Reducing Emotional Distress Using the Stress Inoculation Model for HIV-Infected People in the Pre-AIDS Stage

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LOYOLA UNIVERSITY OF CHICAGO

REDUCING EMOTIONAL DISTRESS USING THE STRESS INOCULATION MODEL FOR HIV-INFECTED PEOPLE IN THE PRE-AIDS STAGE

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE SCHOOL OF SOCIAL WORK
IN PARTIAL FULFILLMENT FOR THE DEGREE OF
DOCTOR OF SOCIAL WORK

SCHOOL OF SOCIAL WORK

BY
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CHICAGO, ILLINOIS
MAY, 1995
REDUCING EMOTIONAL DISTRESS USING THE STRESS INOCULATION MODEL FOR HIV INFECTED PEOPLE IN THE PRE-AIDS STAGE

Nancy Downey Caddick

Research has shown that patients in the first two stages of HIV disease experience significantly higher levels of depression, mood disturbances and anxiety than do those patients with AIDS (Wadland & Gleeson, 1991). As a result of the Concorde Study, treatment for patients in these stages has changed to a more negotiable process often bringing health monitoring rather than active treatment. Survival in this stage of the HIV continuum will depend more on coping skills than on medical interventions.

This experimental study (N=19) examined the effectiveness of a six week biopsychosocial program "Living with HIV" as an intervention to decrease emotional distress, and increase personal control and medical compliance. Scales to assess emotional distress included: Beck Depression Inventory, Hamilton Depression Scale, Hamilton Anxiety Scale, Impact of Event Scale and Multidimensional Health Locus of Control, Form C. A Medical Review Log assessed appointment compliance for three months following the program.

The quantitative findings combined with the participants subjective responses and actions to the study provided findings of clinical significance. The stress inoculation model of "preparation" was bidirectional in its application between those living with HIV, and those providing their medical and mental health care.
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ACKNOWLEDGMENTS

My personal evolution during this research journey has been aided by many in my professional and personal life. I have many people to thank. Foremost is to acknowledge a population of patients whose courage to address the most challenging times of their lives provided the stimulus for this response to AIDS care. For those currently in the battle, and for those who won and moved on, my deepest gratitude for allowing me to be part of the journey.

I wish to acknowledge with deep appreciation the contributions of my dissertation committee. A special note of gratitude to Dr. Sandra Condon, chairperson, who was most generous in her available time, in her guidance and skills in research methodology, and her patience. To Dr. Joseph Walsh whose enduring support throughout this dissertation process was a generous gift to which I will forever be grateful. To Dr. Randolph Lucente whose clinical support and challenge on my earlier work on AIDS continued through the dissertation, thank you.

In addition to my committee, I wish to thank faculty members at Loyola University who have greatly enhanced my clinical social work skills: Carolyn Saari, Gloria
Cunningham, and Tom Meenaghan. A special thanks to Dr. Jack Kavanagh for his support and invaluable statistical advice on this research project.

I acknowledge the invaluable role my doctoral cohorts provided in sustaining my commitment to the completion of this dissertation. To Tom Ireland, Jeanne Engel, Terry Rosander, Mary Beale, Linda Noer, and Gloria Fennell: thanks for sharing clinical skills, energy, friendship, and memories.

I would like to acknowledge with deep appreciation and respect, the staff at the Comprehensive HIV Center at Northwestern Memorial Hospital. A special thanks to Dr. Robert Hirschtick, Dr. Stephan Ferrando, Lisa Williams, Specialist RN, and Donna Graesser, M.Ed., R.D., for their participation in this research project.

I wish to thank those who provided technical assistance to the enhancement of this research effort. To Claire Kanerva for her skills as a statistical computer analyst. To Jim O’Laughlin who provided an objective view as well as insight as a reader. And to Valerie Collier for her word processing skills and conscientiousness to revisions. Thanks for your patience.

My deep appreciation to my family and friends for their years of support and encouragement to keep going. To my mother, Leota Downey, thanks for your faith in me and your love. To my children whose loving support kept me focused;
Ronald, Kevan, Steven, Amy and David. And to Lesley Olson whose friendship and support continues in memory. I’m grateful.

Above all others, I acknowledge the incredible support and love from my life partner, Thomas. His awareness and commitment to AIDS care nursed my spirits and energy during the difficult moments of this journey. He shares in this accomplishment.
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DEDICATION

This research effort is dedicated to the individuals who are courageously living with AIDS, and to those who have died from AIDS.
CHAPTER I

DEFINING THE TOPIC OF THE STUDY

"The challenge of HIV infections to society in general and health care professionals in particular represents the most dramatic and threatening public health problem of the decade, if not the century" (Cohen, 1990, p. 98).

INTRODUCTION

Having the Human Immunodeficiency Virus (HIV) is a major, stressful life event. It forces people to deal with many painful and difficult issues such as declining health with its attendant multiple losses, discrimination, and prejudice. The emotional distress that comes with living with HIV and its medical uncertainty is compounded by that of disclosing the diagnosis and one’s risk factor to family members and employers. This action threatens or destroys one’s supportive relationships from a personal, family, social, and employment perspective. The patient’s battle for survival is dependent on the scientific and medical management of the virus and sustaining hope while combating the stresses of living daily with HIV. We are now into the second decade of extensive scientific research and clinical trials, but are still without a cure for the deadly virus that causes Acquired Immune Deficiency Syndrome (AIDS).
Progress has been seen in the medical management of HIV through the timely use of prophylactic treatments to delay the onset of infections that further destroy the immune system. This focus on early intervention is a means to prolong life and delay the onset of AIDS through the appropriate use of antiretroviral drugs. Zidovudine (AZT) remains the most commonly used antiretroviral agent for treatment and is considered the first line of defense against this disease (Lipsky, 1994). The efficacy on the timely use of this drug has now been challenged.

In light of the recent published data from the Concorde Study, the antiretroviral drug AZT has been shown to have limited effectiveness in terms of disease progression and survival in early HIV disease (Aboulker & Swart, 1993). In response, a panel of experts was convened by the National Institute of Allergy and Infectious Disease which recommended that medical intervention in the earlier stages must now focus on education and counseling. Decisions as to when to start medical therapy must become negotiable, creating a shift away from a paternalistic approach in medicine towards a doctor and patient partnership in medical decision making. These changes will add more uncertainty and an increasing level of stress for those living with HIV and those providing care.
STATEMENT OF THE RESEARCH PROBLEM

With the major disruptions in the medical management of early HIV and the changes in treatment approach the possibility now exists that HIV-infected people in the early stage of the illness could experience a latency period in medical treatment, receiving health monitoring and counseling instead of active therapy. Survival in this stage of the HIV continuum will depend more on coping skills than on medical intervention. Research has shown that patients in the first two stages of HIV disease experience significantly higher levels of depression, mood disturbance and anxiety than do those patients with AIDS (Wadland & Gleeson, 1991). These disturbances, and a sense of helplessness and hopelessness, may be exacerbated by their need to rely on medical technology and a paternalistic approach to medical care.

PURPOSE OF THE STUDY

The purpose of this study was to examine the effectiveness of a biopsychosocial educational program in the pre-AIDS stage of the illness. This research project studied the efficacy of this model as a prophylactic intervention for decreasing stress that leads to depression and anxiety, while increasing the individual's health locus of control and medical compliance. This study was designed
from a cognitive-behavioral perspective utilizing the stress inoculation model to enhance coping, adaptability, and survival by creating hope, while at the same time helping people prepare for an illness defined by its uncertainty and unpredictability. This is a program of "preparation" that is contextual to the needs of HIV-infected patients and their loved ones as they proceed in their personal evolution and journey along the disease continuum to its final stage.

RATIONALE

In the current climate of health care reform and cost reductions, another layer of stress due to limitations of medical therapy is now being felt by people living with the HIV virus. This creates a significant need in this patient population for increased consumer education and mental health counseling that will promote a sense of control and empowerment in the earlier stages of this disease. The need exists for relevant and timely therapeutic methods for adaptive coping that seek to create synergy with the changing medical management for HIV in the early stages. A biopsychosocial perspective for mental health intervention serves as a "stress inoculation" against the emotional despair of being HIV infected. Since the stigma and fear of AIDS continues to be felt in society by those infected and those that care about them an increasing need exists for medical, social, economic, and legal resources.
DEFINITION OF TERMS

For the purpose of this study, the following key terms were defined.

**HIV-INFECTED PERSON:** An adult who has tested positive on the Enzyme-linked Immunosorbent Assay (Elisa) antibody and confirmed by the Western Blot test for HIV virus that causes AIDS.

**DEPRESSION:** Mood disturbance described as sadness, despair and discouragement. Symptoms may include feelings of helplessness and hopelessness with complaints of sleep disturbance, loss of appetite, fears of abandonment and death, along with a high risk for suicide. A range in levels of depression is universally experienced by HIV-infected individuals from a reactive to a clinical to an organic depression in the life-time of the disease.

**ANXIETY:** Apprehension, tension, and fears universally experienced by HIV-infected people when the stress and threat of a catastrophic illness overwhelms their capacity to cope. The presentation of physical and verbal expressions of anxiety begins with their diagnosis and continues at various levels throughout the illness around issues of disclosure of diagnosis, changes in symptoms and in their CD4 (T-lymphocyte cells) counts threatening the ability to cope.

**MEDICAL COMPLIANCE:** The extent to which a patient is
compliant to recommended medical advice by keeping scheduled clinic appointments. Information regarding compliance with clinic appointments was charted in the progress notes in the patients’ medical chart.

**BIOPSYCHOSOCIAL EDUCATIONAL PROGRAM:** A six week educational program designed from a medical model developed in a general systems conceptual framework to meet the patients’ multidimensional needs from a biological, psychological, and social perspective. Each of these needs is given equal weight in clinical formulations from an interdisciplinary perspective in developing the program.

**STRESS INOCULATION MODEL:** A cognitive-behavioral educational-skills-training approach of enabling behaviors as a "preparation" to empower people to cope with impending threatening events rather than being disorganized by anxiety or inappropriate actions as a result of denial of real dangers.

**HEALTH LOCUS OF CONTROL:** The extent to which individuals believe their behaviors result in the ability to exercise some control over their health situation. And they recognize their internal influence on their health as well as the influence of powerful others on health care decisions and outcomes.
This study examined four research hypotheses. The method for addressing their statistical significance is stated in Chapter III. The research findings are found in Chapter IV.

Hypothesis 1: Participation in a biopsychosocial educational program will result in a decrease in anxiety in the experimental group compared to the control group.

Hypothesis 2: Participation in a biopsychosocial educational program will result in a decrease in the mood disturbance of depression in the experimental group compared to the control group.

Hypothesis 3: The experimental group will show increased levels of locus of internal control versus physicians' and significant others' control as a result of their participation in the biopsychosocial educational program in comparison to the control group.

Hypothesis 4: Participation in a biopsychosocial educational program will result in a higher level of medical compliance among the experimental group versus the control group for a period of three months following the completion of the program.
SIGNIFICANCE FOR CLINICAL SOCIAL WORK

The dynamic interplay among the multidimensional needs of the HIV-infected person challenges Social Workers schooled in the biopsychosocial approach to promote survival through education and change. A vital need exists for Social Work leadership to develop multidisciplinary approaches for balancing the medical and psychosocial context of the disease with the internal and external strengths, resources, and supports that enhance coping and survival for HIV infected people. This holistic approach would create a triad of interactions between the person, the illness, and the environment.

Working with this at risk population epitomizes the view of the social work profession as a contemporary practice that is contextual, interactive and multimethod in orientation and characterized by the person-in-situation/person-in-environment interface (Saari, 1986). This psychoeducational program will help HIV-infected people to develop coping strategies that promote self-worth, self-esteem and options to "live with" rather than "die from" HIV/AIDS. This research effort speaks to the inherent social work values. And these values in purpose and method have an ethical responsibility to honor, to preserve, and to facilitate the patient's self-determination (Levy, 1983).
ASSUMPTIONS OF THE STUDY

This study was predicated on the assumption that the organizing content of the biopsychosocial educational program "Living with HIV" is a useful modality for HIV infected adults in the pre-AIDS stage of disease that merits attention. It was assumed, based on the literature and clinical observations, that the stressful situations impinging on this population lead to anxiety and depression. It was further assumed that cognitive-behavioral methods for addressing these stressful situations could result in strategies to increase coping abilities and decrease emotional distress.

The medical setting represents the major resource for the HIV-infected population. This study then assumed that the study methods and site would prove highly relevant for their needs. Further it assumed that graded exposure to the medical and psychosocial aspects of this disease is most appropriate for this setting, and that the interactions with their medical care team will provide a model for the present and future needs.

Finally, it was assumed that a program based on the stress inoculation model of preparation in the earlier stages has sustaining capabilities as the disease progresses.
AIDS, and its manifestations of the HIV infection is a paradigm of a medical illness in crisis. Changes in the early medical management of the HIV disease creates a challenge for an equal focus on the psychosocial management of the disease for those who are HIV-affected. One approach is a biopsychosocial educational program utilizing the stress inoculation model to create synergy between the changing medical care and the psychological, social, and environmental affront to patients' existence. This structured program is designed to provide opportunities to create equilibrium between the crisis reaction to being HIV-infected and the capacity for enhancing coping strategies to live daily with this disease.
CHAPTER II

REVIEW OF THE LITERATURE

In response to a paradigm in crisis, Kuhn (1970) states "let us then assume that crises are a necessary precondition for the emergence of novel theories and ask next how scientists respond to their existence" (p. 77).

INTRODUCTION

The Human Immunodeficiency Virus (HIV), with its manifestations that lead to Acquired Immune Deficiency Syndrome (AIDS), is a paradigm of a medical illness in crisis. Now after more than a decade of extensive research and clinical trials in a consistent effort to unravel the secrets of the HIV virus, the scientific world is still far from developing therapy to abate its advancement, let alone find a cure. In fact, a recent study revealed that the one drug that the medical community put all its hopes on, AZT, proved less effective over time in prolonging life and delaying the onset of AIDS than first anticipated. This unwelcome reality in the medical care of HIV-infected people creates a shift in the decision making process away from the dependency on medical technology and towards the creation of a partnership in care. It is now possible that infected
people in the earlier stage of the disease will depend more on coping skills than on medical intervention.

In the 1980's when AIDS was first diagnosed, the fever pitch for scientific intervention left hope for both control and cure of this deadly disease. Behavioral research at that time focused intensively on risk reduction change processes and, to a lesser extent, on the mental health needs of persons infected with HIV disease (Kelly & Murphy, 1992). The need now exists for research models of intervention that facilitate the psychological well-being of HIV-infected people, a cognitive-behavioral focus that will empower, sustain, and engage them in their health care in the earlier stage of the disease.

The following literature review was organized to be used in two ways: as a resource to support the clinical significance of the study, and as a tool in the therapeutic framework for intervention. The literature review includes: a) stages of HIV disease; b) impact of the earlier stages of disease; and c) theoretical framework for intervention.
STAGES OF THE HIV-DISEASE

AIDS is a life-threatening illness caused by the HIV virus that severely attacks and weakens a portion of the immune system. When the damage is severe, the body is left unable to fight off certain infections and cancers that healthy immune systems destroy with ease. The virus spreads by specific behaviors that directly expose one person's bloodstream to the infected body fluids of another, such as blood, semen, or vaginal fluid. The Center for Disease Control (CDC) reports that 17 million people in the world are infected with the HIV virus. The total number of infected persons in the United States is currently estimated at one million or about 1 in 250 persons. Those diagnosed with AIDS by the end of 1994 will be between 415,000-535,000, and the number of deaths to date along with projected deaths by the end of 1994 will be 312,000-385,000 (CDC, 1994). Statistics continue to draw our awareness to the devastation of this disease and the concomitant limitations of medical interventions. The HIV/AIDS virus is now the leading cause of death among American adult males ages 25-44 (CDC, 1995).

Exposure to HIV is greatest among a population engaging in high risk sexual and/or drug abuse behaviors. The majority of people infected with the virus in the United States are homosexual and bisexual men at 49%. A decline continues in this population due in large part to a well
orchestrated educational effort in the gay community. The areas of increase are among intravenous drug users (IVDU) at 33%, and women, due to both intravenous drug use and heterosexual contacts at 17% (CDC, 1995). Today, the most rapidly growing populations infected with HIV are women and teens. And with the growing number of women infected with HIV, health care providers are witnessing a rising number of newborn children also infected. AIDS is now the leading cause of death for young women between 21-35 years old in four major cities in the United States (CDC, 1994).

The first medical model of AIDS was that of a disease with an acute onset and a prognosis of two years or less. Prolonging life is now possible due to scientific advances in the identification of biological markers and antiviral therapies that slow down or control some infections. This has resulted in a reconceptualization of the HIV virus as a chronic illness (Grohman & MacDonell, 1992). The clinical view of the HIV virus is that of stages on a continuum from seropositive asymptomatic status to AIDS, the final stage. Although disease progression varies widely among individuals (Hamburg & Fauci, 1989) the three stages of illness typically will unfold between nine to twelve years from infection to AIDS:

Stage 1). an asymptomatic period of more than four years average duration.
Stage 2). symptomatic with AIDS-related complex for about five years.

Stage 3). AIDS characterized by various opportunistic infections, i.e., HIV wasting, HIV dementia, lymphomas, and CMV retinitis on an average of nine to 12 months for treated and untreated individuals combined, and 21 months for those receiving antiretroviral treatment (Lemp, et al., 1990).

It now appears that the diagnosis of AIDS will develop in most, if not all, HIV-infected individuals (Grohman & MacDonell, 1992).

The utility of a staging system explicitly imposes both a structure on the natural history of the disease and provides clinical markers for intervention (Royce, et al., 1991). Souri (1991) uses the stages as a schematic that provides his patients with both a basic knowledge of the disease and progression while also providing a realistic assessment of life expectancy. He does not indicate however, what other counseling sources he utilizes prior to and after this frank discussion.

Along with stages comes the biological markers of CD4 (T-lymphocyte cells) counts, the direct measure of the immunologic status that dictates treatment decisions (CDC, 1992). For this reason, CD4 counts are closely monitored
not only by the physician but the patient as well. The rise and fall of these counts due to multiple variables often results in general emotional distress, mood disturbance and anxiety for patients and their loved ones. The normal range for CD4 counts is 1000 with a plus or minus of 500 lymphocyte cells. An expanded classification system of stages includes corresponding CD4 counts and illustrates when medical interventions are indicated:

Stage 1./Category 1: \( \geq \) (greater than) 500 T-cells

Stage 2./Category 2: (between) 201-499 T-cells

Stage 3./Category 3: \( \leq \) (less than) 200 T-cells (MMWR, 1992).

Inherent with this classification system is the knowledge that infected people enter medical settings at various points on this continuum. This demands a bio-psychosocial assessment of the patient with interventions that are stage appropriate from the medical, psychological and psychosocial perspectives.

The paradigm of the AIDS illness that dictated medical management of early HIV infection has changed since the publication of the Concorde Study at the Ninth and Tenth International Conference on AIDS in 1993 and 1994,
respectively. This three year randomized, double-blind, placebo-controlled study found no significant benefits, in terms of either survival or disease progression, of early as opposed to delayed use of AZT, irrespective of the CD4 count (Aboulker & Swart, 1993; Lipsky, 1994). Before the report, newly infected people were typically started on AZT when their CD4 count was 500 or greater.

In response to the study, a panel of experts convened by the National Institute of Allergy and Infectious Disease offered several modifications of this and other aspects of treatment. First, they argued that in the absence of any clear advantage to early initiation of AZT, the decision of when to initiate AZT should become more of a negotiated process between the physician and the patient (Glick, 1993). Second, they strongly encouraged more education and counseling in the earlier stages of the illness. Third, they stressed the importance of creating a partnership in treatment decisions not only in early but also in advanced stage of the illness (Glick, 1993). Summarizing the new directions, Glick (1993) felt "the choice to accept or decline antiretroviral therapy will rest ultimately with the patient (p. 6).

In many clinical settings these recommendations represent a major departure in medical practice for both the physician and the patient. To execute them would entail a cognitive reframing in decision making from the patients'
dependency on technology to a collaborative process that involves more control, that is more empowering for the patients. It is possible that HIV-infected people in the earlier stages of the illness will experience a latency period in medical intervention, instead of active medical therapy they will undergo health monitoring and counseling. In fact, in the overall sequence of stages through which they will live and cope with this fatal disease, patients will spend the greatest amount of time in these early stages.

**IMPACT OF HIV DISEASE IN THE EARLIER STAGES**

Testing positive for HIV is a major stressful life event with feelings ranging from a period of shock and numbness, to excessive intrusive thoughts (Cohen, 1990; Ferrando, 1992; Wadland & Gleeson, 1991). Hearing that one has a disease without a cure, with limited available therapies, high elements of uncertainty, and a stigmatization from a society intolerant due to the route of transmission, is a crisis. Living with the stress of this chronic illness is compounded by living with the daily stresses of the 90’s and the pervasive feelings of insecurity. The reality of being HIV infected brings fears of infecting others, telling others, and losing the love and support of others. The crisis in this early stage, as
Wadland and Gleeson (1991) have observed, is expressed in symptoms of depression such as helplessness, hopelessness and worthlessness.

