Thinking outside the Condom: Incorporating Women's Challenges and Strengths into Safer Sex Interventions for Women Living with HIV/AIDS

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Abstract

Introduction: Developing effective prevention programs for women living with HIV/AIDS hinges on understanding and responding to the myriad contexts in which women make sexual decisions. These include the challenges imposed on women by intersecting social inequities that can limit their relationship power, such as gender, racial/ethnic, and economic inequality. Existing behavioral research on the reasons why HIV positive women make sexual decisions is limited in scope, however, and current prevention programs posit male condoms as a panacea for HIV positive women's complex safer sex needs. This study explored HIV positive women's experiences of structural violence (oppression) and stress-related growth (growth from adversity) in order to understand better the context of their sexual practices.

Methods: The participants included 24 women living with HIV/AIDS who attended skill and peer support groups that were part of the *Protect and Respect* program. The women were predominantly Black (83%), reported earning less than $10,000/year (80%) and reported acquiring HIV through sex with a male partner (58%). I transcribed 30 group sessions verbatim, editing for clarity only; entered the transcripts into Atlas.ti.5.2, a qualitative software analysis package; and employed analytic strategies of grounded theory and narrative analysis to explore women's structural violence and stress-related growth experiences.

Results: Structural violence manifested in the women's lives in three primary ways: (1) daily and overwhelming stress; (2) AIDS related stigma; and (3) unhealthy and violent relationships. The women associated these experiences with emotional pain, suffering and substance use. In addition, the participants responded to these challenges through their examples of: (1) stress-related growth; (2) resilience; and (3) resistance.

Conclusions: Women's experiences with structural violence and stress-related growth revealed their barriers and facilitators to having safer sex and suggested that traditional HIV prevention interventions for women living with HIV/AIDS fail to account for women's challenges and their strengths. The analysis of women's experiences with structural violence revealed that women

have fundamental health and safety challenges that must be addressed in order for them to be able to have safer sex. The analysis of women's stress related growth experiences revealed that women possess various strengths that are ignored in current HIV prevention programming, but that women associate with their health and ability to have safer sex. These findings suggested that interventions that are not grounded in women's experiences may do more harm than good by instructing women to engage in behaviors that are unrealistic or harmful in the context of their challenges (e.g., condom use in violent relationships), reinforcing women's sense of powerlessness, and obscuring the root causes of and solutions for women's sexual risk practices. I discuss the theoretical, practical, research and methodological implications of these findings, all of which focus on the significance of holistic and multi-leveled prevention strategies for women and addressing the precursors that facilitate or hinder safe sex in prevention programs for women, and not just condom use.

Chapter 1: Introduction and Problem Statement

The way that we understand women's sexual risk behaviors determines the adequacy of our prevention response for women living with HIV/AIDS (Mann, 1999). Many HIV positive women in the United States (U. S.) are disadvantaged by the intersection of gender, relational, racial/ethnic, and economic inequities that limit their agency and sexual decision making power (Centers for Disease Control [CDC], 2007a). Research about the context of and reasons for HIV positive women's sexual risk choices is limited in scope, however, and HIV prevention programs that do exist for women focus myopically on individual level outcomes like condom use. This strategy assumes inappropriately that HIV positive women are individual and empowered actors and ignores how women make sexual decisions as members of families, peer groups, relationships, and society (Singer, 1997). This study explored HIV positive women's experiences of structural violence (oppression) and stress-related growth (growth from adversity) in order to understand better the context of their sexual practices and how women's challenges and strengths affected their sexual decision making processes.

The data for this study were from the *Protect and Respect Program for Women Living with HIV/AIDS (Protect and Respect)*, a prevention research intervention that I[1] played a major role in developing, implementing, and evaluating from January 2003 to June 2007. *Protect and Respect* was a randomized controlled trial (RCT) that tested the efficacy of two different strategies to help HIV positive women have safer sex: (1) messages from primary care providers during regularly scheduled medical visits; and (2) messages from a five session skills based group level intervention (GLI) and weekly peer led support groups. The conditions under which I undertook this study included both professional and personal ones. I developed *Protect and Respect* using the best evidence available in the prevention literature about which strategies

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[1] Qualitative research emphasizes the relationship between the researcher and participants.. This relationship promotes higher quality research by revealing the way both parties co-construct the data as well as how the biases and perspectives of the researcher influence the research questions, analysis, interpretation, and written findings (Merrick, 1999). Therefore, the use of first person is appropriate in this dissertation.

would help HIV positive women to have safer sex. When I led the safer sex groups with the women, however, I encountered the jarring incongruities between the intervention's assumptions about the women's lives and the women's lived experiences.

The education and skills that women were learning in the groups were futile in the context of the women's daily challenges and did not build upon the women's existing strengths. The women faced multiple barriers to safer sex that were out of their individual control. It seemed unfair to measure the success of the program by the women's ability to use condoms when their partners wore the condoms and controlled condom use, or more significant worries in the women's lives, like extreme poverty, precluded their concerns for safe sex. The uneasy intersection between the intervention participants and the design of the intervention led me to ask questions about the context of women's risk and how we could account for the circumstances that were driving women's sexual decision making in HIV prevention programs. I chose to explore women's experiences of structural violence and stress-related growth because I was overwhelmed by the pervasive presence of oppression in the lives of the HIV positive women that I encountered as an HIV prevention interventionist, as well as the women's formidable responses to their life circumstances and the apparent inextricable link between their challenges, their strengths, their health, and their sexual choices.

I. HIV/AIDS among Women in the United States

Women comprise one of the fastest growing populations with HIV/AIDS in the U.S (CDC, 2007a). Rates of HIV/AIDS among women in the U.S. have risen sharply over time; women compromised 8% of all cases in 1985 and 26% in 2005 (CDC, 2007a). Approximately 10,000 U.S. women were diagnosed with HIV/AIDS in 2005 and more than 95,000 were living with HIV/AIDS (CDC, 2007a). Most of these women were infected between 15 and 39 years of age and acquired HIV/AIDS via sex with a male partner (80%) (CDC, 2007a). HIV/AIDS rates by race/ethnicity reflect a significant health disparity. The majority of HIV/AIDS cases are among Black (66%), White (17%), or Hispanic (14%) women (CDC, 2007a). HIV/AIDS is most disproportionate among African American women, who account for only 13% of the population, but more than half (66%) of AIDS diagnoses (CDC, 2007a).

II. Prevention for Women Living with HIV/AIDS

Public health researchers define and understand women's sexual risk behavior through biomedical, lifestyle, and psychological theories of disease causation which define sexual risk as a result of individual choices and actions (Fee & Krieger, 1993; Zierler & Krieger, 1997). Operating under the tenets of these theories, HIV/AIDS is perceived to be a preventable illness because women can modify their sexual and drug using behaviors to avoid acquiring or transmitting the virus. Both the preventable nature of HIV/AIDS and the notable lack of a vaccine or a cure for the virus have established HIV prevention as a critical public health approach (CDC, 2001a). The main HIV prevention strategies include condom use, abstinence, and safer injection practices (CDC, 2001b; Wolitski et al., 2006).

HIV prevention programs were developed historically for women at risk for HIV only. Exceptions to this rule were measures to prevent mother-to-child transmission, and HIV-counseling, testing, and referrals programs to identify HIV-positive women and link them to treatment and other supportive services (Wolitski et al., 2006). In 2001 the CDC introduced the Serostatus Approach to Fighting the HIV Epidemic (SAFE) which defined a new framework to improve the health of women with HIV/AIDS and prevent transmission (Janssen et al., 2001). In 2003 the CDC implemented the Advancing HIV Prevention Initiative which formally adopted Prevention with Positives (PWP) as a core element of the U.S. HIV prevention plan (CDC, 2003). PWP programs are also referred to as secondary prevention programs, because they are designed for women who are already living with the virus, versus HIV-negative, at-risk women (primary prevention).

Prevention interventions for women living with HIV address two harms, harm to: (1) others via sexual or injection risk behaviors that can transmit HIV and other sexually transmitted infections (STIs)to HIV-negative individuals; and (2) self via the acquisition of other STIs or reinfection with another strain of HIV (Kalichman, 2004; Purcell, 2003)[2]. While prevention for women living with HIV chances blaming and stigmatizing HIV-infected women, secondary prevention strategies may also help women with HIV adopt healthier sex lives and obtain support as they reflect on difficult intimacy and sex concerns (Collins, Morin, Shriver, & Coates, 2000). Both primary and secondary prevention strategies focus on decreasing risk transmission, but secondary prevention strategies address HIV positive women's unique needs, including how to disclose their status to their partners, and how to communicate about risk to their HIV negative and positive partners (Collins et al., 2000).

Surveillance data informed the PWP initiative (CDC, 2003). HIV prevalence is at its highest level and new HIV/AIDS cases have remained unchanged at 40,000/year for the past decade (CDC, 2003; Schneider, Glynn, Kajese, & McKenna, 2006). As a result of treatment advancements, many HIV positive women are living longer and sexually active lives (CDC, 2003). Therefore, prevention for HIV positive women is important because many women with HIV/AIDS continue to be sexually active after diagnosis (Bova & Durante, 2003; Weinhardt et al., 2004).

Although many HIV-positive women practice safer sex, a sizable number also engage in risky sexual practices (Kalichman, 2000). Sex is a complex human behavior that connotes physical, emotional, and moral significance. This complexity explains in part the tendency for researchers to measure and define sex and unsafe sex differently across disciplines and research studies. For example, some researchers define unsafe sex among people living with HIV/AIDS as unprotected vaginal or anal sex with HIV negative or unknown HIV status partners only, and other researchers include all partners in the definition, regardless of HIV status. This definitional diversity notwithstanding, HIV/AIDS prevention researchers generally conclude that around a third of HIV-positive women have reported having unsafe sex with their partners (Aidala, Lee, Garbers, & Chiasson, 2006; Golden, Wood, Buskin, Fleming, & Harrington, 2007; Kalichman, 2000;

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[2] This dissertation focuses on HIV positive women. Here, "HIV risk" refers to HIV positive women's sexual risk behavior, which poses a risk to themselves and their partners, as described above.

Weinhardt et al., 2004; Wilson et al., 2004). Approximately 20% of HIV-positive women report multiple sexual partners (Weinhardt et al., 2004), unsafe sex with HIV negative or status unknown partners (Golden et al., 2007; Morin et al., 2007; Weinhardt et al., 2004), sex without disclosing their HIV status to their partners (Ciccarone et al., 2003), multiple sexual partners (Weinhardt et al., 2004), and exchanging sex for money or drugs (Aidala et al., 2006; Leone et al., 2005). The growing number of women with HIV/AIDS and evidence of their sexual risk behavior underscores the importance of appropriate prevention interventions for HIV positive women, yet few existing interventions respond to the needs of this population.

Limitations of Existing Prevention Strategies for HIV Positive Women

HIV/AIDS is transmitted in disparate rates to the most disenfranchised women in the U. S., through social activities that are embedded in complex social relations (Bolton & Singer, 1992; Mann 1999; Singer, 1994). For example, women's lack of power in their intimate relationships renders them more vulnerable than heterosexual men to HIV in the first place and less likely to be able to have safer sex once they are infected (Amaro, 1995; CDC, 2007a; Cochran & Mays 1993; Dworkin & Ehrhardt, 2007; McNair & Prather, 2004; Teti, Chilton, et al., 2007; Wyatt, 1994; Zierler & Krieger, 1997). Women's decisions to have safer sex are often inextricably connected to the disadvantages associated with the intersection of gender inequity, poverty, AIDS-related stigma, and racism, including economic dependency, power imbalances, and threats of violence (Farmer, 2005; Gollub, 1990). The renown HIV physician and medical anthropologist Paul Farmer (2005) has referred to the harm inflicted upon individuals by systems of oppression and inequality collectively as "structural violence" (p. 8) and has insisted that mitigating HIV risk depends primarily on the freedom of disenfranchised women to make decisions rather than their knowledge or skill level (Farmer, 1999).

Current prevention strategies for women focus narrowly on condoms, however (Gordon, Stall, & Cheever, 2004; Johnson, Carey, Chaudoir & Reid, 2005). This precludes an adequate understanding of women's risk and reflects the intersection of the science of HIV prevention and social and political forces (Krieger, 1992, 1994; Waldby, 1996). For example, the same inequities that strongly determine HIV positive women's behavioral choices also influence prevention paradigms, including choices about program content, evaluation strategies, the kind of data that will be collected about participants, and desired program outcomes (Bourgois, Prince, & Moss, 2004; Krieger 1992, 1994). While the theoretical underpinnings of HIV prevention programs are often hidden under assumptions of scientific objectivity (Krieger, 1992), they nonetheless inform prevention programs for HIV positive women that fail to reflect women's experiences accurately.

The biomedical, lifestyle, and psychological models that explain HIV/AIDS risk have informed the development of HIV prevention interventions that are predominantly focused on individual's sexual risk practices (Bourgois, Lettiere, & Quesada, 1997; Bourgois et al., 2004; Fee & Krieger, 1993; Krieger, 1994; Mann, 1999; Zierler & Krieger, 1997). For example, psychological models underlying current secondary prevention programs include Social Cognitive Theory (e.g., Fogarty et al., 2001; Kalichman et al., 2001; Patterson et al., 2003; Wingood et al., 2004), Cognitive Behavioral Theory (e.g., Cleary et al, 1995; Wyatt et al., 2004), Information-Motivation-Behavioral Skills Theory (e.g., Margolin, Avants, Warburton, Hawkins, & Shi, 2003), and the Stages of Change Theory (e.g., Fogarty et al., 2001). These models assume that individual-level, rational factors influence women's risk behaviors and largely ignore the restraints imposed by external influences including but not limited to poverty or gender violence (Amaro, 1995; Cochran & Mays 1993; Teti, Chilton, et al., 2007; Wyatt, 1994; Zierler & Krieger, 1997). Several woman-centered interventions have begun to challenge traditional prevention approaches by focusing on skills and options needed by women who can not freely use condoms, the conflict between safe sex and childbearing desires, and the ways that social gender relations shape women's risk practices (Dworkin & Ehrhardt, 2007). These interventions represent the minority of prevention strategies for living with or at risk for HIV/AIDS, however.

Decisions about evaluation methods and types of priority program outcomes can also limit our ability to understand the complexity of women's risk. For example, secondary prevention programs define program success by quantified episodes of safer sex predominantly (Gordon, Stall, & Cheever, 2004; Johnson, Carey, Chaudoir & Reid, 2005). Quantified risk behaviors, which are often self-reported and only surrogate markers for women's multiple risks, are not always the only appropriate measures of a program's success, however (Rhatigan, Connors, & Rodriguez, 1996). For example, a woman may count as a failure by a program's evaluation standards if she has had unsafe sex, but having unsafe sex may have generated income that saved her family from hunger or prevented violence from a jealous partner. It is important to know why program participants do what they do in order to understand the programs' impact and women's prevention needs. Relying on measures of condom use or numbers of risk episodes alone also obscures a broader understanding of the ways that interventions influence women's behaviors and their health.

Prevention Opportunities: Understanding the Context of HIV Positive Women's Risk

Contextual factors that explain the situations and circumstances in which women make decisions about their sexual behaviors, and the ways that situational disadvantages manifest differently for each woman, present themselves when appropriate research methods, such as methods grounded in participants' experiences, not a priori explanations of risk, are applied. As the ethnographer Philippe Bourgois noted, "[many current quantitative] surveys are not asking the right questions; they simply miss the central dynamics of HIV risk" (Bourgois, 1997, p. 166). The primary purpose of evaluating HIV prevention interventions is to assess the efficacy of specific risk reduction strategies, yet program evaluation also provides an opportunity to elicit the reasons why women succeed or fail to enact safer sex practices and possible directions for future and improved intervention responses (Stall &van Griensven, 2005).

As a result, program evaluation is a powerful source of information about participants and their risk practices (Greene, 2003; Guba & Lincoln, 1989). Different evaluation strategies than those that dominate current intervention science are needed, however, to capture how contextual factors influence participants' risk experiences (Wegbreit, Bertozzi, DeMaria, & Padian, 2006). Qualitative data and evaluation methods are well-suited to gather participant-driven information about risk context and the meaning of and explanations for behaviors (Parker & Ehrhardt, 2001). For these reasons, HIV prevention researchers commonly use qualitative evaluation methods, including focus groups, interviews, and observational methods, in the formative phases of intervention development. These methods help researchers to better understand the populations they are serving, refine behavioral intervention strategies to respond to education and skill needs, and enhance the feasibility, acceptability, and cultural relevance of interventions (e.g., Essien, Meshack, Peters, Ogungbade, & Osemene, 2005; Fisher et al., 2004; Tross, 2001; Morrison-Beedy, Carey, Aronowitz, Mkandawire, & Dyne, 2002; Sterk, 2002).

Although many researchers think of qualitative methods as preliminary methods of data collection only, qualitative data can provide valuable information about the lives of intervention participants while they participate in interventions in the same way that these data refine program development with participant perspectives before interventions begin. For example, as an interventionist for the *Protect and Respect* program, I learned the most valuable lessons about women and their prevention needs through facilitating the group intervention. I was overwhelmed by the positive and negative stories women shared about their lives during the groups. While these experiences often influenced and helped to explain women's sexual behaviors, the study's primary survey evaluation instrument was not recording them and I believed that this was a weakness of our methodology (Teti, Raja et al., 2006). I began taping and transcribing the group sessions in an attempt to capture the women's experiences in the program and the reasons for their risk practices.

Group-level HIV prevention interventions (GLIs) provide ample opportunities for participants to talk about their lives and behaviors choices. Not surprisingly, this dialogue also results in rich, qualitative, contextual data. GLIs seek to change individual behavior in a group setting, thereby situating risk behavior in a social context and facilitating discussions among participants about the *reasons* for their behaviors (CDC, 2001b; Krueger, 1994; Madriz, 1994; Wilkinson, 1998). Contrary to a one-on-one conversation, groups encourage participant interaction. Participants agree and disagree with each other, challenge each others' ideas, and create discussions that focus on the details about each other's lives (Madriz, 1994; Wilkinson, 1998). Further, groups focus on the interaction between participants, giving more power to research participants and less control to the researcher's questions, interests, and conceptual framework. Surveys or one-on-one interviews can limit the responses of those who do not answer questions according to the researchers' assumptions (Madriz, 1994; Wilkinson, 1998).

III. Research Questions

Considering the numerous ways that intervention participants benefit from groups, and the opportunities for researchers to learn about women through their group experiences, and through the use of qualitative data and evaluation strategies, the data for this study were from two types of group level interventions from *Protect and Respect*: a skills-based educational group and a peer-led support group.

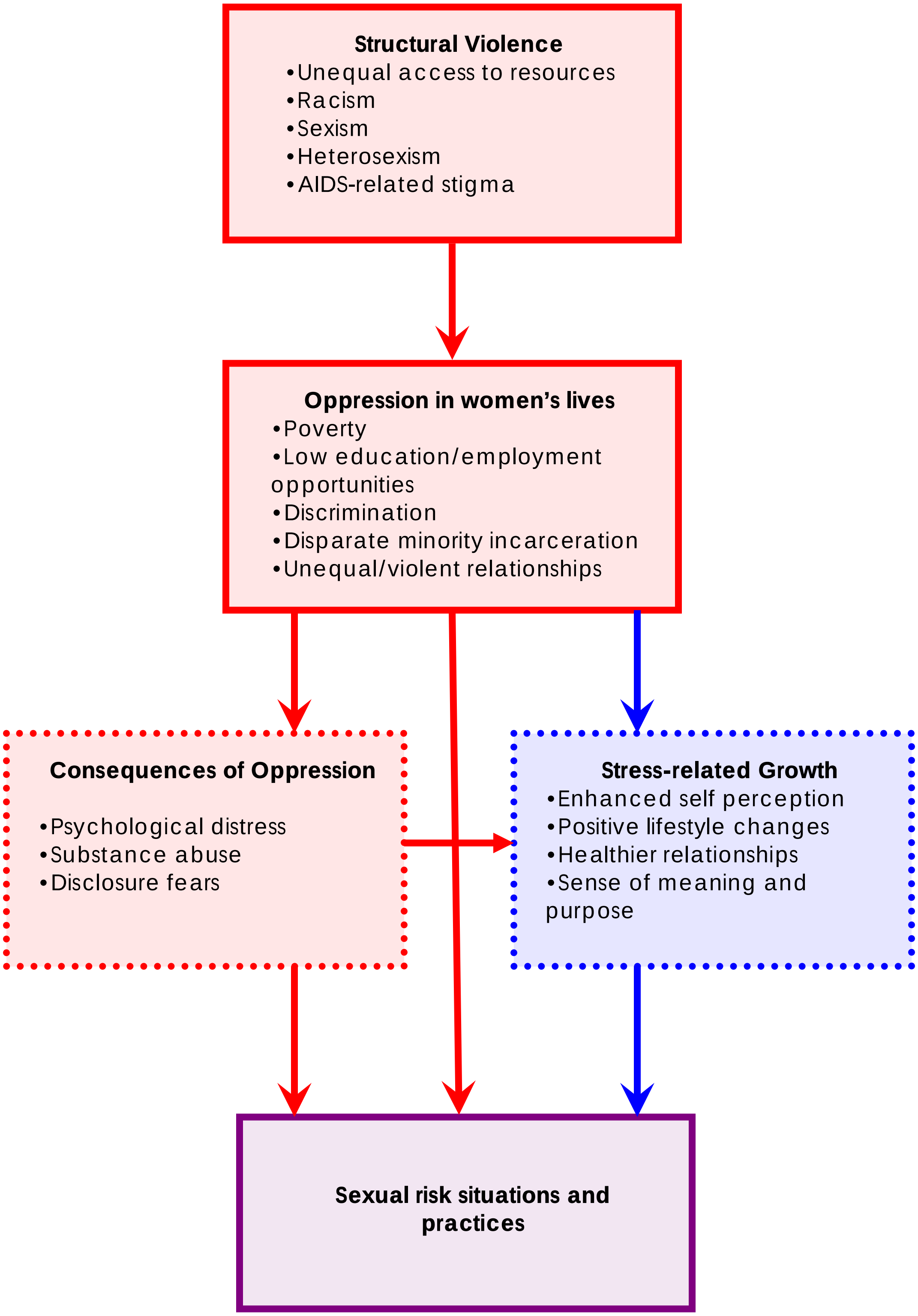
The primary objectives of my research were to explore the following questions by using strategies of grounded theory and narrative analysis to examine the *Protect and Respect* GLI and peer group participants' discussions:

1. How does structural violence manifest in the lives of HIV positive women who participated in *Protect and Respect*?
2. How is structural violence associated with these women's daily experiences of living with HIV?
3. How does stress-related growth manifest in the lives of HIV positive women who participated in *Protect and Respect*?
4. How is stress-related growth associated with these women's daily experiences of living with HIV?

Chapter 2: Background and Literature Review of Structural Violence, Stress-Related Growth, and HIV/AIDS among Women

Figure 1 (on the following page) describes pictorially the relationship between structural violence, stress-related growth, and sexual risk behavior described in the empirical and theoretical literature. A small number of empirical studies link structural violence and oppression with sexual risk behaviors. Peretti-Watel, Spire, Obadia, & Moatti (2007) found an association between experiences of AIDS-related discrimination and unsafe sex among HIV positive men and women living in France. Diaz and Ayala (2001) and Diaz, Ayala, and Bein (2004) found that Latino gay men who reported more instances of sexual and racial/ethnic discrimination and financial hardship were more likely to experience psychological distress and engage in more sexual risk situations and behaviors than those reporting fewer discriminatory experiences. A large body of correlational and theoretical research has linked several forms of structural violence to disadvantages in women's everyday lives (these are cited and explained in detail in the following section) that increase women's vulnerability to HIV/AIDS and their ability to have safer sex once they are infected. Despite negative experiences, however, many women resist oppression and hardship in their daily lives, and thrive in the face of the suffering imposed by structural violence and living with HIV/AIDS. A growing body of research explores HIV positive women's experiences with stress-related growth and their relation to women's health, well-being, and risk practices (these are cited and explained in detail in the following section).

Figure 1. The relationship between structural violence, stress-related growth, and sexual risk practices described in the empirical and theoretical literature.



I. Structural Violence and HIV Risk

Violence usually conveys a physical image, but structural violence is entrenched in longstanding and ubiquitous world views (Galtung, 1969). Researchers often reduce the term to define economic disparities (Farmer, 2005), but in this study I applied Farmer's (2005) and Sen's (1999) definition of structural violence as a broad rubric of oppression and "unfreedoms" that harm human dignity and restrict women's potential, choices, and options (Sen, 1999, pgs. 3-4). Krieger and Basset (1993) challenged that models of disease that blame the social environment are examples of "neutral science" (p. 168), and deny or obscure the source of disparities. It is important to note that social structural forces are not abstract. Rather, they result from the actions of individuals operating within institutional structures and their corresponding ideological belief systems.

A large body of empirical, correlational, and theoretical research has revealed that structural violence cultivates HIV transmission (Farmer, 2005). The primary forms of structural violence identified in the literature that may facilitate HIV transmission include unequal access to resources, racism, heterosexism, sexism, and HIV/AIDS related stigma (Farmer, 2005; Farmer, Nizeye, Stulac, & Keshavjee, 2006; Lane et al. 2004), which often act together to limit women's health and safer sex choices. I describe each of these structural forces and the ways that they may affect or mediate (i.e. through poor mental health and substance addiction) women's sexual risk behavior in detail in this section.

Unequal Access to Resources

Health researchers have established clearly the connection between poverty and poor health (Kawachi, 2000). Researchers have linked HIV/AIDS incidence and prevalence to economic deprivation in Philadelphia (Fife & Mode, 1992a; Fife and Mode, 1992b), Los Angeles County (Simon, Hu, Diaz, & Kerndt, 1995), Massachusetts (Zierler, Krieger, et al., 2000) and globally. Tladi (2007) established an empirical link between poverty and HIV/AIDS infection in South Africa. In addition, several nationally representative and longitudinal studies of HIV-positive women, including the Women's Interagency Health Study (WIHS), The Human Immunodeficiency Virus Epidemiology Research Study (HERS), and the HIV Cost and Services Utilization Study (HCSUS), reported that HIV/AIDS occurs disproportionately among poor women and women who lack educational and employment opportunities. Almost half (46%) of the HIV-positive women in the HERS sample reported less than a high school education, 74% made less than $12,000/year, and 19% said that they did not have a safe place to live in the previous year (Smith et al., 1997). Likewise, only 63% of HIV-positive women in WIHS completed high school and 59% reported living below the poverty line (Barkan et al., 1998). Women in the HCSUS sample were more likely to be poor, unemployed, and less educated than their male counterparts (Bozzette et al., 1998).

HIV/AIDS researchers and clinicians conceptualize poverty as a root cause of HIV among women (Farmer, 1992, 1999, 2005; Parker, Easton, & Klein, 2000; Poundstone, Strathdee, & Celentano, 2004). Unequal access to education, employment and economic resources diminish women's control over their lives and their negotiating power in relationships. Poverty also restricts women's sexual networks, and increases their likelihood of unsafe injection drug practices and exchange or survival sex (Kalichman, 2000).

Qualitative case studies and patient narratives link poor health outcomes and sexual risk practices with the ways that poverty constrains women's agency and decision making power in their relationships (Connors, 1996; Farmer, 1992, 1999). Plowden, Fletcher, and Miller (2005) conducted interviews with men and women engaging in high risk sexual behaviors and found that the respondents' desperation forced them to sell the condoms and needles they received from prevention programs for cash. Numerous studies have found risky sexual practices to be more common among HIV-positive women who are poor or who have limited resources, when compared with HIV-positive women with higher incomes and resources (Aidala et al., 2006; Kalichman, 1999; Wenzel, Tucker, Elliot, & Hambarsoomians, 2006). Leone et al., 2005 found that HIV positive Black women in North Carolina reported financial dependence on their partners as a reason for acquiescing to risky behaviors with these partners. Likewise, Tladi (2007) found that South African women who were dependent on their partners for money were more likely not to use condoms because their partner did not want to, compared with women who did not rely on their partners for money.

The HCSUS data revealed that approximately one in five women with HIV were uninsured, and were half as likely (14%) than HIV positive men (36%) to hold private insurance (Bozette et al., 1998; Schuster et al., 2000). HIV positive women were also more likely to have dependent children, and to live with their children, compared with HIV positive men. For example, 45% of women in HCSUS were living with children under the age of 17, compared with 6% of men (Stein et al., 2000). Women were also more likely to sacrifice basic necessities such as food, clothes or housing to pay for health care than men (Cunnigham et al., 1999). Reilly and Woo (2003) reported that unsafe sex was more common among HIV positive adults who reported unmet needs and who lacked access to medical and social services. Women's lack of basic needs may prevent them from prioritizing safe sex, force them into unhealthy and risky sexual situations or prevent them from accessing prevention interventions and risk reduction messages.

Racial Discrimination

Racial inequality and discrimination, differential access to societal opportunities by race and prejudice and discrimination that results from one's racial/ethnic identity (Jones, 2000), harm women's health in numerous ways (Krieger, 1999). Krieger (1999) contended that epidemiologic research linking discrimination to population health is in its infancy. This stems from the complex interaction between discrimination and other disadvantages, including poverty, as well as the use of race categories (which often identify skin color only) as a proxy for culture or racism (Krieger, 1992, 1999; Wyatt, 1994). Nonetheless, Krieger (1999) summarized 15 studies that examined the relationship between racist experiences and health and found that experiences of racial discrimination were associated with numerous poor health outcomes, including high blood pressure, heart disease, depression, low birth weight babies, self-rated ill health, and chronic health conditions.

Ethnic minority women bear the disproportionate brunt of HIV/AIDS infections. African American women account for 13% of the population and 66% of AIDS diagnoses (CDC, 2007a). The 2005 case rate for Black women was 23 times greater than that for White women (CDC, 2007b). HIV/AIDS is the leading cause of death for Black women aged 25-34 years, the third leading cause of death for Black women aged 35-44 years, and the fourth leading cause of death for Black women aged 45-54 years (CDC, 2007a).

The differences between Black and White women's HIV/AIDS rates are not explained by differences in sexual risk behavior alone but may also result from social structural factors, including racial discrimination, which put women at risk. Yet, with the exception of a handful of empirical studies conducted with gay and bisexual men, few studies have linked empirically *racial discrimination* and sexual risk taking. Diaz and Ayala (2001) and Diaz et al. (2004) found that Latino gay *men's* experiences of racial discrimination were associated with their psychological distress and participation in difficult sexual situations and risk behaviors. To my knowledge, no studies have linked HIV positive or negative *women's* experiences with racism to their physical or mental health or sexual behaviors directly.

Health researchers have theorized that racial discrimination relates to Black women's sexual risk behaviors and disproportionate HIV/AIDS rates in complex ways. Poverty and racial discrimination contribute to racial segregation as well as high levels of community-level illicit drug use, high incarceration rates and low sex ratios in the African American community (Adimora & Schoenbach, 2002, 2005; Krieger, 1999). Together these factors directly and indirectly influence sexual networks and disproportionate rates of STIs and HIV among racial and ethnic minorities (Adimora & Schoenbach, 2002, 2005; Krieger, 1999).

