

EMPLOYMENT, SOCIAL NETWORKS, AND  
PSYCHOSOCIAL ADJUSTMENT OF  
HIV INFECTED PERSONS

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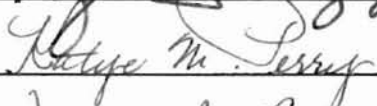
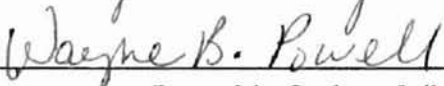
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May the divine assistance remain always with us.

And may the souls of the faithful departed, through the  
mercy of God, rest in peace. Amen.

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## CHAPTER ONE

### INTRODUCTION

The number of deaths from Acquired Immune Deficiency Syndrome (AIDS) in the United States fell in 1996 for the first time in the history of the epidemic (Centers for Disease Control [CDC], 1996a). The 25 percent decrease in the number of deaths from the previous year removed AIDS from its position as the number one cause of death of persons between the ages of 25 and 44 which it had held since 1993. Continuing this trend into the following year there was a 47 percent decline in the number of deaths from 1996 to 1997 (National Center for Health Statistics [NCHS], 1998a). The current death rate related to the Human Immunodeficiency Virus (HIV) of 5.9 deaths per 100,000 is the lowest rate since 1987, the first year mortality data were available for the disease. However, HIV is still the fifth leading cause of death for persons aged 25 - 44.

The number of newly diagnosed AIDS cases and incidence of AIDS opportunistic illnesses both decreased by 6 percent and 7 percent respectively from 1995 to 1996 (CDC, 1997b). However it is still estimated that 40,000 new HIV infections occur every year (NCHS, 1998b). The reported decrease in death rates, decreases in new AIDS diagnoses, and a continued high rate of new HIV infection lead to steady increases in the number of persons living with HIV and AIDS in the United States. These trends reflect the apparent success of newly developed antiretroviral drug therapies both in prolonging

life and slowing the disease process from the point of infection with HIV. They also present the challenge to society of providing additional services, treatment, and care for the increasing number of people living with this disease.

One particular social issue that is becoming more pressing is that of employment and career development for persons living with HIV/AIDS (Goss & Adam-Smith, 1995). The possibility of a long term but chronic disease process coupled with the typically early age of onset make career issues a valid concern for both HIV infected persons looking for or maintaining employment as well as for employers who will probably, at some point, have to confront the existence of HIV in their workplace. The fact that the population most likely to die from AIDS, persons between the ages of 25 and 44, represent more than half of the nation's work-force should clearly provide incentive for the business community to get involved in HIV prevention efforts and the development of universal workplace policies that address the matter.

However, employment issues for Persons Living With AIDS (PLWAs) have not been addressed in any detail by researchers or service providers until recently. As the estimated life span of an infected person continues to increase, it is becoming more apparent that established careers can be maintained and prospective careers may be pursued. Yet, because of the uncertainty of the progression of the illness and rapidly developing medical technology, career goals, expectations, and opportunities may vary widely among infected persons.

Persons who become aware of a seropositive status in the early stages of career development may question the value of investing time and energy in attaining previously set occupational goals. These persons may reduce their career aspirations because of an

unwillingness to expend energy and effort necessary to accomplish these goals. At the same time these persons may worry that choosing to not aggressively pursue a career and letting crucial and irretrievable opportunities pass may have more devastating consequences in the event that a cure is someday found.

Those who discover that they are HIV infected after establishing a career face a different set of adaptive challenges. These persons may view work as a statement of value, identity, self-worth, and an assurance of some "normalcy". The workplace may be one area where the individual maintains a sense of control which can reduce the stress of the uncertainty they are facing in other aspects of life. Perhaps most importantly, the loss of social support from the relationships developed with co-workers may have severe negative effects on their psychological well being.

Many HIV infected individuals are forced into unemployment due to the lack of understanding and support from employers and co-workers or their inability to maintain their previous level of performance before becoming ill. A reduced work load or part-time employment may seem to be a beneficial compromise for both employer and employee. However, part-time employees are usually not allowed to participate in employee sponsored health benefit programs. Under most current policies, reduced number of hours worked may lead to the loss of medical insurance coverage. On the other hand, an AIDS diagnosis typically qualifies one to receive disability income, Social Security benefits, food stamps, subsidized housing, and medical care. However, financial compensation even from part-time employment often disqualifies them from receiving any of these benefits. Persons living with AIDS are usually forced to choose either full-time employment or unemployment in order to meet financial obligations.

In addition to financial security and continued health insurance coverage, remaining in the workplace may benefit the HIV infected employee in several other ways including the continued existence of a social network through relationships with co-workers, and the opportunity to maintain some independence and self-esteem. It is expected that continued employment will be most beneficial to the HIV infected person if the work environment is supportive. However, because of the likelihood of smaller or unstable social networks that these persons may be part of, it is possible that just having additional social contacts with co-workers will be helpful even if they are not understanding or aware of the person's medical condition. Obviously hostile work environments would have fewer if any benefits, and could even be harmful to both psychological and physical health.

#### Statement of the Problem

The problem underlying the present study is that persons infected with HIV or living with AIDS experience a vast array of psychosocial challenges including rejection and social isolation. Discrimination and mistreatment in the workplace, including unjustified dismissal from work, contribute to the difficulty of their plight. Providing a positive work environment could prove to benefit HIV infected employees by enhancing their social support system. The possibility of a positive correlation between physical health and psychosocial functioning broadens the implications for research and treatment concerning psychological adjustment and emotional well-being of HIV infected persons. The medical uncertainties still surrounding this epidemic lend credence to the exploration and pursuit of all possible avenues that could lead to improved health.

Independent samples t tests will be utilized to examine the difference in mean scores for HIV infected persons who are unemployed compared to those who are employed for three dependent variables including psychosocial adjustment to illness, the existence of social networks, and general health status. The results are expected to show that HIV infected persons who continue to work have better psychosocial adjustment to the ordeal of living with this disease, have a greater social network, and experience better and prolonged health.

#### Research Hypotheses

- HO<sub>1</sub> Mean scores measuring psychosocial adjustment of HIV infected persons will differ for participants who are employed from those who are unemployed.
- HO<sub>2</sub> Mean scores measuring the presence of a social network for HIV infected persons will differ for participants who are employed from those who are unemployed.
- HO<sub>3</sub> Mean scores measuring the general health status of HIV infected persons will differ for participants who are employed from those who are unemployed.

## CHAPTER TWO

### REVIEW OF THE LITERATURE

#### Psychosocial Implications of HIV/AIDS

The psychological implications of being diagnosed with HIV/AIDS are very complex. Hoffman (1991) has proposed a psychosocial model of HIV infection in an attempt to capture the complexity of the psychosocial issues that accompany the disease. Some of the more prevalent issues outlined by Hoffman include dealing with an unpredictable disease process, social stigma, and internalized homophobia.

One of the unique psychosocial challenges of living with HIV infection is the fact that this is a progressive yet unpredictable disease. Inevitably, the virus gradually destroys the ability of the immune system to fight infection, and finally will result in death. However, there is not a predictable chronological course that the virus will follow. Hence, psychological functioning may vary greatly within different stages of the disease and with the occurrence of different illnesses or losses. Lutgendorf, Antoni, Schneiderman, and Fletcher (1994) point out that depression, anxiety, and anger often increase at the time of diagnosis and may diminish and recycle as individuals confront realities of living with HIV. Hoffman (1991) emphasizes that persons living with HIV often get through one crisis but are not able to regain equilibrium before another crisis hits.

Another unique issue surrounding HIV/AIDS is the stigma that exists in today's society about this disease. The related concepts of death, sexuality, and moral worth all seem to perpetuate the stigma. Herek and Glunt (1988) point out that AIDS confronts even the noninfected with the reality of death which provokes anxiety concerning one's own mortality. Others (Peters, Boer, Kok, & Schaalma, 1994) found that illnesses associated with sexual behavior (AIDS and syphilis) elicited less sympathy and more anger and contempt than cancer or tuberculosis. Respondents from a university setting perceived AIDS patients as more dangerous, dirty, foolish, and worthless than cancer patients (Walkey, Taylor & Green, 1990).

Implications of these attitudes can be detrimental to an HIV infected person. Feelings of self-hate, shame and contamination may surface leading to isolation or social withdrawal. The person may anticipate or experience discrimination in the areas of employment, housing, and medical care. In addition, persons perceived to be infected with HIV may suffer physical violence. Berrill (1992) reports that 15 percent of anti-gay violence is classified as "AIDS related" (i.e., incidents that involved verbal reference to AIDS by perpetrators or were directed against persons with AIDS). Any of these situations could lead an HIV infected person to seek psychological counseling only to find the same negative attitudes held by the mental health practitioner. Fliszar and Clopton (1995) found that psychologists in training had less positive attitudes toward AIDS patients than toward identically described leukemia patients. However, the same study stated that the attitudes reported were an improvement from those of psychologists studied in earlier research.