Being out of control is one of the most common basic fears. The crisis in learning that one has the HIV virus ignites this basic fear and often results in behaviors in search of control. Upon receiving the positive test results many people will challenge the validity of the test and the laboratory's credibility with demands to be retested. The resulting reenactment of the waiting period produces incredible stress and anxiety only to hear the confirmation that changes their lives forever.

The cognitive theory of stress and coping (Lazarus & Folkman, 1984) is centered on the ability to appraise personal control in a given event for stress reduction and adaptive coping. The reality testing of one's appraisal creates a balance between problem-focused and emotional-focused coping. However, situations of uncertainty and ambiguity prevent the necessary cues from which to make these determinations. An ensuing imbalance of emotional-focused coping occurs and a defense such as denial dominates.

Upon learning of his positive test during a routine physical exam a 27 year old man who claims a monogamous relationship for seven years, refused to accept the results. This was further reinforced when his partner
tested negative. He proceeded to be retested in four different medical settings. To his despair, they were all positive, and he was in the late stage of the disease. And his denial continued. As his counts declined and his disease progressed he still refused to take any antiretroviral therapy.

Traditionally, denial has been viewed as a maladaptive defense that interferes with our perception of reality, a hallmark of mental health. Denial, however, is an important coping defense for many HIV-infected people, for it allows them to continue to live "as if" the disease was not fatal, a workable strategy today given the limits of the scientific achievements against the HIV virus. Lazarus (1985) in his review of the cost and benefits of denial speaks of a "partial" denial that involves the capacity to bring the denied reality into awareness when necessary. An example of this is the reality of being at risk for HIV and being tested. The cost side of this denial is evident in the failure to return for results and avoidance of symptoms only to be suddenly admitted to a hospital with a progressive life-threatening illness. A crisis ensues for the patient and loved ones who were unaware and unprepared.

In our western society, personality is often predicated upon a powerful denial of finitude. Denial allows us to plan for the future, raise children and develop careers and contribute to society. Being HIV infected pierces that
important denial and leaves many individuals vulnerable to extreme existential anxiety. But it is also the process of denial that provides the individual the proper pacing in the revision and rebuilding of one's basic theories and assumptions of life (Janoff-Bulman & Timko, 1987). This important defense, when balanced in the context of the stress and coping theory, provides temporal transitions and the cognitive reframing from fear to hope.

The ability to prolong life through timely interventions has changed HIV from an acute to a chronic illness. Among the factors that enable patients to cope with a chronic illness is their belief in the ability to control their own health. A study examining feelings of control and adjustment to physical illness was conducted among patient's with cardiac disease, cancer and AIDS. The results found that belief in personal control is generally adaptive and appears to reduce anxiety. However, patients that tended to profit psychologically from a sense of personal control were patients with a good prognosis, as opposed to those with a poor prognosis (Taylor, Helgeson, Reed, & Skokan, 1991).

Folkman (1984) theorized that the generalized beliefs about personal control that individuals assume over important outcomes is a major influence in their cognitive appraisals of an event. Rotter (1975) formulated these beliefs into the internal-external locus of control studies.
Here events are contingent on the actions of one’s own behavior as internal control, and the actions of powerful others as external control. Wallston and colleagues (1978) developed the Multidimensional Health Locus of Control Scale based on Rotter's formulation with an interest in beliefs of personal control over one’s health situation. These scales have been recently expanded (Wallston et al., in press) that further splits powerful others between physicians and significant others. This dichotomy is a repeating theme on the HIV continuum between the patient’s desire for control and use of alternative methods compared to physician control. Differences often result in issues of compliance and noncompliance with the medical management of this illness.

Research conducted on the three clinical stages of HIV disease shows that patients in the first two stages experience significantly higher levels of depression, mood disturbance and anxiety than do those patients with AIDS (Wadland & Gleeson, 1991). This has important clinical implications since there are indications to suggest that people with AIDS would experience greater psychological disturbance given a shorter life-expectancy and increasing medical complications. Linn et al. (1993) in his study of depression and anxiety in adults infected with HIV hypothesized that people with more advanced HIV-related illness would experience higher levels of depression and
anxiety. This community based study (N=156) used self reporting scales that involved the Center for Epidemiological Studies Depression Scale, Anxiety Scale and the Perceived Coherence Scale with a predominately educated young male sample.

Study results indicated that the stage of HIV illness does not influence the respondents' sense of meaning and purpose, or their depression or anxiety. However, measures used to determine the stage of illness were based on reported symptoms over a 30 day period of time, and not interfaced with the CD4 counts, the accepted staging criteria. The study also found that regardless of the stage of illness, the degree to which patients derived meaning and purpose was a significant predictor of their level of depression and anxiety.

In another study, as part of a military universal screening for HIV, 422 men were diagnosed seropositive. They were further assessed for symptoms of anxiety and depression. Using both the Hamilton Anxiety Scale and Hamilton Depression Scale, 84.4% had the presence of anxiety and depression in the earliest stages of the illness (Brown, et al., 1992).

The relationship between stressful situations and psychological distress is commonly observed in patients suffering from a chronic illness (Cella, Mahon & Donovan, 1990; Folkman, 1993). The chronicity of HIV has a course
that will wax and wane over several years. The stressful impact of this illness is felt with the rise and fall of the individual's CD4 counts indicating disease activity. A study to measure the impact of disease recurrence was conducted on cancer patients who had been cancer free for at least six months and who experienced a recurrence. Instruments utilized in this study were the Impact of Event Scale and the Psychosocial Adjustment to Illness Scale given to forty eligible participants with a mean age of 60 years old. A significant stress response was evident on the Intrusion and Avoidance subscale of the IES. The mean Intrusion score was 18.0 (SD= 7.5) and the mean Avoidance score was 24.6 (SD=8.0). The researchers felt the results indicated these patients demonstrated as much stress-related symptomatology as people who present with trauma-induced stress disorders (Cella, Mahon & Donovan, 1990).

ANXIETY

The severe psychological stress associated with HIV infection also contributes to a greater prevalence of adjustment reactions with depressed or anxious mood than in the general population (Levine, et al., 1991). The experience of anxiety is universal at some point in asymptomatic or symptomatic HIV or AIDS individuals. However, about 30-50% of this population go on to meet DSM-III-R criteria for anxiety related disorders (Ferrando,
Anxiety for HIV-infected people is expressed in themes of danger or harm to themselves or to significant others, from the severity of panic attacks to the subtleness of inquiry. Differentiating what are unrealistic or excessive worries about bodily functions is made more difficult with HIV as it often presents with vague and diffuse symptoms.

A dynamic often seen with HIV-infected people is the cycle of vigilance "when I'm healthy I look for sickness" versus "when I'm sick I look for wellness." The anxiety of waiting for "something to happen" is expressed often among patients in the earlier stages. One patient was so overwhelmed with anxiety upon learning his diagnosis that he took to daily body scanning and examinations. He kept a flashlight in his bathroom to check inside his mouth and other areas of the body for any sign of change. He would also put on gloves upon entering his apartment and kept them on to protect him from any infections from his pet cat.

The anxiety heard in those who are well is also heard in those who are sick, creating another waiting cycle. Another patient whose progression of disease had become more complicated defined his vigilance in the following way:

"when I was sick before I had HIV there was always that moment when you knew you were getting better. You could feel yourself getting over the hump - now I look for that hump each day".
Another anxiety-provoking experience for those newly diagnosed is the fear of losing control over one's thought processes. They often complain that they are "not on top of things", a way of indirectly asking if they are mentally in control. For the well-informed, the fear of developing AIDS Dementia often leads to HIV Anxiety with symptoms that produce impairment in concentration and memory (Perry, 1990).

Many of those who are themselves infected are also living with HIV-related stresses that include the illness of partners, spouses, or family members. A major concern in this population is the repeated exposure to the trauma of death as caregivers and powers-of-attorneys producing features of post-traumatic stress disorder. This is often expressed in dream recollections and confusion between symptoms of others and their own, along with intrusive thoughts in the form of flashbacks. Anxiety and the overwhelming fears about general well-being and the loss of control are also heard in the discontinuity of "feeling well" yet having a disease that is life-threatening. It creates a sense of urgency and panic over what to do first. "Who can I tell, not who should I tell," now occupies and worries the infected person's thought processes.

Clinical experience with HIV infected people in the first stage finds that, due to emotional distress, many begin to prematurely plan and prepare for death due to their
feelings of helplessness and hopelessness. They tend to withdraw in their work focus or professional career goals. This can often lead to poor judgment and premature disclosure at work that threatens the loss of job, identity, income, benefits, and a quality of life. This phenomenon is often referred to as the Magic Johnson Syndrome.

The degree of generalized anxiety in this population will vary according to personality, culture, coping styles and stage of illness. Its outgrowth is the result of adjustment reactions to being HIV infected. Those struggling for control tend to overwhelm themselves with massive educational materials and alternative treatments. They are determined to be that first person who will "beat" this disease. Others with dependency issues experience overwhelming feelings of helplessness and endure greater adaptive problems in asserting their rights and entitlements. And still others will act out their fears with high risk and self-destructive behaviors such as unsafe sexual contacts, alcohol and drug abuse.

DEPRESSION

Depression is another universal reaction to a life-threatening illness that ranges from reactive to clinical and organic, of which an estimated 20-60% meet the DSM-III-R criteria for major depressions some time in their illness (Ferrando, 1992). Inherent with this disease that
causes immunosuppression is the dual effect on the central nervous system. Perry (1990) has found in his clinical practice that HIV-infected adults experience a subjective sense of mental slowing, forgetfulness, apathy, lethargy, social withdrawal, avoidance of complex tasks and personality change before the development of AIDS. A major difficulty for clinicians is distinguishing depression from the physical and/or organic symptoms from the HIV disease.

Beck (1985) saw three major negative patterns triggered by depression in the individual: a negative view of self; a negative view of experiences and the world; and the loss of an expected future. This triad of cognitive patterns is clinically expressed by HIV-infected individuals who describe feeling defective and separate from the rest of society. Individuals attach a prevailing sense of shame and worthlessness to their diagnosis that is overwhelming and dysfunctional. The negative experiences of rejection and abandonment are recurring themes as the disease unfolds, leaving a view of the future filled with unsurmountable obstacles. And finally, the remeasured life span of those infected with HIV creates an irreversible alteration in their future with the process of saying goodbye and preparing for death.

For homosexual and bisexual men the comorbidity between emotional distress and HIV has been established (Cohen, 1990; Ferrando, 1992; Levine et al., 1991; Perry et al.,
This factor further impacts on the psychological distress of being a member of a minority sexual culture. Perry (1990) found a 50% lifetime prevalence for depression in two major risk groups, homosexual and IVDU populations, prior to testing. It was felt that the emotional distress of being in this minority culture would result in higher scores on distress scales regardless of the HIV diagnosis (Britton, Zorski & Hobfall, 1993). Symptoms such as insomnia, low energy and motivation, decreased appetite, decreased libido, guilt, suicidal ideation and decreased concentration overlap with commonly seen symptoms in HIV. Depression tends to become chronic after the initial "adjustment reaction," especially in patients with a prior history of depression.

For gay men diagnosed with HIV the fears of disclosure dominate the fears of the disease. A major clinical issue with this population is the timing of the diagnosis with the coming out process. How the patients cognitively structure the event is related to their underlying beliefs, attitudes and assumptions about themselves (Beck, 1985). Having HIV according to Cohen and Abramowitz (1990) "may stir up self-blame, self-hatred, and internalized homophobia in certain gay or bisexual men" (p. 163). Along with these feelings are the issues of guilt and shame. Stone (1992) re-examined the role of shame in the post-traumatic stress disorder. He saw the affects of shame and guilt as
coassembled with fear, specifically the fear of punishment for a wrongful act.

Being HIV threatens the secretive lifestyle for many gay men unknown to family, employers and even neighbors, resulting in withdrawal. Anxiety and depression surround the dilemma of who to tell, when and how. Fierson (1987) found that communication was most strained between homosexual men with AIDS and their fathers, and least difficult between siblings. The art of maintaining secrets, not giving them up, has been a surviving technique in this culture. But as one gay infected man explained to his partner "being HIV is like being pregnant, it will soon have to come out".

Survivors' guilt is another dynamic that leads to depressive symptoms in this population. The mere fact of surviving, of existing, when your partner has died creates distress. Given modern medical advances, death among young people has long since ceased to be normal - but not for gay men. Clinics and physician offices continue to see many of the partners and friends of the earliest AIDS casualties whose role as caregivers brings "experience-near" familiarity with HIV. They often speak of these experiences as a mirror reflection of their own destiny. This population has had to endure massive losses with unresolved grief making death less an individual event, and more an environmental event (Sullivan, 1990). With the loss of so
many friends, patients' resources for support and care are limited, if not exhausted.

Newly diagnosed people whose risk factor was (and, for many, continues to be) intravenous drug use (IVDU) bring a history of depression and maladaptive coping to their new medical crisis. Perry (1990) found this major risk group had a 50% lifetime prevalence for depression prior to testing for HIV. Cohen (1990) postulated that psychopathology has a major role in the initiation, onset and course of AIDS in this population. Khantzian (cited in Cohen, 1990) has proposed that IV drug users are depressed individuals who seek drugs to medicate their depression. The affective disorders associated with buying, selling, and using drugs, coupled with HIV, places these individuals at an increased risk for suicide.

The chemically dependent person enters the medical setting with a well developed denial system and self-destructive behaviors. Attempts at cognitive restructuring for risk reduction behaviors, medical compliance and adaptive coping are made extremely difficult. The addictive habits which served to conceal the anxiety and depression in their lives prior to HIV are revisited during the early stage resulting in relapse. Unfortunately, the HIV disease with its debilitating processes eventually forces compliance when they lose ability to physically, cognitively and economically care for themselves.
Women constitute the fastest growing subset of the AIDS pandemic in the United States. HIV disease is more complicated, less understood and more misdiagnosed for women than any other subgroup. Very little literature exists for this population as most research and clinical trials have focused on the homosexual/bisexual male. But this is beginning to change. A study in Milan, Italy investigated the psychosocial problems of 71 HIV positive and negative women. The sample was of predominately single women, average 26 years, who were actively using intravenous drugs. Scales for anxiety, depression, social support and locus of control were utilized.

The findings revealed little difference between the groups. In fact, those who were HIV seropositive had lower levels of psychological morbidity. However, the findings did show that women with or at risk of HIV disease showed high levels of anxiety, depression and distress with a predominate external locus of control. It also found little use of condoms on a regular basis even for those infected. This important area of concern brought highly recommended psycho-educational interventions of counseling and support for those settings where women at risk or HIV-infected receive their medical care (Pergami et al., 1993).

Women, especially middle-class, heterosexual women do not perceive themselves to be at risk for contracting the HIV disease (Stentzner-Gibson, 1991). As a result, the
response to their diagnosis tends to include a more intense
denial with a decidedly heightened anger and rage. Feelings
of betrayal from their partner can be overwhelming as can
the profound grief over the losses of their health, body
image, and childbearing potential. Women with children have
the additional burden of guilt and fears for their
children's health and their future.

Suicidal ideation, with and without intent, among
persons with AIDS is many times greater than that of the
general public (Cohen, 1990; Wadland & Gleeson, 1991;
Ferrando, 1992). Levine et al. (1991) states that among
patients with catastrophic disease, HIV patients have
reported the highest suicide risks. McKegney and O’Dowd
(1992) studied suicidality in their Psychiatric Consultation
Service in a medical hospital. Their data indicated a lower
level of suicidality among patients with AIDS compared to
early stage HIV patients. The organicity level with
delirium and dementia in AIDS patients enhanced the use of
denial, an association reported over decades. Another
factor is that the fear of uncertainty in early HIV is
eliminated with the diagnosis of AIDS, allowing the person
to begin facing and mastering his fears of death.

Features that contribute to the risk of suicide are
feelings of hopelessness, impulsivity, substance abuse,
ilness, loss and grief, all now layered with the diagnosis
of HIV. The premorbid history of depression and suicide
attempts increases that risk. But for others, suicide as a future option is an attempt to take control of one's own destiny.

**THEORETICAL FRAMEWORK FOR INTERVENTIONS**

Several models for coping with stressful life events were found in the literature (Hobfall & Wolfisch, 1986; Shontz, 1975; Silver & Wortman, 1980). The models appear to share similar patterns and stages with a consensus on several facts: 1) people respond to crisis in specific, predictable ways - shock, anger, depression; 2) individuals go through a series of stages over time in attempting to come to terms with their aversive life events; and 3) people experience affective mood distress and anxiety.

In a theory of cognitive adaptation to threatening events, Taylor (1983) found in her research with breast cancer patients three dominant themes:

1). a search for meaning of the event;
2). attempts at regaining mastery and control over the event and over life in general; and
3). an effort to restore one's self-esteem through self-enhancing activities.

It is suggested that successfully resolving these concerns begins with the creation and maintenance of a set of illusions. These illusions are not intended to distort
reality, but cognitively reframe the facts in a particular light that promotes both the courage and the will to continue on in the face of adversity. A goal then of clinicians is to consistently appeal to the cognitive capabilities of the patient. Goldstein (1990) found that "effective practice is less a technical enterprise than it is a creative, reflective, and to a considerable extent, an artistic and dramatic event" (p. 38). Cognitively creating and maintaining hope for a cure, treatment, and time is a necessary goal (illusions) for HIV-infected people living with liminality (on the edge).

Perry et al. (1990) studied the effectiveness of three psychoeducational interventions on newly HIV tested individuals. The subjects were randomized to either standard counselling, six weeks of individual sessions of stress inoculation training, or three weeks of 45 minute video programs. Using self report and observer rated scales including the Beck Depression Scale, the study indicated that six week individual sessions with stress reducing techniques were most effective in reducing depression and anxiety. He concluded, however, that the difference in the response for each format may change in the different stages of the infection.

Cognitive approaches at reducing anxiety and depression for newly diagnosed people were the focus of a study by Wolcott and Fowzy (cited in Levine, et al., 1991) who found
that a ten week psychoeducational support group proved more effective as an intervention than a psychotherapy drop-in group. Levine et al. (1991) found their twenty week session psychoeducational group had very positive outcomes measured by improvement on the Hamilton Depression and Hamilton Anxiety Scales. They also found the group experience most helpful in the promotion of and participation in medical research protocols.

Namir et al. (1987) evaluated the relationship between different coping strategies and the psychological and health status of people with AIDS. They found that those who engaged in avoidance coping had a higher level of depressive symptoms, while those using active behavioral strategies had a lower mood disturbance. Most importantly, they found that strategies that focus on the maintenance of self-worth will increase feelings of control and combat passive, helpless feelings and despair (p. 326).

The sum of all variables for coping with HIV disease lies in the challenge and capacity to live daily with the illness. Siegel and Krause (1991) was the only study that qualitatively examined this issue with HIV-infected people in the pre-AIDS stage. The themes that emerged from the data provided three broad adaptive categories:

1). dealing with the possibility of a curtailed life span (creating a sense of urgency to obtain life goals, deciding to what extent to invest in the future).
2). **dealing with reactions to a stigmatizing illness** (deciding whom to tell about their diagnosis, and dealing with feelings of shame and contamination).

3). **developing strategies for maintaining physical and emotional health** (control and vigilance about one’s health).

In looking at factors that influence the adaptive process for chronic illness, Turk (1979) focused on personal meaning. He felt personal meaning is created in a triad of interplay between the individual person, the illness and environmental factors. The patient’s appraisal of his or her situation and its ascribed meaning is translated into behavioral responses back to the environment. It is important to realize that this dynamic is constantly changing and is bidirectional, with each element acting on the other.

The situational appraisal of control and coping are the two mediating processes in Lazarus and Folkman’s (1984) theory on stress and coping. When a situation is appraised as controllable, the coping tends to be more planful with decreases in emotional distress. Conversely, the more uncertain and ambiguous the situation and less controllable, the more likely the use of emotional-focused coping, and increased distress. Folkman et al. (1993) examined the coping appraisals of 425 gay men who completed self-report questionnaires by mail. They found that those who assessed
their situation as controllable used active strategies in coping and showed decreased depressed mood, while those who appraised their stress as low on controllability used escape-avoidance coping and had increased depressed mood.

The combined impact in the earlier stages of HIV of personal meanings of demoralization and fears and the growing uncertainty in treatment choices suggests the need for interventions that enhance perceptions for situational appraisals and strategies for survival with the current societal stresses.