For example, a disproportionate number of Black and Latino men and women are in prison (Freudenberg, 2001, 2002; Harrison & Beck, 2005). National estimates conclude that incarcerated people are at least five times more likely to be infected with HIV than the general population (Maruschak, 2001), putting minority men who go to prison and their female partners at greater risk for HIV (Comfort, Grinstead, Faigeles, & Zack, 2000; Freudenberg, 2001). Incarceration is one of the contributing factors to high unemployment rates, economic adversity, and low sex ratios between Black men and women, which means that there are fewer Black men available for relationships than women (Adimora & Schoenbach, 2002, 2005; Lane et al., 2004). The combination of incarceration, poverty, stressed relationships, residential segregation, and low male to female sex ratios may facilitate high rates of partner change and limit the pool of available HIV-negative partners. Theoretically, this in turn may contribute to higher rates of HIV and other STIs among African Americans (Adimora & Schoenbach, 2002, 2005; Lane et al., 2004).

Distrust of the medical community may deter African Americans from participating in and benefiting from prevention programs. Gamble (1997) noted that the legacy of the Tuskegee study endures partly because the racism that it embodied mirrors African Americans' contemporary medical experiences. Thomas and Quinn (1991) argued that HIV/AIDS conspiracy theories are related to lingering Tuskegee fears and are common in Black communities. These include the belief that HIV/AIDS is a weapon of racial warfare, HIV/AIDS was created by the government to kill Blacks, and that condoms are a form of genocide targeted at the Black community (Thomas & Quinn, 1991). While these views are extreme, they are important and meaningful because they may influence women's attitudes about their own risk and their opportunity to benefit from prevention messages.

Heterosexism

Heterosexism is the process of defining human experience in heterosexual terms solely and purposefully or unconsciously ignoring, invalidating, or derogating homosexual behaviors, sexual orientation, relationships, or lifestyles (Herek, 1991). Herek (2004) proposed the use of the term heterosexism versus homophobia because "phobia" conveys a fear of homosexuality and does not adequately capture the psychological, social, and cultural processes that underlie the oppression associated with heterosexist attitudes and behaviors. Heterosexism more appropriately acknowledges the systems that rationalize the neglect of homosexual experiences.

Existing empirical data do not link HIV positive women's experiences with heterosexism or homophobia to their sexual risk behaviors. HIV/AIDS researchers have theorized that heterosexism can harm women's health and influence their sexual risk behaviors by: (1) prioritizing the HIV prevention needs of *heterosexual* women and; (2) creating an environment where non-heterosexual men hide their sexual orientation and behaviors, maintain relationships with women, and potentially put their female partners at risk for HIV or STI infection.

Primary and secondary HIV prevention programs for women focus on male condom use to prevent HIV and STI transmission predominantly (Wolitski et al., 2006). This strategy assumes that women who participate in HIV prevention programs are heterosexual and partner with men only. However, this is not necessarily true. HIV prevention program participants include heterosexual and non-heterosexually identified women (Teti, Bowleg, et al., 2006). Additionally, sexual orientation is not synonymous with sexual behavior. Women who identify as heterosexual may partner with women and women who identify as lesbian may partner with men. Therefore, HIV positive women who partner with or have sex with women (WSW[3]) need sexual risk reduction messages because they can put their partners and themselves at risk for STIs and (other strains of) HIV through their unsafe sexual activities with men and women.

For example, many (75%-85%) WSW report one or more lifetime male sexual partners (Baily, Farquar, Owen, & Whittaker, 2003; Diamant, Schuster, McGuigan, & Lever, 1999). Research suggests that samples of women who report recent sex with *women and men* recruited from various samples including public venues, STI clinics, and primary care settings, exhibit a higher number of risk practices compared with women who partner with men only.

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[3] WSW is not an appropriate term because it defines women by their sexual behavior only (Young & Meyer, 2005). I am using WSW because the majority of research reports describe their findings accordingly.

These risk behaviors include sex with gay or bisexual men, high rates of unprotected vaginal and anal sex with men, use of injection drugs, use of crack cocaine, the exchange of sex for drugs or money, and high rates of substance use with sex (Bevier, Chiasson, Hefferman, & Castro, 1995; Lemp et al., 1995; Koh, Gomez, Shade, & Rowley, 2005; Marrazzo, Koutsky, & Handsfield, 2001).

Further, WSW commonly report unprotected sexual encounters with other women, including unprotected oral sex or sex with uncovered sex toys (Dolan & Davis, 2003; Marrazzo, Coffey, & Bingham, 2005; Stevens & Hall, 2001). Case reports suggest that vaginal secretions and menstrual blood are potentially infectious and that oral or vaginal mucous membrane exposure to these secretions can lead to HIV infection (Kwaka & Ghobrial, 2003). The transmission of several common STIs have been reported between women, including herpes (Marrazzo, Stine, & Wald, 2003), human papillomavirus (HPV) (Marrazzo et al., 2001), and trichomoniasis (Kellock & Mahoney, 1996). Bacterial vaginosis is common among WSW and may be sexually transmitted (Marrazzo et al., 2002). Despite their risks, WSW report little concern about having sex safe (Dolan & Davis, 2003; Stevens & Hall, 2001), which likely results in part from the fact that WSW do not receive adequate information tailored to their sexual experiences in heterosexist secondary HIV prevention programs.

Heterosexism also results in societal discrimination towards men who partner with and have sex with men (MSM). This may lead some MSM to hide their same sex behaviors from their female partners, increasing their engagement with multiple and simultaneous partnerships and the spread of STIs or other strains of HIV to their female partners (Lane et al., 2004; McNair & Prather, 2004; Montgomery, Mokotoff, Gentry, & Blair, 2004).

Sexism and Gender Inequality

Mann described male domination a threat to the public health and the success of HIV prevention efforts (Mann, 1995). Sexism and gender inequity influence women’s sexual risk practices in complex ways. First, patriarchy and sexism compromise women’s opportunities for economic and educational advancement. Poverty, racism, and sexism intersect to intensify women's challenges. Therefore, women are at higher risk for participating in sexual risk behaviors because of the disadvantages and dependencies associated with poverty and racism that have already been described.

Second, limited resources compromise women's level of power in their relationships with men (Amaro, 1995). Research suggests that women's perceived power and control in their sexual relationships is related to their ability to effectively use condoms to engage in safe sex with their male partners (Gomez & Van Oss Marin, 1996; Pulerwitz, Amaro, De Jong, Gortmaker, & Rudd, 2002; Pulerwitz, Gortmaker, & DeJong, 2000; Wingood & DiClemente, 1998).

In addition, traditional gender norms reinforce sexual scripts that disadvantage women. Sexual scripts include cultural, interpersonal, and intrapersonal scripts that guide individual's sexual decisions (Simon & Gagnon, 1986). Research suggests that women's sexual scripts include unprotected sex as a normative relationship promoting behavior (Jones, 2006) and condom use as a male controlled activity (Bowleg, Lucas, & Tschann, 2004), and exclude condom use and negotiation with male partners (Hynie, 1998).

In its most extreme form, sexism manifests in violence against women. While the severity of violence distinguishes it from more subtle forms of sexism, gender-based violence ultimately results from gender inequity and represents one of the furthest points on the continuum of harm imposed by sexism. National longitudinal studies report that a disproportionate number of HIV positive women have experienced interpersonal violence during the course of their lives. Two-thirds (66%) of women in the WIHS reported a lifetime history of domestic violence and 31% reported a history of child sexual abuse (Cohen et al., 2000). Similarly, Vlahov et al. (1998) found that 41% of HIV-positive women in HERS reported physical abuse as a child, 41% reported sexual abuse as a child, 66% reported physical abuse as an adult, and 46% reported sexual abuse as an adult. Zierler et al. (2000) reported that 20% of women in HCSUS reported physical harm since their HIV diagnosis; half of the women identified their HIV-positive status as a cause of the violent episode.

Violence and sexual risk taking are related in both direct and indirect ways. Women can acquire sexually transmitted infections (STIs) directly through forced sex (Carlson-Gielen et al., 2007; Maman, Campbell, Sweat, & Gielen, 2000; McFarlane et al., 2005). Abused women may be afraid to demand safe sex. Victims of relationship violence report fewer positive expectations related to condom use, and prefer to use other protective methods, such as spermicide, when compared with non-abused women (Saul, Murphy, and Miller, 2004; Thompson, Potter, Sanderson, & Maibach, 1997).

Women who have experienced sexual or physical violence are more likely than women who have not to report STIs and engage in sexual risk behaviors (Carlson-Gielen et al., 2007; Johnson, Cunningham-Williams, & Cottler, 2003; Wu, El-Bassel, Witte, Gilbert, & Change, 2003; Wyatt et al., 2002). They report high numbers of sex partners, trade sex for money, and partner with high-risk men more than women who have not experienced violence (Cohen et al., 2000; El Bassel, Gilbert, & Raj, 2003; Parillo, Freeman, Collier, & Young, 2001; Thompson et al., 1997; Wu et al., 2003,). Abused women are also less likely to report condom use and more likely to experience violence as a result of using both male and female condoms, when compared with women who have not been abused (Carlson-Gielen et al., 2007; Maman et al., 2000, Wingood & DiClemente, 1997).

HIV/AIDS Related Stigma

AIDS is freighted with profound meaning (Singer, 1992) because the virus is deadly, incurable, and uncertain. The emergence of HIV/AIDS tested our society's faith in and reliance on medicine to cure disease (Epstein, 1996) and our false sense of protection from infectious epidemics (Brandt, 1988). Mann described HIV/AIDS as three separate epidemics. The first was the spread of HIV, the second was the rising rate of AIDS cases, and the third epidemic is the epidemic of political, social, cultural, and economic responses to AIDS, characterized by discrimination and stigma that are as deleterious as the disease itself (Mann, as cited in Parker & Aggleton, 2003).

AIDS-related stigma manifests as anger and negative feelings towards HIV positive individuals, the belief that they deserve their illness, avoidance of people with HIV/AIDS, and support for public policies that restrict the human rights of those with HIV/AIDS (Herek, Capitanio, & Widaman, 2002). Research conducted with nationally representative probability samples suggests that a sizable proportion of the population believe that HIV/AIDS can be transmitted through casual contact, that HIV positive individuals deserve their illness, and feel discomfort and negative feelings towards people with HIV/AIDS (Herek et al., 2002; Lentine et al., 2000).

Epidemiologists initially linked AIDS to already marginalized groups, identifying AIDS as an illness of the four H's: homosexuals; heroin addicts; Haitians; and hemophiliacs (Oppenheimer, 1988). When women were finally recognized as people with AIDS, they were perceived as vectors of the disease for their partners or their children (Triechler, 1999). As Farmer noted, "the majority of women with AIDS had been robbed of their voices long before HIV appeared to further complicate their lives" (1999, p. 62).

In other words, AIDS-related stigma reproduces and worsens existing inequalities. For example, women often experience the stigma of AIDS multiplied by the stigma that results from gender, sexuality, and racial/ethnic minority status (Parker & Aggleton, 2003; Sandelowski, Lame, & Barroso, 2004). Sandelowski et al. (2004) conducted a qualitative metasysnthesis that integrated the findings of 93 studies exploring HIV positive women's experiences of HIV/AIDS related stigma. They concluded that perceived and actual stigma was pervasive in women's lives. HIV positive women lived in fear of social rejection, violence, and discrimination from their relationships with their children, partners, relatives, friends, and health care providers. Women described female-specific stigma including the stigma associated with assumptions that they infected their children or had been infected via prostitution, promiscuity, and drug use.

HIV/AIDS researchers have conceptualized that stigma can influence women's sexual risk behavior through its impact on HIV status disclosure to sexual partners (Gielen, O'Campo, Faden, & Eke, 1997; Gielen et al., 2000) and psychological distress (Clark, Linder, Armistead, &

Austin, 2003; Katz & Nevid, 2005). In addition AIDS-related stigma hinders the success of HIV prevention and care programs by preventing women living with HIV from accessing needed health and social services, disclosing their status to their partners, and talking openly about their sexual risk practices (Valdiserri, 2002). In their ethnographic study of HIV positive women and stigma, Carr and Grambling (2004) stated that:

> The fear of stigma was so overwhelming that on diagnosis, the women were not concerned with the possible physiologic changes or death but rather the psychological ramifications that accompany the disease. This fear became a barrier to women achieving the goals necessary for them to maintain and enhance their health (p. 30).

The Consequences of Layered Oppression

Structural violence creates an environment where all forms of oppression interact synergistically. For example, unequal resources can lead to life stress and depression, which in turn can exacerbate relationship violence, which then fosters harmful behaviors like substance abuse (James et al., 2003; McNair & Prather, 2004). Research suggests that experiences with poverty, racial discrimination, heterosexism, sexism, and HIV/AIDS related stigma can contribute to poor mental health (Bensley, Van Eenwyck, & Winkoop Simmons, 2003; Katz & Nevid, 2005; Clark et al., 2003; Johnson et al., 2003; Koh & Ross, 2006; Richardson et al., 2001) and substance abuse (Diamant, Wold, Spritzer, & Gelberg, 2000; El-Bassel et al., 2003; Johnson et al., 2003; Wyatt, Vargas, Burns-Loeb, & Williams, 2005).

Poor mental health and substance abuse. HIV/AIDS researchers have not explored adequately the link between oppression and substance use and psychological distress among HIV positive women. It is theoretically possible that women's addiction and depression are associated with the various and identified forms of structural violence. In turn, psychological distress and substance abuse may increase women's involvement in sexual risk situations and practices. National probability and convenience sample studies report that women with HIV/AIDS experience high rates of anxiety and depression. Over half (58%) of women in WIHS

(Barkan et al., 1998) and HERS (Smith et al., 1997) reported clinical depression. Cook et al. (2004) concluded that over a third of the women (32%) in the HCSUS reported having depressive symptoms 75% or more of the time during their study visits.

Further, research indicates that unsafe sex is more common among HIV-positive and at-risk women who report negative mood states such as depression (Kalichman, 2000), hostility (Crepaz & Marks 2002; Kalichman, 2000), anger (Crepaz & Marks, 2002), low self esteem, and greater life dissatisfaction (Somlai et al., 2000). Decreased self-esteem, as well as anxiety and depression may make it difficult for women to talk to their partners about sex, particularly women with violent histories (Krug, et al., 2002). In turn, depressed HIV positive women are more likely to abuse substances than non depressed women (Lightfoot et al., 2005; Richardson et al., 2001).

National probability and convenience samples also indicate that HIV positive women report frequent use of drugs and alcohol. Thirteen percent of women in the HERS reported drinking two or more drinks a day in the last 6 months (Gruskin et al., 2002). In addition, 23% reported smoking marijuana, 19% reported smoking crack, 38% reported using cocaine, and 29% reported using heroin (Gruskin et al., 2002). Similarly, 27% of women in the WIHS reported using crack cocaine or injection drugs in the six months prior to their interview (Wilson et al., 1999). Over a third (38%) of women in HCSUS reported drinking in the previous month and16% reported drinking heavily (Galvan et al., 2002).

Research suggests that substance abuse is associated with sexual risk behaviors (Malow, Devieux, Rosenberg, Dyer, & St. Lawrence, 2006; Sikkema et al., 1996; Somlai et al., 2000). Substance abuse can increase sexual risk taking by impairing logical thought processes, leading to the exchange of sex for drugs, and increasing women’s reliance on unhealthy coping mechanisms (El Bassel et al., 2003).

Measuring Structural Violence

It is difficult to capture and measure the devastating impact of structural violence and its consequences on individual behaviors. The impact of social processes is often too complex to measure via traditional HIV research methods such as quantitative surveys (Bourgois et al., 2004). Quantitative measures are likely reflect the biases of public health researchers, whose social position and privilege often renders them unable to truly understand social suffering (Bourgois et al., 2004). Anthropologists study social suffering or everyday violence to account for the tangible injuries that structural violence inflicts (Kleinman, 2000; Scheper-Hughes, 1992).

Qualitative methods are well suited to capture complex social behaviors and to help uncover the diversity of behavioral patterns within larger groups of people (Clatts & Sotheran, 2000; Singer, 1994). By contextualizing individual experiences, qualitative methods can identify the powerful political forces that constrain women's behaviors (Bourgois et al., 2004; Clatts & Sotheran, 2000). For example, allowing a woman to talk about *why* she has unsafe sex may reveal that she is forced to engage in unsafe sex work because she lives in poverty and perceives no alternate options for survival.

HIV is also transmitted in private, stigmatized, and sometimes illegal ways (Parker & Ehrhardt, 2001). It is therefore difficult to measure accurately the intimate practices of marginalized people through self-report structured surveys (Bourgois et al., 1997). In his ethnographic study of homeless heroin addicts, Bourgois et al., (1997) found that many street addicts were incapable of responding accurately on self reports because the reality of their practices were too dangerous and self destructive to admit. As a result, he concluded that qualitative methods were optimal for conducting research with disenfranchised, at-risk, individuals and communities about the impact of oppression on their behaviors. For these reasons, I chose to use qualitative analysis methods to study women's experiences with structural violence in this study (explained in more detail in the methods section).

II. Moving Beyond a Problem-Oriented Focus on Women, HIV, and Risk

The consequences of structural violence are harmful to women and increase their vulnerability to HIV infection. It is important to identify risk factors for modification in prevention interventions, but equally critical for interventions to foster women's strengths (Luthar &Cicchetti, 2000; O'Leary & Ickovics, 1995). Psychological and behavioral research has focused traditionally on what is wrong but has not sufficiently investigated individual and community strengths (Seligman, 2000). Exploring women's strengths resonates with the growing body of research describing positive psychology (Seligman, 2000). The ways that HIV positive women exhibit resistance, growth, courage, and strength when confronting the effects of structural violence and the stress of being HIV positive is an understudied aspect of women's lives.

Stress-Related Growth

Research has suggested that women with HIV report high amounts of traumatic stress and post traumatic stress syndrome (Kimmerling et al., 1999; Martinez, Israelski, Walker, & Coopman, 2002), and stress related to living with HIV and HIV disclosure, poor health, HIV symptoms, medication side effects and difficulty managing care giving responsibilities while ill (Catz, Gore-Felton, & McLure, 2002; Mosack, Abbott, Singer, Weeks & Rohena; Siegal & Lekas, 2002; Siegal & Schrimshaw, 2005; Silver, Bauman, Camacho, & Hudis, 2003). Women describe learning about their HIV infection as a traumatic experience and the point at which many first turn to drugs and alcohol (Stevens & Doehr, 1997; Stevens & Hildebrandt, 2006; Unger & Collins, 2005). Other HIV positive women identify greater life stresses than learning about their HIV infection as traumatic, including poverty (Smith et al., 2001) and addiction (Unger & Collins, 2005).

Although difficult experiences are not *always* precursors to an inevitable growth process, traumatic and stressful experiences can serve as a powerful vehicle for growth. Stress-related growth is the process that occurs when an individual struggles with a new reality created by a trauma (Tedeschi, Park, & Calhoun, 1998; Tedeschi & Calhoun, 2004). The experience of growing from negative circumstances has been alternately labeled thriving (O'Leary & Ickovics, 1995; Park, 1998), stress-related growth (Park, 1998), and post-traumatic growth (Tedeschi et al., 1998). In this study I used the term stress-related growth to correspond with the small but the existing research describing women with HIV and positive growth (Siegal & Schrimshaw, 2000; Siegal, Schrimshaw, & Pretter, 2005).

When individuals face adversity, they may survive, recover, or thrive (O'Leary & Ickovics, 1995). Stress-related growth refers to change that goes beyond survival and recovery to transformation and improved functioning (O'Leary, 1998) and has been applied to the study of various health and social problems, including bereavement, rape and abuse, disabilities, and HIV/AIDS (Tedeschi et al., 1998). Change results when traumas force individuals to confront and change their current ways of thinking and behaving. HIV/AIDS diagnosis can be described as a stressful, traumatic, or life changing experience for some women. For example, Carr and Grambling (2004) described the way HIV positive women in their ethnographic study redefined their lives in response to HIV:

> [The women] may have been mothers, sisters, wives, teachers, secretaries, or designers prior to diagnosis, but afterwards they were simply women with HIV/AIDS. The diagnosis overshadowed everything they had been, everything they had accomplished, and totally redefined who they were (p. 32).

Stress-related growth manifests itself in various ways, including changed perceptions of self, relationships, and life philosophies (Tedeschi et al., 1998). People who report this kind of growth label themselves as survivors of trauma, describe an increased sense of self-reliance, a heightened awareness of the importance and fragility of their life, enhanced personal relationships, a sense of meaning, and appreciation for life, wisdom, and spiritual development (Tedeschi et al., 1998). Stress-related growth is influenced by a number of individual and social resources, including personality factors, social support, and societal privilege and oppression (Blankenship, 1998; Calhoun & Tedeschi, 1998; O'Leary, 1998).

Application of Stress-Related Growth to HIV/AIDS

A small number of studies exploring stress-related growth among HIV positive women have found that women report high levels of stress-related growth and identify positive life changes that result from their illness (Dunbar, Mueller, Medina, & Wolf, 1998; Goggin et al., 2001; Siegal & Schrimshaw, 2007; Siegal & Schrimshaw, 2000; Siegal et al., 2005; Updegraff, Taylor, Kemeny, & Wyatt, 2002). These changes include: a new sense of spirituality and faith (Siegal et al., 2005; Siegal & Schrimshaw, 2000); improved interpersonal relationships(Siegal et al., 2005; Siegal & Schrimshaw, 2000; Updegraff et al., 2002); greater appreciation for life (Siegal et al., 2005; Siegal & Schrimshaw, 2000; Updegraff et al., 2002); motivation to set new goals including the pursuit of career changes (Siegal & Schrimshaw, 2000); finding new meaning and purpose; a sense of empowerment(Siegal et al., 2005; Siegal & Schrimshaw, 2000; Updegraff et al., 2002); and closer and more meaningful relationships with family and loved ones (Siegal et al., 2005; Siegal & Schrimshaw, 2000; Updegraff et al., 2002).

In addition, these studies as well as illness narrative studies of women's experiences of living with HIV (Mosack et al., 2005; Unger & Collins, 2005) have found that some women perceive the virus as a wake up call and a motivation to stop using drugs or alcohol, seek help for addiction, end risky sexual behavior, and take better care of their health (Barroso & Sandelowski, 2004; Mosack et al., 2005; Siegal & Schrimshaw, 2000; Siegal et al., 2005; Unger & Collins, 2005; Updegraff et al., 2002). In a qualitative metasynthesis summarizing the intersection of substance abuse and HIV among women, Barroso and Sandelowski (2004) reported that some women described HIV as a "blessing in disguise" (p. 52) that helped women stop their drug and alcohol use. HIV positive women described HIV infection as a critical event that "helped them find the power to change the trajectory of their lives" (p. 52).

Implications of Studying Stress-Related Growth for HIV Prevention

Identifying how women use their individual and collective strengths to manage stress and make positive changes can direct the content of future prevention programs by revealing the way women's positive attributes may protect them against unsafe behaviors (O'Leary & Ickovics, 1995). O'Leary and Ickovics summarize the importance of this approach, particularly for women's health interventions:

> Inherent in any profound health challenge is the potential for [danger or opportunity]. To date, women's health researchers have primarily focused on the dangerous consequences of challenge, investigating the determinants and consequences of morbidity and mortality. We suggest an alternative focus; one that highlights the opportunity for growth and change. Understanding the factors that promote thriving can provide an important foundation for a paradigm shift away from a focus on illness and pathology towards one that understands, explains, and nurtures [women's] health (p. 138).

Measuring Stress-Related Growth

Massey, Cameron, Ouellette, and Fine (1998) emphasized the importance of studying stress-related growth qualitatively. Massey et al. (1998) argued that quantitative measures are likely to result in narrow examples of thriving by using predetermined definitions of the construct. The open-endedness of qualitative research provides opportunities for unexpected discoveries (Singer, 1992). Because researchers and research participants often perceive risk behaviors differently, qualitative research can identify important information to bridge conceptual differences that would otherwise remain hidden (Marecek, 2003).

Massey et al. (1998) argued that analyzing thriving with a qualitative stance allowed them to understand the context and meaning of thriving, revealing that one person's obstacle to thriving was another person's resolution. New ideas about thriving arose because the researchers did not assign or impose specific meanings and values as relevant, useful, and healthy. They further noted that the likelihood that someone will face a challenge and thrive in response to that challenge is determined by social forces, underscoring the importance of contextual data. For example, marginalized social groups may treat events as routine but the same events would be traumatic for others more privileged groups (Blankenship, 1998; Massey et al., 1998). For these reasons, I chose to study stress-related growth using a qualitative stance (Marecek, 2003) and qualitative methods that prioritized participants' experiences (explained in more detail in the methods section).

Chapter 3: Methods

The data from this study included transcripts of the *Protect and Respect* program's skills based (referred to as the group-level-intervention, GLI) and peer-led group sessions. In this chapter I describe: the design of Protect and Respect and the GLI and peer group sessions; human subjects' considerations; the process of choosing the study sample; and the strategies of grounded theory and narrative analysis that I used to answer my research questions:

1. How does structural violence manifest in the lives of HIV positive women who participated in *Protect and Respect*?
2. How is structural violence associated with these women's daily experiences of living with HIV?
3. How does stress-related growth manifest in the lives of HIV positive women who participated in *Protect and Respect*?
4. How is stress-related growth associated with these women's daily experiences of living with HIV?

I. The Protect and Respect Project Program for Women with HIV/AIDS

Project Description and Design

Protect and Respect was a sexual risk reduction research program designed specifically for HIV-positive women receiving primary care services from the Partnership Comprehensive Care Practice (PCCP) HIV/AIDS clinic in Philadelphia. The goal of *Protect and Respect* was to test prevention strategies to decrease HIV positive women's sexual risk behavior. Specifically, women in the program learned skills to enhance their ability to disclose their HIV status and use male and female condoms with all of their sexual partners. The program focused on risk reduction strategies for heterosexual women, although the needs of women who partner with or have sex with women (WSW) were also recognized and addressed through the project's risk reduction messages (for a more detailed description of the development and implementation of *Protect and Respect*, see Teti, Rubinstein, et al., 2007).

The PCCP provides comprehensive integrated HIV services, including primary care, case management, nutrition counseling, pharmacy, mental health, family planning, and addiction services. Among more than 1300 adult patients served annually, 34% are women, 79% are African-American or Hispanic, most (62%) are 20 to 44 years old, and many are living in poverty (75%) (E. Aaron, Personal communication, March 1, 2006).

Project recruitment began in April, 2004, and ended on June 30, 2006. Follow-up data collection visits ended on June 30, 2007. Women enrolled in *Protect and Respect* when they came to the clinic for their regularly scheduled medical visits. Eligibility criteria for the study included women who were HIV-positive for at least 6-months, over 18 years of age, and English-speaking. Enrolled women were randomly assigned to participate in one of two groups for purposes of the program's evaluation. Group one (the comparison group) received sexual risk reduction messages from their primary medical providers. Group two (the intervention group) received prevention messages from medical providers but also participated in a group-level-intervention (GLI) and peer-led support groups.

We measured our primary outcomes (the number of sexual risk episodes averted) through a cross-site, quantitative, risk behavior survey that captures participant knowledge, attitudes, and behavior at baseline, 6-months, and 12-months. The survey is an Audio Computer Assisted Self- Interview (ACASI), and was designed to prevent participants from having to report sensitive information to an interviewer. The survey included questions about demographics, HIV history and medical status, attitudes toward prevention, self-efficacy to solve problems, sexual risk behaviors, and substance use.

Intervention Groups

The initial plan for *Protect and Respect* was devised by an interdisciplinary team of AIDS service providers and researchers, but I primarily wrote the GLI curriculum and designed the format for the peer groups (my position for the project was Health Educator/Interventionist). Women who were randomized to the intervention group participated in the GLI. When they completed the GLI they were invited to attend weekly support groups led by their peers that occur throughout the length of the project.

Group-Level-Intervention (GLI). The GLI included five, two-hour, weekly education and skill-building sessions that I delivered. The GLI is based on several key principles: 1. recognition of the unique realities and challenges faced by women living with HIV/AIDS; 2. the importance of an accurate understanding of risk behavior and personal risk taking; 3. the need for realistic and safe options for women; 4. the importance of acquiring skills to reduce behavior risks; 5. the belief that women can utilize their individual and collective strengths to improve their lives; 6. the importance of adapting new skills to diverse and changing risk situations over time; and 7. commitment to a process that encourages women to act as agents in their own lives, sharing ideas and helping each face similar challenges.

The sessions and activities taught women skills to decrease their risk behaviors and protect themselves and their partners using the seven aforementioned principles. There were five GLI sessions. During session one the group participants discussed HIV transmission facts as well as the unique challenges and opportunities they face as HIV positive women. During sessions two and three the women learned risk reduction skills, including how to use male and female condoms, how to negotiate condom use with their partners, how to identify triggers to risk behavior, and how to problem solve to make safer sex decisions. Session four focused on helping women identify healthy and unhealthy relationships that may facilitate or hinder their ability to practice safer sex and on how to disclose their HIV status to their partners. The last session focused on goal setting and social support. Role-plays and group activities during all of the sessions encouraged the women to share safer sex strategies and problem-solve difficult situations together. For example, the women role-played condom discussions with resistant partners and discuss HIV-status disclosure options for women in unhealthy or violent relationships. Appendix A describes the group sessions in more detail.

Peer-led support groups. It was essential that women learned skills that they could use when they completed the GLI and returned to their homes, families, and relationships. The goals of the Peer component were to: 1. support women as they used new risk reduction skills learned in the GLI; 2. help women sustain new and healthy behaviors over time; 3. discuss additional risk reduction strategies that may not be adequately covered in the GLI; 4. provide a "positives-only" space for women to support each other; and 5. support a process by which Peer leaders are empowered to support HIV risk reduction in their community.

Peer sessions were on-going, weekly, one-hour, support groups offered to women who completed the GLI. Two Peer Educators facilitated the groups each week. Peers were HIV-positive women who were similar demographically to the participants of *Protect and Respect*. As the study's Health Educator, I hired, trained, and supervised the Peers. I met weekly with the Peers to plan the peer groups and problem-solve group facilitation collaboratively.

The Peers suggested topics for their groups, based upon information or needs identified by the Peers or group participants. Then the Peers and I discussed the topic and the topic's relevance to the overall goals of the program. I provided factual information or education about the topic as needed. Next the Peers and I discussed the best format to address the topic with the group, such as discussion, role-play, or games. I developed the group facilitation materials, and the Peers reviewed the materials and sought further clarification as needed. I also maintained these materials and the Peers re-used topics according to group requests. The intimate involvement of the Peers and their group members in topic selection and group development ensured that the groups addressed important, relevant issues. Because the group topics were generated weekly, the Peers and I developed each week's group around current events.

II. Protection of Human Subjects

Protect and Respect was initially approved by the Drexel University Internal Review Board (IRB) on April 1, 2004 and the IRB approved numerous consent and/or protocol revisions. In January 2005, the IRB approved the taping and transcription of the GLI and the peer groups, for quality assurance and theme analysis, so that the group transcripts could be used to learn more about women's needs and to improve future programs. I was listed as key personnel on the project's Human Protocol Processing Form (HPPF) and the consent form. After IRB approval, the study's Research Assistant and I taped and transcribed all of the group sessions verbatim. The transcripts were stored on a password protected computer and in a locked file cabinet.

III. Sample Selection

There were transcripts of 15 individual GLI sessions (three different cycles), and 71 weekly peer group sessions (86 GLI and peer groups total). Previous analyses determined that sample saturation, the point at which the same patterns arise and additional data fails to lead to new theoretical insights (Charmaz, 2006), was approximately 20 to 30 group transcripts (Teti, Rubinstein, et al., 2006). Therefore, the sample for the proposed study included 30 transcripts, and a total of 24 women. Specifically, the sample included five GLIs and 25 peer groups, equivalent to approximately one third of the total of each type of group (5/15 GLIs and 25/71 peer groups).

