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**NEUROPSYCHIATRIC PREDICTORS OF OCCUPATIONAL
PERSISTENCE IN HIV/AIDS**

by

Stephan L. Buckingham
B.S., Murray State University, 1982
M.S.S.W., University of Louisville, 1983

A Dissertation
Submitted to the Faculty of the
Graduate School of the University of Louisville
in Partial Fulfillment of the Requirements
for the degree of

Doctor of Philosophy

Kent School of Social Work
University of Louisville
Louisville, Kentucky

August 2009

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A Dissertation Approved on

July 27, 2009

By the following Dissertation Committee:

Anna C. Faul, Ph.D., Chair

Ruth Huber, Ph.D.

Terry Singer, Ph.D.

Christina R. Stedts, Ph.D.

Wilfred G. van Gorp, Ph.D.

DEDICATION

This dissertation is dedicated to people living with HIV/AIDS, and to my friends who died as a result of this epidemic.

NECROLOGY

TIM BOGUE
BRUCE CAMPBELL
CRAIG COWAN
JEFF DEMLING
MATTHEW GAREY
STEVE GENDIN
GARY HARRISON
PATRICK HARRISON
PAUL E. KEITH
J. VICTOR LOPEZ
RON LOYD
PAUL ROTHMAN
MICHAEL SHERNOFF
JEFF TRIPLET
DANNY WARNER
RICHARD WARNER
CHARLES WILCOX
JIM WILEY

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Third, I want to thank Wilfred van Gorp for making my dissertation analysis possible. His support and unfailing belief in me, and our work together regarding the neuropsychiatric complications associated with HIV/AIDS, has defined, in large part, my professional career. Our collaboration is a point of great pride, and I look forward to our continued endeavors.

Fourth, I would like to thank my committee members, Anna Faul, Ruth Huber, Terry Singer, Christina Studts, and Wilfred van Gorp. Each contributed in meaningful ways, and in the end, I am certain that I could not have accomplished this without each of them.

Fifth, to my family, especially my sister Sharon, and my friends, most notably my fellow doctoral students, a special thank you. I know the experience was richer because

of them. Also, those special friends that accepted all manner of requests and expectations with unmerited favor—they know who they are—a very special thank you for their encouragement and support.

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In closing, to quote a friend upon completing her doctorate, “I can die now.”

ABSTRACT

**NEUROPSYCHIATRIC PREDICTORS OF OCCUPATIONAL
PERSISTENCE IN HIV/AIDS**

Stephan L. Buckingham

July 27, 2009

It is well established that HIV (human immunodeficiency virus), the virus responsible for AIDS, directly attacks the central nervous system, altering cognition, behavior, and affect, and can result in a full dementia syndrome. HIV-associated neurocognitive complications, along with a myriad of other health threats, resulted in significant disability and unemployment for those infected. However, the advent of more effective antiretroviral medications used in combinations, along with homologous improvements in morbidity and mortality, have allowed for people living with HIV/AIDS to return to work, albeit not without challenges. Even mild cognitive impairment has been shown to affect employability and level of occupational functioning.

The focus of this dissertation was to develop an understanding of the impact of HIV-associated neurocognitive challenges, the most common neuropsychiatric expression of HIV, on occupational persistence. This study analyzed existing data from a parent study conducted in New York City. The sample consisted of 116 community dwelling HIV positive men and women who were actively seeking employment after being unemployed subsequent to learning of their HIV status. The research design was a

longitudinal prospective cohort study testing a multilevel growth model with a two-nested-level structure. The growth model examined individual differences in occupational persistence over a two year time period, testing multiple potential neuropsychological predictors and covariates. Changes in individual growth profiles were investigated, and possible explanations for observed differences were tested.

The analysis found that memory is the most potent neuropsychological predictor of occupational success, both in terms of returning to work in the first six months of the study (event), as well as persisting on the job over time (two years). The second most influential neuropsychological predictor was executive functioning, which significantly influenced occupational persistence over time and an accelerated growth trajectory. These central findings along with other significant control interactions are discussed.

The study limitations are discussed, along with opportunities for future research. The relevance of these findings is explored, specifically addressing the implications for social work practice and social work education.

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CHAPTER I

PROBLEM STATEMENT

The advent of more effective antiretroviral medications used in combinations, along with homologous improvements in morbidity and mortality, have allowed for people living with HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome) to reconsider work and career options in their life planning and priorities. In doing so, they face unique challenges associated with employment. Among the range of issues described in the literature, HIV-associated neurocognitive challenges ranked among the most common and concerning for this population. However, understanding the neurocognitive challenges alone would not provide the necessary understanding to effectively assist this growing population in returning to and persisting in employment. The convergence of many factors must be accounted for if such efforts are to be successful, especially in understanding the unique relevance of neuropsychological functioning to occupational performance. As HIV/AIDS increasingly segues into a chronic illness, albeit not entirely without exceptions and obstacles, current knowledge of the issues related to employment are inadequate. The last 14 years have yielded a considerably improved understanding of what those returning to work experience or perceive as barriers to the transition back to employment. However, the factors that influence persistence in employment are less understood. The relevance of this is of paramount importance given that employment supports sustainability,

subsistence, and their associated relevance to improved quality of life (Applebaum, 1992), and by extension health. Two factors—both of which generally are provided by employers in the form of medical insurance and pharmaceutical benefits—are cited in the literature (AIDS Alert, 1999; Bach, Calhoun, & Bennett, 1999; Kitahata, Van Rompaey, & Shields, 2000) as being the most predictive of well-being among those with HIV/AIDS. They are: (a) full access to antiretroviral medications; and (b) access to experienced physicians. The importance of employment and associated healthcare benefits are immediately clear.

The focus of this dissertation was to develop an understanding of the impact of HIV-associated neurocognitive disorder, which is the most common neuropsychiatric expression of HIV, on occupational success as measured by work persistence among people with HIV/AIDS in New York City. More specifically, the dissertation tested a conceptual model built from the work of Kendall and Terry (1996), Ownsworth and McKenna (2004), and Sadek and van Gorp (2008). This model investigated the influence of neuropsychological factors on occupational persistence, taking into account demographics and life characteristics, situational variables, personal resources, environmental resources, and psychosocial adjustment.

The remainder of this chapter specifically addresses: (a) HIV/AIDS demographics; (b) the history of HIV/AIDS; (c) HIV/AIDS and the central nervous system; (d) HIV-associated neurocognitive disorder; (e) neuroanatomic and clinical features of HIV-associated neurocognitive disorder; and (f) nosology of HIV-associated neurocognitive disorder.

Demographics of HIV/AIDS

According to the Joint United Nations Programme on HIV/AIDS (2008) report on the global AIDS epidemic, “HIV has claimed the lives of an estimated 25 million worldwide, and has resulted in profound demographic changes in the most heavily affected countries” (p.30). The report states that the HIV epidemic has stabilized, although with unacceptably high levels of new HIV infections, and deaths. Key findings regarding prevalence, morbidity, mortality, and disparities include:

1. Globally, there were an estimated 33 million (30 million–36 million) people living with HIV in 2007.
2. Overall, 2.0 million (1.8 million–2.3 million) people died due to AIDS in 2007, compared with an estimated 1.7 million (1.5 million–2.3 million) in 2001.
3. The overall number of people living with HIV has steadily increased as new infections occur each year, HIV treatments extend life, and new infections still outnumber AIDS deaths.
4. Women account for half of all people living with HIV worldwide, and almost 60% of HIV infections in sub-Saharan Africa.
5. Young people aged 15–24 account for an estimated 45% of new HIV infections worldwide.

According to an assessment by the International Labour Organization (2006), an estimated 38.6 million persons are living with HIV globally—an estimation even higher than the Joint United Nations Programme on HIV/AIDS (2008). The vast majority (36.3 million) are 15 years and over and therefore of working age. These statistics illustrate the potential impact of the AIDS epidemic on the world of work.

The Joint United Nations Programme on HIV/AIDS (2008) reports that the United States accounted for an estimated 1.2 million (690,000–1.9 million) of the 2.0 million (1.4 million–2.8 million) people living with HIV in North America. However, in August of 2008, the U.S. Centers for Disease Control announced that the annual infection rate in the U.S. is 40% higher than previously estimated, raising the estimated number of new infections in 2006 from 40,000 to 56,300. According to the full reports (Hall, et al., 2008; Karon, Song, Brookmeyer, Kaplin & Hall, 2008), men of all races and ethnicities who have sex with men, and African American men and women are the groups most affected by HIV in the United States. Additionally, 53% of all new infections in 2006 occurred in men who have sex with men. African Americans, while only 13% of the U.S. population, accounted for 45% of the new HIV infections in 2006, which is an annual infection rate 7 times higher than that of whites and almost 3 times higher than Latinos (Hall, et al., 2008; Karon, Song, Brookmeyer, Kaplin, & Hall, 2008). Given the consistent disparities that have been associated with HIV/AIDS, The Center for Disease Control and Prevention (2009) posts a statement on their website regarding the persistent disparities based on race and ethnicity, as well as associated challenges that increased risk (Appendix A). The number of African Americans living with HIV in the United States is greater than the HIV population of 7 of the 15 PEPFAR (President's Emergency Plan For AIDS Relief) focus countries (Hall, et al., 2008; Karon, Song, Brookmeyer, Kaplin, & Hall, 2008).

While the above numbers are alarming, more alarming are the vast numbers of individuals who do not know their HIV status. For these individuals, the benefits of early HIV treatments aimed at preserving the immune system, and by extension health cannot

be realized. According to a recent study by the Chicago Department of Public Health, 50% of HIV-positive men who have sex with men are unaware of their HIV status, and 67% of HIV-positive African American men who have sex with men are unaware of their HIV status (Parker, 2009). Correspondingly, 85% of all reported cases of HIV infection were in large U.S. metropolitan areas, of which New York City ranked the highest (CDC, 2007a). This distinction is important and relevant for social workers in large metropolitan areas who may encounter many who are unaware of their HIV status until they experience a significant health crisis and disruption in employment as the first expression of their underlying HIV infection.

History of HIV/AIDS

The perfect storm is an idiomatic expression in our culture that has come to mean a rare condition, or convergence of unusual circumstances, that produces extreme results. The expression seems particularly well suited to the early history of AIDS, especially given that in 1981 AIDS was a new, lethal, sexually communicable disease that was first identified in highly stigmatized groups with no curative treatment available. These realities created a public health crisis. The AIDS epidemic, coupled with the highly charged social and political repercussions that formed the early context for HIV/AIDS, resulted in the perfect storm. Sadly, similar contextual realities remain a significant complication in the AIDS pandemic today.

In 1981, Gottlieb et al. described an unusual clustering of rare diseases and opportunistic infections among young, previously healthy gay men with no predisposing factors for immune deficiency who were diagnosed with Kaposi's sarcoma or opportunistic infections such as *Pneumocystis carinii* pneumonia. Prior to this, these

conditions had only been seen in patients with suppressed immunologic functioning, such as cancer patients on chemotherapy. These cases were the first evidence of a newly acquired cellular immunodeficiency syndrome that would dominate the U.S. news and culture for many years. The Centers for Disease Control (1981) reported these as the first cases of what was then termed Gay Related Immune Deficiency (GRID). Later renamed Acquired Immune Deficiency Syndrome (AIDS), this newly identified disease and its etiology remained unknown and created considerable fear and alarm in the culture. In 1981 the median survival rate for people with AIDS was 11 months (Callen, 1990).

Two years later, independent of each other, Luc Montagnier at the Pasteur Institute in France, and Robert Gallo at the National Institutes of Health in Bethesda, Maryland, both isolated the Human Immunodeficiency Virus (HIV) that causes AIDS. Considered at the time a major breakthrough in our understanding of AIDS, this discovery immediately became controversial. In 1985, the availability of the HIV antibody test created significant hope among those concerned with prevention and care, but it also created alarm and fear among those targeted for testing, namely gay men and intravenous drug users (Buckingham, 1987).

In 1985, a diagnosis of AIDS had a mortality rate of 80% within two years of diagnosis (Curran, et al., 1985). Although it is difficult to generalize about the course of the disease at that time, individuals with AIDS typically experienced a panoply of challenging problems, including complete relinquishment of autonomy, extreme weight loss, neurological complications, and chronic pain. Given that no treatment was available for HIV infection, the conventional medical practice was to treat the opportunistic infections and/or cancers as they were diagnosed, address related symptoms (weakness,

fatigue, weight-loss, etc.), and provide emotional support and palliative care for those considered end-stage. During this period, the Centers for Disease Control and Prevention defined an AIDS long-term survivor as someone who lived at least three years after an AIDS diagnosis (Hardy, 1991).

No treatments were available to treat the underlying HIV infection until 1987 when the Federal Drug Administration approved AZT (zidovudine) as the first antiretroviral medicament (pharmaceutical agents that treat retroviruses, primarily HIV) to be used for HIV/AIDS. However, 8 more years would pass before any significant new drugs would prove helpful in the treatment of HIV/AIDS.

In 1994, HIV ranked as the leading cause of death in the United States among all races, both sexes, age 25–44 (Department of Health and Human Services, 2009). In 1995, Saquinavir, the first protease inhibitor was approved for use in treating HIV infection. Protease inhibitors are a class of antiretroviral medications that interrupt a particular phase in the retrovirus life cycle. The next few years saw a steady approval of several new antiretroviral medications, and by 1996, HIV dropped to the fourth leading cause of death in the United States among all races, both sexes, age 25–44 (Department of Health and Human Services, 2009).

Considerable hope accompanied the advances in pharmaceutical developments that became common over the next decade, along with new possibilities for those who had been disabled to consider returning to work. Conversely, the inability of the pharmaceutical industry to produce an HIV/AIDS vaccine or cure has resulted in a shift to, and focus on, the “long haul” (Altman, 2009).

The Central Nervous System and HIV/AIDS

Only two years after the first reported cases, significant mental status changes as part of the HIV/AIDS spectrum pandemic were reported (Snider, Simpson, Nielson, Gold, Metroka & Posner, 1983). Subsequent studies confirmed brain involvement along with a specific pattern of brain changes (Ho, et al., 1985). In 1996, Grey et al. found that HIV can cross the blood-brain barrier during the seroconversion period of early infection, suggesting that brain involvement can begin within days of infection, and is likely a consistent part of HIV disease pathogenesis (Grey, 1996). It was originally thought that while HIV appeared to enter the brain during this period of early infection, specific immune responses in the brain inhibited viral replication sufficient to limit the functional or symptomatic expression in the central nervous system until later (Grey, Scaraville, Overall, Chretien, An, Boche, et al., 1996). However, a recent study found that while functional and symptomatic expression of HIV in the brain is limited in early HIV pathogenesis, the virus is able to replicate, and the brain may serve as a reservoir for HIV to hide (McArthur, Haughey, Gartner, Conant, Pardo, Nath & Sacktor, 2003). HIV involvement in the central nervous system, and the brain in particular, continues to be an evolving disease and a central clinical challenge (McArthur, 1997).

Early studies found HIV in the central nervous system of more than half of those who were infected but asymptomatic, and at death 90% of persons with AIDS have neuropathological evidence of central nervous system abnormalities (Navia, Cho, Petit & Price, 1986). Navia, Jordan, and Price (1986) found that two-thirds of clients with advanced HIV disease demonstrate significant neuropsychological abnormalities (though not sufficiently severe to be diagnosed as dementia).

Before the introduction of protease inhibitors the prognosis for anyone with HIV/AIDS was discouraging at best. However, with this new class of antiretroviral medication came the development of Highly Active Antiretroviral Therapy (HAART), which resulted in significant progress in the treatment of HIV/AIDS, including the complications associated with HIV-associated neurocognitive disorder. The availability of potent and efficacious antiretroviral medications and their recommended use in combinations of three or more drugs significantly improved the clinical outcomes of those with HIV/AIDS and led to significantly reduced mortality and morbidity.

Additionally, the development of clinical laboratory tests such as the Cluster of Differentiation 4 (CD4+) cell count and the plasma Viral Load (VL) assay had significant prognostic value and contributed to improved clinical care. The CD4+ cell count, which is a glycoprotein expressed on the surface of T-helper cells is central to establishing and maximizing the capabilities of the immune system, providing a barometer for immune system functioning. The plasma viral load assay, which directly measures the amount of virus in the blood, serves as an index of viral activity. Both of these laboratory tests have allowed for more individualized and strategic treatment. Furthermore, research regarding the early pathogenesis of HIV found that despite a long period of clinical latency, HIV was significantly active in the early stages of seroconversion and infection despite the lack of clinical expression or symptoms. The advances in antiretroviral medications, laboratory testing, and increased understanding of HIV pathogenesis, not to mention considerable clinical experience, all contributed to the aggressive early approach that defined HAART during the advent of combination therapy. However, toxicities associated with HAART moved treatment paradigms toward waiting as long as possible

before initiating therapy. More recently, the development of less toxic therapies, along with recent studies indicating better outcomes and decreased mortality with earlier initiation of HAART (Robbins, et al., 2009), indicate that the initial strategy of aggressive treatment is again the current clinical standard for HIV treatment.

Despite the protective aspects of highly active antiretroviral therapy in the brain (Mellgren, Price, Hagberg, Rosengren, Brew & Gisslen, 2007), research has shown that 40% of people with HIV have neurocognitive impairment five months after beginning potent antiretroviral treatment, and 21% of those who were not cognitively impaired at five months still developed cognitive impairment later, despite continued antiretroviral therapy (Robertson, Smurzynski, Parsons, Wu, Bosch, Wu, et al., 2007).

HIV-associated neurocognitive complications affect 30% to 40% of adults and children with AIDS, despite the advent and benefits of potent antiretroviral combination therapies (McArthur, 1997). Initially, HIV-associated neurocognitive disorder affects at least one in five people with HIV, becoming more common as patients live longer. McArthur states “HIV is the most common cause of cognitive dysfunction in young people worldwide” (Associated Press, 2006).

HIV-Associated Neurocognitive Disorder

HIV-Associated Neurocognitive Disorder, the term that refers to the neurological changes associated with HIV/AIDS, is well documented in the literature and dates back to the beginning of the epidemic (Snider, Simpson, Nielson, Gold, Metroka & Posner, 1983). Dissimilar to most HIV/AIDS-related illnesses that are caused by other infections or malignancies, HIV-associated neurocognitive disorder is caused by HIV directly infiltrating the central nervous system, altering cognition, behavior, affect and motor

skills, and can result in a full dementia syndrome. The continuum of neuropsychiatric issues that converge in the context of HIV disease often are difficult to recognize, distinguish, and effectively address. Social workers, along with most who work with this population, have been confronted consistently with the complicated challenge of early detection, differential diagnosis, and appropriate intervention (Buckingham, 1998; Buckingham & Shernoff, 1998; Buckingham & van Gorp, 1988a, 1988b, 1994, 1999; van Gorp, Dilley & Buckingham, 1998).

Despite significant advances in the medical management of HIV, there is increased need for healthcare professionals to be vigilant about the effects of HIV in the brain, especially given the range of clinical sequelae that can ensue and their relevance to everyday functioning, including occupation. Even mild cognitive impairment has been shown to affect employability and level of occupational functioning (Heaton, et al., 1994; van Gorp, et al., 1999). In one longitudinal study of HIV positive persons seeking to return to work after improved health on combination therapy, memory function was a potent predictor of ability to find work. Those with best performances on memory tasks were almost three times more likely to find work than those with the poorest performance (van Gorp, et al., 2007). The importance of early detection, correct differential diagnosis, and appropriate treatment is crucial given their relevance to well-being and everyday functioning (Buckingham & van Gorp, 1994). As HIV/AIDS is increasingly considered a chronic condition (Beaudin & Chambre, 1996; Chwalisz, 2008; Moskowitz & Wrubel, 2005; Siegel & Lekas, 2002), the need for stable employment, along with all of its related benefits (financial stability, health insurance, social structure, etc.), becomes paramount for those managing the demands of a complex illness. This is especially true for

HIV/AIDS, which is replete with challenges medically, psychologically and socially. It is important to remember that the neuropsychiatric expression of HIV in the brain can both intensify and/or complicate the long standing range of psychosocial challenges that are common among those living with HIV/AIDS and that have been reported in the literature since the beginning of the epidemic (Christ, Wiener & Moynihan, 1986; Furstenberg & Olson, 1984).

In fact, a recent report (Evans, 2009) detailing the mental health needs of persons with HIV infection, concludes that the majority of people living with HIV experience depression, anxiety, thinking and memory problems and substance abuse. The report goes on to state that they are not receiving the mental health services required. Relevant to this study, the report states that psychological and cognitive problems are commonplace, with only 4% of those surveyed saying they had not experienced problems since being diagnosed.

The biopsychosocial perspective, the multi-disciplined context of healthcare, and the evidence-based practice focus, all of which dominate health and mental health care today, create considerable optimism for better outcomes; however, with these hopeful possibilities comes increased responsibility for social workers to be knowledgeable regarding HIV and central nervous system complications. Vigilance regarding the clinical expression of HIV in the brain, the resulting complications, and their implication for well-being, including employment is crucial. Additionally, and important to note, Yeung, Krentz, Gill and Power (2006) found that neuropsychiatric disorders in patients with HIV/AIDS increase medical costs both before and after diagnosis, primarily these costs are related to management of the neuropsychiatric illness. Those with two or more

neuropsychiatric diagnoses faced significantly higher costs than did those with only one neuropsychiatric disorder. The authors also predicted that health costs related to neuropsychiatric disorders would continue to rise as the use of highly active antiretroviral treatments creates a patient population with increased life expectancy, and these developments will require increased spending for management and care.

Because of these challenges, it is essential for social workers who work with HIV-infected persons to have knowledge regarding the characteristics of cognitive changes common to HIV/AIDS and their relevance to social work practice and client well-being. There is little evidence to suggest that social workers as well as other mental health professionals have received preparation for detecting and/or addressing the spectrum of neurocognitive issues common to HIV/AIDS. Likewise, it is difficult to conclude that the fundamentals of brain and behavior relationships, which are increasingly the focus of psychiatric and mental health research and practice, are understood or accounted for by social workers engaged in the health and mental health arenas.

Neuroanatomic and Clinical Features

An understanding of brain-behavior relationships is necessary to understand the relationship between HIV-associated central nervous system changes and the neuropsychiatric manifestations that result from these changes, primarily HIV-associated neurocognitive disorder. The subcortical structures of the brain, which have been implicated consistently in HIV-related neurologic disease, such as the basal ganglia and thalamus, are known to mediate specific cognitive and motor functions (Table 1). Fine motor imprecision, psychomotor slowing, hypophonia (lowered volume of speaking), bradyphrenia (slowed information processing), memory impairment, and difficulty on

complex cognitive tasks such as shifting of mental sets and planning/strategy formations, have all been documented in diseases differentially implicating subcortical structures, including their rich connections to the frontal lobes of the brain. This produces a similar pattern of cognitive and motor impairment to that found in patients with other dementias resulting from predominantly subcortical pathology, such as Parkinson's disease and Huntington's disease. Damage to some subcortical structures has also been reported to result in delusions, mania and depression (Cummings, 1990). Suicide is also an important factor in these patients given the increased frequency of depression in patients with subcortical disease, such as in Parkinson's disease or Huntington's disease (Dewhurst, Oliver, Trick, & McKnight, 1970).

Table 1

Clinical Characteristics of Cortical and Subcortical Dementias

CLINICAL CHARACTERISTICS	CORTICAL DEMENTIAS	HIV-ASSOCIATED NEUROCOGNITIVE DISORDER (Subcortical Dementia)
BRAIN STRUCTURES	Cortex, Prefrontal Cortex	Basal Ganglia, Thalamus
DIAGNOSIS	Alzheimer's Disease Pick's Disease	Huntington's Disease Parkinson's Disease
ATTENTION	Attentive, Alert, Aroused	Inattentive, Distractible
INTELLIGENCE	Impaired	Preserved, Normal
LANGUAGE	Impaired	Normal, Preserved Speech: May be slowed
MEMORY	Gross Impairment Amnesia	Forgetful
VISUOSPATIAL SKILLS	Impaired	Impaired, Easily Lost
ABSTRACTION & SEQUENTIAL REASONING	Impaired	May Experience Difficulty
MOTOR	Normal until late stages	Gait Disturbance
PERSONALITY	Apathetic, Indifferent	Depressed

HIV-associated dementia is a subcortical dementia that resembles other subcortical dementias and can be contrasted sharply with cortical dementias, such as Alzheimer's disease. Psychomotor slowing, a forgetful pattern of memory disturbance and difficulty on cognitive tasks requiring executive functions (complex cognitive tasks of set shifting, planning, coping with novel situations, etc.) mediated by the frontal/subcortical connections are the hallmark characteristics of subcortical dementia. Unlike the profound memory impairment in Alzheimer's disease, which produces an inability to learn new information, memory impairment in HIV-associated dementia is characterized by a relative preservation in the ability to learn new information, although recall of the information is often impaired. When testing memory, a patient with an HIV-associated dementia may exhibit impaired recall in a list of words shown or in recalling complex medication instructions from a physician or nurse; however, when asked to recognize the correct information from multiple choices, the patient will often be able to perform correctly, indicating that the material has been learned, but that patients have difficulty accurately and spontaneously retrieving it. This forgetful pattern of memory disturbance often leads to the incorrect assumption by some that the person is merely being manipulative and that they can recall it when they want to. Table 1 compares and contrasts the differences between cortical and subcortical disorders and their respective symptomatic expressions and presentations.

On formal neuropsychological testing, multiple cognitive domains should be assessed. The domain in which patients with an HIV-associated dementia have the greatest difficulty is psychomotor speed (Miller, et al., 1990). It is on speed tasks in which thought is tied to action that HIV-associated neurocognitive disorder deficits are

most pronounced. In contrast to deficits in psychomotor speed and memory, language function (including naming items and generating word lists) and overall intellectual function as measured by traditional intelligence quotient (IQ) tests are typically preserved until more advanced stages of HIV-associated neurocognitive disorder are reached, usually placing a patient in the HIV-associated dementia category.

As patients with an HIV-associated neurocognitive disorder become more immunosuppressed and the central nervous system involvement becomes more advanced, more serious memory problems are apparent. Worsening visuospatial problems make them at risk for wandering and becoming lost. Patients may forget to take their medications or forget to turn off the stove. In the end stage, patients with HIV-associated dementia may be bed bound, mute or grossly aphasic, and exhibit hallucinations or delusions. In the final or terminal stage, the patients may be mute and in fetal positions.

Nosology of HIV-Associated Neurocognitive Disorder

The triad of cognitive, motor, and behavioral abnormalities that Navia, Jordan, and Price (1986) observed and described as an *AIDS dementia complex* was the first nomenclature to appear in the literature referring to this new constellation of neurocognitive changes that ranged from mild alterations to more frank dementia. Shortened to *AIDS dementia*, this term continues to dominate the clinical arena despite its myopic focus on one end of the continuum. The following year, the Centers for Disease Control (1987) published diagnostic criteria for HIV encephalopathy, which became one of the AIDS-defining illnesses required for an AIDS diagnosis (Appendix B).

In 1991, The American Academy of Neurology AIDS Task Force published diagnostic criteria for HIV-associated cognitive/motor complex (Appendix C). These

criteria are applicable in cases where less severe changes are evident, reserving the diagnosis of HIV-associated dementia complex to cases where there is frank impairment, including clear impingement of activities of daily living.

In 1994, the release of the American Psychiatric Association's publication of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) included a new diagnosis for dementia due to HIV disease (294.9). This diagnosis remained unchanged in the 2000 release of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR). It is unclear if the planned 2012 release of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* will include diagnostic criteria for HIV-associated neurocognitive disorder (American Psychiatric Association, personal communication, July 1, 2008).

NeuroAIDS, a widely used inclusive term first described by McArthur (1997), describes the novel neurologic disorders, which are a primary consequence of damage to the central and peripheral nervous system by HIV. Not unlike the term AIDS dementia, NeuroAIDS provides an inclusive construct to organize a range of clinical realities and presentations.

In 2007, 16 years after the American Academy of Neurology AIDS Task Force published diagnostic criteria for HIV-associated cognitive/motor complex, the National Institute of Mental Health and the National Institute of Neurological Diseases and Stroke formed an impressive group of scholars and clinicians to review and make recommendations to update the criteria. This group published the *National Institute of Mental Health Panel Diagnostic Classification of HIV-Associated Neurocognitive Disorder* (Antinori, et al., 2007). This new algorithm reflects the spectrum of neurologic

disease, beginning with Asymptomatic Neurocognitive Impairment (ANI) and progressing through Minor Neurocognitive Disorder (MND) to frank HIV-Associated Dementia (HAD). Table 2 delineates the diagnostic requirements for each category.