STRESS INOCULATION MODEL

The stress inoculation model is a therapeutic intervention aligned with cognitive behavioral modification (CBM) or cognitive behavioral therapy (CBT). This widely adopted form of psychotherapy has been evolving since the 1970's. CBT combines the basic principles of cognitive therapy with behavioral activities to invoke adaptation and change in a short-term therapy format (Meichenbaum, 1992). Basic principles of CBT recognize that behavior is reciprocally determined; that emotions drive personal schemas; that behavior is phenomenologically oriented; and that collaboration and discovery processes are critically important. Other psychotherapeutic techniques subsumed under CBT are cognitive restructuring, problem-solving, anxiety management training and self-instructional training.
CBT has proven to be an effective intervention for generalized anxiety, depression, phobias, panic disorders, psychosomatic illness and pain control (Beck, 1993; Chambless & Gillis, 1993). The literature indicates a growing interest in this approach for therapeutic intervention for depression with people with HIV (Fishman, 1990, cited in Beck, 1993; Kelly et al., 1993). This is also true for the application of stress inoculation training for HIV populations (Perry, 1991). However, the literature supports a wider application of the stress inoculation training for anxiety, anger, posttraumatic stress disorders for rape victims, and surgical preparations in the general population.

Meichenbaum (1983) found there is an affinity between the transactional model of stress and the stress inoculation approach. The intervention procedures assist individuals in gaining the skills needed to manage and reduce stress, alter cognitions and develop adaptive behavioral coping strategies to reduce emotional distress (Kelly et al., 1993). Berlin (1983) found that the CBT analysis of coping suggests "that the transactions between people and their environment are primarily in the form of information exchange" (p. 1097). For people coping with the stress of a life-threatening illness the transactions include the patient, the illness and the environment. Due to the changes in life styles that
add to the etiology of disease incidence and prevalence, and to the growing interest in psychosomatic illnesses and stress research, applications of this model in the medical setting have been growing.

The stress inoculation model was developed to assist patients in the health care setting as a means of preparing them to cope with stressful medical situations. Janis (1983) defined stress inoculation as a procedure that "involves giving people realistic warnings, recommendations and reassurance to prepare them to cope with impending dangers or loss" (p. 67). This procedure of preparation can vary on a range of intensity from brief verbal and/or written instructions to a well formulated training program. A program inclusive of graded exposure to the stressful situations with skill enhancing coping strategies will help to reduce emotional distress and create opportunities for personal control.

Interest in helping people psychologically prepare themselves in dangerous situations began with Janis's military experience in World War II. His focus was on reducing battle fatigue and he coined his intervention "battle inoculation," later changed to "stress inoculation." An intervention for combat readiness would certainly include the affect of rage to off-set the paralysis of fear. People with HIV are "battling" an unspeakable foe and were it contained, rage might be an appropriate strategy for coping.
Janis (1983) felt that any preparatory communications are said to function as stress inoculation if it enables a person to increase his or her tolerance for subsequent threatening events. When successful, the process is called stress inoculation because it may be analogous to what happens when people are inoculated to produce antibodies that prevent disease. Strategies for living daily with HIV could thus be seen as psychological antibodies against the stressful assault of this illness.

A growing body of literature on the diverse use of stress inoculation training (SIT) (Blythe & Erdale, 1986; Diffenbacher, 1988; Janis, 1983; Meichenbaum & Cameron, 1983; Perry, 1991) identifies the unique and complementary strengths of the theoretical concepts. These include the rational restructuring and systematic desensitization interface of cognitive and behavioral therapy. The stress inoculation model is based on a collaborative effort in the cognitive reframing and reconstructing of the problem toward solutions that promote personal control and adaptive coping.

Meichenbaum and Cameron’s (1983) general stress inoculation training paradigm was developed as a skills training approach to anxiety management. Their paradigm contains three phases - educational, skills training, and application - that with modification can be applied to HIV seropositive patients in their pre-AIDS stage of disease:
Education/Conceptualization

1) begin to restructure and reframe cognitive schema of the HIV virus on a continuum creating hope.
2) break down the stressors of the disease into specific behaviors and reactions.
3) educate the patient and significant other on the nature and impact of stress.
4) challenge myths about alternative treatments with more realistic expectations that allow for strategies for healthy life styles and adaptation.
5) educate on legal and community resources that promote personal control and empowerment.

Skills Acquisition

1) explore current coping and how it affects the current situations.
2) provide problem-solving skills directed at modification, avoidance and minimization of "triggers" that produce stress.
3) palliative coping for dealing with uncertainty, i.e., self-talk, passive relaxation training.

Application and Rehearsal

1) preparation of use of coping skills through discussion of disclosure, employment dialogue, and physician visits with behavioral rehearsal.
2) use of graded exposure with HIV slides and discussion materials from physician and nurse
3) homework which might include self-talk phrases, relaxation techniques, journals.

Janis's (1983) use of stress inoculation on surgical patients indicated that preparatory information can inoculate people to withstand the disruptive and emotional reactions to surgery. In his review of other medical uses, he found this technique does not apply to all situations and the success of inoculation attempts will vary depending on the nature of the stress. Another recognized success of preparatory training is seen in the widely used Lamaze technique for childbirth.

Diffenbacher (1988) felt that "the best treatment fit would be to match the characteristics of the intervention to the most salient aspects of the patient's anxiety" (p. 94). Clearly, the need exists for expansion of clinical interventions in reducing the emotional stress of HIV in the medical setting, especially methods of preparation that help manage the deleterious effects of the physical, psychological, and social impact of this disease.
SUMMARY

The first two sections of the literature review provides a description of the illness and the emotional distress felt by HIV affected individuals in the early stages. The last section provides an integrative approach for stress reduction through a model that promotes personal control and empowerment. The goal of understanding the HIV disease is not a static event, but an on-going process that begins at the earliest contact and continues as the symptoms and disease progress.
CHAPTER III

METHODOLOGY AND PROCEDURES

When we listen, we forget;
When we read, we remember;
When we do, we understand.
Chinese Proverb

INTRODUCTION

This field research experiment was shaped by the true experimental design with its elements of pretest-posttest, randomization, and comparison groups. The combined characteristics of this design were ideal for providing evidence for a cause and effect relationship between variables (Yegides & Weinbach, 1991). The rigorous controls for validity have made this the most widely used of the experimental designs (Campbell & Stanley, 1963).

This study was designed to test the effectiveness of a biopsychosocial educational program entitled "Living with HIV" which was based on a cognitive-behavioral approach utilizing the "stress inoculation model." It was developed as an intervention for stress reduction and survival for people battling the HIV disease in the pre-AIDS stage. Patients living with the stress created by this
life-threatening illness need help navigating the maze of medical, legal, emotional and social reactions they experience daily. This program provides strategies as a first line of defense in training individuals to anticipate, prevent and cope with the emotional distress of being HIV-infected.

METHODOLOGY OF THE STUDY

This study examined the dependent variables of depression, anxiety, internal health locus of control, and medical compliance, against the independent variable a biopsychosocial educational program. The study subjects were randomized between experimental or control groups and participated in the pre-and-post assessment scales.

INDEPENDENT VARIABLE

"Living with HIV" is a model developed for this study. Its content is based on the major biopsychosocial issues identified through clinical observations in the early stages from a medical, social, legal and psychological perspective. This program was facilitated by a clinical social worker and included speakers from both the clinic and community. This interdisciplinary group included an infectious disease physician, psychiatrist, clinical nurse specialist, social worker, nutritionist, lawyer, and a representative from the
Social Security Administration. The goals of the program were threefold:

1. Promote medical education, medical compliance and risk reduction behaviors.
2. Enable patients to exercise more control over their health by becoming informed consumers of health care issues and services while forming decision-making partnerships with their Health Care Team.
3. Provide skill enhancing techniques for adaptive coping and reduction of emotional distress.

This program utilized the stress inoculation model of preparation for future threatening events and was balanced with a supportive relationship with the health care team, significant others, and community. The agenda for the six weekly sessions of ninety minutes per session consisted of the following:

SESSION 1. Introduction to "Living With HIV" Program

A. Program Overview
   Speaker: Social Worker
   1. Goals, Purpose and Methods
   2. Confidentiality
   3. Resource Packets

B. Introduction to the HIV Clinic
   Speaker: Clinical Nurse Specialist
   1. Overview of Clinic Structure and Operations
2. Clarification of Clinic Services
3. Nursing Role in Clinic Services
4. National Clinical Trial Center
5. HIV Service Team Inpatient Defined

SESSION 2. Medical Management of HIV Disease

A. Introduction to HIV Health Issues
   Speaker: Infectious Disease Physician
   1. Promoting a Partnership in Health Care
      Treatment Decisions
   2. HIV 101 - Basic Knowledge
   3. Primary and Secondary Prevention
   4. Interpreting Laboratory Results
   5. Strategies for Healthy Lifestyles

SESSION 3. HIV Nutrition

A. Introduction
   Speaker: Dietician
   1. Rationale
   2. Nutrition and Immune Function

B. Nutrition Throughout HIV Infection
   1. Prevention
   2. Restorative
   3. Supportive
   4. Palliative

C. Strategies For Improving Nutritional Status
   1. Normal Nutrition
   2. The Role of Each Nutrient
3. Water, Vitamins and Minerals
4. Special Considerations
5. Supplements
6. Ways to Increase Calories /Protein
7. Food Safety, Drug-Nutrient Interactions
8. Alternative Therapies

D. Activity Table
1. Food Recall and Pyramid
2. Supplement Tasting
3. Food Safety Quiz

SESSION 4. Legal Issues / Social Security

A. HIV Legal Issues
Speaker: Lawyer/AIDS Legal Council
1. Discrimination Laws: ADA
2. Confidentiality Laws
3. Power-of-Attorney: Health & Property
4. Estate Planning

B. Social Security Entitlements
Speaker: Social Security Representative
1. Review of benefits -Title II, SSA and SSI
2. Eligibility Criteria
3. Process of Claims and Appeal

SESSION 5. Resources for Empowerment

A. Health Insurance
Speaker: Clinical Social Worker
1. Understanding Managed Care: Traditional, HMO,
PPO, POS, Self Insured and Individual Policies
2. Understanding your Medical Coverage
3. Federal and State Insurance Coverage Medicare, Medicaid and ICHIP
4. Cobra Laws - 18 Months vs 29 Months
   Ryan White Funds - ICHIC

B. Additional Resources
   1. Federal Drug Reimbursement Program
   2. Compassionate Use Programs

SESSION 6. Handling Feelings and Stress

   Speaker: Psychiatrist

A. Identifying Stress
   1. Predisposition to Stress
   2. Coping with feelings and defenses
   3. Common Emotional Concerns
   4. Getting Help for Stress

B. Techniques for Stress Management
   Speakers: Psychiatrist/Clinical Social Worker
   1. Relaxation and Imagery
   2. Self-Statements to Enhance Coping
   3. Strategies for Living Daily with HIV

The sessions concluded with a review of some of the strategies for living daily with HIV with encouragement for participants to continue to build upon these for self-enhancement and empowerment (See Appendix C). In addition, a Program Evaluation was completed by those in
attendance at the last session (See Appendix C).

SAMPLE

The sample for this study consisted of nineteen (N=19) HIV seropositive adult patients registered with the Comprehensive HIV Clinic within a hospital setting. Eligibility for the study required that patients be diagnosed in the early stage of the HIV disease by their physician and be new to the clinic within the past six months. Other criteria for inclusion were: 1) CD4 (T-helper cell) count of greater than 200; 2) no evidence of opportunistic infections that define progression to AIDS; and 3) patients with a history of chemical dependency must have been in recovery for a period of three years.

This clinic population of adults at risk for HIV disease was representative of national norms with a majority of the patients being homosexual but with increasing numbers of intravenous drug users and women. A smaller number of hemophiliac patients completed the risk groups in the clinic. Patients seek medical interventions at various points on the clinical HIV continuum from those newly diagnosed and asymptomatic to those further progressed and symptomatic, to those with full-blown AIDS.

Recruitment for the study involved the posting of notices defining the study and its criteria at the clinic reception desk and the patient waiting room. In addition,
physicians informed those patients who were eligible about the study during their clinic visits. Discussing research protocols with patients was standard practice at this clinic due to the clinic’s participation as a national clinical trial site.

Unfortunately, at the time of recruitment the clinic experienced a majority of new patients further progressed in their illness leaving a smaller number eligible for this study. The nature of the disease with its high element of uncertainty and unpredictability, along with the individual’s idiosyncratic response to the virus and medical intervention, resulted in diagnostic changes from a pre-AIDS status to AIDS. Therefore, in an attempt to maintain criteria for inclusion in the study, the time frame for measuring the efficacy of the independent variable was set to five months.

Initially, 22 subjects agreed to participate, giving eleven (N=11) in the experimental group and eleven (N=11) in the control group. However, one subject (female) in the experimental group attended only one session and was then lost to follow-up after repeated attempts to make contact. Additional adjustments to the sample were made at the post-test period of time due to further attrition of two subjects (males) in the control group. One subject had moved out-of-town and the other was lost to follow-up. Again, numerous attempts to contact them were made without
response. Of the three subjects, two were less than 35 years old, and two had less than 500 CD4 counts.

Furthermore, two subjects in the experimental group had completed both the pre and post tests but didn't attend any sessions; they became part of the control group. This left a final sample configuration of eight (8) in the experimental group and eleven (11) in the control group for a total of nineteen (N=19) study subjects.

CONFIDENTIALITY

A major ethical concern when conducting research was the protection of the individual's confidentiality regarding their participation and response in a research project. From the beginning of the HIV crisis scientific research in the form of clinical trials had been the main source of medical intervention for HIV-infected people. The social and legal risks involved with this population in research had created state and federal laws for their protection. In addition, professional disciplines carried their own standards of ethical practice.

To protect the confidentiality of those in the study, the following steps were taken. All subjects were given a code number after agreeing to participate in the study. Their code numbers, along with their name, social security number and telephone numbers, were kept on a master list and locked in a confidential location and destroyed at the end
of the study. Personal information was needed for contact for pre and post test appointments as well as medical chart review for three months following the posttesting.

For those randomized to the program, first names only were used. Participants and their guests signed their first names on name tags used throughout the program. Finally, subjects were reassured that none of the research data would be included in their medical charts.

Ethical and moral considerations for research with human subjects in a hospital setting carried strict requirements and guidelines for conducting this study. Of major importance were concerns for confidentiality and for the methodological steps to be taken to protect other patient rights. Applications for this project were submitted in a required format and processed by three separate offices. First, the University's Office for the Protection of Research Subjects Institutional Review Board gave its approval for the use of human subjects for research purposes. Second, the Research Office and Research Committee of the hospital gave their approval for both scientific and administrative use. And thirdly, approval for this study was also sought and approved by the Institutional Review Board at Loyola University of Chicago (see Appendix E).
SETTING

The setting was in a large medical teaching center in its Comprehensive HIV Clinic (CHC) in a major midwestern city. This Clinic offered primary care and was a national clinical trial site with approximately 600 patient visits per month. The medical care was managed by an interdisciplinary staff which included infectious disease physicians, post doctorate fellows, psychiatrists, nurses, social workers, a dietitian, a respiratory therapist, and a phlebotomist. In addition, consultation services were also available in the Clinic from an oncologist, neurologist and ophthalmologist. Appointments for the study interviews often coincided with clinic visits or work schedules and were held in the Clinic in private rooms to insure confidentiality. The study program "Living with HIV" was also held in the clinic conference room to accommodate participants and their guests.
The process of quantifying the dependent variables for this study involved both self-report and observer rated instruments. Hamilton (1976) advocated for the observer rated process over the self-report. He felt it had theoretical advantages as observers were more likely to "penetrate the mask which patients tended to use to hide their symptoms" (p. 58). Corcoran and Fischer (1987) reported that quantification was beneficial in work with patients because it allowed you to monitor change mathematically. It was this presentation of change scores that created the interpretive process for clinical significance.

The purpose of this study was to examine the effectiveness of the program (independent variable) comparing the experimental and control groups in a measurement of change scores over time. Seven instruments were utilized beginning with the descriptive demographic data collected from the subjects and their medical records that included: sex, age, ethnicity, marital/partner status, education, employment, risk category, CD4 count and date of diagnosis. The psychological measurements included the following:
THE BECK DEPRESSION INVENTORY: The Beck Depression Inventory (BDI) (Beck, et al., 1961) was a self-administered 21 item scale designed to measure the severity of depressive symptoms with four alternative statements rated from 0 to 3. It had a score range from 1-63. The conventional cutoff score of greater than thirteen (13) was used with other HIV studies (Perry, et al., 1993). This depression scale was subjected to numerous tests to determine its reliability and validity. Internal consistency between the individual category scores and total scores was significantly beyond 0.001 level (Beck et al., 1961) and a split-half reliability coefficient ($r = 0.93$).

This psychological measurement had proven its appropriateness over time with a high level of utility, sensitivity, and directness in measuring manifested behaviors hence its overall suitability for the context of this study. However, the somatic items composing a portion of the BDI (e.g., fatigue, appetite loss and insomnia) may have reflected physical disease rather than depression (See Appendix D).

THE HAMILTON DEPRESSION RATING SCALE: The Hamilton Depression Rating Scale (HAMD) (Hamilton, 1976) was a 17 item scale rated on 3 to 5 point scale designed to assess depressive illness as a self-report or observer rated measurement. This study used the observer rated method following the 17 item Structured Interview Guide (Williams,
1988). This scale gave details on specific symptoms (e.g., suicidal ideation on items 7, 8, & 9) and identified different degrees of severity of depressive illness. A score of greater than thirteen (13) usually marked clinical depression. In combination with the BDI, the literature reported a high correlation in validity between the use of the two scales (HAMD=0.84; BDI=0.77). Reliability for the HAMD is 0.88 (See Appendix D).

**THE HAMILTON ANXIETY RATING SCALE:** The Hamilton Anxiety Rating Scale (HAS) (Hamilton, 1969) was an observer rated scale consisting of 14 biological descriptions designed for the rating of generalized anxiety states. The symptoms are bipolar, splitting them into two subscales between psychic (7) and somatic (7). Studies linking the HAS to diagnosis of generalized anxiety disorder used a cutoff score of greater than or equal to fourteen (14) and a median of twenty-five (25) for the DSM-IIIR Posttraumatic Stress Disorder (Beck et al., 1984; Perry et al., 1993) (See Appendix D).

**THE IMPACT OF EVENT SCALE:** In The Impact of Event Scale (IES) (Horowitz, Wilner & Alvarez, 1979) each subject was asked to complete this 15 item self report instrument designed to measure the stress associated with traumatic events. The authors intentionally did not define the event, but left this to the observer and respondent at the point of instructions on use. This instrument measured two
categories of response to traumatic events in subscales: **intrusive** (7) experiences such as images, troubled dreams and waves of feelings; **avoidance** (8) experiences such as conscious awareness of avoidance of certain ideas, feelings, meanings and their consequences (Horowitz et al., 1979).

A revision of this scale resulted in the current 15 item scale with a split-half reliability of the total score \( r=0.86 \). Additional internal consistency of the subscores using the Cronbach’s Alpha indicated intrusive at 0.78 and avoidance at 0.82. The measure had a test-retest reliability of 0.87. This instrument’s overall appropriateness included elements of utility in its use and scoring, suitability to the context of the population being studied, sensitivity to observation of change over time, and finally in its directness in capturing the signs of living daily with a life-threatening illness. Scoring for the IES in several recent studies had led to a selection of a score of twenty (20) as a cutoff for either subscale. Scores above twenty on either subscale were strongly predictive of a significant stress response and a DSM-IIIR Posttraumatic stress disorder (Cella et al., 1990) (See Appendix D).

**THE MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL SCALES:**
The Multidimensional Health Locus of Control Scales (MHLC) (Wallston et al., in press) was a recent expansion of the MHLC referred to as Form C. It differed from Form A and B in that the health condition was mentioned with the
instructions. Inserting HIV for the word condition added face validity and utility to this measure. Its design was to measure eighteen items of patients' belief regarding control over their health concerns from an internal Locus of Control (6), from chance (6), and from powerful other that further divides between the physician (3) and other (3). This study focused only on the scores for internal, and powerful others, which included physician and significant other.

This 18 item self report measure used a 6-point likert format ranging from strongly disagree to strongly agree scores. The MHLC had been revised from a unidimensional to a multidimensional scale improving the reliability of the internal consistency utilizing the Cronbach's alpha between 0.67 to 0.77. This additional scale increased the criterion validity. Total scores in each category indicated the level of effect HIV has on the subject (See Appendix D).

**THE MEDICAL REVIEW LOG:** The Medical Review Log (MRL) was a form created for this study to log both the experimental and control groups medical compliance for a period of three months following completion of the biopsychosocial education program and posttesting. Included on this form were the date of review, compliance per participant of scheduled clinic appointments, along with medication (oral, intravenous or aerosol) and specialty compliance. The major focus for this study was the participants compliance with clinic appointments. The
appointment book and medical charts were reviewed placing a Y (Yes) and N (No) for indication of compliance and NA (not appropriate) if appointment was not scheduled. No information was added to the patient's chart nor shared with other clinic staff members (See Appendix D).

