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Stress and Functional Status in HIV-positive Women

by

Angela Lynn Hudson

DISSERTATION

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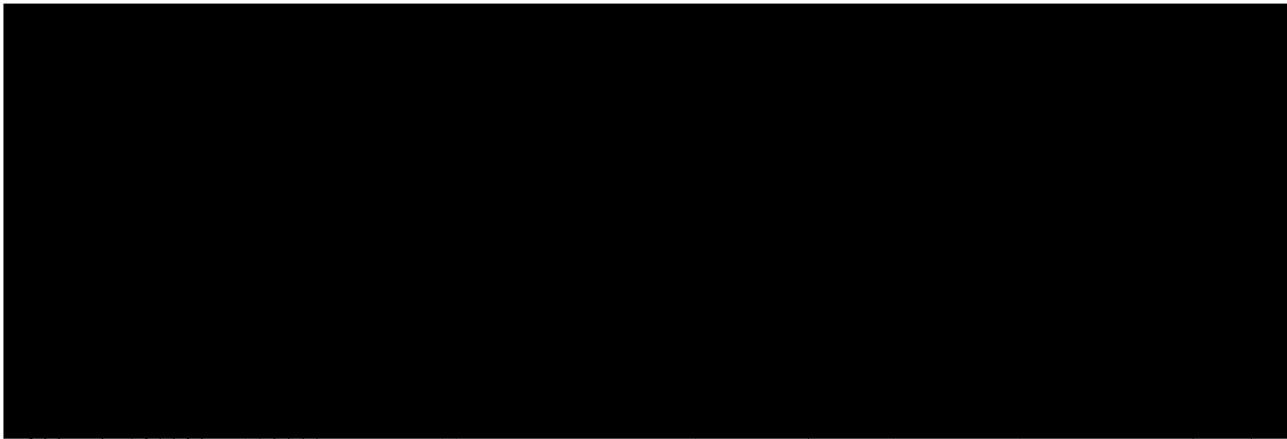
Nursing

in the

GRADUATE DIVISION

of the

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## Dedication

This work is dedicated to my parents, Carl and Ruby Hudson, who have showered me with unconditional support throughout my academic endeavors. It is with love and appreciation that I express thanks for their innumerable sacrifices.



## Acknowledgements

This dissertation research has been a most fulfilling project. I could not have completed this work without the guidance and support from my mentor and teacher, Dr. Kathryn Lee. I wish to thank Dr. Lee for her gifts of scholarship, patience, and humor; and if I can impart some fraction of these gifts to my future students, I can truly say “Well done”.

I extend much appreciation to the members of my dissertation committee, Drs. Janice Humphreys and William Holzemer. Their input and critique of my work added beneficial perspectives to this research project, which is greatly appreciated. I look forward to future collaboration with these nurse scientists for their expertise and important contributions.

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Finally, I wish to thank Dr. Delois Weekes. It was she who made that first telephone call, encouraging me to pursue doctoral study at UCSF. I’m glad she did.

## Stress and Functional Status in HIV-positive Women

Angela Lynn Hudson

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This study used a descriptive comparison design to explore perceived stressors and functional status in a secondary analysis of two independent samples of 104 HIV-positive and 46 HIV-negative women. Aims of the study were to describe and compare the self-reported stressors in a sample of HIV-negative and HIV-positive women and to describe and compare their functional status in relationship to various components of their symptoms and stress experience.

Perceived stressors were operationally defined as level of perceived stress, number of symptoms, self-reported stressors, and level of sleep disturbance. Measures included the General Health Questionnaire, a sleep/activity diary, and the General Sleep Disturbance Scale. The operational definition of functional status was the ability to perform self-care activities, errands, and household chores. Functional status was measured by the Inventory of Functional Status.

Analysis of data revealed that HIV-positive women differed significantly from HIV-negative women in their level of sleep disturbance ( $p < .001$ ), number of symptoms ( $p < .001$ ), and level of functional status ( $p = .001$ ). A significant proportion of HIV-positive women also reported high levels of perceived stress compared to HIV-negative women ( $p = .03$ ).

Because HIV disease is a chronic illness, service delivery is usually provided on an out-patient community-based level. This study supports the need for community-based services for HIV-positive women provided by nurses practitioners, nurse case managers, or home health nurses, and it underscores the importance of providing culturally appropriate care to impoverished HIV-infected women who have limited resources.

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## Chapter I

### Introduction

With the coming millennium, the epidemic of acquired immunodeficiency syndrome (AIDS) will enter its third decade. During the peak of the epidemic in the latter part of the 1980s, AIDS was a leading cause of death in young men ages 25 to 44 (CDC, 1996). With the advent of protease inhibitor anti-retroviral therapy, however, life expectancy of persons infected with human immunodeficiency virus (HIV) has increased. Protease inhibitor anti-retroviral therapy has contributed to a decline in the AIDS case fatality rate from 29.4 deaths per 100 persons in 1995 to 8.8 deaths persons per 100 persons in 1997 (Palella, et al., 1998). This represents a 70% decline in a 2-year period. Currently, the total number of persons living with HIV infection in the United States is estimated at 900,000 persons (Centers for Disease Control and Prevention, 1998).

The incidence of new HIV infections in the U.S. increases by 40,000 new infections each year (HIV Frontline, 1998). A large proportion of these new infections will be among minorities and women of color. Women particularly are at increased risk for HIV infection. The AIDS epidemic has had a major effect on morbidity and mortality of women between the ages of 25 through 44 years and disproportionately affects African American and Hispanic women (CDC, 1998).

Unfortunately, for most people, a diagnosis of HIV infection still instills shock, shame, or fear of disclosure (Cederfjall & Wredling, 1999; Nicolas & Schilder, 1997).



For newly diagnosed HIV-positive women, these reactions might interfere with their taking action to receive adequate treatment, counseling, and support.

### Background to the Problem

As of December 1998, women accounted for 20% of acquired immunodeficiency syndrome cases in the United States (CDC, 1998). African American women comprise the group with the highest prevalence of AIDS (54%), while Hispanic and Caucasian women comprise 13% and 24% of AIDS cases, respectively (CDC, 1997). With the advent of Highly Active Anti-retroviral Therapy (HAART), involving the use of protease inhibitors, the prevalence of women living with human immunodeficiency virus (HIV) and diagnosed with AIDS has increased. Not only has HAART deterred the emergence of dreaded opportunistic infections but it has contributed to AIDS being categorized as a long-term chronic illness rather than a death sentence. Nonetheless, recent research indicates that although women had one-half the viral load of HIV-infected men, women experienced the same number of symptoms as men who had much higher viral loads (Farzadegan, et al., 1998). 'When men and women had the same viral load, women were 1.6 times more likely to develop full-blown AIDS', said the study's co-author, Homayoon Farzadegan, Ph.D., associate professor of infectious disease and epidemiology at Johns Hopkins' (NurseWeek, 1998, p.9).

HIV-infected women in the U.S. are from diverse ethnic and socioeconomic backgrounds; however, most HIV-infected women typically live in inner city urban areas and are low income (CDC, 1997; Gielen, et al., 1997). Low-income women subsist on

federally subsidized programs for financial assistance, housing assistance, and medical care (Hobfoll, et al., 1994). These bureaucratic agencies might meet the tangible needs of impoverished women, but they do not have the resources and financial incentives to address women's self-worth and emotional needs. Many HIV-positive women are economically and emotionally dependent on men who engage in high-risk behaviors, such as intravenous drug use, unprotected sex with sex workers, or unprotected homosexual sex (Gavey & McPhillips, 1997). According to Belle (1990), impoverished women are disproportionately exposed to crime, violence, and illness; and compared to the general population, they often have partners who are incarcerated. Among low-income single mothers, unemployment, inadequate housing, and limited resources are stressors associated with depressive symptoms (Belle, 1990; Nannis, et al., 1997). Consequently, HIV-positive women are more likely to be impoverished and to encounter many stressors from their socio-cultural environment compared to the general population.

Moreover, impoverished African American and Latina women are at high risk for HIV transmission because poverty, lack of personal resources, and cultural beliefs influence their behavior (Goldstein, 1997). Although gender and cultural differences exist in HIV transmission patterns (Cruise & Dunn, 1994), it remains inconclusive whether these differences exist in overall survival rates. Therefore, it is necessary to conduct research to understand differences and similarities in the response to HIV infection among subgroups of women. HIV-infected women are not all alike. The lack of

understanding about these women's experiences might result in delayed health care, poor adherence to treatment regimens, more delayed and severe presentation of HIV disease, prolonged hospitalization, social isolation, or ineffective coping.

### Conceptual Framework

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) provided the framework to guide this study. Stress can contribute to illness through its direct physiological effects and through its indirect effects, via maladaptive health behaviors (e.g., smoking, poor eating habits, inactivity). Stress affects individuals in different ways, based on their experiences and cultural meanings. The way a person copes with stress can have important influences on psychological, financial well-being, quality of life, functional status, and physical health outcomes. Perceived stress can influence how an individual seeks medical care (Schilder et al., 1998) and social support (Nyamathi & Stein, 1997), as well as how well they adhere to health professionals advice (Holzemer, Henry, & Reilly, 1998).

Persons who receive a diagnosis of HIV infection or AIDS often react with a variety of emotions, including shock, depression, hopelessness, grief, anger, and fear (Catalan et al., 1996; Gielen et al., 1997; Nannis, Patterson, & Semple, 1997; Semple et al., 1993). In HIV-infected persons, psychosocial and behavioral factors may explain some of the variation in disease progression that is not predicted by biological (e.g., immunological and serological) factors typically addressed in the Biomedical Model.

Within the Transactional Model of Stress and Coping, the individual appraises

events as stressful or not stressful. Stress is the relationship between the individual and the environment that the individual appraises as overwhelming (Lazarus & Folkman, 1984). Stressors are the conditions, events, or agents that contribute to this overwhelming person-environment relationship. HIV disease, now routinely categorized as a chronic illness, brings with it the stressors commonly associated with chronic illness. Generally, chronic illness is accompanied by a host of illness sequelae: change in functional status, role change, relationship issues, and financial concerns (Friedland, Renwick, & McColl, 1996). In HIV disease, stressors (defined by Lazarus and Folkman as “daily hassles”) include dealing with symptoms, adhering to complicated medication-taking regimens, frequent medical appointments, and preparing for an uncertain future (Porche & Willard, 1998). Other examples of life stressors for persons living with HIV disease include “bereavement, occupation changes, disappointment, disease and illness, family discord, forced unemployment, translocation, transition, and social isolation” (Robinson, et al., 1999, p. 23). The most commonly reported stressors identified by a sample of 31 HIV-positive women was ongoing outpatient medical treatment and gynecological problems (Semple, et al., 1993). The stress of living with HIV infection, other environmental co-factors, and adhering to treatment protocols might be limiting the benefits of therapy to women.

A Model of Understanding Stress and Predicting Functional Status for  
HIV-positive Women

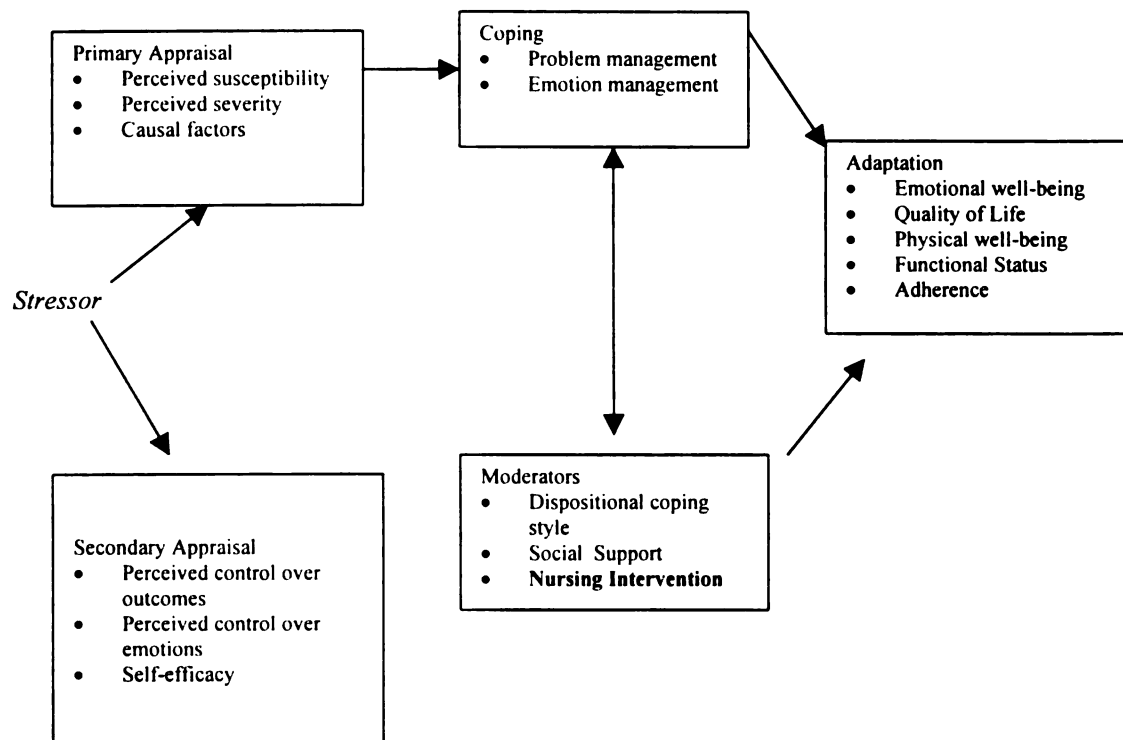


Figure 1.  
Adaptation of theoretical schema of the Transactional Model of Stress and Coping  
(Glanz, Lewis, & Rimer, 1997).

### Significance of the Study

Since 1980s, national attention has been focused on the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), which was primarily prevalent among gay men. In the 1990s, national attention been extended to women. The Centers for Disease Control and Prevention (CDC, 1997) reported that AIDS is the third leading cause of death among United States (US) women ages 25 to 44 years, and is the leading cause of death for African American women of childbearing age. Although current research findings indicate that the route of HIV transmission, symptom manifestations, psychosocial sequel, and rate of survival are different in women than in men, little is known about these stress-related events as they apply to women living with HIV/AIDS and their functional status (Anastasio, McMahan, Daniels, Nicholas, & Paul-Simon, 1995; Melnick et al., 1994). Researchers acknowledge that the unique bio-psycho-social issues faced by HIV-infected women have not been fully explored and that more research is needed to address their experiences (Nicolas & Schilder, 1997).

Nursing is the diagnosis and treatment of the human responses to actual or potential health problems. Nurse scientists are equipped with the skills necessary to conduct research on women and their responses, adaptive or maladaptive, to HIV infection. To minimize stress and stigma, to enhance functional status or quality of life, and to meet the needs of HIV-infected women more knowledge must be gained about this population. Findings from this study can be disseminated to improve treatment outcomes, justify support programs, or influence health policy decisions regarding HIV-infected women.

### Specific Aims of the Study

The specific aims of the study are to: a) describe the self-reported stressors in a sample of HIV-positive women compared to HIV-negative women, b) describe the functional status of a sample of HIV-positive women compared to a sample of HIV-negative women, and c) explore the relationship among stressors and other covariates of functional status in a sample of HIV-positive and HIV-negative women. These aims will be accomplished by a secondary analysis of two studies conducted independently on a sample of HIV-positive women (NRO3969, 1994-1997, K. Lee, principal investigator) and a sample of HIV-negative women (NRO2247, 1989-1994, K. Lee, principal investigator).

## Chapter II

### Literature Review

#### Introduction

The purpose of this literature review is to address the ontological issues concerning the stress-environment relationship for women living with HIV/AIDS. This literature review will describe this relationship in terms of a) epidemiology and social demographics, b) symptom responses, c) psychosocial responses, and d) health issues. The primary focus will be HIV-infected women living in the U.S. A critique and a summary of the trends and gaps in the literature as they relate to future research needed to understand women living with HIV/AIDS will be discussed also. A central thread of this review of literature is that HIV transmission, infection, and treatment stressors for women are inextricably bound to environmental socio-political-economic stressors of race, class, and gender.

#### Epidemiology and Social Demographics of Women with HIV/AIDS

In 1981, six women in the US presented with unexplained underlying cellular immune deficiency (Guinan & Hardy, 1987), a phenomenon similar to five previously healthy young gay white men (CDC, 1981). Although a sociodemographic profile was not reported, a retrospective study of underlying causes of death revealed that 48 “young” women in the U.S. died of AIDS between 1980 and 1981 (Chu, Buehler, & Berkelman, 1990). Forty-four percent of women acquire HIV through injection drug use, and 39% of



women acquire HIV through heterosexual contact with an injection drug-using male, sex with a bisexual male, or sex with an HIV-infected male with non-specified risk (CDC, 1997). Five cases of female-to-female sexual transmission of HIV have been documented (Rich, Buck, Tuomala, & Kazanjian, 1993). Sixteen years after the initial cases of HIV infection in women were identified, US women account for 19% of AIDS cases (CDC, 1998), the majority (74%) of whom are diagnosed during the childbearing years, age 25 to 44 (CDC, 1997). Among persons diagnosed with AIDS, women accounted for 7% in the 1980s to 19% in 1990s (CDC, 1998). In 1994, HIV infection surpassed cardiovascular disease as the third leading cause of death for US women age 25 to 44 years, following cancer and unintentional injuries (CDC, 1996).

The number of cases of AIDS among females climbed from 2,900 cases in 1987 to 12,119 cases in 1997 (CDC, 1997). Conversely, the number of AIDS cases among men increased by only one half, from 25,970 to 39,863 (CDC, 1997). The demographic shift to a fast growing proportion of women with HIV infection is thought to be attributable to the larger pool of infected men and to the probability that transmission of HIV in heterosexual intercourse is more efficient from man to woman than from woman to man (Smeltzer & Whipple, 1991).

Although HIV infection occurs across all ethnic groups in women from all socioeconomic strata, African American and Hispanic women constitute 56% and 20% of AIDS cases among women, respectively (CDC, 1997). Among black women in the 25 to 44 years age group, HIV infection ranks as the leading cause of death, accounting for

over a fifth of deaths each year since 1993. Injection drug use accounted for 49% of AIDS cases in African American women, 44% of Hispanic women, and 45% of Caucasian women (CDC, 1997).

Adding to the gender and ethnic/racial complexity, women of color with HIV infection are often of low socioeconomic status, uneducated, multiparous, live in an inner-city urban environment, and perceive that they are poorly treated by society (Dicks, 1994; Gielen, O'Campo, Faden, & Eke, 1997; O'Connor, Selwyn, & Schottenfeld, 1994). Regardless of their lifestyle, poor Black and Latina women are at excessively high risk for HIV infection because poverty and lack of resources and opportunity keep them in areas of high HIV seroprevalence. Although the incidence of HIV and AIDS among women in relation to social class is not absolute, several studies have noted conditions of poverty and accompanying economic challenges in the lives of women with or at risk of HIV infection in the US (Brown, Melchior, & Huba, 1994; Moore et al., 1995) and outside of the US (Basset & Mihloyi, 1994; Lurie, Hintzen, & Lowe, 1995).

A press release out of Washington, D.C. ("AIDS deaths down sharply," 1998) reports that AIDS deaths in the US have been cut by nearly half since multi-drug cocktails came into widespread use, and the disease is no longer the leading cause of death for young adults. While new multi-drug treatments seem to be effective in extending the lives of people who already have HIV infection, the transmission of HIV has not been significantly reduced; death rates are lower, but more people are still becoming infected with HIV, especially women and people of color (CDC, 1997).

Although there are reports that document the survival rates and effects of anti-retroviral therapy on HIV disease progression, it is unclear whether there are gender differences (Bryan, Sun, & Colford, 1998; Carré et al., 1997; Chiasson, Gallant, Keruly, & Moore, 1998; Schechter et al., 1998). One study indicated a statistically significant difference in survival rate between HIV-infected women and HIV-infected men with women surviving fewer years than men (Sterling et al., 1998). Others report higher mortality rates for HIV-infected women than HIV-infected men, but differences fail to reach statistical significance (Hogg et al., 1998; Perez et al., 1998).

The need to address the special needs of women, especially ethnic minority women, living with HIV/AIDS is clear from national demographic statistics. Illness burden appears to affect the health issues and symptomatology and psychosocial responses of HIV-infected women. For example, findings from Anastasio and colleagues' (1995) study reveal that HIV-infected women gave the highest burden scores to the following: a) home, medical and nursing treatments, b) special diet, c) attaining resources related to their illness, and d) caring for children. The researchers suggested that nurses could ease the burden for women living with HIV/AIDS by providing nutritional information, referral to home care AIDS programs, and referral to other HIV-related support services. In the next three sections, studies that have addressed symptomatology and psychological responses and health issues of women with HIV/AIDS will be discussed.

### Symptom Stressors in Women with HIV/AIDS

HIV is the etiologic agent that causes AIDS (Gallo, 1988). HIV infection impairs the ability of the immune system to ward off infections that normally would not manifest in an uncompromised immune system (Phillips, 1996). The spectrum of opportunistic diseases resulting from immunodeficiency range from asymptomatic to life-threatening diseases (Kaplan, Johnson, Bailey, & Simon, 1987; Phillips, 1996).

The existence of gender differences in the overall survival rate of HIV infection is inconclusive. However, HIV-infected women do incur different symptomatology compared to HIV-infected men and compared to HIV-negative women (Murrain, 1997; Rojansky & Anteby, 1996; Semple et al., 1993). For example, in a longitudinal study of 768 women and 3,779 men infected with HIV, Melnick and colleagues (1994) reported that men and women did not differ significantly in incidence of opportunistic infections, but women were at an increased risk for developing bacterial pneumonia in comparison to men, and the mortality rate was higher for women (27%) than men (12%). The researchers did not report whether they controlled for disease severity or stage. Diverse social factors, such as social support, homelessness, domestic violence, and low socioeconomic status were reported as possible mediators.