Table 2

NIMH Classification of HIV-Associated Neurocognitive Disorder

National Institute of Mental Health Panel Diagnostic Classification of HIV-Associated Neurocognitive Disorder (HAND)	
Asymptomatic Neurocognitive Impairment (ANI)	Acquired impairment in cognitive functioning, involving $\geq$ (greater than or equal to) 2 ability domains, documented by performance of ≥ 1 standard deviation below the mean for age/education-appropriate norms on standardized neuropsychological tests, including: <ul style="list-style-type: none"> • Verbal/language • Attention/working memory • Abstraction/executive • Memory (learning, recall) • Speed of information processing • Sensory perceptual, motor skills
	Impairment does not interfere with everyday functioning
	Impairment does not meet criteria for delirium or dementia
	No evidence of another preexisting cause for the ANI
Minor Neurocognitive Disorder (MND)	Acquired impairment in cognitive functioning, as defined for ANI above
	At least mild interference in daily functioning, including > 1 of the following: <ul style="list-style-type: none"> • Self-reported reduced mental acuity, inefficiency in work, homemaking, or social functioning • Observation by knowledgeable others of at least mild decline in mental acuity resulting in inefficiency in work, homemaking, or social functioning
	Impairment does not meet criteria for delirium or dementia
	No evidence of another preexisting cause for the MND
HIV-Associated Dementia (HAD)	Marked acquired impairment in cognitive function, involving > 2 ability domains (typically, multiple domains), especially in learning new information, slowed information processing, and defective attention/concentration
	Impairment must be ascertained by neuropsychological testing with > 2 domains 2 SD or greater than demographically corrected means
	Marked interference with day-to-day functioning (work, home life, social activities)
	Does not meet criteria for delirium (e.g. clouding of consciousness not a prominent feature) or If delirium is present, criteria for dementia need to have been met on a previous examination when delirium was not present
	No evidence of another, preexisting cause for the dementia (e.g. other CNS infection, CNS neoplasm, cerebrovascular disease, preexisting neurologic disease, or severe substances abuse)

The recent National Institute of Mental Health algorithm specifies that in all categories neuropsychological testing be required to determine the correct diagnostic category. Additionally, the National Institute of Mental Health panel specifies that the diagnosis of HIV-Associated Neurocognitive Disorder must not occur solely as part of a delirium (acute confusional state), and all other possible comorbidities (substance use, head injury, etc.) cannot explain the observed cognitive impairment.

The above review makes clear the consistently evolving and challenging realities of HIV involvement in the central nervous system and the attendant complications. Social workers must be knowledgeable about the range of terms that are used and the multi-dimensional aspects of this spectrum disorder and the associated challenges.

Summary

In summary, advances in pharmaceutical development, clinical assessment techniques, and increased understanding of HIV pathogenesis have all contributed to significantly improved outcomes for those with HIV/AIDS. Moreover, the introduction of Saquinavir in 1995, the first protease inhibitor, and the use of antiretrovirals in combination, led to remarkably improved prognoses, sufficient for many who had been disabled to consider returning to work. While not a cure, this penultimate reconstitution of immune functioning, which some have likened to Lazarus Syndrome (Maleck, Piper, Triem, Boldt, & Zittel, 1999), has received considerable attention, especially in the area of returning to work. However, as HIV/AIDS has emerged from the plague years as a chronic disease, the issues related to employability and occupation persistence are less understood. Understandably, and of paramount importance to this patient population, the

factors that contribute to sustained employment are crucial. With employment come sustainability, improved quality of life, and health-related benefits.

Chapter II provides a review of the literature related to the return to work phenomenon among people living with HIV/AIDS. Additionally, the relevant theoretical perspectives and literature on neuropsychological performance and employment are reviewed, serving as a foundation for this investigation. Questions regarding neuropsychological functioning in HIV/AIDS, as related to occupational persistence represent a gap in the literature, constituting a new emerging field of study and the focus of this dissertation.

CHAPTER II

LITERATURE REVIEW

Overview of the Literature Review

This chapter provides a review of the literature regarding HIV/AIDS and the return to work phenomenon that began in 1996 following significant advances in treatment, specifically the introduction of the first protease inhibitor and the practice of combining antiretroviral medications. The literature identifies a number of consistent issues as barriers and/or concerns that impede the process for those with HIV/AIDS attempting to return to work. Additionally, the literature regarding neuropsychological functioning and vocational performance specific to HIV/AIDS is reviewed as it pertains to the question of occupational persistence in the workplace.

Two models that have informed the majority of research related to neuropsychological functioning and occupational performance are discussed (Kendall & Terry, 1996; Ownsworth & McKenna, 2004). A model developed by Sadek and van Gorp (2009) that focuses on the primacy of neuropsychological functioning to employment is discussed. Finally, a conceptual model based on these theoretical perspectives and models is proposed. The variables are discussed in detail, as well as the literature that supports their inclusion.

The review and discussion reveal a clear gap in the literature regarding HIV/AIDS and work, namely, an understanding of occupational persistence in the workplace, or the

lack thereof. The importance of occupational persistence in the workplace is paramount to the sustained well-being (Applebaum, 1992) of those with HIV/AIDS. This study is timely in the continued evolution of the HIV/AIDS pandemic and the realities of people working while managing the complexities of this chronic illness.

HIV/AIDS and Return To Work

Search Parameters and Process

To explore the literature related to HIV/AIDS and the return to work phenomenon, the following databases were searched: EBSCO Academic, EBSCO Host, OVID, PsycARTICLES, PsycINFO, ProQuest, PUBMED, and Social Work Abstracts. The key terms used were HIV, AIDS, HIV/AIDS, Work, Return, Employment, Unemployment, Vocational, Occupational, Rehabilitation, and Disability. The search was limited to books, book chapters, abstracts, and journal articles published between 1996 and 2009. The period searched was determined based on the timing of the Federal Drug Administration approval of Saquinavir, the first protease inhibitor. Most results were available in PDF (Portable Document Format) or HTML (Hypertext Markup Language), and all were acquired for full review. Books and book chapters that were unavailable online were secured through the University of Louisville Distance Learning Library Services.

Additionally, given the wealth of literature related to HIV/AIDS and the unique constellation of issues associated with the epidemic, the search was limited to HIV/AIDS-specific findings on employment and return to work. The search, despite the predetermined search terms, often included divergent citations, none of which on examination was relevant to the subject area that was the focus of the literature search.

Specific publications related to HIV/AIDS and occupations were reviewed. While interesting, literature that exclusively described programs or practice approaches was not included.

Return to Work Literature

The search yielded 23 relevant publications, 15 of which specifically addressed vocational and occupational rehabilitation/counseling professions (publications 1, 2, 3, 4, 5, 6, 7, 8, 9, 13, 14, 15, 16, 17, & 19 in Table 3), many of which were published in vocational- and occupational rehabilitation-specific publications. Neuropsychology and psychiatry accounted for 6 of the publications (publications 10, 11, 12, 18, 22, & 23 in Table 3), which primarily addressed neurocognitive and neuropsychiatric challenges. Two publications were from social work (20 & 21), which were descriptive and focused on problem identification.

Eighteen journal articles were based on research; 9 were quantitative (publications 1, 3, 8, 10, 11, 12, 18, 22, 23 in Table 3), and 8 were qualitative (publications 4, 5, 7, 13, 14, 15, 17, 20 in Table 3). The majority of these articles were aimed at identifying and describing the barriers that people with HIV/AIDS experienced as they attempted to return to work. The barriers could be real (experienced), perceived (felt), or anticipated (feared). The qualitative articles were focused on describing the experiences of those interviewed and, by extension, the issues they encountered or anticipated. These studies used smaller samples and employed a grounded theory approach. Based on theory and prior research with similar populations, the quantitative research focused on identifying the extent to which a range of issues could be expected by people attempting to return to work. Utilizing larger samples recruited from vocational rehabilitation programs, AIDS

Table 3

Return to Work Literature Content Analysis

	Reference	HAND	Physical Medical	Mental Emotional	Education Training	Finances Benefits
1	Arns, Martin & Chernoff, 2004		✓	✓	✓	✓
2	Bettinger, 1999			✓		
3	Brooks, Martin, Ortiz & Veniegas, 2004	✓	✓	✓	✓	✓
4	Conyers, 2004a		✓		✓	✓
5	Conyers, 2004b		✓			
6	Conyers, 2005		✓			
7	Ferrier & Lavis, 2003		✓		✓	✓
8	Glenn, Ford, Moore, & Hollar, 2003	✓	✓	✓	✓	✓
9	Goldstein & Goldbaum, 1999				✓	
10	Heaton, et al, 2004	✓	✓	✓		
11	Heaton, et al, 1994	✓				
12	Heaton, et al, 1996	✓				
13	Hunt, Jaques, Niles & Wierzalis, 2003		✓	✓		✓
14	Maguire, McNally, Britton, Werth & Borges, 2008		✓	✓		✓
15	Maticka-Tyndale, Adam, & Cohen, 2002	✓	✓	✓	✓	✓
16	McReynolds & Garske, 2001	✓	✓	✓	✓	
17	Nixon & Renwick, 2003		✓			✓
18	Rabkin, McElhiney, Ferrando, van Gorp & Lin, 2004	✓	✓	✓	✓	✓
19	Salz, 2001		✓			
20	Timmons, Ciulla & Lynch-Fesko, 2004	✓	✓	✓		✓
21	Timmons & Fesko, 2002		✓		✓	✓
22	van Gorp, Baerwald, Ferrando, McElhiney & Rabkin, 1999	✓	✓	✓		
23	van Gorp, et al, 2007	✓	✓	✓	✓	✓

HAND: HIV-Associated Neurocognitive Disorder.

Physical/Medical: Issues related to symptoms, disease progression and management of medical appointments and medication side effects.

Mental/Emotional: Issues related to depression, anxiety, stigma, discrimination & social support.

Education/Training: Issues related to educational requirements and job-specific skill or training.

Financial/Benefit Stability: Issues related to stability of income, insurance, and/or benefits.

service organizations, and the community, these studies addressed similar concerns as the qualitative research. Both research approaches resulted in similar findings. The issues and challenges faced by those attempting to return to work generally can be clustered into groups as follows.

HIV-Associated Neurocognitive Disorder

The effects of HIV in the brain, specifically issues related to memory and neuropsychological functioning, can result in limitations and diminished capacity relevant to work. This reality is well known among those with HIV and has generated considerable concern among those trying to return to work (publications 3, 8, 10, 11, 12, 16, 18, 20, 22, & 23 in Table 3). Concerns regarding memory, concentration, intelligence quotient, motor skills, and coordination have all been noted specifically in the literature. Chapter I provided more clinical detail regarding the actual effects of HIV in the brain and the resulting clinical sequelae.

Physical and Medical Issues

There is a wide range of physical and medical issues that are reported in the literature as concerns and barriers for those returning to work. As mentioned above, the issues included real (experienced), perceived (felt), or anticipated (feared) concerns related to changes in health status from stable to unstable, disease progression, medication compliance, medication side effects, fatigue, chronic gastrointestinal issues, as well as anxiety and stress that may undermine health (publications 1, 3, 4, 5, 6, 7, 8, 10, 11, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, & 23 in Table 3).

Mental and Emotional Issues

The mental health and emotional issues consistent in the literature include a number of specific concerns. These can be organized and clustered into the following areas: (a) concerns regarding the ongoing adjustment to the diagnosis, disease progression and/or management of the disease, all of which may involve anxiety, depression, uncertainty/worry and related stress; (b) stigma and discrimination, which can result in anxiety, depression, and stress; and (c) disclosure issues related to HIV status or AIDS diagnosis, and the associated questions that accompany such information related to life style, sexual orientation/behavior, drug use, and health history (publications 1, 2, 3, 8, 10, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, & 23 in Table 3).

Education and Training Needs

Concerns related to educational requirements and job-specific skills and/or training are common among those entering the job market following a period of unemployment due to illness (publications 1, 3, 4, 7, 8, 9, 15, 16, 18, 21, & 23 in Table 3). The issues are reported in simple terms:

1. Having been out of the workforce for almost any period of time is considered a disadvantage specific to returning to work.
2. Required skill sets may have changed during the period of unemployment, requiring new training and education to compensate for their perceived deficits.
3. Individuals often see their levels of education as lacking or inadequate for new jobs, especially among those with HIV who are returning to work.

For some, this break in employment provides an opportunity to reconsider career choices and potentially move into new and different professional arenas.

Finances and Benefit Stability

Concerns over unemployment income, loss of health insurance, and/or other benefits and entitlements are also common (publications 1, 3, 4, 7, 8, 13, 14, 15, 17, 18, 20, 21, & 23 in Table 3). The unifying factor among these concerns was related to stability. Despite the range of benefits associated with working, the movement from unemployed/disabled to employed/able invites many questions about ongoing work demands, continued health sufficient to meet the demands of work, and the associated stability related to benefits and income. As with any chronic illness, the prognosis and course of illness are often hard to predict in any specific way. This is especially true for HIV/AIDS, and is understandable given the relatively brief history of HIV/AIDS. The early history of HIV and associated mortality rates, coupled with concerns about long-term medication effectiveness and associated issues of adherence and resistance, all explain the unease with which individuals with HIV view their futures, despite medical advances.

The issues that people experience are not mutually exclusive, nor easily categorized in discrete terms. For example, anxiety over finances could be categorized as both a mental health/emotional issue and as a financial and benefits concerns. Both areas are relevant and need to be integrated into our understanding. Another example is depression, which could fit in both the HIV-associated neurocognitive disorder category, as well as the mental and emotional category. Research indicates that patients' own assessments of everyday cognitive difficulties are often much more related to mood than to actual ability to perform well on standard neuropsychological tests (van Gorp, et al., 1993). Because of this, patients who state that they are having difficulties with memory

or attention may be experiencing primary depression, incorrectly attributing these symptoms to cognitive problems. Furthermore, professionals often misdiagnose clinical depression in patients with HIV/AIDS (Buckingham & van Gorp, 1994). This misdiagnosis is easily understood in the context of similarities between the early signs of HIV brain involvement and the affective signs of depression. However, the subtle differences are important and relevant to those with a complex illness like HIV/AIDS, and both are accounted for in the content analysis of the literature in Table 3.

As the return to work literature makes clear, the continuum of issues that those with HIV/AIDS encounter are consistently identified and well documented. Among the issues discussed, the concerns and challenges regarding a diagnosis of HIV-associated neurocognitive disorder are among the most common. The six HIV-specific research articles that address neuropsychological functioning and occupation performance are discussed in the next section.

HIV/AIDS Neuropsychological Functioning and Employment

The literature is replete with studies regarding HIV and the central nervous system (Chapter I). Additionally, research related to neuropsychological impairment and employment is well established in the literature and has been applied to a range of diverse medical conditions (Chelune & Moehle, 1986; Heaton, Chelune, & Lehman, 1978; Heaton, & Pendleton, 1981; Newnan, Heaton, & Lehman, 1978; Rao, Leo, & Ellington, 1991). However, knowledge regarding the implications of HIV in the brain and the resulting changes as related to occupation performance are limited, especially as related to occupational persistence, the focus of this study. Questions related to return to work have dominated the HIV/AIDS and employment research since the introduction of

protease inhibitors and combination therapy. However, as these efficacious treatments have changed the pathogenesis of HIV/AIDS, fewer people have experienced periods of unemployment due to disability. This advancement in treatment now raises questions related to how people can *persist* in the workforce while living with HIV/AIDS.

The discussion in this section focuses on the six articles that specifically address HIV/AIDS, neuropsychological functioning, and occupational performance—the foundation necessary to begin exploring issues and barriers to *occupational persistence*. This discussion is organized chronologically, making clear the current state of knowledge as described in the literature regarding HIV-specific neuropsychological functioning and occupation performance.

Heaton, et al. (1994) clarified the significance of neuropsychological impairment in people with HIV as related to employment. In a study of 289 HIV-infected, non-demented men, those with neuropsychological impairment had significantly higher rates of unemployment ($p < .001$) than did their unimpaired counterparts. Among those who remained employed, neuropsychological impairment was strongly associated with a decrease in job-related abilities. Neither depression nor medical symptoms could explain the relationship between the neuropsychological impairment and employment problems. The study findings are consistent with other studies on neuropsychological impairment and suggest that even mild neuropsychological impairment can interfere with employment as a clinically significant factor.

In a later study, Heaton, et al. (1996) described the nature and consequences of neuropsychological impairment in HIV infection. The study found that neuropsychological impairment increases or advances along with HIV disease

progression. As patients move from asymptomatic to mildly symptomatic to more frank expressions of HIV disease, neurological impairment also increases. The changes are not explained by medical or psychiatric factors, but rather by changes in brain structure and functioning. The authors report that tests of attention and speed of information processing and learning efficiency are particularly telling. They also confirm that changes tend to be located in the subcortical structures of the brain. Additionally, they note that neuropsychological impairment is associated with increased unemployment, complaints of job performance difficulties, and worse performance on standardized work samples. Interference with vocational functioning and general life quality may reflect considerable clinical importance of even subtle brain involvement in HIV infection.

Van Gorp, Baerwald, Ferrando, McElhiney, and Rabkin (1999) reported on a study of 130 predominantly symptomatic men with HIV and the relationship between employment and neuropsychological impairment in HIV infection. The study focused on symptomatic men and the differences between those employed (full or part-time for pay) and those unemployed. All participants were administered a battery of neuropsychological tests. When controlling for CD4+ count, age, and physical limitation, the results revealed that unemployed men performed worse than employed men on tasks of memory, set shifting (cognitive flexibility), and psychomotor speed.

Heaton, et al. (2004) evaluated the functional, or real-world impact of HIV-associated neuropsychological impairment in a group of 267 HIV-infected participants. The sample received comprehensive neuropsychological, neuromedical, and standardized functional evaluations that included laboratory measures of shopping skills, cooking skills, financial management, medication management, and vocational abilities. When

compared to the neuropsychological-normal participants, those with neuropsychological impairment performed significantly worse on all laboratory measures of everyday functioning. Analyses revealed that the neuropsychological ability domains of Abstraction/Executive Function, Learning, Attention/Working Memory and Verbal abilities most strongly predicted failures on the functional battery. The study found that both neuropsychological impairment and impairment on the functional battery were significantly associated with experiences of cognitive difficulties, as well as unemployment and increased dependence in activities of daily living. Additional analysis found that depressed mood and biological measures of disease progression were the only unique predictors of all three indicators of real-world functioning.

Rabkin, McElhiney, Ferrando, van Gorp, and Lin (2004) identified patterns and predictors of work status. A sample of 141 men had semiannual neuropsychiatric, psychosocial, and medical assessments over a period of 30 months; 20% were employed continuously full-time, 9% were employed continuously part-time, and 40% were unemployed continuously. The major factors consistently associated with unemployment or partial employment, in order of influence, were (a) financial (disability benefits); (b) psychiatric (past/current diagnosis of major depression and/or dysthymia); (c) medical (physical limitations); (d) cognitive (executive function); and (e) education. In contrast, age, ethnicity, laboratory markers of HIV illness status, vocational rank, and past or current substance dependence did not predict work status.

Van Gorp and colleagues (2007) reported on a two-year longitudinal study of 118 HIV-infected individuals who were actively attempting to return to work in New York City. The sample included men and women and demographically represented the

distribution of HIV infection in greater New York City. A range of measurements was utilized, including sociodemographic measures, medical measures, neuropsychological measures, and psychiatric/psychosocial measures. The study found that memory was the most potent predictor of obtaining employment. Persons who were younger, did not have a diagnosis of AIDS, and had shorter periods of unemployment prior to entering the study also had better chances of finding employment. Those who found employment reported lower levels of depression.

While van Gorp et al. (2007) specifically addressed the convergence of HIV/AIDS, neuropsychological functioning, and occupation performance related to return to work, issues related to occupational persistence were not the foci of the study. As those with HIV/AIDS face challenges associated with chronic illness, research related to maintaining employment, or occupational persistence, is needed. Additionally, research conducted with men and women in larger urban areas will yield findings more consistent with the demographics of HIV/AIDS in the U.S.

Theoretical Perspectives and Models

According to Sadek and van Gorp (2009), there are two functional outcome models based on research from the traumatic brain injury literature that provide the theoretical basis from which most research on neuropsychological functioning has been conducted. Both of these models are comprehensive and contextual, accounting for a range of factors including cognitive abilities. Among the range of non-cognitive factors that are represented in the models are premorbid factors such as pre-illness intellectual abilities, demographic factors, substance use history, premorbid employment history, available resources (such as socioeconomic status of the patient and social support),

situational factors such as the status of the job market, the ability of a job to accommodate certain disabilities, and injury factors such as physical impairment. A third model, by Sadek and van Gorp (2009), is a sequential model based on a directional and causal relationship between brain disease and poor vocational functioning. Finally, a proposed conceptual model is presented that incorporates critical aspects of the three models reviewed and that forms the basis for this dissertation research.

Model of Functional Psychosocial Adjustment Outcomes

Kendall and Terry's (1996) model of functional psychosocial adjustment (see Figure 1) was groundbreaking because it accounts for a range of factors that affect psychosocial adjustment following a traumatic brain injury. Kendall and Terry developed their model because at the time most studies and clinical decisions assumed that neurological factors (e.g., characteristics of the injury, cognitive impairment) explained psychological adjustment and well-being after a traumatic brain injury. Kendall and Terry (1996), following a review of the literature, found several studies that suggested "neurological factors, such as the locus of the lesion, the severity of the injury or the level of cognitive impairment, offered the most parsimonious explanation" (p. 101). Additionally, they found studies indicating that neurological factors are unable to adequately account for individual variation in psychosocial outcome, and there might be a significant role for non-neurological factors. After reviewing the literature on non-neurological factors that influenced adjustment post-traumatic brain injury, it was found that many factors possibly contribute to outcomes. As the model indicates, there are a number of factors that converge in the context of traumatic brain injury, including non-

neurological factors that should be considered when examining possible influences on psychosocial adjustment (see Figure 1).

Figure 1. Model of functional psychosocial adjustment outcomes (Kendall & Terry, 1996).

To clarify, traumatic brain injury is a broad term that refers to brain damage resulting from external mechanical force, such as rapid acceleration or deceleration, impact, blasts, or projectile penetration (Maas, Stocchetti, & Bullock, 2008). Traumatic brain injury is classified as an acquired brain injury, meaning it occurred after birth (Collins & Dean, 2002). The other classification of acquired brain injury is termed non-traumatic brain injury, examples of which would include cerebral vascular accident (stroke) or infection (HIV). A closed head injury is a type of traumatic brain injury that is closed versus a penetrating head injury. Kendall and Terry (1996) base their model on the

literature related to closed head injuries, meaning that the injury was not a penetrating injury resulting in the skull being breached and the brain exposed.

To address this penurious situation, Kendall and Terry (1996) turned to the stress and adjustment literature to provide an appropriate base from which to explore the possible non-neurological determinants of psychosocial outcome following closed head injuries. As a result, their model is based on the work of Lazarus and Folkman's (1984) cognitive-phenomenological theory of stress and adjustment. According to Paterson and Neufeld (1987), closed head injuries are extremely stressful life events. Gainotti (1993) makes the point that consequences resulting from closed head injuries, such as unemployment and financial concerns, are stressful and important to consider in understanding post-injury adjustment.

However, Kendall and Terry (1996) point out that most studies of stressful life events and psychosocial outcomes were not theory-based and usually only considered the effect of one or two mediating variables on psychosocial outcome. This resulted in a large body of work that was limited, characterized as a "meandering unfocused giant that is in need of rigorous methodological designs and a clear theoretical basis." (p. 2315) Kendall and Terry, make the comparison that "closed head injury adjustment research has [had] also fallen into a similar trap" (Taylor, 1984, p. 108)

Lazarus and Folkman (1984; Lazarus, 1990a; 1993) addressed this limitation in the literature by developing a model to account for individual variation in adjustment to stress. Based on a cognitive-phenomenological approach to the study of human behavior, the theory assumes that adjustment following a life event is dependent more on subjective evaluation than on the objective characteristics of the event. Lazarus and Folkman (1984)

specifically proposed that the subjective appraisal an individual makes of an event is central to the adjustment process because an event cannot be considered stressful until it has been defined as such by the individual having the experience. In general, stressful events are those that are appraised as threatening or harmful (primary appraisal) and are perceived as placing considerable demand on the individual's resources, to the point that the individual believes he or she will not be able to cope with, or control, the event (secondary appraisal). According to Lazarus and Folkman, stress resides in neither the person nor the event, but is a reflection of the person's unique response to that event (Lazarus, 1990a, 1990b; 1993; Lazarus & Folkman, 1984).

The concept of coping, as defined by Lazarus and his colleagues (Lazarus, 1990a, 1990b; 1993; Lazarus & Folkman, 1984), involves the process of determining responses to a stressful life event rather than the consequences of that response. Two broad types of coping strategies are identified: problem-focused coping and emotion-focused coping. Based on Lazarus (1993), Kendall and Terry (1996) go on to further define these two types of coping strategy as the primary aim of problem-focused coping is actively to confront the event, either by altering the situation (environment-directed) or by acquiring the necessary information or skills (self-directed). In contrast, emotion-focused coping is a palliative response that aims to minimize the negative emotional reactions to the event. Emotion-focused strategies can range from avoidant methods, such as, suppression, wishful thinking, and distraction, to the more approach-oriented methods of emotional expression, positive re-appraisal and seeking meaning.

Additionally, Lazarus and his collaborators (Lazarus, 1990a; 1993; Lazarus & Folkman, 1984) posit that appraisal and coping are influenced by a number of antecedent

variables, which include personal resources (beliefs and traits), environmental resources (social support), and situational factors (see Figure 2). Important to note, and similar to coping associated with chronic illness (Charmaz; 1990; 1991; 1995), Lazarus and Folkman (1984) viewed the process as recursive, constantly changing, and circular.

Figure 2. Major components of stress and adjustment theory (Lazarus & Folkman, 1984).

This model has had significant influence on researchers and rehabilitation specialists because it formalized the role of non-neurological factors in determining outcome, according to Sadek and van Gorp (2009). It is important to note that psychosocial adjustment is likely influenced by a number of factors that overlap and converge in the context of resulting changes from brain injury or other brain altering possibilities. For this study, HIV-associated neurocognitive challenges are explored.

Model of Employment Outcomes

The second influential model that provides a foundational theoretical perspective that has guided research and clinical decision-making is by Ownsworth and McKenna (2004). While this model focuses on employment outcome, it addresses many of the factors that Kendall and Terry (1996) proposed in their model. This model, (see Figure 3) focuses on rehabilitation post-traumatic brain injury and emphasizes intrapersonal factors such as self-awareness and other metacognitive and emotional factors as influential to successful rehabilitation. In contrast to Kendall and Terry's psychosocial outcomes model, this model was designed specifically to assess employment outcomes.

Figure 3. Model of employment outcomes (Ownsworth & McKenna, 2004).

A comprehensive review of the literature formed the basis of Ownsworth and McKenna's (2004) formative model. They divided their process into two stages. In the first stage they conducted a literature search, which yielded 85 studies published between 1980 and 2003 that specifically investigated factors related to employment outcome following traumatic brain injury. The studies were evaluated and rated according to the quality of their methodology. In the second stage, the 50 studies that met nine criteria for inclusion were analyzed. They all examined a broad range of variables. The goal of the review was to highlight the key variables that most consistently corresponded to employment. Ownsworth and McKenna (2004) identified and concluded that the following factors are the most related to employment: pre-injury occupational status, functional status at discharge, global cognitive functioning, perceptual ability, executive

functioning, involvement in vocational rehabilitation services and emotional status. This review was the basis for their conceptual model that focused on the importance of employment outcome and was defined in terms of type of work, number of hours worked, work modifications, quality of performance and durability. Specifically, the variables are linear and follow a timeline beginning with pre-trauma, through recovery, and ending with long-term adjustment. The major contribution of their model involves the addition of two stages: (a) metacognitive and emotional variables stage, which can be modified through rehabilitation; and (b) the social/environmental variables stage, which can be modified through social and environment adjustments. These two areas of possible modification are major contributions of this model aimed at improving rehabilitation, and by extension, employment outcomes.

Model of Directional Causal Relationships

The third model by Sadek and van Gorp (2009) focuses on cognitive impairment and its posited direct causal relationship to vocational performance (Figure 4). Sadek and van Gorp (2009) state, “Brain dysfunction results in cognitive, emotional, and behavioral impairment, which in turn results in specific disabilities and poor vocational functioning” (p.12).