Within the gay community internalized homophobia may surface in HIV infected

persons leading to self-hate and shame in being homosexual. Viewing one's infection as a retribution for past behaviors is a common reaction (Dilley, Ochitill, Perl, & Volberding, 1985). Sexual promiscuity and intravenous drug use may be seen as actions which made the person deserve infection. An infected person may experience anger toward a sexual partner for being the possible source of their infection or toward oneself for being sexually promiscuous or careless.

Jennings and Jennings (1991) point out that Hoffman's model ignores the biological nature of HIV and that in 10 percent of HIV infected persons the initial manifestations of the disease are psychological, emotional, cognitive, motor or sensory disturbances due to organic brain damage. Neuropsychological impairment is thought to occur in HIV infected individuals at rates between 29 and 87 percent with approximately one third of AIDS patients developing some degree of HIV-associated dementia over the course of their illness (Heaton et al, 1994). The American Foundation for AIDS Research (1996) reports that central nervous system (CNS) and peripheral nervous system (PNS) disorders may result from opportunistic infections, neoplasms, the disease process of the human immunodeficiency virus itself, as well as from the possible toxic effects of various treatments.

HIV-Associated Dementia (HAD) Complex, formerly known as AIDS Dementia Complex (ADC), is a commonly recognized CNS complication of HIV infection and is one of the conditions that can lead to an AIDS diagnosis (CDC, 1993). Later stages of HAD Complex are marked by significant functional impairment and the presence of psychotic symptoms which might include aphasia, confusion, disorientation, delusions, hallucinations, seizures, mutism and paralysis, and coma. However, it is the earlier stage



symptoms of apathy, lethargy, poor concentration, and social withdrawal that often leads to a misdiagnosis of Major Depressive Disorder (Litt, 1996).

An unpredictable disease process, social stigma, and internalized homophobia are but a few of the issues that Hoffman's psychosocial model of HIV infection encompasses. Although, these also seem to be the most commonly addressed issues within the complete body of AIDS related behavioral studies. Considering the paradox of the psychosocial implications of HIV/AIDS, perhaps these three elements are the most essential for a basic understanding of the psychological challenges faced by HIV infected persons. Yet, it should also be understood that physiological conditions may complicate the diagnostic and treatment processes for HIV infected patients presenting with certain symptoms.

### Psychoimmunology

A small body of research has begun to appear regarding the effects that a person's psychological and emotional state can have on his or her immunological status and physical functioning. Using CD4 or T-cell counts to measure immune functioning and disease process researchers can investigate the body's physiological response to various psychosocial stressors. CD4 or "helper" T-cells are lymphocytes responsible for coordinating much of the immune response. These cells are specifically targeted and destroyed by the HIV.

Looking primarily at changes in the CD4 or T-cell count in HIV infected individuals, some studies have focused on the effects of psychosocial distress and depression. Kemeny et al. (1994) found that higher levels of depressed mood correlated with lower CD4 counts. Perry, Fishman, Jacobsberg, and Frances (1992) found

significant correlations between total CD4 cells and both state anxiety and the experience of the death(s) of a spouse or a close sexual partner during the past two years. However, none of the psychological factors explored were predictive of total CD4 cells 12 months later. In looking at the effects of depression on the decline of CD4 cells, Burack et al. (1993) found that the average rate of decline among 50 depressed subjects was slightly greater than the decline among 227 nondepressed subjects.

Other studies have shown that coping styles may have a positive effect on immune functioning. Using less denial and developing a fighting spirit were found to be associated with a slower progression from asymptomatic HIV infection to the symptomatic stage (Solano et al., 1993). Others (Ironson et al., 1994) found that the use of denial to cope with an HIV positive diagnosis was predictive of greater immunological impairment at the one year follow up and a greater likelihood of progression to symptoms and AIDS at the two year follow-up. Finally, Lutgendorf et al. (1994) found that utilizing cognitive behavioral stress management interventions at the point of antibody status notification enhanced the participants' coping strategies and utilization of social support which correlated with improved immune functioning.

In reviewing studies that specifically measure correlations of psychological functioning and CD4 cells, Mulder (1994) provides evidence of results that oppose the findings mentioned above. He gives a detailed list of reasons for the conflicting results including the lack of a theoretical rationale to link the broad set of psychosocial and psychiatric measures assessed and driving the statistical hypotheses. Yet, he does acknowledge that various psychological interventions may lead to a decrease in HIV-related physical symptoms and increases in vigor and hardiness without physical effects

on the clients CD4 count. Although the results are not conclusive, these early studies in psychoimmunology highlight important trends for the further understanding of HIV/AIDS.

### Benefits of Social Support

Empirical research on social support and psychological adjustment to HIV/AIDS consistently reveals similar results. Zich and Temoshok (1987) report that decreases in perceived social support are associated with increases in psychological distress and that the more available social support is perceived to be, the less hopelessness and depression are reported. Others have found that greater social support decreases depression (Hays, Turner, & Coates, 1992; Noh, Chandarana, Field, & Paulma, 1990), lowers distress (Blaney et al., 1990), improves psychosocial adjustment (Kyle and Sachs, 1994), and is related to psychological well-being (Rabkin, Williams, Neugebauer, Remien, & Goetz, 1990; Wolf et al., 1991; Dew, Ragni, & Nimorowi, 1990; Kurdek and Siesky, 1990).

Lesserman, Perkins, and Evans (1992) found a relationship between social support and coping, specifically that satisfaction with social support and participation in the AIDS community were related to greater utilization of adaptive coping strategies such as more fighting spirit, greater striving towards personal growth, and less helplessness. Others (Namir, Wolcott, Fawzy, & Alumbaugh, 1987) found that an active-behavioral or proactive method of coping is negatively associated with worsened mood and that avoidance coping was positively associated with a worsened mood state (Nicholson & Long, 1990). Leserman concluded that social support buffers some of the difficulties associated with the threat of AIDS and helps subjects maintain a positive and

empowering approach to this disease.

Physical well-being of persons infected with HIV has also been linked to perceptions of social support. Ostrow et al. (1989) found that gay seropositive men who had no one to "talk to about serious problems" reported significantly higher scores on depression than did those who had a support system. The depressed men also reported more HIV-related symptoms, regardless of whether symptoms (e.g., swollen glands) could be detected during a physical. Namir, Alumbaugh, Fawzy, and Wolcott (1989) found a similar relationship between physical health and social support in a cross-sectional study of 50 gay men with new AIDS diagnoses in the San Francisco area. They reported that satisfaction with total social support received was significantly positively associated with quality of life, lower pain levels, and better overall health. In addition, the ability of the social network to provide concrete, specific assistance with daily tasks was significantly associated with fewer reported medical symptoms.

#### Lack of Social Support for Persons Living with HIV/AIDS

It is clear that persons living with HIV/AIDS are likely to benefit, on several levels, from having an intact social support network. However, due to the stigma associated with AIDS, infected persons are sometimes abandoned by friends and family when support, comfort, compassion, and closeness are needed most (Kyle & Sachs, 1994). The fear of rejection, abandonment, and loss of existing relationships may prevent HIV infected persons from seeking support. In fact, seropositive persons are inclined to intentionally distance themselves, emotionally and physically, from friends, family and colleagues as a way of keeping their status a secret (Christ & Wiener, 1985; Martin,

1989). Also, support networks that were previously in place may be depleted or displaced by the nature of the illness itself.

Disclosure of one's serostatus to family members frequently means disclosure of one's sexual orientation for the first time, which often leads to rejection by family members. Namir, Alumbaugh, Fawzy and Walcott (1989) found that 52 percent of the homosexual men in his research sample reported "one or no family members" in their support system. Others have experienced an immediate end to a relationship after informing a sexual partner of his positive serostatus (Martin, 1989).

Many gay men establish a social support system within the gay community. As this epidemic continues to ravage the gay population, infected individuals may find their support system dwindling due to the deaths of gay friends, lovers, or caregivers. In one study examining this phenomena in New York City, bereavement, defined as the loss of a lover or close friend to AIDS , was reported by 27 percent of the sample (Martin, 1989). Many respondents had suffered two or three bereavements.

