. Similarly, six participants mentioned the rumor that HIV is a gay disease; none of the participants believed that rumor themselves either, though two of those participants acknowledged having believed it in the past. Each of the other theories was mentioned by a few participants each. Overall, though most participants had heard at least one of the theories, only two participants actually believed any of them. Both of these participants believed that HIV is man-made. One of those participants added that HIV is a government conspiracy. The other participant added that the cause is related to an experiment gone bad, and that the cause relates somehow to a monkey.

Don't nobody know where this disease—just all they know it was man-made... That's all I know about it. I just know it's man made.

People think it's a gay disease, but it's not. I don't think it ever has been... I think it was man-made. That's a I-statement, too... I think it was a man-made disease, but they didn't mean for it to hit home...

Participants' overall perceptions of the government and other institutions were made clear throughout their interviews and extended beyond theories heard or believed about the origins of HIV. For those perceptions, I turn to the next category.

*Perceptions of society/institutions.* This category encompassed participants' observations about how the government and society at large handles HIV/AIDS. It also included participants' perceptions about who is affected by HIV/AIDS, and why. Overall, participants readily identified that African Americans are affected by HIV/AIDS, and held negative opinions about how society deals with HIV/AIDS in general.

Most participants felt negatively about the federal government's handling of the disease. Some participants focused on the financial aspect of the issue, stating beliefs that the government only seeks profit-enhancing actions and conveying disappointment with the way the government spends money. Participants commented that government does not fund HIV/AIDS, that funding has been taken away from HIV/AIDS, that HIV programs have been closed, that money is being spent helping other countries rather than our own, and that the government is "stretching the disease out" in order to earn more money:

If it was up to me, all the government officials that pulled the money away and all that stuff, I'd impeach them, but it's not up to me. They wouldn't be in office. Sometimes I be thinking I could be a better president than the one we got now... Um, I get upset. You know, they taking away from, they taking the money away from people who really need it, you know? Although you have some people who are HIV-positive that abuse the system, but you know, policies could be set

to take care of that. But, um, just taking the money away or “We going to take this away and put it towards something else,” that makes me upset, you know.

The other primary concern voiced about the government by some participants was that the government is not involved enough in working toward HIV prevention, treatment, or cure:

It’s my opinion that if they really wanted to they could probably—no, I’m not going to say probably, I have no doubt that they could cure this thing if that’s what they really wanted to do. If that’s what they really wanted to do, they cured polio damn it, they found Saddam Hussein in a hole in the ground in his backyard. You can’t tell me they can’t fix this. This is not a priority; this is not on the top of their list...If the bigger buck was in curing it it’d be gone...The system is geared towards generating profits, you know what I’m saying?

A minority of participants believed that the government is helpful and is improving. For example, one participant stated, “I was amazed, I said, ‘This is so nice, how the government is playing a part.’ And every day there is something different, new coming for us. Even me.”

A similar pattern emerged regarding participants’ views regarding religious institutions. Six participants asserted that religious institutions ignore HIV/AIDS, and a few specified that the issue is ignored because it goes against traditional religious values. At least one participant noted that this was true primarily with regard to prevention efforts, because birth control and premarital sex are not condoned in certain religions. Again, a minority of participants held positive views—two participants noted that religious institutions can be accepting, “especially with AIDS ministries.” A few participants were careful to differentiate their opinions of religious institutions at large from their own personal experience; a few participants reported having personally been accepted by their own churches.

Some participants also discussed their views of medical institutions, and the reviews in this area were more mixed. A few participants expressed negative opinions that medical institutions are not doing all that they are able to, that HIV/AIDS is not a priority, that pharmaceutical companies are overcharging for medication, and that preventing or curing the disease could hinder profits of pharmaceutical companies. The following excerpts are examples:

Some of these pharmaceutical companies—too many people are going to lose their jobs if they come up with [a cure]...

The medication has come a long ways, the pharmaceutical companies have been getting paid a whole lot of money. And I was watching something on TV and they said the pharmaceutical companies is making a killing because it cost them like maybe two to three cents or five cents at the most to make one pill but here they charging people like hundreds, you know, because one of them, I did a calculation on my medicines for one year and it came over twelve thousand dollars and it take them like maybe two to five cents to make the pill but they charging people all that money.

They don't look for results. They look for profits.

On the other hand, a few participants reported that pharmaceutical companies are making improvements:

I think they're doing good compared to what it used to be. They got a whole lot better medicine than what they used to be. They've really been helping out a whole lot. And there's more people living today than they did years ago because they got better medicine, and people are taking their medicine now so they don't really get sick.

Thus, of the participants who volunteered their opinions about pharmaceutical companies and medical institutions more generally, the reviews were mixed.

About half of the participants offered comments about society in general, and again, their opinions varied, in this case even more widely than their views regarding medical institutions. A few participants were indifferent (e.g., "I don't care about

society”) and a few felt that people were generally ignorant toward the HIV/AIDS community. For example, “There’s still a lot of ignorance and I blame that on society. They’re not up front with it like it should be. We’re still on the back burner.” A few people fell more toward the positive end of the spectrum, stating that society was improving (e.g., “It’s better than it used to be”).

In addition to their perceptions about society in general, participants discussed their views regarding who is affected by HIV/AIDS. Most of the participants mentioned that HIV affects African Americans or Blacks; some mentioned that it affects children or teens, a few mentioned that HIV “does not discriminate” and anyone can get it, and a few mentioned that it affects people from third world countries, particularly Africa. In addition, one participant each mentioned that HIV affects the gay population, Hispanics, Haitians, and people who are poor. The following are excerpts reflecting those beliefs:

I noticed, I’ve heard, that it’s affecting African American women. Their diagnosis is on the rise, you know, and I think that comes from, you know, they have partners that been in jail and for whatever reason, whatever they do in jail, they contact them though when they come back out. They don’t tell, they don’t say nothing, and nothing like that, then go have intercourse with their wife or girlfriend and they probably won’t even think to go get checked until they get sick or something, and then they find out. Or, the boyfriend or the husband is on their dying bed and then they tell them, you know, I know stories from, I know people that have the stories both ways. The African American female diagnosis is on the rise, and also teenagers, too.

Without a doubt, it’s my understanding that the highest rate of infection right now in this town is in African American teenage girls, under 17 years old. Now I understand that to be true, and how do I feel about that? I think that sucks, really. And because that’s just a lack of information. And somebody should be able to get to these kids...I can’t imagine the effort is not being made, but obviously it’s not...Can’t you make the effort to make sure they get this information?...That’s why I understand that it’s affecting poor people, basically. And that’s more than financial, that lack of information. I mean we get information at the bottom of the food chain, too.

Overall, it is clear that participants had critical points to make about the government, religious and medical institutions, and society in general; and most identified that their own racial/ethnic group was particularly affected by HIV/AIDS. The next sections review how the participants emotionally react to and cope with their own HIV diagnosis, and how their societal and personal views overlap and affect one another.

### *Personal Meaning*

*Emotional reaction to diagnosis.* It was very clear from the results of this category that participants had gone through or were in the midst of a change process. Overall, the category reflected tremendous emotional growth that most participants had experienced from the time of their diagnosis until the present. Participants spoke explicitly about their changes, and only two participants reported that they had not experienced any change in their perception of or reaction to their diagnosis.

All participants who discussed their initial reaction to their diagnosis described it as a negative experience, primarily characterized by thoughts about death, and, for at least a few participants, by coping styles that they later identified as negative. For example:

I resorted to drugs and alcohol and for awhile, for a long period of time, I didn't talk about the virus. I felt that if I didn't talk about it, it wasn't there. But as long as I talked about it, it was there. If I didn't talk about it, it wasn't there. And it made me—It took more for me to suppress my thoughts and feelings about the virus than it did to just accept it. I was in a long denial stage.

At some point, most participants changed their views about their diagnosis and their ways of coping, and some were able to identify what contributed to their changes. The intersections of various parts of the theoretical model begin to appear with some clarity through participants' discussion of these change processes:



Not really [any changes in beliefs], only better...Better information. I'm better. I'm more well read, more laid back, I'm more cautious now, I'm more comfortable with me, you know?...it didn't come until the Austin Center, like I said being around peers like me, you know, listening to their stories and being around some peers that have passed on, and you know, it just make me stronger, and like I said, going out in the public, not being afraid about what they think or what, not being afraid about what another human being is thinking...It took time...First it started in the Austin Center, learning from my peers, talking with my peers, then it grew from there. It's grown now.