PROCEDURES

Notices of the study describing its purpose and criteria were posted at both the reception desk and patient waiting room in the Clinic that included the project investigator's (PI) name and telephone number for contact (See Appendix A). The same information about the study was also given to those patients who met criteria from their physician during their clinic appointment. At the point of contact further explanations of the study were given and an appointment for pretesting was scheduled.

Participation in the study was voluntary and patients were not paid a fee. However, for those randomized to attend the program, the clinic provided a small grant to cover parking fees and light refreshments. Due to location and parking difficulties those subjects and guests traveling by car received stickers for the hospital parking facility. And with the time of the program in the early evening, light refreshments approved by the dietitian were provided.

A master list was developed that included the code
number, name, social security and telephone number of each subject as appointments were made (See Appendix A). This personal information was necessary for making contact for scheduling pre and post testing, maintaining attendance at the "Living with HIV" program, and identification of medical charts for the three month review. This master list was kept in the locked desk of the PI and destroyed at the end of the study. Randomization for this study was by code numbers as appointments were made and completed.

Individual appointments for the pretesting were made to accommodate the subjects' clinic or work schedule. Prior to data collection all subjects signed an informed consent to participate in the study (See Appendix B). First the demographic information was obtained that included sex, age, ethnicity, marital/partner status, education, employment, risk category, CD4 count, and date of HIV+ diagnosis (See Appendix D). Next a set of psychological inventories, both self-administered and observer rated, were given in the following order: the Beck Depression Inventory (BDI), Hamilton Depression Rating Scale (HAMD), Hamilton Anxiety Rating Scale (HAS), Impact of Event Scale (IES) and the Multidimensional Health Locus of Control Scale (HLOC) (See Appendix D). Total time for this process was less than 55 minutes.

At the completion of the pretest data collection, randomization between the experimental and control group was
done by code numbers. Those with odd numbers were experimental, and those with even numbers were control. The experimental group was given a schedule with the dates, time, and location for the program. In addition, each program participant was encouraged to invite up to two guests per session for the purpose of building support among their significant others. A secondary gain from such a program was the possible disclosure of patients' HIV medical situation to loved ones. Though this was not an issue being examined in this study, it represented an interest of the investigator. Those randomized to the control group were assured exposure to the program and informed the program would be repeated at the conclusion of the study and they and their guest would be invited to attend. In addition, all support services offered to clinic patients were available upon request.

The experimental intervention "Living with HIV" began one week after completion of the last interview. The importance of attending all six sessions was emphasized as a means of achieving the program's goals. It was expected that illness of the study participants might prevent attendance. In fact, illness was given as a reason for two of the participants missing the final session. However, the illness of the PI who was also the facilitator and speaker for the fifth session resulted in the group's decision to double up the last two sessions of Resources for Empowerment
and Handling Feelings, rather than adding an additional week. Participants were asked to contact the PI if they were unable to attend a session or if guests were not attending.

For those unable to attend a session the PI provided the participant and/or guest an outline and materials covering the topic of discussion. Non-attendance or missing more than three sessions significantly detracted from the program goals and its possible effectiveness on outcome measures. Two subjects who did not attend any sessions but completed pre and post test were excluded from the original experimental group assignment and thus included in the control group.

Sensitivity to the need for confidentiality of those attending the program was maintained by using first names on everyone's name tag. The program was held in the CHC Conference Room for comfort and to accommodate the speakers' audio and visual equipment needs. Resource packets with medical and community resources were given to each participant and their guests at the first session. Additional materials and resources from each session were then added to the packets. At the concluding session a program evaluation was available to the six subjects in attendance as were appointments for posttesting. Telephone contacts were made to all others to arrange for posttesting appointments.
At the posttest the subjects once again completed the psychological inventories that included: the Beck Depression Inventory (BDI), the Hamilton Rating Scale for Depression (HAMD), the Hamilton Anxiety Rating Scale (HAS), the Impact of Events Scale (IES) and Multidimensional Health Locus of Control Scales (HLOC). The average time frame for completing the posttest was less than 45 minutes. At the conclusion of the assessments, any comments given by the subjects about the materials and/or program in addition to the evaluation were noted. The control group was informed of the next scheduled "Living with HIV" program and invited to participate. This was scheduled after the chart reviews.

The three month medical chart review began at the conclusion of the posttest. This study was assessing the medical compliance of all study subjects based on adherence to their clinic appointments. Patients' were given medical appointments based on their individual medical condition and CD4 count, recognizing that not everyone was scheduled on a monthly basis. The Medical Review Log indicated compliance for scheduled appointments. It also looked at agreed upon medications and specialty referrals.

Information was obtained from the patients' medical records verified by name and social security number kept in the CHC record room. The physicians procedure notes were gleaned for compliance during the three month period of time. A clinic procedure for recording missed appointments
was a stamped notice in the medical charts, which provided attendance information for the study. All compliance information was noted on the Medical Review Log (See Appendix D) developed for this study by placing a Y (Yes) or N (No) or NA (Not Applicable) beside each category for each participant for three months.
RESEARCH HYPOTHESES

This study was designed to examine the effectiveness of a stress inoculation model to reduce emotional distress for HIV-infected people in their pre-AIDS stage through the four hypotheses listed below.

Hypothesis 1: Participation in a biopsychosocial educational program will result in a decrease in anxiety in the experimental group compared to the control group.

Hypothesis 2: Participation in a biopsychosocial educational program will result in a decrease in the mood disturbance of depression in the experimental group compared to the control group.

Hypothesis 3: The experimental group will show increased levels of locus of internal control versus physicians' and others' control as a result of their participation in the biopsychosocial educational program in comparison to the control group.

Hypothesis 4: Participation in a biopsychosocial educational program will result in an increase in medical compliance among the experimental group compared to the control group for a period of three months following the completion of the program.
DATA ANALYSIS AND INTERPRETATIONS

Descriptive and inferential statistics were used in the analysis of the demographic data and the four research hypotheses for this study. To begin with, it was customary to compile and present a summary description of the characteristics of the research sample into group form (Yegides & Weinbach, 1991). The descriptive analysis began with frequency tables by total sample then by groups to provide demographic differences and similarities of the sample under study. The Fisher’s Exact Test of Association for small samples was utilized. Summation of the demographic characteristics further defined the sample participants in this study.

Inferential statistics were used to analyze the four study hypotheses utilizing the raw scores from the assessment instruments. The analysis focused on the pretest versus posttest change scores between the experimental group compared to the control group. The most widely used acceptable test for looking at change scores was the t test with the analysis of covariance to level the pretest score (Campbell & Stanley, 1963). This study utilized the parametric t test for small samples with equal-interval data. The student’s t test of significance began with the measurements of differences on assessment scales within the groups utilizing the correlated paired t test for dependent
samples. This measured whether the differences from prescores to postscores within the experimental group and within the control group were different from zero.

The second application of the t test was to test the differences between groups utilizing the pooled t test for an independent two sample case. This procedure provided two separate comparisons to consider. The first compares differences between groups in their mean change from postscores minus the prescores. The second procedure compared differences in mean change of the experimental versus control groups for pre scores, or post scores.

Finally, an analysis of covariance (ANCOVA) permitted "a post-hoc, statistical control for one or more concomitant variables, removing their influence from the comparison of groups on the experiment factor" (Hays, 1994, p. 811). This statistical procedure was a way of testing the effect of the research experiment by adjusting for any equality of the prescore values. This study used the SAS System for Linear Models computer package.
LIMITATIONS OF THE STUDY

Inherent in all research studies is the awareness of limitations that affect the generalizability of its results. This study was no exception with limitations that involved: 1) a smaller sample size meeting criteria during recruitment, 2) adjustment to the "Living with HIV" program schedule, 3) sample attrition and adjustments to the size and group configuration, 4) attendance at the program, and 5) intervening effects of changes in the subjects' medical status and the influence of others.

The study experiment was dependent on the program content, materials, order of presentations and the abilities of the speakers to promote coping, adaptation and empowerment. Assessing the impact on change scores as a result of the independent variable for this population raised limitations on outcome results. For it was recognized that the media impact in reporting scientific failure, concerns over health care coverage, and the stigmatization of the HIV-infected populations during this time could not be controlled for its effects on outcome measurement. In addition, the idiosyncratic responses of the study subjects to their level of infection during the program suggested further implications for changes in emotional distress.

The ability to assess emotional distress within this
population at this stage of adjustment recognized a limitation to the study methods. Ongoing efforts to manage anxiety and depressive symptoms through medications external to the study were not identified or accounted for in this study. Though it might not have been a reason for exclusion for the purposes of this study, this undoubtedly would have added insight to the outcome data.

Such limitations did not diminish the importance of this biopsychosocial intervention as a vehicle for coping and surviving for HIV-infected people in the earlier stage of the disease. It further encourages replication that is content appropriate for the setting, population and stage of the illness.
CHAPTER IV

PRESENTATION AND ANALYSIS OF DATA

"Whether reducing distress or decreasing the risk of suicide is meaningful is a matter of values. By the same token, defining the minimum amount of change necessary to be meaningful is also a matter of values" (Hollon & Flick, 1988, p. 203).

INTRODUCTION

The purpose of this chapter was to report the results of the investigation of the effectiveness of the independent variable "Living with HIV", a biopsychosocial educational program. The study findings for this chapter were divided into three sections: 1) descriptive data, with subject characteristics and frequency findings, 2) inferential statistics, analysis using the t test, and 3) subjective responses, participants' feedback on the study.

The quantitative findings for this study were generated in three distinct time periods. The first time period yielded the data collection of the demographic information followed by the pretest psychological assessments scales. These scales were designed to measure depression, anxiety, impact of the event of HIV disease and health locus of control. Subjects were asked to respond to the assessment
questions based on their feelings and experiences from the past seven days. The instruments included the Beck Depression Inventory (BDI), the Hamilton Depression Rating Scale (HAMD), the Hamilton Anxiety Rating Scale (HAS), the Impact of Event Scale (IES), and the Health Locus of Control Scale (Form C) (HLOC). All participants completed the scales.

The second time period began at the completion of the study intervention that consisted of a six week biopsychosocial educational program entitled "Living with HIV". This program began in January and was completed in February, 1994. At the conclusion of the program, nineteen participants were again administered the same five assessment scales as a post-test measurement. The third time period began at the completion of the post-test and involved a three month medical chart review to assess the participants' medical compliance. Charting of study compliance measurements were made on a form created for this study called a Medical Review Log.

The subjective response of the participants to the study experience was generated at the completion of the study. The experimental group was asked to complete a program evaluation on the last night of the program. Six participants attended and completed the evaluation. Responses are reported here, however, any clinical significance this might add is presented in the next chapter.
on discussion and implications of the study.

DESCRIPTIVE DATA AND ANALYSIS

Demographic information was collected on all 19 subjects at the pretest time period that included sex, age, ethnicity, marital/partner status, education, employment, risk factor, CD4 count, and time of diagnosis. The following presentation and charts are a descriptive analysis of the demographic characteristics of the sample.

SUBJECT CHARACTERISTICS

The sample's age ranged from 25 to 46 years, with a mean age of 34.4 (SD= 6.14). Sixteen percent (N=3) were in their twenties, sixty-three percent (N=12) in their thirties and twenty-one (N=4) in their forties (See Figure 1).

The majority of the sample were men, eighty-four percent (N=16), which is consistent with national norms for this disease. Sixteen percent (N=3) were female. The ethnicity of the sample consisted of sixty-eight percent (N=13) Caucasians, twenty-one percent (N=4) African-American and eleven percent (N=2) Hispanic (See Figure 2).

Educational achievement was evident in this sample with a median education level of 16, which represents a college degree (range 12-19 years). Twenty-six percent (N=5) completed their education with their high school diploma.
FIGURE 1: AGE
PARTICIPANT DEMOGRAPHICS

40 - 46 Years
4

25 - 29 Years
3

30 - 39 Years
12

FIGURE 2: ETHNICITY
PARTICIPANT DEMOGRAPHICS

Caucasian
13

Hispanic
2

African-American
4
Ten percent (N=2) had at least two years of college and ten percent (N=2) had completed three years of college. Further education consisted of thirty-three percent (N=6) who completed a college degree. And twenty-one percent (N=4) achieved graduate degrees with two at the masters level and two doctorate of law degrees (See Figure 3).

A majority of the sample reported they were employed with seventy-four percent (N=14) working full-time, ten percent (N=2) as part-time and sixteen percent (N=3) as unemployed. Of those unemployed, one was a housewife and one was a full-time graduate student.

In terms of marital/partner status, seventy-four percent (N=14) defined themselves as single. Eleven percent (N=2) were married, and eleven percent (N=2) had live-in-partners. And four percent (N=1) were widowed. In terms of risk factors for HIV, eighty-four percent (N=16) reported their risk factor as homosexual, again meeting national norms as the major risk group. Sixteen percent (N=3) reported heterosexual contact as their risk factor (See Figure 4).

Normal CD4 (T-helper cells) counts for healthy individuals was 1000, with a plus or minus 500. The CD4 count was a direct measure of the immunologic status of HIV-infected individuals and was considered the most important marker of the disease progression. Since the CD4 count declined during the course of illness, antiretroviral
FIGURE 3: EDUCATIONAL ACHIEVEMENT
PARTICIPANT DEMOGRAPHICS

- Masters Degree: 2
- Law Degree: 2
- Some/College: 4
- College: 6
- High School: 5

FIGURE 4: HIV RISK FACTOR
PARTICIPANT DEMOGRAPHICS

- Homosexual: 16
- Heterosexual: 3
therapy was now suggested to patients with a CD4 count of less than 500. With less than a 200 CD4 count, therapy to prevent or control pneumocystic carinii pneumonia was initiated.

At the time of the data collection the samples' CD4 (T-helper cells) counts were as follows: twenty-one percent (N=4) were between 201-300; thirty-two percent (N=6) were between 301-400; twenty-one percent (N=4) were between 401-500; ten percent (N=2) were between 501-600; and sixteen percent (N=3) had greater than 601 CD4 counts (See Figure 5).

Finally, HIV seropositive people entered the medical system at different stages on the HIV continuum due to a variety of factors. Among these factors were delayed testing, change in medical services or denial. The following variability in the time since diagnosis in this sample supported this view: fifty-eight percent (N=11) had been diagnosed less than a year; eleven percent (N=2) diagnosed one to two years; eleven percent (N=2) diagnosed three to four years; sixteen percent (N=3) diagnosed five to six years; and four percent (N=1) diagnosed more than six years (See Figure 6).
FIGURE 5: CD4 COUNTS
PARTICIPANT DEMOGRAPHICS

<table>
<thead>
<tr>
<th>CD4 Count Range</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greater Than 601</td>
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<tr>
<td>501 - 600</td>
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<tr>
<td>201 - 300</td>
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</tr>
<tr>
<td>401 - 500</td>
<td>4</td>
</tr>
<tr>
<td>301 - 400</td>
<td>6</td>
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</table>

FIGURE 6: TIME OF DIAGNOSIS
PARTICIPANT DEMOGRAPHICS

<table>
<thead>
<tr>
<th>Time of Diagnosis</th>
<th>Count</th>
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<tbody>
<tr>
<td>Less than a year</td>
<td>11</td>
</tr>
<tr>
<td>1 - 2 years</td>
<td>2</td>
</tr>
<tr>
<td>3 - 4 years</td>
<td>2</td>
</tr>
<tr>
<td>5 - 6 years</td>
<td>3</td>
</tr>
<tr>
<td>Greater than 7 years</td>
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</tr>
</tbody>
</table>
GROUP CHARACTERISTICS

The demographic characteristics were divided into a 2x2 contingency table for evidence of association with the Fisher’s Exact Test for small samples. They are presented first from a total sample perspective (see Table 1), followed by experimental and control group (see Table 2). The findings provided evidence of significant differences between groups at the p < .05 and p < .07 levels.

These demographic findings suggested some divergent patterns between the experimental and control groups. An example of differences was seen with age, education, CD4 count and the time of diagnosis. For instance, comparing those under 35 to those over 35 years old, the experimental group had seventy-five percent (N=6) under and twenty-five percent (N=2) over the age of 35. This compared to the control group with forty-five percent (N=5) under and fifty-five percent (N=6) over 35. Fisher’s exact two-tail test was 0.352 significant at p < .05.

The educational level was divided for this sample between low education (high school plus some college) and high education (college plus). The experimental group had thirty-eight percent (N=3) low and sixty-two percent (N=5) high. This compared to the control group with fifty-five (N=6) low and forty-five (N=5) for high resulting in a Fisher’s Exact Test of 0.650 (two-tail test) at p < .07.
### TABLE 1. SAMPLE DEMOGRAPHIC FREQUENCIES

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<tr>
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</tr>
<tr>
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<tr>
<td>less than 1 Year</td>
<td>11</td>
<td>58</td>
</tr>
<tr>
<td>greater than 1 Year</td>
<td>8</td>
<td>42</td>
</tr>
</tbody>
</table>

M/P = Marital Partner  
TOD = Time of Diagnosis  
CD4 = T-Helper Cells
TABLE 2. DEMOGRAPHIC FREQUENCIES BY RANDOMIZED GROUPS

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Experimental</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
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<td>75</td>
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<td>38</td>
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<tr>
<td>High</td>
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<td>62</td>
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<tr>
<td>EMPLOY</td>
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<td>75</td>
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<td>CD4</td>
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<td></td>
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<tr>
<td>less 500</td>
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<td>100</td>
</tr>
<tr>
<td>greater 500</td>
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<td>0</td>
</tr>
<tr>
<td>TOD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>less 1 Yr</td>
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<td>88</td>
</tr>
<tr>
<td>greater 1 Yr</td>
<td>1</td>
<td>12</td>
</tr>
</tbody>
</table>

Fisher's Exact Test
*Significant at p < .05 - group differences
The CD4 (T-Helper cells) count was divided between less than 500 or over 500 CD4 counts. The experimental group had 100 percent (N=8) under 500, compared to the control group which had fifty-five percent (N=6) under and forty-five percent (N=5) over 500. Results of the Fisher's Exact Test of 0.045 (two-tail test) was significant at p < .05.

Finally, the time of diagnosis was divided between those diagnosed less than a year and those greater than a year. A significant difference was seen with eighty-eight percent (N=7) less than a year and twelve percent (N=1) greater than a year in the experimental group. This compared to the control group with thirty-six percent (N=4) less than a year and sixty-four (N=7) greater than a year. Measurement on the Fisher's Exact Test of 0.037 (two-tail test) was significant at p < .05.

SUMMARY OF DESCRIPTIVE DATA

To summarize the demographic frequency by total sample there were heterogenous patterns beginning with the number of males (84%) versus females (16%). The reported major risk factor was due to homosexual (84%) as against heterosexual (16%) partners. The ethnicity of the sample was caucasian (68%) and African Americans (21%) and Hispanic (11%). Age was divided between those under 35 (58%) and those over 35 (42%).

The majority of the sample defined themselves as single
with married, partners and widowed at (26%). Those working full-time (74%) were compared to part-time or not working at (26%). Subjects who were diagnosed HIV positive less than a year (58%) were compared to those greater than a year (42%). And finally, at the time of the study those with CD4 counts of less than 500 (53%) were compared to those with CD4 counts greater than 500 (47%).

Specific demographic variables that included age, education, CD4 count and time of diagnosis provided information suggestive of sample trends. For instance, the experimental group was younger (75% vs 45%), had higher educated members (62% vs 45%), had a lower CD4 count at the time of the study (100% vs 55%) and finally, had been diagnosed HIV positive within a shorter time period of less than a year (88% vs 36%) than the control group. The possible influence these sample trends had on the outcome data has yet to be established.
INFERENTIAL STATISTICS

Four hypotheses provided focus for this study. These hypotheses were stated in the positive form and tested for significance at the $P < .05$ level. The analysis of the four stated study hypotheses focused on the change scores between groups and within the experimental group for any reliable change. Measurements for change used the t-test for dependent and independent small samples with Analysis of Covariance (ANCOVA) as a statistical control. The data analysis begins with two tables reporting group measures of psychological distress. The first table reported means and standard deviations (see Table 3), and the second reported means and mean change scores (see Table 4). This was followed by reviewing each study hypothesis and its corresponding psychological assessment scores (Hypotheses 1, 2 and 3) and the medical review log (Hypothesis 4).