Figure 4. Hypothetical directional causal relationships model (Sadek & van Gorp, 2009)

According to Sadek and van Gorp (2009), there are three trajectories of cognitive performance associated with acquired brain disease: (a) abrupt onset with gradual

recovery to premorbid level; (b) abrupt onset with recovery to static impairment; and (c) gradual onset with progressive worsening over time. These three trajectories are particularly relevant given the distinction of the third possibility for those with HIV-associated neurocognitive disorder. The first and second trajectories are associated with traumatic brain injury, stroke, brain tumor, encephalitis/meningitis, and delirium. The third trajectory is typically observed in progressive dementia conditions or other degenerative neurological diseases, such as HIV-associated neurocognitive disorder. As HIV is considered a chronic condition, the associations of the neurocognitive expressions and their relevance to work over time certainly has implications for occupational success as measured by sustained employment.

It is interesting to note the full circle aspect of this review of theoretical perspectives. While beginning with the introduction of Kendall and Terry's model, which set precedence for the inclusion of non-neurological factors, Sadek and van Gorp's model underscores the primacy of brain disease and injury and the resulting neuropsychological sequelae, which most certainly can result in poor vocational performance. In the real world, all of these variables must be accounted for if we are to understand fully the challenges with which those with brain alterations are faced and the resulting implications for employment outcomes.

Proposed Conceptual Model

The following section discusses a proposed conceptual model (see Figure 5), which accounts for the critical contributions of the models discussed above. Many of the non-neurological variables identified in the Kendall and Terry (1996) model are used as control variables in the model. The contribution of Ownsworth and McKenna's (1996)

Figure 5. Proposed conceptual model.

model is the focus on employment—specifically occupational persistence in this study—as a functional outcome. The model by Sadek and van Gorp (2009) contributes through its illustration of the primacy and linear relationship between neuropsychological functioning and job performance.

Main Predictor

Neuropsychological Functioning

Sherer, et al. (2002) in their review of neuropsychological factors related to employment found conclusive evidence to support the relationship between early cognitive impairment and poor occupational outcomes (Dikmen, et al., 1994; Fleming, Tooth, Hassell, & Chan, 1999; Fraser, Dikmen, McLean, Miller, & Temkin, 1988; Sherer, et al., 2002). Ownsworth and McKenna (2004) point out that there is empirical support, although not conclusive, for the predictive value of verbal or language functioning (Boake, et al., 2001; Bowman, 1996; Drake, Gray, Yoder, Pramuka, & Llewellyn, 2000), memory functioning (Bowman, 1996; Cifu, et al., 1997; Boake & High, 1996; Heaton, et al., 1994; van Gorp, et al., 1999), and attention or processing speed (Boake, et al., 2001; Bowman, 1996; Cifu, et al., 1997). Additionally, measures of executive functioning have been identified as the most reliable neuropsychological indicators associated with employment outcome (Boake, et al, 2001; Boake & High, 1996; Drake, Grey, Yoder, Pramuka, & Llewellyn, 2000; Hanlon, Demery, Martinovich, & Kelly, 1999; Ip, Dornan & Schentag, 1996; Nybo & Koskiniemi, 1999; Vilkki, Ahola, Holst, Ohman, Servo, & Heiskanen, 1994).

Control Variables

Demographic and Life Characteristics

Age. Ownsworth and McKenna (2004) include age as one of the demographic predictors often analyzed in their review of the literature related to employment outcome following traumatic brain injury. They divide the studies into two categories: those that analyzed age at the time of the study versus those that analyzed age at the time of injury.

They conclude that the level of empirical support for a relationship among age at the time of injury, age at the time of study, and employment is mixed. However, studies that did report a significant relationship between age at the time of the study and employment concluded that older adults tended to experience less favorable employment outcomes than younger adults, although the studies did not specify the age group in which the odds of returning to work decrease (Rao, et al., 1990; Ruff, et al., 1993; Stambrook, Moore, Peters, Deviaenes, & Hawryluk, 1990).

In studies investigating age at the time of injury and employment outcomes, there were a number of significant findings. Asikainen, Kaste and Sarna (1996) report that the individual's age at the time of injury was significantly related to work status. They found that patients in the youngest age group (7 years and younger) with a severe brain injury were more likely to have poor employment outcomes when compared to patients with severe brain injuries in the 17–25 year age group. Nybo and Koskiniemi (1999) found that 27% of those in their study of adult patients who sustained a severe traumatic brain injury at age 7 or younger worked full-time, but no individuals who were injured at age 4 or younger were able to work in adulthood. Keyser-Marcus, et al. (2002) found that individuals who were between 18–39 years at the time of injury were more likely to return to work between 1–4 years post-injury compared to individuals aged 40–55 years. Ponsford, et al. (1995) report that individuals aged 40 or over at the time of injury were less likely to be employed at 2 years post-injury than individuals under age 40.

Ownsworth and McKenna (2004) found that studies comparing different age categories were more likely to produce consistent findings which indicated that poor employment outcome is associated with specific age groups at the time of injury, such as

individuals age 7 or younger or those over age 40. The significance of age remains an areas needing further research.

Gender. Ownsworth and McKenna (2004) report the findings of Crepeau and Scherzer (1993), who concluded in their meta-analysis that females were more likely to return to work than males in studies involving patients with severe traumatic brain injury. In case of less severe brain injuries, males were more likely to return to work. However, they state that none of the studies had sufficient empirical evidence to support gender differences concluding that gender is not a significant predictor of employment outcomes following traumatic brain injury. In HIV/AIDS research, the effects of gender on employment have not been explored, since most of the studies on HIV/AIDS and return to work have been conducted with men. As the epidemiological distribution of HIV/AIDS has dramatically changed in recent years (Chapter I) to include women, the inclusion of gender in this study seems prudent. Additionally, this study sample reflects the demographics of New York City, which proportionately has more women.

Race and Ethnicity. While a number of studies have examined racial or ethnic identity as possible predictors of employment in traumatic brain injury literature (Dikmen, et al., 1994; O'Connell, 2000; Reynolds, et al., 2003; Sander, Kreutzer, Rosenthal, Delmonico, & Young, 1996; Sherer, et al., 1998; Wagner, Hammond, Sasser, & Wiercisiewski, 2002), only two which were rated as commendable by Ownsworth and McKenna (2004) found that race was a significant predictor of employment outcome (Kreutzer, et al., 2003; Sherer, et al., 2002). Sherer et al. (2003) found that several other pre-injury predictors such as pre-injury productivity, education level and cause of injury were related to race. However, after adjusting for the effects of these predictors African

Americans and other racial minorities were approximately twice as likely to be non-productive than Whites.

Owensworth and McKenna (2004) conclude that “although the level of empirical support for race was mixed in our review, given the quality of the methodology employed by particular studies with significant findings (Kreutzer, et al., 2003; Sherer, et al., 2003), the relative influence of race should be considered as a predictor in future research by systematically controlling for potentially confounding demographic and injury-related factors.” (p. 770) Given the disproportionality of HIV/AIDS in the African American and Hispanics/Latinos populations (CDC, 2009), race and ethnicity seem important variables to account for in this research.

Education. A number of studies have examined pre-injury educational status as a predictor of employment outcome. Several studies (Dikmen, et al., 1994; Greenspan, Wrigley, Kresnow, Branche-Dorsey, & Fine, 1996; Kreutzer, et al., 2003; Sherer, et al., 2002) found that individuals who did not complete high school were more likely to be unemployed than those who completed high school or attended college. However, Owensworth and McKenna (2004) point out that overall empirical findings regarding the relationship between pre-injury education and employment outcome are inconsistent, with various studies failing to find a significant relationship between educational status and employment outcomes (Ponsford, Olver, Curran, & Ng, 1995; Malec, 2001). Despite the inconsistencies in findings, the reported concern by people with HIV/AIDS attempting to return to work regarding education (Table 3) warrants the continued investigation of this variable.

Sexual orientation. While research specifically related to sexual orientation and employment outcomes for those with neurological deficits could not be found, several articles reviewed earlier in this chapter examining HIV/AIDS, neuropsychological functioning and return to work exclusively sampled gay men (Heaton, et al., 1994; Rabkin, Martin, Ferrando, van Gorp, & Lin, 2004; van Gorp, Baerwald, Ferrando, McElhiney, & Rabkin, 1999). The identification as gay merits analysis in this research given that HIV was first identified among gay men (Gottlieb, et al., 1981). Moreover, the fears and anxieties related to disease transmission that fueled a public health panic in the early 1980s and further stigmatized an already marginalized community resulted in significant discrimination in housing and *employment* (Shilts, 1987). These effects cannot be overlooked, and they likely continue despite significant education in the culture. Important to note, men who have sex with men continue to be among those most at risk for HIV/AIDS and currently represent the largest group of those newly infected (Hall, et al., 2008). As such, their unique experiences and inclusion as a variable is imperative. Much of our early understanding of HIV/AIDS was based on the exclusive experiences of gay men. With disease spread and shifting demographics there is an opportunity to examine questions related to the unique issues that gay men face versus their heterosexual counterparts.

Time unemployed. Considering that returning to work is a significant problem for those with HIV/AIDS who have been unemployed due to HIV-related illness and disability, the amount of time out of the workforce would seem to be an important variable to consider. Certainly, trying to keep people in the workforce whenever possible would be a preferable option, especially in light of the documented difficulties associated

with the transition back to employment. While not specifically related to time unemployed, length of stay in a hospital, acute care or rehabilitation as a predictor of employment outcomes has received considerable attention in the research on traumatic brain injury (Cifu, et al., 1997; Hoofien, Vakil, Gilboa, Donovanick, & Barak, 2002; Johnstone, Vessell, Bounds, Hoskins, & Sherman, 2003), and numerous studies found empirical evidence suggesting that longer length of stay is associated with poorer employment outcome (Cifu, et al., 1997; Rao, et al., 1990; Sander, Kreutzer, Rosenthal, Delmonico, & Young, 1996). A logical parallel can be made with time unemployed. The differences are obvious, and certainly factors related to severity of injury are relevant. However, length of stay in an acute medical care and length of disabling illness are both significant health disruptions, and the amount of time taken by either is relevant to occupational success—both are potential predictors. Moreover, earlier studies on HIV/AIDS and return to work have accounted for the length of time unemployed, with significant findings (Rabkin, et al., 2004; van Gorp, et al, 2007). As such, their inclusion in this research has merit.

Situational Factors

Health, illness, physical limitations, and fatigue. Physical health and physical limitation, is a central theme in the chronic illness literature (Beaudin & Chambre, 1996; Charmaz, 1990; Charmaz, 1995; Chwalisz, 2008; Moskowitz & Wrubel, 2005; Siegel & Lekas, 2002). Kathy Charmaz, in her seminal work *Good Days, Bad Days: The Self in Chronic Illness and Time* (1991), discusses the ongoing reality of vacillating health and the effect it has on adaption and motivation—both of which have obvious relevance to occupational persistence.

Immune system functioning, as an aspect of wellness, and physical limitation, as an aspect of a viral disease, are relevant factors that merit analysis. AIDS-related complex, a term that was primarily used in the early days of the epidemic, referred to a clustering of symptoms that were due to underlying HIV infection. This condition typically included such complaints as enlarged lymph nodes, fatigue, fever, night sweats, weight loss and unexplained diarrhea. These issues were difficult to live with and sometimes severe and disabling, but failed to meet the required CDC criteria for AIDS (Appendix B). These symptoms were directly related to viral activity. The standard index of immune functioning (wellness) is the CD4+ T-helper cell count. The standard index of HIV viral activity (illness) is the plasma viral load assay that directly measures the amount of virus in the blood. Immune functioning and viral activity are in constant tension. This dynamic between immune functioning and viral infection is mediated by antiretroviral medications, but always vulnerable to change. This fluctuation can be affected by any number of factors, such as medication adherence, health behaviors, stress, and other unrelated illnesses. The ongoing disease pathogenesis results in real physical limitations and related symptomatic expression of viral activity, such as fatigue. This research accounts for physical health and physical limitation, the paradoxically related counterpart to HIV disease (Buckingham, 2009; Hammer et al., 2008).

Personal Resources

Self-efficacy. In 1986 Albert Bandura published *Social Foundations of Thought and Action: A Social Cognitive Theory*, ascribing a central role to cognitive, vicarious, self-regulatory, and self-reflective processes in human adaptation and change. How people interpret their own behavior informs and alters their environments and the

personal factors they possess which, in turn, inform and alter subsequent behavior.

Pajares (2002) identifies this as foundational to Bandura's concept of reciprocal determinism, which is the view that (a) personal factors in the form of cognition, affect, and biological events, (b) behavior, and (c) environmental influences create interactions that result in triadic reciprocity. Bandura emphasized that cognition plays a critical role in an individual's capability to construct reality, self-regulate, process information and perform. William James (1981) said it best when he argued, "Introspective observation is what we have to rely on first and foremost and always" (p. 185). Bandura states, "A theory that denies that thoughts regulate actions does not lend itself readily to the explanation of complex human behavior" (p. 15).

Pajares (2002) states that "Of all the thoughts that affect human functioning, and standing at the very core of social cognitive theory, are self-efficacy beliefs," which Bandura defined as "Peoples judgments of their capabilities to organize and execute courses of action required to attain designated types of performances" (p. 391). In 1997 Bandura asserted, "people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true" (p. 2). Self-efficacy influences the choices people make and the courses of action they pursue. Individuals tend to select tasks and activities in which they feel competent and confident and avoid those in which they do not (Pajares, 2002). Mastery is the single most influential source of self-efficacy and is seen as authentic given it is the individuals experience. Bandura wrote "Successes raise efficacy appraisals; failures lower them" (p. 399).

It is important to remember that those with HIV/AIDS, especially as a chronic disease, naturally face challenges to their sense of self-efficacy. The opportunities to

maintain a sense of mastery, which often is part of work life, are naturally interrupted and undermined with illness and disruption in work.

Environmental Resources

Social support. In Ownsworth and McKenna's (2004) review regarding traumatic brain injury and employment outcome, only one study examined social support as a factor. Vogenthaler, Smith, and Goldfader (1989) found that the strength of individuals' informal social support systems was positively associated with employment outcomes at 4–7 years post-injury. Despite the dearth of research related specifically to social support and employment outcomes, the centrality of social support among those with HIV/AIDS is well documented (Johnson, et al., 2001; O'Brien, Wortman, Kessler & Joseph, 1993; Stulberg & Buckingham, 1988) and therefore included as a control variable in this model.

Psychosocial Adjustment

Quality of life. The degree of enjoyment and satisfaction an individual experiences in every day functioning can be seen as a measure of psychosocial adjustment. Related to psychosocial functions is the concept of quality of life. How well individuals function in their particular matrix of human life and existence is likely to determine an aspect of life quality. Quality of life cuts across a range of domains, including psychological, social functioning and biological realities, such as physical health. The complexities of modern life intrinsically are multifaceted, and all likely contribute to perceived quality of life. Individual assessment of life and the extent to which it is seen as satisfying is relevant to how one manages priorities, including work. Applebaum (1992) states the following regarding work and quality of life:

There is no simple relationship between work and satisfaction in life, nor between work and self-fulfillment. The subject of work is complex, because work is

intertwined with all aspects of human existence. Work is associated with maturity, discipline, and all the moral values of societies, as well as with its economic and political institutions. (p. 590)

Applebaum (1992) makes an important point about the lack of simplicity when it comes to work and life satisfaction, as well as work and self-fulfillment. While it seems logical and natural to view quality of life as indicative of psychosocial adjustment, the realities are likely bi-directional. Work surely has a role in creating a sense of quality of life and life satisfaction. However, given the central focus of this research is employment outcome, the use of quality of life as an indicator of psychosocial adjustment will allow for it being included as a control variable. This methodological determination conforms to the established theoretical models that form the basis of most research in this arena.

Depression. Depression and employment outcome among those with traumatic brain injury has been examined in several studies (Felmingham, Baguley, & Crooks, 2001; Hanlong, Demery, Martinovich, & Kelly, 1999; Ruff, et al., 1993). In one longitudinal study, it was found that individuals who had higher levels of depressive symptoms at six months post-injury were less likely to be employed at one year post-injury (Ruff, et al., 1993). Similarly, Hanlon, Demery, Martinovich, and Kelly (1999) found that level of depression was associated with one-year post-injury employment outcomes.

The literature abounds with findings related to depression among those with HIV/AIDS dating back to the beginning of the HIV/AIDS crisis (Christ, Wiener, & Moynihan, 1986; Furstenberg & Olson, 1984; Saunders & Buckingham, 1988). Moreover, depression, suicidal ideation, and suicidal risk, continue to be a significant threats to individual well-being among those living with HIV/AIDS. Sherr, et al. (2008)

found that nearly a third of their sample of 778 HIV clinic patients reported having had recent suicidal thoughts. Among the factors associated with depression and suicidal ideation in this study were unemployment, elevated physical and psychological symptoms and poorer quality of life. Sherr, et al. (2008) concludes that advances in HIV treatment and care notwithstanding, depression and suicidal ideation are high among those living with HIV/AIDS. Accounting for the literature, research, and experience, the inclusion of depression as a factor related to occupational persistence is merited.

Conclusion

In summary, the literature is replete with findings related to HIV/AIDS and return to work, as well as research on neuropsychological functioning and occupational performance. The lack of understanding related to occupational persistence among people living with HIV/AIDS and the factors that support or undermine people persisting in the workforce represent the gaps in knowledge that this dissertation study addresses.

CHAPTER III

RESEARCH METHODOLOGY

Research Goal and Hypotheses

As indicated in Chapter I, the goal of this dissertation was to develop an understanding of the factors that influence persistence, as measured by number of days worked per six-month period. More specifically, the dissertation tested a conceptual model integrating the work of Kendall and Terry (1996), Ownsworth and McKenna (2004), and Sadek and van Gorp (2009). This model investigated the influence of neuropsychological functioning on occupational persistence over a period of two years. The following overarching research question guided this study: *Is there a significant relationship between neuropsychological functioning and variations in occupational persistence over a period of two years among people with HIV/AIDS returning to work, controlling for demographics and life characteristics, situational variables, personal resources, environmental resources, and psychosocial adjustment?* Thus, the following research questions were posed:

1. Do individuals who return to work differ in their occupational persistence over a period of two years?

Hypothesis 1: Individuals who return to work will differ in their occupational persistence over a period of two years, with some individuals persisting more than others.

2. How do changes within and between individuals in their neuropsychological functioning affect occupational persistence over a period of two years, controlling for demographics and life characteristics, situational variables, personal resources, environmental resources and psychosocial adjustment?

Hypothesis 2: Differences in neuropsychological functioning within and between individuals will be associated with differences in occupational persistence over a two-year time period, controlling for demographics and life characteristics, situational variables, personal resources, environmental resources and psychosocial adjustment.

Data Source

This dissertation study utilized existing data, collected between September 1999 and June 2003 in New York City. The principal investigator was Wilfred G. van Gorp, Ph.D., Professor of Clinical Psychology at Columbia University College of Physicians and Surgeons, Department of Psychiatry. Funding for the original research was provided by the National Institute of Mental Health (#R01 MH060560). The study was initially approved by the Institutional Review Board of Weill Medical College of Cornell University, and subsequently by the New York State Psychiatric Institute when the program relocated to Columbia University College of Physicians and Surgeons. The original study investigated neuropsychiatric predictors of return to work in HIV/AIDS, and findings were previously published (van Gorp, Rabkin, Ferrando, Miontz, Ryan, Borkowski, & McElhiny, 2007).

The sample consisted of community dwelling HIV positive men and women who had stopped working after learning their HIV status and who were then actively seeking

employment (e.g. sending out resumes, attending agency programs designed to promote return to work). Other inclusion criteria were an age requirement of 18-55, documented HIV seropositivity, and a history of at least 12 months full time paid employment. Exclusion criteria included moderate or severe HIV-related dementia, current active substance abuse or dependence, plans to move out of the area within two years, lack of fluency in English, or severe mental illness (schizophrenia, other psychosis).

A purposive, non-probability sample was recruited from the community through several sources: persons newly enrolled in a government-funded program designed to assist HIV positive persons in finding employment (60% of the referrals); responses to advertisements placed in newspapers or community magazines (16%); flyers including a mailing to several hundred subscribers to POZ (a magazine targeted to HIV positive persons); and word of mouth (24%).

Procedure

After a complete description of the study was given to the participants, written informed consent was obtained. Participants were then scheduled for their first visit, followed by return visits at six-month intervals, for a total of five visits over two years. Participants received \$40 plus lunch money for participation in the study at the first visit, with increases of \$10 at each subsequent visit.

Interviewers/psychometrists had master's degrees in mental health or were neuropsychology post-doctoral fellows with at least two years of training. Interviewers received biweekly supervision from a psychiatrist who was an expert in psychiatric diagnosis (Ferrando), by a psychologist with expertise in psychosocial and health issues (Rabkin) and a senior board certified neuropsychologist (van Gorp).

At baseline, 118 participants were assessed and of these, 86 were seen at Visit 5 (Table 4). Some participants missed some of the visits, and some dropped out after a few visits. Participants who missed their scheduled visits were contacted as a matter of protocol; however, no data were collected regarding the reasons for their absence. As the study sample comprised a group of unemployed people dealing with health issues and attempting to return to work, issues related to finances, health status, medical management, and possible employment opportunities were ongoing factors that likely undermined their participation. For this cohort of people who were dealing with HIV/AIDS the attrition rate was 27%.

Table 4

Sample Attrition

Attrition	
Visit	Number
1) Baseline	118
2) 6 month	108
3) 1 year	100
4) 18 month	96
5) 2 years	86

Research Design

This study utilized a secondary analysis of existing data from a parent study conducted in New York City. The design was a longitudinal prospective cohort study testing a multilevel growth model with a two-nested-level structure (Figure 6). The growth model examined individual differences in occupational persistence over a two-

year time period, testing multiple potential predictors and covariates. Changes in individual growth profiles were investigated, and possible explanations for observed differences were tested.

This study was multilevel, because it included time variant within person and time invariant between person data over two years. At baseline, information on only the predictor and control variables was obtained. At each interval after the baseline, data were collected on the days worked in the previous six-month period. This information was treated as the outcome variable for the previous time interval to preserve the predictor-outcome time sequence for each measurement period. Thus, at the final time interval, only the outcome data for occupational persistence were used.

Between Person Neuropsychological Factors Demographics & Life Characteristics	Level 2 Time 0				
Within Person Neuropsychological Factors Situational Variables Personal Resources Environmental Resources Psychosocial Adjustment	Level 1 Time 0	Level 1 Time 1	Level 1 Time 2	Level 1 Time 3	Level 1 Time 4

Figure 6: Multilevel structures and classifications.

This study analyzed change. Change studies were not common until the 1980s, when methodologists developed statistical models that could investigate change over time. As Singer and Willett (2003) stated, “Until then, the technical literature on the measurement of change was awash with broken promises, erroneous half-truths, and name-calling” (p. 3). In fact, researchers were advised to frame their questions in ways

that did not specifically address change. In social work, the analysis of change is in its infancy, with only a few social work researchers engaging in this type of design and analysis. As evidenced by the literature, no change studies have focused on HIV/AIDS and employment. Increasingly, social work researchers are realizing the unique application of change studies to answer the questions that they and their clients confront in the context of contemporary culture.

Not every longitudinal study can analyze change over time. According to Singer and Willet (2003), a study of change must have three methodological features to make them suitable for such a study: (a) there must be three or more waves of data; (b) the values of the outcome must change systematically over time; and (c) there must be a sensible metric for clocking time. In this study, there were four waves of data, making it possible to look at patterns of change over time. Furthermore, it made conceptual and theoretical sense to assume that there was a meaningful parametric form in the individual change trajectories. The assumption for this study was that if people with HIV/AIDS experience worsening neuropsychological functioning over time, controlling for demographic and life characteristics, situational factors, personal resources, environmental resources, and psychosocial adjustment, then they would be less likely to successfully persist in the workforce. Finally, meeting Singer and Willet's criterion, time was measured in months over a period of two years. It was assumed that over a period of 24 months, some study participants would return to work, thereby allowing for the evaluation of pursuant occupational persistence in the workforce.

In cross-sectional studies, maturation can be seen as a threat to internal validity. With the longitudinal growth model design, the issue of maturation was effectively

addressed. The data were collected over a two-year period, and natural maturation or changes are expected that might represent individuals' increased capacity to cope or live with HIV and the attendant contextual realities of HIV in our culture, as well as changes in employment status. The use of a longitudinal growth model in which time variant variables were measured four times over the two-year study period provides for the explicit measurement of and accounting for the effects of maturation in the sample.

However, a number of threats and limitations related to the design used in this existing data study merit discussion. Measurement error, which is always present (Singleton & Straits, 2005), can be divided into systematic measurement error and random measurement error. Systematic measurement error is due to factors that are non-random and affect measurement of a variable across the sample. In this self-report sample of HIV-positive men and women, the issues of stigma and discrimination might be viewed as a bias, one that could influence the entire sample when trying to discern depression and social support.

Conversely, random measurement error is less of a concern. This might be best understood with regard to the individual health status of the participants. For example, scores on the social support scales could be affected by the random fluctuations in how each participant felt on any given day. Random errors are not significant threats to internal validity, as opposed to the bias presented by systemic errors.

History is another potentially relevant limitation of this study, defined as "a threat to internal validity due to events that coincide in time with the manipulation of the independent variable" (Rubin & Babbie, 2001, p. 749). The data in this study were collected in a university hospital by trained behavioral scientists (psychiatrists,

psychologists, and neuropsychology interns). Thus, the collection of data was paired with extensive interviewing and interaction, all of which could have had an unintentional therapeutic effect on participants.

Finally, external validity refers to the extent to which we can generalize the findings of a study can be generalized to settings and populations beyond the study conditions (Rubin & Babbie, 2005). While the study sample demographic distribution is consistent with New York City, it is nonetheless New York City. The extent to which the findings can be generalized to other settings and populations is problematic. However, it should be noted that according to the CDC (2008), HIV/AIDS cases tend to cluster in larger metropolitan areas, with 85% of all reported cases of HIV/AIDS in large U. S. metropolitan areas. Thus, the findings in New York City may have relevance to other large metropolitan areas that have high incidence of HIV/AIDS.

Operationalization of Variables

The proposed conceptual model discussed in Chapter II was tested (see Figure 6). This model includes a range of independent variables as predictors and controls that can either be time variant (within person) or time invariant (between person), and that were selected based on a review of the literature that suggested their influence on employment outcomes among those with neurocognitive challenges associated with traumatic brain injury, as well as HIV/AIDS. The dependent variable, occupational persistence, was time variant (within person).

Dependent Variable

Occupational Persistence

Occupational persistence was measured as the total number of days worked during each six-month interval over the two-year period of study. At any given six month interval a total possibility of 180 days indicated the highest level of persistence. On the other end of the continuum, working only one day indicated the lowest level of persistence. However, during the parent study, data on number of days worked was measured first by asking the respondents how many weeks they worked during the past six months. Then, they were asked how many hours on average they worked during those weeks. In the current study, this information was used to calculate the number of days worked in each time period by dividing the total number of hours worked per six month period by eight. More days worked indicated more occupational persistence, and did not require continuous employment.

Independent Variables

Neuropsychological Predictors

Neuropsychological functioning, comprising the set of primary predictors of interest, was measured by three standard neuropsychological tests: (a) The California Verbal Learning Test (CVLT), which measures verbal learning and memory; (b) The Grooved Pegboard Test, which measures psychomotor speed, fine motor control, and rapid visual-motor coordination; and (c) The Color Trails 2 Test, which measures abstraction and executive functioning. Given the importance of examining differences within the individual as well as differences between individuals, neuropsychological factors were accounted for in the analysis at both Level 1 (time variant, within person)

and Level 2 (time invariant, between person). Snyder, Milici, Slater, Sun, and Strizhakova (2006) in their research regarding effects of alcohol advertising on drinking among youth utilized a similar methodology that allowed for examination of differences within and between individuals. Their work was influential in the methodological design utilized in this dissertation.

For Level 1 (time variant, within person) analysis, standardized scores from test of neuropsychological functioning in three different cognitive domains (memory/learning, executive functioning/abstraction, and motor skills/coordination) were used in the analysis. The standardized scores controlled for participant age and educational background, and are typically used in neuropsychological research (Mitrushina, Boone & D'Elia, 1999). These measures were collected at each time interval.

For Level 2 (time invariant, between person) analysis, baseline scores (Time 0) were used for the Color Trails 2 test (executive functioning) and Grooved Pegboard (motor skills). Due to previous studies indicating that a second administration of the CVLT represents a more stabilized performance than the baseline administration (McCaffrey, Westervelt & Haase, 2001), the standardized score of the CVLT (List A, Trial 1) was used from visit 2 (Time 1—End of first 6-months). A more complete discussion of the tests follows.