I reduced 86 transcripts to 30 transcripts to choose the study sample using the process described below. The steps did not necessarily occur in consecutive order. Rather, I approached the steps together to balance each of my sample goals. I aimed to choose transcripts that maximized the diversity of experiences that a larger group allows, included a range of different participants across the study data collection period, and included content that was relevant to the proposed study's research questions. The specific steps in my sample selection process included:

1. I excluded groups with a relatively small number of participants. I excluded from the analyses GLI sessions with fewer than three participants and peer groups with fewer than five participants. The cut-off points are different for the GLI and peer group because the attendance differed in both groups.
2. I chose GLIs so that each of the five sessions and each of the three GLI cycles were represented in the sample. I chose peer groups that occurred at even time points across the length of data collection (1.5 years). For example the sample contains peer groups from each month of data collection, from January, 2005 to June, 2006, except for the months of July and November, 2005.
3. I chose transcripts with content relevant to the proposed study's research questions. Because groups with discussions provided the richest data, I excluded peer groups that included no discussions or did not focus on HIV (i.e., some groups focused on nutrition, for example).

IV. Analysis: Strategies of Grounded Theory and Narrative Analysis

Denzin and Lincoln (2005) described qualitative researchers as bricoleurs, who use, adapt, and integrate various strategies as needed. I analyzed women's experiences of structural violence and stress-related growth using two different strategies of qualitative analysis consistent with the proposed research questions, grounded theory and narrative analysis. I used grounded theory to examine themes *across* the groups and narrative analysis to explore the way women talked about their experiences *within* particular groups. I entered the sample transcripts into Atlas.ti.5.2., a qualitative analysis software package that facilitated data management, efficient coding, and complex text analysis.

Grounded theory strategies

Definition and history of grounded theory. Glaser and Strauss (1967) developed grounded theory in the late 1960s. Grounded theory differs from other analytic strategies because it advocates for developing theories from the data versus testing hypotheses derived from existing theories. Grounded theory strategies are guidelines for collecting and analyzing data to build theories that explain the data (Glaser & Strauss, 1967). Glaser and Strauss (1967) challenged the notion that qualitative methods were unsystematic, that data collection and analysis were separate, that qualitative research was simply a precursor to quantitative research, and that qualitative research could not generate theory.

The principles of grounded theory have evolved over time. Glaser (1992) and Strauss (Strauss & Corbin, 1990) have modified their initial analysis strategies, but both of their positions are criticized for their positivist and objectivist underpinnings (Charmaz, 2000). For example Glaser (1992) assumed that a neutral scientific observer collected and analyzed the data. Strauss and Corbin (1990) also aimed to collect unbiased data through describing a set of technical and rigid procedures for analysis. The positivist assumptions of their approaches were necessary at the time that they developed grounded theory to justify the validity of qualitative research against the hegemony of quantitative methods.

Constructivist grounded theory. I conducted this analysis using Charmaz's (2006) guide to qualitative analysis. Charmaz (2000, 2005, 2006) promotes constructivist grounded theory, which adopts grounded theory guidelines as tools but does not subscribe to the positivist assumptions of earlier grounded theory formulations. Constructivist grounded recognizes that researchers are not impartial observers in the analysis process but co-produce data with participants. Charmaz (2000, 2005, 2006) argues that data neither await discovery in an external world nor rely on pure induction. Rather, researchers see and hear data through their interpretive frames, biographies, interests, and relationships with participants (Charmaz, 2000, 2005, 2006). Constructivist grounded theory does not aim to identify a true or verifiable theory but seeks to explore the meaning of participant's experiences and generate a set of theories and hypotheses that other researchers can continue to study, interpret, and apply to similar research problems (Charmaz, 2000, 2005, 2006).

Fit for this analysis. Strategies of constructivist grounded theory were well suited to answer the study's primary research questions. They promote beginning the analysis with the data about women's experiences, versus testing existing theories that may exclude important details about women's lives; support the discovery of new and unexpected ideas about structural violence, stress-related growth, and HIV(Charmaz, 2006); provide a way to explore the meaning that women attribute to their experiences with structural violence and stress-related growth (Charmaz, 2000); encourage the exploration of how the relationship between my position, orientation, and knowledge shapes my findings (Charmaz, 2000); and facilitate the comparison between my findings about women's experiences and prevailing intervention practices (Charmaz, 2005).

Analysis steps. The main steps in the analysis process included coding and memo-writing to explore women's experiences with structural violence, stress-related growth, and HIV/AIDS (Charmaz, 2006). Coding is the process of attaching labels to data segments. Coding sorts data and facilitates comparisons between data segments to form the structure of the analysis and thus is the link between data collection and theory development (Charmaz, 2006). Coding strategies include initial and focused coding. The openness of initial coding encourages thinking and new ideas, despite the researcher's prior knowledge of the data (Charmaz, 2006). Initial codes are provisional, comparative, and grounded in the data (Charmaz, 2006).

To conduct initial coding I reviewed all of the transcripts and coded the data to answer my research questions about women's experiences with structural violence, stress-related growth, and HIV. I coded the data according to the constructs identified in the literature, including examples of poverty, violence, HIV/AIDS related stigma, as well as new sense of purpose or motivation to engage in healthy behaviors as a result of negative stress. Importantly, I also remained open to women's experiences with structural violence, stress-related growth, and HIV/AIDS that had not been identified in the literature specifically. Preconceived codes provided a starting point to explore the data but were not automatic codes unless the data supported these assertions (Charmaz, 2006). The benefit of using group transcript data was that it captured participants' unprompted and unexpected ideas. Some of the women's experiences had not been adequately explored in the literature. I used Atlas.ti.5.2 to assist me in managing my list of codes. Initial coding generated a list of 31 different codes describing women's challenges and strengths.

Focused coding is the second major coding phase and is more directed, selective, and conceptual than initial coding. Focused coding uses the most significant and frequent initial codes to categorize the data. During focused coding, I decided which initial codes made the most analytic sense and explored these codes in further and more extensive detail (Charmaz, 2006). I reduced the initial list of 31 codes to nine key codes by eliminating codes that were few in number, did not reflect patterns in the data, or did not relate substantially to the research questions and by collapsing codes that were related to each other. For example, I initially coded several different forms of resource stress, like lack of housing and money, separately. Later I collapsed these codes into one code called poverty and then collapsed the poverty code into one code called daily stress because the women described their lack of resources as a major stress in their lives.

Memo writing was the intermediate step between coding and analysis. Memos should spontaneously catch thoughts, capture comparisons, and develop questions for further exploration. Memos should force researchers to engage codes and categories and explore them to make new data discoveries (Charmaz, 2006; Morse & Richards, 2002). I wrote memos to compare my codes, link codes to the study's primary research questions, and think critically about what the codes meant. I used Atlas.ti.5.2 to manage my list of memos attached to particular codes.

Narrative analysis strategies

History and definition of narrative analysis. Narrative analysis is a category of qualitative inquiry that focuses on the analysis of life stories. It is the study of how respondents make sense of their experiences and create meaning (Riessman, 1993; 2004). Narratives include both short and extended stories. Life histories, which describe *extensive* autobiographies, gained popularity during the 1960s, complementing the civil rights and feminist movements. Feminist researchers were interested in women as social actors and subjects, not objects, in the research process; the meanings that women assigned to events in their lives; and in diminishing the role that researchers' interests played in determining which and whose questions were asked and answered (Chase, 2005; Riessman, 1993). Narratives, like groups, can reveal details about the respondents' cultural and social lives (Riessman, 1993).

Narrative analysis prioritizes the connection between stories, the way stories are constructed, the cultural aspects of stories, and how stories persuade their listeners (Chase, 2005; Riessman, 1993, 2004). The way a narrator tells a story reveals meaning. Different sections of a story represent different perspectives regarding characters, actions, and events (Gee, 1991). Narrative researchers analyze narrators' voices and the language they use to communicate stories (Gee, 1985, 1991, 2006), making new interpretations possible (Mishler, 1986).

Fit for this analysis. Like grounded theory strategies, narrative analysis strategies were well-suited to answer the study's primary research questions because they are grounded in the women's experiences and prioritize the meaning in women's narratives. Narrative analysis complements strategies of grounded theory, however, because it focuses on the voices *within* each narrative, versus the themes across the narratives. This is an important distinction because women often communicated about their experiences in the groups through telling detailed stories. The stories often expressed multiple ideas and themes and had a specific purpose for the narrator and the group. Many times the group was the first time and place that a participant told or shared a story with other HIV positive women. Theme analyses that resulted from grounded theory often eliminated the sequential and structural features that characterized narrative accounts and were ill-suited to capture the way narratives combined multiple themes, the diverse meanings of themes for different women, and the purpose of the narratives (Riessman, 1989, 1990).

Analysis steps. I re-read and re-analyzed portions of the transcripts where women told their stories according to strategies of narrative analysis (Riessman 1993). Stories included sections of the text with sequential, thematic, and structural coherence (Riessman 1993). Pursuant to the strategies that Riessman (1993) has detailed, I reduced specific and long portions of the text into sections that examined key metaphors, narrative structure and organization, word choice, coherence, *why* the participant developed and told her story in the manner she chose, and the purpose that the story served for the respondent and the group. I divided the text according to Gee's (1985, 1991, 2006) linguistic framework. I then chose narratives that related to the key grounded theory themes, and used them to explore the themes in greater depth.

The extent to which quantitative research can be judged, replicated and considered truthful are irrelevant to qualitative research. Qualitative researchers maintain a different work and world view. They acknowledge that there is not one truth, that all knowledge is constructed, and that researchers and research participants co-construct findings (Lincoln & Guba, 1985; Merrick, 1999). For these reasons, qualitative researchers have developed appropriate and meaningful standards for judging the trustworthiness of qualitative inquiry.

Trustworthiness, authenticity, and quality of analysis

Trustworthiness. Lincoln and Guba (1985) originally proposed credibility, transferability, dependability, and confirmability, as parallel but more appropriate criteria to judge the trustworthiness of qualitative analysis, versus the quantitative standards of internal validity, external validity, reliability, and objectivity. Credibility refers to congruence between the realities of the respondents and the researchers; transferability refers to a well-defined context of analysis that allows others to determine how to apply the findings; dependability refers to appropriate documentation of the research process and method decisions; and confirmability refers to data, interpretations, and outcomes that can be tracked to their sources (Lincoln & Guba 1985).

While these initial criteria were foundational and useful, researchers have revised them over time and no one set of criteria to judge qualitative analysis exists (Guba & Lincoln, 1989; Lincoln, 1995; Merrick, 1999). Because parallel criteria inappropriately relied on quantitative standards, Guba and Lincoln (1989) and Lincoln (1995) have since proposed alternate forms of evaluation.

Authenticity. Guba and Lincoln (1989) proposed authenticity criteria to ensure that the *outcomes* of qualitative studies are trustworthy. Authenticity criteria judge qualitative research by how well the results meet the needs of stakeholders or research participants. Guba and Lincoln (1989) argued that it is ethical to prioritize stakeholders' needs because they are the end users of evaluation and research results. Authenticity criteria include fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity. Fairness, ontological authenticity, and educative authenticity refer to how well stakeholders are integrated in the research and evaluation process. Catalytic authenticity and tactical authenticity are the extent to which research results stimulate action and empower stakeholders and research participants to act.

Quality. Lincoln (1995) suggested that standards for the quality of qualitative inquiry are always evolving. She proposed emergent quality criteria that included: positionality, appropriately recognizing and exploring the relationship between the researcher and research participants; appropriately sharing the privileges and the benefits of research outcomes with the research participants; and sacredness, conducting research with concern for human dignity, justice, and respect.

I ensured the trustworthiness, authenticity, and quality of my analysis in several ways:

1. <u>Credibility via prolonged engagement and persistent observation</u>: I chose the sub-sample for this analysis (n = 5 GLIs, 25 peer groups, 24 women) because they

represented a diverse group of women who participated in the project over a span of two years. During this time I gained the trust of the participants and collected rich data that is appropriate in scope and depth.

2. Credibility via peer debriefing: I met with three other members of my committee regularly to discuss my grounded theory codes and memos and narrative analysis interpretations to expose and explore biases and clarify the basis for interpretation.
3. Credibility via member checking: I met with two of the women whose ideas were represented in the analysis to ensure that the results and interpretation matched their experiences. The member checking process is described in detail in the results section.
4. Transferability and dependability: I provided a thorough description of the analysis, participants, setting, and analysis decisions and steps, so that users of the research interested in transferring the results to another population can make appropriate decisions about the applicability of the findings.
5. Positionality/Reflexivity: Throughout the analysis I reflected on how my identity, orientation, and prior knowledge and beliefs influenced the proposed study's research questions, findings, and interpretation.

Chapter 4: Results

This study examined how structural violence and stress-related growth manifested in the lives of HIV positive women who participated in the *Protect and Respect* intervention groups and how these experiences related to their daily lives with HIV/AIDS. First, I reflect on how my personal and professional perspectives influenced the analysis and the results (i.e., reflexivity). Second, I contrast my stance with that of the participants by describing two of the study participants' reactions to the results (i.e., member checking). Last, I present the results of the grounded theory and narrative analysis used to answer the study's research questions by describing the emergent and primary structural violence and stress-related growth themes and how the group intervention format facilitated the discussion of these themes.

I. Reflexivity and Member Checking: Power, Choice, and Analysis

I chose to begin this chapter by writing about reflexivity and member checking to call attention to the important power differentials between researchers and those who are researched and how this discrepancy affects the research process, including the results. Researchers hold the power to make choices about the questions that they will ask, the type of studies that they will design, what will count as data, and how they will define their relationship with participants (Fine, 1998). These decisions shape the results obtained and the conclusions drawn. Participants are likely to possess different perspectives than the researcher. Listening to participants' reaction to research about them is paramount because the results are intended to inform or improve services for them, and thus can not achieve this goal without their input.

Reflexivity: The Role of the Author

As Fine (1998) noted, "the other is not created from nowhere" (p. 136). My position as a researcher, studying a selected population influenced the analysis and the results significantly. In stark contrast to the majority of the project participants, I am a White, middle-class, and HIV negative woman. I have been granted far more opportunities to pursue formal education and develop and improve my critical thinking skills. The analyses and findings described in this chapter result predominantly from my choices, interpretations, and representations. The participants' stories do not speak for themselves. My analysis decisions were influenced by multiple factors, some of which included my relationship and experiences with the *Protect and Respect* project and the study participants, my theoretical perspectives, and my social position.

The conditions under which I undertook this study were both professional and personal, and both have determined practical features of the study and the interpretations to which it has given rise. I developed and facilitated the group-level-intervention (GLI), spent a considerable amount of time with many of the women in this study, and developed a relationship with each of the study participants over the three-year course of the *Protect and Respect* project. When I was developing the intervention, I became fluent in the prevailing HIV prevention strategies and behavioral theories. As soon as I started facilitating the intervention groups, I experienced first hand the sharp difference between the theoretical literature about women's behavior and women's lived experiences. I expected to talk to the women about condoms. The group discussions shattered all of my expectations and assumptions, however. The women did not or could not necessarily discuss safe sex or discuss sex in isolation to other important parts of their lives. They had more to say. They told me the intimate and tangible details about their lives on the social margins, often including stories I found shocking. In addition, I found their responses to adversity to suggest impressive inner resources. Facilitating the groups was at times educational, rewarding, and inspiring for me, but it was also alarming and painful. Overall, my distance from the profoundly challenging conditions under which these women lived, and the discrepancies between the study's design and their life experiences, was disconcerting. As a result, I approached this analysis critical towards the majority of existing HIV prevention theories that offered simple, rational, and individualistic explanations for women's behaviors that failed to explain what I learned about women's suffering and strengths.

As Riessman (1993) noted, representation takes place at various levels of the research process. Undoubtedly, my privileged presence in the room (I was either physically present or symbolically present via the tape recorder) influenced what the women said and what data were produced during the groups. For example, talking about racial discrimination with a White woman, or when you know that a White woman will listen to the tapes, was likely difficult and may partially explain the absence of discussions about racial discrimination in the results. I additionally constructed meaning and interpretation when I made choices about what to notice in the transcripts, how to transcribe data tapes (i.e. should include emotions like crying), and how to analyze the data. The extreme differences between me and the participants influenced what I saw and defined as relevant in the transcripts. Lott and Bullock (2001) noted that middle class researchers struggle to comprehend extreme poverty. Likewise, I was alarmed by the overwhelming amount of suffering and stress that the women faced every day. The women might not have even considered these experiences to be painful, however. I noticed examples of intimate partner violence and stigma because they acted as direct barriers to the goals of the groups (safe sex and disclosure). I paid careful attention to the women’s ability to survive and thrive because I knew them personally and heard and remembered many of their courageous stories.

Riessman (1993) called research a “chorus of voices”, elaborating that:

> “There are strains because most researchers are privileged and White and many women we want to include are not. Some voices have to be restrained to hear voices from below to create a particular harmony, but a different interpreter might well allow other voices to dominate” (p. 16).

I do consider these results to be a blend of my own and the participants’ experiences. I do not deny, however, that I maintained the power to choose what would be presented in the text (Behar, 1993; Bourgois, 1996; Fine et al., 2000). I struggled relentlessly with this privilege. I was uncomfortable translating the women’s stories into academic research for my gain. As Behar

(1996) noted, the dependency on our participants shifts awkwardly to authority at our podiums. Likewise, Stacey (1988) charged that fieldwork creates a situation that the researcher is far freer to leave and may mask a dangerous form of exploitation and intrusion, particularly when the researcher can not fix the harms uncovered (Bourgois, 1990; Stacy, 1988). I often felt guilty writing about, versus acting to alleviate, the pain of these women. Like Fine (2000), however, I believe that to create these results I traded my privilege with the participants for the opportunity to take their "counter narratives" (Fine et al., 2000, p. 115), experiences, and needs to audiences that they could not as easily reach themselves.

Sharing the Analysis through Member Checking

Stacey (1988) called for research that is "rigorously self-aware and therefore humble about the partiality of its ethnographic vision and its capacity to represent self and other" (p. 26). Fine (1998) added that working the "self-other" hyphen enriches data by creating spaces where researchers and participants can discuss whose story is being told and develop alternate interpretations. In order to include the perspectives of the participants in the writing process, I facilitated two meetings and several other conversations with the two Peer Educators about the trustworthiness of the results, a process that Lincoln and Guba (1985) refer to as member checking. I gave each Peer a copy of the draft results section, gave them an instructional handout (Appendix B), and discussed it with them to clarify questions and provide further information. The handout explained the aims of my project, definitions of key terms (structural violence, stress-related growth), and why I needed their help. I told them that I interpreted many different discussions in their groups and was interested in their opinions of these interpretations, to improve the paper's trustworthiness regarding the way it reflected their lives. I have a strong and trusting relationship with the Peers that I have worked to develop over three years. This relationship allowed me to believe that they would not fear being honest with me about their reactions. I still made a point to encourage them, however, to tell me what they thought and not to worry about my reaction to their comments. I reminded them that it was important to all of us that the groups and the participants' experiences were represented appropriately.

I asked both of the Peers to think about five questions (or categories) when they read the dissertation and I used these questions as a discussion guide:

1. What do you like about the paper? What don't you like?
2. In what ways does the paper make sense? How does the paper confuse you?
3. Are they any examples that make you mad? Why?
4. How do you think the paper reflects accurately your groups? How does the paper fail to represent your groups and the women who participated?
5. What more would you want to add to the paper to describe women's challenge and strengths?

One of the Peers said initially that she hated the paper. Her primary complaint was that it made the women sound "dumb". At first response she did not like the way that the women spoke in slang and were misinformed at times about their illness. She believed that this depiction served to further stigmatize women with HIV/AIDS as "dumb, ignorant, and uneducated", and was worried that if middle-upper class readers reviewed the paper that they would think that all HIV positive women were "stupid". She was particularly concerned about her own quotes. She wanted to re-write them or re-say them more eloquently. The other Peer had a different reaction. She disagreed and liked the way the quotes were, "as is". She said that many women with the virus do not have access to formal education and that this was an important truth to reveal. After much discussion, both Peers did agree that they appreciated the "raw and real" nature of the groups and the manuscript. The group decided that the language should remain as is because it was ultimately important to present the conversations as they occurred. They were adverse to "Whitifying" or "middle-classifying" the language.

Both of the Peers thought that the structural violence findings represented accurately their own and the group's challenges. They did not believe the examples (as was the case with the language) stigmatized the women but said that the examples represented “stuff that needed to be known”. They particularly enjoyed reading the narratives because the narratives gave more information and context. Sometimes the quotes in isolation felt like “there was a part missing or something”. As a result, I added more narratives to give context to women’s experiences. Both of the Peers thought that the section on structural violence was more prominent when compared to the stress-related growth findings but said that this was accurate. One Peer commented that “There are only so many positive things you can say about living with HIV/AIDS”.

When I asked them why they thought that the women did not discuss certain experiences like sexism or racism overtly during group discussions, one of the Peers said that the women did not experience racial discrimination. The other Peer was quick to clarify, however, by saying that “HIV/AIDS” is the great equalizer”. She meant that women were too concerned about HIV-related stigma to think or talk about racial discrimination. The Peers stressed that women who acquired HIV in a stigmatized way (e.g., through prostitution) or women who did not know how they acquired HIV, suffered the most from self-blame, stigma, and discrimination. In general, the Peers wanted to acknowledge the overpowering nature of AIDS related stigma in HIV positive women’s lives.

One of the Peers thought that two strengths were missing from the section on stress-related growth. First, she said that the women were inspired by living with HIV/AIDS to become public speakers, further their education, and educate others. She believed that the group gave women the confidence to speak out and was therefore a source of education diffusion. Second, she said that safe sex was not the only appropriate marker of women’s success. She said that the women tried everything to be safe. She reminded me of an example from a peer group (which was not in my sample of transcripts for this analysis) where a woman used a condom as a diaphragm because her partner would not put the condom on. She stressed the importance of harm reduction and said that women do what they can, even if it is not always ideal (i.e., condom as diaphragm versus using a condom as intended).

When I asked the Peers which additional markers of success would be appropriate for a program to increase HIV status disclosure and decrease unsafe sex, they said: acceptance of self; love of self; positive disclosure experiences; support from others; access to needed professional support (e.g., therapy); and the ability to educate others. One Peer noted that, “If you can not accept yourself, you can not be healthy”. As a result, groups should focus on “giving women what they need to do for themselves, to move on, past the virus”. Current safer sex interventions do not define success by high self-esteem or self-love, yet the Peers here suggested that these kinds of psycho-social experiences may be integral to behavioral choices.

Reading the Results with Researcher and Researched Perspectives

When reading the results in this chapter, it is important to pay attention to several incongruities. First, the intervention’s main topics (e.g., safe sex, disclosure) were important but were not the topics that the women focused on during their conversations. They are not even predominant themes in the intervention transcripts. Second, the assumptions about women and their priorities that framed the intervention (i.e., that they want to and can have safe sex and disclose their status) failed to consider that the women may not have the privilege to choose their behaviors. For example, the women said that they enjoyed talking about sex with each other because they did not have any other spaces to discuss sex, but their discussions about *safe sex* were limited predominantly to conversations about their struggles to be safe within unhealthy relationships. Likewise, the women talked mainly about disclosure in relation to AIDS-related stigma. Third, the ways that women were measured as successful (e.g., episodes of safe sex, episodes of disclosure) were incongruent with their strengths -- stress-related growth, resilience, and resistance – and the markers of program success that they described above.

On the other hand, however, it is important to note that the group intervention format *was congruent* with women’s communication needs and facilitated open discussions about women's challenges and strengths. Women learned that they were not alone and that other women faced and surpassed similar barriers. Through the group discussions, the women advised each other and shared strategies to gain control over their lives and challenges. In the group the women relied on each other for support. As a result, the women learned that they mattered, and this feeling gave them a sense of purpose and motivation to be healthy. They were able to imagine making positive and healthy changes amidst multiple and diverse life difficulties.

The results described in this section call attention to the importance of listening to the women to understand what they need to be safe and healthy (in addition to or instead of condoms), and how they create a group space where agency, insight, self-discovery, meaning, and change are possible.

II. Methods Summary

Research study staff used attendance sheets to record the names of the women who attended each group. To protect their confidentiality, the women were not individually named in the group transcripts however. As a result, the quotes in the following chapter are labeled by: (1) the type of speaker: participant or facilitator; (2) the type of group: group-level-intervention (GLI) or peer-led support groups; and (3) the date of the group. I distinguished between the type of speaker (group participant or facilitator) because they had distinct roles in the group. I considered the Peer leaders and the group members equally as "research participants" because the Peers are HIV positive and are similar culturally and demographically to the project's participants. Moreover, their input was equally important for the study's implications for practice. If more than one participant was talking, the participants were labeled with the numerical label that was used to identify them in the group transcripts, to clarify who is speaking.

I used strategies of grounded theory (Charmaz, 2006) and narrative analysis (Chase, 2005; Gee, 1985, 1991, 2006; Riessman, 1993, 2004) to examine how the women experienced structural violence and stress-related growth. The grounded theory analysis captured the major themes related to these concepts in the transcripts. The themes alone were insufficient to understand women's lives or the meaning they ascribed to their experiences. The women did not organize their conversations according to themes. They communicated primarily through narratives or stories. Narrative analysis therefore enhanced my understanding of the context and meaning of women's experiences and the corresponding key themes as well as the ways that women's language emphasized the most significant aspects of their experiences. Narrative sections of text were included because they enhanced the grounded theory analysis and are therefore organized in the text thematically. They are presented in lines and stanzas pursuant to the strategies described by Gee (1985, 1991, 2006) to emphasize the importance of the relationship between women's language, story organization, and meaning, when this relationship was appropriate, present, and apparent. I highlighted key words and phrases in the narratives with underlined text, to draw the reader's attention to the most important aspects of the narratives.

Grounded theory and narrative analysis methods prioritize participants' experiences over existing theories and allow participants' experiences to drive research findings and future research questions (Charmaz, 2006; Riessman, 1993, 2004). Although my original research questions focused specifically on structural violence and stress-related growth, the participants' experiences revealed that it was important to pay attention to: (1) the way forms of structural violence and oppression, such as poverty or sexism, manifested at a micro-level in their daily lives; and (2) the strengths they reported beyond the concept of stress-related growth exclusively. I describe the key themes and narratives below. I explore further the definitions and relevance of structural violence and stress-related growth to participants' lives in the discussion section.

III. Demographics of Study Participants

Table 1 describes the demographics of the study participants (*N* = 24). The women in this study mirrored women living with HIV/AIDS in the U.S. demographically (CDC, 2007a). On average the women were 43 years old (*SD*=9), yet their ages ranged from 28 years to 70 years of age. They had been living with HIV/AIDS for a span of 1 to 21 years, and on average, they reporting having HIV/AIDS for 10 years (*SD*=6). The women reported that they had been attending the Partnership Comprehensive Care Practice (PCCP) for a range of less than one year to 10 years (*M* = 4 years, *SD*=4 years). The women's lives were marked by poverty and few educational opportunities. The majority of the participants reported earning less than $10,000/year (80%) and receiving a high school education or less (92%). The women reported that they were mostly African American (83%), predominantly heterosexual (70%) and most often infected with HIV/AIDS from sex with a male partner (58%). A substantial proportion also reported HIV infection via injection drug use (38%).

Table 1. Participant demographics.

Demographic Characteristic	*N*= 24
Age (average)	43 years (*SD*=9)
Years living with HIV (average)	10 years (*SD*=6)
Years receiving care at the clinic (average)	4 years (*SD*=4)
Race/ethnicity: African American	83%, *n*=20
Income: ≤ $10,000/year	80%, *n*=19
Education: ≤ high school education	92%, *n*=22
Sexual orientation: heterosexual	70%, *n*=17
Relationship status: single	50%, *n*=12
Transmission: heterosexual sex	58%, *n*=14
Transmission: injection drug use	38%, *n*=10

IV. Structural Violence Themes

Structural violence is a broad rubric of oppression and deleterious social forces that harm human dignity, restrict potential, and result concretely in daily affliction (Farmer, 2005). Structural violence manifested in women's lives in three primary ways: (1) daily and overwhelming stress; (2) AIDS related stigma and rejection; and (3) unhealthy and violent intimate relationships.

Intense accounts of pain, suffering, and the use of substances to numb distress tinged all of women's accounts of structural violence.

Table 2 describes the number of groups (of 30) that included each theme, the number of times the women discussed the theme in all of the groups, and the range (minimum and maximum) of the frequency of a theme in any single group session. Quantifying the themes portrays effectively an outline of the themes across the groups. It is important to note that quantifying the themes is also subject to significant limitations, however. First, quantification does not capture the significance or meaning of the themes, which is the aim of this analysis. Second, I did not consistently attach equal length sections of text to the codes. For example, the women discussed the themes in a few sentences and/or in long discussions, both of which may have counted as one incidence of a theme. Nonetheless, Table 2 reveals that women's examples of their daily experiences with structural violence were common and often overwhelming in group conversations.

Table 2. Quantity of structural violence themes in the transcripts.

Theme*	Number of groups (*n*=30)	Number of times: all groups	Range per group (min/max)
Daily stress (poverty, caretaking, illness)	21/30	55	1-6
Stigma and rejection	15/30	39	1-6
Unhealthy/violent relationships	24/30	80	1-11
Pain and suffering	19/30	45	1-7
Addiction	11/30	24	1-7

*The themes are listed in the order of appearance in the results section.

Daily Assaults: Sick, Tired, and Poor "Superwomen"

Most[4] of the women reported daily stressful experiences frequently. The adverse impact of these experiences was exacerbated by their marginalized social position and their HIV status.

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[4] The women were not individually named in the transcripts. Therefore, I can not technically report the number of women who discussed a certain theme. I did choose to use qualifying descriptive terms

The women described diverse stresses in their lives but focused primarily on stress that resulted from: (1) illness and feeling sick; (2) taking care of themselves and others; and (3) their lack of financial and non-financial resources and assistance that were necessary for their survival and health. It is important to recognize how these stressors intersected in women's daily lives.

The physical and emotional stresses of illness. Discussions about illness and its associated stresses were common in the group conversations. Although it may be assumed that most of the women worried about HIV/AIDS predominantly, their conversations about illness included both non HIV-related and HIV-related illnesses. The women talked often about their experiences with illnesses in addition to HIV/AIDS, including seizures, kidney and liver disease, kidney stones, and heart disease. The Peer facilitators missed group for hospital stays and illnesses as well and several group members died throughout the course of the groups.

More often than discussing general illnesses, however, the women discussed the stresses of living with HIV/AIDS. During group they described often feeling tired, run-down, and sick. They were frustrated at the ease with which they contracted colds and viruses. Discussions about doctor visits and hospital stays were commonplace and were a part of participants' normative descriptions of living with HIV. The women were concerned particularly about the progression of their HIV disease and the associated helplessness:

> Participant: I often think about [getting sicker], you know. If it comes to a point where somebody [has] to take care of you. I don't know how I would deal with that. You used to being independent and [taking] care of yourself, and then you have to deal with somebody helping you do things that you used to do for yourself (peer group 3-9-05).

Likewise, this participant articulated further the stresses of illness-related dependence when she told the group a story about what it was like when she found out she had HIV and had to rely on her Dad and others to do everything for her. The participant's repeated use of the phrase "I

---

however, such as many, some, or most, because I am familiar with the data and the participants and possess an accurate sense of the frequency of some of the issues for the women.

couldn't even" reiterated her sense of frustration about her helplessness, which was symbolized most clearly by her inability to eat on her own.