The goal of this research analysis was to test whether the "stress inoculation model", a model of preparation, could serve as a vehicle for reducing emotional distress. And to do so, by investigating change scores for indications of stress reduction and coping improvements. Recognizing that with a disease as threatening as HIV, change even in small increments improved one's quality of life.
### TABLE 3. MEASURES OF PSYCHOLOGICAL DISTRESS BY GROUPS

<table>
<thead>
<tr>
<th>TEST</th>
<th>EXPERIMENTAL (8)</th>
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<th></th>
<th>CONTROL (11)</th>
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<tr>
<td></td>
<td>PRE</td>
<td>M</td>
<td>SD</td>
<td>POST</td>
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<td>SD</td>
</tr>
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<td>12.00</td>
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<td>7.6</td>
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<td>9.12</td>
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<td>9.81</td>
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</tbody>
</table>

*HAMD: fourteen or greater indicates depressive symptoms.
*HAS: fourteen or greater indicates generalized anxiety.
*ISEA: twenty or greater indicates post-traumatic stress.
<table>
<thead>
<tr>
<th>TEST</th>
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<th>POST</th>
<th>CHANGE SCORE</th>
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<th>PRE</th>
<th>POST</th>
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<td>12.00</td>
<td>-4.00*</td>
<td>12.81</td>
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<td>-0.36</td>
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<td>-0.12</td>
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<td>-0.18</td>
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<td>0.37</td>
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</table>

* Paired t-test at -2.29 (one-tail test), P < .05.
**HAMD: fourteen or greater indicates depressive symptoms. Change score = post score minus pre score.
STUDY HYPOTHESES

In this subsection the results of the hypotheses testing are reported. To measure change over time, the correlated t-test and pooled t-test with the statistical control of ANCOVA were used. Level of significance was set at $P < .05$.

Hypothesis 1: Participation in the biopsychosocial educational program "Living with HIV" will result in a decrease in anxiety in the experimental group compared to the control group.

Measuring anxiety as a reaction to stress was obtained from two scales, the Hamilton Anxiety Rating Scale (HAS) and the Impact of Event Scale (IES). The Structured Interview Guide (Sigh-AD) was utilized in the administering of the HAS, an observer rated scale for this study. The potential range in score was 0-56 with the cut-off score of fourteen (14) for generalized anxiety disorder and a median of twenty-five (25) for the DSM III-R Posttraumatic Stress Syndrome. A higher score indicated higher anxiety.

Table 5 presents the HAS means distribution by sample and by group. By sample, fifty-three percent ($N=10$) met the criteria for generalized anxiety disorder in both pre and post test with fifty percent ($N=4$) in the experimental group and fifty-five percent ($N=6$) in the control group. The data
for the experimental group reported a higher level of anxiety than the control group with only a slight decline in the postscore. Their scores on both pre and post scales were above the cut-off of fourteen and highly suggestive of the diagnosis of generalized anxiety disorder during the study. Two of these subjects had positive change scores with decreases in their anxiety scores (20-14; 23-12). One participant showed an increase in anxiety state with an increased score (13-19). Scores for the control group for both pre and post tests were below the cut-off score of fourteen. They showed a slight decline in the post-test.

**TABLE 5. DISTRIBUTION OF GROUP MEAN SCORES ON THE HAMILTON ANXIETY SCALE**

<table>
<thead>
<tr>
<th></th>
<th>PRE TEST</th>
<th>POST TEST</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range</td>
<td>Mean</td>
</tr>
<tr>
<td>ALL (N=19)</td>
<td>1-36</td>
<td>14.36*</td>
</tr>
<tr>
<td>EXPERIMENTAL</td>
<td>4-27</td>
<td>15.50*</td>
</tr>
<tr>
<td>CONTROL</td>
<td>1-36</td>
<td>13.54</td>
</tr>
</tbody>
</table>

* HAS: score of fourteen or greater indicates generalized anxiety disorder.

Analysis of the correlated t-test (t=-0.160) within the experimental group and the pooled t-test (t=0.193) between groups was not statistically significant. This supported
the null hypothesis that there was no decrease in activity between the experimental group compared to the control group. The ANCOVA statistical control found no differences in mean values after adjusting for the HAS prescore.

The HAS assessment for Posttraumatic Stress Syndrome using the median score of twenty-five (25) found the sample (N=19) with a 15.00 for both pre and post scores. The control group had a median prescore of 15.00 and a postscore of 16.00 with an increase of 1.0. The experimental group had a median prescore of 15.00 and a postscore of 14.50 showing a decrease of -0.50. Scores by groups did not meet the criteria for Posttraumatic Stress Disorder, but did so by two individual scores. One (13%) in the experimental group had a prescore of twenty-seven, and a postscore of twenty-five. And one (9%) in the control group had a prescore of thirty-six and declined to eighteen in the postscore. Both subjects' scores are suggestive of the DSM III-R diagnosis for Posttraumatic Stress Syndrome during the study.

Table 6 provided a second look at the HAS but through a modified version of this bipolar scale. Here the scale allowed a measurement of the psychic features separate from the somatic symptoms. Of interest were postscores of the experimental group indicating change in the cognitive reframing of events as promoted with the stress inoculation model. After eliminating items under the somatic subscale
that could be present because of the direct physiological effects of HIV infection, i.e., genitourinary, gastrointestinal, autonomic, cardiovascular, and respiratory symptoms, a seven item psychological subscale was left. It had a rating of 0-4 per item with a possible range of scores from 0-24. The subscale for psychic features included anxious mood, tension, fears, insomnia, cognitive, depressed mood, and behavior during the interview. The following table displays the postscores of the subscale that included both psychic and somatic features for comparisons.

**TABLE 6. SCORES, MEANS AND STANDARD DEVIATIONS FOR HAS POST SUBSCALES**

<table>
<thead>
<tr>
<th></th>
<th>EXPERIMENTAL (N=8)</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Score</td>
<td>Mean</td>
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<td>93</td>
<td>11.62*</td>
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<tr>
<td>SOMATICS</td>
<td>25</td>
<td>4.16</td>
</tr>
</tbody>
</table>

*pooled t-test (t = -1.394 one-tailed test) p < .05

Table 6 outcome data did not provide enough evidence to show the experimental group had less anxiety than the control group using the modified HAS. Psychological distress rather than somatic disturbances of the HAS appeared to represent the major response for this HIV-infected sample. This was particularly evident in the
experimental group where tension was rated highest with feelings of restlessness, startled response and easily moved to tears as most identifiable to their experiences.

The Impact of Event Scale (IES) was a fifteen (15) item self-report scale developed to assess the subjective impact of a stressful life event. The scale was recognized for its sensitivity to detect change in clinical status over time. The items were divided into subscales with seven (7) intrusion and eight (8) avoidance items. It had a response choice of: Not at all, Rarely, Sometimes, and Often, with a range in score from 1-60. Being HIV-infected was the defining stressful life event appropriately inserted for this study at the point of assessment. A score above twenty (20) on either subscale on the IES was strongly predictive of a significant stress response and a DSM III-R Posttraumatic Stress Syndrome diagnosis.

Table 7 presents the score range, mean and standard deviation of the pre and post scores for the two items of intrusion and avoidance by group. Again, the data suggested a higher stress response in the experimental group compared to the control group. The experimental group showed a broader range in scores and a higher level of intrusion and avoidance in their reported subjective responses. The experimental group had five (63%) and the control group had six (55%) subjects above the cut-off in at least one subscale for the pre and post scores. For both groups,
avoidance maneuvers scored higher than intrusive thoughts.

**TABLE 7. MEANS AND STANDARD DEVIATIONS FOR GROUP IMPACT OF EVENT SCALE**

<table>
<thead>
<tr>
<th>EXTERNAL (N=8)</th>
<th>CONTROL (N=11)</th>
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</thead>
<tbody>
<tr>
<td>RANGE MEAN SD</td>
<td>RANGE MEAN SD</td>
</tr>
<tr>
<td>INTRUSION/PRE 9-24 15.60 4.9</td>
<td>7-22 12.00 5.8</td>
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<tr>
<td>INTRUSION/POST 12-21 16.70 3.0</td>
<td>7-19 13.36 4.2</td>
</tr>
<tr>
<td>AVOIDANCE/PRE 8-26 18.00 5.9</td>
<td>8-25 13.63 5.3</td>
</tr>
<tr>
<td>AVOIDANCE/POST 17-26 20.75* 3.4</td>
<td>8-23 14.35 4.4</td>
</tr>
</tbody>
</table>

* t = 3.38 (one-tail test), p < .05 Pooled t-test
* t = 2.65 (one-tail test), p < .05 ANCOVA

The correlated t-test to assess differences within the group was not significant. However, the pooled t-test to assess differences between the groups was significant in the post avoidance. When applying the analysis of covariance control an increase in mean values of avoidance in the experimental group was again significant after adjusting for the pretest. Increases instead of the anticipated decreases in stress response were found in the experimental group.

The study hypothesis was attempting to replicate the stress response theory with an oscillating declining pattern between intrusive thoughts met with avoidance maneuvers in a downward spiralling effect. The data indicated the opposite for both groups with increasing intrusive thoughts met with
increased avoidance maneuvers. For the experimental group, the level of avoidance was more intense in comparison to the level of intrusive thoughts.

Data on the HAS, the modified HAS and the IES scales appeared to indicate the groups were more alike than different. The mean scores for the experimental group tended to display higher levels of anxiety and stress compared to the control group. The hypothesis for decreased anxiety in the experimental group attending the "Living with HIV" program compared to the control group was not supported by the outcome data.

Hypothesis 2: Participation in the biopsychosocial educational program "Living with HIV" will result in a decrease in the mood disturbance of depression in the experimental group compared to the control.

Once again two scales were used to measure mood disturbance, the Beck Depression Inventory (BDI) that was self-administered and the Hamilton Depression Rating Scale (HAMD) that was observer rated. The BDI is a self-administered twenty-one (21) item scale designed to measure the severity of depressive symptoms. The scale has four alternative statements per question with a range in score from 0 to 63. The conventional cut-off score of greater than thirteen (13) was used to indicate the presence of
depressive symptoms (Perry et al., 1993).

Table 8 presents mean scores with range and standard deviation by sample and group. By total sample, both pre and post scores were below the cut-off score for depression. Sixty-three percent (N=5) of subjects in the pretest in the experimental group, and thirty-eight percent (N=3) in the posttest met the criteria for the presence of depression. The mean change score of -1.125 indicates a decline in depression for the experimental group.

| TABLE 8. DISTRIBUTION OF GROUP MEAN SCORES ON THE BECK DEPRESSION INVENTORY SCALE |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                                  | PRE TEST Range  | Mean            | SD              |
|                                  | POST TEST Range | Mean            | SD              |
| ALL (N=19)                      | 1-24            | 10.89           | 7.5             | 0-25            | 10.63           | 7.0             |
| EXPERIMENTAL                    | 2-24            | 13.87           | 8.6             | 2-19            | 12.75           | 8.1             |
| CONTROL                         | 1-22            | 8.72            | 6.1             | 0-25            | 9.09            | 8.1             |

Of those meeting criteria for depression in the control group there were eighteen percent (N=2) in the pretest and forty-five percent (N=4) in the posttest. A decline in depressive symptoms in the experimental group was seen in the mean change scores between groups and within their group. The pooled-t-test between groups had a mean change score of -1.125 with $P < .6360$. The correlated paired
t-test had a mean change score of -1.125, and a \( P < .6658 \). The ANCOVA's were not statistically significant nor were the t tests.

The Hamilton Depression Scale HAMD was a 17 item observer rated scale. Utilizing The Structured Interview Guide (Sigh-AD) the scale had a 0-1 (per 4 items), 0-2 (per 6 items) and 0-4 (per 7 items) and a range in score between 0-44. The scale was designed to assess depressive illness and gave details on specific symptoms (e.g., suicidal ideation 7, 8, 9 & 10) with different degrees of severity. A score greater than thirteen (13) usually marked clinical depression. Reliability for the HAMD was 0.88. In combination with the BDI the literature reported a high correlation in validity between the use of the two scales (HAMD=0.84; BDI=0.77) (Beck et al., 1984).

Table 9 presents the mean scores for HAMD for the sample and by groups. The total sample prescore was above the cut-off score indicating the presence of depression, but the postscore showed a decline. The experimental group reported a higher level of depressive symptoms than the control group with a significant decline in the postscore.

The correlated t-test (\( t = -2.29 \) one-tail test) within the experimental group was statistically significant at the \( P < .05 \) level.
TABLE 9. DISTRIBUTION OF GROUP MEAN SCORES ON THE HAMILTON DEPRESSION RATING SCALE

<table>
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<th>MEAN</th>
<th>SD</th>
<th>RANGE</th>
<th>MEAN</th>
<th>SD</th>
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</thead>
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<td>1-28</td>
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<td>4-22</td>
<td>16.00*</td>
<td>6.8</td>
<td>5-18</td>
<td>12.00**</td>
<td>4.7</td>
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<tr>
<td>CONTROL</td>
<td>1-23</td>
<td>12.81</td>
<td>6.7</td>
<td>1-28</td>
<td>12.45</td>
<td>8.6</td>
</tr>
</tbody>
</table>

* HAMD: scores fourteen or greater indicates depression. **t= -2.29 (one-tail test), p < .05 paired t test. ANCOVA between groups was not statistically significant.

A significant decrease in depression scores indicated improvement for the experimental group. Their individual changes went from seventy-five percent (N=6) in the prescore to thirty-eight percent (N=3) in the postscore. This compared to the control group who had forty-five percent (N=5) in the prescore and forty-five percent (N=5) in the postscores.

The use of the HAMD allowed a closer assessment of suicide ideation (Q 7, 8, 9, & 10), a concern supported in the literature for this stage of the HIV disease. The following is a frequency response to these questions for both pre and posttest scores and by groups (E = Experimental, C = Control):
Q 7. IS LIFE POINTLESS?
PRE  NO = 5 (E) 8 (C), YES = 3 (E) 3 (C)
POST NO = 6 (E) 9 (C), YES = 2 (E) 2 (C)

Q 8. HAVE YOU THOUGHT OF ENDING IT ALL?
PRE  NO = 2 (E) 7 (C), YES = 6 (E) 4 (C)
POST NO = 6 (E) 10 (C), YES = 2 (E) 1 (C)

Q 9. HAVE YOU MADE PLANS TO KILL YOURSELF?
PRE  NO = 2 (E) 9 (C), YES = 6 (E) 2 (C)
POST NO = 5 (E) 11 (C), YES = 3 (E) 0 (C)

Q 10. HAVE YOU ATTEMPTED TO - OR DO YOU INTEND TO - KILL YOURSELF?
PRE  NO = 6 (E) 10 (C), YES = 2 (E) 1 (C)
POST NO = 7 (E) 9 (C), YES = 1 (E) 2 (C)

Those respondents who felt life was pointless did so in the context of their HIV diagnosis. Thoughts and plans for ending their lives were statements that represented attempts at control over future events. Their expressed fears focused on disease escalation and the inability to care for themselves; this made life seem pointless. Many referred to deceased partners or friends and the witnessing of body wasting and deterioration due to AIDS.

Ambivalence was evident in Question No. 10 over wanting to control future events by their actions yet expressing hope for a cure or control of the disease and the desire to live. Two respondents who answered yes to Question No. 10
on the pretest had a history of suicidal attempts. In the posttest one subject in the experimental group had lost a former partner to AIDS in the fourth week of the intervention program. All were referred for psychiatric follow-up at the end of the post assessments.

Results of the outcome data from both scales assessing the mood disturbance of depression indicated decreases in the level of depression within the experimental group between the pre and post scores. Decline was also evident in the number of subjects who met the criteria for depression in the experimental group compared to the control group. However, between the groups the decline was not statistically significant.

Hypothesis 3: The experimental group will show increased levels of internal locus of control versus physicians’ and significant others’ control as a result of their participation in the biopsychosocial educational program "Living with HIV" in comparison to the control group.

The Health Locus of Control (HLOC) Form C (Wallston et al., in press) was an 18 item self report instrument designed to measure the individuals’ beliefs regarding control over their health concerns. These concerns include: internal locus of control (6), chance (6), powerful others
divided between physicians (3) and others (3). The word HIV was inserted for the health condition in the assessment scale.

This study was interested in the level of individuals' sense of internal control over health issues as compared with the effects that physicians and others have on them. The subscale of chance was not included in this study. Scoring was measured on a 6-point likert format from strongly disagree to strongly agree. Total scores in each category indicated the level of effect HIV had on the subject.

Table 10 reports a pooled t test comparing differences between groups in their mean change from the post score minus the pre score. The data indicated both groups experienced a decline in their internal locus of control mean score.

The experimental group went from a 23.37 prescore mean to a 20.63 postscore mean, while the control group started at a lower prescore mean of 19.82 and declined to a postscore mean of 18.64. The influence of physicians on the experimental group showed only a slight decline in both groups. The impact of significant others reversed positions between groups. The post scores declined for the experimental group and increased in the control group.
**TABLE 10.** HLOC POOLED T TEST MEAN DIFFERENCES BY GROUP

<table>
<thead>
<tr>
<th>EXPERIMENTAL</th>
<th>MEAN</th>
<th>STD E</th>
<th>T-VALUE</th>
<th>P. VALUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTERNAL</td>
<td>-2.75</td>
<td>1.48</td>
<td>-0.852</td>
<td>&lt; 0.408</td>
</tr>
<tr>
<td>DOCTOR</td>
<td>-0.13</td>
<td>1.94</td>
<td>-0.025</td>
<td>&lt; 0.980</td>
</tr>
<tr>
<td>OTHERS</td>
<td>-1.37</td>
<td>1.33</td>
<td>-1.211</td>
<td>&lt; 0.256</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CONTROL</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>INTERNAL</td>
<td>-1.18</td>
<td>1.08</td>
<td>-0.874</td>
<td>&lt; 0.394</td>
</tr>
<tr>
<td>DOCTOR</td>
<td>0.18</td>
<td>1.06</td>
<td>0.027</td>
<td>&lt; 0.978</td>
</tr>
<tr>
<td>OTHERS</td>
<td>0.36</td>
<td>0.52</td>
<td>-1.350</td>
<td>&lt; 0.194</td>
</tr>
</tbody>
</table>

Analysis of the correlated and pooled t-test, along with the ANCOVA’s were not statistically significant.

The data suggested a disparity between the experimental and the control group’s internal mean scores. One sample pattern of interest was that of the differences in the length of time since the diagnosis. Here time may have represented an initial reaction and challenge for control, and thus a higher internal score for those recently diagnosed. A lower internal score was seen with those diagnosed for a longer period of time, perhaps a reaction to the failure in scientific efforts.
TABLE 11. SUMMARY OF MEANS FOR HLOC BY TIME OF DIAGNOSIS

<table>
<thead>
<tr>
<th></th>
<th>INTERNAL MEAN</th>
<th>SD</th>
<th>DOCTOR MEAN</th>
<th>SD</th>
<th>OTHERS MEAN</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>LESS THAN YEAR (PRE)</td>
<td>23.54</td>
<td>5.4</td>
<td>15.54</td>
<td>4.1</td>
<td>10.90</td>
<td>2.9</td>
</tr>
<tr>
<td>LESS THAN YEAR (POST)</td>
<td>20.72</td>
<td>6.3</td>
<td>14.45</td>
<td>4.2</td>
<td>10.00</td>
<td>2.8</td>
</tr>
<tr>
<td>GREATER THAN YEAR (PRE)</td>
<td>18.25</td>
<td>5.5</td>
<td>11.62</td>
<td>4.4</td>
<td>9.00</td>
<td>3.3</td>
</tr>
<tr>
<td>GREATER THAN YEAR (POST)</td>
<td>17.75</td>
<td>4.6</td>
<td>12.75</td>
<td>4.0</td>
<td>9.37</td>
<td>3.5</td>
</tr>
</tbody>
</table>

Table 11 presents the HLOC summary of means data by time of diagnosis. Change scores were evident in the post test means for internal locus of control at -2.82 for less than a year, and 0.50 for greater than a year. Influence of a doctor was -1.09 for less than a year, +1.12 for greater than a year. And finally, influence of significant others was -0.90 for less than a year and 0.37 for greater than a year.

Findings suggested those diagnosed less than a year were more vulnerable to decline of internal locus of control as compared with those diagnosed greater than one year. When looking at sample trends and the possibility of influence on outcome data these findings supported this vulnerability. In the experimental group seven (88%) were diagnosed less than a year, and seven (64%) of the control group were diagnosed greater than one year. Further, at the
time of the study, eight (100%) of the experimental group had a lower CD4 count compared to six (55%) in the control group.

One of the goals in this intervention program was to create a partnership in health care decisions between physician and patient. The slight decline in belief of physician as powerful other suggested some change in the balance for health care decisions in the experimental versus the control group. The influence of significant others was relatively stable between groups.

Results of outcome data did not support the hypothesis of an increase in the experimental groups' internal locus of control versus physicians' and others' control compared to the control group. In attempts to create a partnership in health care decisions a slight decline in physician influence did occur within the experimental group, but it was not statistically significant.

Hypothesis 4: Participation in the biopsychosocial educational program "Living with HIV" will result in a higher level of medical compliance among the experimental group versus the control group for a period of three months following the completion of the program.
The Medical Review Log (MRL) was designed for this study to log medical compliance for a period of three months following the completion of the posttests. Medical charts were identified and their progress notes reviewed for evidence of clinic attendance. From the physician narratives evidence of treatment compliance in medication or specialty referrals was also noted. To chart compliance a Y (Yes) or N (No) or a NA (Not Appropriate) was entered for each subject within the three month time period.