In addition to the loss of interpersonal supports, institutional sources of support, such as employment and religion, may have never been developed or are likely to diminish once an infected individual makes his or her positive serostatus known. Although many HIV infected gay or bisexual men identify with a religious denomination (Chuang, Devins, Hunsley, & Gill, 1989), it is possible that those who identify with religions that denounce homosexuality might avoid organized religion as a source of institutional support. Other persons, upon revealing that they are infected with HIV, have been rejected by their religious community regardless of sexuality or mode of transmission.

Place of employment is another setting where social support for HIV positive persons is not necessarily expected to exist or remain stable. The results of a survey of people in the workplace by Blendon and Donelan (1988) revealed that 25 percent of respondents refused to work with an HIV-infected or AIDS diagnosed person and 25 percent believed employers should be able to fire people who were HIV infected or had AIDS. As for those who have established a support network in their place of employment, they face the probability of losing that support as their ability to work declines and they are forced to leave the work environment.

#### Benefits of Continued Employment

The idea that continued employment could be beneficial to HIV infected persons stems from the knowledge of the benefits of employment for the general population.

Statt (1994) states:

For people of both sexes and all ages paid employment, generally speaking, is expected to provide some measure of independence and autonomy, a feeling of competence, achievement and self-worth, a feeling of being valued, of making a contribution and of belonging. (p. 86)

Early investigations into the psychosocial benefits of employment (Friedmann & Havighurst, 1954) have established that work fulfills at least five social functions, namely meeting the employees need for (a) income, (b) expenditure of time and energy, (c) identification and status, (d) association, and (e) source of meaningful life experience. When related to social status, work was perceived to be meaningful by providing a source of self-respect, a way of achieving recognition or respect from others, a definition of role, friendship relations, and peer-group relations.

The importance of work relationships as a source of social support has been documented by social gerontologists in studies of retirees (Howard, Marshall, Rechnitzer, Cunningham, & Donner, 1982; Lowenthal & Haven, 1968; Mutran & Reitzes, 1981). Bosse, Aldwin, Levenson, Workman-Daniels, and Ekerdt (1990) found that co-workers are considered an important source of friends and confidants. Half of their sample reported having at least some friends from work and 42.7 percent reported recently talking to co-workers about a problem. Those who were working after retirement maintained or re-established co-worker friendships, but those not employed at all reported having the fewest number of friends and confidants. In addition, they found that persons out of the work force for a long period of time did not replace work-related losses in friends with other individuals, so they had significantly less extensive social networks and less frequent contact with family and friends.

The negative implications of unemployment have also been documented. Statt (1994) notes that various studies have linked unemployment to social, psychological and physical ailments. For instance, unemployment rates correlate with increased rates of admission to mental hospitals (Brenner, 1973), imprisonment and homicide (Brenner, 1979), and divorce (South, 1984). The psychological effects of unemployment found in other studies (Banks & Jackson, 1982; Cobb & Kasl, 1977; Feather & O'Brian, 1986; Platt, 1984; Warr & Jackson, 1985) include increased anxiety, lack of self-confidence, listlessness, feelings of depression and insomnia and a greater likelihood of the person attempting and committing suicide. In addition, the incidences of stress-related psychosomatic conditions such as headaches, stomach ulcers and dermatitis, as well as the more serious conditions of heart disease and strokes increase for unemployed persons

(Statt, 1994). Individuals of course will react differently to unemployment according to the circumstances of various other aspects of their personal situation.

Age is one personal characteristic which contributes to individual differences of experiencing unemployment. Warr and Jackson (1985) found that persons in their 20s, 30s, and 40s have the most difficult time dealing with the psychological implications of unemployment. Perhaps this is due to the social expectations created by theorists that one's activities during this time period are of vital importance in pursuing the appropriate path toward a successful and fulfilling career.

Super and Bohn (1971) have fueled such expectations through their development of a widely accepted series of life-cycle stages to be visited throughout the process of career development. They labeled the developmental period of age 25 to 44 years the establishment stage which involves the transition to a specific career choice. Super (1990) then proposed that:

Work satisfactions and life satisfactions depend on the extent to which the individual finds adequate outlets for abilities, needs, values, interests, personality traits, and self-concepts. They depend on establishment in a type of work, a work situation and a way of life in which one can play the kind of role that growth and exploratory experiences have led one to consider congenial and appropriate. (p.208)

Thus, by applying Super's model of life-stages, the role of an unemployed young adult may be viewed as unsatisfying, inimical, and inappropriate. Avoiding these types of social criticisms may in itself provide adequate motivation for young HIV infected persons to seek or maintain employment.

Another, probably more practical reason for healthy HIV infected persons to continue working is for financial security. Income, health insurance, and other health



related job benefits can help offset the staggering expenses of prophylactic medications and antiretroviral treatment therapies. For those who maintain relatively good health, the opportunity to invest or save money for future medical or living expenses and the knowledge that they have medical coverage if their health begins to decline can relieve much anticipatory stress.

### AIDS in the Workplace

Although one in six large worksites and one in 15 small worksites has had an employee with HIV/AIDS (CDC, 1996b), the corporate world has yet to adequately address the epidemic. In a national survey the CDC's Business Responds to AIDS (BRTA) Program (1996b) found that only 43 percent of American worksites have general policies addressing HIV/AIDS and few have HIV/AIDS specific policies.

Workplace concerns about HIV/AIDS tend to focus on transmission of the virus and the cost associated with employing an individual with HIV/AIDS (Lin, 1996). HIV/AIDS education is offered to employees 3-4 times more often at worksites where the employees have potential exposure to blood (CDC, 1996b). Potential costs incurred by employers due to AIDS may include expenses for additional recruiting, hiring, and training, productivity declines, premature loss of workers, and increased costs for employee benefits such as health insurance, short- and long-term disability benefits, life insurance, and pension (Farnham & Gorsky, 1994). In a survey of 248 managers in manufacturing, government, and service organizations Vest, O'Brien, and Vest (1990) found that reduced revenues, disruptions in the workplace, and increased insurance costs emerged as the three most frequently identified consequences of employing persons with

HIV/AIDS. In addition, the Americans with Disabilities Act (ADA) compels employers to provide reasonable accommodations to HIV infected employees which can include flex-time for medical appointments, additional unpaid leave, and restructured work schedules with periodic breaks. Although many reasonable accommodations require little or no direct cost to implement, management may find it burdensome and be reluctant to provide such accommodations.

AIDS policies that appear to be cost driven blatantly place the interests of the organization over and above those of the employee. Goss, Adam-Smith, Rees, and Sinclair (1993) found in a review of corporate AIDS policies that some policies were “defensive” in nature. These policies used conditional and exclusionary terms to qualify and limit the companies commitment to non-discrimination practices. They implied that any treatment received by the infected employee should not bring the risk of danger or loss to the organization.

On the other hand, some companies have developed and implemented a more “humanistic” AIDS policy in which the organization accepts responsibility in dignifying and supporting their HIV infected employees. This ideology often extends into action to insure the welfare and protection of the employee (Goss, Adam-Smith, Rees, & Sinclair, 1993). Some companies are willing to go above and beyond the reasonable accommodations requirement for their ailing employee. With recently developed computer technology, employees may be allowed to perform the majority of their occupational duties in their own home or in other environments that are more comfortable than the traditional office setting. Other companies have offered to have former full-time employees with AIDS consult for them on an on-call or part-time basis (Friskopp &

Silverstein, 1996). These examples of a positive employer response, however, are fairly rare and not always feasible for the employee.

### Employment Trends and Issues for HIV Infected Persons

While humanistic workplace policies and employers who are willing to accommodate the needs of the HIV infected employee do exist, the seemingly inevitable outcome regarding employment is not so pleasant for persons living with this disease. Yelin, Greenblatt, Hollander and McMaster (1991) found that 50 percent of those who worked before the onset of symptoms stopped working within two years and all of the participants in their study were unemployed within ten years of symptom onset. Looking more specifically at employment trends Crystal and Jackson (1989) found that 50 percent of HIV infected persons reported job loss due to health problems and 19 percent reported job loss owing to fear or discrimination.

Impaired neurocognitive functioning due to HIV infection has also been identified as a factor contributing to the loss of employment for HIV infected persons. Velin, Heaton, Grant, and the HIV Neurobehavioral Research Center [HNRC] Group (1994) found that significantly more neuropsychologically impaired subjects were unemployed relative to neuropsychologically normal subjects. Neuropsychologically impaired subjects also reported the loss of ability to perform their occupational tasks five times more frequently than their nonimpaired counterparts. Furthermore, it was shown that the majority of the unemployed subjects were in the medically asymptomatic or mildly symptomatic stages of disease so that it was unlikely that unemployment was caused primarily by physical ailments.