I really positioned—put myself in a position that I was going to have a real short life, automatically, that's what I thought, 'Everybody with AIDS dies, real fast and whatnot.' Through going to the different groups and whatnot, I was able to talk about these things, whereas, you know, like before that, as far as even here, when I first came here, I wouldn't sit outside, because I didn't want anybody to know, if they see Whitman-Walker, they know I have the virus, you know, or that it's a lot of gay people, and all those types of things, you know, but then after being here, it's a situation where, you know, gay people, everybody, people that weren't gay, uh, you know, I mean, just, that everybody was getting it, and people got it in so may different types of ways, not necessarily through sex, that it didn't discriminate, that the disease didn't discriminate. So I begin to say, wow, you know, it's not just, you know, a gay disease, it's not just a disease that junkies get, you know...And, uh, being able to just talk about those things, you know, made me able to cope. Then eventually I got to a point where I said—I just wanted to help myself. It didn't matter, like, where it came from. And then I, you know, I was always thinking about what people would think of me and what people would say, but then, you know, eventually I reached the point where if I wasn't sharing a needle with nobody, and I wasn't using anymore, and if I wasn't having unprotected sex, then I didn't care what they think about me. All I had to do was try to, you know, live.

As a result of their change processes, most participants reported that their current ways of coping were helpful and positive:

I'm very religious, I trust in my higher power, it brings a lot of comfort...I'm extremely spiritual.

I mean, I know I have it but I don't let it get me down to a point where I can't do nothing, I can't go nowhere and get myself involved with other people. I go out and party, I go visit peoples, I do all these things, I take my granddaughter out, it keeps me going. As long as I'm moving, and have a positive attitude about things, it don't bother me as much. It used to, but not now, not now. And I love partying.

One particular change that participants discussed was having gained a sense of control vis-à-vis the disease:

I was just sick and tired. Sick of being sick and tired, sick and tired of the drugs and alcohol and everything. Sick and tired of fighting to suppress it and everything. Just tired. So by me going to recovery, I learned to accept the fact—that helped me to grow to accepting the fact that I had the virus. And the only thing I could do now...It didn't happen overnight, it was a process in me. Accepting the fact that I had the virus, and then I had needed to submerge myself and educate myself. The more I know about the virus, the better I can control it...It gives you power...The power in knowing that I can control it. The power in knowing that I can control it.

I have the disease and I have to take control of what I have.

A few participants also acknowledged the presence of stress in their lives as a result of their diagnosis, and why positive coping is necessary:

The HIV is scary because you don't know when this medication...Everybody says that they are working on a cure, but shucks. Who knows how long it's going to take? You may be gone. They're working on it, but nobody never knows when it will come...It's something to think about, but I try not to think about it. I don't want to go into depression and stress, and that's worse than HIV, because stress can kill you.

I mean, dealing with HIV is a mental issue, whether people want to believe that or not. You have to cope with it every single day, it's no getting rid of. There's no not taking your medications every single day. There's no not worrying about getting other shit co-infected with the shit you already have. Yeah, I have mental issues. Yeah, damn skippy I do.

One specific issue that a few participants struggled with, either in the past or during the time of the interviews, was self-blame. For example, one participant stated, "My reality, I did this to myself, I messed myself up. The style of lifestyle I was into, I did it to myself. I guess I only blame to myself." The participants who mentioned such thoughts had to come to terms with such realizations. One participant reported that he used to focus on believing theories about government conspiracies and such as a way of avoiding his own role contracting the disease, but that somewhere along the way, he decided to stop caring

about the cause of the disease and focus on his own role and what he could do to take control. Such stories really capture how societal meaning and personal meaning might interact, and begin to present a picture of what type of global meaning participants might make for themselves.

### *Global Meaning*

Global meaning was not a category into which data were grouped, but rather emerged from the research team's discussions and analysis of the central theme of participants' stories. In fact, while we did not construct a "core story" as prescribed by Strauss and Corbin (1990), the grounded theory concept of searching for a core story guided our search for a potential, overarching meaning in the participants' stories that ultimately resulted in this component of the theoretical model. We concluded that participants' interviews centered on their current understanding of HIV as both a personal and a social issue—an understanding that was influenced by their personal experiences (including personal demographics as well as their experiences with medication, illness, and stigma) and by their support and education. A common meaning that was found among some of the participants was that the perception of the government's or society's inadequacy related to a sense that personal control and action was necessary. At least some participants concluded that since not enough was being done about HIV at an institutional level, coping and change had to take place at an individual or personal level. This included focusing on one's own health and well-being and taking it upon oneself to educate others, for example. Most importantly, a theme that was found among such participants was not an attitude of being "put-upon" (i.e., "The government is not doing anything, so I have to"), but rather, the attitude appeared to be one of self-empowerment

(e.g., “The government is not doing anything—*but I can.*”) The following are some examples of how social meaning and personal meaning intersected with one another and of the overall meaning that participants created for themselves about their relationship with HIV/AIDS.

I try to keep it on me, and try to concentrate on the things that I can effect, that I can do, because you know, the ball is really not in my court so I can't get twisted about what they're doing, you know... To the degree that they haven't put the sufficient amount of resources to really get at it, then you know, I hold them accountable for that. But, once again, how does that play to me? I'm just one guy, they're willing to see a Black man and that attitude, and I don't expect a whole lot from them, is what I'm telling you, you know what I'm saying? I don't expect a whole lot from them, so whatever I get is great, you know what I'm saying? As long as I get to wake up tomorrow I get another chance. So I know that as long as I don't set myself up with too high expectations, then you know, I don't come down with premeditated resentments, you know what I'm saying? 'Cause I don't expect a whole lot out of them, and as long as I'm alive I guess that's really all I've got coming, based on everything else that I see, based on my experience as being who I am and where I am.

I'll just be happy knowing that there are just little bits of things that I can influence here and there—attitudes, basically attitudes, about how people could deal with the AIDS crisis. You know, whether it's the social AIDS crisis or somebody's individual problems with AIDS. You know, I can help, help my peers as much as I can, in a personal way.

Each day, you know, it's a little better each day. And I found out that living with HIV is just another challenge really that you have to fight, you keep going and going. That's what I do, I never give up.

## Chapter 5

### Discussion

The purposes of the current study were to better understand the nature of African Americans' beliefs about HIV/AIDS, particularly as they related to the government and other social institutions, and to gain an understanding of how such beliefs related to the experience of living with HIV/AIDS. Grounded theory analysis resulted in the construction of an emergent theoretical model. The theoretical model and its components enabled me to answer the research questions that were originally posed in the current study.

First, the current study explored what HIV-positive African Americans believe about HIV/AIDS. All of the participants reported that HIV is caused by activities that involve the transmission of blood between individuals (e.g., unsafe sex, needle-sharing). Two participants also reported that HIV is man-made, with one connecting it to an experiment gone bad, and the other connecting it to a monkey (she was unsure about the monkey and how it related to HIV being man-made). Given how prevalent such beliefs were shown to be in previous literature, it is interesting that only a few participants who were interviewed for the current study endorsed such beliefs. Our research team discussed the possibility that more HIV-positive African Americans may hold such beliefs and those individuals may have avoided seeking treatment for their HIV, possibly in relation to their beliefs. It is important to remember that I recruited participants from a clinical population, and as such, they may hold different beliefs from individuals who are not in treatment.

The current study also investigated what HIV-positive African Americans do *not* believe. Most participants had heard and did not believe rumors about causes of HIV (either in terms of its origin or its transmission) that were not scientifically supported. For the most part, participants who had heard that HIV was a gay disease, that casual contact such as kissing or sharing a toilet seat could cause HIV, that a monkey or a plant played a role in the origin of HIV, that HIV originated from an experiment gone bad, that HIV is man-made, or that HIV is government conspiracy, did not believe such assertions. With the exception of one participant who very clearly stated that he used to have such beliefs and no longer does, it was difficult to tell from participants' interview statements whether they had always disbelieved such rumors or whether they had undergone a change. (I did ask about changes in beliefs as part of the interview protocol, but many participants spoke about changes in beliefs more generally, e.g., changes from believing that HIV meant a death sentence to believing that HIV could be lived with.) The one participant who identified a change in beliefs explained his former belief in the rumors as attempts to externalize blame and avoid taking responsibility for his actions; once he dismissed the rumors, he focused on taking personal control.

One clear finding was that while participants did not necessarily believe that the government was actually responsible for causing HIV, they did believe that the government was not responding adequately to HIV/AIDS. Most participants felt that the government ignored the issue, largely by not funding treatment and education. It may be that the political climate of the time influenced participants' beliefs. A few participants discussed government neglect of HIV/AIDS being related to the Bush administration and/or to the war (e.g., government money is currently being spent primarily on the war).