California Verbal Learning Test. The CVLT developed by Delis, Kramer, Kaplan and Ober (1987) is a standard test of memory (Appendix D). The test provides a number of indices related to memory, including retroactive and proactive interference. The testing process involves the following steps: (a) a list of 16 words (Monday List),

which is organized into four semantic categories (tools, fruit, clothing, herbs and spices) is read to the subject five times with a free recall condition after each repetition; (b) a competing list of 16 words (Tuesday List) is read to the subject with a free recall condition; (c) the subject is asked to recall the original list utilizing a free recall procedure; (d) the subject is asked to recall the original list and is cued to the four categories (tools, fruit, clothing, herbs and spices); (e) following a 30-minute delay, the subject is again asked or a free recall followed by a cued recall; and (f) a recognition procedure is used in which a longer list of words is read to the subject, some of which were on the Monday List, others on the competing Tuesday List, and some of which were not on either list.

Paolo, Troster, and Ryan (1997) reported reasonable test-retest reliability in a sample of 151 healthy elderly subjects tested twice over a period of one year. The highest correlation was 0.76 for the total recall of Trail A and for the Long Delay Free Recall scores. Delis et al. (1995) investigated the use of the CVLT with HIV/AIDS and found that HIV positive individuals with minor cognitive motor disorder show impairment, relative to the HIV negative control, on 11 of the 21 CVLT learning and memory measures. Additionally, consistent with subcortical alterations, impaired memory was detected on immediate memory span (List A, Trial 1), and deficient learning was noted across the five immediate recall trials (List A, Trials 1-5). The aggregate sum of trials 1-5 is thus a summary measure of learning and memory, representing how many words the participant acquired over the five trials. This summary measure is useful in data reduction as a measure of learning and memory, with higher scores indicating better learning and memory performance. Also, scores from the last trial (List A, Trial 5) are often reported

as detecting deficient learning (Delis, et al., 1995). Therefore, for the Level 1 analysis, scores taken from last trial were analyzed (List A, Trial 5), as they were the most sensitive measures to detect deficient learning and memory over time.

Standardized scores controlling for age and education were used in the analysis as is common in studies incorporating neuropsychological measures. These scores captured participants' functioning in terms of being above (positive standardized scores) or below (negative standardized scores) the norm for their particular ages and educational groups.

Grooved Pegboard Test. The Grooved Pegboard Test is a motor test that was designed to assess for motor asymmetries between dominant and non-dominant hands. It has recently been used to assess fine motor precision and speed of the dominant and non-dominant hands (Appendix E). The score on the Grooved Pegboard Test is the number of seconds to place small pegs in 25 grooved holes in a 5 x 5 configuration of a metal tray of grooves at different angles, from left to right, and top to bottom. The pegs are located in a metal dish. Individuals start with their preferred hand, and then with their non-preferred. Individuals are allowed several practice trials with each hand to begin. Higher scores, requiring more time to complete the fine motor task, indicate worse performance. This test, which is typically administered during a neuropsychological assessment, is particularly sensitive to HIV-associated neurocognitive disorder when limited to the non-dominant hand (Sacktor, 1999). Therefore, only data related to the non-dominant hand were used for this study. Reliability coefficients of the Grooved Pegboard Test range from 0.68 and 0.78 for the non-dominant hand (Ruff & Parker, 1993). Standardized scores controlling for age and education were calculated for the non-dominant hand based on norms published by Bornstein (1986).

Color Trails 2 Test. Color Trails 2 is derived from Trails Making B, both of which are the second component of a two-part text battery (Trail Making A and B; Color Trails 1 and 2). These are tests of abstraction and executive functioning (Appendix F). Color Trails Tests were developed in response to a request from the World Health Organization in 1989. Specifically, the World Health Organization wanted a test equivalent to the Trail Making Tests A and B in terms of sensitivity and specificity, but that allowed for broader application and was more culturally sensitive, thereby reducing cultural bias.

For Trail Making B, individuals are given a piece of paper on which are numbers and letters. The instructions ask examinees to draw a line for 1 to A, A to 2, 2 to B, B to 3, and so forth, in order, until the end is reached. The examinees must shift between number sequence and alphabetical sequence. Color Trails 2 is different only in that it substitutes letters with the colors pink and yellow, which individuals are asked to alternate (for example, 1 to pink, pink to 2, etc.). If an error is made, the examiner points out the error and asks the examinee to go back to the last correct item and pick up the process again. Examinees are instructed to complete the task as quickly as possible. The score is based on the amount of time taken to finish the test, with higher scores indicating worse performance. Standardized scores controlling for age and education were calculated based on the norms published with the test manual (D'Elia, Satz, Uchiyama, & White, 1996).

An interrater reliability of 0.90 was reported for Trails B by Fals-Stwear (1991). Snow, Tierney, Zorzitto, Fisher, and Reid (1988) reported one-year test-retest reliability to be 0.72 for Trails B. With a group of mixed neurological patients, Goldstein and

Watson (1989) found similar test-retest reliability for Trails B (0.66 to 0.86). Further, Dikmen, Machamer, Winn, and Temkin (1995) examined test-retest reliability of Trails B among cognitively normal adults and found reliability to be 0.89. Trails B has been used successfully in numerous studies with HIV/AIDS (Carery, Woods, Gonzales, et al., 2004; Carter, Rourke; Murji, Shore, & Rourke, 2003; Cherner, et al., 2004; Heaton, et al., 2004). Importantly, Trails B is sensitive enough to differentiate between individuals with and without brain damage (Reitan, 1955, 1958). According to Mitrushina, Boone, and D'Elia (1999), the Color Trails tests retain the same psychometric properties as the Trail Making Tests. By substituting the use of color for the use of English alphabet letters, this version is more culturally sensitive and reduces bias that might be associated with the use of the English alphabet.

Control Variables

Demographics and Life Characteristics

This group of independent variables, included in Level 2 represented data collected only at baseline, due to the time invariant nature of the data. These variables are shown in Table 5.

Situational Variables

Physical health: CD4+ count. Cluster of Differentiation 4 (CD4+) cell count is a glycoprotein expressed on the surface of the T-helper cells that are central to establishing and maximizing the capabilities of the immune system. This count is used as a marker of immune functioning. Normal CD4+ counts are greater than 600 (Department of Health and Human Services, 2008; Hammer, et al., 2008). This variable was measured at each time interval, and was included in Level 1 (time variant within person).

Table 5

Demographics and Life Characteristics

VARIABLE	OPERATIONALIZATION
Age	Years old at baseline
Gender	1= Male 0= Female
Race & Ethnicity	1= White 0= Other (Black and Hispanic)
Education	Total number of years of education completed
Sexual Orientation	1= Gay/Lesbian/Bisexual 0= Heterosexual
Time Unemployed	Number of months unemployed at study entry

Physical health: Plasma viral load. The plasma viral load (VL) assay, a test that directly counts the number of virions in a milliliter of blood, measures the degree to which a pathogen is virulent or active. For this study, the lower limit of detection was considered 400 copies per milliliter of serum, which was the standard at the time of the study was initiated in 1999 (van Gorp, et al., 2007). Given there is no upper limit to the number of virions that can be measured, and counts can often range into the millions, the actual count was transformed with a log 10 transformation. Undetectable test results were conservatively scored as 399 (2.69 log) copies. This variable was measured at each time interval at a local commercial laboratory (Quest Laboratories), and was included in Level 1 (time variant, within person).

RAND Physical Functioning Scale. To assess physical limitations, the Physical Functioning Scale from the RAND Medical Outcomes Study (Brook, Ware, & Davies-

Avery, 1979) was used. This scale is a self-report subscale from the RAND-36 Health Status Inventory administered to assess perceived limitations in physical functioning (Appendix G). The total score is a sum of 10 items with a range from 10 to 30, with higher scores indicating more physical limitations. Items are scored on 3-point Likert scales (A=Yes, I can do this; B=Yes, but only slowly; C=No, I cannot do this). These items assess the ability to perform everyday physical activities such as walking up stairs, cleaning house, and participating in sports. The items are in descending order of difficulty. Reliability coefficients were calculated for subgroups differing in age, sex, ethnicity, education, disease condition, and disease severity. The reliability coefficients ranged between 0.65 and 0.94 for the different subgroups (McHorney, Ware, Lu, & Sherbourne, 1994). This variable was measured at each time interval, and was included in Level 1 (time variant, within person).

Chalder Fatigue Scale. The Chalder Fatigue Scale (Chalder, et al., 1993) was administered to assess fatigue. This scale is a self-report measurement developed to assess physical and cognitive fatigue in general medical populations. The scale consists of 11 items, with 7 items related to physical symptoms and 4 related to mental/cognitive symptoms (Appendix H). Only the 7 items related to physical symptoms were used in this study. Items are scored on 5-point Likert scales (A=Never; B=Rarely; C=Sometimes; D=Often; E=Always), and respondents were instructed to answer questions in terms of the past week. Scores can range from 7 to 35, with higher scores indicating more fatigue. Questions are related to tiredness, energy, strength and weakness, all of which are aspects of fatigue. The 4 items related to mental/cognitive symptoms were not used because they are embedded in the neuropsychological functioning measures. Reliability estimates are

not available in the literature, but Cronbach's alpha for the physical fatigue subscale in the current study was 0.85, indicating an internally consistent scale (Chalder, Berelowitz, Pawlikowska, Watts, Wessely, Wright, & Wallace, 1993). This variable was measured at each time interval, and was included in Level 1 (time variant, within person).

Personal Resources

Return to Work Self-Efficacy Scale. Self-efficacy was measured at each time interval. The self-efficacy scale was designed by Gorp, et al. (2007) for the parent study, and focused on prospects for returning to work (Appendix I). The scale consists of 18 items, and items scored on 4-point Likert scales (A=True; B=Somewhat True; C=Somewhat False; D=False). Total scores range between 18 and 72, with lower scores indicating more self-efficacy. The items developed for this scale were written for individuals with health issues, targeting self-efficacy specific to the returning to work transition. Internal consistency reliability in the current study was good (Cronbach's Alpha = 0.80). This variable was also measured at each time interval, and was included in Level 1 (time variant within person).

Environmental Resources

Wortman Social Support Scale. The Wortman Social Support Scale measured social support (Appendix J). This scale was developed for the Coping and Change Study of the Chicago cohort of the Multicenter AIDS Cohort Study (O'Brien, Wortman, Kessler, & Joseph, 1993). The Wortman Social Support Scale has four subscales that examine features of social relationships, including dimensions of material and emotional support, affirmation, and subjective and objective social integration. Specifically, the subscales are: (a) perceived availability of support (7 items, Cronbach's alpha=0.87); (b)

validation (3 items, Cronbach's $\alpha=0.78$); (c) social conflict (7 items, Cronbach's $\alpha=0.82$), (d) objective social integration (2 items, Cronbach's $\alpha=.089$); and (e) subjective social integration (7 items, Cronbach's $\alpha=0.82$). (O'Brien, Wortman, Kessler, & Joseph, 1993). Items are scored on five-point Likert scales with the first 7 using a slightly different response options (A=Never; B=Rarely; C=Sometimes; D=Frequently; E=All the time) than the last 8 items (A=Definitely not; B=Probably not; C=Possibly; D=Probably; E=Definitely). Scores range from 15 to 75, with higher scores indicating more social support; 5 items were reversed scored. Internal consistence reliability in the current study was high (Cronbach's $\alpha = 0.90$). This variable was measured at each time interval, and was included in Level 1 (Time variant, within person).

Psychosocial Adjustment

Endicott Quality of Life Enjoyment and Satisfaction Questionnaire. The Endicott Quality of Life Enjoyment and Satisfaction Questionnaire (Endicott, Nee, Harrison, & Blumenthal, 1993) was used to assess the degree of enjoyment and satisfaction experienced by the respondents in various areas of life (Appendix K). This measure was administered at each time interval. The short form is comprised of 16 items and is the same as the General Activities section of the long form. The first 14 items assess specific domains such as social relationships, living or housing situations, and physical health. Item 15 is related to satisfaction with medications, and allows respondents to indicate whether they are taking medications. Item 16 is a global rating in which respondents are asked to rate their overall life satisfaction and contentment. Items are scored on 5-point Likert scales (A=Very Poor; B=Poor; C=Fair; D=Good; E=Very

Good). Individuals are asked to respond to the 16 items based on the following stem: “Taking everything into consideration, how do you feel each of the following areas of your life has been during the past two weeks?” According to the Endicott, et al. (1993), item 16 can be used as a single item measure of life satisfaction. Due to the duplication of many of the domains in the overall scale (e.g. social support, health limitations, self-efficacy), it was decided to only use item 16 in this study.

Beck Depression Inventory II. The Beck Depression Inventory II, which is widely used in healthcare for the assessment of depression, was used to measure depression as an indicator of life quality (Beck, 1996). (Appendix L). This version of the Beck Depression Inventory was released in 1996 in response to the DSM-IV, published by the American Psychiatric Association. The 21-item multiple-choice inventory relies on self-report. Answers are scored on a scale ranging from 0 to 3, indicating minimal to severe levels of depression, respectively. Scores range between 0 and 63, with higher scores indicating increased depressive expression. The scores are categorized as follows: 0–13 minimal depression; 14–19 mild depression; 20–28 moderate depression; and 29–63 severe depression. Individuals are asked to respond to the questions based on the past two weeks. The Beck Depression Inventory-II has a high Cronbach’s alpha of 0.91 (Beck, 1996). This variable was measured at each time interval, and was included in Level 1 (Time variant, within person).

Analysis

The most appropriate analysis for this type of study is multilevel modeling or hierarchical linear modeling (HLM), allowing for the identification of patterns within and between individuals, as well as for testing potential interactions between predictors and

time. Standard HLM could not be used in this study, due to the use of count data (number of days worked in a six month time period) as the outcome variable. With count data, the values of the dependent variable are always positive and are most often skewed in a positive direction. Furthermore, the event rates are typically low and many times a large number of individuals have scores of 0, indicating that they did not work in the six month time period. With data like this, transforming the data to create a normal distribution is not possible. With a linear model, predicted values can be negative, and this would make the coefficients of the model not interpretable. Hierarchical generalized linear models can be used in a case like this, offering a modeling framework for multilevel data with nonlinear structural models and nonnormally distributed errors (Raudenbush & Bryk, 2002).

The model fit was accomplished with maximum likelihood (ML) estimation. The ML estimates make use of the well accepted and established normal theory, and are appropriate for this study because (a) the sample size is large enough; (b) the sample comes from a well defined population; and (c) feedback loops were possible, although not tested in this analysis (Singer & Willett, 2003). For a two-level Poisson model with constant exposure, HGLM provides the ability to estimate parameters with a high-order Laplace approximation of ML. This estimation method provides more reliable convergence than the penalized quasi-likelihood method normally used in HGLM. The Laplace estimation also allows for the calculation of deviance statistics for model comparison, offering the benefit of assessing comparative model fit. Therefore, the Laplace approximation of ML was used in the analysis of the data (Raudenbush, Bryk, Cheong, Congdon, & du Toit, 2004).

A specialized multilevel software package, HLM6, was used for this analysis (Raudenbush & Bryk, 2006). HLM is a sophisticated program that can fit complex multilevel models with ML estimation. In preparing the dataset for analysis, the data were organized into two data files, reflective of each of the two levels. Level 1 includes time *variant within person* data of each individual, while Level 2 comprises time *invariant between person* data of each individual.

One of the assumptions of a Poisson distribution is that the variance equals the mean; thus, the standard deviation equals the square root of the mean. Therefore, a Level 1 variance component is not calculated in a Poisson model. However, overdispersion is often encountered in a Poisson distribution. With overdispersion the variance is larger than the mean. This was the case in the data analyzed in this study. Normally, a simple correction for overdispersion can be made in statistical packages where a scalar variance is estimated. Unfortunately, in HLM6, overdispersion can only be corrected using the marginalized quasi-likelihood (MQL) estimation method and not the Laplace approximation of ML. MQL estimation has the tendency to underestimate variance components and regression coefficients (Jang & Lim, 2006). Also, MQL estimation does not allow for the calculation of deviance statistics to determine model fit. Gelman and Hill (2007), illustrated, however, that in many cases correction for overdispersion did not seriously affect the main inferences made. Due to the limitation of the software used, it was, therefore, decided not to correct for overdispersion in the model testing performed in this study.

A standard generalized linear model for count data uses a Poisson sampling model and a log link function to build the model. The same is true for a hierarchical model with

count data that uses a Poisson sampling model. For the Level 1 sampling model (individuals over time), it was assumed that Y_{ti} was the number of days during an interval of time having length m_{ti} . The time interval m_{ij} was termed the exposure. In this study, the exposure was the same for each individual during every time period, namely six months. It was therefore possible to set the exposure as equal to 1. In a model like this, the predicted value of Y_{ti} , will be the event rate λ_{ti} . The standard link function for a Level 1 Poisson model is $\pi_{ti} = \log(\lambda_{ti})$. This means that π_{ti} is the log of the event rate. With such a model the log is 0 when the event rate (λ_{ti}) is 1. The log will be positive when the event rate is greater than 1 and negative when the event rate is less than 1 (Raudenbusch & Bryk, 2002). With this link function the transformed predicted value π_{ti} is now related to the model predictors through the linear structural Level 1 model.

$$\pi_{ti} = \beta_{0i} + \beta_{1i}X_{1ti} + \beta_{2i}X_{2ti} + \dots \beta_{pi}X_{pi}$$

Preliminary analysis investigated the structure of each variable on each level, and bivariate analysis allowed investigation of the relationship among variables and testing for multicollinearity. The distribution of each variable, including outliers, was inspected and corrected as needed to prevent any violation of functional form in the predictor variables.

After the preliminary analysis was concluded, the analytic models for the dependent variable were developed, using hierarchical generalized linear modeling (HGLM). The multilevel model for change had two levels: *Level 1*, which described how individuals changed over time (within-person); and *Level 2*, which described how these changes differed across individuals (between-person). The analytical model was developed in five steps: (a) conducting a visual inspection of the empirical growth plots

for all the participants; (b) estimating an ordinary least square within-person regression model for each participant who returned to work, using a logarithmic scale to explore longitudinal growth and to determine the underlying reasons for random or fixed intercepts (initial status) and slopes (change over time); (c) fitting the unconditional means model which described average event rate ratio across individuals (Model A); (d) fitting the unconditional growth model depicting mean event rate ratio change over time across individuals (Model B); and (e) fitting the model explaining the change in the dependent variable. The final step had three stages: (a) testing of the time-variant neuropsychological predictors, (b) testing of the time-invariant neuropsychological predictors, and (c) adding control variables that increased the fit of the model. In the interest of parsimony, control variables that did not contribute to the model fit, were excluded from the final model (Models C).

The results of fitting the unconditional means model and the unconditional growth model allowed for the investigation of whether systematic variation existed in the response variable that merited further exploration. These steps also provided two valuable baselines against which the success of the subsequent model building could be evaluated.

Power

Power depends on sample size, effect size or parameter values, and the pre-determined level of significance. With multilevel modeling, statistical power must be addressed on all levels. Power for Level 1 (i.e., time variant, within person predictors) depends on the number of observations, while power for Level 2 (i.e., time invariant, between person predictors) depends on the number of individuals (Snijders, 2005). Statistical power issues in multilevel modeling are complicated, as the power differs for

fixed effects versus random effects as a function of effect size, intraclass correlation, and the number of individuals and measurement occasions per individual (Cohen, Cohen, West, & Aiken, 2003).

Simulation studies (Kreft & De Leeuw, 1998) suggest that large samples are needed for adequate power in multilevel models, and the number of individuals included is more important than the number of measurement occasions per individual. According to Snijders (2005), it is desirable to have as many units as possible at the top level of the multilevel hierarchy. Kreft and de Leeuw (1998) suggested that at least 20 individuals are needed to detect cross-level interactions when group sizes are large.

For this study, the significance level was set at 0.05 and the intra-class correlation at a small size of 0.05. This small size is recommended for health and mental health research (Spybrook, Raudenbush, Liu, Congdon, & Martinex, 2008). The model sought to detect at least a medium effect size (0.04) and achieve at least 80% power. Using the Optimal Design Software (Liu, Spybrook, Congdon, Martinez, & Raudenbush, 2006), it was determined that the minimum sample size on Level 2, assuming that each individual on Level 1 had four measurement occasions, would be 69. This study had 71 individuals with four measurement occasions, resulting in 81% power.

Conclusions

This chapter provided the methodological foundation for the current study, by discussing in detail the proposed research questions, research design, sampling procedure, data sources, and operationalization of variables, as well as explaining in detail the data analyses plan. The following chapter provides the detailed results of the statistical analyses of each research question and hypotheses.

CHAPTER IV

RESULTS

The focus of this dissertation was to develop an understanding of the impact of HIV-Associated Neurocognitive Disorder, which is the most common neuropsychiatric expression of HIV, on occupational persistence among a cohort of people with HIV in New York City who were returning to work. More specifically, the dissertation tested a conceptual model that was developed from the theoretical perspectives and models of Kendall and Terry (1996), Ownsworth and McKenna (2004), and Sadek and van Gorp (2009), and accounted for the literature on neuropsychological functioning and brain dysfunction as related to adjustment and employment. This model investigated the influence of neuropsychological functioning on occupational persistence over a period of two years. The research question guiding this study was: *Is there a significant relationship between neuropsychological functioning and variations in occupational persistence over a period of two years among people with HIV/AIDS returning to work, controlling for demographics and life characteristics, situational variables, personal resources, environmental resources, and psychosocial adjustment?*

This chapter specifically addresses (a) data preparation and preliminary analysis, (b) description of the sample, (c) model building process, (d) analysis results, and (e) conclusion. The results from the analysis presented in this chapter are further discussed in

the next chapter as they relate to practice, education, study limitations, and future research opportunities.

Data Preparation and Preliminary Analysis

The first step was the creation of a person-period dataset, in which each participant had multiple records for each of the measurement occasions (Singer & Willett, 2003). For the HLM6 statistical package used to analyze the data, the Level 1 and Level 2 variables had to be separated into two files. Therefore, all the time variant (within person) variables were put into a Level 1 file and all time invariant (between person) variables were included in a Level 2 file (Raudenbush, Bryk, Cheong, Congdon, & du Toit, 2004). Due to possible effects that some of the within person time variant main predictor variables could have between people, scores on the neuropsychological measures were also included in the Level 2 file. This methodology is consistent with the methods used by Snyder, Milici, Slater, Sun, and Strizhakova (2006) in which they investigated the effects of alcohol advertising exposure on drinking among youth. In addition, for the CVLT, the scores of visit 2 for all individuals in the database were included in the Level 2 data file, due to previous studies indicating that a second administration of the CVLT represents a more stabilized performance than the baseline administration (McCaffrey, Westervelt, & Haase, 2001).

For both the Grooved Pegboard and the Color Trails 2 test the baseline scores were included in the Level 2 data file. No serious repeated testing effects have been reported for these two tests, and for the sake of model interpretation, the baseline scores on these two tests were more important than the mean scores over time.

The second step was to perform preliminary analysis to assess and address missing values in the dataset. Data investigation showed that 2 of the 118 participants from the parent study had insufficient information for inclusion in this study. They were therefore deleted from the dataset (ID = 641 & 650). Further investigation showed that of the remaining 116 participants, 71 completed all of their visits, with data available at all four time intervals. For 26 participants, data were available for three time intervals; for 6 participants, data were only available for two time intervals; and for 13 participants data were only available at time zero. In total there were 387 measurement points across the 116 participants.

As indicated by Singer and Willet (2003), a major advantage of multilevel models for change is that all participants can be included in an analysis, even if they did not have the same amount of waves to contribute to the overall data set. The 13 participants for whom data were only available at the first time period helped with the estimation of the intercept for the model. These participants could not provide any information about within-person variation. Similarly, those with two measurement points could only contribute in a limited fashion to understanding the within-person variation.

As discussed in Chapter III, data gathered at baseline only provided information on the predictor variables. At each follow-up time point (Times 1-3) data were collected on the days worked in the previous six-month period. This information was treated as the outcome variable for the previous time interval to preserve the logical predictor-outcome time order. At the final time interval, only the outcomes data for those who returned to work and occupational persistence were used (Figure 7). This treatment of predictor and outcome variables is recommended by Singer and Willett (2003) to prevent reciprocal

causation. There were 13 cases (9 who did not return to work during any of the time periods measured, and 4 who did return at some of the time periods measured) for whom the time interval lapse was longer than usual, due to missed interviews. Table 6 indicates the lags due to missed data collection points for each of these 13 participants.

Figure 7. Visits and time structure

Table 6

Missed Data Collection Points

ID	Time 0	Time 1	Time 2	Time 3	Total Time Periods
503	1	0	1	0	2
507	1	0	1	1	3
509	1	0	1	1	3
523	1	0	1	1	3
524	1	0	1	1	3
531	1	1	0	1	3
543	1	1	0	1	3
566	1	1	0	1	3
581	1	1	0	1	3
625	1	0	1	1	3
638	1	1	0	1	3
662	1	0	1	1	3
663	1	0	1	1	3

In addition, there were 19 individuals with missing data at one point in time on one or more predictor variables. In Table 7 the number of times a value was missing for each predictor variable is shown. The data appeared to be missing at random and were therefore replaced with the mean for each individual on the specific variable that had missing values at a specific time point. Among these 19 participants, the amount of data points missing, per individual ranged between 1 and 4, with a mean of 1.84 per individual.

Table 7

Missing Values

Predictor Variable	Number of Missing Values
Years unemployed	1
CD 4 Count	1
PVL	4
Self-efficacy	8
Social Support	8
Quality of Life	9
Grooved Pegboard ND	2
Color Trails 2	1
Total	33

The third step was to check for the expected linear form on all continuous predictors. Of the Level 1 predictors, two exhibited a non-linear form due to outliers. On the Grooved Pegboard, Nondominant test, two cases had outlier results on their raw scores. These outlier results were replaced with the best score the participants had on the test (ID = 572 and 600). After the scores were standardized, there were still 13 cases with outlier results. These outlier results were replaced with the lowest score for all the other participants to create a truncated mean and better linear form for the standardized scores. For the Color Trails 2 test, two cases had outlier results. For one participant (ID=557),

the outlier score was replaced with the next highest score for the individual. The other participant (ID=600) had three missing values on this test, and the single existing value was an outlier score. This score was replaced with the highest score of all the other participants. These methodological decisions resulted in linear forms for all the predictors.

The fourth step was to test for multicollinearity among all of the predictor variables. Binary correlation coefficients were computed to detect any correlations between predictors that exceeded 0.70 (Tabachnick & Fidell, 2001). None of the pairs of predictors were correlated at levels greater than 0.70; therefore, multicollinearity was not a concern.

Description of Sample

Between Person Variables

Descriptive statistics for the between person variables are in Tables 8 and 9.

Table 8

Sample Characteristics Between Person Continuous Variables

Variable	Mean	SD	Range
Main Predictors			
CLVT – Time 1	-0.90	0.97	-3 - 1
Color Trail 2 – Time 0	0.01	1.01	-3 - 2
Grooved Pegboard ND Time 0	-1.40	1.34	-4 - 1
Control Variables			
Age	41.92	6.77	25–60
Years of Education	13.47	2.54	7–20
Months of Employment	44.42	33.95	2–133

Table 9

Sample Characteristics Between Person Categorical Variables

Variable	f	%
Gender		
Male	79	68.1
Female	37	31.9
Race		
White	27	23.3
Other	89	76.7
Sexual Orientation		
Heterosexual	53	45.7
Gay/Lesbian/Bisexual	63	54.3

Within Person Variables

The descriptive statistics for all the time variant within person variables are depicted in Figures 8 to 21, and Tables 10 to 19. These figures and tables are organized by (a) the dependent variable, (b) main predictors, and (c) control variables.

Dependent Variable: Occupational Persistence

Table 10 and Figure 8 illustrate that for the entire sample, the mean number of days worked in each of the six-month periods ranged between 12.85 and 22.44. These numbers suggest that the participants faced considerable challenges in achieving occupational persistence over the course of the two-year study period.

Table 10

Mean Days Worked per Six Month Period

Time Period	N	Min	Max	Mean	SD
Time 0	116	0.00	170.63	12.85	34.42
Time 1	95	0.00	178.75	15.41	37.79
Time 2	95	0.00	162.50	15.41	37.73
Time 3	81	0.00	195.00	22.44	45.79

Figure 8. Mean days worked.

Main Predictors

California Verbal Learning Test

The sample as a whole scored 1.52 standard deviations (SD) below the norm at study entry, and by the end of the study, improved to 0.94 SD below the norm. It is clear that there was some level of impairment in terms of memory already evident for this sample at study entry. The improvement seen over the two-year period could be due to the effects of repeated testing. According to McCaffrey, Westervelt, and Haase (2001) the mean scores at the second visit are a better reflection of overall performance during the two-year study period (Table 11 and Figure 9).