The data was comprised of the number of appointments completed, missed or not scheduled for three months. The frequency of medical appointments was based on the individual’s medical status, and therefore, not everyone was scheduled on a monthly basis. Each kept appointment allowed for further assessment for compliance of medications and specialty referrals. For this small sample size, the Fisher’s Exact Test of association was utilized to compare the groups.

Table 12 reports the frequency of appointments kept during the three month time period. Clinic appointments scheduled and completed for the experimental group was 100% for all three months. The Fisher Exact Test for Association for the experimental group had a $p < .01$. This compared to the control group who had a compliance rate of 56% in the first month, 50% in the second and 0% in the third.
### TABLE 12. FREQUENCY OF APPOINTMENTS KEPT FOR THREE MONTHS BY GROUPS

<table>
<thead>
<tr>
<th></th>
<th>MONTH 1</th>
<th>MONTH 2</th>
<th>MONTH 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>YES NO NA</td>
<td>YES NO NA</td>
<td>YES NO NA</td>
</tr>
<tr>
<td>EXPERIMENTAL APPONTMENTS</td>
<td>8+ 0 0</td>
<td>3+ 0 5</td>
<td>6+ 0 2</td>
</tr>
<tr>
<td>MEDICATIONS</td>
<td>7 0 1</td>
<td>3 0 0</td>
<td>6 0 0</td>
</tr>
<tr>
<td>REFERRALS</td>
<td>2 0 6</td>
<td>2 0 1</td>
<td>1 0 5</td>
</tr>
<tr>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>CONTROL APPONTMENTS</td>
<td>5 4 2</td>
<td>5 5 1</td>
<td>0 6 5</td>
</tr>
<tr>
<td>MEDICATIONS</td>
<td>1 1 3</td>
<td>3 0 2</td>
<td>0 0 0</td>
</tr>
<tr>
<td>REFERRALS</td>
<td>2 0 3</td>
<td>0 0 5</td>
<td>0 0 0</td>
</tr>
<tr>
<td>56%</td>
<td>50%</td>
<td>0%</td>
<td></td>
</tr>
</tbody>
</table>

* Fisher's Exact Test 0.0052 p < .01 (one-tail test)
+ 100% Compliance with Appointments Scheduled

Medication treatment for the experimental group indicated compliance with all agreed upon treatment for three months. The control group had compliance with three out of four treatment plans. This response represented only two months of activity. The inability to assess for the third month was due to six failed appointments.

The experimental group received two specialty referrals in both the first and second time period and one in the third; all were compliant. Two control subjects received
specialty referrals during their first clinic visits and showed compliance. No referrals were made in the second and none in the third period as appointments were not kept.

For the total three month period of scheduled clinic appointments the data found compliance for the experimental group at one hundred percent compared to forty percent for the control group. The Fisher’s Exact Test was 0.0052 (one-tail test) significant at p < .01. Assessing compliance for medical care and decisions for treatment only occurred during the clinic visit; therefore, attendance was the major variable in assessing compliance for this study.

The results of the MRL for the three month period following the "Living with HIV" program indicated that the experimental group had a significantly higher level of compliance in adherence to their medical appointments than the control group.
1. There was no significant decrease in anxiety in the experimental group compared to the control group as measured on the HAS and the IES scales.

2. There was no significant decrease in mood disturbance between the experimental group and the control group as measured on the BDI and HAMD scales. There was within the experimental group a significant decrease in mood disturbance as measured on the HAMD scale.

3. There was no increase in the internal locus of control compared to physician and significant others control for the experimental group compared to the control group as measured on the HLOC-C scales.

4. There was a significantly higher level of medical compliance in clinic appointments and therefore prescribed treatment in the experimental group compared to the control group for a period of three months following the completion of the "Living with HIV" program.
SUBJECTIVE RESPONSES

PROGRAM EVALUATION

At the completion of the last session of "Living with HIV" six study participants in attendance were asked to complete a program evaluation (see Appendix C). The evaluation offered questions for each of the six sessions and requested comments on the materials and speakers. Three responses were offered for each question from: very much, enough, and not enough. A final question asked for their overall feelings about the program in terms of what was helpful and what was missing, to help guide future programs.

Session I. Introduction to the Program and HIV Clinic

The first question was assessing appropriate preparation in information and scheduled time for attendance at the program. Three answered "very much" and three "enough". The second question asked if the overview of the HIV Clinic as a medical resource was helpful. Five marked "very much" and one "enough". General comments praised the organization and materials as very informative. One comment was "how nice to take part - rather than just listening to".

Session II. Medical Management of HIV Disease

Question one asked if the presentation was helpful in understanding the disease and treatment options. Five marked "very much" and one "not enough". The second question was assessing the discussion on healthy life styles
and a partnership with the physician. Again, five stated "very much" and one "not enough". General comments indicated that they would have preferred two sessions on the medical issues, not one. However, they found the information very helpful. Two felt it was too basic and preferred more options. Three commented on how the material was presented in a relaxed atmosphere. This last comment was important as the medical information covered the HIV continuum from serioconversion to the final stage of AIDS.

Session III. Nutrition

One overall question for this session asked if the presentation was informative enough to assess their eating habits and encourage changes. Four marked "very much", one "enough", and one "not enough". This was a favorite and fun session for all with comments praising the speaker and her presentation. Two commented they were amazed at the food they needed to avoid.

Session IV. Legal Issues/Social Security

This session was divided by subject and speakers. The first section of the instrument asked if the presentation on the legal issues of being HIV seropositive was helpful in understanding their rights. Three responses were "very much", one "enough", and two "not enough". The second section was designed to give an overview of entitlements through social security for future planning. The question asked if the material on social security was helpful. Two
felt it was "very much", and four "enough". General comments said the speakers were very informative. Two people expressed gratitude that the legal issues focused more on rights than living wills as "people are more fearful of losing their rights". One person found the social security information confusing.

**Session V. Resources for Empowerment**

There was only one overall question for assessing the presentation on insurance options and managed care as a resource for planning health care needs. Three responded "very much" and three "enough". General comments were that insurance is so individual and difficult to understand.

**Session VI. Handling Feelings/Stress Management**

This session was divided between discussion on the emotional response to being HIV affected and coping strategies. The first question asked if the session was helpful in discussing how mood and emotions impact on coping with HIV. Three responded "very much" and three "enough". The second question asked if the relaxation techniques and self-statements were helpful strategies. Two stated "very much", two "enough", and two "not enough". Again, this appeared to be a favorite session. Comments suggested that it was helpful for one to know if they were OK, or needed help. Another stated "we all have our own ways, each is interesting and all very individual."

The final question asked for an overall critique of the
program and for comments on what they found helpful and what was missing and should be included for future programs. The following are the six participants’ responses, all made anonymously:

How nice to have so much information presented in a pleasant and concise manner. I was given more than I would have sought - this was great. I feel aware.

I think for the psychiatrist/depression session you should let participants fill out a mini questionnaire which could be discussed so that people could decide if they needed to get further help. This is a great program. Perhaps good for very newly-diagnosed patients, but for patients who have been HIV+ for a length of time and have educated themselves on some issues, some of the information could be more advanced. I found the legal and insurance classes quite valuable. Thank you.

I think the program is of valuable help for persons dealing with HIV. This program has been well thought out. I only wish a little more energy could have been put into making the participants share their thoughts. I’m very grateful otherwise and hope to be able to get more people to come.
The most important part of this program for myself was to really take time and learn what was happening to me. I think anyone living with HIV should be able to take part in this program.

I found this program wonderful. I now know where I can go if I need more information. I would urge anyone who finds themselves dealing with HIV to take this course. Back-up materials have been good. I think most people would like to have stayed longer rather than 1 1/2 hours - maybe two hours or three.

Overall program was excellent on getting to understand issues that I wasn't clear on, or just did not know about. I believe this type of program is extremely helpful for anyone starting an HIV situation, or even at certain stages of this illness, just to keep up on any new or ongoing issues. I don't feel as lost anymore. And the social worker as always was very helpful in the process.
CHAPTER V

DISCUSSION AND IMPLICATIONS OF THE FINDINGS

The war on AIDS will be fought by primary care providers and won by health educators. (AIDS International Conference, 1993)

INTRODUCTION

The central purpose of this research was to determine the efficacy of the clinical intervention "Living with HIV" as a stress inoculation for the emotional distress of being HIV positive and to evaluate its clinical importance to the field of social work practice and research. To achieve this end it is important to first reflect back on the quantitative results reported in Chapter IV. Clearly, a fuller review and interpretation is needed. Through a synthesis of the literature review and findings the clinical significance of this study can be considered.

What do the findings reveal about the intervention model of reducing emotional distress in the earlier stages of HIV? And how should the psychological responses for this sample be interpreted? Importantly, a review of the methodology for this study may add to our understanding of this research effort and help plan for future studies for
this patient population. And finally, how will the clinical significance of this study inform social work practice?

CLINICAL SIGNIFICANCE

To begin with, the study was successful in producing positive responses to the intervention "Living with HIV". Foremost was the experimental group's statistically significant findings for medical compliance. Determining effectiveness of a study can be done through quantitative statistics that are significant, without necessarily being clinically meaningful (Hollon & Flick, 1988). The response to the fourth hypothesis suggests both determinants were met and brings implications for clinical practice in the medical setting.

The first goal of the study's intervention was to promote medical education, medical compliance and risk reduction behaviors. The program strategy of graded exposure to knowledge about the HIV disease with a focus on cognitive reframing was meant to engage and motivate individuals' responsibility in their own health care. Promoting personal control in the health care setting would begin to correct earlier negative experiences. Many individuals learned their seropositive status over the telephone from a clinic or physician's office that they engaged for testing.
Siegel and Krauss (1991) reported that the need to take control of one's health was among the major themes of their qualitative study on HIV-infected gay men. Lazarus and Folkman (1984) suggested personal control was the underpinning for situational appraisal in the stress and coping theory. Opportunities to enhance one's appraisal of a stressful-life event would lead to a balance in coping between planful and emotional focused coping.

Subjective responses from the program evaluation supports both the literature and the outcome data. Of major importance was the insight into how the material was being perceived. Three participants commented that the medical management session was presented in a relaxed atmosphere. This session allowed the physician to be informal and to create an atmosphere for dual dialogue on health concerns and thereby provided a crucial model for future physician and patient interactions. Another commented on receiving information in a "concrete and pleasant manner". And added "I feel aware".

Adding to the sense of personal control were behavioral strategies to reduce anxiety that often accompany clinic visits. In "battle inoculation training" Janis (1983) felt positive behavioral changes resulted from an improved sense of self-efficacy that could help to reduce the disruptive effects of fear. Techniques in reducing stress for clinic appointments involved a suggested list of questions and
concerns on medications and their side effects as well as inquiry on current HIV management. Included were several suggested self-talk statements to manage anxiety. The significance of the data as measured on the Medical Review Log was very supportive of the study effort. Keeping individuals motivated and engaged in the health care system allows them to take full advantage of advances in treatments for HIV. It also creates a framework for hope.

The second program goal focused on health internal versus external control that would enable patients to exercise more control over their health by becoming informed consumers of health care issues and services while at the same time forming decision-making partnerships with their health care team. A major concern for HIV-affected individuals was the fear of losing access to health care. In the era of health care reform, consumer education on the myriad of insurance, legal, and entitlement issues was addressed in the program. Correlational data supports the idea that HIV-affected individuals need to be informed of the medical and legal ramifications of their illness for access and control of their own destiny (Britton et al., 1993; Folkman et al., 1993; Siegel & Krauss, 1991).

Measurement for health locus of control represented the third hypothesis in the study. The findings did not support the anticipated increase in internal locus of control for the experimental group over the control group. In fact,
both groups experienced a decline and were more alike than different. A change score indicating a decrease in physician influence was seen in the experimental group. In two other studies (Kelly et al., 1993; Pergami et al., 1993) comparison groups did not differ significantly in their perceived locus of control. An alternate analysis of the data using the time of diagnosis with the level of perceived internal locus of control, showed similar findings. Those diagnosed less than a year versus those greater than a year had almost identical results. This was due to the fact that the experimental group had 88% diagnosed less than a year compared to the control group with 64% greater than a year.

The findings for this sample suggested a stronger external locus of control versus internal locus of control. Another study came to the same conclusion, however, the sample consisted of HIV positive and negative women (Pergami et al., 1993). It was suggested in Chapter IV that those diagnosed HIV less than a year were more vulnerable to decline. Another implication is that the diagnosis of HIV may stir up self-blame, self-hatred and internal homophobia for some gay or bisexual men, thereby decreasing internal trust and control (Cohen & Abramowitz, 1990). The majority of the sample represented a minority culture whose survival had been more dependent on others than self. Combining this with the growing uncertainty of the medical care for HIV expressed in the community and the media creates additional
obstacles. Finally, a possible influence on outcome data may be the decision for a double session on the final night of the program.

The third program goal was to provide skill enhancing techniques for adaptive coping and reduction of emotional distress. The presence of emotional distress of anxiety and depression for HIV-affected individuals in the earlier stage has been well documented earlier in the literature review. It was evident as well in the findings for this study. Generalized anxiety for this sample tended to reflect psychic or cognitive symptoms more than somatic ones. In another study with early HIV the psychic versus the somatic yielded significant results, but at the three month assessment period (Perry et al., 1991). The experimental group had a consistent pattern of higher emotional distress scores than the control group. And change scores provided evidence of decreases in anxiety and depression within the group rather than the expected changes between groups.

Cohen (1990) felt the ability to cope with the stress and anxiety of being HIV-infected begins with a cognitive appraisal of the crisis. The study intervention utilizing the stress inoculation model contained cognitive reframing sessions for control of anxiety along with behavioral skills. What was not anticipated was the level of anxiety created by attending this program. Ninety minutes prior to the first session of "Living with HIV", one female subject
called to explain "I can't do it, I'm not ready to deal with this yet". She asked to attend the follow-up program and offered to complete the posttest. She became a part of the control group.

At the start of the first session one male subject related thinking about this program all day and feeling almost too anxious to attend. This resulted in a delay of the program to allow other participants to verbalize their anxiety in coming to the program. A means of handling feelings of stress and anxiety by requesting time-out was agreed upon. Interestingly, this defense maneuver was never used.

When reviewing the results of the Impact of Event Scale a noticeable increased use of avoidance maneuvers was seen for the experimental group in comparison to the control group. One might suggest that the anxiety generated by the program compounded the anxiety of being HIV-affected with increasing defensive maneuvers. Perhaps a more viable explanation for the differences is found in the time of diagnosis and CD4 counts between groups. The experimental group had been diagnosed a shorter period of time and had lower CD4 counts compared to the control group. Further, the possibility of increased coping skills gained from the program might have resulted in the lower intrusive thoughts through stronger avoidance maneuvers.

The necessity to combine two topics in the final
session raised concerns of influence on the data. Discussing the complexity of insurance was anxiety provoking on its own, but more so when it was vital to one’s existence. Evaluation comments confirmed this belief even though it provided participants important information. However, the next topic on handling feelings and stress appeared to be the favorite session. It was also the last session and termination issues were raised with the absence of two participants. The informality of the program design, and the relaxed approach of the psychiatrist encouraged interactions among the participants. The difficult area of disclosure of diagnosis to family was interweaved with the stresses that confront the HIV-affected individual. The desire to talk about feelings resulted in less time for rehearsing imagery and self-talk behavioral strategies.

The subjective responses on the last session included a sense of loss and desire to continue in some other form. Several participants referred to the sessions as "classes" and to each other as "classmates". One participant stated "it was helpful to know your (sic) doing OK, or in need of help." This comfort in discussing feelings was repeated in the observer rated Hamilton Depression Rating Scale at the posttest. The outcome data yielded a statistically significant decrease in depressive symptoms within the experimental group.

The current dialogue in psychotherapy over the ability
to assess "reliable change" or "clinically significant change" was reviewed in the literature (Hollon & Flick, 1988; Hsu, 1989; Jacobson & Revenstorf, 1988). Reliable change began with statistical formulas developed as a post hoc measurement for assessing the significance of change scores using the absolute value for the instruments. This approach posed problems for studies with multiple scales making it unclear how to assimilate discrepancies between scales (Jacobson, 1988). For this study the clinical significance is assessed less from quantitative findings and more from the subjective responses and actions of the participants.

In defining clinical significance or meaningfulness Hollon and Flick (1988) felt the ultimate criterion is really a matter of values. A reduction in anxiety or depressive symptoms is meaningful to the person involved. This is especially true for chronically ill population. For example, being capable of entering a medical clinic without feeling panic, is valuable. Feelings of empowerment when advocating for one's legal rights to benefits, entitlements and access to care, is valuable. And the enhancement of personal control through a partnership in medical decision-making promotes dignity. This is valuable.
PARTICIPANTS' CLINICAL RESPONSE

The participants' subjective responses and actions ultimately defined the meaningfulness or clinical significance of this study intervention. Upon completion of the study, four of the eight experimental subjects began individual and group counseling through the hospital's outpatient mental health services. The study appeared to have served as a vehicle for linking patients in need of additional psychological services. Further responses to the psychological instruments found that they served as an intervention for change also. The following examples were shared at the conclusion of the posttest:

#002 (control) He stated after the first assessment he felt the materials were depressing, yet found it mobilizing him into action. First, he decided that he was too anxious and tense at work and needed to reevaluate his work style. He met with his supervisor to help prioritize and pace his work assignments. He then followed through on a referral and saw his physician regarding his sleep disturbance. He is now on medication and reports doing better. Finally, he made an appointment to have his eyes examined and found little change and decided it was stress and anxiety. He stated that being part of the study helped him to resume doing things for his health that he had done before, but had become complacent about.
(experimental) He stated after completing the pretest that he was too tense and had to slow down at work and not be so compulsive. He, too, changed his work pace and style. He felt the scales helped him to develop a new attitude about taking care of himself.

(control) Upon completion of the scales he was informed of the next scheduled program. He was very relieved, stating he thought he had failed on the first scales and would not be included. His scores met criteria for clinical depression, anxiety and posttraumatic stress disorder. He had been referred for counseling and informed the researcher of a pending appointment and plan to start group therapy. He was grateful for the study.
METHODOLOGICAL IMPLICATIONS

The fact that the present study was based on such a small sample suggests caution in the interpretation of the results. The anticipated sample size was not achieved as the majority of CHC patients, new to the clinic, were in more advanced stages than the study required. Even so, the study criteria for selecting research subjects was maintained, as it supported the literature on the earlier stages of the HIV disease. The demographic characteristics of the sample provided a profile of HIV-infected individuals at the time of recruitment. The inclusion of the CD4 count and the time of diagnosis supported both the stage of disease and the variability in time of diagnosis when seeking medical care. It was anticipated that this added dimension might be a contributing factor to the level of emotional distress. The reported findings indicate this to be the case more for the experimental group than the control group.

This research study followed the principles of the classic experimental design, or Design 4 for hypothesis testing (Campbell & Stanley, 1963). Its rigorous characteristics of pretest-posttest, independent variable, control groups, and randomization were intended to equalize the comparison groups and any threats to validity. A review of some extraneous sources of variability for this study for
possible threats to internal and external validity had methodological implications for the study intervention and its responses.

INTERNAL VALIDITY ISSUES

In determining the effects of the independent variable, Monette et al. (1986) felt "the central issue in experimentation is its utility in enabling us to make statements about causal relationships between phenomena" (p. 226). The experience of being HIV-infected would most likely manifest itself equally among the experimental and control groups. However, the likelihood for bias of maturation occurring is a concern with this "at risk" population. In the experimental group one subject experienced a major loss with the death of a former partner during the fourth session. One would anticipate that this significant loss amplified the loss that comes with a diagnosis of HIV-positive and had a direct effect on the dependent variables from pretest to posttest. This subject, who chose to remain in the study, responded yes to the question of "intent to kill yourself" at posttest. However, at the completion of the study he revealed alcohol problems not revealed previously, and accepted and began individual counseling shortly thereafter. The quantitative data for this subject was affected as was the clinical significance.

The testing process produced a reaction to the
instruments at the pretest that served as an intervention for change. This was reported after the posttest by three subjects from both study groups. This dramatic reaction, as described previously under clinical significance, was a surprise to the researcher. On one hand it raised questions of undue influence on outcome data, while on the other hand it provided answers to a moral dilemma with the study design. An ethical concern of this research design was providing equal access to the opportunities of the experimental intervention. This was controlled by duplicating the "Living with HIV" program for the control group and their guests after the three month chart review. Unexpectedly, the choice of instruments and the individual response to them also served as a vehicle for change during the testing period.

Another potential bias was in mortality that resulted in the loss of subjects from the comparison groups. In large studies attrition occurs and is equally distributed between the experimental and control groups. Of concern for this study is the possibility that the experimental stimulus may have affected the attrition rate. The anxiety of attending the program as expressed verbally by one subject and behaviorally by another in the experimental group drew attention to dealing with this problem in this and future studies. Adjustments to the sample were made by moving two experimental subjects who completed pre-and-post test to the
control group.