It is a fact that during Bush's presidency, HIV/AIDS funding such as the Ryan White Care Act has not been increased enough to keep pace with inflation. Locally, about one year before I interviewed the participants, one of Whitman-Walker's suburban clinics closed because of financial limitations. Although none of the participants mentioned that event explicitly, at least a few of them were aware of that event, and may have been aware of others like it. On a national level, a recent report (Open Society Institute, 2006) stated that the United States is failing its own citizens in the response to the epidemic at home, that the federal government has become even less responsive over time, and that

...the country has failed to come to grips with an interwoven set of social factors—including economic inequality, racial and gender disparities, racial discrimination, and homophobia—that create vulnerabilities to HIV infection and lead to poorer outcomes from health care services. (p. 24)

The participants live these issues every day and readily recognize them. In other words, participants' evaluations of the government are astute and appear to be factually based on current policy and funding news.

Another research question investigated what HIV-positive African Americans believe about the role of medications and health care institutions. Most participants reported strict adherence to their medications and a general belief that adherence is not only beneficial, but necessary. This was somewhat surprising, given the complexity of HIV medication regimens and the difficulty of adhering strictly to them. Of course, it is possible that participants' self-reports were at least somewhat affected by social desirability; participants are likely aware that the socially desirable answer to practitioners or other staff (of which I could be considered one) regarding medications is that they are adherent. However, participants' discussion of what they learned about medication, particularly from Whitman-Walker Clinic, suggests that they have

internalized the belief that medication is important, even if their adherence is not as high as their self reports indicate. For example, at least a few participants noted that they observed in themselves or others that health status improves when medications are taken or worsens when they are ignored. In addition, participants reported a strong degree of trust in their doctors, which likely is related to their positive attitudes and behaviors regarding medications.

Regarding medical institutions, the response from participants was more mixed. Several participants expressed beliefs that HIV/AIDS is not a priority, that pharmaceutical companies are overcharging for medication, and that preventing or curing the disease could hinder profits of pharmaceutical companies. On the other hand, a few participants reported that improvements are taking place, and three participants reported using the CDC or NIH as sources of information about HIV/AIDS.

The final research question about the nature of participants' beliefs centered on what sources HIV-positive African Americans believe and do not believe regarding information about HIV/AIDS. Most participants relied on their doctors and/or the clinic in general. Some utilized television, videos, newspapers, magazines, and/or groups (e.g., support groups or focus groups). A few participants also mentioned using the Internet, books or other literature, the CDC or NIH, seminars, or the radio. The most commonly cited source that was not trusted was other people (i.e., laypeople, passersby); six participants discussed not automatically trusting what others say. In general, participants' statements seemed to reflect that they realize false or unreliable information exists, they choose their sources carefully, and they rely on their doctors and the clinic in general for new information and for verifying previously gathered information.



A separate research question, also related to the nature of participants' beliefs, asked how HIV-positive African Americans' beliefs about HIV/AIDS changed over time. The question really asks about two issues: What are the changes, and how did they happen? The changes that were most clear through our analyses were that most participants transitioned from believing that they were going to die from HIV and had very little control over any aspect of HIV, to believing that HIV was something to live with and something that could be survived, and to finding a sense of personal control. The way in which such changes took place is reflected in the theoretical model. In particular, participants discussed that education played a large part in changing their beliefs. Even more specifically, one aspect of education and support that affected at least a few people was spending time around others who had HIV and witnessing others' experiences. In addition, participants appeared to have undergone a process of developing or retaining beliefs about aspects of their situations that could not be controlled (e.g., government funding), but over time, integrated those perceived realities with other knowledge and beliefs that led them to find some sense of control. In fact, the perceived uncontrollability of some aspects of HIV (e.g., its chronic nature, the government's inaction) actually seemed to fuel participants' resolve to be active themselves. Such changes reflect one way in which HIV-positive African Americans' beliefs interacted with their experience of living with HIV.

The primary focus of the study was the intersection between HIV-positive African Americans' beliefs about HIV and their experiences of living with it. The beliefs were defined in the literature review as beliefs about large-scale discrimination, by the government and health care system, against a group (in this case, African Americans;

Bird & Bogart, 2005). Most participants spoke about government discrimination against HIV (e.g., that the government systematically ignored or refused to fund the issue) and identified African Americans or Blacks as being particularly affected by HIV. In combining those two findings, it appears likely that the participants did view the government as discriminatory against African Americans. However, with the exception of one or two participants, they did not say explicitly that they understood the government's stance regarding HIV to be related to the fact that African Americans are disproportionately affected. Thus, one finding is that among this group of African Americans who are living with HIV, their stated beliefs are that the government ignores people with HIV. It is unclear whether they believe that the government's inaction is related to the fact that African Americans are disproportionately affected by HIV.

What is clear is that the participants believed that the government does not pay enough attention to HIV, financially or otherwise, and that such beliefs do interact with their experience of living with HIV. The emergent theory suggests that participants integrated their beliefs about the government and the meaning of HIV at a socio-cultural level with their beliefs about themselves and the meaning of HIV at a personal level to form an overall meaning of HIV. Participants' formation of meaning interacted with their support, education, medication adherence, physical and mental health status, experiences of stigma, and personal demographics in a bi-directional manner. In the sample, participants' beliefs about the government not doing enough related to their overall conviction that personal action could and should be taken.

Our research team discussed our own beliefs that participants' race as well as socio-economic status likely contributed to their overall formation of meaning of what it

meant to live with HIV. Throughout our analyses, we absorbed messages, perhaps at times explicit but certainly at times implied, that the participants were used to not receiving or expecting much assistance from the government or other social institutions. I suspect that for these individuals, the failure of the government to adequately deal with HIV was just one more way among many that they had been failed by the system. I suspect that their resignation and reliance upon themselves extends to other issues besides HIV, and that such attitudes (i.e., resignation, need for personal action) might exist in African American and/or low-income individuals who are HIV negative, as well.

#### *Comparison of the Results to Existing Literature*

As I have made clear throughout, grounded theory is about constant comparison. One final comparison I would like to make is between the study's emergent theory and existing literature, particularly that which I discussed in the literature review. First, as I discussed earlier, the prevalence of beliefs about large-scale discrimination against African Americans, with regard to HIV/AIDS, was quite minimal in the current study—far less than previous empirical literature suggested it might be. Recall that in one study, 70% of participants agreed that the government was not telling the whole truth about AIDS (Parsons et al., 1999), and in another, 27% of participants believed that the government deliberately created AIDS to kill Black people (Klonoff & Landrine, 1999). Thus, a major finding of the study was that only a few participants held these type of beliefs. Granted, the number of participants was small, but as I discussed earlier, the participants were demographically diverse and representative of the Austin Center's client population, and our analysis suggested that we reached a point of saturation within the data—that is, no novel concepts were uncovered once we were about halfway through

our initial coding. Thus, it is likely that the findings were a relatively accurate representation of this population.

There are several potential reasons for the low prevalence of large-scale discriminatory beliefs in the sample. It could be that HIV-positive individuals who seek treatment are those without such beliefs. Indeed, seeking and entering HIV treatment likely requires at least a minimal degree of trust in health care institutions. There also was at least some evidence that participants may have experienced a change in beliefs during the course of their education and their meaning-making processes. We know that one participant explicitly discussed having held those beliefs and then shed them through his evolving coping processes. Unfortunately, my research team members and I had difficulty finding any way in which the participants who held such beliefs were different from the rest of the sample. At any rate, because beliefs about large-scale discrimination against African Americans were discussed so infrequently in the current study, we were limited from exploring the implications of such beliefs. In that sense, we were actually unable to answer the primary research question as I originally intended it. Rather, the research team focused on the beliefs that participants did hold, and how those beliefs related to the other constructs in our emergent theory.

*Medication adherence.* I discussed in the literature review that according to the health belief model (Becker et al., 1977), a patient's decision to be adherent or nonadherent to medication is derived from an assessment of the relative costs and benefits of treatment. Originally, I posited that such a relationship would be found in the current study in that participants might distrust medications, believing them to be experimental, poisonous, or otherwise harmful, and that such beliefs might relate to

nonadherence. I did find one participant who was concerned about experimentation, but she actually perceived that discontinuing her medications—*not* taking medication—would be harmful.