In another longitudinal study by Kellerher, Cox, and McKeough (1997), HIV-infected women ( $n = 59$ ) reported more symptoms of constipation, headache, and musculoskeletal pain than HIV-infected men ( $n = 59$ ). These findings indicate that clinicians need to be aware of specific profiles of various subgroups of persons who are

HIV-infected. Lower respiratory tract infections were more common in women than men, especially among those women who had a history of injection drug use. However, on any of the pain measures in a study (n=249) assessing and managing pain in AIDS care, there were no significant differences related to gender, ethnic group, injection drug users and nonusers, or clinical setting on any of the pain measures (Holzemer, Henry, & Reilly, 1998). There also were no gender differences on quality of life scores or total symptoms reported. In a descriptive study of 147 cervicovaginal smears, Calore and colleagues (1995) reported the frequency of cervicovaginal abnormalities in HIV-positive women in comparison to HIV-negative women. They found a higher proportion of pathologic effects of the following agents in HIV-positive women compared to HIV-negative women: human papilloma virus (26%), Candida albicans (13%), Gardnerella vaginalis (13%), Chlamydia trachomatis (3.4%), and Trichomonas vaginalis (8.4%). The finding of various gynecological complaints among women is consistent with other studies of women living with HIV/AIDS. For example, the prevalence of cervical cancer has been reported to be higher in HIV-infected women than in women without HIV across White, Black, and Hispanic racial/ethnic groups (Chin, Sidhu, Janssen, & Weber, 1998).

Seiple and colleagues (1993) conducted a qualitative study to explore the major stressors in the lives of 31 HIV-positive women, infected primarily through heterosexual contact. The interviews solicited women's perceptions of the circumstances, context, and consequences of stressful life events resulting from HIV seropositivity. Gynecological problems, as opposed to other life-threatening chronic conditions, were identified as the

primary symptom-related stressor among a multitude of life event stressors. Results from the research examining HIV symptomatology indicate that the inclusion of various growing gynecological problems and concerns may need to be included in the revision of the surveillance case definition for AIDS.

### Psychosocial Stressors in Women with HIV/AIDS

Accompanying emotions associated with the diagnosis of a possibly fatal, chronically disabling disease in both men and women include shock, disbelief, depression, loneliness, hopelessness, personal grief, guilt, anger, and fear (Chesney & Folkman, 1994). Researchers have studied various psychosocial sequelae and their interrelationships in HIV-positive men and women. These include, among others, depression (Beedhan & Wilson-Barnett, 1995; Peterson, Folkman, & Bateman, 1996; Valente & Saunders, 1997), ineffective coping behavior (Wolf et al., 1991), and social isolation (Donlou, Wolcott, Gottlieb, & Landsverk, 1985). Other psychosocial-related themes in the literature related to HIV status include broad concepts such as quality of life (Holzemer & Wilson, 1995; Wilson, Hutchinson, & Holzemer, 1997), self-transcendence (Mellors, Riley, & Erlen, 1997) uncertainty (Brown & Cope-Powell, 1991), social support (Hudson & Morris, 1994), and the experience of living with HIV (Siegel & Krauss, 1991). Investigations of sociocultural issues, such as HIV-positive men and their attitudes about homosexuality (Wolcott, Namir, Fawzy, Gottlieb, & Mitsuyasu, 1986) and spirituality (Coleman, 1998; Pace & Stables, 1997) have also contributed to our understanding of the context that envelopes the lives of persons living with

## HIV/AIDS.

Although more efforts are being undertaken to include women in HIV-related clinical trials and social science research, most published reports of the range of psychosocial responses to HIV infection have investigated these responses in gay or bisexual men (National Institutes of Health, 1994). Representations of HIV-positive women and their subgroups have not received the same attention as men (Anastos & Marte, 1989). These subgroups comprise women who are lesbians, physically challenged, mentally impaired, sex workers, women prisoners, women who live in rural settings, homeless, transgendered, ethnic minority, lower socioeconomic status, battered, menopausal, peri-menopausal, elderly, uneducated and well-educated, and women who are in various stages of HIV illness progression.

Extrapolating findings from men to women is no longer “de rigeur.” As the incidence of HIV infection and its related morbidity rises in women, the National Institutes of Health (1994) recognized the need to examine methodological issues and sampling strategies that complement HIV/AIDS-related research with women and ethnic minority populations. From a psychosocial perspective, there is concern among researchers that HIV-infected women do not have adequate resources to manage their symptoms, which might delay disclosure until symptoms are overwhelming. There are studies that indicate that psychosocial stressors may impair immune function, thereby increasing biological susceptibility to the natural course of HIV infection (Ickovics & Rodin, 1992). The following discussion describes the results of studies that dealt with the

psychosocial and environmental stressors of HIV-infected women.

To establish the prevalence of psychiatric morbidity and social functioning, social support, coping style, life events, and sexual difficulties were explored in a convenience sample of 49 HIV-positive and 49 HIV-negative British women (Catalan et al., 1996). Both groups were comparable in age, socioeconomic status, marital status, and employment status. Ethnicity was not reported. Stage of illness progression was based on the CDC's (1986) criteria. Although more than one-third of the entire sample reported substantial levels of psychiatric morbidity, no significant differences were found between groups regarding personal or family psychiatric history. Seropositive females differed significantly ( $p < .05$ ) on social integration and guidance: HIV-positive women did not feel part of a group with shared beliefs and social interests (social integration) and felt less able to turn to someone to discuss problems and decisions (guidance). Social support and life events accounted for 39% of the variance in psychiatric morbidity. Gielen and colleagues (1997) used a qualitative approach to elicit women's fears and experiences regarding disclosure of their HIV-positive status. The study's sample comprised 50 HIV-positive women, ages 16 to 45 years, the majority (86%) of whom were African American. The majority (75%) of the women reported they were initially very apprehensive about disclosing their HIV status to others due to concerns of rejection, abandonment, violence, or discrimination. When they did reveal their HIV-positive status, most women found acceptance, support, and understanding from family and friends. Only 25% of the sample reported very negative responses from significant others,



such as abandonment, verbal abuse, or physical assault. One woman was physically attacked on the street, ostensibly after her girlfriend told others of her status. Another woman reported verbal abuse and harassment by her husband after she disclosed her status. Fear of mistreatment is an important issue for women newly diagnosed with HIV. While the majority of the women found supportive responses, there were ample examples of negative consequences for women who disclose their seropositivity. The impact of violence against HIV-positive women and the concomitant emotional and developmental strains on the children remain to be fully explored.

To understand psychosocial factors that relate to positive coping in HIV-positive women, Nannis, Patterson, and Semple (1997) examined a subsample of 58 HIV-positive women from a larger sample of 109 women. The women in this study were an atypical profile of HIV-positive females in that the majority were Caucasian, had some college or a college diploma, and were employed. The investigators' aim was to determine which of five psychosocial variables (social support, loneliness, anger, depression, and locus of control) would discriminate among HIV-positive women who strongly identified with three coping styles: (a) active-problem solving, (b) hopeless-giving up, or (c) stoic. Strong predictors of active coping were social support ( $r = .84, p < .01$ ) and loneliness ( $r = -.69, p < .05$ ). Women who strongly identified with a helpless/hopeless coping style were characterized by less social support, more loneliness, more depressive symptoms, more anger, and less locus of control. Social support was the only variable that correlated significantly ( $r = .78, p < .01$ ) with a stoic coping style. In general, this sample of HIV-

positive, non-impooverished, asymptomatic women reported lower levels of psychological distress, however, the conclusion that this is typical of impooverished, asymptomatic women cannot be supported.

Ragsdale, Kotarba, Morrow, and Yarbrough (1995) compared the locus of control among 14 indigent HIV-positive women with normative data obtained from a group of college students, a group of other persons with chronic illness, and a group of low-income persons. Locus of control was measured using the Multidimensional Health Locus of Control Scales (MHLIC), designed to measure locus of control in two dimensions: (a) internal sources, (b) chance or powerful others and their influence over events, such as health states or health outcomes. All of the women were asymptomatic for AIDS-defining illnesses. Seventy-one percent of the 18 to 53 year old women were African American, 21% were Caucasian, and 7% were Native American. Significant differences were found between this sample of HIV-positive women who identified themselves as more internally controlled (believed in themselves) compared to the normative sample of low-income persons, who also identified themselves as internally controlled ( $t(12) = 2.34, p < .05$ ). Caution should be exerted, however, in relating this finding to the fact that asymptomatic low-income, HIV-positive women feel empowered, especially given the small sample size. For the purpose of comparison, mean score responses should be compared to a similar cohort of HIV-positive men or women with another chronic illness. A sample of 31 HIV-positive women, receiving care at the HIV Neurobehavioral Research Center in San Diego, were recruited as key informants in a qualitative

exploration of stressors encountered by women with HIV infection ( Semple et al., 1993). This investigation was identified as the "...first paper to use empirical data to identify major life stressors experienced by HIV-infected women" (p. 28). A stress process model was used to frame the presentation and discussion of the study's findings. Problems that resulted directly from HIV seropositivity (wasting syndrome, gynecological problems) were categorized as primary stressors. HIV-related secondary stressors involved concerns about interpersonal relationships with spouse/partner, fear of vertical transmission of HIV to their children, and disclosure of their HIV status to the social network. Another secondary stressor was financial concerns.

As with Nannis and colleagues' previous study, (1997), this sample of HIV-positive women, aged 24 to 43 years, was predominantly Caucasian (80%), employed (52%), educated ( $M = 13.5$  years,  $SD$  not reported), and all of them self-identified as heterosexual with no reported substance abuse history. Undeniably, this is an important subgroup for study, however, their reported life stressors might be different from other HIV-positive women who also face social barriers, such as racism and classism (Krieger, Rowley, Hernan, Avery, & Phillips, 1993).

Some investigators have recognized the power of social networks and social support in affecting the lives of subordinated groups of HIV-infected persons. For example, concepts of perceived coherence, social support, and learned helplessness theory were used to test several hypotheses for the prediction of depression and anxiety in a convenience sample of 255 HIV-infected African American adults, 73% of whom were

males (Linn, Poku, Holzapfel, & Crawford, 1995). Variables used to predict anxiety and depression were stage of illness, social support (number of friends), and number of HIV-related symptoms. A significant gender difference occurred in social support as a predictor of depression: the average number of friends reported by men were 5.42 and 3.00 for women. This might be an expected finding given the uneven proportion of men to women, however, this finding of women being less likely than men to receive support from primary partners and family members is consistent with other studies that have examined social support and gender differences in persons seeking treatment and recovery from drug addiction (Amaro & Hardy-Fanta, 1995). A recommended strategy from this report was for clinicians to help African American women with HIV infection build social support networks. Because of a lack of social support networks, many HIV-infected women rely on their children as a major source of social support (Andrews, Williams, & Neil, 1993). While social support seems to have more positive outcomes than negative outcomes, it is worth noting that in the last decade, social support researchers have queried the early assumption that social support has only positive outcomes (LaGaipa, 1990; Rook, 1990). In light of these recent findings, scholars continue to believe that social support provides resources beyond what healthcare professionals might offer (Nyamathi, Flaskerud, Leake, & Chen, 1996; Friedland, Renwick, & McColl, 1996). Also noted is that intravenous drug use, which has been identified as a common route of HIV transmission among African Americans, was not the reported common route of HIV transmission in this sample of African American subjects,

and therefore, might not represent most African Americans with HIV infection.

While social support has received attention in research studies, its operational definition has limited the utility of research findings. The concept of social support was given cursory attention in this investigation by Linn and colleagues (1995). The investigators used social support as a predictor variable for their model of psychological functioning in a sample of 255 seropositive African American men ( $n = 186$ ) and women ( $n = 69$ ). Given that social support researchers define social support as a complex multidimensional concept, to frame an assessment about social support using one broad question may render social support an insensitive indicator of psychosocial functioning. The one question about social support in this study was "Is there anyone you feel you can tell just about anything to, someone you can count on for understanding or support?" (p. 51) A simple "yes" or "no" answer will not assess the omnibus nature of this concept, as it contains important structural, process and outcome dimensions (Norbeck, 1981). In addition, from a sociocultural perspective, this dichotomous approach dismisses the cultural significance of kinship ties in the African American community (Taylor & Roberts, 1998). The concept of social support must be carefully defined and measured, or researchers will find inconsistencies in study results (Miller, 1999).

A more comprehensive measurement of social support was reported by Williams and colleagues (1997). The investigators posited that women, in general, tend to care for their children and families and are less diligent about their own care needs. With a descriptive survey design, they used the Norbeck Social Support Questionnaire (NSSQ),

to determine how the enhancement of social support networks might increase the use of primary care services by HIV-positive women. The NSSQ measures the type, source, and amount of two critical dimensions of social support, emotional and tangible support, on a 5-point agreement alternate response scale (Norbeck, 1995). Unlike Linn and colleagues' (1995) study, respondents were not held to a dichotomous "yes" or "no" answer when asked about their support network. Over 54% of women included a partner/spouse in their support network, and 42% included a friend. Forty-one percent of the women delayed seeking primary care up to three months after notification of their HIV seropositive status. Those that delayed seeking primary care for their HIV infection also reported less social support. Attenuated support from friends and significant others was similarly found in a study of seropositive women (Hudson, Miramontes, Lee & Portillo, 1998). These results imply that a limited social network might influence health care seeking behaviors and consequently, the progression of disease.

Using a model-testing correlation design, Nyamathi and colleagues (1996) obtained a convenience sample of 3,187 impoverished women at risk for AIDS in order to examine the relationships among social support, acculturation, self-esteem, depression, and emotional distress. The sample consisted of African American, Latina, and Caucasian women. Results indicate that the less acculturated Latina women report lower levels of social support compared to the more acculturated Latinas. Social support availability and self-esteem were significantly related regardless of reported drug use ( $r = .27, p < .001$  for nondrug using women and  $r = .24, p < .001$  for injection drug using women). All other

relationships between drug using and non drug using women were similar in magnitude.

A predictive, correlation design was used to obtain cross sectional data from 264 HIV-positive women to evaluate the influence of social and psychological factors on quality of life (Sowell et al., 1997). Social factors included social support, material resources, disclosure, and family functioning. Psychological factors included stigma, emotional distress, intrusion, avoidance, and fatalism. Quality of life was operationalized as a multidimensional construct, comprising varying levels of anxiety, daily physical functioning, and HIV-related symptoms.

The researchers reported that stigma, fatalism, employment status, and stage of illness accounted for 18% of the variance in daily functioning. Women who worked full time reported an overall better quality of life than those who were unemployed. They reported a higher level of functioning, less anxiety, and fewer HIV-related symptoms. Women who were married or lived with a partner reported greater levels of anxiety and HIV-related symptoms than those who were not married or living with their partner. This finding suggests that carrying out the role of mother/homemaker/partner might be more stressful when one is ill. Material resources, disclosure, intrusion, race, age, and employment status accounted for 30% of the variance in HIV symptoms. Social support and its related factors were not significantly correlated with any of the dependent variables; this finding might be related to the difficulty in quantifying such social factors as social support, material resources, disclosure, and family functioning. Findings from this study support future intervention research to address the psychosocial responses of

HIV-infected women and the influence of these factors on women's quality of life. Nyamathi and Stein (1997) used a quasi-experimental design to assess changes in cognitive, psychological, and risky behavior variables in a sample of 300 African American women at risk for contracting HIV. The theoretical underpinnings for this study were health seeking behaviors and Lazarus and Folkman's (1984) stress and coping theory. Two years after the implementation of an AIDS education risk reduction program, findings demonstrated that the specialized AIDS counseling program produced significant results in improved self-esteem ( $p \leq .001$ ), increased social resources ( $p \leq .001$ ), and decreased HIV risk behaviors ( $p \leq .001$ ). The effect size of the intervention was 2.02, indicating that at-risk, hard-to-reach, low-income women benefit from needs-specific counseling programs that are culturally sensitive.

The role of religious activity in predicting psychosocial adjustment (defined as optimism and depressive symptoms) was explored among 205 inner-city African American women, one-half of whom were HIV-positive (Biggar, et al. 1999). The authors found that while HIV-positive women prayed more, these women reported that prayer was less important in coping with their HIV infection compared to HIV-negative women if the HIV-negative women had a chronic illness. In the overall sample, frequency of prayer was the only measure of religious activity (the others were attending church services and importance of prayer in dealing with chronic illness) that related to optimism. A relationship did not emerge between any measures of religious activity and depressive symptoms. Why did frequency of prayer related to optimism but not to



depressive symptoms? The authors reported that depressive symptoms are an indicator of current adjustment whereas optimism is an indicator of future expectations. Prayer might be utilized, not to alleviate current problems, but to achieve a more positive outcome in the future. The authors did not, however, report how these findings might be applicable to practice or future research with HIV-infected inner-city African American women.

#### Health Issues for Women with HIV/AIDS

Health issues of concern for women with HIV/AIDS are stressors that are inextricably connected with their social experience. These stressors include HIV drug adherence (Crespo-Fierro, 1997; Katzenstein, 1997; Katzenstein et al., 1997), access to care and utilization, (Bozzette et al., 1998), health-seeking patterns (Schilder et al., 1998), and therapeutic regimens, including alternative/complementary therapy (Johnston, Ahmad, Smith, & Rose, 1998; Weber et al., 1998) and therapy used to prevent vertical HIV transmission (D'Ubaldo et al, 1998; Simonds et al., 1998; Turner, McKee-Nelsen, Fanning, & Hauck, 1997). In general, women who are marginalized by age, race, income, sexual orientation, illness, or disability are usually underserved or excluded from services altogether (Zierler & Krieger, 1997). In one study, despite coming from "high risk" groups or presenting with symptomatic disease in the year prior to HIV diagnosis, few (14%) women recalled discussing HIV in either primary or secondary care settings (Madge, Olaitan, Mocroft, Phillips, & Johnson, 1997). HIV-infected women's functional status and utilization of health care and their functional status and quality of life are major concerns for further study because of the stigma associated with their HIV status,

racial/ethnic minority status, poverty, domestic violence and child sexual abuse, and drug use (Kirkham & Lobb, 1998). Even when community-based services were provided for women, an evaluation of these services revealed that agencies appear to do a better job of addressing HIV-infected women's economic stressors than stressors related to gender, such as reproductive health care, family services, and access to clinical trials (Maslanka, Lee, & Freudenberg, 1995).

Nicolas and Schilder (1997) used a phenomenological approach to understand the lived experience of five women with HIV infection residing in Winnipeg, Canada. Emergent themes were health-related issues, marital/partner relationships, child/family issues, occupation, social network, and coping with the illness. The researchers posited that women's experiences with HIV infection are "inseparately linked to their experiences as women" (p. 91). True for any individual, a woman living with HIV/AIDS cannot be taken out of her social context and given treatment, information, and judgement. These women must be able to receive treatment, information and support within their social experience, within women's ways of knowing—for this is the reality to which they must return to live with their HIV/AIDS condition. In Canada, the population of HIV-infected women is scant in comparison to HIV-infected women in the US. In concordance with Sowell and colleagues (1997), the researchers recommended that nurses serve as advocates for HIV-positive women by lessening their social isolation with use of referrals to community services that will respond to their needs.

Many HIV-infected women with children have problems receiving adequate health

care; this lack of health care may result in decreased survival time and quality of life.

Butz and colleagues (1993) examined longitudinally (3 years) the social and health characteristics associated with adequate utilization and adherence to health care in 90 HIV-infected women and their infants ( $n = 99$ ). The women were predominantly African American; half had not finished high school, two-thirds reported drug use as their HIV risk factor, and 13 had a history of incarceration. Findings demonstrated only 41% of mothers had ever sought HIV-related health care for themselves, whereas 73% of infants received adequate medical care. Factors found to be associated with maternal health care adherence care included the HIV status of the infant, history of incarceration, and maternal drug use. These findings suggest a need for culturally-sensitive alternatives for contraception, health care sites where women can be treated in the same visit as their children, exploring the decision-making processes of the women, and developing community systems for women's support.

Because most HIV-infected women are of childbearing age, perinatal HIV transmission is a primary stressor (D'Ubaldo et al., 1998). Turner, McKee-Nelsen, Fanning, and Hauck (1997) examined the impact of zidovudine use by 1,514 HIV-infected women on vertical transmission. Data were obtained from the New York State Medicaid HIV/AIDS database and vital statistics for HIV-infected women between 1985 and 1990. This study differed from the AIDS Clinical Trials Group Protocol 076 (Wilfert, 1996) in that the sample was comprised of women who had "high" access to prenatal care and women with significant immunodeficiency were excluded. Additionally, key factors,

such as lack of prenatal care and disease stage on vertical transmission, were not addressed in the Protocol 076. Although accessibility to care was considered “high” by the researchers, findings indicated that only 50% of the cohort initiated prenatal and HIV care by 14 weeks gestation—the first week a woman in the protocol could begin zidovudine therapy; 14 % received no prenatal or HIV care until the last weeks of pregnancy. Transmission rate varied according to disease state: 44% with advanced disease, 31% with symptomatic disease, and 24% with asymptomatic disease. The research group concluded that risk of vertical transmission occurs when prenatal care is delayed and HIV disease is advanced. An important health policy implication of this research is that proposed mandatory testing might discourage pregnant women from getting tested for HIV, thus driving them away from prenatal care. “If only a small fraction of all pregnant women do not receive prenatal care because of fear of testing, this is likely to have an adverse impact on infant morbidity and mortality (Turner et al., 1997, p. 584). A critical limitation of this study was that the researchers assumed that all the women in the database were offered zidovudine therapy and that their adherence to drug treatment was monitored. The lack of verification of these assumptions might confound the overall conclusions of vertical transmission and zidovudine therapy.

In contrast to Turner and colleagues’ (1997) use of a retrospective study design, Simonds and colleagues (1998) prospectively studies a cohort of 1,533 children born to HIV-infected women between 1985 and 1995 to describe the effect of perinatal use of zidovudine on vertical transmission. For 187 children, exposed antenatally and prenatally

to zidovudine, transmission risk was 13% (95% CI , 8-18) compared to 21% (95% CI, 18-24) for 845 children not exposed to zidovudine. Other factors associated with transmission risk were membrane rupture greater than 4 hours before delivery, gestational age less than 37 weeks, maternal CD4 count less than 500/mm<sup>3</sup>, and birthweight less than 2500 g. The data indicated the importance of providing comprehensive prenatal care to HIV-infected women, offering them zidovudine therapy early in pregnancy, and discouraging breast feeding by HIV-infected mothers. Like Turner and colleagues (1997), adherence to and monitoring of zidovudine therapy were assumed.