Table 11

California Verbal Learning Test

Time Period	N	Min	Max	Mean	SD
Time 0	116	-5.00	2.00	-1.52	1.64
Time 1	95	-5.00	2.00	-1.35	1.74
Time 2	95	-5.00	2.00	-1.25	1.82
Time 3	81	-5.00	2.00	-0.94	1.76

Figure 9. California Verbal Learning Test

Grooved Pegboard Test

The sample as a whole scored 1.4 SD below the norm at study entry, and by the end of the study, improved slightly to 1.14 SD below the norm (Table 12 & Figure 10). Given that the mean score was never above the norm, it is clear that throughout the study there was some level of impairment in terms of motor function. Also important, this test is uniquely sensitive to subcortical disturbances in HIV disease (Sacktor, et al., 1999).

Table 12

Grooved Pegboard Test

Time Period	N	Min	Max	Mean	SD
Time 0	116	-4.00	1.00	-1.40	1.34
Time 1	95	-4.00	1.00	-1.38	1.35
Time 2	95	-4.00	1.00	-1.34	1.31
Time 3	81	-4.00	1.00	-1.14	1.30

Figure 10. Grooved Pegboard Test

Color Trails 2 Test

As opposed to the other neuropsychological tests, the Color Trails 2 mean standardized scores were consistently above the norm across all time points for this sample. This suggests that the sample, as a whole, displayed slightly better executive functioning and attention skills compared to the norm (Table 13 & Figure 11).

Table 13

Color Trails 2 Test

Time Period	N	Min	Max	Mean	SD
Time 0	116	-3.00	2.00	0.01	1.01
Time 1	95	-3.00	2.00	0.21	0.98
Time 2	95	-3.00	2.00	0.25	0.94
Time 3	81	-3.00	2.00	0.23	0.99

Figure 11. Color Trails 2 Test.

Control Variables

CD4+ Count

Healthy individuals typically have a CD4+ count of at least 600 (Department of Health and Human Services, 2009). It is clear that this sample, as a whole, did not have CD4+ counts in the normal range, consistent with what can be expected from a sample of HIV positive participants (Table 14 & Figure 12). The CD4+ counts of the sample varied during the study, with the highest count occurring at time 2 (421.34) and the lowest count occurring at time 3 (383.89).

Table 14

CD4+ Count

Time Period	N	Min	Max	Mean	SD
Time 0	116	3.00	1585.00	391.07	263.71
Time 1	95	12.00	1585.00	403.83	272.65
Time 2	95	16.00	1585.00	421.34	297.69
Time 3	81	25.00	1386.00	383.89	249.64

Figure 12. CD4+ count.

Plasma Viral load

The plasma viral load for the participants as a whole changed from 1698 (3.23 log) copies per milliliter of serum to 954 (2.98 log) copies per milliliter of serum, indicating a health improvement with this reduction in plasma viral load (Table 15 & Figure 13). The apparent incongruity between CD4+ counts and log plasma viral load values likely reflect the distinct difference in what is being measured (immune system functioning versus HIV viral load).

Table 15

Log Plasma Viral Load

Time Period	N	Min	Max	Mean	SD
Time 0	116	1.69	6.68	3.23	1.21
Time 1	95	1.48	5.90	3.20	1.30
Time 2	95	1.60	5.84	3.19	1.25
Time 3	81	1.69	5.88	2.98	1.22

Figure 13. Log plasma viral load.

RAND Physical Functioning

Overall, the participants were not seriously limited in their functioning. In fact, the results show a slight improvement in mean physical functioning during the last six months of the study (Table 16 & Figure 14). However, some participants scored as high as 25, indicating severe limitations in physical functioning.

Table 16

RAND Physical Functioning Scale

Time Period	N	Min	Max	Mean	SD
Time 0	116	10.00	22.00	13.13	2.96
Time 1	95	10.00	24.00	13.39	3.19
Time 2	95	10.00	25.00	13.70	3.36
Time 3	81	10.00	24.00	13.01	3.05

Figure 14. RAND Physical Functioning Scale.

Chalder Fatigue Scale

The results indicate that the participants' mean level of fatigue was relatively consistent throughout the study. Overall, this sample was not seriously fatigued (Table 17 & Figure 15). In contrast to the RAND Physical Limitation Scale, the static finding of the Chalder Fatigue Scale suggests that fatigue levels are not associated with the physical limitations.

Table 17

Chalder Fatigue Scale

Time Period	N	Min	Max	Mean	SD
Time 0	116	7.00	31.00	18.25	5.17
Time 1	95	7.00	31.00	18.73	5.05
Time 2	95	7.00	32.00	18.86	5.52
Time 3	81	7.00	30.00	18.94	5.29

Figure 15. Chalder Fatigue Scale.

Return to Work Self-Efficacy Scale

With this scale, a lower score indicates greater self-efficacy. A high mean score of nearly 60 at study entry, with only a slight improvement over time to 59, makes evident that participants had considerably low self-efficacy with regard to work in the context of illness. Some of the individuals had the maximum possible score on this scale (72), indicating no detectable sense of self-efficacy specific to their transition to employment while managing HIV disease (Table 18 & Figure 16).

Table 18

Return to Work Self-Efficacy Scale

Time Period	N	Min	Max	Mean	SD
Time 0	116	40.00	71.00	59.95	6.55
Time 1	95	41.00	72.00	59.67	6.51
Time 2	95	36.00	72.00	59.63	7.53
Time 3	81	33.00	70.00	58.73	8.19

Figure 16. Return to Work Self-Efficacy Scale.

Wortman Social Support

With this scale, a higher score indicated more social support. Overall, this sample appeared to have good social support, with a slight increase over time in the level of support they experienced. Generally, the participants experienced consistent social support (Table 19 & Figure 17).

Table 19

Wortman Social Support Scale

Time Period	N	Min	Max	Mean	SD
Time 0	116	23.00	75.00	56.17	11.10
Time 1	95	37.00	75.00	58.43	9.38
Time 2	95	25.00	75.00	58.51	10.56
Time 3	81	29.00	75.00	57.99	10.06

Figure 17. Wortman Social Support Scale.

Endicott Quality of life Satisfaction Questionnaire

Participants' quality of life was measured using a single item: How would you rate your overall life satisfaction and contentment during the past week? In responding to this item, they reported a relatively high quality of life throughout the study. Average scores ranged from 3.75 to 3.87 (out of 5 possible), indicating that participants were satisfied and content with their quality of life.

Table 20

Endicott Quality of Life Satisfaction Questionnaire

Time Period	N	Min	Max	Mean	SD
Time 0	116	1.00	5.00	3.78	0.98
Time 1	95	1.00	5.00	3.87	0.90
Time 2	95	1.00	5.00	3.75	0.93
Time 3	81	1.00	5.00	3.77	0.97

Figure 18. Endicott Quality of Life Satisfaction Questionnaire.

Beck Depression Inventory II

With the Beck Depression Inventory, II, depression is categorized as follows: 0–13: minimal depression; 14–19: mild depression; 20–28: moderate depression; and 29–63: severe depression. Higher total scores indicate more severe depressive symptoms. Participants' scores indicate only minimal mean levels of depression throughout the study. In fact, mean depression scores decreased overtime (Table 21 & Figure 19).

Table 21

Beck Depression Inventory II

Time Period	N	Min	Max	Mean	SD
Time 0	116	0.00	37.00	10.29	7.01
Time 1	95	0.00	31.00	9.28	6.20
Time 2	95	0.00	34.00	9.95	7.12
Time 3	81	0.00	43.00	8.49	7.59

Figure 19. Beck Depression Inventory II.

Summary of Descriptives

All of the time variant descriptives for the within person variables for the study period are shown below in Table 22.

Table 22

Summary Descriptives: Mean Scores over Four Time Periods (N=387 observations)

Variable	Mean	SD	Min	Max
Dependent Variable				
Days Worked	16.11	38.65	0.00	195.00
Main Predictors				
California Verbal Learning Test	-1.29	1.74	-5.00	2.00
Grooved Pegboard Nondominant	-1.32	1.33	-4.00	1.00
Color Trails 2 Test	0.17	0.98	-3.00	2.00
Control Variables				
CD4+ Count	400.13	271.13	3.00	1585.00
Plasma Viral Load (log)	3.16	1.24	1.48	6.68
Physical Limitations	13.31	3.14	10.00	25.00
Fatigue	18.66	5.24	7.00	32.00
Self-Efficacy	59.55	7.14	33.00	72.00
Social Support	57.68	10.36	23.00	75.00
Quality of Life	2.79	0.94	1.00	5.00
Depression	9.58	6.98	0.00	43.00

Descriptive Analysis of Main Predictors and Control Variables

Descriptive analysis of the mean days worked over time, organized by the main predictors and the control variables, is presented in Table 23 and Figures 20 and 21. As can be seen in Table 23, all participants worked a mean of 12.85 days at time 0 and a mean of 22.44 days at time 3. Nearly 40% of the sample returned to work at some point during the two years. For these participants, the mean days worked at time 0 was 59.47, increasing to 72.71 days at time 3.

For the neuropsychological measures, the participants who scored in the normal range demonstrated higher mean days worked than those who scored in the impaired range. It is, however, interesting to note that for both the Pegboard Nondominant and the Color Trails 2 Test, the impaired participants originally reported more days worked at time 0, but with less change in days worked by Time 3 than the normal group. The impaired group on the Color Trails 2 Test actually showed a small decline in days worked over the two-year period.

Males increased their mean days worked between time 0 and time 3 at a much higher rate than females, with females showing a slight decline between time 0 and time 3. The Other race/ethnicity group, as well as the Gay, Lesbian and Bisexual group, showed a greater increase in days worked between time 0 and time 3 than the White and the Heterosexual groups, respectively. Participants with more than a high school education showed a larger increase in days worked between time 0 and time 3 than those with less than a high school education, who actually showed a decline. Younger participants (<40 years) appeared to be more successful in persisting on the job than older participants (≥ 40 years). Those with between 2-4 years of unemployment showed the greatest change between time 0 and time 3 in terms of job persistence.

Table 23

Main Predictors and Control Variables by Mean Days Worked From Time 0 to Time 3

Characteristics	% of sample	Mean Days Worked in First Six Months at Time 0	SD	Mean Days Worked in Prior Six Months at Time 3	SD	Mean Change in Days Work from Baseline to Time 3
Total	100.00	12.85	34.32	22.44	45.79	9.59
Returned To Work	39.65	59.47	54.09	72.71	56.41	13.24
Main Predictors (Normal = above the norm; Impaired = below the norm)						
CVLT						
Impaired	62.90	10.16	31.82	14.51	31.84	4.35
Normal	37.10	19.64	39.64	28.47	53.63	8.83
Grooved Pegboard ND						
Impaired	74.10	14.97	35.33	29.87	44.01	14.9
Normal	25.90	7.55	31.61	25.97	50.31	18.42
Color Trails 2						
Impaired	26.70	20.24	45.24	19.31	42.27	-0.93
Normal	73.30	10.16	29.39	23.1	46.77	12.94
Control Variables						
Gender						
Male	68.10	14	37.33	29.89	52.81	15.89
Female	39.90	10.41	27.5	8.33	23.81	-2.08
Race/Ethnicity						
White	23.30	16.58	37.89	21.97	40.73	5.39
Other	76.70	11.72	33.44	22.6	47.65	10.88
Sexual Orientation						
Heterosexual	45.70	12.66	35.48	14.58	32.27	1.92
GLB	54.30	13.02	33.78	27.32	52.17	14.3
Education						
< 12 years	24.10	12.11	34.67	11.09	29.17	-1.02
>= 12 years	75.90	13.09	34.53	25.23	48.8	12.14
Age						
20-39	43.10	17.72	38.91	30.98	54.16	13.26
40-59	56.90	9.17	30.37	15.26	36.47	6.09
Unemployment						
<= 2 year	37.10	20.94	41.75	28.37	52.69	7.43
2-4 years	27.60	8.2	27.2	27.09	53.79	18.89
>= 4 years	35.30	8.01	29.78	13.34	39.45	5.33

Figure 20. Change in occupational persistence over time for predictors.

Figure 21. Change in occupational persistence over time by control variables.

The next section describes the model building process. The discussion is organized by the two research questions, and provides details of the process and resulting model.

Model Building

Question 1

Do individuals who return to work differ in their occupational persistence over a period of two years?

Hypothesis 1: Individuals who return to work will differ in their occupational persistence over a period of two years, with some individuals persisting more than others.

Step One: Visual Inspection of Individual Growth

According to Singer and Willett (2003), the first step in multilevel change analysis is to inspect the empirical growth plots for all participants. The results are shown in Figure 22. This graph clearly shows that the 116 participants differed in terms of their individual trajectories of occupational persistence over time. Of the 116 participants, 70 did not return to work during any of the time periods. Three other participants only reported working during one time interval; therefore, their trajectories could not be graphed.

Figure 22. Variations of occupational persistence (total sample).

For the 43 participants who returned to work and reported days worked at more than one time point, each individual's growth chart is shown in Figure 23. These individual graphs confirm the variation in individual experiences related to occupational persistence.

Figure 23. Variations of occupational persistence: Individual. (Pages 101-108)

(ID = 517)

(ID = 519)

(ID = 522)

(ID = 523)

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(ID = 581)

(ID = 583)

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(ID = 589)

(ID = 590)

(ID = 596)

(ID = 598)

(ID = 603)

(ID = 610)

(ID = 613)

Step Two: Ordinary Least Squares Estimations for Within-Person Regression Model

As explained in Chapter III, step 2 of the model-building process is to estimate an ordinary least squares (OLS) within-person regression model for each participant who returned to work, using a logarithmic scale to (a) explore longitudinal growth and (b) determine the underlying reasons for random or fixed intercepts (initial status) and slopes (change over time). This step is based on recommendations made by Singer and Willett (2003). To account for the fact that count data with constant exposure constituted the dependent variable (i.e., number of days worked over a six month period), a Poisson sampling model and log link function were used to build the final model (Chapter III for details). Therefore, in this initial exploration of the data, a logarithmic scale was used for the estimation. This analysis was only conducted with data from the 43 participants who reported working at least twice over the two-year study period. The results of the estimation are shown in Table 24. It is clear from the table that the individuals differed in terms of both intercept (initial status) and slope (rate of change). Furthermore, the 43 participants all started at different levels at time 0 in terms of days worked in the previous

Table 24

Individual Estimations of Within-Person Exploratory OLS for Days Worked

ID	Initial Status		Rate of Change		R Square	SE of estimate
	Estimate	SE	Estimate	SE		
503	2.69	0.00	-3.88	0.00	1.00	.
509	44.54	43.58	3.32	5.44	0.27	65.36
517	0.37	0.19	-0.60	0.03	1.00	0.34
519	20.64	10.68	1.50	1.54	0.32	19.26
522	52.60	34.52	3.72	4.97	0.22	62.22
523	117.22	0.74	-3.86	0.09	1.00	1.11
524	38.92	22.83	2.23	2.85	0.38	34.24
527	98.62	49.96	7.05	7.20	0.32	90.05
530	35.43	30.46	-5.68	4.39	0.46	54.90
534	1.90	0.96	-3.11	0.14	1.00	1.73
537	80.66	13.33	5.37	1.92	0.80	24.04
544	103.80	7.02	3.45	1.01	0.85	12.65
547	98.31	45.82	-1.98	6.60	0.04	82.59
548	1.44	1.31	-0.10	0.19	0.13	2.36
550	146.22	8.81	0.72	1.27	0.14	15.89
555	2.01	1.93	2.74	2.49	0.38	31.12
562	36.18	34.58	0.16	0.28	0.14	3.47
563	38.76	21.69	2.89	4.98	0.14	62.34
565	38.76	21.69	3.02	3.13	0.32	39.09
566	4.35	4.04	0.34	0.51	0.31	5.94
572	7.48	7.15	0.60	1.03	0.14	12.89
575	38.65	31.39	1.43	4.52	0.05	56.58
579	24.64	25.16	0.46	3.63	0.01	45.35
580	50.65	8.60	3.75	1.24	0.82	15.51
581	58.30	17.01	4.32	2.13	0.80	24.98
583	3.95	3.77	0.31	0.54	0.14	6.80
588	25.35	0.62	1.83	0.08	1.00	0.90
589	177.13	8.73	2.89	1.26	0.73	15.74
590	3.87	2.00	0.30	0.29	0.35	3.61
596	1.27	0.64	-2.07	0.09	1.00	1.15
598	1.69	0.85	-2.76	0.12	1.00	1.54
603	57.20	35.38	4.48	5.10	0.28	63.78
610	22.15	21.74	0.26	3.13	0.00	39.18
613	22.26	18.08	-8.19	2.61	0.83	32.59
617	93.41	58.08	6.97	7.27	0.48	84.16
618	3.44	3.28	-9.69	0.41	1.00	4.75
624	2.46	2.61	0.15	0.38	0.08	4.71
628	6.42	6.39	0.47	0.92	0.12	11.51
630	45.17	43.69	-2.21	5.47	0.14	63.32
636	1.61	1.60	0.12	0.23	0.12	2.88
639	37.72	10.34	2.61	1.49	0.60	18.64
644	26.19	24.97	1.99	3.13	0.29	36.18
649	81.25	0.00	4.00	0.00	1.00	.

six months. Of the 43 participants, 10 declined over time in terms of days worked, and 33 increased. A few showed very little growth over the two years. The presence of these individual differences justified the building of a random intercept and random slope model, which allowed for the estimation of this variability in the regression coefficients across the between person units. The logarithmic fitted line for the entire sample is shown in Figure 24.

Figure 24. Logarithmic fitted line for individual participants (N=43).

Question II

How do changes within and between individuals in their neuropsychological functioning affect occupational persistence over a period of two years, controlling for demographics and life characteristics, situational variables, personal resources, environmental resources and psychosocial adjustment?

Hypothesis 2: Differences in neuropsychological functioning within and between individuals will be associated with differences in occupational persistence over a two-year time period, controlling for demographics and life characteristics, situational variables, personal resources, environmental resources and psychosocial adjustment.

Step Three: Fitting the Unconditional Model (Model A)

For this model, the following equation was written and was run with the HGLM procedure using a Poisson sampling method and a Laplace estimation with maximum likelihood:

$$\pi_{ti} = \beta_{00} + r_{0i}$$

where π_{ti} is the predicted log event rate, β_{00} is the overall event rate ratio (ERR) for an average individual over all of the measurement occasions and r_{0i} is the random error. The results of the variance components and deviance statistics for Model A are shown in Table 25.

Table 25

Variance Components and Deviance Statistics for Model A, B and C

VARIANCE COMPONENTS			
	Model A	Model B	Model C
In initial status (τ_0)	17.08	24.96	29.28
In rate of change (τ_1)		3.17	4.25
Covariance (τ_{01})		-3.82	-4.95
Statistics for Covariance Components Model			
Deviance	6335.4	3382.53	3156.45
Number of estimated parameters	2	5	21
Model Comparison Test			
Chi-square statistic		2952.87***	226.09***
df		3	16

* $p < .05$; ** $p < .01$; *** $p < .001$

Step Four: Fitting the Unconditional Growth Model (Model B)

For this model, the effect of time was added as follows:

$$\pi_{ti} = \beta_{00} + \beta_{10} * \text{TIME}_{ti} + r_{0i} + r_{1i} * \text{TIME}_{ti}$$

where π_{ti} is the predicted log event rate, β_{00} is the overall event rate ratio for an average individual over all of the measurement occasions, β_{10} is the average rate of change, r_{0i} is the random error of the overall ERR and r_{1i} is the overall error of the rate of change. The results of the variance components and deviance statistics for Model B are also shown in Table 25. The deviance statistics suggest that Model B, incorporating the effects of time, demonstrated improved fit compared to Model A.

Step Five: Fitting the Model with Changes in the Dependent Variable (Model C)

As discussed in Chapter III, this step had multiple phases and resulted in the building of model C, based on the hypothetical theoretical framework discussed in Chapter II. In building this final model, the main predictor variables (neuropsychological tests) were first included on both Level 1 and Level 2 (intercept and slope). Next, the time variant control variables were added to Level 1. Those most meaningful in

explaining the within person effects were kept, based on the significance and size of the effect. After this step, the time invariant between person control variables were added to Level 2 for both the intercept and slope, and those most meaningful to explain the between person effects were kept, based on the significance and size of the effect. The main predictor variables were retained in the model until all the controls that improved model fit were added. Once all control variables were added and either retained or removed, some of the main predictor variables were removed from either the intercept or the slope for the between individual effect (Level 2) if (a) the effect was not statistically significant, and (b) their inclusion did not increase the fit of the model. Age and years of education were never included in the final model, due to the standardization of the main predictor variables based on these factors. In effect, using the standardized scores already controlled for age and years of education. In addition, these predictors were not centered due to the meaningfulness of the standardized score of 0, which indicated performance at the norm for the test, adjusted for age and years of education. All other continuous predictors were centered on the individual mean (within person) and the sample mean (between persons).

For the final model, the equation was written as follows:

$$\begin{aligned} \pi_{ti} = & \beta_{00} + \beta_{01} * \text{WHITE}_i + \beta_{02} * \text{UNEMPLOYMENT}_i + \beta_{03} * \text{CVLT}_i + \beta_{04} * \text{PEGBOARD-ND}_i \\ & + \beta_{10} * \text{TIME}_{ti} + \beta_{11} * \text{GENDER}_i * \text{TIME}_{ti} + \beta_{12} * \text{WHITE}_i * \text{TIME}_{ti} + \\ & \beta_{13} * \text{UNEMPLOYMENT}_i * \text{TIME}_{ti} + \beta_{15} * \text{COLOR TRAILS 2}_i * \text{TIME}_{ti} + \beta_{20} * \text{PHYSICAL} \\ & \text{LIMITATIONS}_{ti} + \beta_{30} * \text{FATIGUE}_{ti} + \beta_{40} * \text{SELF-EFFICACY}_{ti} + \beta_{50} * \text{SOCIAL SUPPORT}_{ti} \\ & + \beta_{60} * \text{DEPRESSION}_{ti} + \beta_{50} * \text{CVLT}_{ti} + \beta_{60} * \text{PEGBOARD-ND}_{ti} + \beta_{70} * \text{COLOR TRAILS 2}_{ti} \\ & + r_{0i} + r_{1i} * \text{TIME}_{ti} \end{aligned}$$

The above equation illustrates that all of the main predictor variables were kept for the within person effect, with the second visit score on the CVLT, as well as the baseline score of the Grooved Pegboard (Nondominant), kept for the between person effect at time 0, and the baseline score of the Color Trails 2 Test kept for the between person effect on rate of change (time). The control variables retained in the final model to control for within person effects included physical limitations, fatigue, self-efficacy, social support and depression. The control variables in the final model that controlled for between person effects at time 0 were race/ethnicity and months unemployed. The control variables in the final model that controlled for between person effects on rate of change (time) were gender, race, and the number of months unemployed. The control variables that had no effect on the final model were CD4+ count, plasma viral load and quality of life. These three variables were, therefore, excluded from the final model for parsimony. The variance components and deviance statistics for model C are shown in Table 25. Based on the deviance statistics, it is clear that model C performed better than both Models A and B.

Analysis Results

Within Person Effects

The within person effects are shown in Table 26. The increase or decrease in event rates (days worked) for the main predictor variables are shown in the ERR column of Table 26. Because standardized scores were used for all neuropsychological measures, the ERR for these predictors represent the average difference over time in days worked between average individuals (defined in terms of all control variables included) who

consistently scored 1 SD above the norm on the different neuropsychological measures, compared to those scoring at the norm.

Results regarding the effects of each neuropsychological predictor are illustrated with graphs. These graphs depict the effect of each predictor on days worked for a female person of color with an average number of months unemployed before the study, reporting average levels of physical limitations, fatigue, self-efficacy, social support and depression over the two-year time period of the study.

Table 26

Within Person Effects

Variable	Para- meter	Model A		Model B		Model C	
		Co- efficient	ERR	Co- efficient	ERR	Co- efficient	ERR
FIXED EFFECTS							
Initial Status, π_{0i}							
Intercept	y_{00}	-0.51	0.60	-1.30*	0.27	-1.51***	0.23
WITHIN PERSON EFFECTS							
PRIMARY PREDICTORS							
Neuropsychological Factors (Primary Predictors)							
California Verbal Learning Test	y_{70}					0.10***	1.10
Grooved Pegboard Nondominant	y_{80}					-0.07***	0.93
Color Trails 2	y_{90}					0.04***	1.04
Rate of Change, π_{1i}							
Intercept	y_{10}			0.20	1.22	-0.17	0.84
CONTROL VARIABLES ^a							
Situational Variables							
Physical Limitations	y_{20}					-0.13***	0.88
Fatigue	y_{30}					0.04***	1.04
Personal Resources							
Self-Efficacy	y_{40}					-0.08***	0.93
Environmental Resources							
Social Support	y_{50}					-0.03***	0.97
Psychosocial Adjustment							
Depression	y_{60}					0.03***	0.97

* $p < .05$; ** $p < .01$; *** $p < .001$

^a Centered around individual mean

California Verbal Learning Test (within person)

The results as shown in Table 26 and Figure 25 indicate that an average individual who consistently scored 1 SD above the norm on the CVLT worked on average 10% more days over the four time periods. This finding is significant and reflects the highly predictive power of memory on occupational persistence. The results illustrate that those individuals who consistently performed 1 SD above the norm in terms of memory showed greater occupational persistence over time than those individuals who consistently scored 1 SD below the norm, keeping all other factors constant.

Figure 25. California Verbal Learning Test and mean days worked within person.

Physical limitations. For an illustration of the effect of the most significant control variable (physical limitations) influencing the within person effects of the CVLT (the most potent neuropsychological predictor of days worked), see Figure 26. The graph depicts differences in days worked by average individuals who consistently scored 1 SD above or below the norm on the CVLT, depending on the presence or absence of physical

limitations. Those scoring at the 25th percentile characterized low physical limitations and those scoring at the 75th percentile characterized high physical limitations.

Figure 26: California Verbal Learning Test and physical limitations (within person).

The figure illustrates how the average individuals who consistently scored 1 SD above the norm on the CVLT worked on average more days over the four time periods only if they did not have any physical limitations. Those without physical limitations who consistently scored 1 SD below the norm on the CVLT worked more days than those with CVLT scores 1 SD above the norm who reported physical limitations. All other effects were kept constant.

As expected, participants with better memory and fewer physical limitations demonstrated the highest levels of work persistence, and those with poor memory and more physical limitations persisted the least. However, when considering participants who fell between these two extremes, those with poor memory but better physical functioning demonstrated more days worked than those with better memory and worse

physical functioning. This suggests that physical health was a more important contributor to persistence in work than memory performance, though the combination of good physical health and good memory performance was associated with the highest degree of occupational persistence compared to all other combinations.

Self-efficacy. For an illustration of the effect of the second most significant control variable (self-efficacy) influencing the within person effects of CVLT (the most potent neuropsychological predictor of days worked), see Figure 27. The graph depicts differences in days worked by average individuals who consistently scored 1 SD above or below the norm on the CVLT test, depending on the presence or absence of self-efficacy. Low self-efficacy was characterized by those scoring at the 75th percentile, and high self-efficacy was characterized by those scoring at the 25th percentile.

Figure 27. California Verbal Learning Test and self-efficacy (within person)

The results show how average individuals who consistently scored 1 SD above the norm on the CVLT worked on average more days over the four time periods if they

also had high self-efficacy. Those with high self-efficacy but scores on the CVLT consistently 1 SD below the norm worked more days over time than those with scores 1 SD above the norm but with low self-efficacy. All other effects were kept constant.

The interaction between memory and self-efficacy is similar to that between memory and physical health. As expected, participants who had better memory and better self-efficacy persisted the most, and those with poorer memory and low self-efficacy persisted the least. However, when considering participants who had discordant combinations, those with poorer memory in tandem with better self-efficacy demonstrated more days worked than those who had better memory and worse self-efficacy. This indicates that self-efficacy was a more important contributor to persistence in work than memory functioning, although the combination associated with the highest levels of occupational persistence was good memory and high self-efficacy.

Grooved Pegboard Test Nondominant (within person)

The results, illustrated in Figure 28, indicate that an average individual who consistently scored 1 SD above the norm on the Grooved Pegboard Test Nondominant worked on average 7% less days over the study period. Those who scored below the norm in terms of motor functioning showed slightly better occupational persistence over time than those individuals who consistently scored 1 SD above the norm, keeping all other factors constant. This finding is counterintuitive. Although based on speculation, it may be that the scores on this neuropsychological measurement are a reflection of the tests' sensitivity to subcortical disturbances. Additionally, the relationship between motor skills and functional employment demands is unknown.

Figure 28. Grooved Pegboard Test and mean days worked within person.

Color Trails 2 Test

The results as shown in Table 26 and Figure 29, indicate that as expected, an average individual who consistently scored 1 SD above the norm on the Color Trails 2 Test worked on average 4% more days over the four time periods. This finding is not surprising. The results illustrate that those individuals who consistently performed 1 SD above the norm in terms of executive functioning showed slightly better occupational persistence over time than those individuals who consistently scored 1 SD below the norm, keeping all other factors constant. This finding confirms the importance of executive functions as related to work persistence, highlighting the potential advantage that those with better executive functioning skills have in terms of sustained employment.