In general, participants in the current study held very positive attitudes about medications, believing them to be useful and necessary for survival. Some participants developed such views from spending time around other HIV-positive individuals and observing how they were affected by adhering or not adhering to their medication regimens. Nonetheless, the relationship posited by the health belief model and other adherence literature still was supported by the current study. At least by self-report, participants were very adherent to their medications, which related to their beliefs that the benefits outweighed the costs. At least a few participants actually discussed engaging in a cost-benefit analysis, acknowledging that while side effects could be frustrating or painful, the life-sustaining benefits of medications made taking them worth it. Thus, the health belief model was supported in the current study.

*Illness representations and coping.* Like the emergent theory described in the current study, the common sense model of illness representations (CSM; Leventhal, Meyer, & Nerenz, 1980) describes components that contribute to how individuals make sense of a diagnosis. Earlier, I mentioned the cause dimension, which consists of beliefs about the cause of the illness. The original model also includes dimensions of identity (the label given to the illness and knowledge of its symptoms), timeline (the perceived duration of the illness), consequences (the perceived short and long-term effects of the illness). Additional dimensions have been added by subsequent researchers, such as the control/cure dimension (beliefs about the degree of controllability and/or curability of the

illness) and the affective or emotional dimension (emotional reactions resulting directly from the illness; Oxlad & Wade, 2006).

The dimensions of the CSM bear a great deal of similarity to the Personal Meaning component of the model described in the current study. Personal Meaning encompassed participants' emotional reactions to their HIV diagnosis, much like the CSM's affective dimension. In the current study, participants' emotional reactions involved interpretations about the consequences of the illness (e.g., initial reaction that the illness would lead to death) and the duration of the illness (e.g., a realization that it wasn't going to go away). Participants in the current study also discussed their perceptions about what they could and could not control. As such, the Personal Meaning component of the current study's emergent theory encompasses or relates to four of the six dimensions described in previous research about the CSM. Thus, it appears that the CSM largely captures the personal meaning that individuals create in relation to their illnesses.

Missing from the CSM is the second component of meaning-making in the current study's theory, Socio-cultural Meaning. The current study demonstrated that socio-cultural meaning was just as important to individuals in creating overall meaning of HIV as the personal component. As I discussed earlier, socio-cultural meaning consists of perceptions of society and social institutions, perceptions about who is affected by the disease, and beliefs about the cause of the disease, including perceptions about rumors heard. The CSM model does include a cause dimension, but I view the discussions and perceptions of cause-related issues within the current study as different from those proposed by the CSM in that they relate in the current study to the broader social context

(e.g., stigma [rumors that HIV is a gay disease or is spread by casual contact] or the government [rumors that HIV is the result of a government conspiracy]). Thus, while beliefs about the causes of one's disease are included in the CSM, the idea that the socio-cultural or socio-political context of one's disease affects the sense one makes of it is missing.

The socio-cultural component of disease meaning-making could be missing from such a model for various reasons. It is possible that socio-cultural meaning is important to individuals with all types of diseases and it simply has not been studied or included in that particular model. It also is possible that such a component of meaning-making is unique to HIV, a disease that has been riddled with socio-political conflict from the point of its discovery. Even more narrowly, it is possible that socio-cultural meaning only comes into play among African Americans, who are not only disproportionately affected by HIV but have been discriminated against in a whole host of ways. Certainly, the socio-political views of African Americans—HIV-positive or not—are uniquely shaped by the history of racism that they have experienced in the United States. Perhaps one of the most important findings of the study is that socio-cultural perceptions about HIV play a significant role in how HIV-positive African Americans make meaning of and cope with their diagnosis. Whether such perceptions also play a role in how individuals of other racial/ethnic groups or individuals diagnosed with other illnesses make sense of HIV remains in question, and is mentioned below in my discussion of future directions for research, practice, and advocacy. At this point, however, I return to my comparison of my results to existing literature.

*Grounded theory.* To conclude my discussion of how my results relate to existing literature, I would like to relate the analyses and results of the current study to grounded theory literature in order to demonstrate that the current study met the evaluative criteria of a grounded theory study and the goals of constructivist grounded theory specifically. Corbin and Strauss (1990) outlined criteria for evaluating a grounded theory. They suggested that a grounded theory study be evaluated in terms of its research process and empirical grounding. They noted that while some criteria may seem unconventional to quantitative and even qualitative researchers, they are essential for evaluating grounded theory studies.

First, Corbin and Strauss (1990) recommended that studies be evaluated based on the researcher's use of theoretical sampling rather than statistical sampling. As I discussed in Chapter 3, I accomplished theoretical sampling in the current study by returning to and sampling existing data. For example, my research team constructed a provisional code list of concepts discussed by participants, and we continued to sample new interview transcripts until the code list was saturated. We created our properties and dimensions in the same manner. As we worked to construct our theoretical model, we returned to participants' transcripts multiple times to ensure a fit between the theory and the actual data.

Second, Corbin and Strauss (1990) outlined criteria for how the concepts and categories should be evaluated. They recommended evaluation of whether concepts were generated and were systematically related to one another, and whether the categories are well developed. As discussed above, we developed a comprehensive list of concepts (see Appendix H) through detailed analysis and theoretical sampling. Categories were



developed by identifying and naming higher-order, more abstract concepts and listing which concepts were related to which categories. Categories were thoroughly explored through development of properties and dimensions as well as other descriptors (e.g., lists, graphs). Throughout the process, we ensured that concepts we grouped together were systematically related to one another by comparing our groupings with the original transcript data and continually amending our category list (i.e., which concepts were related to one another within which categories) throughout our development and description of the categories. Thus, concepts and categories were well developed, were grounded in the data, and were systematically related to one another.

Third, Corbin and Strauss (1990) outlined criteria for how the grounded theory itself should be evaluated. They recommended that theories be evaluated based on the variation that exists in the theory. In other words, the theory should account for multiple phenomena and the conditions under which they appear. They also asserted that “macroscopic” conditions such as social movements and cultural values need to be directly related to the theory (i.e., as a component of the model). In addition, they noted that identifying change processes is important and the mechanisms of change should be accounted for. Finally, they recommended asking whether the theoretical findings are useful, insofar as they produce insight into what the data are reflecting. They noted that it is possible for analysis to be technically grounded in the data, but that incomplete use of the data or sheer lack of creative thought might prevent the emergent theory from reflecting what the data really indicate.

I was aware of these evaluative criteria before our research team began to construct our emergent theory and therefore worked to create a theory that was complex

and reflective of the data. We were already aware from having analyzed the data in a myriad of ways that participants' views and experiences were not all the same and thus the model would need to account for variations. I believe our model accomplishes this through the interdependence of its components and the breadth for which each component allows. For example, the component of socio-cultural meaning allows for beliefs that the government is failing or that it is helpful, and either view is explained through its connection to education and support, personal context, and personal meaning. Certainly, the model takes into account "macroscopic" issues by accounting for the treatment that HIV-positive individuals might receive within the current socio-political climate (e.g., stigma) as well as how the government and other social institutions play a role in individuals' creation of meaning regarding HIV. Finally, seven research team members and I all believe that the theoretical model thoroughly captures and accurately reflects the data that we analyzed. One way in which we attempted to accomplish this, in addition to thinking creatively and relying on the data, was through our process in which half of the team members (including me) created the initial model, and the other half evaluated it. Our reasoning was that if those of us who constructed the theory strayed away from what the data truly reflected, the others were far enough removed from our thinking process to be able to notice that and correct it. As it happened, we adhered closely to the provisional model, though the other members gave us additional feedback about its efficacy. The limitations of the theoretical model are discussed below.

#### *Limitations of the Study*

Although the current study's emergent theory describes how HIV-positive African Americans construct meaning regarding HIV, the scope of the findings is limited

in several ways. As constructivist grounded theory acknowledges, the findings are a representation of one reality, as constructed by the participants and the researchers. In the current study, one way in which the construction of this reality may have been shaped or limited is by the fact that the research team members were for the most part unlike the participants relative to the primary variables of interest in the study. That is, all of the research team members including me were HIV-negative, and only one member was Black, and she considered herself Haitian-American. In addition, all research team members were female, while the most of the participants were male. The research team members also were very young as compared to the participants. Thus, our ability to understand and interpret participants' viewpoints may have been limited by our differing backgrounds.

The methodology of the current study resulted in additional limitations. My reliance on existing literature and participants' feedback resulted in my conclusion that my acting as a White interviewer in a study of African Americans was a sound methodological choice. However, it is certainly possible that my serving as interviewer for the current study influenced who participated as well as what the participants discussed and how they did so. Unless the study were replicated with an African American interviewer, it would be impossible to know how much that decision influenced the study.