> When I was in the hospital
> I [was] sick.
>
> [My Dad] was all at the hospital, holding my hands [and] stuff like that...[5]
> He stayed there at the hospital.
> He fed me.
> I couldn't even get up and feed myself...
>
> They took out lymph nodes in my neck,
> and I couldn't even eat.
>
> I couldn't even sit up because [of] the way they operated [on] me.
> I was laying flat on my back,
> and I couldn't even move,
> let alone stand.
>
> He [had to stay] there and feed me (peer group 3-15-06).

Illness increased women's dependence on others, but was also stressful because of the way that feeling sick isolated the women. Many women described days when they did not want to leave their house or get out of bed because they felt ill or were afraid they would be sick in public. This participant described her panic over a hospital stay and illness that threatened to prevent her from seeing her family:

> Participant: I just got this fever. I've been sweating, and I ain't been long out [of] the hospital...
>
> Facilitator: You just got [out of] the hospital?

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[5] The use of ellipses indicates that words or sentences were left out of the quote for clarity.

> Participant: Last week…For my ulcers. And my family is coming on Friday. I'm getting so sick just before they come and shit, I was hoping [to be out of] the hospital [when they come] (peer group 4-19-06).

Several women described their HIV medications as the most important component of their plan to stay healthy. They relied on them for survival. Despite their need for medicine, however, most of the women also talked frequently about feeling ill because of their HIV medications. The women said that side effects were a great source of stress, frustration and anxiety and included physical symptoms such as stomach upset, diarrhea, nausea, numbness, sleeplessness, and rashes as well as mental and emotional symptoms. Many women focused on the emotional stress associated with taking medicine. As this facilitator commented, "I can take [pills but] I am afraid of what's going to happen when I take them" (peer group, 4-20-05). The women experienced stress when they had to change regimens, because they had to manage fears about new side effects. In this discussion, four different women elaborated on the mental stress associated with taking medicine:

> Participant 2: I had an anxiety [attack] when I went on meds for the first time, for six months worrying about the medicine.
>
> Facilitator: I don't want anything to cause me to lose sleep.
>
> Participant 1: You know when they say that they're going to cause all the side effects? Don't think about it. That's like me with my medication. When I start thinking about what it's going to do then…I've been on this medication for a very long time and I still gotta psych myself [up] every time I take it.
>
> All participants: Exactly.
>
> Participant 3: And when I first got diagnosed, it was like a couple of weeks. I got diagnosed in 2000, maybe about a week after that I took my meds. I got sick because I guess that came from the side effects. I was throwing up like a dog. I was sick

> Facilitator: Most people when they start meds get sick because of the toxicity and all that. Your stomach is not used to it.
>
> Participant 1: Sometimes I have to look at my medications for almost half an hour before I can take [them], I have to psych myself to take them.
>
> Participant 2: It can be in the head sometimes, [I went] to [the] ER and they found nothing wrong with me. They said you having another anxiety attack.
>
> Facilitator: People don't really realize what you go through when you sit down with these HIV medications. You sit there and you look at it, and it's taking you an hour to take them.
>
> Participant 2: And those pills are so big.
>
> Facilitator: You don't know what it's going to do to you. Even if it's psychological, most of [us], we can't swallow them. You can swallow a big piece of food but you can't swallow the pills. It's so much to go through just to take a pill (peer group 10-26-05).

Managing their illness, symptoms, and medication side effects consumed many women's daily lives. Illness and its consequences, like helplessness, isolation, and anxiety combined to contribute to women's vulnerability and physical and mental stress.

"I'm sick too you know": Caring for others and themselves. The women noted that they often assumed roles as caretakers. The women said that they took care of children, family members, friends, and partners. Some of the women also had jobs as counselors or Peer Educators that demanded their time and extended their caretaking roles to work. Some women took care of partners with HIV/AIDS or other life threatening illnesses like cancer as well as themselves. While caretaking was not universally a negative experience, the majority of the caretakers said that they were stressed and frustrated by this role, particularly when they were caring for sick partners or children. Some of the women talked about feeling physically and mentally tired, but being afraid to show their fatigue to others who depended on them. As

these participants empathized, they were sick too, which often got lost when they focused their energy on others:

> Participant 1: I'm tired because I'm such an outgoing and bubbly person. Like [other group participant] it's hard for me to be in a bad mood.
>
> Participant 2: Yeah, I'm like, I'm sick too you know.
>
> Participant 3: They expect you to be like Oprah. Everyone can't be like that (peer group 4-20-05).

One participant in this conversation elaborated further on her stress:

> Participant 1: I am tired of taking care of everybody, Glenda[6] do this, Glenda do that, Glenda is the happy go lucky one. Glenda ain't allowed to get fat or cry or get tired. I am tired of everyone thinking that I am superwoman, and I am tired of people thinking that I got stupid written across my forehead, you know? I'm serious. I'm tired of people thinking I'm stupid [and] taking advantage of me, because all that is going to change (peer group 4-20-05).

Caretaking stressed relationships often. Many women commented that the men that they met wanted and needed care. As one woman put it, "I meet needy men. I know I am a caretaker, but damn. I don't want to take care of everyone. I want someone to take care of me" (peer group, 4-20-05). Another participant discussed her situation in multiple group sessions. Her long-term primary partner was sick with cancer and she felt obliged to take care of him, despite the fact that she said that his illness had caused a serious disconnect in their relationship and led her to start seeing another man. She was often frustrated because she said he needed and wanted her care but had difficulty accepting her help. Exasperated, she recounted numerous arguments and discussions with him to the group, because she desperately worried about how to manage his care and their deteriorating relationship:

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[6] All names are pseudonyms.

> [I told him], "You don't seem to be no good for me now." I mean, let me take care of you and appreciate it. He [will not] even let me take care of him. [He is] fucking [with] me, with [these] emotional feelings and all this shit.

On yet another occasion, one of the group facilitators told a story about her decision to take care of her sick husband. Her narrative enhanced the caretaking theme by presenting a different perspective about the burden of caretaking: She enjoyed caretaking. Her word choices stressed the intensity of her feelings for her partner and how important it was for her to take care of him. In addition, she organized her story by countering every one of his sickness-related consequences with her own sacrifices, and chose to end the story by confirming that she forgave him for giving her HIV, to reiterate her identity and role as his willing caretaker.

I just wanted to be with him all the time
and then he did get sick.

And I thought nobody can take care of him better than I can
because I was already a nurse.

His mother wanted to,
but I didn't want that.

When he started to get real sick,
I just took a leave of absence from my job.

And when he went to check in at the hospital,
I checked in with him.

[When] he packed his clothes,
I took my clothes.

I just wanted to be with him
and take care of him.

I did forgive him [for infecting me with HIV/AIDS].

It wasn't really ever a question,
was I mad or did I forgive him (peer group 4-13-05).

While the women sometimes described caretaking as an expected or a rewarding role, they always described it as a task that divested attention from their own needs. It was usually a source of stress, because the caretakers spent significant amounts of time and energy caring for others and not themselves.

"How the hell are we supposed to make it?": Fighting to survive with limited options. While a few of the participants said directly that they did not have any money, the majority of the women experienced stress because of their lack of tangible resources. These included food, shoes, clothes, transportation, housing, air-conditioning in the summer, heat in the winter, access to necessary medical and social services, and even access to proper burial services.

The women reported that transportation was a significant stressor, particularly because of the high price of public transportation in Philadelphia and the transportation strike that occurred during the program. While some of the women described struggling routinely to make it to medical appointments because they lived in neighborhoods that did not have public transportation nearby, others were particularly concerned about the strike, commonly asking, "How the hell are we supposed to make it?" (peer group 8-17-05). Likewise, this participant expressed further her anxiety and fear about managing her daily routine without public transportation: "Last time SEPTA was on strike I had to walk for 40 days and I can't make it this time cause my legs just can't do it (peer group 10-26-05)." The participants strategized together in detail about how they could get to doctor's appointments, discussing planning all of their appointments on the same day, looking for family members and friends to drive them from place to place, and using the limited and poor transportation assistance options in the city. Their lack of mobility was a clear stressor and deterrent to accomplishing their daily goals.

Similarly, many of the women were unable to find secure housing. They discussed the stress associated with living in homeless shelters and/or with friends, including anxiety, noise, chaos, safety, fights between shelter members, fears of sickness in shelters, challenges finding shelters that would house them and their children, and trouble living with other families and other children. Futile housing searches forced them into poor living situations and robbed them of the ability to make healthy decisions about housing. As one participant noted:

> I'm going to stay where I'm at because I have no choice. And the money I was looking for to move didn't come through. So I'm a just stay where I'm at, and my son will stay there with me (peer group 5-24-06).

Another participant described her frustration with her inability to find a simple one floor living space that was her own:

> But you don't know how long I've been going through this. I've been calling around trying to find what programs or whatever I can get into to get on Section 8…All I want is one thing on one floor. That's all I want. I don't want no two story house. [I want] everything on one floor, the kitchen, the bedroom, couches or whatever, the bathroom. Everything on the first floor (GLI 1-10-05).

While many of the women expressed thanks for the support of case managers, doctors, and in particular the churches that "opened their doors for people [with HIV/AIDS]" (peer group 4-13-05), they were also very frustrated with the lack of support for their needs. Some of the women talked frequently about their frustration with services being cut, such as mental health, addiction, or transportation services for people living with HIV/AIDS. In many instances they were surprised to find out that they did not qualify for food stamps or that their housing applications failed. They were frustrated with the paper work, rules, and regulations that they perceived as barriers to their well-being and survival. Sometimes these situations led to anger and frustration towards the procedures and those in helping positions. The women perceived simple answers to their basic needs and were frustrated and angry at the lengthy procedures that stopped them from accessing help. One participant explained her anger towards a state federal financial assistance program that withheld benefits for people with HIV/AIDS unless they took their medicines:

> All [of] these agencies are being paid for [by the federal government]. My point is you gonna go somewhere and someone gonna make you do something that you don't want to do? Sometimes the meds harm you more than help you. So how are you going to tell me I'm not going to get my money to survive if I don't take my meds, which [are] hurting me more? That don't make sense! You go there and you can't get your meds so that means you stuck. You can't get your meds and [the case manager] knows you aren't taking meds. You in a situation where you have to pay rent, groceries and stuff, but [the case manager is] not going to give you your money cause you ain't taking your meds. How are you supposed to survive? (GLI 4-11-05)

Likewise, this participant told the group a story that summarized many of the abovementioned stressors. It involved how she had to sacrifice her housing and custody of her children to get treatment for her drug problem. The narrative highlighted how her stress was exacerbated by her sense of instability. Without a place of her own, she focused on *moving and running* from one place to another to try to get healthier, and her sense of loss over relinquishing her housing and being forced to abandon her children, versus concentrating on taking care of herself and coping with her illness.

I went away to get some help.
I had a drug problem.

And I was under the impression that I would have a place [to live],
if I gave my place up.

So I went away,
and while I was away, um,

my sickness started bothering me.
I started having complications…

I was running back and forth to the [clinic].
It was too much for them to handle.

I couldn't attend [the *Protect and Respect* group].
I was throwing up.

Then, they transferred me to another place,
then to another [place] for a month.

Then I started [having seizures].
Then I went to another [place a few] months later.

I had no [where to live].

The case manager hadn't done my paperwork.

Now I don't have my kids with me.
Cause where I'm at now,
I'm sharing a bed.

Kids are all over me,
and I'm scared of catching a cold [because]
I'm in a room full of kids.

She hadn't even done my paperwork for me (peer group 1-26-05).

Some of the women linked their stress accessing resources directly to their lives with HIV/AIDS. Sometimes these connections were obvious, such as the challenge to obtain appropriate medical care created by limited transportation options or the ill health caused by inconsistent and adequate housing. At other times the connections were less apparent but equally important. For example, because their medications needed refrigeration or to be stored below a certain temperature, a few of the women were upset about their inability to pay utility bills or afford air-conditioning in the summer. Another participant worried about heat in the winter, because it did not work in her apartment building: "[The landlord] said we could not [put our own heaters in there] but guess what I told him? 'I'm sick. I can't die up in here, so I gotta have my heat'" (peer group 8-17-05). Another participant described the struggle between taking time for medical care and needing to work for financial reasons:

> Participant: The doctor told me if I [left] the emergency room I wasn't going to live through the night. Hell, I left there. I said I had to be at work at 10 o'clock...But I got so weak. Then I went to lay down. I was like if I wake-up, I wake-up, if I don't, I don't... Because if they can't figure it out in the emergency room, and they want me to stay forever, you know how they run tests. I was like I ain't got time for this shit (peer group 3-15-06).

Living with inadequate resources forced the women to balance their stress about their health against their concerns about limited resources.

Stigma and Rejection: Suffering from a "dirty person's disease"

The women described AIDS related stigma as a prominent part of their lives and it led to a tremendous amount of fear of rejection from others who were close to them. The women discussed: (1) the relationship between AIDS-related stigma and other forms of discrimination; (2) the shame they felt because they had HIV/AIDS; (3) the way their HIV status changed their own and other's perception of them negatively; and (4) the relationship between disclosure, fear, and stigma.

Worthy victims versus addicts and hookers. AIDS-related stigma appeared to be worse for women who feared the stigma of AIDS in addition to the stigma associated with how they may have acquired HIV. The women discussed a transmission hierarchy, where people who acquired HIV from medical procedures or their jobs were viewed as the most deserving of help and least subject to discrimination:

> Facilitator: [My husband] got it for helping a little girl who fell down an elevator shaft. He wound up in the hospital because he cut his arm and lost a lot of blood. He didn't know, and they weren't screening blood...He got it and gave it to me.
>
> Participant 1: That reminds me of the other lady that [worked] for a rescue squad. She camped out at city hall [because] she had hepatitis [and could not get help]...She got it helping people and stuff.
>
> Participant 2: I can't believe they don't want to help those people, people who get it on the job (peer group 4-13-05).

Some of the women said that they were upset because family members shunned them, assuming that they were infected with HIV from "sleeping around" even when the women were married and faithful to their partners. As one participant put it:

> Some people are scared to talk about it. Some people don't want to admit that they have it because people are going to say, "Oh well you must have been a drug addict, or you must have been a prostitute or something like that, and that's how you got it" (peer group 8-24-05).

During another session the facilitator confirmed these fears, "[People] look at it like it's a dirty person disease...And they quick to judge...They think...hookers, drug addicts, people just having sex" (peer group 6-28-06). Yet another participant explained that her family would have rejected her if she had acquired HIV from "walking the streets". She said: "I know my family. If I was out there, they would have kicked me to the curb, and told me they didn't want nothing to do with me" (group 10-19-05).

These conversations were particularly stressful for participants who could not remember how they were infected or did not know how they were infected because they were engaging in multiple risk practices such as unsafe sex and unsafe injection practices, or unsafe sex with multiple partners. This conversation between group members illustrated the importance of the mode of transmission despite the group facilitator's efforts to remind the group that there was no hierarchy of infection among the group members.

> Participant 3: I don't know how I got it. I'm being honest. I mean I was just out there, and I was sleeping around with two different guys, so I don't know which one.
>
> Participant 5: I know I got mine through a blood transfusion.
>
> Participant 1: I got mine through a blood transfusion too.
>
> Participant 7: Well I got mine through needles so I guess you call that a blood transfusion too.
>
> Participant 1: That's what [mine] was.
>
> Participant 5: No, but mine was actually through a blood transfusion.
>
> Participant 7: If you want to get honest -- straight up, shot up, and been fucked up ever since.
>
> Facilitator: Let me say this. I don't care how each and every one of us got, we all got it and that's the point…It don't make it no difference. Some people got it through a transfusion, and some got it from shooting up and doing drugs. It don't matter (peer group 10-19-05).

Shame and the struggle to feel human. Many women discussed feeling like an outcast because they had HIV/AIDS. Often they said that they were ashamed of having the virus and fearful when they learned that they were HIV positive. For example, in this discussion a facilitator and two different participants discuss their reaction to learning they were HIV positive:

> Participant 1: For a long time I thought I couldn't love or [that] nobody would love me again. It took me a whole year to find out that I'm still human with this stuff.
>
> Participant 6: After my divorce, it was like I was afraid to, you know, to even…
>
> Facilitator: Once you get it, it's like you're all by yourself now.
>
> Participant 1: Yeah, you feel so lonely.

> Facilitator: And [you feel like] there’s not going to be anybody [out] there that wants you, that needs you, that loves you (peer group 10-19-05).

Likewise, this participant told a story about how she was rejected by a family member. Her narrative conveyed clearly the hurt that accompanies HIV-related shame and rejection. She repeated several times that she was pushed away, and expressed disbelief that this could happen to her, especially when her relative acknowledged that she does not look sick.

> As y’all know I went to New York Friday.
> And my step-father,
> he has a sister,
> her name is Sheela.
>
> Every time I go to New York I always ask how she’s doing,
> and I ask my mom, “Let’s go see her.”
>
> Well, when I went to see her this time,
> she was on her way to church.
> So we talked a little bit and then we all walked out together.
>
> She was talking about my hair,
> she thought it was fake and all that,
> and she was telling me how good I look and everything.
> I always give her a hug and a kiss and [ask] for my blessings
> ‘cause that’s a tradition us Puerto Ricans have.
>
> Well, when I went to give her [a] kiss and [a] hug,
> this [is] the first time this happened to me (starts crying),
> she pushed me away.
>
> It…
> I mean, I don’t know…
>
> Like some people they’re giving plastic forks and stuff like that.
> [but] I never experienced nothing like that and it…

Just to push me away like that.
It's hard.

I didn't know how to tell my mom.
We were sitting at the table and I told my step-dad.

I didn't want to let it out,
[but] my step-daddy kept saying "don't worry,
it's ok.
We love you and we know you can't get the virus by touching somebody
and stuff like that."

Facilitator 1: You think it's because she knows [you have HIV/AIDS]?
Facilitator 2: When did she find out?

She already knew.
And the thing about [it] is,
she was telling me how good I looked,
that my skin was nice and red,
and my hair and everything.

Then she just pushed me away.

Now my mom said that she stinks,
and she [is] never going over there again.
She dead.

Changing perceptions: From "up here" to "down near their heels". Several participants described how HIV had changed their identities. They talked about going from role-models to women who worried about what others would think of them:

> Facilitator: I knew my family looked up to me. For me to go tell them some crap like this…I just felt [like] they [were] going to look at me like: ill, she dirty, ill. She's not the person we thought she was (peer group 8-24-05).

Another participant explained her shame powerfully in this story that she told the group about her decision to tell her family about her illness. Her word choices ("down near their heels") elaborated on the shame she felt, which was worsened by her frustration and pain over her family's disbelief. She ended the story repeating that she resolved to make others believe that she had HIV by showing them the hurt on her face.

> I kept it to myself
> because I was ashamed.
>
> I felt nasty
> and I didn't tell my parents
> because I know so many people in my family look up to me.
>
> To them I'm up here.
> But all of [a] sudden
> I felt down there with them,
> down near their heels.
>
> How am I going to tell my family?
> They will all look at me in a different way.
> I thought they would treat me so bad.
>
> I wound up telling,
> most of my family I told over the phone,
> my immediate family,
> that is who I told.
>
> Nobody would believe me.
> They would hang up on me sometimes [and] call me back.
>
> It was so frustrating to me that I would start crying,
> and that's when they would believe me.
>
> I didn't cry to make them believe me.

> It would frustrate me that they wouldn't believe me,
> so I would cry.
>
> So, [because of] the experience I got telling them over the phone,
> I thought, no more phone calls.
>
> I want people to see my face,
> you know.
> I want them to see my face (peer group 5-11-05).

Disclosure fears: Rejected, dropped, and pushed away. The women discussed disclosing their status to many different people in their lives. These included family, friends, children, relatives, health care professionals, and partners. When they talked about disclosure, only a few women described positive disclosure experiences, as this woman expressed about her experience with her partner:

> I got my courage to tell him, I was like, "Look, I have to let you know something. I don't know if you gonna still be with me or you're not". And I let him know, "I'm HIV positive". We was going together for a while, and he cared about me. He said, "I don't care. I love you for who you are… I think you're a nice person. 'Cause you're sick, that don't bother me." We got kids and everything and I'm still with him (GLI 2-7-05).

The majority of times that the women discussed disclosure, however, it was a stressful experience because of women's fears about stigma and violence. The women also discussed how disclosure consumed their energy.

Disclosing to their intimate partners was an incredible stress to many of the women, who feared their partners' reactions. Most often they feared being rejected, "being dropped" (peer group 3-23-05), and being "pushed away" (peer group 6-28-06). Fear of rejection led some women to desperation. One of the peer group facilitators discussed her intense fears about disclosure and rejection:

> The virus makes you be afraid to tell people. I know some people probably think…I know when I was diagnosed I felt like I needed to find a man because I got this [and] I'm all by myself. I'm gonna infect him and that man will stay with me and [we] will be together, you know. That is how I used to think. I mean I never acted on this but that's how I thought. That's the only way I can get a man if I [get] one and [infect] him. 'Cause he won't have no choice but to stay with me (peer group 4-13-05).

Sometimes these fears were complicated by the fact that women delayed telling their partners about their HIV status:

> Participant: I've been with this guy, my friend now for like going on 10 years. Now I don't know if I should tell him, and I don't know if I shouldn't. Like I said I don't know how he [is] going to react [or] how he going to take it. He might say, "Leave. Why ain't you tell me this from the door?"…It's hard. I can't (GLI 2-7-05).

Similarly, this woman did not initially tell her partner and then was afraid of what he would do or say when she did tell him. Her narrative clarified her fear and discomfort about "sneaking" and hiding her status.

> I was in a situation one time where my partner didn't know I was HIV-positive.
> I continued to have sex with him,
> and I even tried to use condoms.
>
> I was in the same situation,
> "Why would I want him to use condoms now when all this time we hadn't been?"
>
> So I continued not to use condoms
> because I was afraid of losing him
> and what the repercussions were of me sleeping with him without condoms
>
> and that is being real.
>
> I did not want to tell him because I was afraid of the repercussions of letting him know
> that I slept with him without telling him…

> What ended up happening is that I ended up 7 months pregnant,
> sneaking medication,
> sneaking to the doctors.
>
> It got to the point where he was around enough
> that I was not going to be able to keep sneaking.
> 'Cause eventually he would say, "Where are all these pills coming from?"

Many women often feared violent reactions to disclosure of their status. As one participant warned the group: "You have to be very careful [when you disclose your status] because if [your] spouse is using or drinking or something like that, they can be violent" (peer group 8-24-05). Another woman shared her fears about violence and disclosure in her personal relationship: "Look at it like this…what if someone tells [their partner they have HIV], [and the partner] get offended…upset…ready to fight you… ready to shoot you or whatever" (GLI 2-7-05)? On yet another occasion a participant admitted that she could not tell her partner that she was HIV positive and a fellow group member responded immediately to her situation with worry: "But how about when he finds out later and starts kicking you upside [your] damn head?" (peer group 2-9-06). It was common for women to say that they feared a violent reaction to their positive HIV status.

Almost all of the women described disclosure as a major event that consumed their energy, time, and worries. A few of the women who had not told anyone about their HIV status agonized about what would happen if they became very sick and their medical contacts found out during a medical emergency. Some of the women admitted to telling others that they had other illnesses, like cancer, to explain their symptoms. Many women worried that those they told would tell everyone else they knew without their consent, but an equal number of women hoped that the news would travel this way because they did not know how to tell other people themselves. As this participant explained: "I didn't actually tell my family, I told [my mom] to tell them…I told my mom to tell everyone else. I didn't want to…fuck it. I made that decision myself for her to tell. I didn't want no bullshit" (peer group 5-11-05). Similarly, another woman described how she told her neighbor and knew that she would tell others:

> So now check this out. When I go home I know that [it will be] all over the building which is cool, because I wanted to disclose anyway. [I] was just waiting for the right time. I'm like, "God must be really working", because the way she tell it, it's out by now. That's what she do is talk (peer group 2-8-06).

All of the women were unanimously relieved when a disclosure experience was successful. As one group facilitator explained, the relief associated with disclosure was overpowering:

> I know for myself when I first disclosed, 'cause I didn't disclose right away…it took such a [relief] off me. It took the monkey off my back. I must have had about 10 monkeys on my back and when I disclosed for that first time those monkeys were gone and that opened all sorts of doors for me. After that I could eat, sleep. I got a lot once I disclosed, I mean that's how I felt (peer group 8-24-06).

In the transcripts AIDS related stigma was omnipresent in most of the women's lives. Almost everyone described experiencing AIDS related discrimination, shame, rejection or isolation at some point. Many of the women also said that they struggled to create worthy identities as women with AIDS because their positive HIV status stole their previous identities as "good" women. Disclosure was not universally a negative experience but women usually described the process as stressful because they feared rejection, stigma, discrimination, and sometimes even violence. Their relief over positive experiences matched the magnitude of their anxiety to disclose.

Unhealthy Relationships with Men: "I never knew anyone with a healthy relationship"

Included among the women's narratives were numerous examples of unhealthy relationships with men. Unhealthy relationships included relationships marked by arguing, distrust, upset, emotional, verbal, economic, and physical violence. The women discussed unhealthy relationships in most of the group sessions. One participant remarked, “I’d like to know what a healthy relationship is because I never knew anyone with a healthy relationship” [peer group 2-9-05]. A different participant echoed, “I never heard of [a person in a healthy relationship], or met them in my life” (peer group 2-9-05). Unhealthy relationships occurred on a continuum and spanned from: (1) relationships defined by a lack of support and trust, to; (2) emotionally abusive, and; (3) physically violent relationships. Lastly, the women also discussed (4) the relationship between violence and safer sex.

“Going through it” on their own: Unsupportive relationships with men. Some women shared stories of loving and supportive partners. For example, this participant described her partner in loving terms:

> Since I’ve been with [my partner, I haven’t been lonely. He was the best thing that could happen to me. He was the best thing that could’ve came into my life. He really loves me, *with* the virus. I’m just a happy go lucky person right now (peer group 5-24-06).

For the most part, however, many women’s relationships with men were defined by arguing, accusations, cursing, and profound disappointment. Generally, women characterized the men in their lives as irresponsible and financially and emotionally undependable. Likewise, their expectations of the men in their lives were low. For example, this participant responded to one woman’s description about her partner’s love and support by saying:

> That [is a] crock right there when he says he loves you. That’s a bunch of bull shit. What man, all jokes aside, listen up, listen up, all jokes aside. What man feel as though he going to accept you for what you are? The majority of the men out here now, they want to go off on you ‘cause [their] partners or [their] females or [their] women told them that they have HIV/AIDS (GLI 2-7-05).

Another woman’s narrative elaborated further the unsupportive theme by describing how her partner had failed to give her appropriate care and attention. She began her narrative by stressing that she was upset by her partner's actions. She organized her story around the fact that she needed only a hug, but could not even get that from him.

> I'm upset about my day yesterday,
> and the way the people that I wanted to talk to,
> like [my partner, reacted].
>
> I went to [him],
> and said I need a hug.
> He said "Why?"
>
> I said "I'm feeling kind of down on me",
> and he wouldn't even give me a hug.
>
> I called him this morning.
> I said, "Well, can I come over today?"
>
> "You don't mean right away?" He says,
> "Don't come over."
>
> I said, "Well, look, yesterday I was going through something,
> and all I asked you for was a damn hug,
> I couldn't even get that."
>
> He's like, "You are coming over today?
> Well, don't come over unless you are going to stay for a while."
>
> When I told him I was going through it yesterday, he goes,
> "Well next time you are going through it,
> stay home and go through it by yourself" (peer group 4-20-05).

"Undercover" men. It was commonplace for women to talk about cheating partners. One woman described her fears about the consequences of her partner's cheating by saying: "Uh-uh, I don't share my men. I'm sorry. It's bad enough I have the virus. You gonna try to kill

me. It's bad enough I got this. I ain't trying to die earlier" (peer group, 2-9-05). Accompanying the distrust, many of the women said that they believed that the men in their lives were really "gay" but hiding their sexual orientation. Women talked often about "undercover men, men on the down low" (peer group, 1-26-05), as this discussion exemplified (peer group 3-3-05):

> Participant 3: How do the behaviors of their partners affect women's risk for HIV or STIs? How do the behaviors of the partners affect the women? Because they be out banging anything, not using condoms. Because they dogs.
>
> Participant 1: And mainly the down-lows, if they get it the ass.
>
> Participant 3: Not all men get screwed in the ass.
>
> Participant 4: Well they [are] either giving it or getting it (laughter).
>
> Participant 1: How do the behaviors of their partners affect these women? Okay, but it's a behavior of their partners, so their partners are getting fucked in the ass, and fucking everything out in the street and coming home bringing it back.
>
> Participant 4: Yeah, they bringing it back, giving [their partners] HIV or other STDs
>
> Participant 1: Whatever is out there.
>
> Participant 4: Some women are just totally so surprised when they find out their man is out there, like they had no clue.
>
> Participant 3: I would say about 80% of men have homosexual tendencies, even though they might [not] act on it, they have the homosexual tendencies...
>
> Facilitator: A lot of men have the tendencies but they just don't act on it with a man, you feel me? (peer group 3-3-05)

According to their group conversations it was normative for women to worry about the risks of their partners, which were often out of their control but could harm their health. As this facilitator's story illustrated, her partner's dishonesty (she described this partner in a previous passage as on the "down low") resulted directly in her HIV infection. Her narrative clearly conveyed how hurt she was by this relationship and her partner's betrayal. Her ambiguity about getting HIV from someone that she cared about was clear by the way that she told her story. She oscillated between forgiving him for hiding his status and his behaviors from her, and denouncing him and the relationship because he lied to her, chose to protect himself versus her, and took away her choices and her health.

> I got [HIV] from my partner.
> I don't even know if I should say partner...
> I've forgiven him
> 'cause I [don't] think he did it on purpose.
>
> I understand why he didn't tell me.
> Now that I have it,
> I understand why he didn't tell,
>
> the stigmas behind it,
> the way it makes you feel...
>
> I would have never found out.
> I don't have a great immune system in the first place...
>
> It was herpes that started the whole thing.
> I had sex with him,
> and a couple days later I had this thing.
>
> Later that month,
> I broke out with a whole bunch of them,
> and I had to go the hospital.
>
> I had meningitis.
> I talked to the doctor and they said,
>
> "You have a type of meningitis that is associated with HIV".
> That's how I found out.
>
> He could never tell me.

And um, except for all this stuff he told me about being in the hospital
and all [these] procedures,
he…never gave me names…

I think he was in denial.
I think he was so much in denial.

One thing I really liked about this guy
is that he always had condoms…
So I think he was trying to put that barrier there.
But unfortunately he wasn’t using the right condoms.

I think before he was trying to tell me.
He was trying to talk to me…

I did forgive him,
but I wasn’t able to tell him [because he died].

I was going to go out to lunch with him and tell him,
“I forgive you, I know you didn’t mean it in the first place.”

I wish I would have told him
‘cause I really don’t think he did it on purpose…

I couldn’t stay with him because he could look me in my face every day
and be around me,
knowing I had this virus and not say anything.

So I left him.

I [couldn’t] be around him…

I did forgive him.
Maybe he didn’t know.

> But to me I feel like
> he did it on purpose
> because he protected himself.
>
> The only thing he is guilty of is not telling me,
> not giving me a choice.