Others (Massagli, Weissman, Seage, & Epstein, 1994) identified certain job characteristics that affect the likelihood of employment loss. They found that respondents who worked 35 hours or more a week, had jobs that required a lot of mental effort, and had jobs requiring little physical effort were employed much longer after AIDS diagnosis. In addition, individuals insured by HMOs at diagnosis worked significantly longer than those privately insured or insured by the government, and individuals who were never hospitalized after diagnosis worked significantly longer than those hospitalized at least once. Massagli et al. also noted that for those who remained in the workforce reported income at the time of the study was close to 60 percent of their highest earning level, a rate which decreased to 26 percent for those no longer employed

HIV infected persons attempting to re-enter the workforce, perhaps after regaining an adequate level of health, are also likely to face an array of obstacles. In a study to assess the attitudes of rehabilitation counselors towards working with clients infected with HIV, Alston, Silkins, and Holbet (1995) found that although 73 percent of respondents reported being "comfortable" or "neutral" with personal and vocational counseling, 52 percent of rehabilitation counselors reported that they were "uncomfortable" contacting employers about hiring persons in this disability group. Alston et al. also found that rehabilitation counselors believed that clients with AIDS would encounter the greatest difficulty obtaining employment compared to 13 other disability groups including the blind, mentally retarded, and former prisoners.

Although obtaining or maintaining employment was identified relatively early as an issue for HIV infected persons (Christ, Wiener, and Moynihan, 1986), only recently have researcher begun to explore specific psychosocial implications of employment for

this population. Preliminary studies have yielded somewhat conflicting results. One study (Velin, et al., 1994) specifically looking at possible psychiatric indicators found that there were no significant differences on measurements of depression between employed and unemployed HIV positive persons. However, others found that involvement in work or vocations provided certain psychological benefits such as a way to maintain hope (Hall, 1994) and a way to keep minds productively employed and to keep persons from dwelling on failing health (Friskopp & Silverstein, 1995).

Green (1995), in an attempt to gain insight into the employment experience of HIV infected persons, found that there is a complex mix of emotions related to work. In a series of in-depth interviews of 66 HIV infected persons Green identified themes of guilt, fear and insecurity. Participants reported feeling afraid that employers or co-workers would somehow learn of their HIV status and respond negatively. HIV infected employees also felt guilty about "having to live a lie" by concealing their status and about the possibility of putting others at risk for infection. In addition, Green found that the mere expectation of unfavorable reactions by others was as compelling as actual discrimination in dissuading an HIV infected person from seeking or keeping a job. These psychological stresses caused some HIV infected persons to cease employment expecting that continued employment would ultimately have a detrimental effect on their health, or because they felt incapable of continuing to perform adequately their job responsibilities due to their disturbed psychological state.

Most of the literature pertaining to the employment of HIV infected persons approaches the issue from a management perspective. However, as employment and career development once again become viable options for HIV infected persons

researchers have begun to consider the employee aspect as well. Two studies have specifically investigated possible psychological effects of employment status on HIV infected persons. Velin et al. (1994) utilized the Beck Depression Inventory (BDI) and the Depression/Dejection sub-scale scores from the Profile of Mood States (POMS) to compare psychological diagnoses of employed and unemployed HIV infected persons. While the findings of this study, that there were no differences in depression scores between the two groups, are relevant in understanding the ramifications of employment status for this population, it should be considered that mood state is but one limb comprising the psychosocial physique of human functioning. Green (1995), on the other hand, provided direction but no measurement, identifying patterns of emotion experienced in situations of both employment and unemployment, but no quantitative comparison of psychological functioning between the two groups.

The review of literature provides empirical support for the notion that employment generally provides certain social and psychological benefits. The complex array of psychosocial challenges faced by HIV infected persons, the correlation between social support and improved emotional well-being, and the link between improved psychological and physical health raises questions concerning the possible benefits of continued employment for HIV infected persons. This study attempts to identify employment issues and trends for HIV infected persons specifically relating to their psychosocial adjustment to living with HIV/AIDS.

## CHAPTER THREE

### METHODOLOGY

#### Participants

Participants were recruited through various AIDS related community service organizations. Flyers (Appendix A) were displayed and survey packages were made available in offices of AIDS service organizations throughout the state including: Regional AIDS Interfaith Network (RAIN) Oklahoma, Western Oklahoma office; The Mariah Foundation; CarePoint, Inc.; HIV Resource Center; American Red Cross; Center Station; and Community of Hope, UMC.

Health care professionals who provide treatment and care to HIV infected persons on a regular basis relayed information about the study to their patients and made survey packages available to those who wished to participate. Participating health care facilities include: Enid Family Medicine Clinic, Enid, Oklahoma; Associates in Medical and Mental Health, P.C., Tulsa, OK; University of Oklahoma Health Science Center, Early Intervention Services Clinic, Oklahoma City, Oklahoma.

In addition formal presentations outlining the study were offered at meetings of the AIDS Coalition of Central Oklahoma; Oklahoma State Department of Health, Community Planning Group for Northwest Oklahoma; and the AIDS Task Force of Central Oklahoma. Persons attending these meeting were presented with detailed

information about the study and its ramifications and were asked to pass the information on to each of their clients and to deliver survey packages to clients who were interested in participating

Other recruitment efforts focused on the gay population in Oklahoma. This decision was based on reports from the Oklahoma State Department of Health that 68% of AIDS cases in the state were exposed to HIV through sexual activity between men (OSDH, 1998). An advertisement soliciting participants was placed in *The Gayly Oklahoman*, a bi-monthly publication circulated within gay communities throughout Oklahoma and some surrounding states. Flyers were displayed at retail establishments in Oklahoma City who cater to a gay clientele. A word of mouth campaign was initiated within gay networks in smaller towns to encourage HIV infected persons to participate in the study.

Survey packages could be immediately acquired at the locations outlined above or by mail if requested by telephone or e-mail. Each package included an information page addressing the purpose and parameters of the study, voluntary participation, and instructions on returning the survey (Appendix B), and the measurement instruments. Self addressed stamped envelopes were provided to return the completed surveys to the researcher. The issue of confidentiality was addressed by allowing all subjects to participate anonymously.

## Measures

### Psychosocial Adjustment to Illness Scale - Self Report (PAIS-SR)



The PAIS-SR (Derogatis, 1983) is a multiple domain measure developed to assess the quality of a patient's psychosocial adjustment to a current medical illness or the sequelae of a previous illness. The instrument is designed to be completed by the respondent, with the test and instructions printed in a consumable booklet. It is comprised of 46 items arranged along a 4-point Likert-type scale and requires 20 to 25 minutes for completion. Lower scores indicate better psychosocial adjustment while higher scores indicate psychosocial maladjustment. This scale provided a continuous, quantitative measurement of psychosocial adjustment.

Seven primary domains of adjustment are addressed by the PAIS-SR: Health Care Orientation, Vocational Environment, Domestic Environment, Sexual Relationships, Extended Family Relationships, Social Environment, and Psychological Distress. The seven domain scores of the PAIS-SR are summed to generate a PAIS Total Adjustment Score. The PAIS-SR has demonstrated high interrater reliability for the Total Adjustment Score (median alpha = .86) and good internal consistency reliability estimates for the domain scores (Cronbach's alpha = .68 - .93). Validation of the PAIS has been extensive, with studies of convergent, predictive and construct validity, as well as confirmation of dimensional structure reviewed thoroughly in Derogatis & Derogatis (1990) and Derogatis & Fleming (1996).

#### Lubben Social Network Scale (LSNS)

The LSNS (Appendix C) is a 10 item, self report measure designed to examine the existence of one's social network (Lubben, 1988). Three subcategories of a social network are examined: Family Networks, Friends Networks, and Interdependent Social

Supports. The LSNS score is obtained from an equally weighted sum of ten items, each of which range in value for 0 to 5 creating a total continuous, quantitative, measurement of social networks that may range from 0 to 50. This measurement was designed so that higher scores indicate a greater social network, however for the purposes of this study the scores were inverted so that lower scores indicate a greater social network. The LSNS was reported to have high internal consistency (Cronbach's Alpha = 0.70) and showed significant correlations with the more extensive Berkman-Syme Social Network Index (Berkman & Syme, 1979) from which the current instrument was developed. It should be noted that the LSNS does not attempt to measure the quality of social support but rather the extent to which a social network does or does not exist in the subjects' life.