As discussed earlier, I also was limited by my inability to return to participants and conduct theoretical sampling by probing for detail in certain areas in order to further develop the theory. Although the study clearly resulted in an emergent theory and was not dependent on that particular method of theoretical sampling, it might have added

more depth or complexity to the theory. One such example that I gave earlier is that further interviewing might have helped the research team to better understand how the participants who had beliefs about HIV being man-made might have differed from the other participants. Of course, our inability to further understand that phenomenon may have been more influenced by the extremely low number of participants who held those beliefs than by our inability to re-interview them.

Finally, all personal and HIV-related demographic data were collected by self-report. This included data concerning participants' date of diagnosis, physical health (e.g., CD4 count, co-morbid diagnoses), and medication adherence. Such data were contained in the clinic's client records, but my limited time prevented me from attempting to acquire IRB approval to view client records, which likely would have been difficult. As it stood, I already had to obtain IRB approval from two sources, the clinic and my university. Self-report is obviously potentially less accurate than client records, particularly regarding data such as medication adherence, for which there might be a social desirability effect. Nonetheless, asking participants about such details within the interviews allowed them to add detail to their self-report. Much like grounded theory overall, the results thus reflect participants' perceptions of reality and reports of reality as opposed to a universal truth.

The implications of the study also are limited by the nature of the sample. The participant sample for the current study was self-selected, which raises the question of whether the participants who volunteered to be interviewed were different in any way from those who did not. For example, it is possible that the low prevalence of beliefs about large-scale discrimination (e.g., beliefs that the government created HIV to

eliminate African Americans) is related to the choice of individuals with those beliefs not to be interviewed. In addition, while the sample was demographically representative of the day treatment center's population, several groups were overrepresented. First, the sample was two-thirds male. Given the rise of HIV infection among African American women (CDC, 2007), it would have been interesting to have more women represented in the sample. Second, while the total age range of the sample was 36-60, almost all of the participants were in their fifties. That may represent the Austin Center's population, but may not represent other clinical populations well. The relatively limited age range of the sample raises questions about age or cohort effects. As one participant pointed out, treatments and other aspects of HIV change rapidly over time. Since the sample consisted of relatively older individuals, they may have been influenced by the initial discovery and reaction to HIV, by the evolution of medications over time, or by the amount of time they foresee living in the future.

Finally, it is important to remember that the sample for the current study was taken from a clinical population. In order to qualify for day treatment at the Austin Center, clients not only have to be HIV-positive, but also must have Medicaid, a health insurance program that is provided to low-income children, seniors, and individuals with disabilities. All participants in the current study reported receiving income related to disabilities, which presumably were HIV related, though not necessarily, since I did not ask about the exact nature of participants' disabilities. At any rate, the sample for the current study consisted of low-income individuals with disabilities (again, probably related to their HIV). In addition, many of the participants were in recovery from alcohol or drugs and some had diagnosed mental health issues. The model accounted for these

demographics by including personal context in the theory. Thus, it is possible that the model might hold for non-clinical populations in that individuals' personal contexts might interact with the same variables, albeit perhaps to create different meaning. It also is possible that the model of how HIV-positive African Americans construct meaning around their HIV might look very different in a non-clinical population. As such, the emergent theory in the current study is probably best conceptualized as a theory most relevant to a clinical population.

#### *Implications for Research, Practice, and Advocacy*

Implications for future research follow from the limitations of the study. It would be helpful to explore the efficacy of the emergent theory in additional clinical samples, as well as larger samples of females, younger individuals, and non-clinical samples. Future research should explore such samples using both qualitative and quantitative approaches, which would enhance the judgment of whether the results of the current study generalize to other populations. Examining how the components of theory unfold (if at all) among individuals of other racial/ethnic groups and with other chronic illness would address interesting and important research questions. Is the importance of socio-cultural meaning in the theory related to how African Americans have been treated historically and currently, or might any racial/ethnic group see flaws in how our society has dealt with HIV/AIDS and also incorporate it into what HIV means to them? Similarly, is the importance of socio-cultural meaning in understanding one's chronic illness unique to HIV, or does it play a role in how individuals make meaning of living with other chronic illnesses, as well? Certainly, other illnesses elicit reactions from society at large and may need government or other institutional attention. The model might hold up to variability

in those domains (e.g., perhaps some illnesses are well-funded and well-received by the public, which might lead to a different global meaning than was found in most of the participants in the current study). However, it also is possible that the model would not fit at all if the population were different. Finally, what does meaning-making of HIV look like in other countries, where societal or institutional responses have been very different from the United States? Would people still incorporate socio-cultural meaning into their overall view of living with HIV, or would socio-cultural meaning not play a role in their thought process? Overall, it will be interesting and important to explore how well the emergent theory generalizes to other populations. The current study explored low-income African Americans who are HIV-positive. How much more broadly might the theory extend?

The results of the current study also highlight some other research questions that will be important to explore in future research. One issue that deserves further attention is the finding that most participants in the current study disbelieved rumors they have heard about HIV/AIDS (e.g. that HIV is a gay disease, that HIV is spread through casual contact, that HIV is a government conspiracy). As I discussed earlier, with the exception of two people who acknowledge having believed in the past that HIV was a gay disease and one person who discussed an overall change from believing most rumors to disbelieving them or at least not concerning himself with them, it was unclear whether participants had always disbelieved such rumors or whether they had undergone a change. Results indicate that at least a few people underwent a change in beliefs. It appears that such changes were related to the support and education they received, but it

is important to further explore whether people underwent changes in beliefs, and if so, how.

Another extremely important question is how the participants in the current sample (and anyone in HIV treatment of any sort) felt willing and able to seek such treatment in the first place. Participants were very vocal about how much they benefited from their medical treatment, from being around others who are HIV-positive, and from the support and education they received. Clearly, the support and treatment that the participants received worked. Future research should explore how to engage more HIV-positive individuals in such treatment or care.

The success of the Whitman-Walker Clinic in successfully supporting, educating, and treating the participants in the current study has practice implications, as well. On a practical level, interventions like those used by Whitman-Walker Clinic should be extended to as many HIV-positive individuals as possible. Practitioners could also work to further pinpoint what aspects of the clinic or the day treatment program specifically are most effective and create ways to bring those interventions to others. Overall, the participants and the researchers involved in the current study found the Whitman-Walker Clinic to be a model for HIV care. Of course, such interventions cannot be carried out without funding, so practitioners of all disciplines must continue to work as advocates, as well.

Additional implications for practice stretch across multiple disciplines. First, the results of the study have implications for those who treat HIV-positive individuals medically. Participants identified their doctors as their primary source of information and were aware when their practitioners were not specialists or otherwise did not understand



what it was like to live with HIV (e.g. one participant whose doctor was of the opinion that he should not date). It is important for doctors to be extremely knowledgeable and also sensitive when discussing patients' HIV status. That extends to realizing the types of rumors that are heard. Medical practitioners need to be aware of the rumors that exist about HIV so they can respond frankly when questions are asked, and even bring the issues up for discussion themselves. Of course, many experienced practitioners likely do this already. However, it might be particularly important to include such issues in the training of newer HIV practitioners.

The implications are similar for those who treat HIV-positive individuals from a mental health perspective (i.e., psychologists or social workers). It is important to be aware of the types of rumors and stigmas that exist and for practitioners to be willing to discuss them. It also is important to realize the realities that are disappointing and frustrating, such as the current dearth of government funding and other attention to HIV, and it is important to let individuals mourn those conditions that are at least to some degree uncontrollable. At the same time, it seems important to encourage HIV-positive individuals to figure out what they can control, and how. Most of the participants in the current study felt bolstered by identifying aspects of HIV that they could control.

In the current study, the topic of education was of vital importance to the participants. At all levels, it is crucial to connect HIV-positive individuals with accurate education about their diagnosis. This is particularly important given the finding that nearly all of the participants in the current study first believed that they were going to die and largely focused on their mortality, and later changed their beliefs and were able to focus more on enjoying life. Thus, while medical professionals likely are used to

supplying information and education to their patients, that practice must extend to anyone else who has contact with HIV-positive individuals, whether they are involved in health care (e.g., psychologists or social workers) or not (e.g., clergy and other community members). Disseminating education beyond those who are already in treatment is crucial.

As participants in the current study pointed out, funding and other attention to HIV is lacking in the current socio-political climate in the United States. In some ways, the current climate motivated participants to overcome barriers and to seek personal control. But why should the social and institutional response to HIV/AIDS be something that has to be overcome? Perhaps the participants in the current study did not expect any better, but I do. We must continue to advocate for increased HIV/AIDS related funding, for more effective and moderately priced medications, for a more tolerant religious response to the issue, and for better prevention and education. As the participants made very clear, HIV is still very much a concern in the United States, and we need people, from political leaders to families next door, to understand that.