Emotional violence: Under tight control. Some of the women described unhealthy relationships that included both emotional and physical violence but emphasized emotional violence more frequently. Emotional violence, which the women experienced as controlling behaviors, name calling, and other verbal insults, was very damaging, as one of the facilitators explained:

> Facilitator: I was sick with somebody. They weren't treating me [right]. And he didn't hit me. He wasn't hitting me. Like, it was mental abuse.
>
> Participant: First of all, mental abuse is worse.
>
> Facilitator: I think so. He might as well just come out and hit me (peer group 2-08-06).

The women also talked about how the emotional abuse served the purpose of keeping their self esteem low, which in turn hurt their chances for being confident enough to leave the relationship.

Examples of emotional abuse ranged in severity. The most extreme example came from a woman who said that her partner inspected her underwear when she came home to make sure she was not cheating on him (peer group 4-6-05). The most common form of emotional abuse that women reported was controlling behaviors. As one woman put it:

> [My boyfriend] has to know where I am going [and] who I am going to be with. He needs to know everything before I can leave out the house...He gotta know everything before I even leave the house. I can't even go outside without him saying, "where you going?" (peer group 4-6-05)

Another woman echoed that her partner "[tries] to keep me at home" (peer group 4-19-06). Women also often described partners who did not like when they spent time with their friends, or would not let them go out with their friends. One participant described her reaction to her partner's multiple controlling behaviors:

> You think I'm going to stay with someone that like to beat your ass and like to control you. Like to take over your life. You can't go no where. They gotta stay with you. They going to tell you what to do. You can't go upstairs and take a bath without him right behind you. You can't go to the store. That's a bunch of bullshit (peer group, 2-08-06).

Enduring physical and sexual violence. Some of the women talked about being shoved, hit, and pushed but did not give as much detail as when they described emotionally violent partners, which may reflect greater stigma associated with admitting physical violence. Women talked around the subject of physical violence. For example, several women discussed their frustration getting men out of their house and mentioned that they had restraining orders, but did not talk about the violence that preceded the restraining order. Similarly, women alluded to sexual violence but did not describe it directly. One woman noted, "He always says no [to sex] but I can never say no" (peer group, 4-6-05). The threats that the women faced went beyond their intimate relationships only. Several women mentioned negative experiences with male nurses who acted in "perverted" ways and tried to take advantage of them sexually (peer group 3-9-05). For example, one woman described a nurse who touched her inappropriately and made lewd comments when he helped bath her in a medical care facility. Several women recounted that they got HIV from men who infected them "on purpose" (peer group 4-13-05). These women may have meant that they acquired HIV through forced sex, but they did not clarify this during the discussions, which again may have been related to the stigma of admitting and talking about sexual abuse.

There were exceptions, however. One participant described her physical relationship violence in detail during a group-level-intervention session where she told the group a story about her abusive partner (GLI 4-11-05). Her narrative enhanced the violence theme by describing the severity of violence and how different forms of violence (physical, emotional, verbal and economic abuse, and control) interacted. Her narrative was very action oriented and she focused on what she did to fight back against the abuse using the skills she learned in the GLI, even though her narrative clarified that the skills may not have been safe for her to implement because of her partner's abuse:

> I learned to use "I statements",
> 'cause I tell my old man I think he should go to hell.
>
> He think he's right,
> he think he's always right,
> and I'm always wrong.
>
> So I told him,
> I think you should go to hell...
>
> I learned how to,
> I learned how to talk back.
>
> One time I wouldn't say nothing.
> I would sit there and listen to him.
>
> I [sat] there and listen[ed] to him, thinking,
> I don't like to be hollered at.
> You holler at me and hurt my feelings and I cry.
>
> I got into the habit now,
> if he hollers,
> I holler at him,
> and don't do cryin' no more.
>
> I pick up something and hit him over the side of the head now.
> I got me like a baseball bouncing stick...

I go over the side of his head with it…

I hit him to keep him from choking me.
I'm defending [myself].
I look at him and stick him…

He feels like I need him…

I pay for the electric,
he pay for the gas.
[but he don't pay for the gas [and]…

Then when they send me a shut off notice,
he [bitches] and stuff about it
but he hasn't paid no gas bill since we been there…

Just last night, I'm sitting there and he got an attitude.
He said you know what, "You a dumb stupid bitch."
I said, "No, your mother is".

I don't want to give him nothing so he gets an attitude…

He knows my problems,
and he throws them in my face (GLI 4-11-05).

Unhealthy relationship and safe sex? Sometimes women's conversations indicated that having safer sex was complicated by unhealthy or controlling relationships or partners' refusal to wear condoms. Unhealthy and violent relationships and negative attitudes towards partners clearly did not facilitate condom use. One participant even explained that she failed to protect men during sex because of her hateful feelings towards them. Arguments over condom use were a common component of unhealthy relationships. Another participant said that her partner was so resistant to condoms that she took free condoms at the clinic secretly when he was not paying attention, and tried to convince him to use them at home:

> My [boyfriend] felt like why should I have to use condoms if it is just me and him. So when we come here to the Partnership they ain't allowed to give me no condoms. I got to get them on the sneak tip, you know, because I want them (GLI, 3-28-05).

Condoms often implied that a partner was cheating. As this participant explained, she believed that her partner assumed immediately that she was cheating when she asked him to use a condom: "He looked at them and said 'condoms?' I said to myself, 'yeah condoms…I ain't been messing with nobody'" (GLI, 2-7-05).

Partners' refusal to use condoms created considerable relationship stress. Because of this, one of the most popular activities in peer group was learning how to put a condom on a man without his knowledge. One of the facilitators showed the women how to put the condom on with their mouth. A few women said that their partners were not worried about acquiring HIV/AIDS. For many of the women, this situation generated much upset and confusion. They did not know how to handle a situation where their partner seemed to freely choose or demand to have unprotected sex. This facilitator explained the complexity of the situation by comparing it to other health-related risks:

> That's their right to choose if they want to smoke or not, [and] you know it causes cancer. So, [you don't force them to stop] smoking, just because they say you get lung cancer or emphysema. So, why should you say, "Well we ain't having sex if you ain't gonna wear no condom". That's like [saying], "I ain't gonna feed you if you smoke because I know you gonna want a cigarette after you eat" (peer group 10-19-05).

During another part of this session the other facilitator agreed that a partner's refusal to be safe presented a complicated set of decisions: "If he don't want to use them…I'll feel guilty. Even though I know I told him [that I have HIV], and reassured him about certain things, and he still don't want to use a condom. I'll still feel guilty" (peer group 10-19-05).

For the most part, women's relationships were not a protective factor against their daily challenges. If anything, their relationships with men contributed to their stress. Men were frequently unsupportive and did not meet their physical or emotional needs. Further, men's extra-relationship affairs jeopardized the women's health. Women's relationships were not only unhealthy; sometimes they were outright abusive -- emotionally, physically, and sexually. Promoting safe sex did not often even make sense in the context of stressed, unhealthy and violent relationships.

Women's Suffering: "Pain on top of pain, hurtness on top of hurtness"

The majority of the women expressed frequent feelings of distress, sadness, depression, anxiety, and fear. As one woman explained it, "This September it will be 10 years I have been *suffering with HIV*" (peer group 6-29-05). The women described pain as a normal part of their daily lives. Suffering existed on a continuum and ranged from: (1)sadness, to; (2) grief, to; (3) suicidal feelings.

Unbearable fear and sadness. One participant noted: "The majority is scared, like half of us women out here right that [have HIV/AIDS], we are scared for real" (GLI 1-10-05). Participants were scared and upset about many challenges in their lives including all of the barriers that I have reported previously: caretaking burdens, illness, violent relationships, stigma, rejection, and a lack of resources and support. Many women described how depression resulted from learning that they were HIV positive. They talked often about the intense sadness and fear that accompanied waiting to hear the results of their HIV test, as this woman explained: "All that waiting to find out if I was positive. I cried every day until that test came" (peer group 4-13-05). Sometimes women linked their distress to the way they were told that they were HIV positive:

> I was in the hospital my last year of high school. I was trying to get into the military, that's how I found out. They [sat] down and [said], "You have HIV, take it like you will." It's horrible. No counselors, nothing, you know? I hope they do things differently now.

> Somebody had to go home thinking that, no counseling, no support, you know (peer group 4-13-05)?

Many of the women described having days where they cried for most of the day, and were unable to be soothed by others. One participant articulated her agony poignantly:

> I went through some hell. Believe [it], sick, operations and all that. I went through it and I'm still going though it. Death here, sickness here, surgery here, so on and so on and so on. But, [a] lot of people don't really know about the virus. They think they do when they don't. That's the bad part about it, and [they] keep saying to me, "Oh I know about this, and about this, your CD4 counts, your viral loads and stuff like that". You don't know shit about it. You don't know how we [are] feeling inside. You don't know how much pain we [are] going through inside. A lot of [people are] like me. I don't show my pain, not out here in public. Like if I'm behind closed doors, or by myself, I might shed a tear now and then, and sit back and think about it and try to let go and stuff like that, but it's not going away…A lot of time I'm going through a lot of shit. It ain't just stress. I have pain on top of pain. I have hurt-ness on top of hurt-ness (GLI 2-7-05).

"It still hurts": Ongoing grief. Many of the women said that their lives were filled with loss. It was common for group members to know someone close to them who died. The women described their struggles to manage grief, even years after their loss. A few women were angry at those who died because they felt like they could not recover from the loss. At times during group sessions it seemed like all of the participants were grieving the loss of someone, as four different participants described below:

> Participant 6: My mom been dead for about 16 years, and I have a picture on my wall in my bedroom. It still hurts.
>
> Participant 2: Me and my mom were real close, like I could start a sentence and she would finish it or I could just think of something and she would know before I said anything, that's how close we was.

> Participant 4: My grandmother passed away and my dad passed away on my birthday of last year.
>
> Participant 3: My mother passed away on my birthday (peer group 5-10-06).

These deaths were painful for the group members to handle. One woman commented specifically on her pain over the loss of her mother:

> If I'm at home I sit in my house and just take it. I can't do nothing. The tears might come down, tears might not. But I wish she was still here for real. It's a lot. You know I ain't going to say that you can't talk to your Dad, but woman to woman talk now for instance…My mom was my sister. She was my best friend…I can't even think about it (GLI 2-7-05).

They tried to console each other through their mutual experiences of loss, by normalizing these experiences, but it remained difficult:

> Participant 2: It seems to me like it's getting harder…[my boyfriend's] death…I'm crying more…
>
> Participant 3: It's gonna be like that for a while.
>
> Participant 2: It's like I'm crying almost every day…He supposed to be here with me.
>
> Facilitator: He's in a better place. Everybody can't be here. Everybody loses somebody they wish they could stay. I wish my husband could've stayed.
>
> Participant 3: I wish my son or my mother was still here
>
> Facilitator: That's right, everybody has lost somebody…you [are not] the only one (peer group 5-3-06).

One woman summarized the overwhelming sense of daily suffering and grief experienced by the participants when she told a story about her baby who was dying of AIDS. Her narrative revealed the complicated nature of her suffering. Her word choices indicated that she was concerned about multiple losses and stresses: her sickness, her baby's sickness, and the loss of her previous child. She blamed herself, referring to her actions as "Russian roulette" twice.

She said she was afraid to get close to her child, mentioning several times that the baby was "touch and go". She described being highly dependent on the love of others to help the baby survive, making her concern for the child and her desperation clear.

> Participant 4: My last baby is sick,
> real sick,
> as we speak...
>
> She's still in the hospital.
> I had her a month ago.
> Then I caught pneumonia.
>
> Participant 5: Do you think it's okay, I mean, for you to have safe sex so you don't get pregnant again?
> Participant 4: I don't have to get pregnant.
> Facilitator 2: You don't take birth control pills?
>
> Participant 4: I brought it up,
> as something I could discuss before.
> [I] was like, "Alright,
> I'm playing Russian roulette."
> Cause I have one who is 3 [and kids who are] 4, 7, 8, 14, 11, 18, 22, 27, 31, [and] 33.
>
> And none of my kids had [HIV/AIDS].
> And I had it since 1982.
>
> But the last one has got it,
> because my [CD4 count] was only 20...
> Then I started getting sick.
>
> But, [I've had it] for a long time.
> I didn't even expect myself to live this long.
> Most of my friends are dead...
>
> Facilitator: How old are you?

Participant 4: 44.

Facilitator: So, do they think the baby will get better? Oh, so they think the baby is going to pass?

Participant 4: Yeah, it's touch and go.
I can't say it's not,
and I can't say.

I mean I was that touch and go too.
So you know
I don't believe what the doctors say.
I just pray…

God may just have meant for a better way.
He is the planner.

Facilitator 2: Do you go see her?

Participant 4: Yeah
She has plenty of people up there,
giving her love and attention…

Love can bring her through it.
Love can bring you through it.
She'll get through it…
Love can bring you through it.

But I would hate for her to be here and suffer,
because I've seen how people suffer.
I would hate for her to go through that…

Facilitator: She CAN live with it, just like you did. I hope she makes it. I know a young lady born with it. She is 22 now…

Participant 4: I buried a child before.

I buried a child when I was 14.

So I just hope for the best
but I don't want to get that close to this [baby].
Since it's touch and go,
know what I'm saying?

Facilitator: Don't not get too close. Let her feel your love, even if she doesn't make it, she will know her mom's love.

Participant 4: I just,
cause I always think
it was my fault.
If I wasn't playing Russian roulette....

She is something,
my baby.
She was 1 lb too.

I had at her 6 months.
I never had a big baby...

I had 11 kids,
none of [them] stayed in there 9 months.

Doctor said I'm good for 10 more [babies] [peer group 1-26-05].

"Hurry up and die": Fighting suicidal feelings and finding the will to live. Many women said their initial reaction to learning that they were positive was thinking that they would die. It is important to note that the women in this study were living with HIV/AIDS for 10 years, on average, which means that many women likely learned of their status during a time when less treatment options were available. As this woman explained, "When [I found out I had HIV] I cried for a whole day. I was crying for a whole day because I figured I was going to pass" (peer

group 6-29-05). Some women described wanting to take control and take matters into their own hands, which often led to suicidal feelings. As one peer group facilitator put it: "Most people that I knew, when [they] first found out about HIV, killed themselves" (peer group, 5-3-06). Another woman reflected sadly: "When I first found out what I had, honestly, I was thinking about walking across the Ben Franklin bridge and jumping the fuck off" (peer group, 4-6-05). Another woman described it this way: "I know I didn't get no help when I first found out. I was in die-high mode. And I didn't care" (peer group, 3-03-05). Another woman said, "That's what I was like, I was suicidal at first, I was always trying to kill myself over and over" (peer group, 6-29-05).

Although most of the women linked suicidal ideation to learning about their HIV status, a few of the women said that these feelings persisted. One of the facilitators and a group member noted that sometimes being sick was so awful that they welcomed death:

> Facilitator: When I was sick I wanted to hurry up and die.
>
> Participant: Yeah, me too, when I was sick.
>
> Facilitator: I was like, "Oh gosh, death has to be better than what I'm going through" (peer group 5-24-06).

Sometimes women described their daily burdens and sadness as unbearable:

> Participant 1: Yesterday I was vulnerable…I even thought about death…I said I could kill myself…
>
> Participant 2: Sometimes it is like, "Why is I here, why is I here?" We think it is just not working out right but the next day it turns out different. I go through that.

As one woman articulated clearly, she not only experienced stress, but suffered from pain on top of pain, and hurt on top of hurt. Feelings of sadness were pervasive in women's discussions. Daily sadness was worsened by grief and feelings of suicide as many women had examples of time periods where they questioned what they should live for. Their pain was prominent, striking, and hard to ignore.

Fighting for sobriety: The cycle of HIV infection and substance abuse

Many of the women searched for ways to relieve the pain and suffering in their everyday lives. To this end, the group participants often discussed their struggles with substance abuse. It was common for group participants and their friends, partners, family members and children to struggle with drugs and alcohol. The women talked predominantly about: (1) substance use that contributed to their HIV infection; (2) resulted from learning that they had acquired HIV/AIDS; and (3) the current and past power of addiction in their lives.

"I infected myself": Acquiring HIV through substance use. Many of the women attributed their HIV infection to the use of substances, which in turn led them to desperate and risky acts. As this participant explained, once she started using drugs she could not think of anything except crack cocaine. She attributed her HIV infection to her crack use:

> Okay, so [at first] I was just a weekend high. Then it went to Monday, Tuesday, Wednesday, Thursday… Then I had to have something every day. It's like it just added up every day. After I got to crack, it was like every God-damn day. You miss work…lying, irritable. Because I used to smoke weed everyday and I could still get up and go about my routine. But that crack, all from being curious. That's why I say I don't [want to] be curious about nothing else in my life. It got me, I caught the virus (peer group, 6-7-06).

One woman blamed herself for her infection, and said, "I infected myself by using needles" (peer group 4-13-05). Another woman explained that she was so concerned with getting high that she did not think about taking time to make sure that she used a clean needle:

> Participant 1: I think [my HIV] erupted. Like, I might have had it before I got sick because the dude that I was messing with and getting high [with], he said he had the virus but we shot up anyway. After I shot that needle up there, a couple days later, I felt real sick. Thrush came in my mouth [and] all the way to my back.
>
> Participant 2: You gotta clean the needle out first.

> Participant 1: We did…I thought we did. Shit, I don't know. I was getting high. I didn't have time for that shit (peer group, 5-11-05).

Some of the women said that their blackouts from substance use caused their HIV infection. They could not remember their behaviors, how they became infected, or how they even wound up in care. As this participant reflected, "I don't know what happened. I was out there getting high. I don't know how I got to the hospital. I still don't know how I got to the hospital" (GLI 1-10-05).

"What do I got to live for now?": Using substances to cope with HIV/AIDS. Some of the women also talked about using drugs and alcohol in connection to finding out that they were HIV positive. Upon hearing the news they reported that they kept drinking or doing drugs because they felt like they were going to die anyway. This participant explained her desperation when she learned she was HIV positive:

> The way I found out was in this program, the WRAP program. [The] hospital paid you $20 to take the test [and] $20 to come back and get the results. She was like "You're positive". And then that was it, you know I what I mean? Like, bye, here's your $20. How about I took the money and went and bought two bags, because that's where I was. Like nobody said it was going to be alright. I just broke down and cried. I was like well fuck it. I banged both bags at one time. I was like what do I got to live for now (peer group, 6-29-05)?

Similarly, three different participants discussed the relationship between learning they were HIV positive and using drugs and alcohol. The intertwined narratives explained that all of the participants had similar experiences with drugs and alcohol once they found out that they had HIV. They all stopped using at one point though, and participant three's repeated use of the word "refuse" clarified the strength of her commitment to keeping away from the substances now.

> Participant 2: When I found out I still kept drinking
> Participant 3: I did too

Participant 1: You did?

Participant 3: Yeah, I still kept getting high…
you think you gonna die anyway…

Participant 1: You know my niece passed away
‘cause she thought the same way,
like she kept getting high,

and I talked to her,
I told her I had HIV even before she passed away…
She passed a couple years ago…

And she kept getting high off crack,
and not taking her medication,
nothing,
I mean she looked bad…

Oh my God…
I said I refuse,
I refuse,
I refuse,
to go out like that…

I was on drugs too,
but I wouldn’t go back on no crack no more,

I wouldn’t use drugs,
I wouldn’t dare…

Participant 3: I looked that way…
I looked that way too,

so I just asked somebody to help me stop using crack and alcohol,
help teach me how to pray (peer group 5-3-07).

Fearing the power of addiction. Even when some women talked about being *recovering* addicts, they said that the threat of relapse was still a major concern. One participant called crack all powerful, "the alpha drug" (peer group 6-7-06). Another participant noted that, "Crack makes you forget your mother, your father, everybody" (peer group 6-7-06). Several women commented that they were "doomed" (peer group 6-7-06) after their first hit of drugs. Another woman noted that she feared addiction more than any other illness:

> How about [that] with all the diseases I've had, I fear addiction. I fear relapse accruing. Like, I just had a friend who came out of prison. She was only out for six hours, and they found her on a bridge with a needle in her arm. And she got four beautiful kids. Now they don't have a Mom…I know if I relapse and I use my drug of choice that could be me. How about that shit would probably kill me before the HIV, diabetes, cancer. Chasing that addiction will kill you quicker (peer group 6-29-05).

In order to survive several women noted that they needed to stay away from anyone who continued to use drugs and alcohol because the temptation was too great to resist. Almost all of the women who had used drugs worried constantly about going back to using drugs or alcohol:

> Participant: When I was out there tricking and all that, [I] sold my clothes. [I tried] to sell a stereo and all that. Me and [this] dude got together and that was it. We smoked that one little pipe. I kept going around smoking pipe after pipe after pipe. That was my problem, I didn't care who I was smoking that pipe [with], you know what I'm saying? That was my problem, the weed. Don't smoke no weed around me. I'm telling you now, that was my problem [and] it's still my problem. I got friends that get high [and] that old smell comes back, you know? You gonna wanna hit that, you know what I'm saying? But you know you can't do it no more (GLI 1-10-05).

For many women, the powerful nature of addition made it a core component of their identity. In this narrative the participant chose first to identify herself as HIV positive, but next identified herself as a recovering alcoholic. She said that she could manage her virus effectively because she stopped drinking. She equated sobriety with "living", exemplified for her repetition of the phrase "I am living now".

> My name is [Rita],
> and what [am I] about?
> Well, for one, I am HIV positive…
>
> I'm a recovering alcoholic,
> and I haven't drank in three and a half years.
> The day that I stopped drinking,
> that made me even stronger to deal with the virus…
>
> Facilitator: Really, that's good. What is your greatest challenge?
> Participant: My greatest challenge?
> My greatest challenge…
> Facilitator: Do you have any, anything that you really struggled with, that you really achieved but you worked really hard at?
> Participant: All my traveling,
> because before I went nowhere,
> [I] struggled…
> Facilitator: You wouldn't go before?
>
> Participant: No,
> I was too busy drunk.
> And then I was too depressed with the virus.
>
> Now it's just like fuck it.
> I'm living now.
> I'm living now (peer group 6-29-05).

Likewise, in this narrative, the participant organized her story around drugs and alcohol, reiterating their importance to her life story. She called them her downfall and associated sobriety with her proudest moments because when she is sober people can trust her, and she can trust herself.

> Well, I'm a black woman.
> I'm 50 years old.
> I've been living with the virus since 96.
>
> They say I had it longer than that,
> but like I stopped getting high,
> I stopped using drugs and alcohol.
> That was my down fall.
>
> I've been clean for 4 years.
> I just take my medicine [and] do what I gotta do.
> I'm healthier than I ever was…
>
> My most proud moment is that people can trust me today,
> people trust me.
> That's the main thing I think that keeps me sober and clean.
> I know if I go back out there,
> ain't nobody going to trust me again.
> And I won't trust myself,
> and I trust myself (peer group 6-29-05).

Women described substances like alcohol, marijuana, and crack as overpowering forces in their lives. A dangerous cycle of substance abuse and HIV infection existed where substances rendered women incapable of acknowledging or paying attention to their risk behaviors and led subsequently to HIV infection. Once infected, women in turn relied on substances to manage their pain. Whether past or present, substances had an important role in women's narratives and identities.

Relationship between all Structural Violence Themes

The three major structural violence themes (stress, stigma, and unhealthy and violent relationships) and the two themes that described the consequences of structural violence (suffering and addiction) did not exist independently but overlapped in important ways. Daily stresses such as illness, the need to care for themselves as well as others, and scarce resources increased women's vulnerability by creating a constant level of strain for the women. This strain made it harder for women to manage specific and major challenges like stigma and violent relationships. For example, poverty and lack of housing reduced women's mobility which was particularly problematic for women in abusive relationships. In turn, stigma and violence increased women's daily stresses. For example, several women commented that bad relationships made them ill. Stigma was related to unhealthy and violent relationships, because partners used women's HIV status against them, making women feel like they needed their partners to take care of them or manage their finances, for example. Other women accepted abuse because they were afraid to be alone with HIV/AIDS. Women suffered and used substances as a result of their experiences with structural violence. Suffering and addiction in turn complicated women's experiences with daily stress, stigma, and violent relationships. For example, drugs and alcohol exacerbated illness stresses. In sum, the structural violence themes created a web of daunting challenges for women to navigate in their daily lives.

While the participants discussed openly their overwhelmingly negative experiences with structural violence, the women in this study did not talk about their challenges only. They also defined themselves by the ways that they met and grew from these challenges. I describe the women's strengths in detail in the following section. A description of the women's reported strengths is in no way intended to minimize, romanticize, or patronize their struggles or dichotomize the participants into "good" and "bad" women with HIV (Wacquant, 2002). I explore more thoroughly the importance of viewing women's barriers and strengths in the context of their capabilities and the structural forces and inequalities that shaped their choices and the ethics of representation in the discussion section.

V. Stress-related Growth Themes

Stress-related growth refers to change in response to adversity that goes beyond survival and recovery to transformation and improved functioning (O'Leary, 1998). Change results when traumas, such as learning that one is HIV positive and/or living with HIV/AIDS, compel individuals to confront and modify their current or past ways of thinking and behaving (Tedeschi et al., 1998). The women in the groups described a stress-related growth process that resulted from learning that they had HIV/AIDS and/or living with HIV/AIDS. The participants also provided many examples of resilience and resistance.

Table 3 describes the number of groups (of 30) that included each theme, the number of times the women discussed the theme in all of the groups, and the range (minimum and maximum) of the frequency of a theme in any single group session. As with the structural violence findings, quantification provides an important general outline of these themes but is subject to the same limitations that I have discussed previously.

Table 3. Quantity of stress-related growth themes in the transcripts.

Theme*	Number of groups (*n*=30)	Number of times: all groups	Range per session (min/max)
Stress-related growth	5/30	9	1-3
Resilience	9/30	23	1-7
Resistance: Unhealthy and violent relationships	7/30	16	1-4

*The themes are listed in order of their order of appearance in the results section.

Stress-related growth: HIV as a "Blessing in Disguise"

Although most of the women were aware of the acute challenges associated with living with HIV/AIDS, some viewed HIV/AIDS as a motivating event to change their lives in positive ways. Some women tied their goals and accomplishments to changes they made upon learning their HIV status and perceived HIV/AIDS as a catalyst for (1) positive health changes, and (2) new opportunities.

Good health: "I'm living better than when I didn't have it". Some of the women described their health as poor preceding their knowledge of their HIV status. They made decisions to be healthier once they found out that they were HIV positive. One woman noted, "I am living better than when I did not have HIV". The facilitator responded, "Exactly, we know you improved your life so [you'd] be able to get over this" (peer group 10-26-05).

While it is true that many women reported that they turned to drugs and alcohol upon learning their HIV status (see previous section), several women also specifically linked their HIV/AIDS status to sobriety. It was common for women to say that they or others that they knew stopped using drugs or alcohol once they learned that they had HIV/AIDS. One of the facilitators noted the connection between HIV/AIDS, sobriety, and safer sexual behavior:

> I know a lot of people who are HIV positive or full-blown AIDS, and they say [that] had they not gotten this disease, they would still be out there in their addiction. I think a lot of people come off their addiction, you know. Maybe [learning they are HIV positive is] something that scares some people and might make them a little less promiscuous…[and] it's changed a lot of people's thoughts against drugs (peer group 5-3-06).

A participant agreed and explained: "I got sick [and] then I found out this is the better way for me to do it. If I hadn't gotten sick, I might not be sitting here at all. I probably would've kept on with my addiction. I might have kept on going how I was going, you know?" (peer group 5-3-06)

HIV as an opportunity. Likewise, some of the women saw learning that they had HIV as an opportunity to make positive changes in their lives and change their outlook on life. For example, in this narrative the participant focused on how learning her HIV status led her to pursue her goals energetically. Her language choices, including her choice of pronoun use, focused on her action and accomplishment. For example, in the third stanza she used the pronoun "you" and described how everyone can achieve what they want if they go after it. In the final stanza she used the pronoun "I" and focused specifically on her accomplishments.

> [I am most proud of] being a recovering addict,
> and being incarcerated.
>
> Going through the shit I went through

> has made me a stronger person today.
> No goals are unaccomplishable…
>
> If you want it, it's out there.
> You just gotta go after it.
> That's all.
>
> I think the HIV is a blessing in disguise …
>
> Everything that I have accomplished,
> Everything that I went for,
> I have accomplished (peer group 6-29-05).

Likewise, this facilitator described the way HIV changed her outlook on life:

> I don't feel bitter [about having HIV/AIDS]. I never felt bitter. I think it has changed a lot of things in my life, you know, as far as being [positive]. It's made me not take life seriously [and] I take better care of myself. I didn't [used to] live my life the way I do now [peer group 4-13-05].

Several other women described having HIV as an opportunity to help others. The other facilitator responded:

> I don't feel bitter either. I'm not saying I'm glad I got [HIV/AIDS], but I'm not sorry I have it, because this gives me an opportunity. This disease is going to be out here whether I have it or not. But I'm kind of glad that I have it so I can help others, have workshops, support groups, and do things that will help better other people's lives. I'm using my situation to help other people. Being sorry or mad or disappointed, I've never felt none of that [peer group 4-13-05].

One another occasion the same facilitator confirmed her commitment to using her HIV status as an opportunity to help others by saying, "There might be one person that you tell it to that you gonna be able to help them through your example. If I can just help one person out of 90, then I did something" (peer group 5-3-06).

Resilience and Fortitude: "I know I'm a outlive this disease"

Resiliency is the process of successful adaptation despite challenges or experiences of significant adversity (Luthar & Cicchetti, 2000). The women expressed an incredible resiliency and will to survive, despite numerous odds and barriers that they faced in their daily lives. I explained these barriers in the previous section and included struggles with violent relationships, violent neighborhoods, stigma, health concerns, and lack of resources. Their resilient experiences can be summarized in three primary categories: (1) strength and persistence to succeed; (2) hopefulness and will to live with HIV/AIDS;, and (3) reliance on God and spirituality to help them cope with living with HIV/AIDS.

Strength and persistence: "Some days I forget I have HIV". Many of the women expressed that they were determined to stay strong and on a positive course, and to "not let anybody stagnate [their] progress" (GLI 4-11-05). Many women also described how they wanted to accept their challenges and deal with them. As one woman noted, "You got to deal with what you're dealt" (peer group 6-29-05). Similarly, another women said:

> As long as I take care of myself and stay healthy and do what I am supposed to do, I know I am going to live as long as God wants me to live. When I think about it, I try not to cry and be strong. I'm really dealing with it now (GLI 2-7-05).

Similarly, in the following intertwined narratives, the participants focused on the importance of dealing with their present challenges and accepting their challenges in order to survive. Their repeated use of the phrases "one day at a time" reinforced their grounding in the present rather than the future. The women said that they needed to manage the present ("one day at a time") so that they could enjoy the future ("you got to be around in order to see tomorrow"). The repeated use of "I want to live" clarified the strength of their will to manage their difficulties.

> Participant 1: Take one day at a time.
> You know they'll be some rough times…
> you know sometimes it might not go good,
> or medication gives you side effects.

But try to hang in there,
one day at a time.
Tomorrow may be different from today,
but you got to be around in order to see tomorrow.

Participant 2: That's what I believe.
Like I was suicidal at first…

Facilitator: You don't think like that now?
Participant 2: No,
uh uh.
I want to live.
I want to live now.

I accepted it,
whatever is going to be
I just got to deal with it.
Like she said, one day at a time (peer group 6-29-05).

Many of the women did not simply deal with their situations or manage them, however. Rather, they described a process by which they met their challenges with energy and resolve. As one woman put it:

> Some days I forget that I have this shit[HIV]. I be moving so fast then I gotta tell myself to slow down a little bit. You know, everybody be like, 'The virus got me sick, the virus got me this, the virus got me'. No, the virus don't do a darn thing (peer group 8-24-05).