#### Health Assessment

The general health of each subject was evaluated (Appendix D) within the context of HIV infection. A local physician who has been recognized throughout the state of Oklahoma as a medical authority on AIDS assisted in the development of this instrument particularly reviewing it for medical accuracy. A list of commonly experienced infections or symptoms known to be related to HIV/AIDS (CDC, 1992) was provided to each subject. Each item was ranked on a seven point Likert-type scale to indicate the timeliness and severity of the subjects' experience with each symptom or infection. The sum of the ranking for all of the items provided the total score, which was utilized as a continuous, quantitative measurement of the subjects' health. Lower scores indicate better general health status while higher scores indicate the presence of more identified symptoms or indications of HIV. The purpose of this measurement was not to obtain a

complete medical report on the subject, but rather to assess the subjects' general health status.

### Demographic and Employment Information

Basic demographic information was collected i.e. age, gender, and race or ethnic background, (Appendix E) and various aspects of the subjects' current and past work experience were investigated (Appendix F). The primary concern for the study was the subject's employment status, employed or unemployed, at the time the instrument was completed. However, because of the complex nature of career development and occupational identity, other topics regarding work were examined. Investments in education or training, benefits offered by employers, income, attitudes of and relationships with co-workers, are a few examples of the work-related topics that were addressed.

## CHAPTER FOUR

### FINDINGS

#### Participants

Participants in this study were 31 persons who are HIV infected or living with AIDS. Twenty-nine participants returned survey packages by mail which were postmarked from cities or towns in Oklahoma. Two participants returned packages which were mailed from other states.

Demographic characteristics of participants are as follows: 6 females (19 %), 25 males (81%); 24 White/Anglo (77%), 3 Black/African American (10%), 1 Hispanic/Latino (3%), 5 American Indian (16%); 5 age 20 - 29 years (16%), 22 age 30 - 39 years (71%), 3 age 40 - 49 years (10%), 1 over age 49 (3%); 6 heterosexual (19%), 24 homosexual (74%), 1 participant did not reveal sexual orientation (3%).

Because participants were primarily solicited in the state of Oklahoma, the HIV Epidemiologic Profile for Oklahoma (Oklahoma State Department of Health [OSDH], 1995) was utilized as a guideline to attempt to attain an appropriate proportion of infected individuals from specific population groups characterized by gender, race, age, and sexual orientation. See Table 1 for a comparison of demographic characteristics of participants in the current study with those of persons represented in the OSDH statistical data.

TABLE 1

DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS IN THE  
CURRENT STUDY COMPARED TO PERSONS REPRESENTED IN THE  
HIV EPIDEMIOLOGIC PROFILE FOR THE STATE OF OKLAHOMA

DEMOGRAPHICS	OKLAHOMA		CURRENT STUDY	
	#	%	#	%
AGE				
20 - 29	1,459	30	5	16
30 - 39	2,189	44	22	71
40 - 49	800	16	3	10
Over 49	361	7	1	3
RACE/ETHNICITY <sub>a</sub>				
White/Anglo	3,501	71	24	77
Black/African American	911	18	3	10
Hispanic/Latino	173	4	1	3
American Indian	311	6	5	16
GENDER				
Male	4,360	88	25	81
Female	571	12	6	19
SEXUAL ORIENTATION				
Homosexual	3,338	68	24	77
Heterosexual	374	8	6	19
Not Identified	1,181	24	1	3

<sup>a</sup>Two participants identified themselves as both White/Anglo and American Indian.

It should be noted that sexual orientation of individuals is not specified within the OSDH demographic profile. Rather, persons are categorized by their means of exposure to HIV. For the purposes of this study all persons who reported either their primary or secondary means of exposure as “men who have sex with men” were designated as homosexual on Table 1. Persons who reported “heterosexual contact” as their primary means of exposure were designated as heterosexual. Persons who reported any other means of exposure to HIV were designated, under sexual orientation on Table 1, as not identified. Participants in the current study were specifically asked to report their sexual orientation and responses were precisely recorded on Table 1.

Participants were categorized as either employed or unemployed. Twelve participants (39%) reported that they were employed and nineteen participants (61%) were unemployed. Independent samples *t* tests were utilized to compare mean scores on measurements for psychosocial adjustment to illness, the existence of a social network, and general health status for all participants. An alpha level of .05 was used for all statistical tests. See Table 2 for a summary of these findings.

TABLE 2  
DEPENDENT VARIABLE MEASURES BY EMPLOYMENT STATUS

MEASURE	EMPLOYED (n = 12)		UNEMPLOYED (n = 19)		SIGNIFICANCE TESTS		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>	<i>p</i>
PAIS-SR	34.92	23.95	56.16	25.71	29	2.30	.03
LSNS	18.58	6.64	20.58	7.41	29	0.76	.45
Health	16.42	11.25	47.26	23.39	29	4.25	.00

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Health	16.42	11.25	47.26	23.39	29	4.25	.00

## Psychosocial Adjustment

It was found that persons who were employed at the time of the study experienced better psychosocial adjustment to living with HIV/AIDS than persons who were not employed ( $M_{\text{employed}} = 34.92$ ;  $M_{\text{unemployed}} = 56.16$ ),  $t(29) = 2.30$ ,  $p = 0.029$ . It was also revealed that there was a positive relationship between a participant's psychosocial adjustment and his/her general health status  $r^2(31) = .59$ ,  $p = .001$  and a positive relationship between psychosocial adjustment and the existence of a social network  $r^2(31) = .62$ ,  $p = .000$ .

## Social Networks

There was no difference in the existence of a social network for employed persons compared to unemployed persons ( $M_{\text{employed}} = 18.58$ ;  $M_{\text{unemployed}} = 20.58$ ),  $t(29) = 0.76$ ,  $p = .45$ . Further analysis of responses on the Employment Information questionnaire revealed that emotional support was an important aspect of employment for only 17% of participants who were employed. It should be noted that all of the respondents who valued emotional support from co-workers were employed in HIV/AIDS service related fields. An equal percentage (17%) of employed persons complained that interaction with co-workers and/or management was one of the worst aspects of their job. See Table 3 for a summary of responses regarding the most positive and the most negative aspects of employment.

Of those who were employed 58% reported that neither co-workers nor management were aware of the participant's HIV status. In addition, 71% of those who



TABLE 3

SUMMARY OF RESPONSES REGARDING THE MOST POSITIVE  
AND THE MOST NEGATIVE ASPECTS OF EMPLOYMENT

EMPLOYED PARTICIPANTS <u>(n = 12)</u>		UNEMPLOYED PARTICIPANTS <u>(n = 19)</u>	
What is the best or most important thing about continuing to work?		What do you miss most about work?	
<u>Response</u>	<u>%</u>	<u>Response</u>	<u>%</u>
income	58	income	42
having a purpose	33	social contacts/friends	32
emotional support	17	being active	26
health insurance	17	making a contribution	26
being active	8	accomplishment	16
accomplishment	8	having a purpose	5
normalcy	8	health insurance	5
sense of self-worth	8	sense of self-worth	5
sense of well-being	8	sense of well-being	5
		liked job	5
What is the worst or most difficult thing about continuing to work?		What types of things are influencing your decision about returning to work?	
<u>Response</u>	<u>%</u>	<u>Response</u>	<u>%</u>
physical discomfort/illness	42	physical discomfort/illness	32
fatigue	25	can not find employment	11
don't like job	17	fatigue	5
stress	17	stress from co-workers	5
co-workers	17	following medication schedule	5
lack of motivation	8	bored with unemployment	5
following medication schedule	8	need health insurance	5

Note. The information disclosed in Table 3 was gathered through open ended questions on the Employment Information questionnaire. Responses were grouped into the reported categories, at the discretion of the investigator, based on ideas or emotions expressed within the statements made by respondents. The statements may not have contained the exact terms used here.

\*8 participants were considering returning to work, 9 participants were not considering returning to work, 2 participants did not respond to this question.

had not revealed this information felt that doing so would result in negative consequences. In spite of the reports that participants rarely received social support from co-workers and sometimes experienced or expected hostility, 32% of unemployed participants reported that one of the things they missed most about working was having social contact with others. This was the second most frequently missed aspect of work with income being the first.

### Health Status

Participants who were employed generally experienced better health than unemployed participants ( $M_{\text{employed}} = 16.42$ ;  $M_{\text{unemployed}} = 47.26$ ),  $t(29) = 4.25$ ,  $p = .000$ . Further analysis of the Health Assessment and the Employment Information questionnaire revealed that 32% of those who were unemployed were not considering returning to work specifically because of poor health. These persons reported that they frequently experienced pain, fatigue, and/or diarrhea. They also expressed concern about being exposed to contagious illnesses of co-workers and concern about keeping up with medication schedules while on the job.