The clinical significance and meaning of this can be seen through Hollon and Flick's (1988) model which supported the notion that at least three constituencies are interested in the outcome of treatment. These three include the patient, society, and the professionals involved. The value in keeping the two subjects in the study as control was the inclusion of their important responses as well as providing another opportunity for their exposure to the experimental intervention. Secondly, the societal interest came from the gain in increased coping and healthy life-styles, and conversely, a decrease in the spread of HIV. Third, the value for the professional involved was enhanced by the patient's continued engagement in the process of change.

In this study another bias or advantage was in the selection of the instruments that were sufficiently balanced in content, criterion and construct validity for the population being studied. The five scales utilized for hypotheses testing (the Beck Depression Scale, the Hamilton Depression Rating Scale, the Hamilton Anxiety Rating Scale, the Impact of Event Scale and the Multidimensional Health Locus of Control Scale) all had properties of validity, sensitivity and reliability for this study. Hamilton (1976) recognized that patients have many reasons for minimizing their symptoms or emphasizing them. This view was the impetus for the use of both self-report and clinically rated
scales. It also represented this researcher's bias in exposing this population to opportunities to openly assess, and express, the level of impact their seropositive status may have on their functioning.

The IES and the HLOC had added face validity by inserting HIV as the event in question. These scales were given after the anxiety and depression scales. This order of use might have achieved a different response if the IES was given as the first self-report with its attention to the impact of HIV, followed by the other scales with the HLOC as the end point.

EXTERNAL VALIDITY ISSUES

The efficacy of the independent variable for this study has been established. Its application to practice, however, raises questions about generalization. As Campbell and Stanley (1963) succinctly describe the problem:

Whereas the problems of internal validity are solvable within the limits of the logic of probability statistics, the problems of external validity are not logically solvable in any neat, conclusive way. Generalization always turns out to involve extrapolation into a realm not represented in one's sample (p. 17).

One major threat to external validity is the possibility that experiencing the pretest can alter the subjects' response to the independent variable, "Living with HIV."

The subjective responses at the posttest supports the influence of the pretesting on two subjects whose reactions
lead to self-adjustments in coping with stress. From this example one could extrapolate influence on the other experimental and control subjects.

Campbell and Stanley (1963) felt the effects of the pretest as it restricts external validity will be governed by the extent of repeated measures characteristic of the population which one wants to generalize. HIV-infected individuals are exposed to numerous research studies and clinical trials that cover medical intervention, quality of life, coping, and prevention. Continuous research serves to inform the scientific community in their efforts at primary and secondary interventions. Therefore, generalization of this study's findings to practice with other stage HIV-affected individuals is possible. A duplication of the pretest effects could mean those individuals unable to attend all the sessions had accrued some properties for self-adjustment through participation in the pretest alone.

Another threat to external validity is the concern that those studied are indeed "representative" of other populations. Monette, Sullivan and Dejong (1986) caution that volunteers for studies tend to differ from the general population as they are better educated, come from a higher social class and are more sociable. The demographics in this study sample appear to support that view as they were highly educated, with medium to high incomes and volunteered to participate. There remains the possibility that the
effects of validity demonstrated hold only for the unique population that the experimental and control groups were jointly selected from. However, the core issue for people infected with HIV is in learning how to survive with this disease. The study model was structured to allow for adaptation of its strategies to fit the focus needs of other HIV-affected populations, thus supporting generalization.

Other methodological implications to the generalizability of this study is in the interactions of the setting on the effectiveness of the intervention. Again, a caution from Campbell and Stanley (1963) on the characteristics of the setting that could support the experimental intervention in ways not replicated in other settings. The program goals were designed to support a response to the changing medical management of HIV. Therefore, the main focus was on empowerment of individuals toward the ability to negotiate and form partnerships with their health care team. The ability to create a cognitive reframing of their health concerns within the same setting, and with some of the same medical staff where the subjects receive their primary care provided a unique opportunity. Obtaining similar results is more likely to occur in a medical setting than in a nonmedical community based setting.

Achieving the desired balance between internal and external validity is important to experimental research, but
not always possible as this study suggests in one single study. As Campbell and Stanley (cited in Monette et al., 1986) suggest "in the last analysis, external validity . . . is a matter of replication" (p. 244). The literature review provided guidance in the development of this research model. Perry et al. (1991) felt "the ability to use our research findings to accurately generalize about all subjects will only be assured after similar prospective studies are conducted elsewhere in other populations" (p. 147). Successful replication of the research results across time as well as settings will increase confidence in the importance of this research design and its findings.

Finally, the analysis of the findings focused on change scores as an assessment of treatment effect. The most widely used test is the t test both within the group and between the group (Campbell & Stanley, 1963) and proved most appropriate for this study. All data except the Medical Log Review had preintervention controls with the ANCOVA's procedure. This study proved that the reliability of change scores is a necessary, but not sufficient condition for "clinical significance".

It is important to keep in mind that this was a small sample study (N=19). Of course, it is always easier to obtain a statistically significant result with larger samples than with smaller ones. In discussing the lack of statistically significant findings in the Concord Study the
researchers' explanation is worth repeating here. They felt "with a disease as devastating as AIDS, a chance of even a 5% reduction in progression may be attractive to an HIV-infected individual" (p. 867). Given the uncertainty of an illness which will wax and wane over many years, changes, even small ones, are a window of opportunity for increased quality of life.

IMPLICATIONS FOR SOCIAL WORK PRACTICE

This study has practice implications for clinical social workers, and in particular, for those working in medical settings. With the new perspective on the medical treatment decisions for HIV comes the recognition of a change from a biomedical model of AIDS to a biopsychosocial model, an approach already inherent in social work practice with the "person-in-situation-person-in environment" perspective. Social Workers in AIDS care in the beginning of this illness described their role more as that of "witness" or "mirrors" to HIV-infected individual's struggle and personal evolution (Ryan, 1989). This countertransference to the overwhelming feelings of hopelessness and helplessness needs a cognitive reframing.

The task of working with HIV-affected people is overwhelming, but not unfamiliar to the social work field of practice. The study stress-inoculation model, a model of
preparation is truly bidirectional in its application. A goal of this study was to proactively assist patients in the pre-AIDS stage of their disease with cognitive-behavioral skills for coping and survival for the present and future. The complexity and dynamics of this disease challenges social workers schooled in the biopsychosocial model as agents and advocates of change. The social worker Code of Ethics mandates that social workers be leaders in seeking solutions to the complex problems that HIV infection and disease present to individuals and society.

The process of empowering the experimental group as consumers of health care services was positively correlated with their medical compliance. The intervention "Living with HIV" served as a transactional model between the patient, their health care team, and the community. The professionals participating in the program reported feelings of "helpfulness" in providing strategies for participants to cope and live with HIV. These shared feelings define the stress inoculation model of preparation as bidirectional in its application between those living with HIV, and those providing their care.
RECOMMENDATIONS

This model of intervention was developed from clinical practice with a predominately homosexual population. The face of AIDS is changing and bringing more complexity with the growing number of infected women and children, as well as dual and triple diagnosed individuals. Group interventions will need to be structured to meet the particular stressful needs of those targeted populations (Janis, 1983). This study provides some guidance for future efforts along with some recommended changes.

First, the study responses were significantly different for those diagnosed less than a year and those for a longer period of time. The criteria for this study attempted to combine those subjects in the earlier stages of HIV as defined by the clinical stages, with the new guidelines for medical management in the earlier stages of the disease, to patients new to the clinic within the past six months. Understanding that people enter the medical system at different points along the HIV continuum, this created a dichotomy in time since diagnosis and time in adjustment. It is suggested for future studies that more careful attention be given to the selection of subjects in terms of length of diagnosis, and the stage of their disease.

Second, the use of anti-depressant medications should be considered as it would affect data results. Inclusion or
exclusion of these subjects must be based on the goals and intent of the study. Third, the order of the use of scales might produce a different response if the scale measuring the impact of the HIV illness begins the assessments. This researcher encourages the replication of the research design that includes pretesting. Results have shown that they too serve as interventions for change, motivating cognitive reframing to those unable to unwilling to be exposed to the intervention.

Fourth, the order of the program might produce a different result. The issue of termination needs attention, but having the last session focus on handling feelings may or may not have influenced the absence of two participants. Fifth, the program needs to be extended through identification of additional adaptive characteristics. Sixth, finally the need for participants to talk about their feelings requires more than a half-session of time; a full session on this topic is recommended, along with a follow-up session for behavioral interventions giving more time and attention to self-talk, imagery and relaxation techniques.
CONCLUSION

The findings from this study are encouraging. The psychoeducational program, "Living with HIV" proved to be effective in producing awareness and change within the experimental versus the control group for this sample population. The national trend for infection rates for HIV continues to grow, and with it, increased complications that challenge social workers to provide new and more creative modalities for effective coping. The medical setting is the core to the linkage of care for HIV-infected individuals, and the medical social worker is their advocate in the systems of care. Intrinsic in all empirical research efforts with this population is the need for patient empowerment for coping and survival while living with HIV. It proves vital in the medical setting where the uncertainty, unpredictability, and complexity of this disease demands a partnership in medical decision-making.
APPENDIX A

RECRUITMENT DOCUMENTS
RESEARCH STUDY

"LIVING WITH HIV"

THIS RESEARCH STUDY WILL EXAMINE THE EFFECTIVENESS OF A COMPREHENSIVE EDUCATIONAL PROGRAM IN REDUCING THE EMOTIONAL DISTRESS OF BEING HIV-INFECTED IN THE PRE-AIDS STAGE OF THE DISEASE.

THIS 6 WEEK PROGRAM WILL MEET ONCE A WEEK FOR 90 MINUTES PER SESSION AND BE FACILITATED BY THE CLINIC SOCIAL WORKERS AND INCLUDE AN INFECTIOUS DISEASE PHYSICIAN, A PSYCHIATRIST, CLINICAL NURSE SPECIALIST, DIETITICAN, LAWYER AND A SOCIAL SECURITY ADVISOR. THE PROGRAM INTERVENTIONS DESIGNED FROM THE LITERATURE REVIEW ON THE IMPACT OF HIV IN THE EARLIER STAGE OF DISEASE ARE INTENDED TO:

1) PROMOTE MEDICAL EDUCATION, MEDICAL COMPLIANCE, AND RISK REDUCTION BEHAVIORS.

2) ENABLE PATIENTS TO EXERCISE MORE CONTROL OVER THEIR HEALTH BY BECOMING INFORMED CONSUMERS OF HEALTH CARE SERVICES, AND FORMING PARTNERSHIPS WITH THEIR HEALTH CARE TEAM.

3) PROVIDE SKILL ENHANCING TECHNIQUES FOR ADAPTIVE COPING AND REDUCTION OF EMOTIONAL DISTRESS.

THERE IS NO CHARGE TO ATTEND THIS PROGRAM.

CRITERIA: PATIENTS WHO ARE NEW TO THE COMPREHENSIVE AIDS CENTER WITHIN THE PAST SIX MONTHS WITH A CD4 COUNT OF GREATER THAN 200 WITH NO RECORD OF OPPORTUNISTIC INFECTIONS THAT DEFINE PROGRESSION TO AIDS CONFIRMED BY THEIR MEDICAL RECORDS. PATIENTS WITH A HISTORY OF DRUG ABUSE MUST BE IN RECOVERY FOR AT LEAST THREE YEARS.

SCHEDULE: THE STUDY IS SCHEDULED TO BEGIN ON THURSDAY, JANUARY 13th FROM 6:00 -7:30 PM. THIS RANDOMIZED STUDY MEANS HALF OF THE PARTICIPANTS WILL BE INVITED TO ATTEND THIS PROGRAM AND THE OTHERS WILL BE ASKED TO ATTEND OUR NEXT SCHEDULED PROGRAM IN APRIL. AN HOUR INTERVIEW BEFORE AND AFTER THIS PROGRAM IS REQUESTED. THEREFORE, PLEASE CONTACT ME UPON RECEIPT OF THIS LETTER TO SCHEDULE AN APPOINTMENT AT YOUR CONVENIENCE. PLEASE CALL NANCY CADDICK AT (312) 908-5116 BETWEEN 9:00 AM AND 5:00 PM, OR PAGE ME THROUGH (312) 908-2060. THANK YOU FOR YOUR CONSIDERATION.
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APPENDIX B

PARTICIPANT CONSENT FORM
EFFECTIVENESS OF A COMPREHENSIVE EDUCATIONAL PROGRAM IN REDUCING EMOTIONAL DISTRESS FOR HIV-INFECTED PEOPLE IN THE PRE-AIDS STAGE OF DISEASE.

INFORMED CONSENT

INTRODUCTION

This research study will examine the effectiveness of this educational program in reducing the emotional distress of being HIV-infected for patients new to the Comprehensive AIDS Center within the last six months, and whose CD4 count is greater than 200 with no record of opportunistic infections that define AIDS.

Research has shown that patients in the earlier stages of the HIV disease experience significantly higher levels of depression, mood disturbance and anxiety than do those patients with AIDS. Thus, the need exists for a comprehensive approach towards adaptive coping by providing consumer education on medical care, mental health care, nutrition, and legal and insurance advice.

PURPOSE

The purpose of this study is to examine the effectiveness of the program "Living with HIV" as an intervention to reduce depression and anxiety while at the same time increasing a sense of control and preparation through consumer education and stress reducing techniques. The program interventions designed from the literature review on the impact of HIV in the earlier
stage of the disease are intended to:

1) promote medical education, medical compliance, and risk reduction behaviors.

2) enable patients to exercise more control over their health by becoming informed consumers of health care services, and forming partnerships with their Health Care Team.

3) provide skill enhancing techniques for adaptive coping and reduction of emotional distress.

PROCEDURES

Should I be eligible to participate in this study, and I agree, I will be interviewed and asked demographic information such as age, sex, ethnicity, marital/partner status, education, employment status, HIV risk factor and CD4 count. I will also be asked to complete 5 psychological assessment scales that will take approximately 55 minutes. Next I will be randomized (assigned by chance) to either:

1. attend a six week, 90 minute per week session of the "Living with HIV" program, and I may bring two guests. Information about the program schedule and location will be made available to me.

2. offered current clinic services and be invited to attend the next program anticipated early in 1994.

Upon completion of the six week program, I will be asked to once again complete 5 psychological assessment scales that will take approximately 55 minutes.
BENEFITS

The benefits to me for my participation in this study are to receive from my Health Care Team a comprehensive educational program to aid me and my significant others in understanding and living with the HIV disease.

By participating in this study I will be assisting in determining the importance of this model as a continuing intervention for patients in the pre-AIDS stage of the disease at the Comprehensive AIDS Center.

RISKS

The only slight concern involves the possibility of an emotional reaction to the psychological assessment scales or with the materials presented at the program. Should this occur in any slight way, I am encouraged to contact one of the clinic social workers. If these feelings persist, I am free to withdraw from the study at any time, and that this would not affect my relationship with the clinic or any member of the medical staff.

ALTERNATIVE PROCEDURES

New Comprehensive AIDS Center patients receive a clinic packet describing the various services and staff members. Should I desire additional information or resources I can request an appointment with one of the clinic social workers.

COSTS

There are no related costs to participating in this study.

CONFIDENTIALITY

My research records will be kept confidential and in a locked
file. I will be identified by a number code on the demographic and psychological assessment scales listed on a master list to be destroyed at the completion of the study. Only first names will be used during the program. None of the study information will be included in my medical records. I will not be personally identified in any publication about this study.

SUBJECTS RIGHTS
Participation in this study is voluntary and refusal to participate will involve no penalty or loss of benefits. As stated above, subjects may withdraw at any time without penalty or loss of benefits, and that withdrawal will not affect their relationships with the clinic or any member of the medical staff. Any additional questions or concerns regarding this study should be directed to Nancy Caddick at (312) 908-5116 between the hours of 9:00am to 5:00pm, Monday through Friday.

CONSENT
I agree to participate in the research study outlined above and I will receive a copy of the consent form.

__________________________________________  __________________________
Signature of Subject                              Date

__________________________________________  __________________________
Signature of Witness                              Date
APPENDIX C

PROGRAM DOCUMENTS
Dear Study Participants;

The "Living with HIV" research study is scheduled to begin next Thursday, January 13th, and for the next five consecutive Thursdays ending on February 17th. The program will run from 6:30 to 8:00 pm and will meet in the Conference Room on the eighth floor of the Passavant Pavilion at 303 E. Superior Street. The agenda for the program is enclosed and is designed to address the medical, psychosocial and psychological issues of being HIV-infected. Several psychoeducational strategies have been created to help you cope and live daily with HIV, therefore, we hope you will arrange your calendar to allow attendance at each session.

We would like to know in advance if you will be bringing guests (up to two) and if you will be driving in order to arrange for parking at the NMH parking lot on Erie and McClurg Streets (across from CBS). Also, we plan to have light refreshments, and for confidentiality, we will use only first names during the program.

Please leave a message for me at (312) 908-5116 regarding your ability to attend as well as parking needs and if you will bring guests. Looking forward to seeing you on Thursday, January 13th.

Nancy Caddick
Clinical Social Worker
STRATEGIES FOR LIVING DAILY WITH HIV

1. AWARENESS OF THE HIV CLINIC'S OPERATION AND STRUCTURE
   CREATES ACCESS TO SERVICES AND INFORMATION TO ASSIST
   IN YOUR HEALTH CARE NEEDS.

2. DEVELOPING A PARTNERSHIP IN HEALTH CARE TREATMENT
   DECISIONS WITH YOUR PHYSICIAN AND HEALTH CARE TEAM.

3. PREPARE FOR YOUR CLINIC APPOINTMENTS WITH QUESTIONS
   AND/OR CONCERNS. BRING A LIST OF YOUR MEDICATIONS.

4. ATTENTION TO YOUR NUTRITIONAL HABITS IN FOOD CHOICE,
   PREPARATION AND SUPPLEMENTS.

5. UNDERSTANDING YOUR RIGHTS TO LEGAL PROTECTION UNDER
   THE LAW, AND ELIGIBILITY TO FEDERAL AND STATE
   ENTITLEMENTS AND PROGRAMS AS NEEDED.

6. BECOME A CONSUMER OF HEALTH CARE SERVICES - KNOW YOUR
   POLICY AND ITS BENEFITS - KNOW WHO DOES WHAT, WHEN
   AND HOW.

7. PAY ATTENTION TO YOUR MENTAL HEALTH NEEDS AND SEEK
   HELP THROUGH INDIVIDUAL OR GROUP THERAPEUTIC SUPPORT.
LIVING WITH HIV
PROGRAM EVALUATION

We would appreciate your comments on this program to help us prepare for future ones. Please place an X through the word that best describes your feelings.

SESSION I. Introduction to the Program and HIV Clinic:

1. Did you feel you received enough information to organize your time and prepare you for this program?

   VERY MUCH      ENOUGH      NOT ENOUGH

2. Did you feel the information on the HIV Clinic provided you with a working understanding of how it operates that will be helpful to you?

   VERY MUCH      ENOUGH      NOT ENOUGH

COMMENTS ON MATERIAL AND SPEAKERS: ____________________________

SESSION II. Medical Management of HIV Disease:

1. Did you find this presentation helpful in understanding the HIV disease and treatment options?

   VERY MUCH      ENOUGH      NOT ENOUGH

2. Were the suggestions for strategies for a healthy lifestyle along with ways to work with your physician helpful?

   VERY MUCH      ENOUGH      NOT ENOUGH

COMMENTS ON MATERIAL AND SPEAKER______________________________

SESSION III. Nutrition

1. Did you find the presentation on nutrition provided the information you needed to assess your eating habits and make appropriate changes?

   VERY MUCH      ENOUGH      NOT ENOUGH

COMMENTS ON MATERIAL AND SPEAKER______________________________
SESSION IV. Legal Issues/Social Security

1. Did you find the presentation on the legal issues on being HIV-infected helpful in understanding your rights?

   VERY MUCH  ENOUGH  NOT ENOUGH

2. Was the information on Social Security helpful for you at this time?

   VERY MUCH  ENOUGH  NOT ENOUGH

COMMENTS ON MATERIAL AND SPEAKERS______________________________

SESSION V. Resources for Empowerment

1. Did you find this presentation on insurance issues helpful in understanding your choices in health care, as well as ways to plan for your health care needs?

   VERY MUCH  ENOUGH  NOT ENOUGH

COMMENTS ON MATERIAL AND SPEAKER______________________________

SESSION VI. Handling Feelings/Stress Management

1. Did you find this session helpful in discussing the ways that mood and emotions impact on coping with HIV?

   VERY MUCH  ENOUGH  NOT ENOUGH

2. Do you feel that using the relaxation techniques and self-statements will be helpful for you to cope with your feelings?