Because HIV disease progression is related to viral load, combination anti-retroviral therapy is the drug treatment currently in use to decrease HIV to undetectable levels (Brodt et al., 1997). Although they are the most highly effective drug therapies thus far, these combination drug therapies can be complicated and arduous as they require astute attention to dose maintenance. Studies that looked specifically at adherence to anti-retroviral regimen for HIV-infected women revealed that child care and confidentiality were the greatest barriers to their adherence; while transportation and family support promoted adherence (Kosko, Neff-Smith, & Kim, 1998). Women with a history of using crack cocaine were less likely to adhere than women whose HIV disease was more advanced as measured by CD4 count were more likely to adhere (Williams, Mezger, & Yu, 1998).

Women who report a history of childhood sexual abuse have an increased risk for HIV transmission (Miller, 1999). The mental health effects of sexual assault can affect

HIV transmission risk for women. The use of drugs to self-medicate, sex risk-taking, and psychopathology (e.g. depression, low self-esteem) are examples of underlying mechanisms that increase HIV risk behaviors in women. Miller presents a model of understanding the relationship between sexual abuse and HIV risk among women. She suggests that research be conducted not on the individual woman but at multiple interpersonal levels (the dyad and social network members) in which women interact to develop social and community interventions for women at risk for HIV infection. Because women's emotional responses might delay health promotion behaviors or lead to poor engagement with their health care providers, the gap in mortality between HIV-infected men and women could widen.

Holzemer and colleagues (1999) did not find gender differences for adherence and health-related quality of life in a sample of 420 HIV-infected individuals (84 were females). Adherence was operationalized as taking medication, following providers' advice, and keeping appointments. In comparison to clients who reported having a meaningful life, feeling comfortable and well cared for, using their time wisely, and taking time for important things, HIV-infected clients with higher symptoms scores, particularly depression, were more likely to be non-adherent.

The advent and availability of combination therapies has contributed toward a new optimism and an improved quality of life for many HIV positive people. However, increasing numbers of HIV-infected clients are now reporting stressors related to sexual problems, such as erectile dysfunction and decreased libido or loss of sexual desire in

HIV-infected women (Cooke, 1998). If attention is not given to these stressors, non-adherence to the treatment regimen is likely, and the optimism could be short-lived. There is a need to explore eclectic approaches, such as combining clinical psychology therapies and modified sex therapy techniques. Other complementary therapies with HIV-infected persons have been used, for example, Chinese herbs (Weber et al., 1998; Wilson & Cohen, 1998), mega-doses of vitamins and minerals (Keiserman et al., 1998), and marijuana. Alternative therapy has also been used with disadvantaged and ethnic minority populations (Johnston, Ahmad, Smith, & Rose, 1998). Although innovative and creative, many of these studies consisted of a small number of women.

#### Summation: Critique of the Literature and Gaps, Trends and Implications

The purpose of this chapter was to address the ontological issues related to the stressors for women face while living with HIV/AIDS. These stressors were described in terms of a) epidemiology and sociodemographics, b) symptom experiences, c) psychosocial responses, and d) health issues, such as adherence to treatment, access to care, and current therapies with potential and real benefit. The implications are addressed as they relate to future research.

#### Critique of the Literature

The studies presented, while providing an ontology of HIV infection in women, do not provide the full explanation of HIV-infected women's experiences. For example, although several studies found no statistically significant differences in symptoms and psychosocial responses of HIV infection, there continues to be a gap in survival rates

between HIV-infected women and men. If this gap continues, will its existence then become status quo, and will research on HIV-infected women become complacent and accepting of this trend? Although achieving statistical significance allows one to make some inferences about the target population, there are practical and clinical considerations that warrant attention. The gap in mortality and incidence of HIV infection among underserved and underrepresented populations is of statistical, practical and clinical significance from a public health standpoint.

The issue of accessibility of HIV care to women residing in rural regions of the US is of concern because most of the research consists of women who live in urban settings near large teaching/research institutions. Although it is clear that most women who are HIV-infected live in urban communities, it is not known from the literature whether women from rural locales have the same access to care and delivery models available to urban-dwelling women. In addition, health care providers might not be as savvy about current research findings, interventions, or therapies. Presumably, access to care for rural-dwelling women is not the same. These women might or might not be benefiting from research conducted with women from the inner city. For instance, it is unclear whether interventions based on research samples that are more easily accessible can be generalized to a regionally different group of women.

Abstracts from the 12<sup>th</sup> World AIDS Conference in Geneva, Switzerland demonstrate the need to examine the gamut of the epidemiology and social demographics, symptoms, psychosocial responses, and health issues of women living



with HIV/AIDS. More evaluation research is needed on the efficacy of programs specific to HIV-infected women. Similarly, comparative research is needed at the municipal level to describe the effectiveness of community-based programs that address the specific needs of women living with HIV infection within their social fabric. It is necessary to promote women's participation in the planning phase of program development so that the programs will be best suited for them based on their cultural needs.

### Problem and Significance

There was sufficient background and evidence to support observations that the HIV epidemic is increasing in women, and that there is a need for better understanding about women living with HIV infection in order to improve their quality of life. This background and evidence included substantial epidemiologic and demographic profiles of HIV-infected women, using primarily CDC statistics. Most of the researchers mentioned stressors that women encounter due to their HIV status, their poverty, and the specific stressors racial and cultural issues in society. Several of the studies noted the need for changing the larger social structures so that HIV-infected women from lower socioeconomic backgrounds would have greater access to health care.

### Conceptual Frameworks

Conceptual frameworks, if proposed at all, were not well-developed, and were given only brief attention, except in the papers by Linn et al. (1995) and Nannis et al. (1997). This brevity may be related to the page limitations set by the publishing journal. Concepts of the model proposed by Linn and colleagues (1995) were taken from

established theories of social support and learned helplessness. They presented conceptual variables and their hypothesized relationships in figure form, as a type of conceptual map. Nannis et al. (1997) used Lazarus and Folkman's (1984) stress and coping model to guide their research, noting that stressors per se are not uniquely damaging to one's physiological and psychological self; rather, it is the way in which one responds or copes with stressors that is important. Subsequently, they did not attempt to measure stressors (life events) in and of themselves, but examined them indirectly, through concepts such as coping, social support, loneliness, depression, and locus of control. In this way, the conceptual model guided their choice of salient concepts in the lives of women living with HIV/AIDS.

The biomedical studies that were reviewed, such as the one by Melnick and colleagues (1994) made no attempt to discuss theoretical linkages among variables. Qualitative studies, such as the one by Gielen et al., (1997) did not use preset theory because the goal of qualitative research is not to test, predict, or explain a phenomenon, but to explore the experiences of women's disclosure of their HIV status in narrative form (Miller & Crabtree, 1992).

Although conceptual frameworks were not explicitly presented, most authors adequately defined the variables in operational terms, such as HIV stage of illness, social support, depression, life events, adherence, and coping. An explanation for the researchers' interest in a particular concept would have been insightful. Any linkage between the theoretical framework and the concepts to be measured were only implied

from the background information presented by the researchers. For example, it is well-documented that the majority of HIV-positive women have lower incomes than both HIV-infected men and the general population, that they have more reports of child sexual abuse than non-infected women in the general population, and that they usually contract HIV through unprotected heterosexual contact (CDC, 1997). If investigators are interested in using Lazarus and Folkman's (1984) stress and coping framework to guide a study of HIV prevention in women in addition to knowing the epidemiologic and demographic profile of HIV-positive women, then the investigator might choose to measure stress and functional status.

#### Methodologies

Study Designs. The most common research design used in the reviewed articles was a correlational design, of which there were two different types: a) predictive (Catalan et al., 1996; Nannis et al., 1997) and (b) model testing designs (Linn et al., 1995). Two studies used a phenomenological approach (Gielen et al., 1997; Semple et al., 1993) and one study used an exploratory survey design (Ragsdale et al., 1995). None of the reviewed studies reported using pilot data to aid in the development of the research design.

At this point in the evolution of research that aims to understand women living with HIV/AIDS, the research designs seemed appropriate for obtaining preliminary data. Yet to be explored, however, are the main effects and interaction effects of HIV infection in women from different subgroups (e.g., lesbians, elderly, and menopausal women).

Knowledge generation tends to be incremental (Polit & Hungler, 1995), therefore, it is necessary to continue to build a foundation of knowledge about women and specific subgroups of women who are living with HIV/AIDS so that culturally and socioenvironmentally appropriate interventions can be developed and tested.

Because the majority of these studies report cross-section data, the ability to establish a cause and effect relationship between the variables and the outcome variable of interest is difficult (Newman, Browner, Cummings, & Hulley, 1988; Polit & Hungler, 1995). Moreover, the lack of intervention studies, with the exception of Nymathi and colleagues (1993), hinders the ability to determine the effectiveness of treatment regimens for enhancing the quality of life of HIV-infected women. This creates threats to internal and external validity, which had limited discussion in the reviewed articles. Similarly, as expected, qualitative researchers did not purport to generalize their findings to the total population of women living with HIV/AIDS.

The next step to increase knowledge about the health of women living with HIV/AIDS would be to conduct more extensive research, using comparison groups as was done in the study by Catalan and colleagues (1996), to yield more understanding about possible differences among subgroups of women with HIV/AIDS. For example, a study designed to compare HIV-positive African American women with HIV-positive Caucasian women on psychological responses (depression, anxiety, locus of control) and health status (functional ability, stage of illness, symptom distress) might elicit significant differences. The difference in women's cultural values, beliefs, and experiences is under

reported in the literature. This could be followed by replication studies with similar samples of women to enhance the validity and generalizability of findings to the larger population of African-American and Caucasian women with similar demographic and epidemiologic characteristics (Polit & Hungler, 1995). Furthermore, intervention research should be conducted longitudinally, as opposed to cross-sectional, to obtain trends and patterns through several data collection points and ascertain the long-term effect of an intervention on the outcome variable(s).

**Sampling.** All of the studies in the literature review included convenience samples, using primarily the snowball technique, obtained through community-based social service agencies and clinics. The advantage of convenience sampling, especially related to confidentiality issues for persons with HIV/AIDS, is that there is some assurance that individuals participated voluntarily in the studies. While the accessible population is easily designated and recruited, convenience sampling is not an inclusive approach, leaving out the views of many persons who belong to the target population. It is difficult for obvious reasons of confidentiality, to obtain a list of persons with HIV/AIDS for random selection into a study. However, once subjects are identified as willing to participate in the proposed study, then random assignment to a control or treatment group, education for example, can occur to increase generalizability of results. This was the technique used in a sample of 916 women at risk for HIV infection by Nyamathi and colleagues (1993).

Surprisingly, eligibility criteria were not clearly specified in most of the studies

reviewed. Catalan and colleagues (1996) reported inclusion criteria as "...HIV seropositive women receiving care for their HIV infection at the AIDS Unit" (p. 40). No eligibility requirements were expressed about age, psychiatric history, or stage of illness. "...those determined to be mentally and physically capable of completing a questionnaire" was the criteria given by Linn and colleagues (1995, p. 49). Characteristics of individuals who declined to participate, response rates, and attrition rates were not always described, but most investigators reported that their sample could not be considered representative of all women living with HIV infection.

With three exceptions (Linn et al., 1995; Nyamathi et al., 1993; Nyamathi et al., 1996), a majority of the studies that address women-specific issues and HIV reported small ( $n < 30$ ) sample sizes. If one adheres to a positivistic view, a small sample size decreases power and makes it difficult to explain, control, or predict women's responses to HIV infection with few data points on any variable. Nonetheless, what is noteworthy is that there appears to be an attempt to include more African American and Latina women in these investigations, compared to studies from the 1980s and early 1990s.

Most of the studies consisted of poor women. This might be a limitation of the studies or it may reflect the recognition of researchers that HIV-infected women of lower socioeconomic levels are a vulnerable group with needs that demand attention from health the care system. The other possibility is that HIV-infected poor women are more accessible. If this is the case, then scientific caution should be exercised that these women are not exploited for the purposes of research.

Measures. Presentation of instruments was not comprehensive. Only one report (Linn et al., 1995) provided comprehensive information regarding reliability, validity, and response sets. Nannis et al. (1997) provided validity and reliability evidence by simply reporting that validity and reliability were “well-documented” and “established” for their measures (p. 8). It would have been more informative to report the type of indicator used to establish reliability (such as test-retest reliability or internal consistency reliability) and validity (such as content/face, concurrent, predictive, and/or construct validity). None of the researchers reported information regarding their measures' length, response rates, scoring, or pre-testing.

Despite these limitations, some progress has resulted from these studies to increase our understanding of how to better serve the physiological and psychosocial stressors of women with living with HIV/AIDS. While there are many methodological limitations and challenges for researchers to overcome, there are many opportunities for further research (see Table 1).

Table 1. Summary of the Literature's Major Strengths, Weaknesses, Opportunities and

Threats

Strengths	Weaknesses	Opportunities	Threats
<ul style="list-style-type: none"> <li>• Sufficient demographic &amp; epidemiologic background &amp; evidence to support observations that HIV epidemic is increasing among women, especially women of color.</li> <li>• Increasing number of studies done within the context of gender.</li> <li>• Some subgroup specificity among HIV-infected women.</li> <li>• Evidence of increasing support from NIH to include women &amp; ethnic minorities in studies.</li> <li>• Evidence that symptomatology &amp; psycho- social responses are different for HIV-infected women.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of comparative research between HIV+ and HIV-women.</li> <li>• Nonexperimental designs.</li> <li>• Small sample sizes.</li> <li>• Convenience sampling.</li> <li>• Limited generalizability.</li> <li>• Lack of theoretical linkages among variables specific to women.</li> <li>• Lack of valid and reliable measures that are specific and sensitive to changes in HIV-infected women.</li> <li>• Subject inclusion eligibility criteria not clearly delineated.</li> <li>• Lack of gender specific therapies.</li> </ul>	<ul style="list-style-type: none"> <li>• Continued building of the knowledge base regarding women with HIV/AIDS.</li> <li>• Determine the main &amp; interaction effects of HIV-infected women from different groups (e.g. lesbians, elderly &amp; menopausal women).</li> <li>• More culturally, socially &amp; economically relevant intervention designs to enhance HIV-infected women's quality of life and health status, especially gynecological problems.</li> <li>• Increase ethnic-minority &amp; underserved representativeness.</li> <li>• Building community, social networks &amp; resources.</li> </ul>	<ul style="list-style-type: none"> <li>• Confidentiality issues.</li> <li>• Recruitment/access.</li> <li>• Community resistance or declining cooperation.</li> <li>• Nonacceptance of research team.</li> <li>• Topic is of a sensitive nature.</li> </ul>

Gaps, Trends, and Implications

Several trends, gaps and implications are revealed from a review of the literature related to women living with HIV/AIDS. First, researchers continue to study HIV-infected women as a homogeneous group. As previously mentioned, HIV-positive women are a socially, culturally and economically diverse group. They have diverse needs and issues, and probably would benefit from group-specific interventions (lesbians, physically challenged, mentally impaired, sex workers, women living in rural settings,



homeless women, transgendered, ethnic-minority, poor women, battered, menopausal and perimenopausal, elderly, uneducated and well-educated, stage of HIV disease progression). For example, no studies were found that addressed treatment and support for lesbian with HIV infections. Because data on sexual identity were not included for most published studies on HIV infection in women, distinctions between identity (as lesbian, bisexual, or heterosexual) and practice (sex with women, with men, or both) have been blurred. These distinctions may matter, since women who identify as lesbian may have experiences of social isolation and discrimination in addition to those resulting from class, gender and racial/ethnic position (Zierler & Krieger, 1997).

Second, within the realm of symptom experiences of HIV-infected women, researchers tend to focus almost exclusively on gynecological problems, because it is an obvious area of difference between women and men. Few prescriptions are offered for problems such as sleep disturbance, fatigue, symptom management of HIV-infected women, alternative and complementary therapies or other therapies to decrease viral load and symptomatology in women. "Although human immunodeficiency virus disease is increasing rapidly among women, no prior studies have investigated gender-based therapeutic strategies for the treatment of acquired immunodeficiency syndrome and its complications in this population" (Miller et al., 1998, p. 2717). Intervention research regarding HIV/AIDS tends to focus on prevention of HIV infection or prevention of vertical transmission to infants with zidovudine therapy, rather than on the symptomatology of women living with HIV/AIDS. In addition, there is a need for

continued efforts to explain biological mechanisms to reduce susceptibility and develop effective vaccines and therapies to reduce viral replication in not only men, but women as well, especially for the reduction of vertical transmission of HIV.

The most frequently explored psychosocial responses to HIV infection in women were stigma, depression, social isolation, concerns regarding children and disclosure to significant others. There has been a considerable effort to include more HIV-infected women in research studies. However, the impact of these stress-related concepts that may be gender specific have not been examined fully in HIV-infected women. For example, given that spirituality/religiosity is a strong influence and sustaining source of support in the social and personal lives of most women, (especially African American and Latina women , Arp & Boeckelman, 1997), a third gap in the literature pertains to the lack of attention given to religiosity/spirituality and other "strength" variables among HIV-infected women. Moreover, a tendency to report HIV-positive women as victims is underscored by the lack of investigations on "strength" variables, such as resilience, motivation, spirituality, hardiness, resourcefulness, cultural beliefs, cultural practices, and other related concepts that empower women to have adaptive outcomes times of crises (Belenky, Clinchy, Goldberger, & Tarule, 1986). These are areas in need of further investigation.

A fourth and final gap in the existing literature is that the interaction effects of HIV and the aging process are not fully understood in HIV-positive women. For example, while women of childbearing years (25 to 44) continue to become infected with HIV at

alarming rates, it is not unusual for an infected person to show symptoms as long as 15 years after infection. If there continues to be no cure for HIV infection, these women will grow into middle age with the concomitant symptoms associated with menopause. Stressors of importance to older HIV-infected women need to be explored longitudinally. A potential stressor over the course of these women's lives, whether short-lived or prolonged, is the ever-growing number of children who may be orphaned, estimated to be as high as 125,000 to 150,000 children by the year 2000 (Michaels & Levine, 1992).

For many women, being seropositive has been life enhancing (personal communication Pricilla Abercrombie and Catherine Lyons, April 22, 1998). For the first time in years these women are drug and alcohol free; they have established and sustained relationships with their children; and they are loving and taking care of themselves. They do not perceive themselves as victims. It is clear from the literature review that classism, ethnicity, and gender are stressors that affect the lives of HIV-infected women, both physiologically and psychologically. Although forthcoming, the paucity of data-based studies that describe the form and nature of stress for women living with HIV/AIDS prevents the framing of research that can influence health policy. There is much more research that is needed to validate the stressors of women living with HIV/AIDS (see Table 2). Emerging patterns that potentially threaten the public's health should be identified, and appropriate interventions should be planned, coordinated, implemented, tested, and evaluated in collaboration with the personal lives affected by HIV.

Table 2. Summary of the Literature's Gaps, Trends and Implications

Gaps & Trends	Implications
<p><u>Gap 1.</u> Researchers continue to explore HIV-positive women as a homogenous group (lesbians, physically challenged, mentally impaired, sex workers, women prisoners, women living in rural settings, homeless women, transgendered, ethnic-minority, poor women, battered, menopausal &amp; perimenopausal, elderly, uneducated &amp; well-educated, HIV stage progression).</p>	<p>Lack of cultural specificity and diversity in the design of research is thought to be a potential major factor in less frequent participation in ethnic-minority populations. Human responses need to be studied within the social context and from the vantage point of the persons targeted in order to better understand their actions and practices (emic view).</p>
<p><u>Gap 2.</u> As far as physiologic responses of HIV-infected women, researchers tend to focus on gynecological problems. Little prescriptions are offered in terms of sleep disturbance, fatigue, functional status enhancement, symptom management of HIV-infected women, or for vaccines &amp; therapies that reduce viral replication in women and minimize the vertical transmission of HIV.</p>	<p>Researchers concur on the importance of the need to understand the physiological responses of HIV-infected women, but not on the particular analytic, conceptual &amp; prescriptive strategies that should inform such a perspective. There is a need for continued efforts to explain biological mechanisms to reduce susceptibility.</p>
<p><u>Gap 3.</u> Lack of investigations on "strength" variables, such as resilience, motivation, spirituality, hardiness, resourcefulness, cultural beliefs and practices, &amp; related concepts that empower HIV-infected women.</p>	<p>These are the variables/concepts that represent the socioconscious architecture of nursing the ability to deal with human responses holistically.</p>
<p><u>Gap 4.</u> Lack of investigations that look beyond the immediate concerns of HIV-infected women, e. g., the interaction effects of HIV and the aging process, orphaned children of HIV-infected women.</p>	<p>A sensitive &amp; accurate database on the longitudinal effects of HIV infection on the normative developmental process of HIV-infected women &amp; their children is critical to the design, implementation &amp; evaluation of appropriate and relevant interventions.</p>

## Chapter III

### Methodology

#### Study Design

This chapter presents the study design for this secondary analysis. Incorporated into the study design are the purpose of the study, aims of the study, research questions, study hypotheses, sampling technique, inclusion/exclusion criteria, data collection procedures, measures, and analysis plan.

The study used a descriptive, comparison design to explore the stressors and functional status in a secondary analysis on a sample of 105 HIV-positive women and a sample of 45 HIV-negative women in two separate studies.

#### Purpose

The purpose of this study was to describe perceived stress and types of stressors experienced by a group of HIV-positive and HIV-negative women and to describe their functional status in relationship to various components of their symptom and stress experience.

#### Aims of the Study

Aim 1: To describe the self-reported stressors in a sample of HIV-positive and HIV-negative women. There were five research Questions for Aim 1:

1.1 Is there a significant difference in the number of stressors self-reported by HIV-positive and HIV-negative women?

1.2. Is there a significant difference in the number of symptoms self-reported by

HIV-positive and HIV-negative women?

1.3. Is there a significant difference in the level of sleep disturbance self-reported by

HIV-positive and HIV-negative women?

1.4. Is there a significant difference in other types of stressors self-reported by

HIV-positive and HIV-negative women?

1.5. Is there a significant difference in the perception of stress between HIV-positive and

HIV-negative women?