Medication schedules were reported as a consideration for both employed and unemployed participants. Employed participants were taking significantly fewer pills per day than unemployed participants ( $M_{\text{employed}} = 12$ ;  $M_{\text{unemployed}} = 19$ ),  $t(29) = 2.26$ ,  $p = .031$ . Nevertheless five percent of employed participants reported that keeping up with medication schedules was one of the worst aspects of continued employment. Others stated that the most negative aspects of continued employment included frequent bouts with fatigue, diarrhea, and pain.

## Other Findings

The Employment Information questionnaire was utilized to gain insight into various aspects of career development and employment. There was one important finding gleaned from the information provided on this questionnaire specifically pertaining to income. It was found that there was a significant decrease in average monthly income for the entire subject pool ( $M_{\text{paired differences}} = - 1775$ ),  $t(23) = - 5.09$ ,  $p = .000$ . Seven participants did not provide complete information on income. Participants reported their current monthly income and their maximum monthly income ever earned. Persons who were unemployed had a 72% drop in income while persons who remained in the workforce experienced a 50% decline in their average monthly wages.

## CHAPTER FIVE

### CONCLUSION

#### Summary and Discussion of Findings

The findings revealed that HIV infected persons who are actively employed experience better psychosocial adjustment to living with HIV/AIDS. This outcome was expected and is consistent with the large body of literature investigating the psychological implications of employment for the general population. However, because of the complex array of psychological and sociological issues that merge within the concept of psychosocial well-being, it can only be stated that the experience of continued employment contributes to but does not fully explain the variation in psychosocial adjustment within the population of persons living with HIV/AIDS.

In fact, the relationships between psychosocial adjustment and the existence of social networks, and between psychosocial adjustment and health status reveal that the former variable is likely being influenced by both of the latter. These relationships have been noted in previous research which is supported by the current study. However, from information gathered here these relationships cannot be considered causal . It is not clear whether HIV infected persons who are in relatively good health adjust better to their illness or whether better psychosocial adjustment leads to improved health. Moreover, do HIV infected persons with an existing social network adjust better to their illness or do

persons who have adjusted well attract and maintain a social network? These are issues that should be clarified in further studies.

The second major finding of this study was that there was no difference in the existence of a social network for employed participants compared to unemployed participants. This is contrary to the findings of Bosse, Aldwin, Levenson, Workman-Daniels, and Ekerdt (1990) which revealed that for their sample population co-workers were considered an important source of friends and confidants. One explanation may be that negative attitudes toward HIV infected employees by potential co-workers have not changed much in the last decade since Blendon and Donelan (1988) reported such reactions from persons in the workplace.

Responses addressing relationships with co-workers varied widely among participants. Some, particularly those working in HIV/AIDS related services, experienced a supportive and uplifting work environment. Others continued to conceal their HIV positive status from co-workers and supervisors anticipating that they would at least be shunned and possibly fired upon revealing this information.

Although co-workers may not be considered part of one's social support network, it seems that casual contact with persons on the job remains an important element of employment. Some persons who were employed and some who were unemployed reported that having social contacts at work was a positive experience. Conversely, others who were employed and unemployed reported that maintaining relationships with co-workers was difficult and stressful. Perhaps interacting with others on a superficial level fulfills a certain psychological need as long as it remains unexpected or inappropriate to share details of one's personal life (i.e. sexual orientation or HIV status).

Finally, it was found that HIV infected persons who were employed generally experienced better health than those who were unemployed. Again, this relationship cannot be considered causal. In fact, it may be that some HIV infected persons are more likely than others to be employed because they are healthy. However, the relationship between general health status and psychosocial adjustment is encouraging. Since being in a positive and supportive work environment for HIV infected persons is related to better psychosocial adjustment which is related to improved health, employers and co-workers can possibly contribute to improving the length and quality of life for many persons simply by allowing them, even encouraging them, to remain in the workforce.

In addition to the findings related to the specifically identified dependent variables, it was also found that participants had experienced a significant decrease in average monthly income. It is not surprising that persons who were unemployed at the time of the study would have lost income since they are no longer earning wages. However, persons who had remained in or returned to the workforce also experienced a loss of income. Some of this difference can be accounted for in the reduction of hours worked since a few of the employed participants are currently only working part-time. However, this disturbing trend in decreased wages for HIV infected persons has been previously acknowledged (Massagli et al., 1994). With the high costs of medical care, particularly medication, and the possibility of living without support of family or spouse/partner, it seems that HIV infected persons are being forced to live with lower quality of life standards specifically due to various aspects of their illness.

#### Limitations

The sample population for this study was relatively small and taken from a limited geographic region. There were 31 participants 29 of whom returned survey packages from within the state of Oklahoma. Two participants returned the material from two other states. Sociological differences among geographic regions in the United States could contribute to different findings if a larger and more representative sample of HIV infected persons was considered. Religion, politics, the size and visibility of the gay population, and local HIV infection rates, among other things, may all contribute to the responses that HIV infected persons encounter from others. This in turn may effect the existence of a person's social support system and his/her psychosocial adjustment to living with HIV/AIDS. Just as laws protecting the rights of gay individuals differ from state to state, it is likely that outward attitudes and behaviors toward this group and the sample population would differ as well, at least to some extent.

There were also limitations regarding the measurement instruments. All of the findings were based on self reports as an indicator of the variables being observed. This may particularly be troublesome on the Health Assessment. Although the instrument presented a comprehensive and medically relevant index of symptoms and conditions associated with HIV infection, the terminology can be confusing and the sheer expanse of the list can be overwhelming. The amount of knowledge participants possess regarding a complete and accurate view of his/her medical condition is likely to be inconsistent. However, the concept of one's psychosocial well-being is probably related to the participants own perception of his/her health status as much as or more than his/her actual physical state. In addition, precautions were not taken to prevent a response set on this measurement.

Finally, there were some concerns with the scoring of the PAIS-SR. This instrument has not been normed specifically for persons living with HIV/AIDS. Derogatis and Derogatis (1990) found it necessary to develop "normative libraries" which include formal norms for seven specific illnesses. Although norms are presently being developed for HIV/AIDS this information was not available for interpreting the results of the current study. Personnel at Clinical Psychometric Research, Inc. suggested that norms for multiple sclerosis patients could be used as a normative reference. However, doing so presented a negatively skewed distribution of scores for the participants in this study. Although there may be some similarities in the psychosocial challenges faced by persons with multiple sclerosis and those infected with HIV, it is not appropriate, within the context of this study, to make comparisons between the psychosocial adjustment of persons living with these two distinct illnesses. Since adequate data was not available for normative comparisons of persons infected with HIV raw scores on the PAIS-SR were utilized in the statistical analysis which provides more precision by avoiding the rounding error associated with standardized scores.

#### Implications and Future Directions

Persons who are HIV infected experience greater psychosocial adjustment and improved health when they are able to remain in the workforce. However, co-workers do not necessarily contribute to the social support network of these individuals. These findings present implications for employers, for the general workforce, and particularly for HIV infected persons.

The findings regarding the lack of social support in places of employment should



particularly be of interest to employers. This is a clear indication of the need for more and better AIDS education programs in the workplace. Employers and business owners should be educating their workforce at every level to respond appropriately, both socially and legally, to HIV infected co-workers. In addition it is in the best interest of the employer to provide adequate educational programs that might help prevent the further spread of this virus in order to maintain a healthy employee pool.

Considering the current trends in the rates of new HIV infection, the success of medical treatments, and the decline in HIV related death rates it is more and more likely that individuals will find themselves working next to an HIV infected person. However uncomfortable this may be for some employees, it must be understood that HIV infected persons have every legal right to be employed and there are no legal grounds on which to pursue dismissal of an HIV infected co-worker from his/her position based solely on their illness. Under the Americans with Disabilities Act (ADA) the rights of persons with AIDS are protected in the place of employment. This also includes the right to confidentiality. Most persons probably do not realize that revealing another persons HIV positive status in a casual conversation at the pop machine could incur criminal and civil damages. Employees need to get the facts concerning all aspects of this disease in order to protect themselves from infection and legal or civil liability and in order to better understand the needs of the HIV infected co-worker.

The somewhat miraculous effects of new drug treatments for HIV has caused a tremendous change in the way infected persons view their lives and particularly their future. The prospect of living a longer healthier life certainly lends credit to the previously meaningless notion of career development for many HIV infected persons of

all ages. The “normal” developmental task of finding and maintaining gainful employment will once again be a relevant issue in the lives of persons living with HIV/AIDS. The current findings should provide even more motivation for HIV infected persons to strive to achieve this important aspect of normalcy within the complicated context of their ever changing disease process.