Figure 29. Color Trails 2 Test and mean days worked within person.

Between Person Effects

The between person effects are shown in Table 27. The increase or decrease in event rates (days worked) for the main predictor variables are shown in the ERR (Event Rate Ratio) column of Table 27. Results for each neuropsychological predictor are illustrated with a graph. These graphs illustrate the effects of the neuropsychological measures on occupational persistence as measured by days worked for the average female person of color with an average number of months unemployed before the start of the study, reporting average levels of physical limitations, fatigue, self-efficacy, social support and depression over the two-year time period of the study.

Table 27

Between Person Effects

Variable	Parameter	Model A		Model B		Model C	
		Coefficient	ERR	Coefficient	ERR	Coefficient	ERR
FIXED EFFECTS							
Initial status, π_{0i}							
Intercept	y_{00}	-0.51	0.60	-1.30*	0.27	-1.51***	0.23
BETWEEN PERSON EFFECTS							
PRIMARY PREDICTORS ^a							
Initial status							
CVLT	y_{03}					0.94***	2.56
Pegboard Nondominant	y_{04}					-0.27 **	0.76
CONTROL VARIABLES							
Demographics and Life Characteristics							
White ^b	y_{01}					0.70	2.01
Months Unemployed ^a	y_{02}					-0.05 ***	0.95
Rate of change, π_{1i}							
PRIMARY PREDICTORS							
Neuropsychological Factors							
Color Trails 2	y_{14}					0.26**	1.31
CONTROL VARIABLES							
Demographics and Life Characteristics							
Male	y_{11}					0.96***	2.61
White	y_{12}					-1.17**	0.31
Months unemployed	y_{13}					0.01**	1.01

* $p < .05$; ** $p < .01$; *** $p < .001$ ^a Centered around means of all individuals^b Reference: Other race**California Verbal Learning Test (between persons)**

For between person effects, the ERR for initial status indicates the degree of difference in days worked at time 0 (first six months) between individuals who scored 1 SD above the norm versus at the norm on the CVLT at time 1. The results as illustrated in Table 27 and Figure 30 indicate that individuals who scored 1 SD above the norm on the

CVLT test at time 1 worked 156% more days during the first six months than individuals who scored at the norm. The CVLT was a significant predictor in terms of initial status but was not significantly related to rate of change over time. This result clearly illustrates the importance of memory in obtaining employment. Moreover, participants with higher CVLT scores achieved more days worked overall, indicating the importance of memory in both returning to and persisting in work.

Figure 30. California Verbal Learning Test and mean days worked (between persons).

Gender. Gender was the most significant control variable influencing the between person effect of the CVLT as a predictor of days worked. Figure 31 depicts the differences in the effects of memory on days worked, depending on gender. The results indicate that males who scored 1 SD above the norm at time 1 (second six month period) worked more days than females who also scored 1 SD above the norm on the CVLT test. The interaction between gender and memory was strong: males who scored 1 SD below the norm persisted more than females who scored 1 SD above the norm. Overall, females declined in their job persistence, regardless of memory functioning.

Figure 31. California Verbal Learning Test and gender (between persons).

Unemployment. Unemployment also significantly influenced CVLT as a predictor of days worked. Figure 32 shows how individuals who scored 1 SD above or below the norm on the CVLT at time 1 (second six months) differed over time in their days worked based on length of unemployment before the start of the study. Those at the 25th percentile characterized less unemployment and those at the 75th percentile characterized more unemployment.

The results indicate that those with fewer months unemployed prior to study enrollment who scored 1 SD above the norm at time 1 worked more days than any of the other groups. The individuals who scored 1 SD above the norm at time 1 but had a longer period of unemployment prior to the study took longer to re-enter the workforce. Over time, those with longer periods of unemployment before the study with CVLT scores 1 SD above the norm were able to persist more than the group with scores below the norm and fewer months of unemployment at the beginning of the study.

Figure 32. California Verbal Learning Test and unemployment (between persons).

Despite the significant and predictive value of memory as measured by the CVLT, the length of time individuals were out of the workforce prior to study initiation was a very important factor in determining how quickly they could obtain employment. Still, both groups with better memory functioning demonstrated greater occupational persistence over the two-year time period than those with memory functioning below the norm.

Grooved Pegboard, Nondominant (between persons)

The results illustrated in Table 27 and Figure 33 show that individuals who scored 1 SD above the norm on the Grooved Pegboard Nondominant test at time 0 worked 24% fewer days during the first six months than individuals who scored at the norm. This effect was significant but much smaller than that associated with memory functioning.

Figure 33. Grooved Pegboard Test and mean days worked (between persons).

Although these results are contrary to what was expected, it may be that the Grooved Pegboard Test is uniquely sensitive to disturbances in motor functioning, but its association to work performance may be less relevant. As discussed in Chapter III, this neuropsychological test is consistently sensitive in detecting subcortical disturbances resulting from HIV infection. However, impaired fine motor precision may not mean that a person is unemployable.

Another possible explanation of this unexpected finding is that unlike memory, fine motor precision may not weigh as heavily in terms of work success as measured by occupational persistence. This negative effect of motor functioning on number of days worked is likely a spurious effect, but further investigation regarding its relevance to occupational persistence is indicated. These findings do suggest the unique sensitivity this neuropsychological test has with regard to the detection of subtle, sub-clinical, fine motor precision impairment.

Color Trails 2 Test (between persons)

The ERR for rate of change (time) indicates differences in changes over time between individuals who scored 1 SD above the norm on the Color Trails 2 Test at time 0. The Color Trails 2 Test was only a significant predictor in terms of rate of change over time and was not significantly related to initial status.

The results as illustrated in Table 27 and Figure 34 suggest that individuals who scored 1 SD above the norm on the Color Trails 2 Test at time 0 increased the number of days worked over time by 30% more than individuals who scored at the norm. Higher levels of executive functioning were associated with an accelerated rate of days employed over time.

Figure 34. Color Trails 2 Test and mean days worked (between persons).

Color Trails 2 Test, which measures abstract reasoning and executive functioning involves the task of shifting between sets of stimuli. This cognitive domain has been documented to be highly vulnerable to deterioration in the subcortical structures of the brain resulting from HIV disease (Chapter I). These skills are often associated with

higher occupational performance, and the finding seems to confirm that over time executive functioning is a uniquely predictive variable for occupational persistence.

Gender. Gender was the most influential control variable influencing the between person effects on growth rate for individuals who scored 1 SD above the norm on the Color Trails 2 Test. Figure 35 illustrates that over time, individuals who scored 1 SD above or below the norm on the Color Trails 2 Test at time 0 differed in their days worked based on gender.

Figure 35. Color Trails 2 Test and gender (between persons).

The results indicate that males who scored 1 SD above the norm at time 0 on the Color Trails 2 Test accelerated at a much higher rate in terms of persistence on the job than females who scored 1 SD above the norm. In fact, females declined in their job persistence even when scoring 1 SD above the norm. To further illustrate the differences over time based on gender, males who scored 1 SD below the norm at baseline still exceeded the number of days worked by females who scored 1 SD above the norm.

Disappointingly, women, despite scoring better in executive functioning at study entry, persisted far less than their male counterparts. While not conclusive, these findings

highlight the continued sexism that likely dominates in the world of work. Very similar results were reported above regarding the CVLT and gender, underscoring the effects of gender in the workplace.

Race and ethnicity. Race/ethnicity was another control variable influencing the between person effect on growth rate for individuals who scored 1 SD above the norm on the Color Trails 2 Test. Figure 36 depicts how, over time, individuals who scored 1 SD above or below the norm on the Color Trails 2 Test at time 0 differed in their days worked based on their race/ethnicity.

Figure 36. Color Trails 2 Test and ethnicity (between persons).

The results indicate that people of color who scored 1 SD above the norm at time 0 on the Color Trails 2 Test accelerated at a higher rate of days worked compared to White participants who scored 1 SD above the norm, who actually declined in their level of persistence. Those who scored below the norm on Color Trails 2 Test, regardless of race/ethnicity, had unremarkable persistence patterns, indicating little to no improvement in number of days worked. People of color with better executive functioning at baseline

had more favorable occupational persistence patterns than any of the other groups despite the advantage that whites often have in the workplace.

Summary

Within Person Effects

In summary, the above findings show that memory is the most powerful predictor of occupational persistence over time. Individuals who scored 1 SD above the norm on the CVLT worked an average of 10% more days than those who scored 1 SD below the norm over the two-year study period. This significant finding reflects the highly predictive power of memory on employment over time.

However, while memory was the most potent neuropsychological predictor of occupational persistence, the realities of the effects of illness and physical limitations must be taken into account. Those with better memory and fewer physical limitations demonstrated increased occupational persistence, but when physical limitations were present, the limiting effects of poor physical functioning subsumed the positive effects of memory. Similarly, self-efficacy was a powerful covariate. Those with poorer memory in tandem with better self-efficacy demonstrated more days worked than those with better memory and worse self-efficacy, suggesting that self-efficacy may be a more powerful contributor to persistence than memory functioning. The combination of better memory and better self-efficacy was the most potent combination related to higher levels of occupational persistence.

The second most influential neuropsychological predictor of occupational persistence over time was executive functioning. Those individuals who scored 1 SD above the norm on the executive functioning (Color Trails 2 Test) worked on average 4%

more days than those who scored 1 SD below the norm over the two-year study period. This finding confirms the advantage that those with better executive functioning skills have in terms of sustained employment.

Between Persons Effect

When considering the effects of neuropsychological predictors between individuals, those who scored 1 SD above the norm on the memory (CVLT) worked 156% more days during the first six months than individuals who scored at the norm. This significant predictor of initial status, or obtaining employment, illustrated the potent effects of memory. Moreover, participants with higher memory scores achieved more days worked overall, indicating the importance of memory in returning to work and occupational persistence.

The effects of gender were significant when examining the between persons effect of memory on occupational persistence. Men who scored 1 SD above the norm during the first six months persisted much more than females who scored 1 SD above the norm. In fact, overall, females declined in their occupational persistence, regardless of memory functioning.

Similarly, the amount of time a person had been unemployed prior to study entry interacted significantly with memory as related to occupational persistence. Those with fewer months unemployed who scored 1 SD above the norm at time 1 worked more days than any of the other groups. However, those who scored 1 SD above the norm for memory, but had been unemployed longer at the beginning of the study, took longer to re-enter the workforce. Interestingly, over time, those with longer periods of unemployment but with memory scores 1 SD above the norm were eventually able to

persist more than the group who scored below the norm on memory but had fewer months of unemployment.

Executive functioning was a significant predictor of the growth rate of days worked over the study period. An individual who scored 1 SD above the norm on executive functioning worked more days by 30% than those who scored on the norm. Better executive functioning was associated with an accelerated rate of growth of occupational persistence.

Gender, as a control, exhibited the most significant interaction with executive functioning in terms of growth rate of occupational persistence. Males who scored 1 SD above the norm during the first six months on executive functioning accelerated their days worked at a much higher pace than females who scored 1 SD above the norm. In fact, females declined in the job persistence regardless of level of executive functioning. Notably, males who scored below the norm in executive functioning persisted more than females who scored above the norm.

Race/ethnicity also influenced the relationship between executive functioning and rate of growth in occupational persistence. People of color who scored 1 SD above the norm on executive functioning during the first six months accelerated their days worked at a higher rate than White participants with similar scores, who declined over time in number of days worked. Overall, people of color with better executive functioning at baseline had more favorable occupational persistence patterns than any of the other groups.

In closing, this study found that memory and executive functioning are two potent neuropsychological predictors of occupational persistence among those with HIV/AIDS.

The relevance of these findings is discussed in the next chapter, specifically addressing the implications for future research, social work practice, and social work education.

CHAPTER V

IMPLICATIONS

The results from the analysis (Chapter IV) are further discussed in this chapter as related to social work practice and education, organized by the two research hypotheses. Additionally, the study limitations are reviewed, and opportunities for future research are identified. Specifically, this chapter is organized as follows: (a) implications for social work practice; (b) implications for social work education; (c) study limitations; (d) future research; and (e) conclusions.

Implications for Social Work Practice

Hypothesis One

Individuals who return to work differ in their occupational persistence over a period of two-years, with some individuals persisting more than others.

Employment Transition Challenges

Among this cohort of New Yorkers attempting to return to work following a period of unemployment due to HIV/AIDS, only 40% were successful in finding employment, with the majority not working at any point during the study period. Those who did work, ranged from a mean of 59 days during the first six month period, to a mean of 73 days in the last six month period, suggesting increased persistence over time. As is clear from the visual inspection of trajectories of days worked among participants who returned to work (Figures 22 and 23), the variation in individual experiences were

wide-ranging, suggesting that the experience of returning to work may be a difficult transition to make and sustain.

Social workers who work with this population should consider recommending that those dealing with health issues related to HIV/AIDS do so in the context of employment, when possible and appropriate. Given the results of this research and previous studies focusing on return to work, the majority of people who have experienced a break in employment due to HIV/AIDS do not easily make the transition back to employment, if at all (Rabkin, McElhiney, Ferrando, van Gorp, & Lin, 2004; Van Gorp, Baerwald, Ferrando, McElhiney, & Rabkin, 1999). Additionally, developing support services specifically for those with HIV/AIDS who are working is recommended. For example, the development of support groups specifically aimed at supporting those who are working while managing the complexities of HIV disease may be appropriate. The demands required of anyone dealing with a chronic illness are considerable, but support from others in similar situations may provide valuable support and increased possibilities for sustaining employment.

Hypothesis Two

Differences in neuropsychological functioning within and between individuals will be associated with differences in occupational persistence over a two-year time period, controlling for demographics and life characteristics, situational variables, personal resources, environmental resources and psychosocial adjustment.

California Verbal Learning Test: Learning and Memory

When examining the neuropsychological predictors between individuals, those who scored 1 SD above the norm on memory (CVLT) worked 156% more days during

the first six months than individuals who scored at the norm. This significant predictor of initial status, or getting a job, illustrated the potent effects of better memory. Moreover, participants with higher memory scores achieved more days worked overall, highlighting the importance of memory with regard to returning to work and occupational persistence.

Within individuals, memory was the most potent predictor of occupational persistence over time. Individuals who scored 1 SD above the norm on the CVLT worked an average of 10% more days than those who scored 1 SD below the norm over the study period. This significant finding further reflects the highly predictive power of memory on employment over time.

While these findings are encouraging for those with more preserved memory, the implications of this finding underscore the increased challenges that those with impaired memory face. Early detection is a key clinical concern and correct differential diagnosis is paramount. Given the similarities in the clinical presentations of depression and early symptomatic HIV-associated neurocognitive disorder, many may be incorrectly diagnosed with one or the other. Each diagnosis leads to different treatment implications, as well as disparate implications for work and career planning. More specifically, treating those with organic brain compromise with interventions aimed at depression, or conversely treating those with depression as a dementing illness, invites further complications and stress. Accurate assessment of the underlying cause of presenting symptoms will enable clinicians to select congruent and appropriate treatment strategies.

Physical limitations. Issues related to physical limitations and illness must also be accounted for in social work practice. Physical limitation had a significant interaction with memory performance as a control variable in this analysis. Those with better

memory and fewer physical limitations demonstrated increased occupation persistence, but when physical limitations were present, the limiting effects of illness reduced occupational persistence. Thus, despite the potency of memory, physical health was an important factor related to persistence in work.

Significant practice implications are clear. As with any chronic illness, vacillating health is to be anticipated among those with HIV/AIDS, and the implications for employment are important. Helping those with HIV/AIDS stay healthy is the first priority, but also necessary is managing the potential co-occurring issues of impaired memory and physical limitation, which seem to have potentially catastrophic implications for employment. Services aimed at helping those with HIV/AIDS develop compensatory skills to overcome these limitations, as well as assisting with planning for such a complication, may help circumvent employment instability.

Self-efficacy. Self-efficacy also had a powerful influence on occupational persistence in this study, and its effects should be accounted for in social work practice. Those who had poorer memory in tandem with better self-efficacy demonstrated more days worked than those who had better memory and worse self-efficacy, illustrating self-efficacy's powerful contribution to occupational persistence.

Social workers who interface with people living with HIV/AIDS should consider efforts aimed at building self-efficacy as a means to support occupational persistence. Identifying ego strength, and providing cognitive therapy that supports more affirming internal self-talk may increase self-efficacy, while at the same time help to sustain stable employment and occupational persistence.

Gender. Gender was the most significant control variable when examining the between persons effects of memory. Men who scored 1 SD above the norm during the first six months persisted much more than females who scored 1 SD above the norm. In fact, overall females declined in their occupational persistence, regardless of better memory. While sexism may account for part of this finding, issues of childcare and other demands unique to women are unknown. Additional studies are needed to better understand this phenomenon.

Prior unemployment. Similarly, the amount of time a person had been unemployed prior to study entry had a significant interaction with memory as related to occupational persistence. Those with fewer months unemployed who scored 1 SD above the norm at time 1 persisted much better on the job than any of the other groups. However, those who scored 1 SD above the norm on memory, but who had been unemployed longer at the beginning of the study, took longer to re-enter the workforce. Interestingly, over time, those with longer periods of unemployment but CVLT scores above the norm were eventually able to persist more than the group with poorer memory functioning but fewer months of unemployment.

This finding highlights the importance for those with HIV/AIDS of maintaining employment, if possible. However, for those who cannot avoid unemployment due to disabling health changes, limiting the duration of unemployment may greatly improve the chances of resuming work once sufficient health improvements are restored.

Color Trails 2 Test: Executive Functioning

The second most influential neuropsychological predictor of occupational persistence over time was executive functioning. Those individuals who scored 1 SD

above the norm on the executive functioning (Color Trails 2 Test) worked on average 4% more days than those scored 1 SD below the norm over the two-year study period. This finding confirms the advantage that those with better executive functioning skills have in terms of sustained employment.

The implications here may be more pertinent to those with diminished executive functioning skills. Developing practical approaches to compensate for these deficits may offset the disadvantage in the workplace. Planning and problem solving skills to manage the more cognitively demanding aspects of employment may help support occupational stability and persistence.

Between individuals, executive functioning was a significant predictor of increased occupational persistence over the study period. An individual who scored 1 SD above the norm on executive functioning increased the number of days worked by 30% more than those who scored at the norm. Better executive functioning resulted in an accelerated rate of growth of days worked.

Gender. Gender, as a control variable, had the most significant interaction with executive functioning in term of growth rate of occupational persistence. Males who scored 1 SD above the norm for executive functioning during the first six months accelerated at a much higher pace in terms of days worked than females who scored 1 SD above the norm. Females declined in the job persistence regardless of executive functioning. In fact, as mentioned earlier, males who scored below the norm persisted more than females who scored above the norm. More information regarding the unique experiences of women with HIV/AIDS in the workplace is needed. Developing support services and programs specific to women may help bridge the gap that exists in terms of

women sustaining employment. Additional research is needed to fully understand this interaction.

Race and Ethnicity. Race/ethnicity was the second most significant control variable in terms of growth rate of occupational persistence. People of color who scored 1 SD above the norm on executive functioning during the first six months accelerated at a higher pace in terms of persistence on the job. In contrast, Whites scoring 1 SD above the norm actually declined in their level of occupational persistence. Overall, people of color with better executive functioning at baseline had more favorable occupational persistence patterns than any other group. This finding was unexpected. One possible explanation may be that White people are less prepared for the adjustments associated with HIV/AIDS in a metropolitan area where the disease has been primarily associated with gay men and people of color, and where the focus of much education has been targeted to gay men and people of color. Of course, the exceptions here are gay men who regardless of race and ethnicity have received considerable educational attention. More information is needed to better understand this finding, as well as the development of congruent and appropriate services.

Implications for Social Work Education

Neuropsychological Understanding of the Brain and Behavior

The relationship between the brain and behavior, as well as the neuropsychiatric understand of human behavior and mental illness (Carvajal, Dumont, & Quirion, 2006), have increasingly contributed to the current understanding of behavioral healthcare needs, and mental illness in particular (Insel & Quirion, 2005; Kopelman, 1996; Northoff, 2008; Phillips, 2006; Spense, 2004). The last two decades have seen significant evolution

in the professional disciplines that provide services to those with behavioral health needs. Kopelman (1996) made the point that the converging interests of psychiatrists, neurologists, and psychologists have led to emerging areas of specializations that combine and account for a range of clinical expertise. More specifically, the fields of psychiatry, neurology, and psychology, which share overlapping areas of practice, have seen the emergence of cognitive neuropsychiatry modeled after cognitive neuropsychology. Both specializations account increasingly for the neurological aspects that in the past were often divided by disciplines. Kopelman suggests that while this evolution was welcomed, it was not without challenges. Reorganizing professional disciplines is a dynamic process and necessary as science and research continue to inform our understanding of human behavior and clinical phenomena. However, the process is likely a threatening one. Attendant changes in both traditional professional preparation, and collaborative endeavors across disciplines are required.

While social work as a profession has no claim to these professional areas of specialization, those impacted by these clinical realities are frequently served by social workers. As a profession, to be on the outside of this neuroscience evolution, or to be lacking in our professional preparation, is to collude with a lesser standard of care for our clients, and by extension the community. Social workers providing services in these clinical arenas, regardless of codified roles and professional claims to expertise, need more intentional preparation and clinical acumen in order to successfully collaborate in this evolving neurological context that our colleagues claim as common ground, and our clients find themselves.

Social workers need a more sophisticated understanding of brain and behavior dynamics, and social work education needs to consider a more expanded view of this content area. Having a better understanding of brain and behavior relationships will improve social workers' contributions to understanding and serving the needs of this population. A more productive and dynamic exchange, and one that represents the efforts of social work and our regard for an enlarged perspective, as well as the needs of those serve, is needed. Social work educators can, with preparation, better equip social work students for the likely challenges that face them in practice. Re-engineering our educational preparation—especially as the collaborative, multidisciplinary context of evidence-based practice continues to influence our understanding of best practice approaches—is paramount. To collaborate in the interest of our clients with disciplines that are moving forward in their understanding of the neurological basis of many issues, social work education will need to make adjustments in social work curriculum standards, and by extension practice ethics. To do less is to abandon our primary focus—videlicet our clients.

HIV/AIDS Content in Social Work Curriculum

Given the changing demographics of HIV/AIDS, which is increasing at alarming rates and disproportionately affecting people of color and other frequently marginalized groups (Chapter I) HIV/AIDS-focused content needs to be expanded in the context of social work education, including the neuropsychiatric challenges that social workers will likely face in serving this population. This need is especially relevant for those who are interested in health-related social work and are anticipating careers in the healthcare field. Understanding of the unique neuropsychiatric issues associated with HIV/AIDS is likely

to be needed in the course of professional practice. Preparation in this area will ensure better services to clients and the community.

Study Limitations

A limitation related to this study of occupational persistence is the length of the study. Longer periods of investigation may be needed to better approximate the long-term realities of and adjustments to chronic illness and work. As is often said, a happy ending depends on when a story ends; the amount of time those with HIV/AIDS require to achieve occupational persistence will inevitably vary. Studies that are time limited create an artificial end point that may assume prematurely an outcome that likely continues to evolve and change. Therefore, these findings should be tempered and viewed within the context of two years.

Another limitation, and one that is consistently mentioned in the literature, is an assumed correspondence between performance based on neuropsychological testing in strictly controlled conditions and performance in the unstructured real world of work (Burgess, Alderman, Evans, Emslie, & Wilson, 1998; Sadek & van Gorp, 2009). No neuropsychological test score can precisely predict vocational performance, although measuring neurocognitive functioning and abilities is clearly relevant in terms of occupational performance. Neuropsychological testing as a predictor of vocational ability should be interpreted with caution since the procedure is not an actual measure of vocational performance. The testing situation is rarely similar to the actual employment environment and, therefore findings must be interpreted with caution. In addition to neuropsychological test scores, many other factors should be considered in assessing potential vocational ability. Past or current substance abuse, psychological disorders and

stressors, and medical, neurological and developmental disorders are all mentioned in the literature as important considerations (Sbordone & Guilmette, 1999).

Additionally, the return to work self-efficacy scale that was developed by the researchers had no established reliability or validity, and as such is mentioned here as a limitation. Also, the use of a single item as a measurement of quality of life is potentially problematic given the lack of variability and reliability associated with single-item measures (DeVellis, 2003).

Finally, while 85% of HIV/AIDS cases are clustered in metropolitan areas (CDC, 2007a), the generalizability of these findings to other areas cannot be simply assumed. Despite similarities to other metropolitan cities, New York may be a unique context that necessitates caution when generalizing these research findings. New York City was among the first and hardest hit cities when HIV/AIDS was first identified among gay men. As such, New York City has a longer history with the disease than other locales, and a full complement of programs and services geared to this population have been developed during this history. Increased caution must be employed when generalizing these finding to smaller, less urban metropolitan areas, where a range of issues may impact those with HIV/AIDS in the workforce (e.g., social support, stigma, fear, etc.). Additionally, treatment standards can vary with physician experience and, by extension, location (AIDS Alert, 1999; Bach, Calhoun, & Bennett, 1999; Kitahata, Van Rompaey, & Shields, 2000). The improvements in neurocognitive functioning that can be realized with the use of HAART may depend physician experiences and other practice-related factors. Those living in New York City may be more likely to receive expert care from savvy

prescribers, a clinical combination that may be associated with large urban areas and better outcomes.

Future Research Opportunities

This research represents findings in a new area of clinical research related to HIV/AIDS: neurocognitive functioning and occupational persistence. Thus, replication of these findings is needed. Additionally, more research is needed to further understand the complexities of neurocognitive functioning and occupational persistence among those with HIV/AIDS, especially over longer periods of time. As HIV/AIDS is considered a chronic illness, the effects of neurocognitive performance on real world functioning must be further explored to more fully understand the challenges that those with HIV/AIDS experience.

As discussed in Chapter I, HIV involvement in the central nervous system is well documented, and the resulting clinical sequelae have been a consistent challenge for those impacted by the disease. With the advent of more efficacious treatments, reconstituted immune functioning and improvement in neurocognitive functioning have allowed many to resume a more normal life, including employment. As the pharmacokinetics of HAART continued to be researched, the degrees to which the individual drugs penetrate the central nervous system have been reported (Letendre et al., 2006). Given their centrality to preserved neuropsychiatric functioning, inclusion of antiretroviral agents that penetrate the blood-brain barrier are pivotal. Current treatment recommendations suggest the inclusion of at least one antiretroviral agent that penetrates the central nervous system (Hammer et al., 2008). However, research is lacking that accounts for the varying penetration levels of antiretroviral medications, their correlation

to neuropsychological functioning, and resulting effects on job performance. More specifically, research regarding central nervous system penetrating drugs and their effects on occupational persistence is nonexistent.

Considering that substance abuse is associated with HIV transmission and is disproportionately represented among those with HIV/AIDS (CDC, 2000; Leigh & Stall, 1993), research is also needed regarding the relationship among substance abuse, the neuropsychiatric challenges in HIV/AIDS, and job performance. A number of studies found that premorbid substance abuse is predictive of long-term employment outcome among those with neurocognitive disturbances resulting from traumatic brain injury (Ip, Dorman & Schentag, 1996; Sherer, Bergloff, High & Nick, 1999; Wagner, Hammond, Sasser & Wiercisiewski, 2002). Sherer, Bergloff, High and Nick (1999) found that after adjusting for the effects of other predictors such as education, substance abuse was the only variable significantly associated with employment outcomes, indicating that those without a history of pre-injury substance abuse were eight times more likely to find employment following a traumatic brain injury compared to patients with a history of pre-injury substance abuse. Wehman, Targett, Yasuda and Brown (2001) point out that an individual with either a traumatic brain injury or a substance abuse disorder would most likely have difficulties with employment; thus, the combination of both may make a bad situation worse. Although different from traumatic brain injury, HIV/AIDS-associated neurocognitive disorder and the co-occurring effects of substance abuse require more research.

Finally, taking into consideration the changing demographics of HIV/AIDS, an opportunity now exists to improve understanding of the unique employment experiences

of gay men. New populations provide variability that potentially allows for the unique aspects of gay men—and, similarly, other subgroups of interest—to be explored. This issue in particular has continued relevance, given that 53% of all new infections in 2006 occurred in men who have sex with men (Hall, et al., 2008; Karon, Song, Brookmeyer, Kaplin & Hall, 2008).

Conclusion

In conclusion, memory and executive cognitive functioning are important factors in employment for those with HIV/AIDS. Both of these neuropsychiatric factors have relevance to the transition back to work, as well as to occupational persistence. These factors need to be addressed in both social work practice and education. Continued research aimed at further elucidation of the confluence of factors that support occupational persistence is crucial, especially given that employment supports sustainability, subsistence, and their associated relevance to improved quality of life and health.