**Aim 2: To describe the functional status of a sample of HIV-positive and HIV-negative women. There were two research questions for Aim 2:**

**2.1 Are there significant differences in functional status related to self-care activities and household chores between HIV-positive and HIV-negative women?**

**Aim 3: To explore the relationship between stressors and functional status in a sample of HIV-positive and HIV-negative women. The research question for Aim 3 was**

**3.1 Is there a relationship between level of functional status and stressors that include 1) ethnicity, 2) income, 3) age, 4) hemoglobin, 5) sleep disturbance, 6) number of symptoms, 7) level of perceived stress, and 8) time since HIV-positive diagnosis?**

### Sample

Data for this secondary analysis were obtained from two previously funded NIH studies of women's sleep and fatigue. In one study, a convenience sample of 100 ethnically diverse women with HIV were recruited from the San Francisco Bay Area, outpatient clinics, a group home for women recovering from substance abuse, and

snowball technique (NRO3969, 1994-1997). Data on perceived stress, types of stressors, symptom stress, sleep disturbance, and functional status were obtained from this sample.

The second sample was obtained from a longitudinal study of 45 HIV-negative women. This sample was used for comparative purposes. Data on perceived stress, types of stressors, symptom stress, sleep disturbance, and functional status were obtained from an NIH-funded study of healthy women recruited for a longitudinal study of sleep and fatigue during pregnancy (NRO2247, 1989-1994). Subjects were recruited from advertisements placed in consenting obstetricians' offices and in local Bay Area newspapers. Letters of institutional support and approval by the UCSF Committee on Human Research (CHR) were given to the principal investigator, Kathryn Lee, Ph.D., R.N. (CHR# H5464-03699 and #H5464-10510 for both of these studies).

### Power Analysis

From the review of literature in Chapter II, adequate power for determining statistical significance can be based on a medium effect size. Anderson (1995) found a medium effect ( $r = .30, p < .05$ ) between stress (threat appraisal) and activity disruption (functional status) in a sample of 50 HIV-positive women. Therefore, assuming medium effect sizes for the hypotheses, a sample of over 50 women per group will provide adequate power (.80) to demonstrate statistically significant differences between the two groups and significant relationships between variables. According to Thorndike (1978), a rudimentary technique for estimating the minimum sample size for multivariate analyses is 10 subjects per variable, plus 50 additional subjects. For the final hypothesis involving

eight variables, 100 subjects will be sufficient for a statistically significant  $R^2$  (Cohen, 1988).

### Inclusion/Exclusion Criteria

Eligibility criteria for inclusion of HIV-positive women were: a) 18 years or older, b) able to understand and sign an English consent form, c) HIV positive, 4) no diagnosis of AIDS-related dementia, 5) no moderate (Grade II) or severe neuropathy, and 6) no prior hospitalization within the last week. Eligibility criteria for HIV-negative women were: a) women are 18 years or older, b) planning to get pregnant in the next year, c) no history of infertility, miscarriage, chronic health conditions, psychiatric illness or sleep disturbance.

### Data Collection Procedures

Potential participants who were HIV-positive were accessed through their health care provider at the four clinic sites. During a clinic visit, the research assistant asked the health care provider to inform potential participants about the study. If the potential participant expressed interest in the study, she met with the research assistant who reviewed the purpose, nature, risks, and benefits of the study and obtained informed consent. In addition, potential subjects were recruited through Restoration House, a group home for women recovering from substance abuse. To maintain confidentiality and anonymity, potential subjects from the group home were asked to call the research assistant or principal investigator if they were interested in participating in the study.

Potential subjects in both studies met with the research assistant who explained the



participants were enrolled and completed the questionnaires. In addition, HIV-positive participants presented the most recent CD4 t-lymphocyte count based on their current laboratory report. All participants in both studies completed a two-day diary during the two days that their sleep was monitored. The two-day diary asked for information about their sleep, activity level, presence or absence of stress, and symptoms (see Appendix A for questionnaires).

Participants met with the research assistant or principal investigator in a private office to complete the necessary demographic information and variable questionnaires. The research assistant or principal investigator was present to answer any questions from participants. The instruments took approximately 45 minutes to complete.

### Variables and Instruments

The Transactional Model of Stress and Coping guides the study by addressing variables in three areas: person, environment, and health.

Person. *Socio-demographic variables* were defined as age, ethnicity, income, marital status, education, CD4 T-lymphocyte count, time since HIV-positive diagnosis, hemoglobin count (normal vs. abnormal), and religious affiliation. These variables were assessed on interview with a similar questionnaire devised for both samples (see Appendix B for instruments).

Environment. According to the model, the relationship between the individual and the environment can be appraised as taxing, demanding, or burdensome. This appraisal is an indicator of *perceived stress*. For the purpose of this study, level of perceived stress was measured on a single-item 100 mm visual analog line with seven other lines measuring

was measured on a single-item 100<sub>mm</sub> visual analog line with seven other lines measuring energy, well-being, fatigue, health, sleepiness, and anxiety. The single-item visual analogue line ranged from 0<sub>mm</sub> (no perceived stress) to 100<sub>mm</sub> (high perceived stress). Subjects also were asked to indicate whether or not they experienced stress during a two-day period and to report the specific stressor in a personal diary. Participants completed the diary in the evening before going to sleep and in the morning upon their final awakening for two days.

*Symptom Stress* is conceptualized as the frequency with which study participants experience somatic responses. These somatic responses incorporate physical (night sweats) as well as psychological (anxiety) symptoms. Symptom stress was measured by the General Health Questionnaire (Lee, 1992). The GHQ is a 36-item instrument that assesses the type and frequency of a symptom. Responses can range from 0 (never) to 7 (every day). The higher the score, the more frequent the symptom is experienced. Test-retest reliability estimates are not reported since symptoms can change over time; internal consistency reliability is not reported since each symptom is unique and not necessarily interrelated to another sign or symptom.

Symptom stress also encompasses sleep disturbance as a stressor or as a response to stress. Sleep disturbance stress was measured by the General Sleep Disturbance Scale (GSDS), a 21-item questionnaire that addresses aspects of sleep disruption and daytime sleepiness within the past week (Lee, 1992). Item examples are “have difficulty getting to sleep”, “sleep poorly”, and “feel sleepy during the day”. Responses range from 0 “never”

to 7 “every day”. Scores can range from 0 to 147, with a higher score indicating more sleep disturbance. Validity for the instrument was established in a study of 760 employed women (Lee, 1992), where the mean sleep disturbance score for day workers was 47.3 (SD=13.8), and the mean sleep disturbance score for night workers was 60.5 (SD=16.3). Cronbach’s alpha for the GSDS was .88 in a study of sleep disturbance among 266 midlife women (Lee & Taylor, 1996).

**Health.** *Functional status* is the health outcome variable that refers to the ability to perform self-care activities, household chores, errands, and shopping. These attributes of functional status were measured with Parts I and III of the Inventory of Functional Status (IFS) developed by Fawcett, Tulman, and Myers (1988). Compared to men, women are socialized to care for their home and their children. In addition, women of color tend also to be more involved in kinship care of relatives’ children (Bing & Soto, 1991). The model would stipulate, therefore, that the ability to care for home and children, along with self-care is an adaptational health outcome for women.

Part I of the IFS consists of a 12-item Household Activities subscale that assesses the extent to which participants were engaged in household responsibilities, such as caring for family members, cleaning, doing laundry, cooking, or washing dishes. Item responses are 1 “never”, 2 “sometimes”, 3 “most of the time”, and 4 “all the time”. Scores range from 12 to 48 on the Household Activities subscale; a high score indicates higher functioning related to performing household chores.

Part III of the IFS consists of the 8-item Self-Care subscale, which asks women to

rate the extent to which they performed self-care activities during the past week or two: walking, standing, climbing stairs, sitting, reclining, sleeping, and dressing. Item examples include “Spend much of the day lying down”, “Take walks”, and “Spend much of the day in my bathrobe or night clothes”. Responses include 1 “never”, 2 “sometimes”, 3 “most of the time”, and 4 “all the time”. Scores on this subscale range from 8 to 32, and a higher score indicates lower self-care functioning. Fawcett et al. (1988) reported adequate content validity for this instrument, and Cronbach’s alpha was .76 for the total scale. Items 1, 2, 3, 4, 5, and 8 on the Self-Care subscale will be reverse-coded such that a higher score indicates higher functioning. For a multidimensional measure of functional status, the Self-Care subscale and the Household Activities subscale will be analyzed separately for Aim 2 and combined into one outcome measure of functional status for Aim 3. Scores can range from 20 to 80; the higher the score the better the individual’s functional status. This functional status measure will be evaluated for internal consistency reliability using Cronbach’s alpha prior to analysis of Aim 3.

## Hypotheses and Data Analyses

### Research Questions for study Aim 1:

1.1. Is there a significant difference in the proportion of HIV-positive women who report the incidence of stress in a two-day period compared to the proportion of HIV-negative women who report stress in the same period?

1.2. Hypothesis 1.1: There will be a significant difference in the proportion of HIV-positive

women who report the incidence of stress in a two-day period compared to the proportion of HIV-negative women who report stress in the same period.

**Data Analysis  $H_{1,1}$ :** The investigator will compare the proportion of HIV-positive women who report stress in the two-day diary to the proportion of HIV-negative women who report stress in the two-day diary. These two proportions of women will be analyzed using Chi-square for the difference in the proportion of each group who self-report stressors on one or both days.

1.2 Is there a significant difference in the number of symptoms self-reported by HIV-positive and HIV-negative women?

**Hypothesis  $H_{1,2}$ :** There will be a significant difference in the number of symptoms self-reported by HIV-positive and HIV-negative women.

**Data Analysis  $H_{1,2}$ :** An unpaired t-test will be conducted to test the difference in mean number of symptoms on the General Health Questionnaire between HIV-positive and HIV-negative women.

1.3 Is there a significant difference in the level of sleep disturbance self-reported by HIV-positive and HIV-negative women?

**Hypothesis  $H_{1,3}$ :** There will be a significant difference in the level of sleep disturbance self-reported by HIV-positive and HIV-negative women.

**Data Analysis  $H_{1,3}$ :** An unpaired t-test will be conducted to test the difference in the mean level of sleep disturbance on the General Sleep Disturbance Scale between HIV-positive and HIV-negative women.

1.4 Is there a significant difference in other types of stressors self-reported by HIV-positive and HIV-negative women?

Hypothesis<sub>1.4</sub>: There will be a significant difference in “types” of stressors self-reported by HIV-positive and HIV-negative women.

Data Analysis H<sub>1.4</sub>: To ascertain “types” of stressors, stressors self-reported in the subjects’ diary data will be coded as follows: 1 “work-related stress”, 2 “education-related stress”, 3 “schedule-related stress”, 4 “spouse-related stress”, 5 “family-related stress”, 6 “financial-related stress”, 7 “children-related stress”, and “Other” stressors. The investigator’s adviser will conduct a random check of 10% of the diaries to ascertain agreement (inter-rater reliability) with the stressor category. If agreement is not greater than .90, both raters will discuss discrepancies and reach consensus on the coding category to be used in the analysis. A Chi-square test will be performed to test the difference in prevalence for “type” of stressor self-reported by group (HIV-positive vs. HIV-negative) status. If statistical significance is obtained, the *phi* coefficient will provide the percent of explained variance in the group by each stressor.

1.5 Is there a significant difference in the perception of stress between HIV-positive women and HIV-negative women?

Hypothesis<sub>1.5</sub>: There will be a significant difference in the level of perceived stress self-reported by HIV-positive women and HIV-negative women.

Data Analysis H<sub>1.5</sub>: Level of perceived stress is measured on a single-item visual analogue

scale ranging from 0<sub>mm</sub> (no perceived stress) to 100<sub>mm</sub> (high perceived stress). The mean difference in mean level of perceived stress between HIV-negative and HIV-positive women will be analyzed by unpaired t-test.

**Research Question for study Aim 2:**

Are there differences in functional status related to self-care or household activities between HIV-positive and HIV-negative women?

**Hypothesis** <sub>2,1</sub>: There will be a significant difference in self-care and household activities between HIV-positive and HIV-negative women.

**Data Analysis**  $H_{2,1}$ : Unpaired t-tests will be performed to test the differences in mean level of self-care activities and mean level of household activities between HIV-positive and HIV-negative women.

**Research Question for study Aim 3:**

Is there a relationship between level of functional status and stressors that include 1) ethnicity, 2) income, 3) age, 4) hemoglobin (normal vs. abnormal), 5) sleep disturbance, 6) number of symptoms, 7) perceived stress, and 8) time since HIV-positive diagnosis (0 to 10 or more years)?

**Hypothesis** <sub>3,1</sub> Ethnicity, income, age, hemoglobin (low vs. normal), level of sleep disturbance, number of symptoms, level of perceived stress, and time since HIV-positive diagnosis will be significantly related to the total functional status score (self-care plus household activities).

**Data Analysis**  $H_{3,1}$ : Pearson Product Moment correlations will be performed to identify

significant zero-order correlations among continuous variables of age, income, sleep disturbance, number of symptoms, level of perceived stress, and functional status. Time since HIV-positive diagnosis will be coded in years diagnosed as a categorical variable. For example, HIV-positive women diagnosed less than one year will be category 1. Category 2 will be women diagnosed one to five years, and category 3 will be women diagnosed greater than five years. Differences in mean functional status by hemoglobin group (low vs. normal ) will be analyzed by unpaired t-test. Differences in functional status by ethnic group and time since HIV diagnosis will be analyzed by analysis of variance. If statistical significance is obtained, *eta squared* will provide the percent of explained variance in total functional status scores. Only those variables significantly related to total functional status will be entered into a regression analysis to test this hypothesis. If mean total functional status scores differ by ethnicity and time since HIV diagnosis, these variables will be dummy-coded for the regression analysis. Significance will be set at  $p < .01$ , with the expectation that 30% of the variance in total functional status scores will be explained by up to eight predictor variables.

### Potential Risks and Benefits

There were no anticipated physical risks to participants. No subject refused to participate in either original study. Any emotional risks were associated with the questionnaires that focused attention on HIV seropositive status, depression, or stress. Maintaining confidentiality might have been a concern for women residing at Restoration House, since the program was for women involved in substance abuse recovery.



Snowball sampling technique occurred in both studies. Response burden was minimal.

Participants did not express any complaint about completing the questionnaires. At completion of the questionnaires, participants expressed their appreciation about being a part of the study. Some participants requested to be contacted again for involvement in future research. Participants in both original studies received \$25.00 for each two-day component of the study. \_

## Chapter IV

### Results

This chapter presents the results of the secondary data analysis. These results include sample demographics, Chi Square tests, non-parametric tests, t-tests, correlation, and regression analysis. This secondary analysis comprises a sample of 46 HIV-negative women and 104 HIV-positive women. The sample size of HIV-positive women differs on some of the instruments, such as the General Health Questionnaire (GHQ) and the General Sleep Disturbance Scale (GSDS), because the study on HIV-infected women was conducted in two phases. During the first phase, HIV-positive participants did not complete these questionnaires. Therefore, the first 75 subjects did not complete the General Health Questionnaire and the General Sleep Disturbance Scale. Finally, a discussion of the psychometric properties of all instrument, including the Inventory of Functional Status (IFS), will be presented.

### Sample Characteristics

The mean age for the total sample was 36.3 years (SD= 7.46). The mean age for HIV-positive women was 38.3 years (SD=7.72) and significantly higher than the mean age for HIV-negative women, which was 31.8 years (SD= 4.21). HIV-negative women had significantly higher income and educational levels than HIV-positive women. The majority (56%) of HIV-positive participants were African American, while the majority (87%) of HIV-negative participants were Caucasian (see Table 3 for sample description). The two groups were significantly different on the variables of age, income, ethnicity,

education, and employment status. These variables were controlled in the statistical analysis, if they correlated significantly with outcome variables of perceived stress, number of symptoms, sleep disturbance, or functional status.

Table 3  
Sample Characteristics by HIV Status

<u>Variable</u>	<u>HIV-Positive</u>	<u>HIV-Negative</u>	<u>Test/p-value</u>
	<u>Mean (SD)</u>	<u>Mean (SD)</u>	
<u>Age</u>	38.32 (7.72)	31.78 (4.21)	$t = 6.68, p < .001$
<u>CD4 Count</u>	338.56cells/mm <sup>3</sup> (240.55)	N/A	N/A
<u>Hemoglobin</u>	14.16 (6.73)	13.72 (.640)	
<u>Time since HIV dx</u>	N (%)	N (%)	
Less than 1 year	11 (11.3)	N/A	
One to five years	49 (50)	N/A	
Greater than five years	<u>38 (38.7)</u>	N/A	
Total	98 (100)	N/A	
<u>Low Hgb (less than 10g/dl)</u>	3 (.04)	0 (0)	
<u>Ethnicity</u>			$\chi^2 = 66.54, p < .001$
African American	61 (57)	0 (0)	
Caucasian	30 (28)	40 (87)	
Hispanic	13 (12)	1 (2.2)	
Other	<u>0 (0)</u>	<u>5 (10)</u>	
Total	104 (97)	46 (100)	

Table 3  
Sample Characteristics by HIV Status (continued)

<u>Variable</u>	<u>HIV-Positive</u>	<u>HIV-Negative</u>	<u>Test/p-value</u>
	N (%)	N (%)	
<b><u>Income</u></b>			$\chi^2 = 96.09, p < .001$
Less than \$10,999	81 (75.7)	3 (6.5)	
\$11,000-\$24,999	21 (19.6)	6 (13)	
Greater than \$25,000	<u>5 (4.7)</u>	<u>37 (80.4)</u>	
Total	107	46	
<b><u>Education</u></b>			$t = 9.42, p < .001$
Some high school	30 (30)	0 (0)	
Completed high school	61 (61)	14 (30.4)	
Attend college	6 (6)	0 (0)	
Completed college	2 (2)	18 (39.2)	
Completed graduate school	<u>0 (0)</u>	<u>14 (30.4)</u>	
Total	99 (99)	46 (100)	
<b><u>Employment Status</u></b>			$\chi^2 = 82.68, p < .001$
Employed	15 (14.5)	40 (87)	
Unemployed	<u>89 (85.5)</u>	<u>6 (13.0)</u>	
Total	104	46	

Table 3  
 Sample Characteristics by HIV Status (continued)

<u>Variable</u>	<u>HIV-Positive</u>	<u>HIV-Negative</u>	<u>Test/p-value</u>
	<u>N (%)</u>	<u>N (%)</u>	
<u>Religious Preference</u>			N/A
None	21 (19.6)	10 (21.8)	
Protestant	52 (48.6)	14 (30.4)	
Catholic	23 (21.5)	14 (30.4)	
Jewish	1 (.9)	4 (8.7)	
Other	<u>8 (7.5)</u>	<u>4 (8.7)</u>	
Total	105 (98.1)	46 (100)	

### Incidence of Self-Reported Stressors

Subjects were asked to report whether or not they had experienced stress in a two-day diary (see Table 4). On day one, HIV-positive women differed significantly in the proportion of respondents who reported stress compared to HIV-negative women. Compared to 25% of HIV-negative women, 50% of HIV-positive women reported they had experienced stress that day ( $\chi^2 = 7.36, p = .007$ ). However, on day two, there was no significant difference in the proportion of HIV-positive (35%) and HIV-negative (34%) women reporting stress ( $\chi^2 = .009, p = .92$ ). When the days were combined to determine if there was a significant difference between the two groups on “total stress”, to incorporate stress on either day, 30% of HIV-positive and 23% HIV-negative women reported stress. The difference in proportions was not significant ( $\chi^2 = 2.12, p = .35$ ).

Table 4

#### Incidence of Stress in Women During Two-day Diary Period by HIV Status

	HIV-negative	HIV-positive	$\chi^2$
Stress on Day 1	25%	50%	7.36*
Stress on Day 2	35%	34%	NS
Stress on Both days	30%	23%	NS

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\*  $p = .007$

### Visual Analogue Measure of Level of Perceived Stress

It was hypothesized that HIV-positive women would report a significantly higher level of perceived stress. Level of perceived stress was measured on a single-item visual analogue line, ranging from 0<sub>mm</sub> (no stress) to 100<sub>mm</sub> (high perceived stress). The mean level of perceived stress for HIV-positive women was 55.68<sub>mm</sub> (SD = 31.85); the mean level of perceived stress for HIV-negative women was 45.95<sub>mm</sub> (SD = 22.82). Although HIV-positive reported higher perceived stress, their mean level of perceived stress did not differ significantly from the mean level of perceived stress reported by HIV-negative women (see Table 5).

When the visual analogue line was divided and re-coded into “low perceived stress” (0<sub>mm</sub> to 33<sub>mm</sub>), “moderate perceived stress” (34<sub>mm</sub> to 66<sub>mm</sub>), and “high perceived stress” (67<sub>mm</sub> to 100<sub>mm</sub>), a majority (75.6) of HIV-negative women were in the low to moderate perceived stress categories. On the other hand, a majority (48.4%) of HIV-positive women were in the “high perceived stress” category compared to HIV-negative women (24.4%). Table 6 presents the difference in proportions of HIV-positive women and HIV-negative women in these categories, which were significant ( $\chi^2 = 7.27, p = .03$ ).



Table 5  
Visual Analogue Measure of Level of Perceived Stress Between HIV-positive and HIV-negative Women (n=71)

Variable	Group	Mean	SD
Level of Perceived			
Stress	HIV-negative (n=41)	45.95	22.82
	HIV-positive (n=30)	55.68	31.85

$t = 1.44, p = .16$

Mean difference = 9.73

Table 6  
Categories of Perceived Stress by HIV Status

	HIV-negative women	HIV-positive women
Low perceived stress	31.7%	35.5%
Moderate perceived stress	43.9%	16.1%
High perceived stress	24.4%	48.4%

$\chi^2 = 7.27, p = .03$

Cramer's  $V = .32$

Type of stressors: In addition to being asked to report in the two-day diary whether or not they had experienced stress, women also were asked to report the type of stressors they experienced. There were eight categories of stressors, including “other”. Categories were “work-related”, “family-related”, “partner-related”, “child-related”, “financial-related”, “education-related”, “schedule-related”, and “other”. Tables 7 through 14 present each stressor category by group.