I have mentioned the need for specific educational programs to address the issue of AIDS in the workplace. Education has been proven to be an effective tool in improving relationships between social groups at odds with each other. Sometimes it seems that persons concerned about the issue of HIV/AIDS often find themselves at odds with the world. However, social scientists and professional educators have a responsibility to ensure that abundant and accurate information is disseminated to the general public. Continuing research on all aspects of HIV/AIDS is necessary to develop appropriate educational programs and to evaluate their effectiveness both in decreasing the numbers of new HIV infections and improving the lives of persons living with the disease.

#### Concluding Comment

The findings and ramifications of the current study may perhaps influence employers, educators, social service providers, policy makers and the general population to more closely consider employment issues and trends for HIV infected persons. Perhaps changes in attitudes and workplace policies could be made that would benefit both individuals and the greater society. Most importantly, though, is the possibility that information gained from this study could actually prolong the life of infected persons

or at least make their journey a little less lonely and hopefully more tolerable.

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## Appendices

## Appendix A

Flyer for Soliciting Participants

**HIV+ PERSONS NEEDED  
TO PARTICIPATE IN A  
SOCIAL SCIENCE SURVEY  
CONCERNING  
EMPLOYMENT  
ISSUES & TRENDS**

**ALL PARTICIPANTS MAY REMAIN  
\*\*\*\*\* ANONYMOUS \*\*\*\*\***

**FOR MORE INFORMATION CALL  
(580) 234-2270**



## Appendix B

### Study Information and Instructions

## EMPLOYMENT, SOCIAL NETWORKS AND PSYCHOSOCIAL ADJUSTMENT OF HIV INFECTED PERSONS

Your participation is being requested in the above titled study which is being conducted by Alisa Hankins, candidate for a Master of Education degree in the School of Applied Health and Educational Psychology at Oklahoma State University, and supervised by John Romans, Ph.D., Committee Chair, and other faculty members in accordance with the guidelines of the Institutional Review Board at Oklahoma State University.

The purpose of this study is to examine any effects of employment status on the psychological and emotional well-being of persons infected with Human Immunodeficiency Virus (HIV) an/or diagnosed with Acquired Immunodeficiency Syndrome (AIDS). The results of this study will be utilized to assist business owners, managers, and leaders, policymakers, AIDS service providers and HIV+ individuals in better understanding employment issues and improving the current employment situation for the population under consideration.

As a participant you will be asked to complete five questionnaires concerning psychosocial adjustment to illness, social support networks, employment information, personal or demographic information and your health. Participation in this study is of and by your own free will. At no time will pressure be place on you to participate. You may withdraw from the study at any time without consequences.

Names or other specific identifying information will not be requested and confidentiality regarding personal identity and HIV status will be strictly maintained in accordance with Oklahoma State Law which makes the unauthorized release of such information a criminal offense. However, due to the anonymity of the participants and the variety of organizations assisting in the distribution of this survey, you are asked to complete one and only one set of questions so that we may gather the most fair and accurate representation of the information under study.

If you have any questions about your rights, or feel you have been placed at risk, you can contact University Research Services, 305 Whitehurst, Oklahoma State University, Stillwater, OK 74078, (405) 744-5700. Any questions about the study or your participation should be directed to Alisa Hankins at (580) 234-2270.

**Please return all five completed questionnaires in the attached self-addressed stamped envelope. Your participation is greatly appreciated!!!!**

## Appendix C

Lubben Social Network Scale

# Lubben Social Network Scale

## Family Networks

1. How many relatives do you see or hear from at least once a month?  
(NOTE: Include in-laws with relatives.) 1. \_\_\_\_\_

0 = zero                      3 = three or four  
1 = one                      4 = five to eight  
2 = two                      5 = nine or more

2. Tell me about the relative with whom you have the most contact.  
How often do you see or hear from that person? 2. \_\_\_\_\_

0 = less than monthly      3 = weekly  
1 = monthly                4 = a few times a week  
2 = a few times a month    5 = daily

3. How many relatives do you feel close to? That is, how many of them do  
You feel at ease with, can talk to about private matters, or can call on for  
help? 3. \_\_\_\_\_

0 = zero                      3 = three or four  
1 = one                      4 = five to eight  
2 = two                      5 = nine or more

## Friends Networks

4. Do you have any close friends? That is, do you have any friends with  
whom you feel at ease, can talk to about private matters, or can call on  
for help? If so, how many? 4. \_\_\_\_\_

0 = zero                      3 = three or four  
1 = one                      4 = five to eight  
2 = two                      5 = nine or more

5. How many of these friends do you see or hear from at least once a  
month? 5. \_\_\_\_\_

0 = zero                      3 = three or four  
1 = one                      4 = five to eight  
2 = two                      5 = nine or more

6. Tell me about the friend with whom you have the most contact. How  
often do you see or hear from that person? 6. \_\_\_\_\_

0 = less than monthly      3 = weekly  
1 = monthly                4 = a few times a week  
2 = a few times a month    5 = daily

(Lubben Social Network Scale Continued)

Confidant Relationships

7. When you have an important decision to make, do you have someone you can talk to about it? 7. \_\_\_\_\_

Always	Very Often	Often	Sometimes	Seldom	Never
5	4	3	2	1	0

8. When other people you know have an important decision to make, do they talk to you about it? 8. \_\_\_\_\_

Always	Very Often	Often	Sometimes	Seldom	Never
5	4	3	2	1	0

Helping Others

9a. Does anybody rely on you to do something for them each day? For example: shopping, cooking dinner, doing repairs, cleaning house, providing child care, etc.

No - if no, go on to 9b.

Yes - if yes, 9 is scored 5 and skip to question number 10.

9b. Do you help anybody with things like shopping, filling out forms, doing repairs, providing child care, etc.? 9. \_\_\_\_\_

Very Often	Often	Sometimes	Seldom	Never
4	3	2	1	0

Living Arrangements

10. Do you live alone or with other people? (NOTE: include in-laws with relatives.) 10. \_\_\_\_\_

5 = Live with spouse or partner  
4 = Live with other relatives or friends  
1 = Live with other unrelated individuals (e.g., paid help)  
0 = Live alone

TOTAL LSNS SCORE: \_\_\_\_\_

# Appendix D

## Health Assessment

## HEALTH ASSESSMENT

Please rank each of the following medical conditions from 0 to 6 according to the scale below. Choose the statement that most closely describes your experience.

- 0 - Never been diagnosed or experienced and have never taken medicine for...
- 1 - Past diagnosis or experienced, was treated, not currently taking medication for....
- 2 - Never diagnosed or experienced, but currently taking medication to prevent...
- 3 - Past diagnosis or experienced, treated, but taking medication to prevent reoccurrence of ...
- 4 - Current diagnosis and receiving treatment for...
- 5 - Currently experiencing, but not taking medication for...
- 6 - Hospitalized in past six months for...

- \_\_\_ Anxiety
- \_\_\_ Attention deficit (short attention span)
- \_\_\_ Candidiasis of bronchi, trachea, or lungs
- \_\_\_ Candidiasis, esophageal
- \_\_\_ Cervical cancer, invasive
- \_\_\_ Coccidioidomycosis, disseminated or extrapulmonary
- \_\_\_ Concentration problems (loose concentration or train of thought)
- \_\_\_ Cryptococcosis, extrapulmonary
- \_\_\_ Cryptosporidiosis, chronic intestinal
- \_\_\_ Cytomegalovirus (CMV) disease (other than liver, spleen, or nodes)
- \_\_\_ Cytomegalovirus retinitis (with loss of vision)
- \_\_\_ Depression
- \_\_\_ Diarrhea
- \_\_\_ Encephalopathy, HIV-related
- \_\_\_ Fatigue
- \_\_\_ Fever
- \_\_\_ Forgetfulness
- \_\_\_ Herpes simplex: chronic ulcers; or bronchitis, pneumonitis, or esophagitis

(Health Assessment Continued)