One aspect of the participants' meaning-making that the research team members and I found striking, and worked to incorporate into our theory, was that it does not have an end. HIV-positive individuals struggle to make sense of HIV every single day.

In the words of a participant:

The big picture is the fact that I think that every real disease, serious disease, that mankind has faced, has been...come to some kind of terms with. Either it's been eradicated or cured or alleviated, or relieved, to some real extent. And this is, even though the toughest, I think, one that we've come up with so far, and we're in the middle of it...We need a lot of people that have that kind of attitude that it is something that can be done [so] that they'll go and do something about it.

## Appendix A

## Contact Information Regarding the Study

Contact information regarding study:

Ruth Fassinger  
University of Maryland  
301-405-2873  
[rfassing@umd.edu](mailto:rfassing@umd.edu)

WWC 24-hour hotline:

***The Crisis Intervention Line*** offers emergency, 24 hour, Crisis Intervention consultation by phone to individuals experiencing a mental health emergency and to their partners, family and friends. Call **(202) 797-4444**, leave your name and a number where you can be reached, and a counselor will return your call promptly.

Appendix B  
Field Notes Form

**PARTICIPANT CODE:** \_\_\_\_\_

**Field Notes Form**

Date:

Length of interview:

Comments on rapport:

General themes:

Other noteworthy information (may include interruptions or difficulties in conducting interview, questions that were unclear to interviewee, prior contact with interviewee, notes on interviewee's tone of voice or speaking style, etc.):

## Appendix C

## Interview Protocol

Date:

Participant Code:

(Introduce self.) I'd like to thank you very much for giving me this opportunity to interview you. I will be taping this interview for the purposes of data collection and analysis only. The only people who will hear this tape will be members of the research team. Everything you say on this tape will be kept confidential and your responses will not be tied to you as an individual in any way. Your responses will not be shared with anyone else at the clinic. In this interview I'll be asking you several topics. First, I'm going to ask you a little bit about the clinic and your HIV status. Then I'll move on to ask you how you get information about HIV, what some of your thoughts are about HIV generally, and then about your own experiences. I'll give you an opportunity at the end to add anything I may have missed. If at any point there's something you don't want to answer, just let me know and I'll move on to the next question.

CLINIC  
EXPERIENCES

**Tell me a little bit about your relationship to Whitman Walker Clinic.**

- How did you hear about/choose the clinic?
- What services have you used?
- What were your expectations/first impressions, what are your current impressions, and (if applicable) how/why did they change?

HIV-RELATED  
DEMOGRAPHICS

**Now I'd like to ask you a few questions about your HIV status.**

- [Interviewer: Refer to demographic form, section entitled, "HIV-Related Demographics." ]

INFO.  
RECEIVED

**What have you heard or read about how or why people get or have HIV/AIDS?**

- What have you heard or read about HIV affecting any particular groups of people?
- What have you heard or read about society's role? (e.g., religions, the government, medical institutions)
- What have you heard or read about HIV/AIDS treatments or medications?
- What are the sources of that information?

BELIEFS  
ABOUT  
HIV

- What are your own thoughts or beliefs?**
  - What are the sources of your thoughts or beliefs?
  - Which sources do you believe, which sources do you not believe? Why/why not?

BELIEFS AND  
LIVING WITH  
HIV

- What, if any, connections do you see between your thoughts that we just discussed and your experience of living with HIV?**
  - Connections between thoughts and the amount or types of treatment you have chosen?
  - Connections between thoughts and the ways you've reacted to or coped with your HIV status?

CHANGES IN  
BELIEFS

- Have your thoughts changed over time? How? (i.e., what are your past beliefs and how are they different?)**
  - How did that change in beliefs come about?
  - What role, if any, did the clinic play in that change?

REMAINING  
DEMOGRAPHICS

- Now I'd like just like to round things out by asking you some background questions about yourself. If there's anything you don't want to answer, just let me know, and I'll move on to the next question.**
  - [Interviewer: Refer to demographic form.]

OTHER

- Is there anything else that you'd like to share?**
  - Would you like to share any feedback with me about the interview questions or the interview process?
  - May I contact you again in the future if I have any questions about this interview?

Offer interviewer's contact information to participant and inform participant that participant may contact the researchers for results of the study. Remind participant of Whitman-Walker Clinic's 24-hour hotline and offer the hotline number to participant. Thank participant.

## Appendix D

## Demographics Form

Participant Code \_\_\_\_\_

HIV-Related Demographics

1. What was the date of your HIV diagnosis? \_\_\_\_\_

2. What was your age at that time? \_\_\_\_\_

3. How many years have you been living with HIV? \_\_\_\_\_

4. Have you been diagnosed with AIDS? \_\_\_\_\_

5. If applicable – What was the date of your AIDS diagnosis? \_\_\_\_\_

6. If applicable – What was your age at that time? \_\_\_\_\_

7. If applicable – How many years have you been living with AIDS? \_\_\_\_\_

8. What is your current CD 4 count? \_\_\_\_\_

9. What is your current viral load? \_\_\_\_\_

10. Are you currently prescribed to take any medications for HIV or AIDS?

 Yes No

11. If yes – Can you please list medications prescribed to you:

---



---



---

12. If yes above (currently prescribed to take medications) – how often do you take your medications exactly as prescribed? (List choices aloud.)

1  
never2  
seldom3  
sometimes4  
usually5  
always

13. Have you ever experienced side effects from your medications? (List the effects and the time/duration.)

---

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Personal Demographics

14. What is your current age? \_\_\_\_\_
15. How do you identify your gender?  
 Female  
 Male  
 Transgender, Female to Male  
 Transgender, Male to Female  
 Other (indicate): \_\_\_\_\_
16. How do you identify your sexual orientation?  
 Bisexual  
 Gay/Lesbian  
 Heterosexual  
 Uncertain  
 Other (indicate): \_\_\_\_\_
17. What is your relationship status? (List choices if necessary.)  
 Divorced/Separated from spouse/partner  
 Married/Partnered  
 Single and...  
 In a committed/monogamous relationship but not married/partnered  
 Not currently in a committed/monogamous relationship  
 Widowed (spouse/partner is deceased)
18. What is the highest level of education that you have completed?  
 Some grammar school (less than 8<sup>th</sup> grade)  
 Completed 8<sup>th</sup> grade  
 Some high school  
 High school degree  
 Some college  
 College degree  
 Some post-graduate work  
 Graduate degree
19. What is your current yearly income? \_\_\_\_\_
20. What is the source of your income? \_\_\_\_\_

21. Do you have any children? \_\_\_\_\_
22. If yes – How many? \_\_\_\_\_
23. If yes – How old are they? \_\_\_\_\_
24. Do you identify with a particular religion or spirituality? \_\_\_\_\_
25. If yes – What is it? \_\_\_\_\_
26. Besides HIV, have you had any significant medical or mental health issues or diagnoses? If yes – When?
- |              |              |
|--------------|--------------|
| Issue: _____ | Dates: _____ |
| Issue: _____ | Dates: _____ |
| Issue: _____ | Dates: _____ |
| Issue: _____ | Dates: _____ |
| Issue: _____ | Dates: _____ |
27. Have you ever had mental health treatment or therapy?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
28. Have you ever had a problem with alcohol or drugs?
29. If yes – When? \_\_\_\_\_
30. If yes – What is/was your drug of choice? \_\_\_\_\_
31. If yes – Have you ever been in a treatment or recovery program? \_\_\_\_\_
32. If no – About how often do you currently drink alcohol or use drugs? \_\_\_\_\_

Whitman Walker Clinic-related Demographics

## 33. Whitman Walker services used – CHECK ALL THAT APPLY:

- Bridge Back (residential addiction treatment)
- Case management
- Crisis intervention telephone line
- Day treatment (Austin Center or Max Robinson)
- Dental
- Food bank
- Gay men peer counseling
- HIV testing
- Individual counseling/psychotherapy
- Legal
- Lesbian peer counseling
- Medical (primary care, HIV care)
- Pharmacy
- Support group
- Therapy group
- Transgender health services
- WWAS (outpatient addiction treatment)

## 34. Do you pay for your services at WWC? If yes – with what method?

- Insurance, commercial (example: Blue Cross)
  - Medicare/Medicaid
  - Ryan White (no payment - fees are covered by clinic's HIV funding)
  - Self-pay (Full fee)
  - Sliding scale
  - Other:
-

## Appendix E

## Research Team Recruitment Flyer

# Wanted: Research Assistants

Holy Cross grad ('01) is seeking to form a research team for her counseling psychology doctoral dissertation. The topic is African Americans' experiences with and beliefs about HIV/AIDS. The study is qualitative and involves analyzing interview transcripts through a team process. Time commitment will be approximately 4 hrs/week (negotiable). Psychology, sociology, and non-majors all welcome.