Another participant stressed similarly that she remained confident about herself and her will to live despite her negative experiences:

> I say I'm a outlive anybody that do mean things to me, or say bad things to me, or try to put me down or something. I say watch. I say just because I'm sick it don't mean I'm not going to outlive all of you. And that's how I keep myself healthy, and keep myself from

> crying and trying to hurt myself and all that. I stay strong like that because I know I'm a outlive this disease. I mean I know I'm a still have it but I'm a live for a long time (GLI 1-10-05).

These women resisted being defined by their illnesses or their struggles alone.

Hope to live: "There IS life with HIV". The women talked often about their insecurities and their fears of dying from AIDS. But many women told numerous hopeful stories that overwhelmed their stories of fear. As one participant asserted: "You can have AIDS [and] you *can* have a relationship, [and] you *can* get married, [and] you *can* have kids" (peer group 6-7-06). Another participant echoed that her most proud moment was learning that she "could live with the virus, and not be ashamed of it" (peer group 6-29-05). Another participant said emphatically that "HIV is not a death sentence. I know people who've had the virus for 20-25 years, and [are] still going like the energizer bunny. So I know there is life with HIV" (peer group 6-29-05).

Most of the women agreed that education and support from others who are HIV positive and self-acceptance gave them hope to live. In this narrative the facilitator elaborated on the importance of these factors, by choosing language that repeated their significance in her narrative.

> Negative thoughts that run through our head,
> [they put us at the] point where it's like,
> "You know,
> forget it,
> I'm a die…"
>
> But it's like once you get that education in you,
> and you start learning all the stuff there is,
> and start being around people that are infected,
> or however you want to call it.
>
> When you start being around people,

and learning
you know that gives you hope…

You start listening to you.
You start accepting,

"Ok I got this disease,
I need to live with it,
[and] find a way,
even if I'm not gonna tell everybody."

When you start accepting it,
that you have it,

then it'll be a much,
it's much easier,
to deal with it (peer group 5-3-06).

Likewise, the participants and facilitators talked about the hope and the social support that they gave each other to survive by acting as living examples of healthy HIV positive individuals. One of the facilitators explained the way she reached out to a patient at the clinic:

> I'm sitting before her and I'm like, "Girl, you don't need to cry, because I've been living with it for 10 years." She kind of stopped crying and looked at me like, "You've been living with it for 10 years?" This is what she says to me. I said, "Yeah, I've been living with the virus for 10 years, and yes, I work here. HIV positive people work too." I said, "You do not have to get sick… you will never die from HIV." I said, "You may die from complications and things, but something else is going to kill you." And by the time I got finished with her, she was smiling. She felt a lot better. I really explained to her that, you know, you're not going to die. I said, "Don't go home and shut yourself away, you go home and live your life like you normally do (peer group 6-29-05)."

While the women said that they worried about their mortality, they were equally as adamant about living with HIV/AIDS.

Faith as strength. The women talked about gathering their strength from their higher power, God, or their spirituality. It was very common for women to thank God and praise God for their health, survival, and other positive experiences. One woman said that faith in God and religion were two of women's unique strengths during one group session. Another woman noted that faith was literally healthy: "When you do give [your worries] to God, for some reason your [CD4] counts seem to stay way up there" (peer group 6-29-05). In this narrative the participant elaborated on this theme by explaining clearly that she relied on God and thanked God for supporting her through a tragic experience by repeatedly using the refrain, "God is good":

> It scared me cause Sunday my house burned to the ground.
>
> Baby, everything [I own is gone].
> I'm a tell you today as God is my witness,
> Red Cross gave me $205 to go to K-mart in the Gallery,
> enough for one coat, one pair of shoes,
> coat was $65, shoes was $30, and $105 for clothes.
>
> I had a coat already.
> I had shoes but not these shoes for the snow.
>
> I took the $205 that they gave me yesterday up in that place,
> and baby the lady said
> you look like you got four hundred and something dollars,
>
> cause I know how to shop.
> I ain't walking out with no name brand this,
> and $25 this.
>
> And you know this is how God is good.

I counted me having 8 complete outfits,
4 pair of pants,
a pair of boots that cost $42,
and had change over.

I asked the lady if I could get the money,
she said no.
I said hold on,

I got some bras, panties, socks,
and brought me a soda and a bag of potato chips
and that was my money.

Tell me I don't know how to shop,
cause I had nothing.

When the fire hit me,
it took everything I own except what I ran out the house with.

Everything,
but God is good.
Cause guess what?
My sister had my social security, birth certificate and an ID of mine.
God is good.
God is good (peer group 12-14-05).

Many of the women said that they commonly relied on God's plan for them and their faith helped them make sense of difficult situations. As this participant noted, however, they worked *with God* to manage difficulties:

> I solve problems like my mother did… When she was solving her problems like that, I used to fuss at her about that all the time [and say], "How come you always waiting on God, when is *you* gonna do something?" [She'd] be like, "He's coming," [and I'd] say, "I ain't see him get here yet. 'Cause my mom used to always frown on stuff and always say she

> gonna let God handle it, right, and I always [said], "Sometimes you just gotta do things for yourself, you can't [wait] on God all the time". But now, thinking it out, I do that now myself. I pray a lot (peer group, 3-22-06).

Similarly, another woman stressed that anyone can make changes and progress with God's help:

> People feel as though you make a mistake, you gotta keep constantly making that mistake over and over again. But that's all because you want to. If you want to change your life, and do what you supposed to do, you can do it. See, people out here keep telling me I can't do this and I can't do that. If you put your mind and your heart, and God with it, oh you can do anything you wanna do (GLI 1-10-05).

Many of the women said that they relied on their spirituality or the faith in God to bring them through difficult challenges or to explain their struggles. In sum, their faith played an important role in the way women managed their daily barriers.

Resisting Violence: I'd rather be happy by myself than to be sick with somebody else."

As previously described, numerous women recounted having had many negative, unhealthy, or violent relationships with men. One of the facilitators stated she would rather be by herself than sick because of an abusive partner (peer group 2-8-05). Many of the women who experienced violence were emphatic in their descriptions of resistance and willingness to do something to change these situations. To resist unhealthy relationships, the women discussed: (1) what they would not accept in relationships; (2) the way they fought back; and (3) what they believed that they deserved in relationships.

Refusing to get "stuck" with violent partners. Women's conversations about their relationships often included the ways that they had resisted violence in relationships and advised others to do the same. Regardless of whether or not they described their own violent experiences, they asserted that it was simply not acceptable to live with extreme forms of emotional or physical violence. While this may represent the women's desires to describe themselves in a socially desirable way, their consistent descriptions of resistance to violence were noteworthy, nonetheless.

Many women were adamant that they would not tolerate violent behavior and several women noted that they refused to be owned by men. A facilitator confirmed, “I ain’t gonna stay in no kinda relationship were I’m agonizing, getting sick, worrying, [or crying]” (peer group 2-9-05). Another woman responded angrily to a participant’s description of her controlling partner by reiterating her refusal to endure similar behavior by saying, “Shit, I’ll be damned. Don’t nobody own me. He thinks you can be his little slave” (peer group 4-19-06). Many participants were particularly vocal about physical violence. One woman said, “I couldn’t be in no relationship where somebody was hitting on me and stuff because somebody is going to get killed” (peer group 2-9-06). These two participants summarized further:

> Participant 2: I wouldn’t be stuck with nobody that’s going to be violent like that. I mean first of all, I won’t let a nigger put his hands on me period, without me putting my hands back on him. It’s a lot of women out here right now, right, they in these so-called aggressor relationships, right. They feel as though that’s love. That ain’t no love if you getting your ass whooped like that every damn day. Come on now.
>
> Participant 3: If you put your hands on somebody then you don’t love them. If you gotta put your hands on somebody I don’t think that’s love. That’s not love.
>
> Participant 2: That’s what I’m saying. You can’t be too aggressive in no relationship. You can’t be too like you got the power over somebody, you know what I’m saying? You ain’t got power over nobody (peer group 2-8-06).

The Peer facilitators were clear however, to stress that it was difficult to resist violence and leave relationships easily, but the participants had a difficult time excusing this situation. Both facilitators defended those in violent relationships often, like in this example:

> Facilitator 1: You know what? You always have to think about people who are much weaker than those of us who are stronger. You figure if you grow up and somebody is kicking your butt all the time, that's what you used to, so...
>
> Facilitator 2: You think that's normal.
>
> Facilitator 1: It's a normal thing unless somebody shows you that it's different (peer group 2-8-06).

Fighting back. The majority of the women who reported violence also discussed the ways they fought back against violence. Often, they said that they were forced to use violence themselves. For example, this woman said that she would have to retaliate if her partner used violence:

> If [my mate felt] as though [he wants to] go out and get drunk and come home and hit somebody? Oh they'll come and get a body out my damn house, ain't no ifs and buts about it. You swing at me that'll be your last time you ever swung at me (GLI 2-7-05).

Likewise, in this narrative, the participant described how she had defended herself from a partner who had pushed her. After stating that he had hit her, she immediately stressed that she fought back. Her word choices reinforced that she did not need her partner and was not with him anymore. Her narrative also explained how drinking featured prominently in her abusive relationship and clearly conveyed that she is not drinking anymore either, indicating that in the present she is healthier without alcohol or this hurtful partner.

> When I was drinking back then,
> thank God I ain't drinking no more,
> one guy I was with,
> me and him stayed in an argument.
>
> I was drinking some Old English,
> that shit had me on me rams.
>
> Me and [this] dude was together,
> he like pushed me up against a gate you use for a store.

I knocked the shit out of his ass,
so me and him
ain't together no more

every time I see him [he says,] "How you doing, how you been?"
[I say,] "Yeah, I don't need you no more".
That's what I said, "Fuck you"...
I don't need you no more (peer group 2-8-06).

The women's violent relationships sometimes placed them in situations where they chose to or had to use violence themselves, to retaliate and protect themselves.

Demanding equal and caring partnerships. Most of the women also talked about what they deserved in relationships. This conversation between facilitators and participants stressed the qualities that women look for:

Facilitator 1: We need to be wanted.

Facilitator 2: We need to be wanted.

Participant 7: That's right, we need love too.

Participant 5: We need attention.

Facilitator 1: I know that's right.

Participant 6: Support, we need support too (peer group 10-19-05).

In this narrative, the facilitator explained the importance of good communication for her relationships. During the narrative she repeated that it was important for her partner to understand what she wanted, liked, and did not like. She was adamant that she did not have time for someone who was not going to respect her:

I do have a person in mind.
We've been talking for the last 5 months.

We gonna sit down and have a talk [and I'll tell him],
"This is what I like,

what I don’t like”.

[I’ll] lay it all out on the table.
I don’t have time for
[not being able to talk as equals].

You gonna have to go.
No sense of me getting into something that I’m not going to be able…
I’m not trying.
I’m getting too old to be sitting around playing…

I’m letting him know what I’m about.
He is listening to me.
He hasn’t had a problem with anything I’m saying to him…

We are connecting,
you know,
“This is what I like,
this is what I don’t like.”,
You know there will be things he’ll do that I don’t like,
but I’m gonna try to deal with things,
to let him know when things are bothering me.

I expect him to listen.
I told him all this stuff,

Communication is what is going to keep our relationship going.
If you can’t work at it,
you can leave,

At this age,
and all the things I’ve gone through,

I’m a no nonsense person,
I don’t have time for it (peer group 2-9-05).

The participants also appeared to like to help each other realized what they deserved. One participant said this assertively in one of the groups as she advised another woman to leave an abusive relationship that was hurting her physically and mentally:

> Let me tell you something, we are women. I know for me, I know I don't have [to] tolerate that nonsense. I used to have a man say things like that to me, "you HIV positive bitch." You know what? Let me tell you something, I might be all of that, but there is somebody else out there who wants me and will treat me like a woman. You don't have to settle for that, no compromise (GLI 4-11-05).

Women were not passive participants in violent relationships. They refused violence and retaliated. Despite the unhealthy and violent reality of some of their relationships, the women recognized and believed it was important to talk about what they wanted and needed from their partners and supported other women in embracing this fact.

Relationship between the Stress-related Growth Themes

Women's descriptions of resistance, resilience, and stress-related growth were not independent. Rather, they intertwined. Sometimes women converted their traumatic experiences with HIV into growth opportunities, a feat that her resilience made possible. For example, women recounted often that they had to rise above multiple adverse experiences before they could reframe traumas in a positive perspective. On the other hand, sometimes the women described examples that showed that they did not have the opportunity to grow from trauma because they were too consumed with survival. For example, in some instances their resistance to a violent relationship was a form of resilience, and they were not yet capable of transforming the challenges to growth. In sum, women displayed incredible strengths and resources through their group discussions that ranged from resistance, to resilience, to stress-related growth.

VI. Group support: Linking Structural Violence and Stress-related Growth

Women's experiences of structural violence (i.e., stress, stigma, unhealthy and violent relationships, suffering, and addiction) were related to their experiences of resistance, resilience, and stress-related growth. The latter were often reactions to their challenges, imposed by the impact of structural violence in their daily lives. The group format of the intervention facilitated discussions about both women's challenges (i.e., structural violence themes) and their strengths (i.e., stress-related growth themes). The women used the group to support each other as they managed their daily challenges that ranged from death of loved ones to feeling sick to recovering from stigmatizing reactions to their HIV status. Unlike the goals of the group (i.e., safe sex and disclosure) which did not always make sense in the context of women's lives, the group aspect of the intervention was appropriately matched to women's needs for communication. In the group their challenges became normal and they could talk about them. Similarly, they learned from each other's strengths too. During the groups, the women discussed their challenges and strengths as they (1) gave each other advice; (2) demonstrated care and support for each other; and (3) created a woman-only space where they could help each other.

Giving and getting advice

The women advised each other about many different areas of their lives. Often they talked to each other about their health. They always asked each other how they were feeling, were sure to follow-up with a woman if she had just completed a medical test or surgery, and even helped each other watch their diets. As this participant exemplified, the women encouraged each other to see their doctor despite their stress and fear. In this example the participant was concerned that another woman in the group may have cancer and needed to see her doctor:

> Let me tell you something, it's a lot of things the doctor told me [to let me know] I might have had it. Back then I went through the same thing you went through. [I] got myself

> all upset, got myself nervous. I ain't eat, I ain't take the medications, I ain't seen a doctor, I ain't do nothing. But at the last minute, I went in there and saw that doctor, took that test, and the doctor did the surgery. I'm fine now, you know what I'm saying? I know what you going through. You gonna be scared, you gonna be nervous, yes. I been through it already. This is a group. We supposed to lean on one another, Okay? I mean don't shut yourself out, that's all I gotta say to you (peer group 3-22-06).

In another group session the facilitator advised a participant about leaving a unhealthy relationship, while being sensitive to the fact that the participant loved her partner:

> Don't put anyone down in their relationship cause everybody is not strong. I've been the weak one in my life. I've met many negatives out here. It [is] just a situation in yourself that you have to get better, whether you want to be with this man or not…Ain't nothing wrong with you feeling something for that man, just as long you know you are taking care of yourself (peer group 2-9-05).

Similarly, one of the facilitators and a participant helped another woman with her decision to disclose her status to her family by saying:

> Facilitator: She has to do it when she is ready to do it.
>
> Participant: When she is ready, when she is ready.
>
> Facilitator: Yeah, this is her choice. This is her life. This is her information. She doesn't have to share it with anybody that she doesn't want to. But when she is ready… (peer group 6-7-06).

The group members took their group membership seriously and appeared devoted to helping each other learn from their mutual experiences.

Care and support: "It takes one to bring one, to save one, and to just keep it going"

The women showed an immense amount of care and encouragement towards each other. One of the facilitators, who the group lovingly referred to as "Mom" told the group members frequently that she loved and cared about them. They also missed each other when a regular participant stopped coming to group, as this discussion exemplified:

> Participant: I gotta start [coming] back to these groups. I stopped coming for a while.
>
> Facilitator: Yeah, you don't know what you are missing.
>
> Participant: Yeah, I missed a lot.
>
> Facilitator: We miss you (peer group 2-8-06).

They often praised each other for coming to group. As one facilitator put it: "Education is the key. You all being here, you doing the best thing you can do for yourself, to come here every week" (peer group 5-3-06). They congratulated each other in group for their successes and for knowing information and doing well in group. They often ended their group session clapping for each other and cheered openly for each other in group when a participant told a positive story. Likewise, they supported each other through hard times. This Peer facilitator consoled a group member who was upset about being rejected for being HIV positive:

> Don't let it weigh on you, just pass it off and forget it, don't hold it. Let it out now, just leave it go. Because the more you harbor bad feelings and feel bad about something, it brings you down. [It] brings your count down, you know makes you sick and worse. Don't worry, just let it roll off your back like dust. Just don't even worry about it (peer group 10-26-05).

On another occasion this facilitator captured the benefit of the group's cohesiveness:

> It takes one to bring one, to save one, and just keep it going. Keep passing [it] on, you can't keep it to yourself. Thank you so much for coming. Everybody have a safe and happy Fourth of July. We'll look forward to seeing you next week (peer group 6-29-05).

Woman-only space and support: Learning to connect with other women

The women described the group as one of the first places that they were able to connect with other women. As this participant explained:

> I learned that I can open up and talk to other women cause I usually take on all my problems. And, I've always was around men all my life, and [I] always would discuss all my problems with them. I never let women in my circle. Never. I learned in here that I can talk to other women and cause another man can't give me no advice, you know what I'm saying? They will tell me some crazy stuff, no what I mean? Like, but I learned that I could talk to other women about what is going on with me and find out either they going through what I'm going through, or that they understand exactly what I'm saying. I was able to go back and check on a whole lot of things, especially from you all (GLI 4-11-05).

Another participant similarly explained:

> Because at first I never talked about it, and I've had it for 11 years now. I just really started talking about it since I've been coming here, coming to the group. I never talked about it 'cause I felt ashamed that I had it, always putting myself down, saying I wish I never had this, this and that (GLI 1-10-05).

The group members enjoyed the space they created and were resistant to interruptions. On several occasions the clinic staff had to tell them to keep their voices down because they talked and laughed so loud in group. This was distracting to the clinic but they also talked so loud that people in the waiting room could overhear their conversations, even though group took place in the conference room. The group usually responded angrily to these requests to keep quiet:

> Facilitator 1: We have to cut the volume a bit, 'cause they can hear everything we are saying [in the waiting room].
>
> Facilitator 2: I don't care about them.
>
> Participant 1: I don't give a you know what.
>
> Participant 3: 'Cause they're ears are open, that's why.
>
> Facilitator 1: And they complaining.

Facilitator 2: Well, it's only an hour, and it's their lunch time. They can deal with it.

Group solidarity and group support permeated the women's discussions. They advised each other and expressed care and love for one another. Many women said that the group broke their isolation and represented one of the first times that they had the opportunity to connect with other HIV positive women. It was this supportive environment that allowed such intense, meaningful, and detailed discussions of structural violence and stress-related growth.

Chapter 5: Discussion

I. Summary of Results

In this study I examined four research questions using strategies of grounded theory and narrative analysis: (1) How does structural violence manifest in the lives of HIV positive women who participated in *Protect and Respect*? (2) How is structural violence associated with these women's daily experiences of living with HIV? (3) How does stress-related growth manifest in the lives of HIV positive women who participated in *Protect and Respect*? (4) How is stress-related growth associated with these women's daily experiences of living with HIV?

I chose to explore the links between the women's challenges, strengths, health, and sexual choices because I was overwhelmed by the pervasive presence of oppression in the lives of the HIV positive women that I encountered as an HIV prevention interventionist, as well as the women's formidable responses to their life circumstances. My study sample included HIV positive women (*N*=24) who participated in the intervention groups of the *Protect and Respect* program. I did not interview the women directly about their experiences with structural violence or stress-related growth. Rather, the intervention groups, which were designed to focus on safe sex, provided the context for women's discussions about these concepts. The findings, therefore, revealed as much about the women's lives as they did about the intersection between their lives and the intervention. The women's experiences with structural violence and stress-related growth uncovered many of their complex barriers and facilitators to having safer sex. The intervention's singular focus on a specific safer sex goal, condoms[7], neither accounted for the women's challenges, nor acknowledged their strengths. Ultimately, the juxtaposition of the women's experiences and the intervention's goals and assumptions about their experiences challenged the individualistic and myopic focus on male condoms for women dominating

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[7] The intervention focused on two key skills, condom use and HIV status disclosure. Because the purpose of HIV status disclosure was to promote condom use, in this chapter I often summarize the intervention's focus and purpose by condom use only.

current HIV prevention best practices for women (CDC, 2007c), and generated suggestions for program improvement.

After describing how this study's structural violence and stress-related growth findings contribute to the existing literature about HIV positive women and their sexual risk practices, the discussion section will focus primarily on three key results, followed by their implications for HIV prevention:

(1) The analysis of women's experiences with structural violence revealed that women have fundamental health and safety challenges that must be addressed in order for them to be able to have safer sex;

(2) The analysis of women's stress related growth experiences revealed that women possess various strengths that are ignored in current published HIV prevention programming, but that women associate with their health and ability to have safer sex, and;

(3) Interventions that ignore women's challenges and their strengths may do more harm than good by instructing women to engage in behaviors that are unrealistic or harmful in the context of their challenges (e.g., condom use in violent relationships), reinforcing women's sense of powerlessness, and obscuring the root causes of and solutions for women's sexual risk practices.

These three findings are based on the results of the grounded theory and narrative analysis of structural violence and stress-related growth in women's lives, which were described in detail in chapter four. In sum, the women in this study experienced structural violence in three primary ways: (1) daily and overwhelming stress; (2) AIDS related stigma and rejection; and (3) unhealthy and violent relationships. The women associated these experiences with emotional pain, suffering and substance use. In addition, the participants responded to these challenges through their examples of: (1) stress-related growth; (2) resilience; and (3) resistance.

II. Structural Violence Findings

The Visible and the Obscure forms of Structural Violence in Women's Lives

Existing theoretical research[8] suggested that poverty, racism, sexism, heterosexism, and AIDS-related stigma were key sources of structural violence that ultimately enhanced women's risk of acquiring HIV and hindered their efforts to protect themselves and their partners from HIV/AIDS and other STIs once they were living with the virus (e.g., Farmer 1999, 2005). As I expected, the women did confirm the roles of poverty, violence, and AIDS stigma in their lives. However, despite my expectations, racism, sexism, and heterosexism did not appear explicitly in my analysis.

Several reasons may explain the absence of explicit mentions of racism, heterosexism, and sexism in the women's conversations. The ubiquitous and overwhelming nature of oppression hides its culpability as a cause of daily harm. Routine oppressive experiences become normal, acceptable, and uncontested (Bourgois et al., 2004; Scheper-Hughes, 1997). Therefore, it is extremely challenging for women who are oppressed to identify oppression and think critically or speak openly about how oppression harms their daily lives. This type of inaction is consistent with the aim of the oppressors (Bourgois et al., 2004; Cuadraz & Uttal, 1999; Fine, 2000, 1996; Gorelick, 1991). Alternatively, the women may have been aware of the impact of oppression in their lives but may have chosen not to talk about it to avoid defining themselves by their perception of helplessness. For example, Crosby (1984) found that women confirmed the existence of social discrimination against women in general, but denied experiencing sexism personally to avoid feeling uncomfortable about individual-level discrimination. At the same time, in my study, women may not have talked overtly about oppression because they were too focused on daily survival and did not perceive this kind of talk to be relevant or useful. A woman may be comfortable talking about an abusive relationship that she can leave (or at least try to leave in some circumstances) but find it more difficult to discuss the barriers created by constant

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[8] These are described in detail in the original structural violence and stress-related growth model in the *Background and Literature Review* section.

and oppressive social forces, like sexism, that create an environment where violence against women is common and accepted, even to some degree to the women themselves.

The absence of overt conversations about oppression may have been related to the specific type of oppression. As the peers remarked during the member checking process, the women may not have focused on certain forms of oppression like racism, because other forms of discrimination (e.g., AIDS-related stigma) were more prominent in their daily lives. As I commented in the results section, the women may have avoided discussions about race or racism when I was in the room because I am White, or because the women knew that I would listen to the tapes of group sessions. In the case of heterosexism, the research tools and the intervention were neglectful of women who have sex with women's (WSW) experiences and the absence of discussions about female partnerships during the intervention groups did not give the women opportunities to talk about this form of oppression. Socially desirable reporting likely affected discussions about specific forms of oppression as well. The women may have talked openly about their struggles and stresses with resources (e.g., housing) because that was less stigmatizing then describing themselves as poor.

The absence of certain subjects that I expected to encounter created a complex analytical challenge. I had to decide how to write about the structural forces that the participants did not discuss, yet which I believed to play at least some role in their social circumstances. Claiming to be able to identify determinants that were hidden to the participants implied that I knew more than the participants themselves about their own experiences. On the other hand, ignoring the structural forces would continue to obscure the harms of oppression in these women's lives (Gorelick, 1991). As Cuadraz and Uttal (1999) noted, however, researchers do not organize the world and their experiences like participants and therefore must interpret the data beyond the stated or given accounts:

> It is unrealistic to expect that every [research participant] will explicitly articulate all categories of social existence and we suggest that it is the responsibility of the researcher

> to learn about the context and relate it to the individual views presented in the [qualitative data] (p. 171).

Following the lead of other qualitative researchers (Cuadraz & Uttal, 1999; Gorelick, 1991) and my aim to understand better the lives of these women and the implications of these findings for prevention, I chose to acknowledge the presence of oppression in this discussion of the results and their implications for prevention, whether the women discussed it overtly (e.g., AIDS-related stigma) or not (e.g., racism).

HIV Positive Women's Lived Experience of Oppression: "Everyday" Stress, Suffering, and Violence

It is also important to note that the women also described structural violence in ways that I did not or could not (i.e., not described in the current literature) anticipate. They defined structural violence by the way it manifested in their daily lives, as constant stress, pain, and suffering. At the very least, these experiences made it difficult for women to prioritize their sexual health amid their other pressing concerns and in other cases undermined directly women's ability to have safer sex. To my knowledge, no published research explores how HIV positive women experience oppression in their daily lives or the connections between oppression and their sexual risk practices. Therefore, this study's structural violence findings stand to contribute to a basic and necessary understanding of how HIV positive women define and make meaning of their experiences of oppression and how it may relate to their health and sexual risk practices.

Existing research describes the presence of stress in HIV positive women's lives (Jones, Beach, Forehand, & Foster, 2003; Mosack et al., 2005; Siegal & Schrimshaw, 2005) and details the negative impact of stress on HIV positive women's health, including the association between stress and depression (Remien et al., 2006), isolation (Hudson, Lee, Miramontes, & Portillo, 2001), and poor physical health (Jones et al., 2003). Likewise, research indicates that HIV positive women experience harmful rates (over 50% of study samples) of depression and anxiety (Barkan et al., 1998; Cook et al., 2004; Smith et al., 1997). These reports simply fail to document the extent of the all-consuming nature of distress in HIV positive women's lives, however.

Numerous harmful structural forces combined to make women's lives a mire of daily stress, pain, and suffering every day. Suffering both stemmed from and was an extension of women's stress. As one woman clarified, stress did not describe the depths of her pain. Rather, she felt "hurtness on top of hurtness". This research exposed that the women's pain was not an illness per se (as mental health diagnoses suggest), but resulted from years of oppression and mistreatment. The women carried layers of accumulating hurt and tragedy with them daily.

These findings built on existing research about everyday suffering and violence (Bourgois, 2001; Bourgois et al., 1997, 2004; Farmer, 1999; 2005; Scheper-Hughes, 1992; 1996; 1997). As these anthropologists conceptualized, everyday violence captures the continuity of painful experiences that harm marginalized women as they contend regularly with intersecting and multiplicative forms of oppression. Similarly, in this study, many of the women's stories revealed that survival consumed their energy. On a regular basis they experienced physical and emotional relationship abuse; powerlessness; physical and mental illness; addiction; shame; stigma and discrimination; sadness, fear, and isolation. Abuse and tragedy were so commonplace that the women were forced to develop ways to manage them as a "normal part of their lives. The women attended the weekly *Protect and Respect* intervention groups burdened by these challenges and concerns. While the women learned the intricacies of various STIs, browsed diagrams of the female reproductive anatomy (often for the first time) and put male and female condoms on anatomical models, they worried about far more basic survival needs. In sum, this study's findings indicated that oppression-related barriers hindered women's ability to participate in and learn from the intervention, as well as use the safer sex behaviors and skills that they learned.

Looking farther Upstream: What Needs to Come Before Condoms?

When programs offer condoms as a safer sex solution for women, they assume that women's reasons for having unsafe sex stem from a failure to understand why or how to use a condom, and therefore do not acknowledge that many women can not convince their partner to use condoms. This study's findings about the impact of structural violence and oppression in the women's lives, however, revealed that women faced overwhelming psychosocial needs that required attention before they could consider protecting themselves and their partners from the risks associated with unsafe sex with condoms. The women described four primary needs that were precursors to safe sex and condom use: (1) a healthy sexuality; (2) safe relationships; (3) freedom from stigma and shame; and (4) help for substance abuse.

A healthy sense of sexuality. *Protect and Respect* was about sex, but some of the women said that they did not even realize that it was permissible for HIV positive women to have sex at all, let alone safe sex. They struggled to reconcile the importance of a positive and healthy attitude towards sexuality with a highly stigmatized and deadly STI. Some of the liveliest conversations occurred when women tried to encourage each other to enjoy sex and talked openly their sexual experiences. Likewise, many of the women understood AIDS and could recite facts about complex medication regimens with ease, but the physical and emotional oppressive experiences that they discussed, such as AIDS stigma, past and current abuse, and few educational opportunities contributed to women's lack and knowledge and comfort about sexuality and how their own bodies worked. For example, some women only experienced sex in the context of abuse, and learning that they had HIV/AIDS added to their sexual shame and discomfort. They did not want to talk about sex or their sexuality because this would force them to confront painful experiences. By starting with condoms, interventions assume that women can and will talk openly about sex, sexuality, and their bodies and at the very least ignore the emotional safety and confidence that is required for HIV positive women to talk about the intimate aspects of their lives. At worst, they obscure terribly damaging experiences that have rendered women fearful of violence in their sexual encounters.

Safe, equal, and healthy relationships. Violence creates overt and subtle barriers to safe sex. Clearly, if a woman's partner threatens to hit her for suggesting that they use a condom, violence acts as an overt and direct barrier to safe sex (Maman et al., 2001). Many of the women in this study also said that they had never experienced a healthy relationship and did not know anyone else who had. Additionally, the barrage of stresses created by illness, care-taking responsibilities, and few resources, compelled women to settle for partnerships that were far less than ideal or even hurtful, because some women said that they simply could not bear the pain in their lives alone and needed their partner's support, even if that partner was abusive. In other words, the risk of battling AIDS and its related illnesses and other extreme tragedies (e.g., the loss of a child) alone were less aversive options than pleasing (and keeping) a partner via unsafe sex. Yet, current interventions assume that women have at least some control over the sexual decisions in their relationships, can communicate safely with their partners about sex, and have the luxury to make rational or calculated decisions about sex (Amaro, 1995; Dunkle & Jewkes, 2007; Zierler & Krieger, 1997).