   VERY MUCH  ENOUGH  NOT ENOUGH

COMMENTS ON THE MATERIAL AND SPEAKER__________________________

WHAT IS YOUR OVERALL FEELINGS ABOUT THIS PROGRAM? WHAT DID YOU FIND HELPFUL, WHAT WASN'T? YOUR COMMENTS ARE GREATLY APPRECIATED.( you can use the other side if needed)
DEMOGRAPHICS

CODE NO: _______________ START _______________

DATE: _______________

SEX: M____ F____

AGE: _____

ETHNICITY: White African-American Hispanic Asian Other______________

MARITAL/PARTNER: Single Married/Live-in-Partner
                              Separated Divorced Widowed

EDUCATION: <HS HS <C C G Highest Level_____

EMPLOYMENT: Full-Time Part-Time Unemployed

RISK FACTOR: Gay IVDU Transfusion Hemophiliac Partner

CD4: _____

DATE OF DX: MONTH/YEAR _______________
On behalf of Aaron T. Beck, M.D., I am responding to your recent inquiry regarding our research scales.

You have Dr. Beck's permission to use and reproduce the scale(s) checked below only for the designated research project that you described in your letter. There is no charge for this permission.

However, in exchange for this permission, please provide Dr. Beck with a complimentary copy of any reports, preprints, or publications you prepare in which our materials are used. These will be catalogued in our central library to serve as a resource for other researchers and clinicians.

- Beck Depression Inventory (BDI)
- Beck Anxiety Inventory (BAI)
- Hopelessness Scale (HS)
- Suicide Intent Scale (SIS)
- Scale for Suicide Ideation (SSI)
- Cognition Check List (CCL)
- Anxiety Checklist (ACL)
- Beck Self-Concept (BSCT)
- Dysfunctional Attitude Scale (DAS)

If you have any further questions, feel free to contact me.

Sincerely,

Karen A. Quinn
Assistant to Aaron T. Beck, M.D.

NOTE: Permission for inclusion of the BDI, BAI, HS, SSI, and BSCT in any publication must be obtained from The Psychological Corporation; telephone #: 1-800-228-0752.
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<thead>
<tr>
<th>Question</th>
<th>Scoring</th>
<th>Options</th>
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<tbody>
<tr>
<td>Q1 How depressed are you?</td>
<td>Score 0 if not at all</td>
<td>Score 1 if a little</td>
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<tr>
<td></td>
<td>Score 2 if moderately so</td>
<td>Score 3 if a lot</td>
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<td></td>
<td>Score 4 if extremely so</td>
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<tr>
<td>Q2 Do you feel guilty about things that you have done or thought?</td>
<td>Score 0 if not at all</td>
<td>Score 1 if a little</td>
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<tr>
<td></td>
<td>Score 2 if moderately so</td>
<td>Score 3 if a lot</td>
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<tr>
<td></td>
<td>Score 4 if extremely so</td>
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<tr>
<td>Q3 Is it taking longer to get off to sleep?</td>
<td>Score 0 if no</td>
<td>Score 1 if sometimes</td>
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<td>Score 2 if always</td>
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<td>Q4 Do you sleep fitfully — often awakening?</td>
<td>Score 0 if no</td>
<td>Score 1 if sometimes</td>
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<td>Score 2 if always</td>
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<tr>
<td>Q5 Do you waken earlier than usual and then find yourself unable to get back to sleep?</td>
<td>Score 0 if no</td>
<td>Score 1 if sometimes</td>
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<td></td>
<td>Score 2 if always</td>
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<td>Q6 Have you lost interest in your work or hobbies?</td>
<td>Score 0 if not at all</td>
<td>Score 1 if a little</td>
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<td></td>
<td>Score 2 if moderately so</td>
<td>Score 3 if a lot</td>
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<td></td>
<td>Score 4 if extremely so</td>
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<td>Q7 Is life pointless?</td>
<td>Score 0 if no</td>
<td>Score 1 if yes</td>
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<tr>
<td>Q8 Have you thought of ending it all?</td>
<td>Score 0 if no</td>
<td>Score 1 if yes</td>
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<tr>
<td>Q9 Have you made plans to kill yourself?</td>
<td>Score 0 if no</td>
<td>Score 1 if yes</td>
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<tr>
<td>Q10 Have you attempted to — or do you intend to — kill yourself?</td>
<td>Score 0 if no</td>
<td>Score 1 if yes</td>
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<td>Q11 Do you feel that you are slower than your normal or usual speed?</td>
<td>Score 0 if not at all</td>
<td>Score 1 if a little</td>
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<td></td>
<td>Score 2 if moderately so</td>
<td>Score 3 if a lot</td>
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<td></td>
<td>Score 4 if extremely so</td>
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<td>Q12 Do you feel anxious or tense?</td>
<td>Score 0 if no</td>
<td>Score 1 if sometimes</td>
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<td>Score 2 if always</td>
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<td>Q13 Do you suffer from any physical symptoms?</td>
<td>Score 0 if no</td>
<td>Score 1 if sometimes</td>
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<td>Score 2 if always</td>
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<td>Q14 Are you worried that you might have a serious illness such as cancer or VD?</td>
<td>Score 0 if not at all</td>
<td>Score 1 if a little</td>
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<td>Score 2 if moderately so</td>
<td>Score 3 if a lot</td>
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<td>Score 4 if extremely so</td>
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<td>Q15 Have you lost interest in sex?</td>
<td>Score 0 if no</td>
<td>Score 1 if sometimes</td>
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<td>Score 2 if always</td>
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<td>Q16 Have you lost weight recently — excluding that due to dieting?</td>
<td>Score 0 if not at all</td>
<td>Score 1 if a little</td>
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<td>Score 2 if moderately so</td>
<td>Score 3 if a lot</td>
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<td></td>
<td>Score 4 if extremely so</td>
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<tr>
<td>Q17 Are you at your worst early in the day — but improve as the day goes on?</td>
<td>Score 0 if no</td>
<td>Score 1 if sometimes</td>
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<td>Score 2 if always</td>
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</table>

HAMD Score (Items 1-17) 153
Hamilton Anxiety Rating Scale

Instructions: This checklist is to assist the physician or psychiatrist in evaluating each patient as to his degree of anxiety and pathological condition. Please fill in the appropriate ratings:

<table>
<thead>
<tr>
<th>Item</th>
<th>Rating</th>
<th>Item</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety mood</td>
<td></td>
<td>Somatic (sensory)</td>
<td></td>
</tr>
<tr>
<td>Worry, incitement of</td>
<td></td>
<td>Tinnitus, blurring of</td>
<td></td>
</tr>
<tr>
<td>the worst, tearful</td>
<td></td>
<td>vision, hot and cold</td>
<td></td>
</tr>
<tr>
<td>anticipation, instability</td>
<td></td>
<td>flushed, feelings of</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>weakness, picking</td>
<td></td>
</tr>
<tr>
<td>Tension</td>
<td></td>
<td>Cardiovascular symptoms</td>
<td></td>
</tr>
<tr>
<td>Feelings of tension,</td>
<td></td>
<td>Tachycardia, palpitations,</td>
<td></td>
</tr>
<tr>
<td>fatigability, startle</td>
<td></td>
<td>pain in chest, throbbing of</td>
<td></td>
</tr>
<tr>
<td>response, moved to tears,</td>
<td></td>
<td>vessels, tainting feelings,</td>
<td></td>
</tr>
<tr>
<td>easily, trembling, feelings</td>
<td></td>
<td>missing seal</td>
<td></td>
</tr>
<tr>
<td>of restlessness, inability to talk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fears</td>
<td></td>
<td>Respiratory symptoms</td>
<td></td>
</tr>
<tr>
<td>Of dark, of strangers, of</td>
<td></td>
<td>Pressure or constriction in</td>
<td></td>
</tr>
<tr>
<td>being left alone, of</td>
<td></td>
<td>chest, tainting feelings,</td>
<td></td>
</tr>
<tr>
<td>animals, of traffic, of</td>
<td></td>
<td>sighing, dyspnea</td>
<td></td>
</tr>
<tr>
<td>crowds</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insomnia</td>
<td></td>
<td>Gastrointestinal symptoms</td>
<td></td>
</tr>
<tr>
<td>Difficulty in falling</td>
<td></td>
<td>Difficulty in swallowing,</td>
<td></td>
</tr>
<tr>
<td>asleep, broken lines,</td>
<td></td>
<td>wind, abdominal pain,</td>
<td></td>
</tr>
<tr>
<td>unsatisfying sleep and</td>
<td></td>
<td>burning sensations,</td>
<td></td>
</tr>
<tr>
<td>fatigue on waking,</td>
<td></td>
<td>abdominal cramps, nausea,</td>
<td></td>
</tr>
<tr>
<td>dreams, nightmares,</td>
<td></td>
<td>vomiting, diarrheas,</td>
<td></td>
</tr>
<tr>
<td>nightmares, night screams</td>
<td></td>
<td>looseness of bowels, loss</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>of weight, insomnia</td>
<td></td>
</tr>
<tr>
<td>Intellectual (cognitive)</td>
<td></td>
<td>Genitourinary symptoms</td>
<td></td>
</tr>
<tr>
<td>Difficulty in concentration, poor memory</td>
<td></td>
<td>Frequency of micturition,</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Depressed mood</td>
<td></td>
<td>Autonomic symptoms</td>
<td></td>
</tr>
<tr>
<td>Loss of interest, lack of</td>
<td></td>
<td>Dry mouth, flushing, pallor,</td>
<td></td>
</tr>
<tr>
<td>pleasure in hobbies,</td>
<td></td>
<td>tendency to yield,</td>
<td></td>
</tr>
<tr>
<td>depression, early waking,</td>
<td></td>
<td>tinitus, tension, headache,</td>
<td></td>
</tr>
<tr>
<td>diurnal swing</td>
<td></td>
<td>raising of lid</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fidgeting, restlessness or</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>palming, tremor of hands,</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>furrowed brow, strained</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>face, signing or rapid</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>respiration, facial pallor,</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>swallowing, tachicng,</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>brisk tendon jerks, dilated</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>pupils, exophthalmos</td>
<td></td>
</tr>
</tbody>
</table>

Addition comments:______________________________________________

Investigator's signature:______________________________________

Being HIV-infected is a stressful life event. Below are some statements made by people about this stressful life event. Please read each item and decide how frequently each item was true for you during the last seven (7) days in regards to being HIV-infected. If the item did not occur in the past seven days, choose the "Not at all" option. Circle the number that best describes each item. Please complete each item.

1. I thought about it when I didn’t mean to.  
2. I avoided letting myself get upset when I thought about it or was reminded of it.  
3. I tried to remove it from memory.  
4. I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.  
5. I had waves of strong feelings about it.  
6. I had dreams about it.  
7. I stayed away from reminders of it.  
8. I felt as if it hadn’t happened or wasn’t real.  
9. I tried not to talk about it.  
10. Pictures about it popped into my mind.  
11. Other things kept making me think about it.  
12. I was aware that I still had a lot of feelings about it, but I didn’t deal with them.  
13. I tried not to think about it.  
14. Any reminder brought back feelings about it.  
15. My feelings about it were kind of numb.
MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL SCALE
(HLOC)

Form C

INSTRUCTIONS: Each item below is a belief statement about HIV with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE 4=SLIGHTLY AGREE
2=MODERATELY DISAGREE 5=MODERATELY AGREE
3=SLIGHTLY DISAGREE 6=STRONGLY AGREE

SD MD D A MA SA

1. If my HIV worsens, it is my own behavior which determines how soon I feel better again.

2. If I see my doctor regularly, I am less likely to have problems with my HIV.

3. Most things that affect my HIV happen to me by chance.

4. Whenever my HIV worsens, I should consult a medically trained professional.

5. I am directly responsible for my HIV getting better or worse.

6. Other people play a big role in whether my HIV improves, stays the same, or gets worse.

7. Whatever goes wrong with my HIV is my own fault.

8. Luck plays a big part in determining how my HIV improves.
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<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>9. Whatever improvement occurs with my HIV is largely a matter of good fortune.</td>
<td>SD</td>
<td>MD</td>
<td>D</td>
<td>A</td>
<td>MA</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
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<td>5</td>
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</table>

10. The main thing which affects my HIV is what I myself do.

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11. If my HIV worsens, it's a matter of fate.

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12. Following doctor's orders to the letter is the best way to keep my HIV from getting any worse.

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</table>

13. If my HIV takes a turn for the worse, it is because I have not been taking proper care of myself.

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14. The type of help I receive from other people determines how soon my HIV improves.

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</table>

15. In order for my HIV to improve, it is up to other people to see that the right things happen.

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</table>

16. I deserve the credit when my HIV improves and the blame when it gets worse.

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<td>3</td>
<td>4</td>
<td>5</td>
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</tbody>
</table>

17. If I am lucky, my HIV will get better.

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<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

18. As to my HIV, what will be will be.

<p>| | | | | | |</p>
<table>
<thead>
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<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
### MEDICAL REVIEW LOG

<p>| | | | |</p>
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<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>MONTHS</strong></td>
<td><strong>FIRST</strong></td>
<td><strong>SECOND</strong></td>
<td><strong>THIRD</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>COMPLETED APPOINTMENTS</strong></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td><strong>MEDICATIONS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Oral</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Intravenous</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Aerosol</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SPECIALTY REFERRAL</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Guidelines: Kept appointments, took all medications agreed upon and followed through on specialty referrals

Key: Y (YES), N (NO), NA (Not Appropriate)
November 1, 1993

Nancy Caddick, LCSW
Comprehensive AIDS Center
Passavant, 826
Chicago Campus

Re: Effectiveness of a Biopsychosocial Educational Program in Reducing Emotional Distress Using the Stress Inoculation Model for HIV-Infected People in the Pre-AIDS Stage of Disease

Dear Ms. Caddick:

At its October 29, 1993 meeting, the Institutional Review Board considered and approved* your submission referenced above for a one-year period ending October 31, 1994. This approval applies to the use of human subjects only, and does not constitute scientific approval of the project. Scientific approval must be obtained from the NMH or RIC Research Committee before the project may be initiated.

IRB approval is given with the understanding that no changes may be made in the procedures to be followed nor the consent form(s) to be used until such modifications have been submitted to the IRB for review and have been given approval.

Any unanticipated problems involving risk to human subjects and any serious adverse effects must be reported promptly to the IRB.

One month prior to the expiration of this approval, you will receive notification of the need for updated information to be used for the project’s periodic review. Information concerning implementation and results to date will be required at that time.

Sincerely,

Joanne G. Richmond
Manager

*Please delete the first sentence in the Risk section. Copy the IRB when this is done.

cc: John Phair, M.D.
    Robert Murphy, M.D.
    Baiba Berzins
    Tamara Norman
December 8, 1993

Nancy Caddick, LCSW
Comprehensive AIDS Center
Passavant, Room 826
Chicago Campus

RE: Research Study #93-11-14
Effectiveness of a Biopsychosocial Educational Program in Reducing Emotional Distress Using the Stress Inoculation Model for HIV-Infected People in the Pre-AIDS Stage of Disease

Dear Ms. Caddick:

The above referenced project received scientific and administrative APPROVAL from the NMH Research Committee and Office of Research on November 17, 1993. The committee wishes you success in your endeavor to accomplish this project.

You may commence with this project provided that APPROVAL has been received from the Institutional Review Board for the use of human subjects, and administrative issues are resolved (i.e. executed contract containing an indemnification clause, account established for ancillaries services, etc).

If you need any additional assistance regarding this project, please do not hesitate to contact us. Thank you.

Sincerely,

Peter J. Kahrilas, M.D.
Chairman
NMH Research Committee

Bonnie Aguda
Director of Research
Dear Colleague,

Thank you for submitting the following research project for review by the Institutional Review Board for the Protection of Human Subjects:

Project Title: Effectiveness of a Biopsychological Education Program in Reducing Emotional Distress Using the Stress Inoculation

After careful examination of the materials you submitted, we have approved this project as described for a period of one year from the date of this letter.

Approximately eleven months from today, you will receive from the IRB a letter which will ask whether you wish to apply for renewal of IRB approval of your project. You will be asked whether there have been any changes in the nature of the involvement of human subjects in your project since it was first approved, and whether you foresee any such changes in the near future. If your responses to these questions are timely and sufficiently explicit, the IRB will at that time renew your approval for a further twelve-month period. If you do not return that form by October 13, 1994, however, your approval will automatically lapse.

This review procedure, administered by the IRB itself, in no way absolves you personally from your obligation to inform the IRB in writing immediately if you propose to make any changes in aspects of your work that involve the
participation of human subjects. The sole exception to this requirement is in the case of a decision not to pursue the project—that is, not to use the research instruments, procedures or populations originally approved. Researchers are respectfully reminded that the University's willingness to support or to defend its employees in legal cases that may arise from their use of human subjects is dependent upon those employees' conformity with University policies regarding IRB approval for their work.

Should you have any questions regarding this letter or the procedures of the IRB in general, I invite you to contact me at the address or the telephone number shown on the letterhead. If your question has directly to do with the project we have just approved for you, please quote file number 1080.

With best wishes for your work,

Sincerely,

Matthew Creighton, SJ

cc: Graduate School/WTC
    inter-office memorandum S. Condon
## ANALYSIS OF COVARIANCE TABLE

<table>
<thead>
<tr>
<th>SCALE (POSTTEST)</th>
<th>EXPERIMENTAL-CONTROL (Differences)</th>
<th>STD E (Differences)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>BDI</td>
<td>0.819</td>
<td>0.28</td>
<td>0.785</td>
</tr>
<tr>
<td>HAMD</td>
<td>-2.821</td>
<td>-1.08</td>
<td>0.295</td>
</tr>
<tr>
<td>HAS</td>
<td>1.598</td>
<td>0.62</td>
<td>0.543</td>
</tr>
<tr>
<td>IES-I</td>
<td>1.719</td>
<td>1.20</td>
<td>0.246</td>
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<tr>
<td>IES-A</td>
<td>4.853</td>
<td>2.65</td>
<td>0.017</td>
</tr>
<tr>
<td>HLOC-I</td>
<td>-0.784</td>
<td>-0.43</td>
<td>0.673</td>
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<tr>
<td>HLOC-D</td>
<td>0.507</td>
<td>0.29</td>
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<tr>
<td>HLOC-O</td>
<td>-1.467</td>
<td>-1.24</td>
<td>0.233</td>
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</table>
### POOLED T-TEST TABLE
**(POST-PRE)**

<table>
<thead>
<tr>
<th>SCALE</th>
<th>EXPERIMENTAL</th>
<th></th>
<th>CONTROL</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>STDE</td>
<td>P</td>
<td>M</td>
</tr>
<tr>
<td>BDI</td>
<td>-1.125</td>
<td>2.490</td>
<td>0.643</td>
<td>0.363</td>
</tr>
<tr>
<td>HAMD</td>
<td>-4.000</td>
<td>1.742</td>
<td>0.165</td>
<td>-0.363</td>
</tr>
<tr>
<td>HAS</td>
<td>-0.375</td>
<td>2.329</td>
<td>0.847</td>
<td>-1.000</td>
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<td>IES-I</td>
<td>1.125</td>
<td>1.630</td>
<td>0.905</td>
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<td>IES-A</td>
<td>2.750</td>
<td>1.810</td>
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</tr>
<tr>
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<td>-2.750</td>
<td>1.485</td>
<td>0.408</td>
<td>-1.181</td>
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<tr>
<td>HLOC-D</td>
<td>-0.125</td>
<td>1.940</td>
<td>0.980</td>
<td>-0.181</td>
</tr>
<tr>
<td>HLOC-O</td>
<td>-1.375</td>
<td>1.335</td>
<td>0.256</td>
<td>0.363</td>
</tr>
</tbody>
</table>
REFERENCES


AIDS Care, 5, 43-45.


General Hospital Psychiatry (1990, March). In support of M.A. Cohen (Editor's Note) p. 98.


event scale: A measure of subjective stress. 

*Psychosomatic Medicine, 41*, 209-218.


The author, Nancy Downey Caddick, was born in Alton, Illinois and moved to Chicago, Illinois at the age of eight. She is the fifth of seven children and raised by her mother following the death of her father when the author was five years old.

Early adulthood was influenced by the entertainment business delaying completion of college until 1982. While raising three sons and attending school part-time she was active in community programs and instrumental in the development of a large scale community volunteer program to assist neighbors with little emergencies. While working as the office manager for the Respiratory Therapy Department at Northwestern Memorial Hospital, she returned to school to complete her Masters in Social Work at Loyola University of Chicago, in the School of Social Work in 1985. She returned to the same University in 1988 to begin her doctoral studies in Clinical Social Work with a desire to continue practice and teaching in both the medical and university settings.

Ms. Caddick has focused her practice in the medical setting beginning with a combined coverage to lung transplant and hospice patients in 1985, to the new Hospice Unit in 1987. Her interest in the AIDS population resulted
in a transfer in 1989 to the hospital's expanded Comprehensive HIV Center to specialize in HIV/AIDS care where she is currently in practice.