Based on self-reported types of stressors from the two-day diary, HIV-positive and HIV-negative women differed significantly only on self-reported categories or types of stressors related to “education” and “other” sources of stress. More HIV-negative women reported stress in the education category. What was more interesting was the category of “other” stressors, reported by significantly more HIV-positive women. For example, HIV-positive women reported more stress concerning their children’s school work, behavioral problems, or their own anxiety about not being able to see their children more frequently. Within the “other” category of self-reported stressors, one HIV-positive woman had been in a car accident; other subjects reported feeling overwhelmed by symptoms, such as “frequent headaches”, “worrying”, or “feeling tired and sick”. More examples of self-reported stressors by HIV-positive women were:

# 53: “I made a decision to quit work due to fatigue and blood work results.”

# 65: “Disrespected by the doctor and medical staff.”

# 67: “Went to the pharmacy to get meds at 1 p.m. and was told Medi-Cal cut down on Bactrim-PCP prophylaxis to 14 pills and is making everyone come in on the 15<sup>th</sup> day for 14 more two times a month instead of once a month and 30 pills.”

# 78: "One of my friends is having man problems, and she always wants to tell them to me. This is right before I go to bed."

# 82: "I lost my patience today. I didn't want to hang at the doctor's office any longer."

# 77: "Indescribable stress."

Table 7

Cross-Tabulation of Work-Related Stress on Day 1 or Day 2 by Group

Variable				Totals
Work-Related		HIV-positive	HIV-negative	
Stress	Present	6 (5.9%)	5 (11.4%)	11
	Absent	96 (94.1%)	39 (88.6%)	135
Total		102	44	146

$$\chi^2 = 1.33, p = .25$$

Table 8

Cross-Tabulation of Schedule-related Stress on Day 1 or Day 2 by Group

Variable				Totals
Schedule-Related		HIV-positive	HIV-negative	
Stress	Present	2 (1.9%)	4 (9.0)	4
	Absent	100 (98%)	42 (95.5%)	142
Total		102	46	146

$$\chi^2 = 3.97, p = .046$$

Table 9

Cross-Tabulation of Education-Related Stress on Day 1 or Day 2 by Group

Variable	Totals		
Education-Related Stress	HIV-positive	HIV-negative	
Present	0 (0%)	5 (11.4%)	5
Absent	102 (100%)	39 (88.6%)	141
Total	102	44	146

$$\chi^2 = 12.00, p = .001$$

Table 10

Cross-Tabulation of Spouse/Partner-Related Stress on Day 1 or Day 2 by Group

Variable	Totals		
Spouse/Partner-Related Stress	HIV-positive	HIV-negative	
Present	6 (5.9%)	1 (2.3%)	7
Absent	96 (94.1%)	43 (97.7%)	139
Total	102	44	146

$$\chi^2 = .877, p = .35$$

Table 11

Cross-Tabulation of Family-Related Stress on Day 1 or Day 2 by Group

Variable			Totals	
Family-Related Stress		HIV-positive	HIV-negative	
	Present	4 (3.9%)	2(4.5%)	6
	Absent	98 (96.1%)	42(95.5%)	140
Total			146	

$$\chi^2 = .03, p = .86$$

Table 12

Cross-Tabulation of Financial-Related Stress on Day 1 or Day 2 by Group

Variable			Totals	
Financial-Related Stress		HIV-positive	HIV-negative	
	Present	4 (3.9%)	1 (2.3%)	5
	Absent	98 (96.1%)	43(97.7%)	141
Total			146	

$$\chi^2 = .25, p = .62$$

Table 13

Cross-Tabulation of Children-Related Stress on Day 1 or Day 2 by Group

Variable			Totals	
Children-Related Stress		HIV-positive	HIV-negative	
	Present	9 (8.8%)	1 (2.3%)	10
	Absent	93 (91.2%)	43(97.7%)	136
Total		102	44	146

$$\chi^2 = 2.07, p = .15$$

Table 14

Cross-Tabulation of "Other"-Related Stress on Day 1 or Day 2 by Group

Variable			Totals	
"Other"-Related Stress		HIV-positive	HIV-negative	
	Present	32 (31.4%)	1 (2.3%)	33
	Absent	70 (68.6%)	43 (97.7%)	113
Total		102	44	146

$$\chi^2 = 16.98, p < .001$$

$$\text{phi coefficient} = .34$$

### Symptoms as Stressors

Because the sample distribution of self-reported symptom frequencies differed markedly from a normal distribution, the Mann-Whitney U test was conducted to evaluate group differences by rank. The frequency of self-reported symptoms is shown in Table 16 for both groups of women, such as night sweats and various types of pain. Several symptoms were significantly more frequent for HIV-positive women compared to HIV-negative women.

Women were asked to indicate the frequency with which they experienced 33 different symptoms during the past week, from 0 (never) to 7 (everyday/always). The mean number of actual symptoms reported by HIV-negative women was 4.8 (SD= 2.6). The mean number of symptoms reported by HIV-positive women was 14.5 (SD= 7.6). The number of symptoms was related to age, income, education, ethnicity, and employment. HIV-positive women and HIV-negative women still differed significantly in their number of symptoms after controlling for these variables ( $F[6, 78] = 11.37, p < .001$ ). Forty-nine percent of the variance in number of symptoms is explained by group membership.



Table 15

ANOVA on the Number of Symptoms by Group (controlling for age, income, education, ethnicity, and employment)

Variable	Group	Mean	SD	Confidence Interval	$\eta^2$
Number of	HIV-negative (n=46)	4.8	2.6	(8.01-10.62)	.49
	HIV-positive (n=57)	14.5	7.6		

Mean difference = 9.65

$F[6, 78] = 11.37, p < .001$

**Table 16**  
**Average Frequency of Self-Reported Symptoms by HIV-Positive and HIV-Negative Women •**

	HIV-positive			HIV-negative			Mann-Whitney
	N	Mean	SD	N	Mean	SD	
Back pain	30	3.37	2.46	43	2.09	2.69	448. **
Night sweats	30	3.07	2.60	46	.39	.98	254. **
Urinary frequency At night	30	3.07	2.26	46	2.39	2.42	556.5 *
Headaches	28	2.93	2.55	43	1.58	1.98	422.5*
Joint pain	30	2.80	2.43	43	.77	2.07	316.5 **
Hay fever	28	2.83	2.80	43	1.63	2.51	450.5
Constipation	29	2.66	2.39	43	.47	.85	275 **
Leg cramps	28	2.64	2.50	43	.21	.74	250 **
Shortness of breath	28	2.50	2.25	43	.093	.43	210.5**
Muscles weakness	28	2.50	2.53	43	.047	.30	244.5**
Vision	30	2.30	2.37	43	.02	.15	265.5**
Hearing	30	2.27	2.59	43	.09	.48	265.5**
Heartburn	30	2.23	2.30	43	.33	.78	319**
Skin/Nails	30	2.03	2.33	43	1.58	2.96	492

• Range is from 0 “never” to 7 “always”

\*  $p < .05$ , \*\*  $p < .001$

**Table 16**  
**Average Frequency of Self-Reported Symptoms by HIV-Positive and HIV-Negative Women •**  
**Continued**

	HIV-positive			HIV-negative			Mann-Whitney
	N	Mean	SD	N	Mean	SD	
Abdominal pain	30	1.97	2.20	43	.14	.47	316.5**
Nausea & Vomiting	30	1.67	1.99	43	.26	.54	365**
Allergic skin reactions	28	1.54	2.30	43	.72	1.78	475
Dizzy spells	28	1.43	2.17	43	.06	.26	352.5**
Diarrhea	30	1.40	1.85	43	.63	1.05	519
Abdominal Distention	29	1.38	1.82	43	.14	.47	385**
Hemorrhoids	30	1.00	2.23	43	.09	.29	544.5
Sore throat	28	.82	1.28	43	1.02	1.28	523
Bladder infection	30	.80	1.61	44	.14	.77	492.5**

• Range is from 0 “never” to 7 “always”

\*  $p < .05$ , \*\*  $p < .001$

Symptom stress was further explored by asking participants to complete the General Sleep Disturbance Scale (GSDS). Table 17 illustrates the results. It was hypothesized that there would be a significant difference between HIV-positive and HIV-negative women in sleep disturbance. The range of scores on the GSDS is from 0 to 147. Findings show that the mean score for HIV-positive women was 64.8 (SD= 21.2); the mean score for HIV-negative women was 22.96 (SD=11.2). There was a statistically significant difference between these two groups on their mean sleep disturbance scores even after controlling for age, ethnicity, income, education, and employment ( $F[6, 101] = 24.00, p < .001$ ).

Table 17  
ANOVA on the General Sleep Disturbance by HIV Group, controlling for age, income, ethnicity, education, and employment.

Variable	Group	Mean	SD	Confidence Interval	$\eta^2$
Sleep Disturbance	HIV-negative (n=45)	22.96	11.2	(40.74-47.92)	.60
	HIV-positive (n=57)	64.8	21.2		

Mean difference = 41.83

$F[6, 101] = 24.00, p < .001$

### Instrument Analysis of the General Sleep Disturbance Scale

According to Polit and Hungler (1995), reliability coefficients above .70 are considered indicators of stability of instrument items. Reliability coefficients of the General Sleep Disturbance Scale for HIV-positive and HIV-negative women were .91 and .78, respectively (see Appendix A). These estimates demonstrate that the GSDS is a reliable and stable measure of sleep disturbance in HIV-positive and HIV-negative women. This study established construct validity with the GSDS by using the “known groups approach”, whereby a group hypothesized to score high (HIV-positive women) on the attribute of sleep disturbance did so.

### Instrument Analysis of Inventory of Functional Status

Two subscales of the Inventory of Functional Status (IFS) were used to obtain a parsimonious measure of functional status. Reliability analysis of The Household Activities and Self-Care subscales of the Inventory of Functional Status (Fawcett, Tulman, & Myers, 1988) was conducted using Cronbach’s alpha as an estimate of internal consistency between items. Establishing good internal consistency reliability of this instrument is important for future research with HIV-positive women.

Part I of the IFS consists of a 12-item Household Activities subscale to assess the extent to which participants were engaged in household responsibilities, such as caring for family members, cleaning, doing laundry, cooking, or washing dishes. Item responses are 1 “never”, 2 “sometimes”, 3 “most of the time”, and 4 “all the time”. Scores range from 12 to 48; a high score indicates higher functioning related to performing household chores.

Part III of the IFS consists of the 8-item Self-Care subscale, which asked women to rate the extent to which they performed self-care activities during the past week or two: walking, standing, climbing stairs, sitting, reclining, sleeping, and dressing. Item examples are “Spend much of the day lying down”, “Take walks”, and “Spend much of the day in my bathrobe or night clothes”. Responses include 1 “never”, 2 “sometimes”, 3 “most of the time”, and 4 “all the time”. Scores on this subscale range from 8 to 32, and a higher score indicates lower self-care functioning. Items 1, 2, 3, 4, 5, and 8 on the Self-Care subscale were reverse-coded such that a higher score indicates higher functioning. For a multidimensional measure of functional status, the Self-Care subscale and the Household Activities subscale were combined into one outcome measure of functional status, where scores range from 20 to 80; the higher the score the better the individual’s functional status.

Reliability estimates for the combined subscales of the Inventory of Functional Status (Fawcett, Tulman, & Myers, 1988) were .84 and .75 for this sample of HIV-positive and HIV-negative women, respectively (see Appendix A). The reliability estimate for the entire sample of HIV-positive and HIV-negative women was .84. These reliability coefficients are considered a stable measure of item consistency within the instrument since they are above .70 (Polit & Hungler, 1995). The two components of the IFS demonstrated that its subparts (items) are equivalent in measuring the attribute of functional status, and this parsimonious measure can be used in future research with HIV-positive women. Together, these 20 items on the IFS can discriminate the concept of

functional status between symptomatic and non-symptomatic women and shows evidence of construct validity.

Table 18 presents the findings related to the difference in functional status between groups. The variables of income, age, ethnicity (African American), and employment significantly correlated with functional status (see Tables 20 and 21). HIV-positive and HIV-negative women differed significantly in their mean functional status score ( $F[6, 146] = 4.24, p = .001$ ) after controlling for these variables.

Table 18  
ANOVA on Functional Status by Group n=147 (controlling for income, age, ethnicity, and employment)

Variable	Group	Mean	SD	Confidence Interval Grand Mean
Functional Status (20 items)	HIV-negative (n=43)	60.88	6.17	(54.46-58.28)
	HIV-positive (n=104)	55.21	10.09	

Mean difference = 5.67

$F[5, 146] = 4.24, p = .001$

Average functional status scores by ethnicity, income, and employment status are presented in Table 19. African American women, all of whom were HIV-positive, had a lower mean score on functional status compared to other ethnic women in the study. The mean functional status score for low-income women in general was lower compared to middle and higher income women in the study. The majority (59.3%) of low-income, poverty level women was African American.



Table 19  
Average Functional Status Scores by Ethnicity, Income, and Employment Status for Total Sample

<u>Ethnicity</u>	<u>Mean Functional Status Score (SD)</u>
African American (n=61)	54.05 ± 10.31
Caucasian (n=66)	59.68 ± 8.46
Hispanic (n=15)	55.41 ± 7.53
Other (n= 5)	58.60 ± 6.80
 <u>Income</u>	
Less than \$10,999 (n=83)	54.00 ± 10.19
\$11,000-\$24,999 (n=26)	58.59 ± 7.23
Greater than \$25,000 (n=40)	61.43 ± 6.65
 <u>Employment</u>	
Employed full time (n=49)	61.82 ± 6.81
Employed part time (n=3)	49.33 ± 7.09
Unemployed (n=95)	54.55 ± 9.71

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Results of the exploration of relationships between categorical variables of ethnicity, employment, time since HIV diagnosis (in categories of years diagnosed), hemoglobin group (low vs. normal) and functional status are presented in Table 20. Functional status differed only by ethnicity and employment. Continuous variables of age, income, sleep disturbance, and number of symptoms were significantly correlated with functional status and are shown in the correlation matrix in Table 21.

Note the high correlation between sleep disturbance and number of symptoms ( $r = .82$ ) and sleep disturbance and income ( $r = -.67$ ). It is conceivable that one who experiences a greater number of symptoms, the more likely she is unable to sleep and rest adequately. Conversely, the negative relationship between sleep disturbance and income reveals what HIV-positive women reported in the study (most of whom were low-income). That is, more HIV-positive women reported concern and worry about their children and their health compared to HIV-negative women. These concerns would influence sleep quality.

Only those variables significantly related to functional status were entered into a regression model to determine if these variables were predictive of functional status. Note the absent relationship between level of perceived stress and functional status in Table 21 ( $r = -.02$ ). Ethnicity was dummy-coded (African American vs. other) and entered into a regression model along with age, income, sleep disturbance, number of symptoms, and group.

Table 20

Differences in Functional Status by Ethnicity, Time Since Diagnosis, and Hemoglobin Group (low vs. normal) in HIV-positive and HIV-negative Women

<u>Variable</u>	<u>N</u>	<u>Mean</u> <u>(SD)</u>	<u>F(df)</u>	<u>p</u>	<u><math>\eta^2</math></u>	<u>Confidence</u> <u>Interval</u>
<u>Ethnicity</u>			4.18 (3,143)	.007	.08	
African American *	61	54.05 (10.31)				(1.45-9.81)
Caucasian	66	59.68 (8.46)				
Hispanic	15	55.41 (7.53)				
Other	5	58.60 (6.80)				
<u>Time since HIV diagnosis</u>			1.11 (2, 95)	.334	N/A	
Less than one year	11	51.37 (15.8)				
1-5 years	49	56.28 (8.11)				
Greater than 5 years	38	55.08 (10.0)				

---

\* indicates significant group membership

Table 20 (continued)

Differences in Functional Status by Ethnicity, Time Since Diagnosis, and Hemoglobin Group (low vs. normal) in HIV-positive and HIV-negative Women

<u>Variable</u>	<u>N</u>	<u>Mean</u> <u>(SD)</u>	<u>F(df)</u>	<u>p</u>	<u><math>\eta^2</math></u>	<u>Confidence</u> <u>Interval</u>
<u>Hemoglobin group</u>			.014 (1, 107)	.906	N/A	
Low hemoglobin group	3	9.1 (.46)				
Normal hemoglobin group	103	12.9 (1.1)				

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Table 21

**Differences in Functional Status by Education and Employment in HIV-positive and HIV-negative Women**

<u>Variable</u>	<u>N</u>	<u>Mean</u> ( <u>SD</u> )	<u>F(df)</u>	<u>p</u>	<u><math>\eta^2</math></u>	<u>Confidence</u> <u>Interval</u>
<b><u>Education</u></b>			1.861 (4,142)	.121	N/A	
Some grade school	5	49.65 (6.20)				
Completed grade school, Some high school	30	54.70 (12.9)				
Completed high school, Some college	75	56.94 (8.68)				
Completed college, some Graduate school	24	59.27 (5.79)				
Completed graduate School	13	59.7 (9.55)				
<b><u>Employment</u></b>			12.09 (2,144)	<.001	.14	
Employed full time *	49	61.82 (6.81)				(3.43-11.10)
Employed part time	3	49.33 (7.09)				
Unemployed	95	54.55 (9.71)				

\* indicates significant group membership in comparison to other groups

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Table 22

Correlation Matrix for the Dependent Variable Functional Status (n=70)

	Age	Sleep Disturbance	Perceived Stress (mm)	Total Symptom Score	Income
Functional status	-.25*	-.33*	-.02	-.29*	.51**
Age		.54*	.15	.47**	-.44**
Sleep Disturbance			.26*	.82**	-.67**
Perceived Stress (mm)				.20	-.09
Total Symptom Score					-.57**
Income					

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\*  $p < .05$

\*\*  $p < .01$

Table 23

Regression Analysis on Functional Status (n=74)

	Standardized Beta	Partial Correlation	<i>t</i>	p-value
Group	.053	.025	.209	.835
Employment	.229	.145	1.20	.234
Age	.041	.037	.303	.763
Income	.376	.248	2.115	.038
Number of symptoms	.125	.083	.678	.50
African American vs. other	-.307	-.257	-2.190	.032
Sleep disturbance	.011	.006	.05	.960

---

Multiple R = .54

$F [6, 68] = 4.56, p = .001$

$R^2 = .29, \text{ Adjusted } R^2 = .22$

The overall regression model was significant holding the variables of African American ethnicity, employment, age, income, sleep disturbance, number of symptoms, and HIV group constant ( $F [6, 68] = 4.56, p = .001$ ). It appears, however, that income and ethnicity are more predictive of functional status (presented in Table 22) than HIV group, symptoms, or sleep disturbance in this sample of women. Nonetheless, there were significant differences between HIV-positive and HIV-negative women in the earlier

analyses concerning sleep disturbance, number of symptoms, and self-reported “other” stressors, such that a trend is evident to support interventions and further research with HIV-positive women. The interpretation of the analyses will follow in the next chapter.



## Chapter V

### Study Implications

This research study was a secondary analysis of samples from two different studies describe and compare the stressors and functional status between HIV-positive and HIV-negative women. This chapter presents the implications of the study's findings, limitations of the study, and directions for future research.

#### Implications of Findings

##### Incidence and Type of Self-reported Stressors

There was a significant difference between HIV-positive and HIV-negative women in the incidence of stressors in the two-day diary data. Univariate analyses found that while there were no differences in level of perceived stress between HIV-positive and HIV-negative women, HIV-positive women reported significantly more symptom and sleep disturbance-related stress compared to HIV-negative women.

It is plausible that HIV-positive women might not perceive that they live inherently stressful lives, but their stress response is manifested in their self-report of symptoms and sleep disruption. According to Nicolas and Schilder (1997), women experience chronic illness within the context of their ability to carry out their roles as mother, wife, or partner, along with culturally-defined roles. The duties and tasks women traditionally perform are difficult when one is chronically ill. Consequently, an HIV-infected woman who is bombarded with symptoms might be more inclined to perceive

her illness state in the context of her ability to function in the role as a mother, caregiver, or head of household (Chung & Magraw, 1992).

### Self-reported Symptoms as Stressors

As hypothesized, HIV-positive women and HIV-negative women in this study differed significantly in the frequency and number of self-reported symptoms. Previous studies also have reported that HIV-positive women consistently report their symptoms as primary stressors in their lives (Semple, et al., 1993; Spijkerman, Langedam, van Ameijden, Coutinho, & van den Hoek, 1998). This finding is congruent with the conclusion by Sowell and colleagues (1997), "...those with the least access to needed material resources reported the greatest number of HIV symptoms." (p. 510). The implication is that HIV-positive women might delay care until their symptoms are too overwhelming. More research is needed to explore the relationship between symptom onset and functional status as they relate to care-seeking behaviors.

The finding of a higher mean sleep disturbance score for HIV-positive women compared to HIV-negative women was congruent with a study by Darko et al. (1992). In that study, Darko and colleagues explored daytime sleepiness and sleep habits in 62 HIV-positive and 50 HIV-negative persons. HIV-positive persons slept more, napped more during the day, experienced more early morning awakenings, and reported feeling less alert in the morning compared to HIV-negative subjects.

It has been reported that HIV "hides" in the brain and lymphatic tissue reservoirs that are difficult to penetrate by antiretroviral medications (Furtado, et al., 1999). It also

has been documented that HIV enters the brain, lymphoid tissues, and central nervous system early in the acute phase of the infection (Cohen, 1997). In addition, research supports the notion that the 'acute phase response peptides' are a principal factor in HIV-related sleep disturbance (Darko, et al., 1998, p. 317). Consequently, sleep disturbance can be potentially disabling stressor related to HIV infection. Although HAART has changed the nature of HIV infection into a chronic illness, a longer life coupled with an eroding quality of life due symptoms and poor quality sleep is a questionable benefit of HAART. Nursing interventions to promote self-management of sleep disturbance is a viable option.

An important implication of the comparison of sleep disturbance scores between HIV-positive and HIV-negative women is the possibility of attenuated physical and cognitive performance from disrupted sleep. For example, as people living with HIV infection are encouraged to continue or to resume employment, a relevant question is to what extent will the employer allow the employee to compensate for fatigue or cognitive impairment due to sleep deprivation? A recent June 1999 Supreme Court decision narrowed the definition of disability under the Americans with Disabilities Act (one plaintiff was a man who was fired from his job because he had to take anti-hypertension medication). "Employers could provide employees with the option to accumulate work hours in anticipation of a future need for time off arising from one's own illness or that of a family member." (Semple et al., 1993; p. 31). An expanding literature is suggestive of the relationship between neuropsychological deficits in early HIV infection and work

disability (Albert, et al., 1995; Darko, Mitler, & Miller, 1998; Heaton, et al., 1994).