Benefits: No pay : ( However—This is a great experience for your resume, mentoring and help with grad school/future is available, and the study will be submitted for publication (co-authorship).

Interested? Contact Heather Walton at [heather.walton@gmail.com](mailto:heather.walton@gmail.com).

## Appendix F

## Provisional Code List

1. origin of info. about clinic
2. length of time at clinic
3. benefits of clinic
4. program/structural support (clinic and non-clinic)
5. personal support
6. first signs of sickness (e.g., way person found out about diagnosis, went for testing, etc.)
7. weight issues, wasting
8. hospital stay
9. energy level
10. substance use and recovery
11. realization regarding diagnosis
12. legal issues
13. HIV diagnosis
14. AIDS diagnosis
15. date of HIV diagnosis
16. date of AIDS diagnosis
17. age at HIV diagnosis
18. CD4 count
19. viral load
20. medications (e.g., what meds are taken)
21. medication adherence
22. side effects
23. switch in medication regimen
24. past perception(s) of HIV cause/contraction/etc.
25. current perception(s) of HIV cause/contraction/etc.
26. past reactions to diagnosis, including fears
27. current reactions to diagnosis
28. change in perception of—or reaction to—HIV, including cause of change (e.g., education) – e.g., participant is discussing past vs. present
29. theories/rumors heard about HIV/AIDS
30. perception of government role in HIV/AIDS
31. perception of religion/church role in HIV/AIDS
32. perception of medication institutions' role in HIV/AIDS
33. perception of society response to HIV/AIDS (not better accounted for by a more specific piece of society or by experience or fear of stigma)
34. education about HIV/AIDS (participants' education obtained/received)
35. sources of info./education about HIV/AIDS
36. effects of education, support, etc.
37. fear of stigma, or lack thereof (e.g., "I don't care what people think") (If discussing past vs. present, also code as change (26))
38. experiences of stigma

39. ways of coping with HIV/AIDS
40. involvement in educating others
41. trust, or lack thereof
42. (perceptions of) others' perceptions of HIV/AIDS
43. perceptions of/regarding medications, treatment
44. reactions to interview, including reason for participation, feelings about participation
45. age
46. gender
47. sexual orientation
48. relationship status
49. educational history, level
50. income level and source
51. children
52. identification w/religion/spirituality
53. other illnesses, diagnosis (besides HIV)
54. mental health treatment history (including current)
55. use of clinic services (yes, no, why, and payment)

## Appendix G

## Second Code List

1. origin of info. about clinic
2. length of time at clinic
3. benefits of clinic
4. program/structural support (clinic and non-clinic)
5. personal support
6. first signs of sickness (e.g., way person found out about diagnosis, went for testing, etc.)
7. weight issues, wasting
8. hospital stay
9. energy level
10. substance use and recovery
11. realization regarding diagnosis
12. legal issues
13. HIV diagnosis
14. AIDS diagnosis
15. date of HIV diagnosis
16. date of AIDS diagnosis
17. age at HIV diagnosis
18. CD4 count
19. viral load
20. medications (e.g., what meds are taken)
21. medication adherence
22. side effects
23. switch in medication regimen
24. past perception(s) of HIV cause/contraction/etc. – *general beliefs, not personal story – see 59*
25. current perception(s) of HIV cause/contraction/etc. – *general beliefs, not personal story – see 59*
26. past reactions to diagnosis, including fears
27. current reactions to diagnosis
28. change in perception of—or reaction to—HIV, including cause of change (e.g., education) – e.g., participant is discussing past vs. present
29. theories/rumors heard about HIV/AIDS
30. perception of government role in HIV/AIDS
31. perception of religion/church role in HIV/AIDS
32. perception of medication institutions' role in HIV/AIDS
33. perception of society response to HIV/AIDS (not better accounted for by a more specific piece of society or by experience or fear of stigma)
34. education about HIV/AIDS (participants' education obtained/received) – *including lack thereof – yes/no, amount, level; Ex: I used to be really uneducated about HIV.*

35. sources of info./education about HIV/AIDS – *including sources believed, sources not believed, and sources “unjudged”*
36. effects of education, support, etc.
37. fear of stigma, or lack thereof (e.g., “I don’t care what people think”) (If discussing past vs. present, also code as change (26))
38. experiences of stigma
39. ways of coping with HIV/AIDS
40. involvement in educating others
- ~~41. trust, or lack thereof~~
42. (perceptions of) others’ perceptions of HIV/AIDS
43. perceptions of/regarding medications, treatment
44. reactions to interview, including reason for participation, feelings about participation
45. age
46. gender
47. sexual orientation
48. relationship status
49. educational history, level
50. income level and source
51. children
52. identification w/religion/spirituality
53. other illnesses, diagnosis (besides HIV)
54. mental health treatment history (including current) – *type, level, whether not in treatment only – otherwise, see #57*
55. use of clinic services (yes, no, why, and payment)
56. reactions to, or perceptions of, other clients
57. mental health issues/stress
58. thoughts regarding cure
59. HIV contraction – *personal story – general perceptions, see 24, 25*
60. perception of HIV affecting particular groups
61. perceptions about role of education – *Ex: “People have HIV because of lack of education”; Ex: HIV would be eliminated if people were better educated.” (e.g., both current and future/hypothetical)*

Other topics to think about, that we haven’t figured out yet...

1. doctors/role of doctors (Is this its own category or does all doctor info. fall into other categories?)
2. thoughts about death
3. statements like, “This is not going to kill mankind”
4. statements like, “Something good is going to come through”
5. statements like, “The climate in the country has gotten better for gays and lesbians”



## Appendix H

## Third Code List

1. origin of info. about clinic
2. length of time at clinic
3. attitudes/expectations/perceptions re: clinic
4. program/structural support (clinic and non-clinic)
5. personal support
6. physical symptoms (other than side effects)
7. ~~weight issues, wasting~~
8. hospital stay
9. energy level
10. substance use and recovery
11. realization regarding diagnosis
12. legal issues
13. HIV diagnosis
14. AIDS diagnosis
15. date of HIV diagnosis
16. date of AIDS diagnosis
17. age at HIV diagnosis
18. CD4 count
19. viral load
20. medications (e.g., what meds are taken)
21. medication adherence
22. side effects
23. switch in medication regimen
24. past perception(s) of HIV cause/contraction/etc. – *general beliefs, not personal story – see 59*
25. current perception(s) of HIV cause/contraction/etc. – *general beliefs, not personal story – see 59*
26. past reactions to diagnosis, including fears
27. current reactions to diagnosis
28. change in perception of—or reaction to—HIV, including cause of change (e.g., education) – e.g., participant is discussing past vs. present
29. theories/rumors heard about HIV/AIDS
30. perception of government role in HIV/AIDS
31. perception of religion/church role in HIV/AIDS
32. perception of medication institutions' role in HIV/AIDS
33. perception of society response to HIV/AIDS (not better accounted for by a more specific piece of society or by experience or fear of stigma)
34. education about HIV/AIDS (participants' education obtained/received) – *including lack thereof – yes/no, amount, level; Ex: I used to be really uneducated about HIV.*
35. sources of info./education about HIV/AIDS – *including sources believed, sources not believed, and sources “unjudged”*

36. effects of education, support, etc.
37. fear of stigma, or lack thereof (e.g., “I don’t care what people think”) (If discussing past vs. present, also code as change (26))
38. experiences of stigma
39. ways of coping with HIV/AIDS
40. involvement in educating others
41. ~~trust, or lack thereof~~
42. (perceptions of) others’ perceptions of HIV/AIDS
43. perceptions of/regarding medications, treatment
44. reactions to interview, including reason for participation, feelings about participation
45. age
46. gender
47. sexual orientation
48. relationship status
49. educational history, level
50. income level and source
51. children
52. identification w/religion/spirituality
53. other illnesses, diagnosis (besides HIV)
54. mental health treatment history (including current) – *type, level, whether not in treatment only – otherwise, see #57*
55. use of clinic services (yes, no, why, and payment)
56. reactions to, or perceptions of, other clients
57. mental health issues/stress (*including guilt, self-blame*)
58. thoughts regarding cure
59. HIV contraction – *personal story – general perceptions, see 24, 25*
60. perception of HIV affecting particular groups
61. perceptions about role of education – *Ex: “People have HIV because of lack of education”; Ex: HIV would be eliminated if people were better educated.” (e.g., both current and future/hypothetical)*
62. doctors/role of doctors
63. thoughts about death
64. gay and lesbian issues