- \_\_\_\_\_ Histoplasmosis, disseminated or extrapulmonary
- \_\_\_\_\_ Isosporiasis, chronic intestinal
- \_\_\_\_\_ Kaposi's Sarcoma (KS)
- \_\_\_\_\_ Learning deficits (problems learning and retaining new information)
- \_\_\_\_\_ Loss of appetite
- \_\_\_\_\_ Loss of motor control (unable to control physical movement or weakness in muscles)
- \_\_\_\_\_ Lymphoma, immunoblastic
- \_\_\_\_\_ Lymphoma, primary, of brain
- \_\_\_\_\_ Memory loss (unable to recall past events)
- \_\_\_\_\_ Mycobacterium avium complex or *M. kansasii*, disseminated or extrapulmonary
- \_\_\_\_\_ Mycobacterium tuberculosis, any site (pulmonary or extrapulmonary)
- \_\_\_\_\_ Mycobacterium, other species or unidentified species
- \_\_\_\_\_ Night sweats
- \_\_\_\_\_ Pneumocystis carinii pneumonia (PCP)
- \_\_\_\_\_ Pneumonia, recurrent
- \_\_\_\_\_ Progressive multifocal leukoencephalopathy
- \_\_\_\_\_ Salmonella septicemia, recurrent
- \_\_\_\_\_ Significant weight loss
- \_\_\_\_\_ Skin rashes
- \_\_\_\_\_ Speech problems
- \_\_\_\_\_ Swollen lymph glands
- \_\_\_\_\_ Toxoplasmosis of brain



(Health Assessment Continued)

\_\_\_\_\_ Vision problems (blurred vision or partial loss of vision)

\_\_\_\_\_ Wasting syndrome due to HIV

**Answer the following questions as completely as possible to the best of your knowledge. Please type or print clearly.**

1) How long do you think you have been infected with HIV? \_\_\_\_\_

2) What was your most recent T-cell count? \_\_\_\_\_

3) What was your lowest T-cell count? \_\_\_\_\_

4) Explain any changes in your viral load in the past year. \_\_\_\_\_  
\_\_\_\_\_

5) What medications are you currently taking? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

6) How many pills do you take each day? \_\_\_\_\_

7) Please describe any "alternative" methods of treatment that you have experienced and your opinion of their effectiveness. \_\_\_\_\_  
\_\_\_\_\_

8) Please describe any changes in behavior or lifestyle that you have made specifically to improve your health (examples: stopped smoking, changes in alcohol consumption, changes in diet, exercise, sleep, etc.). \_\_\_\_\_  
\_\_\_\_\_

9) How often do you see a doctor? \_\_\_\_\_

10) Please add any additional information that you wish to share concerning health, medication or other treatments. \_\_\_\_\_  
\_\_\_\_\_

## Appendix E

Personal/Demographic Information

## PERSONAL/DEMOGRAPHIC INFORMATION

1. Age: \_\_\_\_\_
2. Gender: \_\_\_\_\_
3. Sexual orientation: \_\_\_\_\_
4. Religious preference (denomination), if any: \_\_\_\_\_
5. Race or Ethnic Origin
  - White/Anglo
  - Black/African American
  - Hispanic/Latino
  - American Indian
  - Asian American
  - Other \_\_\_\_\_
6. Educational background (please check the highest level you have completed):
  - Jr. High School
  - High School
  - GED
  - Some College
  - Associate's Degree
  - Bachelor's Degree
  - Master's Degree
  - Doctoral Degree
  - Vocational Training
  - Other (please describe): \_\_\_\_\_
7. If you have received a degree, what area of study is the degree in?  
\_\_\_\_\_
8. Please list any professional certificate or license you have received.  
\_\_\_\_\_
9. Are you currently employed?  Yes  No
10. If you are not currently employed, how are your financial needs being met?  
(please list any assistance you are receiving for medical care, housing, food, etc.)  
\_\_\_\_\_  
\_\_\_\_\_
11. Please list any other types of assistance you are receiving (examples: RAIN Team,  
Buddy, support group, etc.) \_\_\_\_\_
12. Have you read the attached statement explaining the purpose and content of this study and the  
guidelines for anonymous participation in the study?  Yes  No
13. Do you understand that participation in this study is of and by your own free will and that you can  
withdraw from participating in the study at any time without consequences?  Yes  No

## Appendix F

### Employment Information

## EMPLOYMENT INFORMATION

Please relate the following questions to your current job or, if you are not currently working, to your most recent job. If you work more than one job, please give information on the job you consider to be your primary occupation. If you need more space to answer these questions please feel free to attach additional pages.

1. Occupation or job title: \_\_\_\_\_

2. Length of time employed at this job: \_\_\_\_\_

3. Length of time in this line of work (include all previous jobs at different locations but same or similar position or responsibilities): \_\_\_\_\_

4. Total number of hours worked per week (include all part-time & full-time jobs): \_\_\_\_\_

5. Current monthly income \_\_\_\_\_ Highest monthly income ever earned \_\_\_\_\_

6. Please check all benefits that you receive(d) through your employment:

Health Insurance

Life Insurance

Retirement Benefits

Investment or Savings Plans

Paid Vacation

Paid Sick Leave

7. Are (were) benefits available for your spouse or partner?  Yes  No

8. Are (were) benefits available for your children?  Yes  No

9. If you **are** currently employed, what is the best or most important thing about continuing to work?

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10. If you **are** currently employed, what is the worst or most difficult thing about continuing to work?

---

---

11. If you **are not** currently employed, what do you miss most about work?

---

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12. If you **are not** currently employed, have you considered returning to work?  Yes  No

(Employment Information Continued)

13. What types of things are influencing your decision about returning to work?

---

---

14. Do people at your place of employment know your HIV status?     Yes             No

If so, describe their reaction. \_\_\_\_\_

---

If not, how do you think they would react if they knew? \_\_\_\_\_

---

15. Do you think that current laws are protecting HIV+ persons from discrimination at work?

Yes     No

What would you like to change about these laws? \_\_\_\_\_

---

16. If laws were passed requiring all employers to provide health and other benefits to same sex or domestic partners would you and/or your partner apply for these benefits?             Yes     No

How would these laws effect you? \_\_\_\_\_

---

How would these laws effect employers? \_\_\_\_\_

---

17. What types of things can be done to improve the work environment for persons who are HIV+ ?

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---

18. Please comment on any other aspect of work or the employment situation for HIV + persons that has not been addressed here or that you would like to see addressed in the future.

---

---

# Appendix G

Institutional Review Board  
Approval Form

OKLAHOMA STATE UNIVERSITY  
INSTITUTIONAL REVIEW BOARD  
HUMAN SUBJECTS REVIEW

Date: 03-27-98

IRB #: ED-98-098

Proposal Title: EMPLOYMENT, SOCIAL NETWORKS AND PSYCHOSOCIAL ADJUSTMENT OF  
HIV INFECTED PERSONS

Principal Investigator(s): John Romans, Alisa Hankins

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

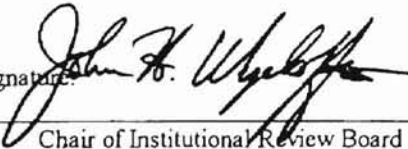
ALL APPROVALS MAY BE SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT  
NEXT MEETING, AS WELL AS ARE SUBJECT TO MONITORING AT ANY TIME DURING THE  
APPROVAL PERIOD.

APPROVAL STATUS PERIOD VALID FOR DATA COLLECTION FOR A ONE CALENDAR YEAR  
PERIOD AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE  
SUBMITTED FOR BOARD APPROVAL.

ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

---

Comments, Modifications/Conditions for Approval or Disapproval are as follows:

Signature: 

Chair of Institutional Review Board

cc: Alisa Hankins

Date: April 24, 1998



VITA

Alisa T. Hankins

Candidate for the Degree of

Master of Science

Thesis: EMPLOYMENT, SOCIAL NETWORKS, AND PSYCHOSOCIAL ADJUSTMENT OF HIV INFECTED PERSONS

Major Field: Counseling and Student Personnel

Biographical:

Education: Graduated from Garber High School, Garber, Oklahoma in May 1997; received Bachelor of Arts degree in Psychology from the University of Oklahoma, Norman, Oklahoma in August 1993. Completed the requirements for the Master of Science degree with a major in Community Counseling at Oklahoma State University in December, 1998.

Experience: Employed as Northwest Oklahoma Associate Coordinator for Regional AIDS Interfaith Network (RAIN), Oklahoma, 1995 to 1997; member, Board of Directors for the Mariah Foundation, 1998 to present; volunteer HIV/AIDS Education Instructor for the American Red Cross, 1995 to present; member and elected officer, Enid HIV/AIDS Coalition, 1994 to 1997; member, AIDS Coalition of Central Oklahoma, 1995 to present; member and elected chairperson, Oklahoma State Department of Health, Community Planning Group (CPG) for HIV Prevention, Northwest Oklahoma Region, 1995 to 1997; member, Oklahoma State Department of Education, Committee to Review and Revise Oklahoma Public School Curriculum for AIDS Education, 1996.

Professional Memberships: Kappa Delta Pi, an International Honor Society in Education, American Psychological Association (APA), The Society for the Psychological Study of Social Issues (SPSSI)