### Functional Status

For the purpose of this study functional status was defined as the ability to perform certain tasks, such as self-care activities and household chores. HIV-positive and HIV-negative women differed significantly in their mean functional status scores. The hypothesis that level of perceived stress, when measured as a continuous variable, was related to functional status was not supported. In a study by Sowell et al. (1997), stigma (stressor) was significantly related to functional status in a sample of 264 HIV-positive women. For future research, it might be best to measure the psychological attribute (distress or depression or anxiety) itself rather than the concept of “stress” to better understand these women’s experiences.

The finding in this study that ethnicity and income are related to functional status is consistent with findings from a study by Stanton, et al. (1994). In that study of 728 HIV-infected adults, functional status differed by gender and level of income, but not by race. This research suggests that demographic variables of income, ethnicity, and gender are related to physical functioning in HIV-positive persons and continue to support the need for culturally appropriate support and treatment programs for HIV-positive persons.

A further implication of this study was the significant difference in functional status between HIV-positive and HIV-negative women. This difference refers to a deficit in tasks necessary for HIV-positive women to live independently. To illustrate, except for an acute exacerbation of HIV disease, most therapeutic interventions for HIV-positive

women occur on an outpatient basis, such as in clinics or case management agencies (Fleishman & Crystal, 1998). This study provides evidence that maintaining HIV-positive women in the community, many of whom are single low-income women, requires supportive services to aid in their self-management of symptoms and stressors that potentially affect their physical functioning capabilities (Stanton, et al., 1994).

The finding of significant differences in sleep disturbance, symptom experiences, and functional status between HIV-positive and HIV-negative women in this study supports the existence of community-based support programs for women living with HIV infection. Because fear of stigma primarily isolates HIV-positive heterosexual women, this group has the greatest need for support services (personal communication with Priscilla Abercrombie, June 9, 1999). This is consistent with a study by Catalan, et al. (1996) who found that heterosexual HIV-positive women were significantly less likely to seek support for instrumental activities of daily living and more likely to use avoidant coping behavior to deal with their HIV disease compared to HIV-negative women. To provide appropriate and effective community-based health services to HIV-infected women, providers must target these women and persistently monitor their needs. “Interventions to support independence may be as important as drug therapy in maintaining quality of life” (Stanton, et al., 1994, p. 1055).

### **Instrument Findings**

The reliability estimates of the General Sleep Disturbance Scale and the parsimonious version of the Inventory of Functional Status demonstrate that these

instruments are stable measures of the concepts of sleep disturbance and functional status in non-symptomatic women and HIV-infected women. There also was evidence of the instruments' ability to discriminate between those persons hypothesized to score high or low on the attribute. For example, HIV-positive women and HIV-negative women differed significantly in their mean sleep disturbance scores and mean functional status scores as hypothesized.

The regression analysis underscores the importance of assessing sleep quality in persons infected with HIV. Although there is recent research on sleep disturbance in HIV-positive men and women (Cohen, et al., 1996; Nokes & Chidekel, 1999; Nokes & Kendrew, 1996; White, et al., 1995), these studies did not address the relationship between sleep disruption, symptom experiences, perceived stress, and functional status in a large sample of HIV-positive women. Therefore, this relationship needs further investigation because it is not fully understood in this population.

Although significantly correlated with functional status, the variables of age, number of symptoms, and sleep disturbance did not in and of themselves contribute significantly to the overall regression model with functional status as the dependent variable. The overall model explained approximately 29% of the variance in functional status, with income and ethnicity contributing significantly to predicting functional status in this sample of women.

This finding is plausible, given what we know about health as a relative condition. People generally see themselves as healthy if they are able to carry out their routines of

daily living, irrespective of how ill they are. Presumably, other factors explain or predict physical functioning better than a disease state, and these must be given consideration in care planning.

### Study Limitations

A number of factors constrain the generalizability of findings from this study to all women living with HIV. First, the ability to generate a randomly selected sample was not possible given the laws protecting the confidentiality of one's HIV-positive serostatus. There are no sampling frames available to the public from which to generate a random sample of HIV-positive subjects. A second constraint was that the data available for analysis were previously collected by someone other than this doctoral student. Third, another constraint was self-selection. HIV-positive women in the study who were willing to reveal their HIV-positive status might be different in many ways from HIV-positive women who did not participate the study.

Another limitation of this study was that data collected were cross-sectional in time, and conclusions about causality cannot be determined. Based on the study design and type of statistical analyses conducted, one could not conclusively state that their current functional status was caused by their African American ethnicity, their income, their self-reported symptoms, or their sleep disturbance. Finally, two measures, the General Sleep Disturbance Scale (Lee, 1992) and the Inventory of Functional Status (Fawcett, Tulman, & Myers, 1988), had not previously been used with HIV-positive women. Notwithstanding these limitations, however, this study's findings

and implications lean toward congruence with previously published research.

### Implications for Nursing

Over the next decade, the survival time and overall quality of life for women with HIV infection are anticipated to increase with effective highly active combination antiretroviral therapy (HAART) (Fowler, Melnick, & Mathieson, 1997). However, a cure is not foreseen in the near future, and HAART is not effective for all HIV-infected persons. Because HIV disease is a chronic condition, findings in this study have particular implications for delivery of community-based services for women living with HIV infection.

Persons with HIV infection might experience sleep disturbance for a variety of the following reasons: infection, fever, fatigue, depression, or medication side effects (Cohen, et al., 1996). In this study there was a significant positive relationship between level sleep disturbance and number of symptoms ( $r = .82, p < .01$ ) for HIV-positive and HIV-negative women. As their HIV-related symptoms appear, low-income women are probably likely to first present to nurse practitioners in community clinics. This would be an important opportunity for nurses to evaluate the stressors in these women's lives, including their symptoms and their sleep quality.

A study by Wright, Henry, Holzemer, and Falknor (1993) supports this conclusion. They found that nurse case managers were more inclined to report that comprehensive client assessment, functional status assessment, and health teaching of patients and caregivers were important case management activities compared to social workers who



worked in the same setting. Fleishman and Crystal (1998) found that energy-demanding activities, such as getting to medical appointments, laundry, shopping, and housekeeping were the most prevalent types of home care assistance reported by 1784 persons with AIDS. Therefore, assessment of sleep quality and symptom experiences of HIV-positive women should be an important part of a nursing case management assessment.

An important service delivery implication is also evident. Traditionally, case management in community-based organizations has been under the domain of social work (Wright et al., 1993). However, because HIV/AIDS is a chronic illness, most HIV-infected women live in the community. Case management is a service delivery model that can be conducted most efficiently by nurses. They have the skills to perform physical assessments, symptom management, coordination of services, monitoring of health status, and evaluation of functional status in HIV-positive women.

### Future Research and Conclusions

Most chronic illnesses have periods of exacerbation with periods of improvement. As HIV becomes a long-term chronic illness, research conducted on the overall quality of life for women living with HIV infection will be needed to determine their care needs. This particular study is the beginning for further research to help clarify the findings. For example, longitudinal studies that incorporate subjective and objective measures of sleep disturbance and other symptom experiences would provide information by which appropriate nursing interventions could be developed. Then, studies that incorporate nursing interventions to mediate sleep disturbance and other stressful symptom

experiences in HIV-positive women would show the effect of those interventions. A longitudinal repeated measure design could explore whether or not symptoms in HIV-positive women diminish or abate over time with nursing intervention. More research is needed to explore the relationship between the stressor of aging, HIV disease, and functional status. For example, large sample prospective studies are needed to evaluate the risks and benefits to functional status of hormone replacement therapy among HIV-positive post-menopausal women (Clark & Bessinger, 1997).

In this era of containment of health care costs, the following research question is an example of further research with HIV-positive women that evolves from this study: Do self-reported stressors, symptoms, and sleep disturbance decrease among symptomatic HIV-positive women who are case managed by nurses compared to those case managed by non-nurses? What is the effect of nursing case management on functional status over time at each stage of HIV disease?

More research is needed to test relevant theory for HIV-positive women. Anderson (1995) reported that HIV-positive women use social support as a mediator between stressors and adaptive outcomes. She suggested more theoretical development and testing using stress and coping frameworks for HIV-positive women. Similarly, further testing of appropriate measures for concept/attributes is needed with this population as well. A strength of this study was the testing of psychometric properties of two instruments, whereby initial normative data were obtained from healthy Caucasian females.

To address the needs of women living with HIV infection, it is important that nurses

influence these women's care expectations, symptom management options, support availability, and their functional status. The professional service must match the need. In this case, nurses are uniquely able to match their professional skills to the service needs of HIV-positive women.

### References

- AIDS deaths down sharply in U.S., government says. (1998, October 7). Reuters.
- Albert, S. M., Marder, K., Dooneief, G., Bell, K., Sano, M., Todak, G., & Stern, Y. (1995). Neuropsychologic impairment in early HIV infection: a risk factor for work disability. Archives of Neurology, *52*, 525-530.
- Amaro, H., & Hardy-Fanta, C. (1995). Gender relations in addiction and recovery. Journal of Psychoactive Drugs, *27*, 325-337.
- Anastasio, C., McMahan, T., Daniels, A., Nicholas, P.K., & Paul-Simon, A. (1995). Self-care burden in women with human immunodeficiency virus. Journal of the Association of Nurses in AIDS Care, *6*, 31-42.
- Anastos, K., & Marte, C. (1989). Women—the missing persons in the AIDS epidemic. Health/PAC Bulletin, *Winter*, 6-15.
- Anderson, S. E. H. (1995). Personality, appraisal, and adaptational outcomes in HIV seropositive men and women. Research in Nursing & Health, *18*, 303-312.
- Andrews, S., Williams, A. B., & Neil, K. (1993). The mother-child relationship in the HIV-1 positive family. Image: Journal of Nursing Scholarship, *25*, 193-198.
- Arp, W., & Boeckelman, K. (1997). Religiosity: A source of Black environmentalism and empowerment? Journal of Black Studies, *28*, 255-267.
- Basset, M., & Mihloyi, M. (1994). Women and AIDS in Zimbabwe: The making of an epidemic. In N. Krieger & G. Margo (Eds.), AIDS: The politics of survival.

Amityville, NY: Baywood.

Beedham, H., & Wilson-Barnett, J. (1995). HIV and AIDS care: Consumers' views on needs and services. Journal of Advanced Nursing, 22, 677-686.

Belenky, M. F., Clinchy, B. M., Goldberger, N. R., & Tarule, J. M. (1986). Women's ways of knowing: The development of self, voice, and mind. New York: Basic Books, Inc.

Belle, D. (1990). Poverty and women's mental health. 45(3), 385-389.

Biggar, H., Forehand, R., Devine, D., Brody, G., Armistead, L., Morse, E., & Simon, P. (1999). Women who are HIV infected: the role of religious activity in psychosocial adjustment. AIDS Care, 11(2), 195-199.

Bozzette, S., Berry, S. H., Duan, N., Frankel, M. R., Keesey, J., Lefkowitz, D., & Shapiro, M. F. (1998, June-July). Characteristics of HIV-Infected Patients Receiving Regular Care in the US: Results from the HIV Cost and Services Utilization Study (HCSUS). Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Brodt, H. R., Kamps, B. S., Gute, P., Knupp, B., Staszewski, S., & Helm, E. B. (1997). Changing incidence of AIDS-defining illnesses in the era of antiretroviral combination therapy. AIDS, 11, 1731-1738.

Brown, M. H., & Cope-Powell, G. M. (1991). AIDS family care-giving: Transitions through uncertainty. Nursing Research, 40, 338-345.

Brown, V. B., Melchior, C. R., & Huba, G. F. (1994). Mandatory partner

notification of HIV test results: Psychological and social issues for women. AIDS Public Policy Journal, 9, 86-92.

Bryan, J., Sun, R., & Colford, J. (1998, June-July). Survival differences over time related to gender and age at diagnosis among California AIDS cases. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Butz, A. M., Hutton, N., Joyner, M., Vogelhut, J., Greenberg-Freidman, D., Schreibeis, D., & Anderson, J. R. (1993). HIV-infected women and infants: Social and health factors impeding utilization of health care. Journal of Nurse-Midwifery, 38, 103-109.

Calore, E., Cavaliere, J., Shirata, K., & Araujo, M. F. (1995). Papilloma virus in cervicovaginal smears of women infected with human immunodeficiency virus. Revista de Medicina, 113, 1009-1011.

Carré, N., Prins, M., Meyer, L., Brettle, R. P., Robertson, J. R., McArdle, H., Goldberg, D. J., Zangerle, R., Coutinho, R. A., & van den Hoek, A. (1997). Has the rate of progression to AIDS changed in recent years? AIDS, 11, 1611-1618.

Catalan, J., Beevor, A., Cassidy, L., Burgess, A. P., Meadows, J., Pergami, A., Gazzard, B., & Barton, S. (1996). Women and HIV infection: Investigation of its psychosocial consequences. Journal of Psychosomatic Research, 41, 39-47.

Chung, J. Y., & Magraw, M. M. (1992). A group approach to psychosocial issues faced by HIV-positive women. Hospital and Community Psychiatry, 43, 891-894.

Cederfjall, C., & Wredling, R. (1999). The expressed needs of a group of HIV-

infected gay men subsequent to hospital care. Journal of the Association of Nurses in AIDS Care, 10(2), 66-74.

Centers for Disease Control and Prevention (1994). HIV/AIDS Surveillance Report, 6 (1).

Centers for Disease Control and Prevention (1996). Update: Mortality attributable to HIV infection among persons aged 25-44 years—United States, 1994. Morbidity and Mortality Weekly Report, 45, 121-125.

Centers for Disease Control and Prevention (1997). HIV/AIDS Surveillance Report, 9 (1).

Centers for Disease Control and Prevention (1998). HIV/AIDS Surveillance Report, 10 (2).

Chesney, M. A., & Folkman, S. (1994). Psychological impact of HIV disease and implications for intervention. Psychiatric Clinics of North America, 17, 163-182.

Chaisson, R. E., Gallant, J. E., Keruly, J. C., & Moore, R. D. (1998). Impact of opportunistic disease on survival in patients with HIV infection. AIDS, 12(1), 29-33.

Chaisson, M. A., Li, W., Berenson, L., Schwartz, S., Singh, T., & Forlenza, S. (1998, June-July). Declining AIDS mortality in New York City (NYC). Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Chin, K. M., Sidhu, J. S., Janssen, R. S., & Weber, T. (1998). Invasive cervical cancer in human immunodeficiency virus-infected and uninfected hospital patients. Obstetrics & Gynecology, 92 (1), 83-87.

Chu, S. Y., Buehler, J. W., & Berkelman, R. L. (1990). Impact of the human immunodeficiency virus epidemic on mortality in women of reproductive age, United States. Journal of American Medical Association, 264, 225-229.

Clark, R. A., & Bessinger, R. (1997). Clinical manifestations and predictors of survival in older women infected with HIV. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, 15, 341-345.

Cohen, F. L., Ferrans, C. E., Vizgirda, V., Kunkle, V., & Cloniger, L. (1996). Sleep in men and women infected with human immunodeficiency virus. Holistic Nursing Practice, 10(4), 33-43.

Cohen, M. (1997). Natural history of HIV infection in women. Obstetrics and Gynecology Clinics of North America, 24, 743-758.

Cruise, P. L., & Dunn, S. M. (1994). Ethnography and AIDS: a methodology for identifying culturally relevant risk-reducing behaviors. Journal of the Association of Nurses in AIDS Care, 5(4), 21-27.

Crespo-Fierro, M. (1997). Compliance/adherence and care management in HIV disease. Journal of the Association of Nurses in AIDS Care, 8, 43-54.

Darko, D. F., Mitler, M. M., & Miller, J. C. (1998). Growth hormone, fatigue, poor sleep, and disability in HIV infection. Neuroendocrinology, 67(5), 317-24.

Darko, D. F., McCutchan, J. A., Kripke, D. F., Gillin, J. C., & Golshan, S. (1992). Fatigue, sleep disturbance, disability, and indices of progression of HIV infection. American Journal of Psychiatry, 149(4), 514-520.



D'Ubaldo, C., Pezzotti, P., Rezza, G., Branca, M., Ippolito, & the DIANAIDS Collaborative Study Group (1998). Association between HIV-1 infection and miscarriage: A retrospective study. AIDS, 12, 1087-1093,

Dicks, B. (1994). African American women and AIDS: A public health/social work challenge. Social Work in Health Care, 19, 123-143.

Donlou, J. N., Wolcott, D. L., Gottlieb, M. S., & Landsverk, J. (1985). Psychosocial aspects of AIDS and AIDS-related complex: A pilot study. Journal of Psychosocial Oncology, 3, 39-55.

Farzadegan, H., Hoover, D. R., Astemborski, J., Lyles, C. M., Margolick, J. B., Markham, R. B., Quinn, T. C., & Vlahov, D. (1998). Sex differences in HIV-1 viral load and progression to AIDS. Lancet, 352(9139), 1510-4.

Fawcett, J., Tulman, L., & Myers, S. T. (1988). Development of the Inventory of Functional Status After Childbirth. Journal of Nurse-Midwifery, 33, 252-260.

Fleishman, J. A., & Crystal, S. (1998). Functional status transitions and survival in HIV disease: evidence from the AIDS Costs and Service Utilization Survey. Med Care, 36(4), 533-43.

Fowler, M. G., Melnick, S. L., & Mathieson, B. J. (1997). Women and HIV: epidemiology and global overview. Obstetrics and Gynecology Clinics of North America, 24, 705-729.

Friedland, J., Renwick, R., & McColl, M. (1996). Coping and social support as determinants of quality of life in HIV/AIDS. AIDS Care, 8 (1), 15-31.

Furtado, M., Callaway, D. S., Phair, J. P., Kunstman, K. J., Stanton, J. L., Macken, C. A., Perelson, A. S., & Wolinsky, S. M. (1999). Persistence of HIV-1 transcription in peripheral blood mononuclear cells in patients receiving potent antiretroviral therapy. The New England Journal of Medicine, 340, 1614-1622.

Gallo, R. (1988). HIV-the cause of AIDS: An overview on its biology, mechanisms of disease induction, and our attempts to control it. Journal of Acquired Immunodeficiency Syndrome, 1, 521-535.

Gavey, N., & McPhillips, K. (1997). Women and the heterosexual transmission of HIV: risks and prevention strategies. Women & Health, 25(2), 41-64.

Gielen, A. C., O'Campo, P., Faden, R. R., & Eke, A. (1997). Women's disclosure of HIV status: Experiences of mistreatment and violence in an urban setting. Women & Health, 25, 19-31.

Glanz, K., Lewis, F. M., & Rimer, B. K. (1997). Health behavior and health education: Theory, research and practice. (2nd ed.). San Francisco: Jossey-Bass Publishers.

Goldstein, N., & Manlowe, J. L. (Eds.). (1997). The gender politics of HIV/AIDS in women. New York: New York University Press.

Guinan, M. E., & Hardy, A. (1987). Epidemiology of AIDS in women in the United States: 1981 through 1986. Journal of American Medical Association, 257, 2039-2042.

Heaton, R. K., Velin, R. A., McCutchan, J. A., Gulevich, S. J., Atkinson, J. H.,

Wallace, M. R., Godfrey, H. P., Kirson, D. A., & Grant, I. (1994). Neuropsychological impairment in human immunodeficiency virus-infection: implications for employment. Psychosomatic Medicine, *56*, 8-17.

Hobfoll, S. E., Jackson, A. P., Lavin, J., Britton, P. J., & Shepherd, J. B. (1994). Reducing inner-city women's AIDS risk. Health Psychol, *13*(5), 397-403.

Hogg, R., Yip, B., Craib, K. J. P., Schechter, M. T., O'Shaughnessy, M. V., & Montaner, J. S. G. (1998, June-July). Improved survival among men and women on triple anti-Retroviral therapy. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Holzemer, W. L., Corless, I. B., Nokes, K. M., Turner, J. G., Brown, M., Powell-Cope, G. M., Inoye, J., Henry, S. B., Nicholas, P. K., & Portillo, C. J. (1999). Predictors of self-reported adherence in persons living with HIV disease. AIDS Patient Care and STDs, *13*, 185-97.

Holzemer, W. L., Henry, S. B., & Reilly, C. A. (1998). Assessing and managing pain in AIDS care: The patient perspective. Journal of the Association of Nurses in AIDS Care, *9* (1), 22-30.

Holzemer, W. L., & Wilson, H. S. (1995). Quality of life and the spectrum of HIV infection. Annual Review of Nursing Research, *13*, 3-29.

Hudson, A. L., & Morris, R. I. (1994). Perceptions of social support among African Americans with acquired immunodeficiency syndrome. Journal of National Black Nurses Association, *7*, 36-49.

Hudson, A. L., Miramontes, H., Lee, K. A., & Portillo, C. J. (in progress) Social support and level of distress in ethnically diverse HIV-positive women. Unpublished manuscript.

Ickovics, J. R., & Rodin, J. (1992). Women and IADS in the United States: Epidemiology, natural history, and mediating mechanisms. Health Psychology, 11 (1), 1-16.

Johnston, B. E., Ahmad, K., Smith, C., & Rose, D. N. (1998, June-July). Alternative therapy use among HIV-infected patients of the inner city. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Kaplan, H. B., Johnson, R. J., Bailey, C. A., & Simon, W. (1987). The sociological study of AIDS: A critical review of the literature and suggested research agenda. Journal of Health and Social Behavior, 28, 140-157.

Katzenstein, D. A. (1997). Adherence as a particular issue with protease inhibitors. Journal of the Association of Nurses in AIDS Care, 8 (Supplement), 10-17.

Katzenstein, D.A., Lyons, C., Molaghan, J. P., Ungvarski, P., Wolfe, G. S., & Williams, A. (1997). HIV therapeutics: Confronting adherence. Journal of the Association of Nurses in AIDS Care, 8, 46-58.