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APPENDIX A

CDC Statement on Persistent Disparities and Associated Challenges

The Centers for Disease Control and Prevention (2009), posts the following statement on their website regarding the persistent disparities based on race and ethnicity:

In 2006, the overall rate of HIV diagnosis (the number of diagnoses per 100,000 population) in the 33 states that report was 18.5 per 100,000 (CDC, 2006). The rate for blacks was roughly 8 times the rate for whites (67.7 per 100,000 versus 8.2 per 100,000).

African American males continue to bear the greatest burden of HIV infection. In 2006, the HIV diagnosis rate for all black males in 33 states (119.1 per 100,000 population) was the highest of any group—more than 7 times that for white males (16.7), more than twice the rate for Hispanic males (50.9), and more than twice the rate for black females (56.2). The diagnosis rate for Hispanic males was approximately 3 times that for white males.

African American females are also severely and disproportionately affected by HIV infection. In 2006, the HIV diagnosis rate for black females (56.2) was more than 19 times the rate for white females (2.9). The rate for Hispanic women was 15.1, more than 5 times that for white females.

Among American Indians/Alaska Natives, the rate of HIV diagnosis for males (17.7) was slightly higher than the rate for white males, and the rate for females (4.6) was nearly twice the rate for white females. Among Asians/Pacific Islanders, the rate of HIV diagnosis for males was 13.5, and the rate for females was 3.2.

The Centers for Disease Control and Prevention (2009) posts the following statement regarding the multiple challenges that place African Americans and Hispanics/Latinos at increased risk:

Race and, ethnicity are not, by themselves, risk factors for HIV infection. But studies show that African Americans and Hispanics/Latinos are more likely than their white counterparts to face multiple challenges associated with risk for HIV infection. These challenges include high rates of sexually transmitted diseases, which can facilitate HIV transmission (CDC, 2007d); substance abuse, which may increase the risk for HIV infection through sexual or drug-related transmission (CDC, 2000; Leigh & Stall, 1993); and socioeconomic factors, such as limited access to high-quality health care (Diaz, 1994). Studies have also suggested that poverty may place African American women at increased risk

because of the power imbalance created by financial dependence on men (CDC, 2005). Among MSM [Men who have Sex with Men] of minority races/ethnicities, cultural barriers that may impede the acknowledgment of risk behaviors and the ability to access prevention services may result in increased risk (CDC, 2000; CDC, 2003; CDC, 2004; Montgomery, 2003; Diaz, 1997). For Hispanics/Latinos, language barriers may also affect the quality of care (Timmins, 2002). Additionally, because many Hispanics/Latinos or their parents have emigrated from diverse countries or regions, there is no single culture for persons of Spanish origin in the United States. Research shows that Hispanics/Latinos born in different countries have different behavioral risk factors for HIV (CDC, 2007; CDC, 2008).

APPENDIX B

Centers for Disease Control and Prevention AIDS-Defining Conditions Centers for Disease Control (2008)

- Bacterial infections, multiple or recurrent*
- Candidiasis of bronchi, trachea, or lungs
- Candidiasis of esophagus[†]
- Cervical cancer, invasive^β
- Coccidioidomycosis, disseminated or extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis, chronic intestinal (>1 month's duration)
- Cytomegalovirus disease (other than liver, spleen, or nodes), onset at age >1 month
- Cytomegalovirus retinitis (with loss of vision)[†]
- **Encephalopathy, HIV related**
- Herpes simplex: chronic ulcers (>1 month's duration) or bronchitis, pneumonitis, or esophagitis (onset at age >1 month)
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis, chronic intestinal (>1 month's duration)
- Kaposi sarcoma[†]
- Lymphoid interstitial pneumonia or pulmonary lymphoid hyperplasia complex*[†]
- Lymphoma, Burkitt (or equivalent term)
- Lymphoma, immunoblastic (or equivalent term)
- Lymphoma, primary, of brain
- *Mycobacterium avium* complex or *Mycobacterium kansasii*, disseminated or extrapulmonary[†]
- *Mycobacterium tuberculosis* of any site, pulmonary,^{† β} disseminated,[†] or extrapulmonary[†]
- *Mycobacterium*, other species or unidentified species, disseminated[†] or extrapulmonary[†]
- *Pneumocystis carinii* pneumonia[†]
- Pneumonia, recurrent^{† β}
- Progressive multifocal leukoencephalopathy
- *Salmonella* septicemia, recurrent
- Toxoplasmosis of brain, onset at age >1 month[†]
- Wasting syndrome attributed to HIV

* Only among children aged <13 years.

[†] Condition that might be diagnosed presumptively.

^β Only among children aged <13 years.

APPENDIX C

American Academy of Neurology AIDS Task Force

Criteria for Clinical Diagnosis of AIDS-Related Central Nervous System Disorders in Adults and Adolescents

HIV-1-Associated Cognitive/Motor Complex

All of the following diagnoses require laboratory evidence for systemic HIV-1 infection (ELISA test confirmed by Western blot, polymerase chain reaction, or culture).

I. Sufficient for diagnosis of AIDS

A. HIV-1-associated dementia complex¹

Probable (must have each of the following):

1. Acquired abnormality in at least two of the following cognitive abilities (present for at least 1 month): attention/ concentration, speed of processing of information, abstraction/reasoning, visuospatial skills, memory/learning, and speech/language. The decline should be verified by reliable history and mental status examination. In all cases, when possible, history should be obtained from an informant, and examination should be supplemented by neuropsychological testing. Cognitive dysfunction causing impairment of work or activities of daily living² (objectively

¹ For research purposes, HIV-1-associated dementia complex can be coded to describe the major features:

HIV-1-associated dementia complex requires criteria 1, 2a, 3, and 4.

HIV-1-associated dementia complex (motor) requires criteria 1, 2a, 3, and 4.

HIV-1-associated dementia complex (behavior) requires criteria 1, 2b, 3, and 4.

² The level of impairment due to cognitive dysfunction should be assessed as follows:

Mild: Decline in performance at work, including work in the home, that is conspicuous to others. Unable to work at usual job, although may be able to work at a much less demanding job. Activities of daily living or social activities are impaired but not to a degree making the person completely dependent on others. More complicated daily tasks or recreational activities cannot be undertaken. Capable of basic self-care such as feeding, dressing, and maintaining personal hygiene, but activities such as handling money, shopping, using public transportation, driving a car, or keeping track of appointments or medications is impaired.

Moderate: Unable to work, including work in the home. Unable to function without some assistance of another in daily living, including dressing, maintaining personal hygiene, eating, shopping, handling money, and walking, but able to communicate basic needs.

verifiable or by report of a key informant). This impairment should not be attributable solely to severe systemic illness.

2. At least one of the following:
 - a. Acquired abnormality in motor function or performance verified by clinical examination (e.g. slowed rapid movement, abnormal gait, limb incoordination, hypertonia, or weakness), neuropsychological tests (e.g. fine motor speed, manual dexterity, perceptual motor skills), or both.
 - b. Decline in motivation or emotional control or change in social behavior. This may be characterized by any of the following: change in personality with apathy, inertia, irritability, emotional lability, or new onset of impaired judgment characterized by socially inappropriate behavior or disinhibition.
3. Absence of clouding of consciousness during a period long enough to establish the presence of #1.
4. Evidence of another etiology, including active CNS opportunistic infection or malignancy, psychiatric disorders (e.g. depressive disorder), active alcohol or substance use, or acute or chronic substance withdrawal, must be sought from history physical and psychiatric examination, and appropriate laboratory and radiologic investigation (e.g. lumbar puncture, neuroimaging). If another potential etiology (e.g. major depression) is present, it is not the cause of the above cognitive, motor, or behavioral symptoms and signs.

Possible (must have one of the following):

1. Other potential etiology present (must have each of the following):
 - a. As above (see *Probable*) #1, 2, and 3.
 - b. Other potential etiology is present but the cause of #1 is uncertain.
2. Incomplete clinical evaluation (must have each of the following):
 - a. As above (see *Probable*) #1, 2, 3.
 - b. Etiology cannot be determined (appropriate laboratory or radiologic investigations not performed).

B. HIV-1-associated Myelopathy

Probable (must have each of the following):

1. Acquired abnormality in lower-extremity neurologic function disproportionate to upper-extremity abnormality verified by reliable history (lower-extremity weakness, incoordination, and/or urinary incontinence) and neurologic examination (paraparesis, lower-extremity

Severe: Unable to perform any activities of daily living without assistance. Requires continual supervision. Unable to maintain personal hygiene, nearly or absolutely mute.

spasticity, hyperreflexia, or the presence of Babinski signs, with or without sensory loss).

2. Myelopathic disturbance (see #1) is severe enough³ to require constant unilateral support for walking.
3. Although mild cognitive impairment may be present, criteria for HIV-1-associated dementia complex are not fulfilled.
4. Evidence of another etiology, including neoplasm, compressive lesion, or multiple sclerosis must be sought from history, physical examination, and appropriate laboratory and radiologic investigations (e.g. lumbar puncture, neuroimaging, myelography). If another potential etiology is present, it is not the cause of the myelopathy. This diagnosis cannot be made in a patient infected with both HIV-1 and HTLV-I; such a patient should be classified as having possible HIV-1-associated myelopathy.

Possible (must have one of the following):

1. Other potential etiology present (must have each of the following):
 - a. As above (see *Probable*) #1, 2, and 3.
 - b. Other potential etiology is present but the cause of the myelopathy is uncertain.
2. Incomplete clinical evaluation (must have each of the following):
 - a. As above (see *Probable*) #1, 2, and 3.
 - b. Etiology cannot be determined (appropriate laboratory or radiologic investigation not performed).

II. Not sufficient for diagnosis of AIDS

A. HIV-1-associated minor cognitive/motor disorder

Probable (must have each of the following):

1. Cognitive/motor/behavioral abnormalities (must have each of the following):
 - a. At least two of the following acquired cognitive, motor, or behavioral symptoms (present for at least 1 month) verified by reliable history (when possible, from an informant):
 - i. Impaired attention or concentration
 - ii. Mental slowing
 - iii. Impaired memory
 - iv. Slowed movements
 - v. Incoordination

³ The severity of HIV-1-associated myelopathy should be graded as follows:

Mild: Ambulatory, but requires constant unilateral support (e.g., cane) for walking.

Moderate: Requires constant bilateral support (e.g. walker) for walking.

Severe: Unable to walk even with assistance, confined to bed or wheelchair.

- vi. Personality change, or irritability or emotional lability.
- b. Acquired cognitive/motor abnormalities verified by clinical neurologic examination or neuropsychological testing (e.g. fine motor speed, manual dexterity, perceptual motor skills, attention/concentration, speed of processing of information, abstraction/reasoning, visuospatial skills, memory/learning, or speech/language).
- 2. Disturbance from cognitive/motor/behavioral abnormalities (see #1) causes mild impairment of work or activities of daily living⁴ (objectively verifiable or by report of a key informant).
- 3. Does not meet criteria for HIV-1-associated dementia complex or HIV-1-associated myelopathy.
- 4. No evidence of another etiology, including active CNS opportunistic infection or malignancy, or severe systemic illness determined by appropriate history, physical examination, and laboratory and radiologic investigation (e.g. lumbar puncture, neuroimaging). The above features should not be attributable solely to the effects of active alcohol or substance use, acute or chronic substance withdrawal, adjustment disorder, or other psychiatric disorders.

Possible (must have one of the following):

- 1. Other potential etiology present (must have each of the following):
 - a. As above (see *Probable*) #1, 2, and 3.
 - b. Other potential etiology is present and the cause of the cognitive/motor/behavioral abnormalities is uncertain.
- 2. Incomplete clinical evaluation (must have each of the following):
 - a. As above (see *Probable*) #1, 2, and 3.
 - b. Etiology cannot be determined (appropriate laboratory or radiologic investigations not performed).

⁴ Able to perform all but the most demanding aspects of work or activities of daily living. Performance at work is mildly impaired but able to maintain usual job; social activities may be mildly impaired, but person is not dependent on others. Can feed self, dress, and maintain personal hygiene, handle money, shop, use public transportation, or drive a car, but complex daily tasks such as keeping track of appointments or medications may be occasionally impaired.

APPENDIX D

California Verbal Learning Test

TRIAL 1: LET'S SUPPOSE THAT YOU WERE GOING SHOPPING ON MONDAY. I'M GOING TO READ A LIST OF ITEMS FOR YOU TO BUY. LISTEN CAREFULLY, FOR WHEN I'M THROUGH, I WANT YOU TO SAY BACK AS MANY OF THE ITEMS AS YOU CAN. IT DOESN'T MATTER WHAT ORDER THEY ARE IN – JUST TELL ME AS MANY AS YOU CAN.

TRIALS 2 – 5: I'M GOING TO REPEAT MONDAY'S LIST. AGAIN, I WANT YOU TO SAY BACK AS MANY OF THE ITEMS AS YOU CAN, IN ANY ORDER, INCLUDING ITEMS YOU MAY HAVE ALREADY TOLD ME.

MONDAY LIST	Trial 1	C	Trial 2	C	Trial 3	C	Trial 4	C	Trial 5	C
Drill										
Plums										
Vest										
Parsley										
Grapes										
Paprika										
Sweater										
Wrench										
Chives										
Tangerines										
Chisel										
Jacket										
Nutmeg										
Apricots										
Pliers										
Slacks										
# Correct _____		# Correct _____		# Correct _____		# Correct _____		# Correct _____		
# Persev _____		# Persev _____		# Persev _____		# Persev _____		# Persev _____		
# Intrusion _____		# Intrusion _____		# Intrusion _____		# Intrusion _____		# Intrusion _____		
Cluster _____		Cluster _____		Cluster _____		Cluster _____		Cluster _____		

Instructions for Tuesday List

Now let's suppose that you planned to go shopping again on Tuesday. I'm going to read a new list of items for you to buy. When I'm through, I want you to say back as many items as you can, in any order.

<u>Tuesday List</u>	C
Toaster	
Cherries	
Halibut	
Ginger	
Pineapple	
Spatula	
Oregano	
Flounder	
Sage	
Lemons	
Cod	
Skillet	
Salmon	
Cinnamon	
Bowl	

Correct _____
 # Perseverations _____
 # Intrusions _____
 Cluster _____

Short Delay Free Recall

Now I'd like you to tell me all of the shopping items from the Monday list.

	C

Correct _____
 # Perseverations _____
 # Intrusions _____
 Cluster _____

Short Delay Cued Recall

Tell me all of the items from the Monday list that are: _____
 (category)

<u>SPICES & HERBS</u>	<u>FRUITS</u>

<u>TOOLS</u>	<u>CLOTHING</u>

Correct _____
 # Perseverations _____
 # Intrusions _____

I read some shopping items to you earlier. I'd like you to tell me all the items you can from the Monday list – that was the first list I gave you.

[illegible]

Correct: _____
Perseveration: _____
Intrusion: _____
Cluster _____

Tell me all of the shopping items from the Monday list that are: _____
(category)

[illegible]

Correct _____
Perseverations _____
Intrusion _____

I'm going to read a list of shopping items. After I read each item, say "yes" if the item was from the "Monday" list and "no" if it was not.

	Y/N		Y/N
swearer		grapes	
oregano		salmon	
flounder		paprika	
rug		racket	
tires		ginger	
pepper		slacks	
jacket		books	
aspirin		parsley	
wax		vest	
drill		apples	
apricots		grill	
spatula		plums	
cherries		wrench	
drums		lemons	
chives		tapes	
film		vitamins	
chisel		pliers	
briefcase		bowl	
pastry		hammer	
tangerines		nutmeg	
clock		chimes	
shoes		soap	

Total Correct: answered/765778*correct/total=64/100

APPENDIX E

Grooved Pegboard Test

GROOVED PEGBOARD

BACKGROUND

Grooved Pegboard (Klæve, 1963). This is a test of fine motor coordination and speed. In this test, subjects are required to place 25 small metal pegs into holes on a 3" x 3" metal board. All pegs are alike and have a ridge on one side, which corresponds to a notch in each hole on the board. First the dominant hand is tested, and subjects are asked to place the pegs in the holes as fast as they can. This is then repeated with the nondominant hand, and the total time for each hand is recorded

INSTRUCTIONS

Examiner's verbal instructions to the subject are in *italics*.

1. The subject should be seated comfortably at a table with the pegboard directly in front of him. The grooved pegboard should be at the edge of the table with the peg tray away from the subject. The dominant hand is tested first, then the non-dominant hand.

2. The examiner should say the following:

"This is a pegboard and these are the pegs. (The examiner points out each and then picks up one of the pegs and continues.) All the pegs are the same. They have a groove, that is, a round side and a square side and so do the holes in the boards. What you must do is match the groove of the peg with the groove of the board and put these pegs into the holes like this." The examiner demonstrates by filling the top row.

3. Remove the pegs.

4. RIGHT HAND: Examiner points to the top left hole, then says:

"When I say 'Go' begin here (point to the top left groove) and put the pegs into the board as fast as you can, using only your right hand. Fill the top row completely from this side to this side. Do not skip any, fill each row the same way you filled the top row. Any questions? Ready, as fast as you can, go!"

5. LEFT HAND: Examiner points to the top right hole, then says:

"When I say 'Go' begin here (point to the top right groove) and put the pegs into the board as fast as you can, using only your left hand. Fill the top row completely from this side to this side. Do not skip any, fill each row the same way you filled the top row. Any questions? Ready, as fast as you can, go!"

6. Begin timing when the subject touches the first peg. Record, in seconds, the time required to place all 25 pegs in the holes.

7. Discontinue test if subject cannot complete task in 301 seconds (5 minutes, 1 second).

NOTES

1. For the right hand trial, the examiner demonstrates that the pegs are placed from the subject's left to right, and from right to left for the left hand trial. The subject must pick up the pegs one at a time.

1 of 2

Grooved Pegboard Test (Continued)

2. The examiner encourages the subject to perform the task as quickly as possible, telling him or her to speed up if necessary. The pegs must be put in the board in the exact order and in the correct direction. Frequently, it will be necessary to point out the first hole of a new row, particularly during the nondominant hand trial. Only one peg is to be picked up at a time and the subject should immediately be told if more than one is picked up.
3. Also, only one hand is to be used. Occasionally, a subject will attempt to use his or her other hand to help turn the peg around. It may be necessary to hold it. If necessary, the board should be held steady for the patient. In the case of severe motor impairment, the subject should attempt the task just to see if any of the pegs can be put in. Any factor which may affect the subject's performance should be noted, e.g., sore finger, bandage, etc.
4. If a peg is dropped to the floor, the examiner should not make an attempt to pick it up during the trial; rather, one of the pegs correctly placed should be taken out and used again. (Usually, the first or second peg.)
5. If necessary, the examiner should show the subject which hole to start with in a new row, but do not stop timing.
6. Since performance in a task such as this increases markedly with practice, all persons tested should be at the same state of practice. It is recommended that no practice be given before the actual timed trial.

SCORING

1. Record in seconds, the length of time required to perform each trial. Record on the record form for both dominant and non-dominant hand: Time (sec.), Number In and Number Dropped.
2. A count should be kept of any pegs which are dropped during the test. A drop is defined as any unintentional drop of a peg from the time the subject attempts to pick up the peg from the tray until it is placed correctly in the hole. If more than one peg is picked up from the tray and the subject intentionally discards all but one of the pegs, it is not considered a drop. If a peg is intentionally laid down on the side of the tray or table, in order to purposefully manipulate the peg, it is not considered a drop.

REFERENCE

Klæve, H. (1963). Grooved Pegboard. Lafayette, IN: Lafayette Instruments.

Grooved Pegboard Test (Continued)

GROOVED PEGBOARD TEST SUMMARY SHEET

DOMINANT TRIAL

Handedness (CIRCLE): LEFT RIGHT

Time: SECONDS

No. In: PEGS

Dropped: PEGS

NON-DOMINANT TRIAL

Handedness (CIRCLE): LEFT RIGHT

Time: SECONDS

No. In: PEGS

Dropped: PEGS

NOTES:

APPENDIX F

Trail Making Tests

TRAIL MAKING TEST - FORM A & B

BACKGROUND

Trail Making Test A (Army Individual Test Battery, 1944; Reitan and Davison, 1974). This is a measure of psychomotor speed, attention and cognitive sequencing. Subjects are asked to connect quickly (in ascending order) a series of randomly arranged dots numbered from 1 to 25.

Trail Making Test B (Part A is considered under Speed of Information Processing) (Army Individual Test Battery, 1944; Reitan and Davison, 1974). This is a measure of psychomotor speed, attention, and cognitive sequencing. Part B requires subjects to connect a series of randomly arranged circles in a designated sequential order, based on alternating numbers and letters (i.e., 1 to A to 2 to B, etc.). In addition to the skills required in part A of this test, shifting cognitive sets is also required.

INSTRUCTIONS

Examiner's verbal instructions to the subject are in *italics*.

1. The subject and examiner should be seated comfortably at a table. When ready to begin the test, place the sample side of Part A on the table directly in front of the subject. The bottom of the test sheet should be approximately six inches from the edge of the table.

Give the subject a pencil and say:

"On this page are some numbers (point). Begin at number 1 (point to 1) and draw a line from 1 to 2, (point to 2) 2 to 3, (point to 3) 3 to 4, (point to 4) and so on, in order, until you reach the end (point to the circle marked end). Draw the lines as fast as you can. Ready - Begin!"

2. If the subject completes the sample item correctly, and in a manner which shows that he/she knows what to do, say:

"Good! Let's try the next one."

3. Turn the page over and give Part A of the test.
4. If the subject makes a mistake on Sample A, point out the error and explain it. The following explanations of mistakes serve as illustrations:

"You started with the wrong circle. This is where you start" (point to number 1).

"You skipped this circle " (point to the circle omitted). "You should go from number 1" (point) "to 2" (point), "2 to 3" (point), "and so on, until you reach the circle marked END" (point).

5. If it is clear that the subject intended to touch a circle but missed it, do not count it as an omission. Caution the subject, however, to touch the circles.
6. If the subject still cannot complete Sample A, take his/her hand and guide his pencil (eraser end down) through the trail. Then say:

"Now you try it."

7. Return the pencil to the subject with the point down and say:

1 of 3

Trail Making Tests (Continued)

"Remember, begin at number 1 (point), and draw a line from 1 to 2 (point to 2), 2 to 3 (point to 3), 3 to 4 (point to 4), and so on, in order, until you reach the circle marked 'end' (point). Do not skip around but go from one number to the next in the proper order. Remember to work as fast as you can. Ready - Begin!"

8. If the subject succeeds this time, go on to Part A. If the subject still has difficulty, repeat the procedure until the task is completed successfully, or if it becomes evident that the subject cannot do the task.

9. Turn the page over to Part A and say:

"On this page are numbers. Do this the same way. Begin at number 1 (point to 1) and draw a line from 1 to 2 (point to 2), 2 to 3 (point to 3), 3 to 4 (point to 4), and so on, in order, until you reach the end (point to the circle marked END). Remember, work as fast as you can. Ready - Begin!"

10. Start timing as soon as the instruction is given to begin.

11. The examiner must watch closely in order to catch any errors as soon as they are made. If the subject makes an error, call it to his/her attention immediately and have him /her proceed from the point the mistake occurred. Cue:

"You skipped a circle. Go back to _____."

12. Do not stop the timing! If the subject completes Part A without error, remove the test sheet. Record the time in seconds and the number of errors made. Then say:

"That's fine. Now we'll try another one."

13. Proceed immediately to Part B, sample. Place the test sheet for Part B, sample side up, flat on the table in front of the subject, in the same position as the sheet for Part A was placed. Point to the sample and say:

"On this page are some numbers and letters. Begin at number 1 (point to 1), and draw a line from 1 to A (point to A), A to 2 (point to 2), 2 to B (point to B), B to 3 (point to 3), 3 to C (point to C), and so on, in order, until you reach the end (point to circle marked "END"). Remember, first you have a number (point to 1), then a letter (point to A), then a number (point to 2), then a letter (point to B), and so on. Draw the lines as fast as you can. Ready- Begin!"

14. If the subject completes the Sample B correctly, say:

"Good. Let's try the next one."

15. Proceed immediately to Part B. If the subject makes a mistake on Sample B, point it out and explain it. The following explanations of mistakes serve as illustrations:

"You started with the wrong circle. This is where you start." (Point to number 1.)

"You skipped a circle. (Point to the circle omitted). You should go from 1 (point), to A (point), A to 2 (point), 2 to B (point), B to 3 (point), and so on until you reach the circle marked END" (point).

16. If it is clear that the subject intended to touch a circle but missed it, do not count it as an omission. Caution the subject, however, to touch the circles.
17. If the subject cannot complete Sample B, take his/her hand and guide the pencil (eraser end down) through the circles, step by step, as in Part A.

2 of 3

Trail Making Tests (Continued)

18. If the subject succeeds this time, go on to Part B. If the subject still has difficulty, repeat the procedure until the task is performed successfully, or if it becomes evident that the subject cannot do the task.
19. Turn the page over to Part B and say:
"On this page are both numbers and letters. Do this the same way. Begin at number 1 (point to 1), and draw a line from 1 to A (point to A), A to 2 (point to 2), 2 to B (point to B), B to 3 (point to 3), 3 to C (point to C), and so on, in order, until you reach the end. (point to circle marked "END"). Remember, first you have a number (point to 1), then a letter (point to A), then a number (point to 2), then a letter (point to B), and so on. Do not skip around, but go from one circle to the next in the proper order. Draw the lines as fast as you can. Ready! Begin!"
20. Start timing as soon as the subject is told to begin.
21. Again, remember to be alert for mistakes. If the subject makes an error, call it to his attention immediately and have him/her proceed from the point the mistake occurred. Cue:
"You skipped a circle. Go back to _____. " Do not stop timing.
22. If the subject completes Part B without error, remove the test sheet. Record the time in seconds and the number of errors made.

NOTES

1. The subject has not made an error unless his pencil line has touched an incorrect circle. If the subject draws his lines very quickly and it is apparent to the examiner that he drew the line through another circle on his/her way to the intended circle, this is not an error. However, caution the subject to touch only the intended circles. Quickly draw a line through the subject's incorrect line, preferably in another color. The subject will then be able to see the error, and will see that he has not used that circle yet.
2. In correcting an error, have the subject return to the point from which he had made the error. Then if the subject doesn't proceed immediately, repeat that part of the instructions that is pertinent to his error (e.g., *"Remember, first you have a number, then a letter."*), or show him the sequence of his last two or three circles (e.g., *"You came from 5 to E to 6 -- now what do you need next?"*). The goal is to give the correction rapidly because the stopwatch is not turned off during the correction. Some subjects, however, will not comprehend the correction unless it is delivered more slowly; so the examiner should decide upon the appropriate rate for each subject.
3. Trails A test is discontinued at 96 seconds (1 minute, 36 seconds) and Trails B test should be discontinued at 301 seconds (5 minutes, 1 second) unless the patient is making good progress and will finish soon if the test is not discontinued, and it should be noted how far the subject has progressed and how many errors he has made at that point.

SCORING

4. The scores, as indicated in the text above, are recorded as the time in seconds required to complete each part.

REFERENCE

Reitan, R.M. & Davison, L.A. (Eds.). (1974). Clinical Neuropsychology: Current status and applications. Washington, D.C.: V.H. Winston & Sons.

3 of 3

Trail Making Tests (Continued)

TRAIL MAKING TEST - PART B

SAMPLE
TIME:

PART-B
TIME:

PART-B
ERRORS:

SAMPLE

Trail Making Tests (Continued)

Trail Making Tests (Continued)

Color Trails 2

Louis F. D'Elia, PhD, and Paul Satz, PhD

Form A

Name: _____

ID#: _____ Date: _____

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Trail Making Tests (Continued)

APPENDIX G

RAND Physical Functioning Questionnaire

These questions are about any physical limitations you might have. For these activities, please indicate which response best describes you by darkening the circle for the appropriate response after EACH STATEMENT.

- Ⓐ = Yes, I can do this
Ⓑ = Yes, but only slowly
Ⓒ = No, I cannot do this

Answer each statement on the WHITE LINE.