## Appendix I

## Category List

- **DEMOS – HEATHER**
  - 13 – HIV diagnosis
  - 14 – AIDS diagnosis
  - 15 – date of HIV diagnosis
  - 16 – date of AIDS diagnosis
  - 17 – age at HIV diagnosis
  - 45 – age
  - 46 – gender
  - 47 – sexual orientation
  - 48 – relationship status
  - 49 – educational history, level
  - 50 – income level and source
  
- **EDUCATION – BRONWYN**
  - 34 – education about HIV/AIDS (participants' education obtained/received)
  - 35 – sources of info./education about HIV/AIDS
  - 36 – effects of education, support, etc.
  - 40 – involvement in educating others
  - 61 - perceptions about role of education – *Ex: “People have HIV because of lack of education”*; *Ex: HIV would be eliminated if people were better educated.” (e.g., both current and future/hypothetical)*
  - 62 – doctors/role of doctors
  
- **MEDICATION – AMY**
  - 20 – medications (e.g., what meds are taken)
  - 21 – medication adherence
  - 22 – side effects
  - 23 – switch in medication regimen
  - 43 – perceptions of/regarding medications, treatment
  
- **CLINIC – SUELEIDY**
  - 1 – origin of info. about clinic
  - 2 – length of time at clinic
  - 3 – attitudes/expectations/perceptions re: clinic
  - 4 – program/structural support
  - 35 – sources of info./education about HIV/AIDS – *including sources believed, sources not believed, and sources “unjudged”*
  - 55 – use of clinic services (yes, no, why, and payment)
  - 56 – reactions to, or perceptions of, other clients
  - 62 – doctors/role of doctors

- **PERCEPTIONS OF SOCIETY/INSTITUTIONS – KRISTIN**
  - 29 – theories/rumors heard about HIV/AIDS
  - 30 – perception of government role in HIV/AIDS
  - 31 – perception of religion/church role in HIV/AIDS
  - 32 – perception of medication institutions' role in HIV/AIDS
  - 33 – perception of society response to HIV/AIDS (not better accounted for by a more specific piece of society or by experience or fear of stigma)
  - 60 – perception of HIV affecting particular groups
  
- **CAUSE/CONTRACTION – HEATHER**
  - 11 – realization regarding diagnosis
  - 24 – past perception(s) of HIV cause/contraction/etc. – *general beliefs, not personal story – see 59*
  - 25 – current perception(s) of HIV cause/contraction/etc. – *general beliefs, not personal story – see 59*
  - 28 – change in perception of—or reaction to—HIV, including cause of change (e.g., education) – e.g., participant is discussing past vs. present
  - 29 – theories/rumors heard about HIV/AIDS
  - 34 – education about HIV/AIDS (participants' education obtained/received) – *including lack thereof – yes/no, amount, level; Ex: I used to be really uneducated about HIV.*
  - 36 – effects of education, support, etc.
  - 59 – HIV contraction – *personal story – general perceptions, see 24, 25*
  
- **SUPPORT - LYNN**
  - 4 – program/structural support (clinic and non-clinic)
  - 5 – personal support
  
- **PHYSICAL HEALTH/SYMPTOMS / DISEASES/DISORDERS – KATE (and Heather)**
  - 6 – physical symptoms (other than side effects)
  - 8 – hospital stay
  - 9 – energy level
  - 10 – substance use and recovery
  - 18 – CD4 count
  - 19 – viral load
  - 22 – side effects
  - 53 – other illnesses, diagnoses (besides HIV)
  - 54 – mental health treatment history (including current) – *type, level, whether not in treatment only – otherwise, see #57*
  - 57 – mental health issues/stress

- **EMOTIONAL REACTION TO DIAGNOSIS – KATE**
  - 10 – substance use and recovery
  - 11 – realization regarding diagnosis
  - 26 – past reactions to diagnosis, including fears
  - 27 – current reactions to diagnosis
  - 28 – change in perception of—or reaction to—HIV, including cause of change (e.g., education) – e.g., participant is discussing past vs. present
  - 37 – fear of stigma, or lack thereof (e.g., “I don’t care what people think”) (If discussing past vs. present, also code as change (26))
  - 39 – ways of coping with HIV/AIDS
  - 57 – mental health issues/stress
  
- **VIEWS OF THE HIV/AIDS COMMUNITY - LYNN**
  - 37 – fear of stigma, or lack thereof (e.g., “I don’t care what people think”) (If discussing past vs. present, also code as change (26))
  - 38 – experiences of stigma
  - 42 – (perceptions of) others’ perceptions of HIV/AIDS
  - 60 – perception of HIV affecting particular groups
  - 64 – gay and lesbian issues

## Appendix J

## Properties and Dimensions of the Categories

CAUSE/CONTRACTION

Understands Medical Causes of HIV	Inaccurately-----Accurately
Cites Role of Self in Personal Cause/Contraction	No-----Yes
Believes HIV is a Gay Disease	No-----Yes
Believes Monkey Plays Role in Cause/Contraction	No-----Yes
Believes Casual Contact Plays a Role	No-----Yes
Believes Plant Plays a Role	No-----Yes
Believes Cause is Related to Experiment Gone Bad	No-----Yes
Believes HIV is Man-Made	No-----Yes
Believes HIV is a Government Conspiracy	No-----Yes
Has Heard Theories Re: Cause that are Other than Medical/Scientific	No-----Yes
Believes Theories (one or more) that are Other than Medical/Scientific	No-----Yes

CLINIC/SUPPORT

Attitudes Regarding Clinic	Negative-----Positive
Reactions/Perceptions Re: Other Clients	Negative-----Positive
Initial Responses to the Gay Community	Rejection-----Acceptance
Role of Doctors	Negative-----Positive
Reliance on Doctors	Low-----High
Trusts Doctor/Uses Doctor as Resource	No-----Yes
Level of Support/Assistance Received in Caring for Self	Low-----High

EDUCATION

Education of Kids/Teens is Needed	No-----Yes
Educates Others	No-----Yes
Education Helps with Coping	No-----Yes
Believes Information from Others	No-----Yes
Doctor is Source of Education	No-----Yes

EMOTIONAL REACTION TO DIAGNOSIS

Ways of Coping	Negative-----Positive
Past Reaction to Diagnosis	Negative-----Positive
Sense of Control	Lack of Control-----Control
Change in Perception/Reaction to Diagnosis	None-----Significant Change

MEDICATION

Experiences Side Effects Currently	No-----Yes
Experienced Side Effects in the Past	No-----Yes
Number of Medications Taken	Few-----Many
Adheres to Medication	Never-----Always
Views of Medication	Negative-----Positive

PERCEPTIONS OF SOCIETY/INSTITUTIONS

Perception of Government	Negative-----Positive
Believes that Government Misspends Money	No-----Yes
Believes that Government is Helpful/Improved	No-----Yes
Perception of Religious Institutions	Negative-----Positive
Believes that Religions/Church Ignore HIV	No-----Yes
Perception of Personal Religion/Spirituality	Hurtful-----Helpful
Has Found Religious Acceptance Personally	No-----Yes
Perception of Medical Institutions	Negative-----Positive
Believes Pharmaceutical Companies Focus on Profits/Do Not Prioritize HIV	No-----Yes
Believes that Medical Institutions are Improving	No-----Yes
Perception of Society	Negative-----Positive
Believes Society's Response to HIV has Improved	No-----Yes
Believes Society Ignores/Ostracizes People w/HIV	No-----Yes

PHYSICAL AND MENTAL HEALTH

Discussed/Experienced Physical Symptoms/Illness	No-----Yes
Positive/Determined Re: Symptoms/Health	No-----Yes
History of Substance Abuse	No-----Yes
Mental Health Issues	None-----Diagnosed

STIGMA

Ease of Disclosing HIV Status	Difficult-----Easy
Perceptions of Stigma Experienced by Others	A little-----A lot
Perceptions of Stigma Experienced Personally	A little-----A lot

Properties w/out Traditional Dimensions

Types of Theories/Rumors Heard (Cause/Contraction)	
Number of time theories/rumors mentioned (among the whole sample) (Cause/Contract)	
Origin of Info. Re: the Clinic (Clinic/Support)	
Use of Clinic Services (Clinic/Support)	
Sources of Support (Clinic/Support)	
Acceptance by Community (Emotional Reaction)	
HIV diagnosis – path of discovery (Health)	
Other Physical Disorders (Health)	
Perceptions of Who HIV Affects (Perceptions of Society/Institutions)	

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