Keiserman, M., Tuveson, J., Maimares, J., Schmidt, J., Kim, L., Abrams, D. I., & Koch, J. (1998, June-July). Alternative therapy use in patients with HIV: "Snake Oil" or Panacea? Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Kellerher, P., Cox, S., & McKeogh, M. (1997). HIV infection: The spectrum of symptoms and disease in male and female patients attending a London hospice.

Palliative Medicine, 11, 152-158.

Kirkham, C. M., & Lobb, D. J. (1998). The British Columbia positive women's survey: A detailed profile of 110 HIV-infected women. Canadian Medical Association Journal, 158, 317-323.

Kosko, D., Neff-Smith, M., & Kim, M. (1998, June-July). Adherence barriers to complex anti-Retroviral regimen: The perceptions of HIV+ women and nurses. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Krieger, N., Rowley, D. L., Herman, A. A., Avery, B., & Phillips, M. T. (1993). Racism, sexism, and social class: Implications for studies of health, disease, and well-being. American Journal of Preventive Medicine, 6 (Supplement), 82-122.

LaGaipa, J. (1990). The negative effects of informal support systems. In S. Duck & R. Silver (Eds.), Personal relationships and social support (pp. 122-139). Newbury Park, CA: Sage.

Lazarus, R., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.

Lee, K. A. (1992). Self-reported sleep disturbances in employed women. Sleep, 15, 493-498.

Lee, K. A., & Taylor, D. L. (1996). Is there a generic mid-life woman? The health

and symptom experience of employed mid-life women. Menopause: The Journal of the North American Menopause Society, 3(3), 154-164.

Linn, J. G., Poku, K. A., Holzapfel, K. M., & Crawford, D. F. (1995). Psychosocial outcomes of HIV illness in male and female African American clients. Social Work in Health Care, 21, 43-60.

Lurie, P., Hintzen, P., Lowe, R. A. (1995). Socioeconomic obstacles to HIV prevention and treatment in developing countries: The roles of the International Monetary Fund and the World Bank. AIDS, 9, 539-546.

Madge, S., Olaitan, A., Mocroft, A., Phillips, A., & Johnson, M. (1997). Access to medical care one year prior to diagnosis in 100 HIV-positive women. Family Practice, 14, 255-257

Maslanka, H., Lee, J., & Freudenberg, N. (1995) An evaluation of community-based HIV services for women in New York State. JAMWA, 50, 121-126.

Mellors, M. P., Riley, T. A., & Erlen, J. A. (1997). HIV, self-transcendence, and quality of life. Journal of the Association of Nurses in AIDS Care, 8, 59-69.

Melnick, S. L., Sherer, R., Louis, T. A., Hillman, D., Rodriguez, E. M., Lackman, C., Capps, L., Brown, L. S., Carlyn, M., Korvick, J. A., & Deyton, L. (1994). Survival and disease progression according to gender of patients with HIV infection. Journal of the American Medical Association, 272, 1915-1921.

Michaels, D., & Levine, C. (1992). Estimates of the number of motherless youth orphaned by AIDS in the United States. Journal of American Medical Association, 268,

3456-3461.

Miller, K., Corcoran, C., Armstrong, C., Caramelli, K., Anderson, E., Cotton, D., Basgoz, N., Hirschhorn, L., Tuomala, T., Schoenfeld, D., Daugherty, C., Mazer, N., & Grindspoon, S. (1998). Transdermal testosterone administration in women with acquired immunodeficiency syndrome wasting: a pilot study. Journal of Clinical Endocrinology and Metabolism, 83, 2717-2725.

Miller, W. L., & Crabtree, B. F. (1992). Primary care research: A multimethod typology and qualitative road map. In B. F. Crabtree & W. L. Miller (Eds.), Doing qualitative research: Research methods for Primary Care: Vol. 3 (pp. 3-28). Newbury Park, CA: Sage.

Miller, M. (1999). A model to explain the relationship between sexual abuse and HIV risk among women. AIDS Care, 11(1), 3-20.

Murrain, M. (1997). Caught in the crossfire: Women and the search for the magic bullet. In N. Goldstein & J. L. Manlowe (Eds.), The gender of politics of HIV/AIDS in women (pp. 63-73). New York: New York University Press.

Nannis, E. D., Patterson, T. L., & Semple, S. J. (1997). Coping with HIV disease among seropositive women: Psychosocial correlates. Women & Health, 25, 1-22.

National Institutes of Health. (1994). Outreach notebook for the NIH guidelines on inclusion of women and minorities as subjects in clinical research. Bethesda, MD: author.

Newman, T. B., Browner, W. S., Cummings, S. R., & Hulley, S. B. (1988). In S.B. Hulley & S. R. Cummings (Eds.), Designing clinical research (pp. 75-86). Baltimore:

Williams & Wilkins.

Nicolas, S., & Schilder, E. (1997). The lived experience of Winnipeg women with HIV/AIDS. AIDS Patient Care and STDs, 11, 86-92.

Nokes, K. M., & Chidekel, J. H. (1999). Exploring the complexity of sleep disturbances in persons with HIV/AIDS. Journal of the Association of Nurses in AIDS Care, 10(3), 22-29.

Nokes, K. M., & Kendrew, J. (1996). Sleep quality in people with HIV disease. Journal of the Association of Nurses in AIDS Care, 7(3), 43-49. Norbeck, J. S., Lindsey, A. M., & Carrieri, V. L. (1981). The development of an instrument to measure social support. Nurs Res, 30(5), 264-9.

Norbeck, J. S. (1995). Scoring instructions for the Norbeck Social Support Questionnaire (NSSQ). University of California, San Francisco.

Nyamathi, A. M., Flaskerud, J., Leake, B., & Chen, S. (1996). Impoverished women at risk for AIDS: Social support variables. Journal of Psychosocial Nursing, 34, 31-39.

Nyamathi, A. M., Leake, B., Flaskerud, J., Lewis, C., & Bennett, C. (1993). Outcomes of specialized and traditional AIDS counseling programs for impoverished women of color. Research in Nursing & Health, 16, 11-21.

Nyamathi, A. M., & Stein, J. A. (1997). Assessing the impact of HIV risk reduction counseling in impoverished African American women: A structural equations approach. AIDS Education and Prevention, 9, 253-273.



O'Connor, P. G., Selwyn, P. A., & Schottenfeld, R. S. (1994). Medical care for injection-drug users with human immunodeficiency virus infection. New England Journal of Medicine, 331, 450-45.

Pace, J. C., & Stables, J. L. (1997). Correlates of spiritual well-being in terminally ill persons with AIDS and terminally ill persons with cancer. Journal of the Association of Nurses in AIDS Care, 8, 31-42.

Palella, F. J., Delaney, K. M., Moorman, A. C., Loveless, M., Fuhrer, J., Satten, G., Aschman, D., & Holmberg, S. (1998). Declining mortality among patients with advanced acquired immunodeficiency virus infection. The New England Journal of Medicine, 338, 853-966.

Perez, J., Ortega, O. L. M., Joanes, J. F. J., Lantero, L. M. I., Rivero, R. W. J., Alonso, A. M. E., & Arazoza, A. R. H. (1998, June-July). Disease progression in a cohort of HIV+ individuals diagnosed in 1986 in CUBA. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Peterson, J. L., Folkman, S., & Bateman, R. (1996). Stress, coping, HIV status, psychosocial resources, and depressive mood in African American gay, bisexual, and heterosexual men. American Journal of Community Psychology, 24, 461-487.

Phillips, K. D. (1996). Protease inhibitors: a new weapon and a new strategy against HIV. Journal of the Association of Nurses in AIDS Care, 7, 57-70.

Polit, D. F., & Hungler, B. P. (1995). Nursing research: Principles and methods (5<sup>th</sup> ed.). Philadelphia: J. B. Lippincott.

Ragsdale, D., Kotarba, J. A., Morrow, J. R., & Yarbrough, S. (1995). Health locus of control among HIV-positive indigent women. Journal of the Association of Nurses in AIDS Care, 6, 29-36.

Rich, J. D., Buck, A., Tuomala, R. E., & Kazanjian, P. H. (1993). Transmission of human immunodeficiency virus infection presumed to have occurred via female homosexual contact. Clinical Infectious Disease, 17, 1003-1005.

Rojansky N., & Anteby, S. O. (1996). Gynecological neoplasias in the patient with HIV infection. Obstetrical and Gynecological Survey, 51, 679-683.

Rook, K. (1990). Parallels in the study of social support and social strain. Clinical Psychology, 9, 118-132.

Schechter, M., Lopes, G., Pinho, A. M. F., Lima, L. A. A., Hofer, C. B., Harrison, L. H., Moulton, L. H., & Schechter, M. (1998, June-July). Gender and progression of HIV-associated immunodeficiency. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Schilder, A. J., Hogg, R. S., Goldstone, I., Strathdee, S., Schechter, M. T., & O'Shaughnessy, M. V. (1998, June-July). Adult social identity is part of culturally competent HIV care for sexual minorities and affects care-seeking behaviors and therapeutic adherence. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Semple, S. J., Patterson, T. L., Temoshok, L. R., McCutchan, J. A., Straits-Troster, K. A., Chandler, J. L., & Grant, I. (1993). Identification of psychobiological stressors

among HIV-positive women. Women & Health, 20, 15-36.

Siegel, K., & Krauss, B. J. (1991). Living with HIV infection: adaptive tasks of seropositive gay men. Journal of Health and Social Behavior, 32, 17-32.

Simonds, R. J., Steketee, R., Nesheim, S., Matheson, P., Palumbo, P., Alger, L., Abrams, E. J., Orloff, S., Lindsay, M., Bardeguet, A. D., Vink, P., Byers, R., & Rogers, M. (1998). Impact of zidovudine use on risk and risk factors for perinatal transmission of HIV. AIDS, 12, 301-308.

Smeltzer, S., & Whipple, B. (1991). Women and HIV infection. Image: The Journal of Nursing Scholarship, 23, 249-256.

Sowell, R. L., Seals, B. F., Moneyham, L., Demi, A., Cohen, L., & Brake, S. (1997). Quality of life in HIV-infected women in the southeastern United States. AIDS Care, 9, 501-512.

Spijkerman, I. J., Langendam, M. W., van Ameijden, E. J., Coutinho, R. A., & van den Hoek, A. (1998). Gender differences in clinical manifestations before AIDS diagnosis among injecting drug users. Eur J Epidemiol, 14(3), 213-8.

Stanton, D. L., Wu, A. W., Moore, R. D., Rucker, S. C., Piazza, M. P., Abrams, J. E., & Chaisson, R. E. (1994). Functional status of persons with HIV infection in an ambulatory setting. J Acquir Immune Defic Syndr, 7(10), 1050-6.

Sterling, T., Lyles, C., Quinn, T. C., Astemborski, J., Margolick, J., Macalino, G., & Vlahov, D. (1998, June-July). Gender-specific differences in HIV-1 RNA level in a longitudinal study of HIV-1 seroconverters. Poster session presented at the meeting of the

12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Taylor, R. D., & Roberts, D. (1998). Kinship support and maternal and adolescent well-being in economically disadvantaged African-American families. Child Development, 66, 1585-1597.

Thorndike, M. R. (1978). Correlational procedures for research. New York: Gardner.

Turner, B. J., McKee-Nelsen, Fanning, T. R., & Hauck, W. W. (1997). Prevention of vertical HIV transmission with zidovudine: Projected impact of HIV testing and prenatal care. AIDS Care, 9, 577-588.

Valente, S., & Saunders, J. (1997). Managing depression with people with HIV disease. Journal of the Association of Nurses in AIDS Care, 8, 51-67.

Weber, R., Loy, M., Christen, L., Schaller, S., Christen, S., Joyce, C. R. B., Cohen, M. R. (1998, June-July). Treatment of HIV infected persons with Chinese Herbs: A randomized, placebo-controlled trial. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

White, J. L., Darko, D. F., Brown, S. J., Miller, J. C., Hayduk, R., Kelly, T., & Mitler, M. M. (1995). Early central nervous system response to HIV infection: sleep distortion and cognitive-motor decrements. Aids, 9(9), 1043-50.

Wight, R. G., LeBlanc, A. J., & Aneshensel, C. S. (1998). AIDS caregiving and health among mid-life and older women. Health Psychol, 17(2), 130-7.

Wilfert, C. M. (1996). Prevention of perinatal transmission of human

immunodeficiency virus: A progress report 2 years after completion of AIDS clinical trials group trial 076. Clinical Infectious Disease, 23, 438-441.

Williams, A., Mezger, J., & Yu, C. (1998, June-July). Adherence to gynecologic examinations among HIV positive women. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Williams, A. B., Shahryarinejad, A., Andrews, S., & Alcabes, P. (1997). Social support for HIV-infected mothers: Relation to HIV care seeking. Journal of the Association of Nurses in AIDS Care, 8, 91-98.

Wilson, C. J., & Cohen, M. R., (1998, June-July). Traditional Chinese medicine increasing in popularity as complementary therapy in HIV/AIDS. Poster session presented at the meeting of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland.

Wilson, H. S., Hutchinson, S. A., & Holzemer, W. L. (1997). Salvaging quality of life in ethnically adverse patients with advanced HIV/AIDS. Qualitative Health Research, 7, 75-97.

Wolcott, D. L., Namir, S., Fawzy, F. I., Gottlieb, M. S., & Mitsuyasu, R. T. (1986). Illness concerns, attitudes towards homosexuality, and social support in gay men with AIDS. General Hospital Psychiatry, 8, 395-403.

Wolf, T. M., Balson, P. M., Morse, E. V., Simon, P. M., Gaumer, R. H., Dralle, P. W., & Williams, M. H. (1991). Relationship of coping style to affective state and perceived social support in asymptomatic and symptomatic HIV-infected persons: Implications for clinical management. Journal of Clinical Psychiatry, 52, 171-173.

Wright, J., Henry, S. B., Holzemer, W. L., & Falknor, P. (1993). Evaluation of community-based nurse case management activities for symptomatic HIV/AIDS clients. Journal of the Association of Nurses in AIDS Care, 4(2), 37-47.

Zierler, S., & Krieger, N. (1997). Reframing women's risk: Social inequalities and HIV infection. Annual Review of Public Health, 18, 401-436.

## Appendix A

## Results of Reliability Analysis of the General Sleep Disturbance Scale for Total

Sample of HIV-positive and HIV-negative Women (n=100)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Have difficulty getting to Sleep	44.10	651.51	.90
Wake up during your sleep Period	42.28	689.33	.91
Wake up too early at the end of a sleep period	43.61	647.88	.90
Feel rested upon awakening at the end of a sleep period	43.49	703.06	.91
Sleep poorly	43.92	659.85	.91
Feel sleepy during the day	43.07	661.56	.91
Struggle to stay awake during the day	44.49	652.96	.91
Feel irritable during the day	44.61	666.50	.91
Feel tired or fatigued during the day	43.31	663.31	.91
Feel satisfied with the quality of your sleep	43.51	692.78	.91
Feel alert and energetic during the day	43.42	711.24	.91
Get too much sleep	44.54	673.36	.91
Get too little sleep	43.00	679.07	.91
Take a nap at a scheduled time	45.30	685.38	.91
Fall asleep at an unscheduled Time	44.55	661.77	.91

			121
Drink an alcoholic beverage to help you get to sleep	46.14	716.55	.91
Use tobacco to help you get to Sleep	45.82	703.40	.91



**Results of Reliability Analysis of the General Sleep Disturbance Scale for Total Sample of HIV-positive and HIV-negative Women (n=100)**

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Use marijuana to help you get to sleep	46.19	717.71	.91
Use an over-the-counter Sleeping pill to help you get to sleep	46.16	714.48	.91
Use a prescription sleeping pill to help you get to sleep	45.24	672.08	.91
Use aspirin or other analgesic to help you get to sleep	45.85	697.20	.91
Reliability coefficient = .914	Standardized item alpha = .911		
Standard deviation = 27.36	Number of items = 21		

## Results of Reliability Analysis of the General Sleep Disturbance Scale for

Sample of HIV-positive Women (n=56)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Have difficulty getting to Sleep	61.45	383.59	.78
Wake up during your sleep Period	60.34	396.26	.78
Wake up too early at the end of a sleep period	60.96	384.76	.78
Feel rested upon awakening at the end of a sleep period	61.41	438.03	.81
Sleep poorly	61.55	382.00	.78
Feel sleepy during the day	60.45	409.42	.79
Struggle to stay awake during the day	61.88	385.89	.78
Feel irritable during the day	62.29	380.97	.77
Feel tired or fatigued during the day	60.82	402.73	.79
Feel satisfied with the quality of your sleep	61.48	419.16	.80
Feel alert and energetic during the day	61.30	447.62	.81
Get too much sleep	61.77	425.16	.81
Get too little sleep	60.98	396.71	.79
Take a nap at a scheduled time	63.13	400.44	.79
Fall asleep at an unscheduled Time	61.59	419.81	.80
Drink an alcoholic beverage to help you get to sleep	64.54	408.73	.79
Use tobacco to help you get to Sleep	63.84	414.90	.80

Table

Results of Reliability Analysis of the General Sleep Disturbance Scale for Sample of HIV-positive Women (n=56)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Use marijuana to help you get to sleep	64.50	416.22	.80
Use an over-the-counter Sleeping pill to help you get to sleep	64.50	408.11	.79
Use a prescription sleeping pill to help you get to sleep	62.80	396.05	.80
Use aspirin or other analgesic to help you get to sleep	64.05	392.09	.78
Reliability coefficient = .799	Standardized item alpha = .803		
Standard deviation = 21.03	Number of items = 21		

## Results of Reliability Analysis of the General Sleep Disturbance Scale for

Sample of HIV-negative Women (n=44)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Have difficulty getting to Sleep	22.02	118.72	.80
Wake up during your sleep Period	19.30	114.91	.82
Wake up too early at the end of a sleep period	21.52	108.07	.78
Feel rested upon awakening at the end of a sleep period	20.68	107.85	.78
Sleep poorly	21.48	110.26	.79
Feel sleepy during the day	20.95	105.77	.78
Struggle to stay awake during the day	22.36	115.17	.79
Feel irritable during the day	22.11	122.48	.81
Feel tired or fatigued during the day	21.02	104.39	.77
Feel satisfied with the quality of your sleep	20.64	102.84	.77
Feel alert and energetic during the day	20.55	108.86	.78
Get too much sleep	22.61	128.01	.81
Get too little sleep	20.11	98.94	.78
Take a nap at a scheduled time	22.61	125.36	.81
Fall asleep at an unscheduled Time	22.86	127.28	.81
Drink an alcoholic beverage to help you get to sleep	22.73	125.32	.80
Use tobacco to help you get to Sleep	*		

Results of Reliability Analysis of the General Sleep Disturbance Scale for

Sample of HIV-negative Women (n=44)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Use marijuana to help you get to sleep	*		
Use an over-the-counter Sleeping pill to help you get to sleep	22.82	127.41	.81
Use a prescription sleeping pill to help you get to sleep	*		
Use aspirin or other analgesic to help you get to sleep	22.68	122.87	.80
Reliability coefficient = .803	Standardized item alpha = .779		
Standard deviation = 11.3	Number of items = 18		

\*Items “use tobacco to help you get to sleep”, “use marijuana to help you get to sleep”, and “use a prescription sleeping pill to help you get to sleep” had zero variance.

Results of Reliability Analysis of Inventory of Functional Status for Total Sample of HIV-positive and HIV-negative Women (n=132)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Care of family members	54.64	71.74	.83
Cleaning the house	54.1	71.13	.82
Tidying the house (picking up items, etc.)	53.91	71.05	.83
Laundry	53.89	70.43	.82
Doing dishes	54.20	70.11	.82
Cooking	54.26	69.53	.82
Household business (paying bills, banking, etc)	54.27	73.17	.84
Grocery shopping	54.23	68.30	.82
Shopping, other than groceries	54.34	69.36	.82
Doing errands	54.36	71.06	.83
Heavy housework (painting, Cleaning, etc.)	55.24	71.99	.83
Caring for pets	55.37	73.21	.84
Spend much of the day lying Down	53.81	74.57	.83
Sit during much of the day	54.25	77.40	.84
Spend much of the day Sleeping or dozing	53.62	76.05	.84
Stand for only short periods of time	54.18	76.06	.84
Spend much of the day in my Bathrobe or night clothes	53.46	75.62	.83

Results of Reliability Analysis of Inventory of Functional Status for Total

Sample of HIV-positive and HIV-negative Women (n=132)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Take walks	54.79	75.01	.84
Go up and down stairs	54.56	76.25	.84
Walk slowly	54.24	76.37	.84

Reliability coefficient = .839

Standardized item alpha = .8400

Standard deviation = 8.95

Number of items = 20

Results of Reliability Analysis of Inventory of Functional Status for

Sample of HIV-positive Women (n=96)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Care of family members	53.28	79.19	.84
Cleaning the house	52.64	77.01	.83
Tidying the house (picking up items, etc.)	52.50	77.12	.83
Laundry	52.54	77.47	.83
Doing dishes	52.80	76.29	.83
Cooking	52.97	76.10	.83
Household business (pay- ing bills, banking, etc)	52.82	79.26	.84
Grocery shopping	52.97	74.74	.83
Shopping, other than groceries	53.06	76.31	.83
Doing errands	52.99	76.26	.83
Heavy housework (painting, Cleaning, etc.)	53.95	76.18	.84
Caring for pets	54.06	81.20	.85
Spend much of the day lying Down	52.63	82.51	.84
Sit during much of the day	52.89	85.51	.85
Spend much of the day Sleeping or dozing	52.35	84.02	.84
Stand for only short periods of time	52.86	83.89	.85
Spend much of the day in my Bathrobe or night clothes	52.16	83.04	.84



Results of Reliability Analysis of Inventory of Functional Status for Total

Sample of HIV-positive Women (n=96)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Take walks	53.35	81.20	.84
Go up and down stairs	53.20	85.56	.85
Walk slowly	53.02	84.93	.85

Reliability coefficient = .844

Standardized item alpha = .842

Standard deviation = 9.37

Number of items = 20

Results of Reliability Analysis of Inventory of Functional Status for

Sample of HIV-negative Women (n=36)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Care of family members	58.28	34.89	.73
Cleaning the house	57.81	37.30	.73
Tidying the house (picking up items, etc.)	57.69	36.45	.72
Laundry	57.5	34.94	.71
Doing dishes	57.94	35.60	.72
Cooking	57.72	36.83	.73
Household business (paying bills, banking, etc)	57.69	40.96	.76
Grocery shopping	57.61	36.64	.72
Shopping, other than groceries	57.75	36.02	.72
Doing errands	58.00	40.17	.75
Heavy housework (painting, Cleaning, etc.)	58.69	40.40	.75
Caring for pets	58.86	36.41	.75
Spend much of the day lying Down	56.97	41.00	.75
Sit during much of the day	57.89	38.84	.75
Spend much of the day Sleeping or dozing	57.00	40.46	.74
Stand for only short periods of time	57.69	39.53	.75
Spend much of the day in my Bathrobe or night clothes	56.94	40.51	.74

Results of Reliability Analysis of Inventory of Functional Status for Total Sample of HIV-negative Women (n=36)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Alpha if Item Deleted
Take walks	58.61	39.67	.75
Go up and down stairs	58.19	37.19	.75
Walk slowly	57.5	40.31	.75

Reliability coefficient = .748

Standardized item alpha = .758

Standard deviation = 6.46

Number of items = 20

**Appendix B**

DEMOGRAPHIC AND SCREENING INFORMATION

Date \_\_\_\_\_  
Sub. # \_\_\_\_\_

1. Circle the number that best describes **your** racial or ethnic identification.

- African-American .....1
- Chinese-American .....2
- Caucasian, Anglo ..... 3
- Filipino-American .....4
- Hispanic-American .....5
- Japanese-American .....6
- Something different ....7 (please specify \_\_\_\_\_)

2. Circle the number that best describes your marital status **now**, and indicate how long you have been in this current status.