Freedom from stigma and shame. AIDS-related stigma acts as a direct deterrent to women's disclosure of their HIV status to their partners (Gielen et al., 2000), which can in turn act as a barrier to safe sex (Simoni & Pantalone, 2004). It is important to note that women in this study described stigma as a consuming and overwhelming force. AIDS-related stigma did not act in isolation. It built upon pre-existing stigma and/or stigma that was related to how women acquired (or were assumed to have acquired) HIV. There was a hierarchy where women who were infected in seemingly blameless ways (i.e., blood transfusion) faced less discrimination than women who were infected by behaviors marked by stigma (i.e., drugs, prostitution). Women who did not know how they acquired HIV suffered tremendously emotionally. Current interventions focus on helping women to disclose their status but fail to acknowledge that it is difficult to expect women to talk about HIV/AIDS with their partners if they have not come to terms with how they acquired HIV/AIDS themselves. Likewise, for women who said that they acquired HIV "on purpose", through force, or during the most desperate and shameful periods of their addiction, telling others about their HIV required them to come to terms, at least on some level, with the reality of the pain associated with their HIV acquisition.

Substance abuse help. Using substances can interfere with women's judgment while making sexual decisions and force women into situations were they have unsafe sex for drugs (Kalichman, 2000). Women in this study also described the power of addiction as constant and nagging on their pursuit to being healthy. Triggers to use substances were powerful and omnipresent at times, especially in light of the challenges that the women faced. Some women defined themselves by their addiction and/or recovery and cited substances as a much more powerful health concern than HIV/AIDS or other STIs. Current interventions do not integrate well the connections between substance abuse and sexual risk taking but women may need to talk about the connection between alcohol or drug use and their pain and stress, and access help for addiction, if they define drugs or alcohol as higher priorities than HIV.

Researcher-Defined Risk versus HIV Positive Woman-Defined Risk

My analysis of structural violence showed that the intervention and the participants defined risk differently. Similarly, Rhodes (1997, 2005) pointed out that researchers construct notions of sexual risk and decision-making that follow rational thought, but often fail to match participants' risk experiences. In addition, women may prioritize love, the ideal of romantic love and/or the perfect relationship, or motherhood over having safe sex (Anderson, 1999; Bourgois et al., 2004; Bowleg et al., 2007; Sanders, 2004; Sobo, 1993; Worth, 1989). For example, Bowleg et al., 2007 found that women did not use condoms in long-term, serious or emotional relationships because they equated condom use with casual relationships. Anderson (1999) noted that unsafe sex gave a woman with few other opportunities respect via motherhood, and a child with whom she could create a worthy identity. Mays and Cochran (1988), Worth (1989), and Sobo (1993) explained that low income racial/ethnic minority women sometimes chose to have unsafe sex to protect their self esteem and convince themselves that their relationships were loving and monogamous.

Similarly, in this study, violence, stress, pain, suffering, stigma and addiction exemplified women's needs that preceded the possibility of even considering condom use. Women may have not even defined unsafe sex as a risk in their lives given all of their other stressors. Being alone, rejected, hit, and discriminated against posed relatively higher serious risks to their physical and mental health. Using a condom to protect themselves from additional STIs (in addition to the deadly and incurable disease that they already had), or protecting their partners (who may refuse to even use condoms) seemed to pale in comparison to the other dangerous risks in their lives.

III. Stress Related Growth Findings

Disenfranchised women, who may be poor or sick, can still maintain a sense of action and agency and exhibit strength despite numerous and overwhelming challenges (Bourgois et al., 2004; Phoenix, 2000; Sanders, 2004). The women in this study suffered, but also defined their lives with examples of stress-related growth, resilience, and resistance, topics absent in most HIV prevention research or policy.

Unlike the existing literature about stress-related growth, which focuses on women's strengths without remarking about the larger context of their lives and their struggles (Siegal & Schrimshaw, 2005), this study explored stress-related growth alongside a thorough description of women's challenges imposed by structural forces. This is important because it avoids the tendency to simplify participants' experiences. Wacquant (2002) argued for understanding participants' challenges and strengths in the context of their social position and through a lens that acknowledges how oppression forces women into making decisions that may be unhealthy for themselves, their partners, and their families (Wacquant, 2002). In other words, it is critically important to acknowledge that oppressive situations sometimes render ideal decisions impossible and provide opportunities for relatively healthy solutions only.

In addition, the fact that the women in this study gave numerous examples of their strengths does not mean that HIV/AIDS is "not so bad" or that all women with HIV/AIDS can transform their experiences into positive opportunities. Likewise, it does not mean that there are deserving and undeserving women with HIV/AIDS, depending on whether or not they could report stress-related growth (Katz, 1989). While it is essential to recognize HIV positive women's positive attributes, it is equally important to recognize that different women may face different challenges to succeed. For example, Sen (1992) focused on freedoms and capabilities in his analyses of equality and inequality, versus using a standard equality outcome measure like income level. He argued that the outcome or end result was not as important as having the capability, freedom or opportunity to pursue and achieve a goal. In this study, reports of stress-related growth were just as important as the opportunities that they had to transform HIV into a catalyst for positive change.

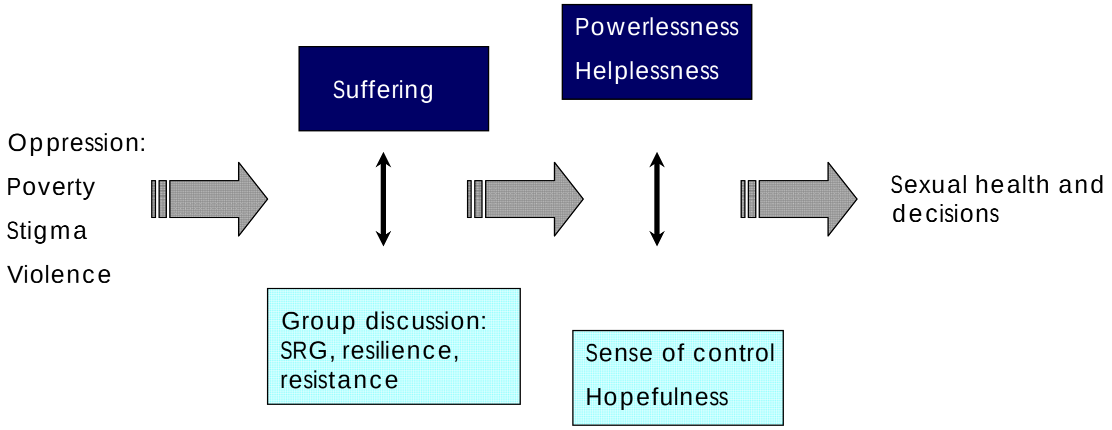
The challenges that the HIV positive women in this study faced were not homogenous. Each woman faced a different set of challenges and facilitators, and thus each had a different definition of success. For example, a woman with a support system may have had an easier time labeling her illness a blessing in disguise than an isolated woman. Some women could not possibly transform HIV/AIDS into a growth experience because they did not have the freedom or the opportunity to do so. They were too focused on survival. Therefore, it was also important to focus on women's unique experiences of stress-related growth, resilience and resistance, to generate a broader picture of women's strengths and their implications for HIV prevention.

The findings in this study added to a small body of existing research about stress-related growth, resilience, and resistance among HIV positive women (Milam, 2004; Siegal & Schrimshaw, 2006). To my knowledge, however, few studies link any form of women's strengths to their sexual risk behaviors, and fewer interventions capitalize on women's strengths to help them make safer sex decisions. Therefore, in a broader sense, these findings stand to contribute to an understanding of women living with HIV as complex individuals, who *do* possess strengths and do experience joy and happiness, particularly when sharing these strengths with each other. Too often existing research defines HIV positive women narrowly by sickness and strife, and not as whole human beings who experience a range of emotions and life events. This range is, however, vital to understand and develop holistic and appropriate safer sex interventions for HIV positive women.

Acknowledging the Connection between Women's Inner Resources and their Sexual Health

The most important finding about women's experiences with stress-related growth, resilience, and resistance was that these experiences were associated with women's sexual health. Talking about these strengths as a group: (1) gave women a sense of individual and collective power and control which appeared to help ameliorate the powerlessness imposed by oppression in their daily lives; (2) helped women to realize that HIV was not a death sentence, and; (3) identified resources that women could use to manage their stress and identify and solve their problems. The relationship between oppression, the stress-related growth findings, and sexual health are depicted in figure 2.

Figure 2. Oppression, stress-related growth (SRG), and sexual health.



Women's experiences of stress-related growth, resilience, and resistance were important for women's sexual health because they fostered empowerment and hope, and helped the women to realize that their lives mattered, which in turn gave the women the confidence and motivation to prioritize their health including having safer sex. The previous section's findings about structural violence identified that the causes of unsafe sex among women were often closely tied to their experiences of oppression, as poor women living with HIV/AIDS, and were often not under their individual control. A focus on women's strengths in relation to their health and sexual risk behaviors is not intended to negate the importance of structural risk factors, but is relevant to the discussion about safe sex for several reasons. First, like the structural violence findings, the analysis of women's strengths revealed that the women wanted to talk about areas of their life that the intervention did not address. Second, the women themselves connected their strengths to their health. Last, talking about their strengths gave women a way to talk about the harms of oppression, which helped them to manage these harms and stressors. Their resistance was both individual and collective. When they identified their own resources and learned that other women faced the same challenges, they began to identify the impact of structural forces in their lives. This realization appeared to cultivate confidence, hope, power, and control and a sense of visibility and self-importance. In other words, the women's strengths were precursors to good health and safer sex.

For example, the women said that HIV was a wake up call that led them to take their health more seriously. It motivated them to think about making specific health changes, like decreasing their substance use or choosing sexual partners differently. The women could not change the past, but some women used HIV as an opportunity to take control of their health and think about the future differently. Moreover, for the women in this study, hopefulness gave the women something to live for and gave them reasons to care about their health and that of their partners. For some of the women fighting back or simply surviving, particularly in the context of relationship violence, was a form of resiliency. Specifically, when the women did discuss violence, they were very vocal about their intolerance for violent relationships. Through processing how they fought back and detailing how they escaped abuse or avoided severe abuse, the women redefined themselves as active and strong survivors instead of passive victims. Through their stories, the women took control of experiences with which they previously had little agency. They believed that their lives and experiences were valuable.

Researcher-Defined Success versus HIV Positive Woman-Defined Success

The analysis of stress-related growth, resilience, and resistance revealed that HIV positive women possess various strengths, that they want to talk about them, and that their strengths are associated with their health and sexual decisions. These findings revealed, nonetheless, that there was a discrepancy between how the women defined their strengths and successes, and how the intervention defined the women's success. Intervention-defined indicators of success included quantified summaries of women's condom use and disclosure. Alternatively, these women defined themselves as successful by their ability to persevere despite learning that they had an incurable illness; becoming hopeful and acknowledging that they had something to live for; recognizing that having HIV was not a death sentence; taking control over their challenges or decisions; and fighting back against partner violence.

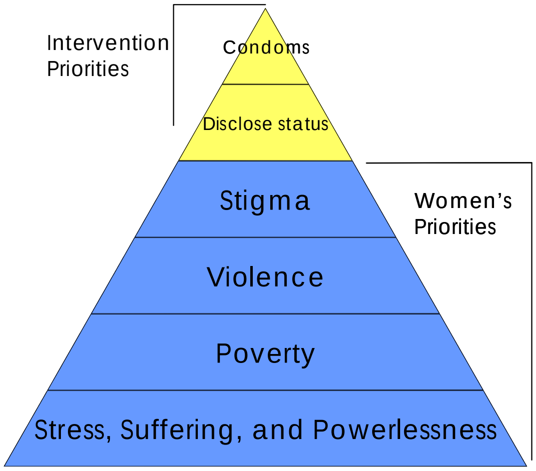
The women's inspiring stories suggested subtle but important upstream mediators to safe sex previously unexplored in HIV prevention research. Likewise, during the member checking process the peers pointed out that women could not be healthy or think about safe sex before they accepted themselves and accepted that they were living with HIV/AIDS, and acquired skills to "move past the virus" (i.e., acknowledge that they can live with the virus). If women do not expect to live, live in despair, or do not envision any sort of control over their lives, they will not value their health or the health of their partners. Currently, however, interventions do not include any of the strategies or markers of success that the women discussed and suggested were related to their sexual health.

Whose Intervention Was It, Anyway?

In sum, this study's structural violence and stress-related growth findings highlighted discord between the women's experiences and the intervention's goals and assumptions about their experiences. *Protect and Respect* defined HIV positive women's health in terms of safe sex only, and prioritized individual behaviors as solutions to women's sexual risk practices. My analysis of structural violence revealed that some women ranked basic health and safety concerns, like homelessness, violence, stigma, and substance abuse as priorities before safe sex or even HIV/AIDS. In turn, these challenges prevented safe sex from being an individual decision. Some women relied on their partners for resources and had little bargaining power in relationships, others could not safely talk to their partners about safe sex, and others were too consumed by stress and pain to even think about safe sex. The intervention defined the women as successful if they used condoms. My analysis of stress-related growth, resilience, and resistance showed that women believed they were successful when they thrived or survived in spite of the daily challenges that they faced. Focusing on their strengths gave them an individual and collective sense of power and control over chaos in their lives because it gave them hope, which was foundational to their motivation to prioritize their health or safe sex.

As figure 3 illustrates, this study's findings revealed that the women's hierarchy of needs and the intervention's assumptions about women's priorities, were divergent. The juxtaposition of the intervention's simple and individualist myopic focus on condoms and the women's complex challenges and strengths led me to ask questions about whose needs and objectives the intervention was truly serving.

Figure 3. The Intervention's priorities versus the women's priorities.



My findings indicated that structural violence manifested in women's lives in overwhelming and daily stress, suffering, and powerlessness. These experiences colored all of the women's decisions and are therefore located at the base of the figure. These feelings of helplessness were caused by structurally imposed barriers including poverty, violence, and stigma that precluded the priorities of the intervention. It is important to note that the women also believed that disclosure and safe sex were important priorities and goals, but only when they were isolated from their challenging life circumstances.

My analysis led me to believe that there were serious consequences to implementing an intervention that was not fully grounded in women's experiences, thereby posing solutions (i.e., condoms) that missed the women's primary problems almost entirely. By not accounting for how structural forces hindered women's safer sex decisions, the intervention itself acted as another structural risk factor for women, an institutional impediment to the healthy behavior changes among women that it intended to promote. Using *Protect and Respect* as a lens through which to understand HIV prevention interventions for women, my research cast interventions that are not grounded in the experiences of the women that they are intended to serve as potentially unhealthy public health strategies (Castro & Singer, 2004). As Castro and Singer (2004) explained:

> Health policy formation and implementation unfold in a world of competitive social interest, opposed class agendas, unequal genders, and overt and covert power conflicts. Health policy may reproduce structural violence…As a result, health related policies, which have the ostensive goal of improving and protecting the health of the general public or sectors thereof, may, in their service of other masters, harm rather than enhance the public health (p. xiii-xiv).

Most broadly, my findings cast doubts on the ethics of putting prevention resources towards condoms and sex primarily and/or solely when women's homelessness, lack of access to physical or mental health, or relationship safety precluded their use of condoms. Further, this research warned that ordering women to engage in behaviors that are unrealistic in the context of their lives and challenges, such as asking an abusive partner to use condoms, could be harmful or dangerous to women's health.

Defining the intervention's "effectiveness" by numeric episodes of these behaviors obscured this harm. *Protect and Respect* may have been increasing safe sex at the expense of other risks in the women's lives. For example, was *Protect and Respect* effective if women achieved safe sex at a cost of physical or emotional violence? If women traded HIV status disclosure for stigma, rejection, or abuse? If women reported safe sex because they stopped having sex all together? Further, by structuring an intervention (and women's) "effectiveness" around women's responsibility for a tool that they did not even wear on their own bodies, the basis of the intervention absolved men of responsibility and placed the burden of safety on the women alone.

My findings added to a small body of existing analyses that question the premise and the value of HIV prevention interventions that focus on skills that do not match women's experiences. Interventions disparage women when they assume incorrectly that knowledge will give them power to change their lives. Bourgois (2002; Bourgois et al., 1997, 2004) and Mays and Cochran (1988) noted that knowledge only equals power in middle class, White, society and that giving people at risk for HIV knowledge that they can not use just serves to further blame them for their behaviors. Interventions neglect women's needs by teaching them skills that pressure women to choose the intervention's goals over other risks in their lives. Worth (1989) added that advocating for condom use fails to consider the risks of condom use among poor and marginalized women, explaining that:

> By not insisting on the use of condoms, women avoid paying the present cost of their use: disruption in a relationship through violence, or through loss of economic support, a father figure or a place to live, at the expense of protecting themselves from a possible future cost, such as HIV infection or illness (p. 305).

She pointed out that by increasing women's awareness of risk and teaching them skills that they do not have the power to use, interventions create decision-making discord:

> Where awareness of risk runs contrary to traditional values and attitudes, survival strategies, personal goals, or actual behavior, the result is often denial of both the behavior and its consequences, or postponement of decision-making to protect oneself. Denial results in an inability to consider or undertake sexual behavior change (p. 306).

Similarly, Sobo (1993) noted that among poor women unsafe sex may be a strategy for women to convince themselves that their relationships are monogamous and intact. In addition, culturally relevant norms privilege heterosexual relationships for women, particularly in Black communities (Mays & Cochran, 1988). These stories help women to feel good about their lives, which is so important and necessary. She claimed that prevention efforts fail when they revictimize and stigmatize women who can not follow messages incompatible with their values and needs. Likewise, despite good intentions, the *Protect and Respect* intervention's focus on specific safer sex skills did not match the complexity of the women's challenges or acknowledge their pertinent strengths.

At worst, this research suggested that there are serious consequences to interventions that are not grounded in women's experiences. Despite their aim to improve women's health and decrease HIV/AIDS rates, these interventions can act as subtle agents of symbolic violence. Just as structural violence results from forms of social oppression, and not a single violent actor, symbolic violence is violence that is inherent in our social institutions, including health interventions (Bourdieu & Wacquant, 2005). A danger of symbolic violence is that is goes unrecognized and uncontested by its own victims. When interventions pose individual solutions for structural problems, they inadvertently blame the spread of HIV/AIDS on the women themselves, masking deeper social and structural inequities that truly limit women's behavioral choices and health. The intervention itself oppresses, convincing marginalized women that AIDS is their fault and thus stifling their resistance to such accusations.

I did not intend to create an intervention that neglected women's lived experiences poorly or contributed to women's' oppression. I believed in and followed national public health recommendations that encouraged women with HIV/AIDS to have safer sex, to protect themselves and their partners. The results of my research, however, challenged me to think more closely about who the "public" really was. Were poor, Black HIV positive women the "public"? Waldby (1996) charged that "the shape of the official AIDS discourse…is complicit with a phallocentric social order" (p. 9) which equates heterosexual White middle class men's health with the "public's health", and protects these men against the "others" who are blamed for disease. In general, prevention interventions for women living with HIV/AIDS encourage HIV positive women to buy into a collective sense of responsibility (i.e., protect others from getting HIV/AIDS) that may not make sense in their lives. My analysis showed that this was an unfair and unrealistic expectation. The social and structural challenges imposed on women prohibited them from protecting themselves or others and they simply had other priorities before safe sex. If those deeply consequential priorities are not acknowledged, safer sex interventions may hold little likelihood of success. At the very least, failing to acknowledge women's life circumstances discourages address of the systemic causes of these circumstances.

V. Implications of Findings

My findings pointed to several limitations in current prevention practice for women living with HIV, but they also suggested opportunities for advancing prevention, including theoretical, practical, research and methodological implications, all of which I describe in further detail below. These implications focus on: the significance of holistic and multi-leveled prevention strategies for women; listening to women to understand how to meet their safer sex needs; and prioritizing the precursors that facilitate or hinder safe sex, not just condom use.

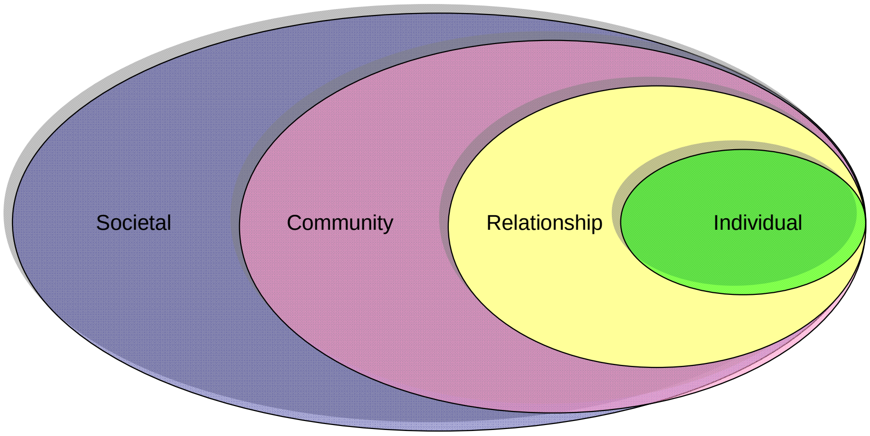
Theoretical Implications

My findings suggested that three theoretical frameworks, which are not currently used often in HIV prevention, should guide HIV prevention strategies for women living with HIV/AIDS:

(1) Ecological Theory; (2) Health and Human Rights Theory, and; (3) Empowerment Theory. The ecological model is a helpful overall guiding framework for women's HIV prevention, because it recognizes the importance of structural, community, relationship, and individual change for HIV prevention. The health and human rights framework emphasizes that changes in the structural level are necessary for health and that meeting women's basic human rights will enable them to have safer sex. Empowerment strategies emphasize the relationship between powerlessness and health and the links between women's behavioral choices and the structural forces that hinder their decisions. I describe all of these theories in detail below.

Ecological model: Structural, community, relationship and individual change. Ecological models (see figure 4) have been used widely to understand the causes and solutions for violence prevention but underutilized to frame HIV prevention. An ecological framework posits that HIV/AIDS is caused by multiple, interacting, and embedded levels of causality and that no single strategy can account for prevention (Heisse, 1998). The individual level of risk includes personal factors such as knowledge, attitudes, and specific behaviors, like sexual practices or substance abuse. The relationship level describes how sexual behavior is influenced by close relationships, such as the needs of intimate partners or the norms of friends. The third level explains how community contexts influence sexual behavior, including community unity (e.g., social capital or social efficacy); and access to prevention or medical services. The fourth and broadest level identifies societal factors that encourage or inhibit risk practices, including economic or gender inequality, racism, or poor social policies.

Figure 4. The ecological model of prevention (Heisse, 1998).



The levels overlap because the factors at each level are strengthened by factors at another (Krug et al., 2001). Individual experiences are inextricably connected to social experiences. Individual behavior puts women at risk, but women's relationships and environments shape their individual decisions. For example, in my study, poverty (societal risk factor) decreased women's resources, such as housing or education (community risk factors), and contributed to their sense of hopelessness (community and individual risk factors). Together, these challenges stressed women's relationships and limited their relationship options, leaving them vulnerable to relationship violence (relational risk factor), which in turn appeared to influence their sexual risk behaviors (individual risk factors).

The ecological model posits that changes in all levels are necessary simultaneously. Similarly, my study's findings suggested that structural risk factors were the root of women's risk practices, but that changes at every level were necessary to help the women modify their sexual risks. Structural forces isolated and marginalized women, making it difficult for them to identify the structural causes of their suffering or believe that societal changes could benefit them. As a result, the women focused on the risks in their immediate environment. Women require collaborative prevention strategies that acknowledge both their individual needs as well as the social conditions that need to be met for them to make healthy sexual choices. For example, learning and practicing HIV status disclosure skills were one of the major goals of *Protect and Respect*, but this is only one piece of the prevention puzzle. If supported by anti HIV-discrimination laws that do not punish people living with HIV criminally for having sex with HIV negative partners and social marketing campaigns to combat AIDS-stigma women may be more likely to be successful when they use the skills that they have learned in interventions. My findings revealed that HIV positive women were not responsible for HIV transmission alone (i.e., their sexual decisions were influenced by their partners and their social environment) and an ecological framework appropriately suggests that HIV prevention is a shared responsibility.

Health and human rights: Framework for prioritizing structural HIV interventions. The health and human rights framework prioritizes change at the structural level and holds governments responsible for these changes. Human rights are internationally recognized norms, stated originally in the 1948 Universal Declaration of Human Rights (UDHR), and reiterated in covenants and treaties that translate this declaration into specific, legally binding obligations to promote and protect human rights (Mann, 1999). A health and human rights framework is based on the premise that there are three identifiable links between health and human rights: (1) the neglect or violation of human rights leads to poor health outcomes; (2) the promotion of human rights promotes health; and (3) health policies and programs can protect or violate human rights in the way they are designed and implemented (Mann, 1999).

All three of these links were apparent in the findings of this dissertation. Rates of HIV/AIDS are rising among women, particularly among racial/ethnic minority women. This disparity results from violations to women's right to safety and freedom from discrimination, which continue to hinder women's efforts to have safer sex once they are living with HIV/AIDS. In addition, this study's findings indicated that structural violence also harmed women when it resulted in the neglect of their basic needs and resources including safety or housing. In sum, this study's findings indicated that the combination of violations of women's right to safety, freedom from discrimination, health (e.g., appropriate housing, health care) and educational and employment opportunities limited women's sexual negotiating power and precluded safer sex decisions.

The health and human rights framework calls on *governments* to legally and politically protect, respect, and fulfill human rights (World Health Organization [WHO], 2002). Specifically, fulfilling the right means that the government must take all appropriate measures, including developing and implementing HIV prevention initiatives and strategies that promote human rights (Krieger & Gruskin, 2001). The health and human rights framework is important for HIV prevention, therefore, because it can help redirect interventions' priorities away from focusing on individualistic solutions such as condoms only and towards broader issues and rights violations that underlie women's sexual risk taking. It can do this by holding the U. S. Government responsible for HIV prevention strategies, including prevention programs, funding opportunities, and research that address the underlying causes of unsafe sex among women.

Key international health leaders, such as the Joint United Nations Programme on HIV/AIDS (UNAIDS) endorse using a rights based approach to HIV/AIDS prevention (UNAIDS, 2007). The International Guidelines on HIV/AIDS and Human Rights and the Declaration of Commitment on HIV/AIDS were adopted at the U. N. General Assembly Special Session on HIV/AIDS in 2001 (UNAIDS, 2006). These documents recognize that the full realization of human rights is an essential element of an effective global response to HIV/AIDS, set specific goals and objectives for governments, and identify specific actions that governments should take to respond to HIV/AIDS according to their human rights obligations. The U.S. lags far behind other nations in adopting such far reaching and specific methodologies in their officially endorsed HIV prevention efforts. This study's findings indicated however that prevention strategies, whether globally or nationally, that fail to recognize the underlying human rights violations that preclude women's ability to have safer sex, will not achieve success.

Empowerment theory: Framework for individual and group change. In this study, the women's experiences with structural violence created powerlessness and invisibility, which appeared to act as immediate barriers to their health in general, and their sexual health in particular. By providing a space where they could share their struggles and more importantly, their strengths (i.e., stress-related growth, resilience, and resistance), the intervention groups seemed to offer the women individual and collective opportunities to counter their feelings of powerlessness and to develop hope, motivation to care about their health, and dialogue about solutions, amidst the pain and chaos in their lives. In sum, during the groups the women, and their health, mattered.

In other words, if oppression leads to powerlessness and ultimately unsafe sex, one possible HIV prevention solution is empowerment via critical consciousness raising, a key component of the Brazilian educator Paulo Freire's (1970) empowerment education theories. Empowerment is:

> A social action process that promotes participation of people, organizations, and communities towards the goals of increased individual and community control, political efficacy, improved quality of life, and social justice (Wallerstein, 1992, p. 198).

Stated simply, empowerment broadens the range of women's choices or options (Diaz, 2007). Empowerment is a multilevel construct. For example, psychological empowerment incorporates individual beliefs, behaviors, and self efficacy to make changes, but also collective efficacy, the belief that people can work together for change, and their ability to help each other critically analyze their problems and generate possible solutions, and their ability to participate in the change process (Zimmerman, 1995).

In the *Protect and Respect* Intervention, individual women seemed to change as a result of the group process of discussing their barriers and their strengths. According to Freire and other health researchers who have applied his theories, empowerment happens when people work together to identify their problems and the roots of these problems, envision a healthier society, and develop solutions (Freire, 1970; Wallerstein, 1992; Wallerstein & Bernstein, 1988; Wallerstein & Sanchez-Merki, 1994). Freire defined this group process of problem identification as problem-posing, versus problems-solving, because problem posing acknowledges the complexity of individual and community change and the recognition that some problems do not have immediate solutions. Freire believed in the importance of conscientization or consciousness-raising for health and defined three levels of consciousness. At level one, individuals remain trapped by an acceptance of the status quo. At level two, they recognize the social situation but do not analyze their problems. At the third level, individuals understand oppression and how it affects their choices, and learn to think critically about solutions (Freire, 1970).

Establishing a space where they could think critically was equally important to the women in this study. From the group process, the women seemed to gain a sense of control over their varying challenges at a personal level. Together, the women learned that they were not responsible for their barriers to safer sex, and as a result of their shared dialogue, they developed new solutions and ideas about how to be healthy. Establishing a sense of visibility and hope in the belief that they and their circumstance could change (e.g., HIV/AIDS was not a death sentence) was critical for these women who faced intense and daily barriers to their health and healthy sexual decisions.

Empowerment theories are an appropriate framework for HIV prevention because they forge links between individual, group, community and structural change by highlighting the association between power, health, and safer sex. They are underutilized as frameworks for HIV prevention, however. For example, to my knowledge, only one published group intervention for HIV negative women, “Woman to Woman” (Romero et al., 2006) has used empowerment and critical consciousness concepts as a premise to help women develop safer sex strategies. According to my study’s findings, however, empowerment is crucial to fostering hope and dialogue for positive health related changes among HIV positive women.

Implications for Intervention Practice

These findings highlight specific recommendations for both structural and group level interventions for women living with HIV/AIDS. This study’s findings about structural violence underscore the importance of structural interventions. This study’s findings about structural violence and stress-related growth also highlighted the importance of the group environment to foster individual and group change. I describe the implications for specific structural and group interventions in detail below.

Structural interventions needed to uproot the epidemic. My findings revealed that the ultimate causes of women's sexual risk practices were not always immediate and/or within their control. Stigma, poverty, abuse, and addiction increased women's vulnerability to participate in risky behavior. Therefore, to truly help HIV positive women have safer sex, prevention strategies must prevent the roots of sexual risk taking, not just the act of unsafe sex (Bourgois et al., 2004; Dunkle & Jewkes, 2007; Farmer, 1999; Mann, 1999). Structural interventions alter structural risk factors by changing the oppressive context in which health practices occur, and by identifying the source of health problems in the social, economic, and political environments that influence health outcomes (Blankmenship, Bray, & Merson, 2000). This study's findings indicated that various specific structural interventions could help women have safer sex. These are outlined in Table 4. The first column in the table lists the study's structural violence finding. The second column explains the link between the form of structural violence and safe sex, and the third column explains the necessary structural intervention.

Table 4. Structural Interventions to prevent HIV positive women's sexual risk practices.

Structural violence finding	Link to unsafe sex	Structural intervention
Overwhelming daily stress and suffering, including stress induced by poverty and lack of resources	• Decrease negotiating power • Increase relationship dependence • Trump safe sex as priority issue	1. Microcredit loans 2. Educational and skill building programs 3. Employment training and job opportunities 4. Housing subsidies 5. Transportation resources 6. Links between medical care and prevention
Abuse (emotional and physical)	• Forced unsafe sex • Decrease negotiating power • Increase relationship dependence • Trump safe sex as priority issue	1. Laws that hold partners accountable for violence 2. Domestic violence shelters 3. Legal support 4. Collaborations between domestic violence providers and HIV prevention providers 5. Access to mental health services
Stigma (shame and violence)	• Barrier to disclosure • Barrier to medical care and prevention • Trump safe sex as priority issue	1. Laws that hold people accountable for HIV/AIDS discrimination 2. Anti AIDS stigma social marketing campaigns
Pain and suffering (sadness, grief, suicide) and addiction	• Increase relationship dependence • Influence safe sex judgment • Trump safe sex as priority issue	1. Access to mental health/substance abuse treatment 2. Collaboration between mental health/substance abuse providers and HIV prevention providers 3. Support groups for women

Despite their promise, (because of the strong empirical and theoretical links between structural factors and risk practices) few structural interventions have been implemented and evaluated for their direct impact on sexual risk practices and decreasing the spread of HIV/AIDS. A small number of structural interventions have resulted in increased HIV/AIDS knowledge, condom use, and safe sex (Roca et al., 2002; Sherer, Bronson, Teter, & Wykoff, 2004). My study's findings indicate, however, that structural interventions are a key component of a comprehensive HIV prevention strategy for women.

The need for structural interventions highlights the importance of collaboration between various health, social service, and legal professionals for effective HIV prevention. HIV positive women have needs that extend beyond the expertise of any one discipline or professional. Meeting all of these interdependent needs (e.g., relationship violence, housing, sexual health) requires a team of efforts (P. Farmer, Personal communication, November 20th, 2007). For example, HIV prevention interventionists need to collaborate with violence and addiction service providers to understand how to integrate these needs into their interventions and how to better link intervention participants to referred services. Likewise, HIV prevention efforts need to be linked to case management and medical care to meet participants' needs. At the same time, existing job or skill training programs that may not necessarily focus on HIV should collaborate with prevention interventionists need to integrate HIV prevention into their curricula. This is particularly important when applying this study's findings to HIV negative women, who may not as easily reached in a medical setting as women living with HIV (i.e., they do not attend regular HIV/AIDS medical visits every few months). The task of implementing and evaluating structural interventions is daunting, but collaborations between various service providers and researchers and policies and funding opportunities that support the union of prevention and care can help prevention programs respond to women's needs and experiences holistically. My findings confirmed that sex is just one part of women's lives and they think about sex and safe sex amid many other priorities and that these kinds of multidisciplinary collaborations are necessary.

Group intervention as a means of individual and group change. The most important aspects of *Protect and Respect* were those that resulted in group dialogue, problem-posing, and critical thinking because these aspects allowed women to talk about their challenges and their strengths and to start to develop a sense of agency, hope, and solutions for their challenges. These findings suggested that activism and advocacy could be forms of HIV prevention in and of themselves. I describe four components of the groups that enhanced individual and collective health below: group support; peer support; story-telling; and role playing.

Group Support. The group environment was essential for breaking many of the women's sense of isolation. Many women said that this was the first time that they had shared their experiences with other HIV positive women. As such, the intervention enhanced the women's social support system. They called group members "family" or at the very least, close friends. On the one hand, the group environment helped the women to see their challenges as more than individual and isolated struggles for which they were solely at fault. On the other hand, with the group's validation, the women believed in their strengths because others wanted to listen to them and took them seriously. In the groups the women's lives mattered. Groups, and especially all female groups, can act as a safe place, where girls and women can enhance their positive sense of self (Bertram, Hall, Fine, & Weis, 2000; Fine, et al. 1998). Additionally, groups are a culturally appropriate setting for African American women, who have historically used group conversation to communicate and manage struggle (hooks, 1993; Madriz, 2000; Taylor, 2000). My findings suggest that group-level interventions are an important component of an HIV prevention strategy for HIV positive women.

Peer Support. These findings revealed that the women needed and wanted a space that was "HIV positive-only". They protected the group space by giving each woman a chance to talk, keeping the conversations confidential, and returning each week to share their stories. The Peer leaders empathized with participants and led the group by creating a safe environment where all of the women could talk openly about their challenges and their strengths and felt comfortable sharing private and even shameful stories. Building upon the success of this aspect of *Protect and Respect*, prevention programs for women living with HIV should include Peer leadership.

Storytelling. The women in this study wanted and needed an open space to tell their stories. Their conversations suggested that they had few alternative opportunities to talk about themselves and share their intimate experiences, hopes, and fears. Through the narratives, the women self-created identities. This self-definition was important because too often, some other entity such as the media, their doctors, their partners, or their children had defined them; seldom had the women done so and rarely on their own terms. Banks-Wallace (1998, 2002) noted that story telling is a culturally appropriate method of communication for African American women, particularly because it can facilitate resisting the dominant (i.e., White middle class) story line, which often prevails in interventions and inaccurately defines African American women's experiences (Banks-Wallace, 1998, 2002).

Storytelling had important implications for the women's health. HIV prevention requires changing very intimate and deep rooted behaviors. The group sessions indicated that telling their stories allowed the women to think deeply and critically about themselves and how and why they made decisions about their overall health and their sexual health. Non traditional and creative forms of storytelling, like photovoices interventions, which use photographs to encourage participants to engage in dialogue and policy action, may also be effective formats for HIV prevention interventions. Photovoices projects have been used to understand better the employment experiences of people with HIV (Hergenrather, Rhodes, & Clark, 2006; Rhodes, Hergenrather, Wilkin, & Jolly, 2007) but in limited ways to understand risk behavior of men or women at risk or living with HIV/AIDS (Mamary, McCright, & Roe, 2007). This study's findings indicated, however, that story-telling is an important component of an HIV prevention strategy for HIV positive women.

Role-playing and Interactive learning. One of the other key ways that women interacted in the group was through role playing. Role playing allowed them to think in concrete ways about how to manage their challenges and use their strengths. Role playing enriched their discussions, allowed the women to practice and actively learn communication and disclosure skills, enhanced their interaction with each other, and allowed the women to have fun. Role playing allowed the women to play out how barriers would stand in their way to safer sex (e.g., violent partners) and think critically about what they could do if they encountered such situations. In other words, the role plays allowed the women to personalize the prevention messages that they were receiving and fashion solutions for their unique experiences. It is therefore important to integrate role-playing into safer sex interventions for HIV positive women.

Implications for Future Research

This study's findings revealed several important implications for future research. First, the value of the women's insights about their HIV prevention needs highlighted the importance of community based participatory research. Second, this study's findings confirmed the importance of narrative research to understand women's risk behaviors and learn about the lives of HIV positive women. Third, as a result of this research, several specific research topics require further qualitative and quantitative exploration, including the relationship between sex and oppression, stress-related growth, and women's individual and collective power. Last, using *Protect and Respect* as a lens through which to understand HIV prevention interventions for women, my findings indicated that interventions may be generally mismatched with women's lives. Therefore, additional research about intervention practice is necessary to explore this discrepancy and opportunities to reconcile the differences that I found between women's experiences and the Intervention's goals. I describe all of these research implications in further detail below.

Community Based Research. This study showed that the differences between researchers and participants can be vast and that researchers may not know or identify the most important and relevant questions to ask participants. For example, the women in this study perceived that they faced greater risks in their lives than having unsafe sex, such as partner violence, which hindered their ability to prioritize the goals of the Intervention. This study's findings revealed that HIV positive women have insight about their prevention needs but that they require meaningful opportunities to talk about their ideas and solutions. This requires community involvement in HIV prevention program development and not just participation in an HIV prevention study only. In a broader sense, therefore, this study's findings indicated that research conducted about HIV positive women can benefit from a community based participatory research (CBPR) approach. CBPR is a partnership approach to research that equitably includes community members, organizational representatives and researchers in all research processes (Israel, et al. 2003). In start contrast to traditional research, CBPR does not privilege the knowledge of "established experts" only.

Although there is no single formula for CBPR, CBPR's premise differs from other research strategies by: facilitating a collaborative, equitable partnership in all phases of the research; fostering co-learning and capacity building; and integrating and achieving a balance between knowledge generation and intervention for the mutual benefit of all partners (Israel et al., 2003). Some aspects of the *Protect and Respect* Intervention fostered this kind of collaborative process, such as the study's community advisory board (CAB) and the active role of the Peers as group facilitators and in the analysis process. For example, the Peers contributed to the analysis via the member checking process, adding a discussion of the participants' language to the results section and highlighting results that they believed were the most important for HIV prevention, such as AIDS-related stigma.

To remain true to the goals of CBPR, however, future prevention research projects should take additional steps to ensure meaningful participation by HIV positive women in all phases of intervention research. For example, I developed *Protect and Respect* and the CAB simply gave their feedback on the curricula. It would have been helpful for HIV positive women to have developed the group curricula or developed the curricula with me. Likewise, I set the goals for the Peer groups and the Peers offered additional suggestions and facilitated the groups. If the Peers set the groups goals, the groups would have likely addressed different topics. Last, I analyzed the results and invited the Peers to review them, but I alone made the decisions about the final analysis of the data. Enhanced participation in HIV prevention research by women living with HIV is important because this study's findings revealed that the women had important needs (e.g., their barriers to safer sex) there were not well integrated into this prevention program that was designed for them but not necessarily with them.

In addition, by pointing out differences between the values of researchers and participants, CBPR encourages academic researchers to be reflexive about their privilege and how it affects their work (Chavez, Duran, Baker, Avila, & Wallerstein, 2003). HIV prevention research publications often describe the participants only and omit how the researcher's identities, values, and motivations may affect the research. Researchers' identities (e.g., demographics, life and work experiences, philosophy, and politics) are critically important, however; they influence the choices that investigators make about research or intervention design, research questions, analytical methods, and the interpretation of results or outcomes. Analyzing how the perspective of the HIV prevention researcher affects the intervention and research findings will highlight key differences between researchers and participants and gaps in the questions being asked (and answered), revealing previously unexamined assumptions and new opportunities for research and practice. For example, being reflexive about my race/ethnic and class privilege allowed me to examine and critically analyze the assumptions underlying the *Protect and Respect* intervention. I understood that by failing to account for predominantly ethnic minority and low-income women's challenges and strengths, the intervention's design may have reflected my own middle class notions of knowledge as power better than it reflected the experiences of the participants themselves.

Narrative Research. This study confirmed the usefulness of narrative research to learn more about the context of and reasons for women's risk practices. Few researchers have used narratives to understand sexual risk. In one notable exception, Grinstead (2006) capitalized on the connection between narratives and the risk practices of gay and bisexual HIV positive men in the Seroconversion Narratives for AIDS prevention (SNAP) study. The basis of SNAP was the rationale that an individual's interpretation of how or why he was infected could influence how he chose to protect himself and his partners through how he attributed blame or responsibility. Additional research needs to explore the relationship between women's narratives and their risk practices by examining women's narratives about becoming infected with HIV/AIDS, learning about their infection, and telling others about their infection, as well as narratives describing other important events in their lives, including unprocessed traumatic events.

Oppression. To my knowledge, this is the first study to explore the meaning of oppression for HIV positive women. Clearly, oppression is harmful for health and this study's findings support the development and implementation of education, policies, and practices that eradicate oppression. The importance of that goal notwithstanding, it is still important to understand better how oppression harms health in order for our health care system and health care programs, including HIV prevention interventions, to help alleviate oppression and the harms of oppression.

Additional qualitative research is needed to understand HIV positive women's complex experiences with oppression, including ethnographic research, focus groups and interviews. Further understanding of how HIV positive women perceive and experience oppression is important because, as this study indicated, researchers and participants do not always explicitly articulate oppression or define it in similar ways. For example, I expected the women to talk openly about various oppressive experiences. The women did not talk openly about racism, however. They defined oppression in ways that I did not expect, such as everyday stress and suffering. Both of these findings indicated that oppression is complex and poorly understood by researchers. Understanding and documenting how oppression harms health is important however, to direct health funding opportunities to alleviate the harms of structural violence on health. Once this understanding is developed, qualitative and quantitative research is needed to explore the prevalence of oppressive experiences among HIV positive women, the intersectional impact of oppression on women, and how these experiences are associated with women's sexual risk taking behaviors.

Stress-related growth. Future studies need to explore in more detail the relationship between stress-related growth, resilience (e.g., hope and spirituality), resistance, and women's sexual behaviors. For example, existing studies of stress-related growth focus on the changes women living with HIV/AIDS make regarding their drug and alcohol use (Siegal & Schrimshaw, 2005) but explore in much less detail the specific links between stress-related growth and safer sex behaviors. My analysis of women's discussions suggests that all of these concepts were positively related to their health and appeared to be associated with their sexual decision making choices, but this study's design and methods were not appropriate to measure fully the effects of women's strengths on their sexual risk practices.

The health benefits of individual and collective empowerment. This study's findings suggested that oppression resulted in powerlessness, which hindered women's sexual decision making. Conversely, the study's findings suggested that talking about their experiences with oppression and their strengths in a group setting helped the women to understand their complex barriers to safer sex, begin to understand their challenges as part of broader structural problems that were not solely their fault, learn from each other's strengths, gain hope, and pose solutions with each other. In other words, these group discussions may have fostered women's empowerment, and raised women's individual self and collective efficacy and critical consciousness. The way HIV positive women define empowerment, collective efficacy, and critical consciousness are poorly understood however. A few scholars and researchers have attempted to measure marginalized men and women's process of critical consciousness (Carlson, Engebretson, & Chamberlain, 2005; Freire, 1970; Wallerstein & Sanchez-Merki, 1994; Watts, Griffith, & Abdul-Adil, 1999), but HIV positive women were not the focus of this work. Additional qualitative research is needed to help define the way HIV positive women describe empowerment, collective efficacy, and critical consciousness. Once an understanding of these concepts is developed, additional qualitative and quantitative research is needed to explore the relationship between them and women's health and sexual risk taking, to form the basis of HIV prevention program that integrate prevention with advocacy and activism.

Research about practice. My findings revealed that interventions sometimes do not make sense for participants. For example, interventions focus on specific behavioral goals, like condom use, but not on the factors that inhibit participants from using condoms. Because funding specifications drive decisions about intervention content and outcomes, research is needed to examine prevailing funding and intervention practice to understand how to change the direction of interventions. Such research could explore: the degree to which interventions focus on outcomes that are irrelevant and incongruent to HIV positive women's lives; the political and moral assumptions underlying interventions; why interventions are defined as effective by quantitative outcomes only; and what rewards and pressures lead researchers and institutions with otherwise helpful and beneficent intentions, to undertake potentially harmful activities (e.g., teaching women with little decision making power to demand that their partners use condoms). These questions could be explored by analyzing existing funding opportunities and funded risk reduction interventions for HIV positive women to better understand: (1)the goals of these programs, and; (2) the similarities and differences between program goals and women's lives. Questioning and exploring funding and intervention practice will examine the forces that promote specific HIV prevention strategies and guide and constrain how interventions define HIV positive women's safer sex problems and solutions, thereby defining new ideas and solutions that match women's experiences.

Methodological Implications

This study's findings revealed several important implications regarding which methods should be used to learn about HIV positive women and evaluate HIV prevention interventions. Specifically, I describe the use of qualitative methods to: (1) gather information about structural violence and stress related growth; and (2) evaluate the intervention and highlight the relationship between women's lives and the intervention, in further detail below.

Methods to learn about structural violence. This study's findings added to a growing body of work that regards qualitative data and methods as ideal for understanding how structural forces relate to women's sexual practices (Bourgois et al., 1997, 2004; Parker & Ehrenhardt, 2001). Qualitative data provided rich descriptions of the context of women's experiences and the reasons for their risk behaviors; not just numeric summaries of their sexual behaviors. Strategies of grounded theory and narrative analysis prioritized the *women's* explanations for their risk decisions, versus pre-existing theories and researchers' assumptions about how to understand sexual behavior. This was particularly important because my analysis of the women's discussions suggested that they were seldom asked about their lives or their opinions, even when the information was collected putatively for their benefit (i.e., evaluating interventions to determine their safer sex needs).

Methods that prioritized the women's experiences revealed the links between macro forces and women's individual behaviors, indicating that for the women in this study, using a condom was not a simple decision. For example, analyzing the women's narratives conveyed that stigma was a very personal and emotional experience that generated fear, which in turn acted as a barrier to HIV status disclosure. The narratives showed how multiple barriers, such as stigma and interpersonal violence, interacted. This type of data and analysis about the intensity and complexity of social discrimination in women's lives positioned the qualitative stance (Marecek, 2003), which prioritizes the women's lived experiences, as integral to understanding women's sexual risks.

Using methods that prioritized women's experiences allowed the women to define their struggles in unanticipated ways, like focusing on suffering versus typical mental health diagnoses, like depression. Likewise, learning about the women through their open ended discussions and through analytical methods that prioritized their experiences challenged my predetermined framework about what was important to women who were participating in an HIV prevention intervention (e.g., having safe sex) and brought women's life experiences that transcended HIV/AIDS to the forefront.

Measuring stress-related growth, resilience, and resistance. Similarly, my findings revealed that it was also important to study women's strengths qualitatively, and using methods that prioritized the women's experiences versus using predetermined questions about women's strengths. Women faced different barriers to succeed, defined success differently, and could not be measured in one standard way. To learn about and report the women's strengths, it was necessary to learn about the context of their lives and the experiences that they endured. For example, some women defined themselves as resilient or strong because they left a violent relationship, but other women defined themselves as strong for simply admitting that their relationship was unhealthy or violent. Methods that prioritized the meaning that women gave to their relationships made these distinctions visible.

In addition, using open-ended methods of data collection revealed clearly the disconnect between the women's and the researcher's notions of success. According to the Intervention, the women were successful if they (i.e., their partners) used condoms. Methods that prioritized women's experiences revealed, however, that women defined themselves as successful when they accepted themselves, found the will to live, gained hope or fought back against abuse. Surveys that tested pre-existing theories about women's strengths, without prior qualitative formative information, may have likely missed much of what women had to say about their experiences.

Implications for the evaluation of interventions. Current interventions are evaluated routinely using quantitative methods and by specific outcomes only, such as quantified summaries of condom use (CDC, 2007c). Quantitative summaries of risk behavior are integral to the evaluation of HIV prevention interventions, but my findings indicated that is equally important to understand why women take risks and how the intervention helps and possibly deters women from changing their behaviors. This requires that evaluation of interventions use both quantitative and qualitative methods and prioritize both outcome (i.e., what happened as a result of the intervention) and process information (i.e., how it happened).

Quantitative methods are the gold standard in the evaluation of HIV prevention programs because, presumably, numbers provide an objective way to compare treatment and control intervention groups. Quantified summaries of condom use, however, are not the only way to understand or summarize an intervention's success. The basis of program evaluation is value judgment (Guba & Lincoln, 1991). When researchers evaluate HIV prevention interventions, they make conscious and unconscious decisions about what kind of data to measure or exclude that embody their beliefs and values about which information is necessary to understand HIV risk behaviors (Krieger, 1992). HIV prevention researchers often reduce outcomes to quantifiable measures only, such as individual behaviors, because these are the easiest to measure (Aronowtiz, 1998; Bourgois et al., 1997, 2004; Krieger, 1994; Morse, 2006).

My study's findings revealed that reducing women to quantified summaries of their risk behavior only failed to acknowledge the complexity of their sexual decisions. On the other hand, adding qualitative summaries of their behaviors explained their behaviors in context, clarifying *why* women made certain decisions. In addition to collecting information about women's sexual behaviors, intervention evaluation plans should focus on understanding the reasons for women's behaviors. For example, in addition to measuring traditional intervention outcomes like sexual acts, quantitative and qualitative intervention evaluation instruments should ask women about their relationships and their experiences with stress, substance abuse, relationship violence, and stigma, because these experiences are related to their decisions about sex. And because women may face unanticipated barriers, qualitative data about their barriers and facilitators to having safer sex and/or using the safer sex skills that they learn in interventions should be collected via group transcripts and post intervention interviews, and analyzed using methods that prioritize women's experiences, like strategies of grounded theory and narrative analysis, to understand better women's reasons for their sexual risk practices.

Likewise, intervention researchers should conduct process evaluations that explain the intervention experience and the operational details that made the intervention successful. Process evaluations reveal more than project outcomes, by helping to explain intervention feasibility, acceptability, and methods of behavior change (Diaz, 2007). For example, in *Protect and Respect*, the group environment may have been a larger influence on behavior than the actual skills the women learned in the group. When researchers report intervention outcomes only, they hide all of the details about what happened during the intervention (Bourgois, 2002). Researchers should be required to explain what happened during interventions by using process data that describe: the research or intervention setting; who enrolled in the intervention and who declined; why or why not the interventionists did or did not follow the intervention curricula; the interventionists' insight about the effectiveness of the intervention; description, qualifications, and training of intervention staff; and most importantly, input from the participants about whether or not they enjoyed the intervention, how the intervention helped them to change their behaviors, and/or what more they needed to change their behaviors if the intervention was insufficient. These types of information are important additions to traditional quantitative outcomes about changes in women's behaviors.

In this study the group transcripts also served as process data by explaining in detail how the women's lives and experiences clashed with the intervention, which resulted in very meaningful information about women's HIV prevention needs. In theory, the Intervention aimed to help women have safe sex. In practice, the women had more valuable information to convey about their lives and their barriers and facilitators to safe sex, which would have been invisible without reviewing the tapes of the group sessions. Intervention evaluations often focus on limited quantitative outcomes about sex only and accordingly, only publish statistically significant findings. This study's results indicated, however, that to understand women's sexual behaviors, a much broader range of qualitative and quantitative outcome and process measures about their lives, health, and intervention experiences, are significant and necessary. Valuing a broader range of outcomes and evidence will require meaningful participation in the research process by women living with HIV/AIDS (e.g., CBPR practices), and study designs in addition to RCTs, including quasi experimental intervention designs as well as ethnographic and observational intervention studies, which allow multiple qualitative and quantitative outcomes.

VI. Study Limitations and Strengths

Limitations

This study was subject to several limitations. Individuals' names were not attached to specific sections of text in the group transcripts. This prevented me from knowing which individual was speaking at any given time. The data were only really relevant therefore, on a group level. In other words, I knew which issues were important to the group, but I could not delineate the prevalence of specific issues in this sample. For example, I learned that violence was a common group topic, but I could not report the prevalence of relationship violence among women in the sample.

Likewise, the data were limited to what women could and/or wanted to discuss in a group setting. Although group settings provide rich information about collective experiences and norms, individual interviews generate more personal and sorrowful narratives (Fine et al., 2000). The group conversations highlighted much pain and suffering in women's lives, but if the data came from individual interviews, I may have been able to explore the women's experiences on an even deeper level. Experiences like stigma or relationship violence may have been too difficult for some women to discuss in the group setting. At the same time, some of the women may have overestimated their ability to leave violent relationships or their intolerance for violent partners to present themselves as strong in front of other group members.

Another limitation was that the data did not result from direct questions about oppression or stress-related growth. In fact, those concepts were never really addressed directly in the intervention's design. If I had been able to ask women directly about these subject areas using specific interviews or focus groups in addition to the intervention transcripts, I may have gained a deeper understanding of structural violence and stress related growth in the women's lives.

Strengths

This study possessed several strengths. It provided a better understanding about two under explored experiences among women living with HIV/AIDS (i.e., structural violence and stress-related growth) and about the context of HIV positive women's risk. This is especially important because the psychosocial barriers to HIV positive women's condom use and safer sex have not been well explored (Stevens & Galvao, 2007). It is also important to understand the context of women's risk given that HIV positive women are often stigmatized for the HIV status and their sexual behavior. Research that explores *why* HIV positive women do not or cannot use condoms decreases blame for HIV/AIDS on HIV positive women and can generate useful intervention solutions grounded in the realities of women's lives rather than in norms that dictate how women should behave.

This study used mixed qualitative analytic strategies. Grounded theory strategies captured the major themes in the transcripts. Narrative analysis enhanced the grounded theory findings by giving themes context, linking women's language and meaning, and highlighting the important role of storytelling in these women's lives. Neither of these strategies alone would have been able to produce such rich analyses. Both strategies prioritized the importance of the women's experiences over pre-existing theories and ideas, bringing HIV positive women's insight, ideas, and experiences to the forefront.

Likewise, the majority of data were not controlled or limited by a researcher's agenda or questions because (in 25/30 groups) the groups were co-designed and facilitated by HIV positive women only. The women spoke freely in the groups and directed the conversation. This created a natural environment where women talked honestly about their barriers and positive life experiences (Madriz, 2000). Group data revealed the intimate connection between group members and the importance of group experiences for individual and community behavior change.

Chapter 6: Conclusion

More than 25 years into the HIV/AIDS epidemic, designing interventions to respond to the complex context of women's sexual risk behaviors remains a prevention challenge. Interventions for women continue to prioritize the male condom, a prevention option that women do not even use on their own bodies, but must convince or persuade their male partners to wear. The emergence of prevention for HIV positive women as a national priority complicates existing prevention dilemmas further. Women living with HIV/AIDS face layers of inequity that complicate their ability to make sexual choices, including gender and racial/ethnic inequalities, poverty, and AIDS stigma, among other challenges. The current focus on condoms as the single measurement of the effectiveness for HIV prevention for women reflects the sexism inherent in science and HIV prevention practice (Krieger, 1992). In addition, Fee and Krieger (1994) argued that this practice also stems in part from our society's refusal to acknowledge fully the inextricable connection between injustice and health.

By exploring the challenges imposed on women with HIV/AIDS by structural violence, the way women resisted those challenges, and the connection between women's challenges, strengths, and their sexual health, this study examined the uncomfortable link between social inequality and individual health behavior in order to generate different prevention strategies for HIV positive women by raising new questions. These include, but are not limited to: How can we account for women's social and structural challenges in HIV prevention programs? Why do current interventions focus on women's powerlessness, versus their strengths? How can we acknowledge sex appropriately as just one part of women's lives and build interventions with meaningful links between the services that women need? What aspects of our intervention practices are preventing us from helping HIV positive women be safe and healthy?

These findings exposed the weaknesses of current HIV prevention strategies but also shed light on new opportunities. As Morse (2006) explained, qualitative research is vital for public health practice because of the insight that it offers about people's lived experiences. These findings revealed clearly the discrepancies between the women's lives and the intervention's design and the potential dangers of this incongruity. When prevention programs focus on women's individual actions, such as condom use exclusively with no consideration of context, they conspire with harmful structural forces (e.g., sexism and/or poverty) by ignoring the presence and influence of these forces on women's decisions. This cultivates the continued misrecognition of the association between social inequality and women's sexual risk practices (Tesh, 1988). Prevention and care providers may fail to acknowledge the negative consequences of their well-intentioned services and interventions because their lives are so far removed from the impact of oppression and daily suffering stifling the experiences of program participants (Lott & Bullock, 2001). As Gollub (1999) has aptly noted:

> [The] lack of adequate contact between the policymakers and the women at greatest risk of HIV infection creates a void of ignorance about the real context of women's risk. Because the void is often filled with notions that are more fantasy than fact, women are effectively abandoned by national agencies charged with helping them stay healthy (p.1484).

This analysis of structural violence and stress-related growth helped to fill this void with testimonies from the women about what they needed from prevention interventions in order to have healthier lives, including safer sex. *Protect and Respect* focused mainly on condoms (and on disclosure so that women would use condoms), yet the women used aspects of the Intervention (e.g., the group process) to meet their need for a safe space where they could share their experiences, stories, hopes, and fears. The need for this space preceded their need for information and skills about sex. One participant summarized how the group was an impetus for personal development and growth, and thereby facilitated the conditions in which the women could actually make and sustain safer sex behaviors.

> And let me tell you, this group made me want to live again because I was giving up. I couldn't talk to anybody. I was embarrassed to talk. I was scared to talk. I was scared to have a relationship with myself [or] with my family. …If it wasn't for the group, I would be lost. I would be out there lost, [do] you understand? So…I've lived with this for what, 11 years now, and [the group] helped me, and I'm doing damn good. It brought my blood count back up, [do] you know what I'm saying? If you don't hear it in my voice, you're going to see it in my face. I'm a person that wants to live, so if [the group] can do that to me, it can do that to anybody, because I'm a hard person to reach, you see what I'm saying? I'm really hard, I'm telling you. This group is damn good and I'll be hurt if it stops.

In short, neither the design and content, nor the goals of existing HIV prevention programs for women yet reflect fully the experiences of the women with whom I worked. I consider this dissertation research to be a step towards the recognition and resolution of these incongruities. As such, this dissertation represents a move towards a more just, human rights informed, comprehensive, open, and affirming understanding of HIV positive women's safer sex needs and their challenges and strengths.

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Appendix A. Detailed description of the *Protect and Respect* Group-Level-Intervention

Session	Goal	Activities
1	Introduce women to each other and the program goals.	• Detailed program overview and description • Ice-breaker activity re: motivation to be healthy • Creation of group rules via group consensus • Activities and discussion re: making behavior changes • Group discussion about gender pride and strengths and challenges for HIV positive women • "Homework" assignment
2	Provide HIV/STI education and help women identify why they engage in risky behavior.	• Session introduction, review, and check-in • HIV myth/fact quiz game • Paired activity re: rating and discussing risky behaviors • Skill teaching and group discussion: identifying triggers • Skill teaching and activities: problem solving to address triggers • "Homework" assignment
3	Teach women to use safe sex skills.	• Session introduction, review, and check-in • Anatomy/female reproductive system lesson • Skill teaching, demonstration, and practice: male and female condoms • Activity re: pros and cons of different contraceptive methods • Group discussion re: partner resistance to condoms • Skill teaching: assertive communication and negotiation • Group discussion re: unhealthy and healthy relationships and women's safety • Role-plays re: asking partners to use condoms • Homework assignment
4	Teach women disclosure skills	• Session introduction, review, and check-in • Group discussion re: pros and cons of disclosure • Skill teaching and activities: identifying triggers to disclose status, anticipating disclosure situations • Skill teaching and activities: communication, disclosure • Group discussion re: positive and negative disclosure experiences • Movie clip re: disclosure • Group discussion re: handling reactions to disclosure • Group discussion re: unhealthy and healthy relationships and disclosure safety • Role-plays to practice disclosure • Homework assignment
5	Teach women to set goals to maintain healthy behaviors and support systems.	• Session introduction, review, and check-in • Review activity game • Group discussion re: goals • Skill teaching and activities: setting goals • Group discussion and activities re: social support • Concluding activity to review experiences in the program • Graduation ceremony

Appendix B: Member Checking Instructions

To: the Peer Educators

Re: Feedback on the analysis of the group sessions

Date: June, 2007

I am writing a paper about the groups (both your groups and my groups). The paper really has three points:

1. To show how many challenges (in the paper this is sometimes called "structural violence"). HIV positive women deal with everyday and how this may make it hard to have safe sex.
2. To show how many strengths HIV positive women have (in the paper this is sometimes called "stress-related growth") that may not be getting enough attention in programs.
3. To use this information to make better programs.

The quotes in the paper come from the tapes of groups. They were chosen because they gave the best example of the point I was trying to make. I quote myself in there too. It is normal to feel weird when you see yourself quoted and you may not always be happy about what you said, but remember no one knows who we are, the quotes are just there to make a point.
Here is what I want YOU to do:

Read the paper. You can both read the introduction (pages 1 and 2) and then Rhonda needs to read pages 3-27 and Dianne needs to read pages 27-41. FEEL FREE TO READ ALL OF IT IF YOU HAVE TIME.

1. Do you like the paper? Why or why not?
2. Does it make sense? If not, what is confusing?
3. Does any of it make you mad? Why?
4. Do you feel like it accurately describes your groups? If not, why?
5. What more would you want the paper to say about women's challenges and strengths?