- |                            |   |
|----------------------------|---|
|                            | For how long? <u>months</u> or <u>years</u> |
| living with partner .....1 |   |
| married .....2             | _____                                       |
| separated .....3           | _____                                       |
| divorced .....4            |   |
| single .....5              |   |

3. Who, if anyone, lives at home with you at this time?

<u>Relationship</u>	<u>Age (yrs)</u>	<u>Relationship</u>	<u>Age (yrs)</u>
_____	_____	_____	_____
_____	_____	_____	_____

4. How much formal education have **you** had?

- no formal education or some grade school .....1
- completed grade school or some high school ...2
- completed high school or some college ..... 3
- completed college or some graduate school..... 4
- completed a graduate degree .....5

**Your partner's** education?    1   2   3   4   5

5. **Your** present work situation is best described as:

- employed .....1
- self-employed .....2
- unemployed .....3
- part-time work .....4
- temporary job .....5
- laid off .....6
- leave of absence from job.7
- suspended or dismissed  
from job.....8

**Your partner's** work?    1   2   3   4   5   6   7   8

6. What is **your** present occupation? \_\_\_\_\_  
**Your partner's** occupation? \_\_\_\_\_

Do either of you work nights? \_\_\_ YES \_\_\_ NO

How many hours/week do **you** work? \_\_\_\_\_ hours

How many hours/week does **your partner** work \_\_\_\_\_ hours

7. What is **your** religious affiliation?  
no religion ....1  
Protestant .....2  
Catholic .....3  
Jewish .....4  
Other.....5 (please specify \_\_\_\_\_)

8. What was your approximate net family income, from all sources, after taxes last year?  
less than \$10,000 ....1  
10,000 - 14,999 .....2  
15,000 - 24,999 .....3  
25,000 - 34,999 .....4  
35,000 - 44,999 .....5  
45,000 - 54,999 .....6  
55,000 - 64,999 .....7  
over 65,000 .....8

9. What is **your** current age? \_\_\_\_\_ years  
What is **your partner's** age? \_\_\_\_\_ years

10. Have **you** ever seen a psychiatrist or counselor? \_\_\_ YES \_\_\_ NO  
If yes, describe when, for how long, and for what reason:

11. Are you currently taking any medications? \_\_\_ YES \_\_\_ NO  
If yes, describe the medication and reason for use:

**Medical Record:**

**Date**  
\_\_\_\_\_ CD4 count \_\_\_\_\_  
\_\_\_\_\_ Lymphocyte count \_\_\_\_\_  
\_\_\_\_\_ Hemoglobin \_\_\_\_\_  
\_\_\_\_\_ Albumin level \_\_\_\_\_

\_\_\_\_\_ Last Hospital Admission: chief complaint/diagnosis \_\_\_\_\_

When was HIV Diagnosed?

Pregnancy/menstrual status \_\_\_\_\_

DATE \_\_\_\_\_

Please remember to press the event marker at your final awakening.

MORNING INFORMATION - complete after awakening

1. I did or took something to help fall asleep.  NO  
 YES (describe: \_\_\_\_\_)
2. Last night I went to bed at: \_\_\_\_\_ o'clock.
3. It took me \_\_\_\_\_ minutes to fall asleep, which was  typical/normal for me  
 shorter than usual  
 longer than usual
4. During the night, I woke up \_\_\_\_\_ time(s).  
(Describe what woke you up):  
\_\_\_\_\_

Were any awakenings longer than 5 minutes?  NO  YES

The number of awakenings was:

- fewer than usual
- typical for me
- more than usual
- way too many
- don't remember

The time spent awake was:

- no time at all
- less than usual
- about the usual amount
- longer than usual
- way too long

5. I woke up this morning at \_\_\_\_\_ o'clock and I got up at \_\_\_\_\_ o'clock.
6. I awoke:  much too early  with help from an alarm clock  
 earlier than usual  with help from a person  
 the usual time  without any assistance  
 way too late
7. I feel:  very alert  very rested  
 alert  rested  
 somewhat drowsy  somewhat rested  
 very drowsy  not at all rested
9. My sleep was:  very poor  poor  
 fair  good  
 good  very good
10. I dreamt:  not at all  
 very little  
 a normal amount  
 more than usual  
 don't remember

DATE \_\_\_\_\_

**EVENING INFORMATION** - Complete prior to sleep time

1. I napped from \_\_\_\_\_ to \_\_\_\_\_ from \_\_\_\_\_ to \_\_\_\_\_ from \_\_\_\_\_ to \_\_\_\_\_

2. I did \_\_\_\_\_ no activity today (stayed in bed, sat in chair)  
\_\_\_\_\_ basic activity (showered, prepared a snack, light housekeeping)  
\_\_\_\_\_ mild exercise (walking, vacuuming, etc.)  
\_\_\_\_\_ moderate or strenuous exercise (describe) \_\_\_\_\_  
at \_\_\_\_\_ o'clock at \_\_\_\_\_ o'clock at \_\_\_\_\_ o'clock

3. I ate \_\_\_\_\_ my usual diet \_\_\_\_\_ an unusual diet (describe: \_\_\_\_\_)

4. I ate \_\_\_\_\_ my typical amount \_\_\_\_\_ less than usual \_\_\_\_\_ more than usual

5. Today, I drank:  
Type of Drink Approximate Time Amount

6. Today, I felt: \_\_\_\_\_ not at all healthy  
\_\_\_\_\_ somewhat healthy  
\_\_\_\_\_ fairly healthy  
\_\_\_\_\_ very healthy

7. Today, I felt: \_\_\_\_\_ very happy  
\_\_\_\_\_ fairly happy  
\_\_\_\_\_ somewhat happy  
\_\_\_\_\_ not at all happy

8. Did you encounter any particular **stress** today?  
(If yes, please describe)

9. What, if any, **symptoms** did you experience today?  
(If yes, please describe)

10. What, if any, **medications** did you take today?  
Name of medicine/drug Approximate Time Amount Taken



EVENING INFORMATION - complete prior to sleep

Date \_\_\_\_\_

- I napped from \_\_\_\_\_ to \_\_\_\_\_; from \_\_\_\_\_ to \_\_\_\_\_
  - I did \_\_\_\_\_ no activity today  
 \_\_\_\_\_ basic activity (light housekeeping, etc.)  
 \_\_\_\_\_ mild exercise (walking, isometrics, etc.)  
 \_\_\_\_\_ moderate exercise (heavy housework, etc.)  
 at \_\_\_\_\_ AM \_\_\_\_\_ AM; \_\_\_\_\_ PM \_\_\_\_\_ PM  
 strenuous exercise (jogging, swimming, etc.)  
 at \_\_\_\_\_ AM \_\_\_\_\_ AM; \_\_\_\_\_ PM \_\_\_\_\_ PM
  - I ate: \_\_\_\_\_ my usual diet  
 \_\_\_\_\_ an unusual diet (describe: \_\_\_\_\_)
  - I ate: \_\_\_\_\_ my typical amount  
 \_\_\_\_\_ less than usual  
 \_\_\_\_\_ more than usual
- MEAL TIMES: \_\_\_\_\_ AM \_\_\_\_\_ AM  
 \_\_\_\_\_ PM \_\_\_\_\_ PM
- SNACKS: \_\_\_\_\_ AM \_\_\_\_\_ AM  
 \_\_\_\_\_ PM \_\_\_\_\_ PM
- Today, I felt: \_\_\_\_\_ Today, I felt: \_\_\_\_\_  
 \_\_\_\_\_ not at all healthy \_\_\_\_\_ very happy  
 \_\_\_\_\_ somewhat healthy \_\_\_\_\_ fairly happy  
 \_\_\_\_\_ fairly healthy \_\_\_\_\_ somewhat happy  
 \_\_\_\_\_ very healthy \_\_\_\_\_ not at all happy
  - Did you encounter any particular stress today?  
 (describe: \_\_\_\_\_)
  - What, if any, symptoms did you experience today?  
 (describe: \_\_\_\_\_)
- Alcohol or caffeine beverages consumed today:  
 approximate time \_\_\_\_\_ type of beverage \_\_\_\_\_ amount (cups) \_\_\_\_\_
- Medications used today:  
 approximate time \_\_\_\_\_ name of medication \_\_\_\_\_ amount taken \_\_\_\_\_

MORNING INFORMATION - complete after awakening

Date \_\_\_\_\_

- I did or took something to help fall asleep. NO \_\_\_\_\_  
 If yes, describe: \_\_\_\_\_ YES \_\_\_\_\_
  - Last night, I went to bed at \_\_\_\_\_ PM
  - Falling asleep took \_\_\_\_\_ minutes,  
 which was: \_\_\_\_\_ no time at all  
 \_\_\_\_\_ not the usual amount of time  
 \_\_\_\_\_ longer than usual  
 \_\_\_\_\_ way too long
  - I awoke \_\_\_\_\_ time/times during the night.  
 What awakened you? \_\_\_\_\_  
 Were any awakenings longer than 5 minutes? NO \_\_\_\_\_  
 If yes, describe: \_\_\_\_\_ YES \_\_\_\_\_
- |                          |                         |
|--------------------------|-------------------------|
| The number of awakenings | The time spent awake    |
| was: _____               | was: _____              |
| _____ fewer than usual   | _____ no time at all    |
| _____ typical for me     | _____ less than usual   |
| _____ more than usual    | _____ about the usual   |
| _____ way too many       | _____ longer than usual |
| _____ don't remember     | _____ way too long      |
- I awoke this morning at \_\_\_\_\_ AM and got up at \_\_\_\_\_ AM  
 I awoke: \_\_\_\_\_ much too early  
 \_\_\_\_\_ earlier than usual  
 \_\_\_\_\_ the usual time  
 \_\_\_\_\_ way too late
  - I feel: \_\_\_\_\_ 7. I feel: \_\_\_\_\_  
 \_\_\_\_\_ very alert \_\_\_\_\_ very rested  
 \_\_\_\_\_ alert \_\_\_\_\_ rested  
 \_\_\_\_\_ somewhat drowsy \_\_\_\_\_ somewhat rested  
 \_\_\_\_\_ very drowsy \_\_\_\_\_ not at all rested
  - My sleep was: \_\_\_\_\_ 9. I dreamt: \_\_\_\_\_  
 \_\_\_\_\_ very poor \_\_\_\_\_ not at all  
 \_\_\_\_\_ poor \_\_\_\_\_ very little  
 \_\_\_\_\_ fair \_\_\_\_\_ a normal amount  
 \_\_\_\_\_ good \_\_\_\_\_ more than usual  
 \_\_\_\_\_ very good \_\_\_\_\_ don't remember

### GENERAL SLEEP DISTURBANCE SCALE

How often in the <u>past week</u> did you:	NEVER							EVERY DAY
1. have difficulty getting to sleep.....	0	1	2	3	4	5	6	7
2. wake up during you sleep period .....	0	1	2	3	4	5	6	7
3. wake up too early at the end of a sleep period...	0	1	2	3	4	5	6	7
4. feel rested upon awakening at the end of a sleep period.....	0	1	2	3	4	5	6	7
5. sleep poorly .....	0	1	2	3	4	5	6	7
6. feel sleepy during the day .....	0	1	2	3	4	5	6	7
7. struggle to stay awake during the day.....	0	1	2	3	4	5	6	7
8. feel irritable during the day.....	0	1	2	3	4	5	6	7
9. feel tired or fatigued during the day..	0	1	2	3	4	5	6	7
10. feel satisfied with the quality of your sleep .....	0	1	2	3	4	5	6	7
11. feel alert and energetic during the day .....	0	1	2	3	4	5	6	7
12. get too much sleep .....	0	1	2	3	4	5	6	7
13. get too little sleep .....	0	1	2	3	4	5	6	7
14. take a nap at a scheduled time .....	0	1	2	3	4	5	6	7
15. fall asleep at an unscheduled time ....	0	1	2	3	4	5	6	7
16. drink an alcoholic beverage to help you get to sleep.....	0	1	2	3	4	5	6	7
17. use tobacco to help you get to sleep...	0	1	2	3	4	5	6	7
18. use marijuana to help you get to sleep.....	0	1	2	3	4	5	6	7
19. use an over-the-counter sleeping pill to help you get to sleep.....	0	1	2	3	4	5	6	7
20. use a prescription sleeping pill to help you get to sleep.....	0	1	2	3	4	5	6	7
21. use aspirin or other analgesic to help you get to sleep .....	0	1	2	3	4	5	6	7



How often do you have .... ?

NEVER

ALL THE  
TIME

12.	back pain	0	1	2	3	4	5	6	7	8	9
13.	joint pain	0	1	2	3	4	5	6	7	8	9
14.	chest pain	0	1	2	3	4	5	6	7	8	9
15.	ankle swelling	0	1	2	3	4	5	6	7	8	9
16.	headaches	0	1	2	3	4	5	6	7	8	9
17.	dizzy spells	0	1	2	3	4	5	6	7	8	9
18.	nausea	0	1	2	3	4	5	6	7	8	9
19.	muscle weakness	0	1	2	3	4	5	6	7	8	9
20.	clumsiness or uncoordination	0	1	2	3	4	5	6	7	8	9
21.	shortness of breath or trouble breathing	0	1	2	3	4	5	6	7	8	9
22.	leg cramps	0	1	2	3	4	5	6	7	8	9
23.	allergic skin reactions	0	1	2	3	4	5	6	7	8	9
24.	colds or sore throats	0	1	2	3	4	5	6	7	8	9
25.	hay fever or sinus trouble	0	1	2	3	4	5	6	7	8	9
26.	hemorrhoids	0	1	2	3	4	5	6	7	8	9

**How often do you have .... ?**NEVERALL THE  
TIME

27.	loose stools	0	1	2	3	4	5	6	7	8	9
28.	straining for bowel movements	0	1	2	3	4	5	6	7	8	9
29.	urgency for bowel movement	0	1	2	3	4	5	6	7	8	9
30.	incomplete bowel emptying	0	1	2	3	4	5	6	7	8	9
31.	gas or gas pains	0	1	2	3	4	5	6	7	8	9
32.	mucus in your stools	0	1	2	3	4	5	6	7	8	9
33.	trouble digesting food	0	1	2	3	4	5	6	7	8	9
34.	heartburn or acid indigestion	0	1	2	3	4	5	6	7	8	9
35.	abdominal distention, bloated (not related to menses)	0	1	2	3	4	5	6	7	8	9
36.	abdominal pain (not related to menses)	0	1	2	3	4	5	6	7	8	9

If I had not eaten for 24 hours. I would be extremely hungry and would place an "X" through the following line close to the "high" end to indicate how hungry I am:

**HUNGER**            low \_\_\_\_\_ high

**NOW, CONSIDERING THE PAST WEEK,  
PLACE AN "X" THROUGH EACH OF THESE 8 LINES  
TO INDICATE YOUR GENERAL LEVEL OF:**

a.    **WELL BEING**        low \_\_\_\_\_ high

b.    **STRESS**            low \_\_\_\_\_ high

c.    **FATIGUE**            low \_\_\_\_\_ high

d.    **TENSION**            low \_\_\_\_\_ high

e.    **HAPPINESS**        low \_\_\_\_\_ high

f.    **SLEEPINESS**        low \_\_\_\_\_ high

g.    **HEALTH**            low \_\_\_\_\_ high

h.    **ENERGY**            low \_\_\_\_\_ high

INVENTORY OF FUNCTIONAL STATUS  
(Fawcett, Tulman, & Myers, 1988)

Part I. Please circle the number that indicates to what extent you participate in the following household activities:

	NEVER	<u>EXTENT OF HOUSEHOLD RESPONSIBILITY</u>		
		SOMETIMES	MOST OF THE TIME	ALL THE TIME
1. Care of family members	1	2	3	4
2. Cleaning the house	1	2	3	4
3. Tidying the house (make bed, pick up items, etc.)	1	2	3	4
4. Laundry	1	2	3	4
5. Doing dishes	1	2	3	4
6. Cooking	1	2	3	4
7. Household business (pay bills, banking, etc.)	1	2	3	4
8. Grocery shopping	1	2	3	4
9. Shopping, other than groceries	1	2	3	4
10. Doing errands	1	2	3	4
11. Heavy housework (painting, cleaning, etc.)	1	2	3	4
12. Caring for pets	1	2	3	4

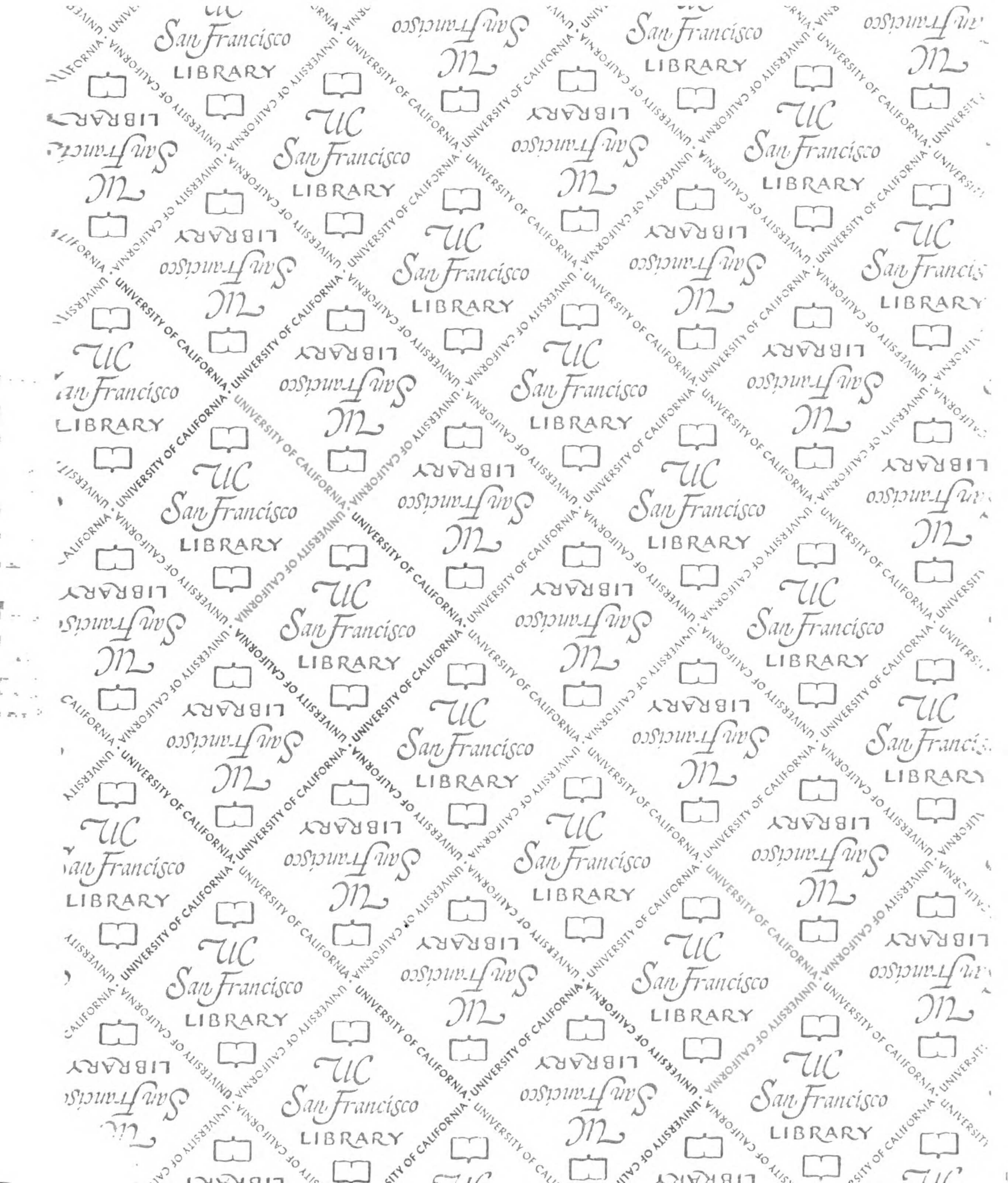
**What do you do about these household chores when you are feeling too tired to do them?**

Part III. Please respond to the following phrases based on how your life has been during the **past week**.

	NEVER	SOMETIMES	MOST OF THE TIME	ALL THE TIME
1. Spend much of the day lying down	1	2	3	4
2. Sit during much of the day	1	2	3	4
3. Spend much of the day sleeping or dozing	1	2	3	4
4. Stand for only short periods of time	1	2	3	4
5. Spend much of the day in my bathrobe or night clothes	1	2	3	4
6. Take walks	1	2	3	4
7. Go up and down stairs	1	2	3	4
8. Walk slowly	1	2	3	4

**Are there any other comments you would like to make about how you spend your day?**





# For reference

Not to be taken from the room.

7065280



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