1. Can you do heavy work at home, like scrubbing floors, lifting or moving heavy furniture? -----	▶ Ⓐ Ⓑ Ⓒ
2. Can you do moderate work at home like moving a chair or table, or pushing a vacuum cleaner? -----	▶ Ⓐ Ⓑ Ⓒ
3. Can you do light work around the house like dusting or washing the dishes? -----	▶ Ⓐ Ⓑ Ⓒ
4. If you want to, can you participate in active sports such as swimming, tennis, basketball, volleyball, or rowing a boat? -----	▶ Ⓐ Ⓑ Ⓒ
5. If you want to, can you run a short distance? -----	▶ Ⓐ Ⓑ Ⓒ
6. Can you walk uphill or upstairs? -----	▶ Ⓐ Ⓑ Ⓒ
7. Can you walk a block or more? -----	▶ Ⓐ Ⓑ Ⓒ
8. Can you walk around inside the house? -----	▶ Ⓐ Ⓑ Ⓒ
9. Can you walk to a table for meals? -----	▶ Ⓐ Ⓑ Ⓒ
10. Can you dress yourself? -----	▶ Ⓐ Ⓑ Ⓒ
11. Can you eat without help? -----	▶ Ⓐ Ⓑ Ⓒ
12. Can you use the bathroom without help? -----	▶ Ⓐ Ⓑ Ⓒ

APPENDIX H

Chalder Fatigue Questionnaire

Please rate the following questions in terms of the PAST WEEK. For EACH QUESTION, DARKEN the circle next to the appropriate response, using the scale:

- Ⓐ = Never
- Ⓑ = Rarely
- Ⓒ = Sometimes
- Ⓓ = Often
- Ⓔ = Always

Fill in the answer to each question on the WHITE LINE.

1. Do you get tired easily?	▶	Ⓐ	Ⓑ	Ⓒ	Ⓓ	Ⓔ
2. Do you need to rest during the day?	▶	Ⓐ	Ⓑ	Ⓒ	Ⓓ	Ⓔ
3. Do you feel sleepy or drowsy?.....	▶	Ⓐ	Ⓑ	Ⓒ	Ⓓ	Ⓔ
4. Do you find it difficult to start doing things?	▶	Ⓐ	Ⓑ	Ⓒ	Ⓓ	Ⓔ
5. Do you have enough energy?	▶	Ⓐ	Ⓑ	Ⓒ	Ⓓ	Ⓔ
6. Do you have enough strength in your muscles?	▶	Ⓐ	Ⓑ	Ⓒ	Ⓓ	Ⓔ
7. Do you feel weak?	▶	Ⓐ	Ⓑ	Ⓒ	Ⓓ	Ⓔ

APPENDIX I

Return To Work Self-Efficacy Scale

Here are some statements about finding work. There are no right or wrong answers. For EACH STATEMENT, please darken the circle next to the response that best applies to you. Answer each statement on the WHITE LINE. Use the scale:

Ⓐ = TRUE

Ⓑ = SOMEWHAT TRUE

Ⓒ = SOMEWHAT FALSE

Ⓓ = FALSE

1. I will find work that interests me-----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
2. I will find a job for which I am qualified -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
3. I am not qualified to do many jobs -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
4. I will be offered a job that I will want -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
5. I am able to learn new skills -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
6. I am unsure of my ability to follow through on job-related tasks -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
7. I am confident that I can stick to a work schedule -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
8. I am anxious about being in a work environment -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
9. I have enough energy to handle a job -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
10. It is difficult for me to convey my strengths to a prospective employer in a job interview-----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
11. Failing at a job will just make me try harder -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
12. If I don't find a job soon, I will give up -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
13. I am confident that I will persist until I find a job -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
14. I think that I can stick to a job once I start working -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
15. It is difficult for me to make friends with co-workers -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
16. I don't think that my health will be a problem when I start working --	▶	Ⓐ Ⓑ Ⓒ Ⓓ
17. I will be able to manage my medications while working -----	▶	Ⓐ Ⓑ Ⓒ Ⓓ
18. I can take care of my medical appointments even with a regular job --	▶	Ⓐ Ⓑ Ⓒ Ⓓ

APPENDIX J

Wortman Social Support Scale

Please rate the QUESTIONS 1-7 in terms of the PAST WEEK. For EACH QUESTION, **DARKEN the circle** next to the appropriate response, using the scale:

- Ⓐ = Never
- Ⓑ = Rarely
- Ⓒ = Sometimes
- Ⓓ = Frequently
- Ⓔ = All the time

1. Did you feel that the people in your life let you down by not showing you as much love and concern as you would have liked? ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
2. Have the people in your personal life really gotten on your nerves? ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
3. Did the people in your personal life make you feel respected? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
4. Have you felt loved and wanted? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
5. Have you felt tense from arguing or disagreeing with people in your personal life? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
6. Have you felt irritated or resentful toward people in your personal life? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
7. Did you feel misunderstood by people in your personal life?----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ

ANSWER NEXT THREE QUESTIONS AS INDICATED

<ul style="list-style-type: none"> • Is there someone you feel you can tell just about anything to, someone you can count on for understanding and support? If so, how many such people are there (choose one): ----- ▶ <div style="display: flex; justify-content: space-between; margin-top: 5px;"> Ⓐ) No one Ⓑ) 1 person Ⓒ) 2-3 people </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> Ⓓ) 4-5 people Ⓔ) 6 or more people </div>	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
<ul style="list-style-type: none"> • How many of these people are members of your family? (choose one) ▶ <div style="display: flex; justify-content: space-between; margin-top: 5px;"> Ⓐ) No one Ⓑ) 1 person Ⓒ) 2-3 people </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> Ⓓ) 4-5 people Ⓔ) 6 or more people </div>	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
<ul style="list-style-type: none"> • During the past month, about how often were you involved in a social interaction or exchange that was unpleasant or distressing? (choose one)----- ▶ <div style="display: flex; justify-content: space-between; margin-top: 5px;"> ○ Every day Ⓒ) 2-3 times during the months </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> Ⓐ) Several days a week Ⓓ) Once during the month </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> Ⓑ) Once a week Ⓔ) Not at all </div>	○ Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ

FOR QUESTIONS 8-15 USE THE SCALE:

Ⓐ = Definitely not Ⓑ = Probably not Ⓒ = Possibly
Ⓓ = Probably Ⓔ = Definitely

8. Is there someone who would help take care of you if you were confined to bed for several weeks? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
9. Is there someone you could turn to if you needed to borrow \$10, a ride to the doctor, or some other small, immediate help? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
10. Is there someone you could turn to if you needed to borrow several hundred dollars for a medical emergency? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
11. Would the people in your personal life give you information, suggestions, or guidance if you needed it? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
12. Would someone be available to talk to you if you were upset, nervous or depressed? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
13. Is there someone you could turn to if you needed advice to help make a decision? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
14. Is there someone you could contact if you wanted to talk about an important personal problem you were having? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ
15. Is someone around to confide in or talk to about yourself and your problems if you want to? ----- ▶	Ⓐ Ⓑ Ⓒ Ⓓ Ⓔ

APPENDIX K

Endicott Quality of Life Enjoyment and Satisfaction Questionnaire

Please **darken the circle** to the right for the response that best applies for EACH ITEM. Mark only one circle for each item. Do not skip items. Fill in the answer to each question on the WHITE LINE. Use the scale: (A) = Very Poor

(B) = Poor

(C) = Fair

(D) = Good

(E) = Very Good

Taking everything into consideration, how do you feel EACH of the following areas of your life has been during the PAST TWO WEEKS?	
1. Physical health -----	▶ (A) (B) (C) (D) (E)
2. Mood -----	▶ (A) (B) (C) (D) (E)
3. Work ----- (if not working, check here _____ & do not darken any circle for #3)	▶ (A) (B) (C) (D) (E)
4. Household activities -----	▶ (A) (B) (C) (D) (E)
5. Social relationships -----	▶ (A) (B) (C) (D) (E)
6. Family relationships ----- (if not applicable, check here _____ & do not darken any circle for #6)	▶ (A) (B) (C) (D) (E)
7. Leisure time activities -----	▶ (A) (B) (C) (D) (E)
8. Ability to function in daily life -----	▶ (A) (B) (C) (D) (E)
9. Sexual drive and interest -----	▶ (A) (B) (C) (D) (E)
10. Economic status -----	▶ (A) (B) (C) (D) (E)
11. Living/housing situation -----	▶ (A) (B) (C) (D) (E)
12. Ability to get around without feeling dizzy or unsteady or falling -	▶ (A) (B) (C) (D) (E)
13. Vision in terms of ability to do work or hobbies-----	▶ (A) (B) (C) (D) (E)
14. Overall sense of wellbeing-----	▶ (A) (B) (C) (D) (E)
15. Medications ----- (if not taking any, check here _____ & do not darken any circle for # 15)	▶ (A) (B) (C) (D) (E)
16. How would you rate your overall life satisfaction and during the past week?-----	▶ (A) (B) (C) (D) (E)

APPENDIX L

Beck Depression Inventory II

On this questionnaire are groups of statements. Please read each group of statements carefully. Then pick out the one statement in each group which best describes the way you have been feeling the **past two weeks, including today!** Fill in the circle beside the statement you picked. If several statements in the group seem to apply equally well, fill in each one. **Be sure to read all the statements in each group before making your choice.**

CORRECT MARK ●

1. ① I do not feel sad.
 ① I am sad.
 ② I am sad all the time and I can't snap out of it.
 ③ I am so sad or unhappy that I can't stand it.
2. ① I am not particularly discouraged about the future.
 ① I feel discouraged about the future.
 ② I feel I have nothing to look forward to.
 ③ I feel that the future is hopeless and that things cannot improve.
3. ① I do not feel like a failure.
 ① I feel I have failed more than the average person.
 ② As I look back on my life, all I can see is a lot of failures.
 ③ I feel I am a complete failure as a person.
4. ① I get as much satisfaction out of things as I used to.
 ① I don't enjoy things the way I used to.
 ② I don't get real satisfaction out of anything anymore.
 ③ I am dissatisfied or bored with everything.
5. ① I don't feel particularly guilty.
 ① I feel guilty a good part of the time.
 ② I feel quite guilty most of the time.
 ③ I feel guilty all of the time.
6. ① I don't feel I am being punished.
 ① I feel I may be punished.
 ② I expect to be punished.
 ③ I feel I am being punished.

7. ① I don't feel disappointed in myself.
 ① I am disappointed in myself.
 ② I am disgusted with myself.
 ③ I hate myself.
8. ① I don't feel I am any worse than anybody else.
 ① I am critical of myself for my weaknesses or mistakes.
 ② I blame myself all the time for my faults.
 ③ I blame myself for everything bad that happens.
9. ① I don't have any thoughts of killing myself.
 ① I have thoughts of killing myself, but I would not carry them out.
 ② I would like to kill myself.
 ③ I would kill myself if I had the chance.
10. ① I don't cry any more than usual.
 ① I cry more now than I used to.
 ② I cry all the time now.
 ③ I used to be able to cry, but now I can't cry even though I want to.
11. ① I am no more irritated now than I ever am.
 ① I get annoyed or irritated more easily than I used to.
 ② I feel irritated all the time now.
 ③ I don't get irritated at all by the things that used to irritate me.
12. ① I have not lost interest in other people.
 ① I am less interested in other people than I used to be.
 ② I have lost most of my interest in other people.
 ③ I have lost all of my interest in other people.
13. ① I make decisions about as well as I ever could.
 ① I put off making decisions more than I used to.
 ② I have greater difficulty in making decisions than before.
 ③ I can't make decisions at all anymore.
14. ① I don't feel I look any worse than I used to.
 ① I am worried that I am looking old or unattractive.
 ② I feel that there are permanent changes in my appearance that make me look unattractive
 ③ I believe that I look ugly.

15. ① I can work about as well as before.
 ① It takes any extra effort to get started at doing something.
 ② I have to push myself very hard to do anything.
 ③ I can't do any work at all.
16. ① I can sleep as well as usual.
 ① I don't sleep as well as I used to.
 ② I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
 ③ I wake up several hours earlier than usual and find it hard to get back to sleep.
17. ① I don't get more tired than usual.
 ① I get tired more easily than I used to.
 ② I get tired from doing almost anything.
 ③ I am too tired to do anything.
18. ① My appetite is no worse than usual.
 ① My appetite is not as good as it used to be.
 ② My appetite is much worse now.
 ③ I have no appetite at all anymore.
19. ① I haven't lost much weight, if any, lately.
 ① I have lost more than 5 pounds.
 ② I have lost more than 10 pounds.
 ③ I have lost more than 15 pounds.

I am purposely trying to lose weight by eating less.

- ☐ Yes
☐ No

20. ① I am no more worried about my health than usual.
 ① I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
 ② I am very worried about physical problems and it's hard to think of much else.
 ③ I am so worried about my physical problems that I cannot think about anything else.
21. ① I have not noticed any recent change in my interest in sex.
 ① I am less interested in sex than I used to be.
 ② I am much less interested in sex now.
 ③ I have lost interest in sex completely.

CURRICULUM VITAE

STEPHAN L. BUCKINGHAM

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EDUCATION

Doctor of Philosophy—July 2009

University of Louisville/University of Kentucky Joint Ph.D. in Social Work

Dissertation: Neuropsychiatric Predictors of Occupational Persistence in HIV/AIDS

Master of Science in Social Work—July 1983

University of Louisville, Kent School of Social Work

Louisville, Kentucky

Specialization: Mental Health

Bachelor of Science—May 1982

Murray State University

Murray, Kentucky

Major: Social Work

Minor: Psychology

PROFESSIONAL CREDENTIALS

California - Licensed Clinical Social Worker (License Number: LCS 11840)

New York - Certified Social Worker (License Number: R053043)

Diplomate in Clinical Social Work

Academy of Certified Social Workers

NASW Register of Clinical Social Workers

Qualified Clinical Social Worker

PROFESSIONAL APPOINTMENTS AND DISTINCTIONS

Consulting Editor, *Journal of HIV/AIDS and Social Services*, Haworth Press, 2007-present

Doctoral Student Representative, University of Louisville, Kent School of Social Work, Doctoral Faculty Committee, 2006-2008

Academic Appointment, Ad Hoc Member of the Graduate Faculty, University of Louisville, Kent School of Social Work, 2006-2009

Board of Directors, Lesbian and Gay Psychotherapy Association of Southern California, 2001 to 2003

Adviser, National Institute of Mental Health Training Grant to Cornell University Medical College, Neuropsychology of HIV/AIDS Fellowship, 1998-2003

Work Group Adviser-DSM-IV, Delirium, Dementia, and Amnestic and Other Cognitive Disorders Group, *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV), American Psychiatric Association, 1994

Advisory Committee, The National HIV/Mental Health Training Project, Center for Mental Health Services Contract to the National Association of Social Workers, 1995-1998

Appointed Member, Affirmative Action Committee of the California Chapter of the National Association of Social Workers, 1995-1996

Examiner, California Board of Behavioral Science Examiners, 1994-1996

Guest Editor, Special issue on AIDS, *Families in Society*, June 1994

Guest Editor, Special issue on AIDS, *Social Casework*, June 1988

Journal Reviewer, *Social Work*, *Families in Society*, 1988-Present

Appointed Member, Scientific Advisory Committee, American Foundation for AIDS Research (AmFAR), 1985-1988

PROFESSIONAL HONORS

Alumni Fellow, University of Louisville, Kent School of Social Work, 2005

Faculty Member, Paul Weber Departmental Excellence in Teaching Award, Kent School of Social Work, 2008

Outstanding Alumnus, Murray State University, Social Work Program, 1988

Outstanding Employee, UCLA Medical Center, Department of Clinical Social Work, 1985

Outstanding Employee, UCLA Medical Center, Department of Clinical Social Work, 1984

President, Alpha Delta Mu (Social Work Honor Society), Murray State University, 1982

Outstanding Member, Alpha Delta Mu (Social Work Honor Society), Murray State University, 1982

Member, Alpha Delta Mu (Social Work Honor Society), 1981

PROFESSIONAL MEMBERSHIPS AND AFFILIATIONS

National Association of Social Workers

Society for Clinical Social Work

Council on Social Work Education

Society for Social Work and Research

USC School of Social Work, Certified Field Instructor (1994 to present)

UCLA School of Public Policy & Social Research, Certified Field Instructor (1994 to present)

Lesbian and Gay Psychotherapy Association of Southern California (2001 to 2004)

University of Louisville, Kent School of Social Work Alumni Council (2005-2008)

TEACHING ASSIGNMENTS

University of Louisville, Kent School of Social Work

<i>Course Number</i>	<i>Course Title</i>	<i>Term</i>
SW 619	Human Behavior in the Social Environment II	Spring 2006
SW 601	Human Behavior in the Social Environment I	Fall 2006
SW 619	Human Behavior in the Social Environment II	Spring 2007
SW 601	Human Behavior in the Social Environment I	Fall 2007
SW 619	Human Behavior in the Social Environment II	Spring 2008
SW 601	Human Behavior in the Social Environment I	Fall 2008
SW 619	Human Behavior in the Social Environment II	Spring 2009

PROFESSIONAL EXPERIENCE

8/09 to Present **Assistant Professor**
California State University, Department of Social Work
Long Beach, California

- Teach “Human Behavior in the Social Environment I and II”
- Serve on the “Human Behavior in the Social Environment” Curriculum Committee
- Serve on thesis committees as needed

1/06 to 8/09 **Graduate Faculty Instructor**
University of Louisville, Kent School of Social Work
Louisville, Kentucky

- Served on Search Committee (3 positions: BSW, BSW Director & MSSW)
- Serve on the “Human Behavior in the Social Environment” Curriculum Committee
- Taught “Human Behavior in the Social Environment I and II”

1/85 to Present **Private Clinical and Consulting Practice**
New York, New York & Los Angeles, California

- Provide psychotherapy to individuals, couples, families, and groups
- Provide clinical supervision and professional training
- Provide consultation to the healthcare communications industry and medical practices
- Contract mental health service to *Center Infusion Homecare* (1/93 to 9/94)
- Contract Consultant/Therapist to *UCLA Staff and Faculty Counseling Center* (12/93 to 9/94)
- Contract Consultant to *AIDS Project Los Angeles*, Home Health Department (1994)

- Contract Trainer, *The National HIV/Mental Health Training Project*, Center for Mental Health Services Contract to the National Association of Social Workers, (1995-1998)
- Marketing Consultant to *Smart+Strong LLC* and *POZ Magazine* (11/98 to 1/00, Full-Time)
- Contract Consultant to *Harrison & Star Healthcare Advertising and Communications* (1/98 to 7/98, Full-Time)
- Contract Consultant to *The Maple Center*, Executive Director Search Committee (2004)
- Contract Consultant to *St. Luke's/Roosevelt Hospitals*, The Center for Comprehensive Care (12/04 to 3/05, Full-Time)

10/05 to 8/06

Program Administrator

Department For Mental Health and Mental Retardation
Division of Mental Health and Substance Abuse
Frankfort, Kentucky

- Acted as liaison to assigned regional community mental health centers
- Developed policy and procedures for mental health and substance abuse programs
- Reviewed proposed legislation, specific to mental health and substance abuse issues
- Served on the Professional Standards and Clinical Audit Committee

7/01 to 11/03

Program Manager, Mental Health Services

The Actors' Fund of America
Los Angeles, California

- Responsible for the daily operations of the Mental Health Program, including the clinical services, community outreach activities, and educational and training components
- Provided administrative and clinical supervision of three clinical social worker/case managers
- Served as liaison to other industry-related professional organizations
- Provided clinical supervision and professional training to social work interns

5/97 to 12/97

Vice President, Group Account Supervisor

MediSolutions, Inc. *Member of Sciens Worldwide Healthcare Communications*
New York, New York

- Maintained primary contact with Pharmacia & Upjohn for RESCRIPTOR
- Responsible for the development of strategic market planning and implementation of educational programs, specifically in the area of antiretroviral therapies
- Provided consultation regarding the health/mental health care delivery system and HIV/AIDS
- Provided strategic direction and consultation regarding managed care
- Assisted in the development of new business
- Managed and developed direct reports to ensure timely and accurate completion of projects

6/96 to 3/97

Vice President, Account Supervisor

Kallir, Philips, Ross, Inc. *Member of Omnicom Healthcare Communications*
New York, New York

- Maintained primary contact with Janssen Pharmaceutica for RISPERDAL and PATHWAYS TO CHANGE, a disease management program for patients with severe mental illnesses
- Provided consultation regarding the health/mental health care delivery system
- Assisted in the development of new business
- Managed and developed direct reports to ensure timely and accurate completion of projects

9/94 to 3/96

Program Director, Mental Health Department

AIDS Project Los Angeles
Los Angeles, California

- Responsible for the daily operations of the Mental Health Department, including the clinical services, community outreach activities, and educational and training components
- Managed the administrative activities of the Mental Health Department, including staff recruitment, supervision, and deployment
- Responsible for developing and managing a \$700,000.00 budget
- Assisted the agency in obtaining and managing mental health grants and contracts
- Served as liaison with professional and paraprofessional community through participation on several community advisory boards, task forces, and committees
- Provided clinical supervision and consultation to Mental Health Department staff
- Responsible for organization/management of internship training program
- Designed and implemented the Psychiatric Consultation/Liaison Program
- Created a joint APLA/ UCLA Neuropsychological Consultation Program
- Designed Continuous Quality Improvement Program and Staff Development Program
- Initiated a Mental Health Lecture Series for agency and community professionals
- Developed policies and procedures for the Mental Health Department

7/87 to 9/94

Director of Psychosocial Services

Pacific Oaks Medical Group
Los Angeles, California

- Responsible for planning, development, and management of psychosocial services
- Provided individual and group psychotherapy to patients and their significant others
- Developed neuropsychological collaboration with UCLA Neuropsychiatric Institute
- Participated in research with UCLA School of Medicine faculty
- Developed and published an informational brochure on HIV-Associated Dementia for patients entitled "*A Practical Guide to Coping with HIV-Associated Dementia*"
- Provided leadership in the development of marketing strategies for special projects
- Served as Program Director for the Immune Suppressed Unit, Sherman Oaks Community Hospital (7/87 to 9/88)

7/86 to 7/87

Program Director, Immune Suppressed Unit

Hollywood Community Hospital *Paracelsus Healthcare Corporation*
Los Angeles, California

- Responsible for the planning and implementation of psychosocial services for Immune Suppressed Units at selected Paracelsus hospitals
- Administrative responsibility for selecting, training, and deploying staff
- Assisted in development of marketing strategies for Immune Suppressed Unit
- Served as liaison with professional community

11/83 to 7/86

Clinical Social Worker/AIDS Liaison

UCLA Medical Center
Department of Clinical Social Work
Los Angeles, California

- Conducted in-depth psychosocial assessments of patients
- Provided individual and group psychotherapy to patients and their significant others
- Served as member of the Staff Development Committee
- Provided supervisory back-up to adult medical/surgical unit
- Provided leadership in program planning for the HIV/AIDS population
- Developed social work policy and procedures for patients with HIV/AIDS
- Developed and implemented HIV/AIDS educational programs for staff and patients
- Conducted needs assessment/feasibility study to determine psychosocial needs of patients with HIV/AIDS, resulting in funding for an additional social work position
- Served as member, UCLA Medical Center AIDS Task Force
- Served as community liaison and resource specialist

PUBLICATIONS

PEER-REVIEWED JOURNAL ARTICLES

- Conley, C. L., Buckingham, S. L., & Huber, R. (in press). Does negotiation reduce social work's gender-based income gap? Implications for social work education. *Journal of Teaching in Social Work*.
- Patterson, D. A., & Buckingham, S. L. (in press). Does motivational interviewing stages of change increase treatment retention among HIV-infected and addicted clients? *Journal of HIV/AIDS and Social Services*.
- Barney, R. J., Buckingham, S. L., Friedrich, J. M., Johnson, L. M., Robinson, M. A., & Sar, B. K. (in press). The President's Emergency Plan for AIDS Relief (PEPFAR): A social work ethical analysis and recommendations. *Journal of Sociology and Social Welfare*.
- Van Gorp, W.G., Miller, E.N., Marcotte, T.D., Dixon, W., Paz, D., Selnes, O., Wesch, J., Becker, J.T., Hinkin, C.H., Mitrushina, M., Satz, P., Weisman, J.D., Buckingham, S.L., & Stenquist, P.K. (1994). The relationship between age and cognitive impairment in HIV-1 infection: Findings from The Multicenter AIDS Cohort Study and a Clinical Cohort. *Neurology*, 44, 929-935.
- Hinkin, C., van Gorp, W., Satz, P., Weisman, J., Thommes, J., & Buckingham, S. (1992). Depressed mood and its relationship to neuropsychological test performance in HIV-1 seropositive individuals. *Journal of Clinical and Experimental Neuropsychology*, 14, 287-297.
- Saunders, J. M., & Buckingham, S. L. (1988). Suicidal AIDS patients: When the depression turns deadly. *Nursing*, 18(7), 59-64.
- Buckingham, S. L., & van Gorp, W. G. (1988). Essential knowledge about AIDS dementia. *Social Work*, 33(2), 112-115.
- Buckingham, S. L. (1987). The HIV antibody test: Psychosocial issues. *Social Casework*, 68(7), 387-393.
- Buckingham, S. L. & Rehm, S. J. (1987). AIDS and women at risk. *Health and Social Work*, 12(1), 5-11.

PEER-REVIEWED JOURNAL ARTICLES IN SUBMISSION

- Buckingham, S. L. (2008). *HIV-Associated Neurocognitive Disorder (HAND) and occupational challenges: What every social worker should know*. Manuscript submitted for publication.

INVITED JOURNAL ARTICLES

- Buckingham, S. L. (Guest Editor). (1994). AIDS: The next wave of the crisis. *Families In Society*, 75(6), 323.
- Buckingham, S. L., & van Gorp, W. G. (1994). HIV-Associated Dementia: A clinician's guide to early detection, diagnosis, and intervention. *Families In Society*, 75(6), 333-345.
- Buckingham, S. L. (Guest Editor). (1988). AIDS: Bridging the gap between Information and practice. *Social Casework*, 69(6).
- Buckingham, S. L., & van Gorp, W. G. (1988). AIDS Dementia Complex: Implications for practice. *Social Casework*, 69(6), 371-375.
- Stulberg, I., & Buckingham, S. L. (1988). Parallel issues for AIDS patients, families and others. *Social Casework*, 69(6), 355-359.

BOOK

- Van Gorp, W. G. & Buckingham, S. L. (Eds.). (1998). *Practitioner's guide to the neuropsychiatry of HIV/AIDS*. New York: Guilford Publication, Inc.

BOOK CHAPTERS

- Buckingham, S. L., & van Gorp, W. G. (1999). HIV-associated cognitive/motor complex: Early detection, diagnosis, and intervention. In M. Shernoff (Ed.), *AIDS and Mental Health Practice: Clinical and Policy Issues* (pp. 285-306). New York: Harrington Park Press.
- Buckingham, S. L., & Shernoff, M. (1998). Psychosocial interventions in persons with HIV-associated neuropsychiatric compromise. In W. G. van Gorp & S. L. Buckingham (Eds.), *Practitioner's guide to the neuropsychiatry of HIV/AIDS* (pp. 228-240). New York: Guilford Publication, Inc.
- Buckingham, S. L. (1998). Identifying and treating HIV-associated dementia. In D. M. Aronstein & B. J. Thompson (Eds.), *HIV and Social Work* (pp. 281-291). New York: Harrington Park Press.
- Van Gorp, W. G., Dilley, J. W., & Buckingham, S. L. (1998). The diagnosis and management of HIV-related organic mental disorders. In J. W. Dilley & R. Marks (Eds.), *The UCSF AIDS Health Project Guide To Counseling: Perspectives on Psychotherapy, Prevention, and Therapeutic Practice* (pp. 290-311). San Francisco: Jossey-Bass Publishers.
- Levin, R. D., Buckingham, S. L., & Hart, C. B. (1996). Gay men as caregivers. In V. Lynch & P. Wilson (Eds.), *Caring for the HIV/AIDS caregiver* (pp. 73-90). Westport, CT: Auburn House Publishers.

EDUCATIONAL BROCHURE

Buckingham, S. L., & van Gorp, W. G. (1990). *A practical guide to coping with AIDS dementia complex*. [Brochure]. Los Angeles: Pacific Oaks Medical Group.

BOOK REVIEW

Buckingham, S. L. (1988). [Review of the book *AIDS: Facts and issues*]. *Health and Social Work*, 13(1), 79.

PRESENTATIONS

PEER-REVIEWED PRESENTATIONS

Huber, R., Conley, C., & Buckingham, S. (2008, October). *Negotiation reduces salary inequities among social workers*. Paper presented at the Annual Program Meeting of the Council on Social Work Education, Philadelphia, PA.

Barney, R., Buckingham, S., & Johnson, L. (2008, May). *The ethics of the President's Emergency Plan for AIDS Relief (PEPFAR): A social work analysis and call to action*. Paper presented at the Twentieth Annual Conference on Social Work and HIV/AIDS, Washington, DC.

Conley, C., Buckingham, S., & Schapmire, T. (2008, May). *Parental concerns regarding HIV/AIDS: Implications for research, education and practice*. Paper presented at the Twentieth Annual Conference on Social Work and HIV/AIDS, Washington, DC.

Barney, R., Buckingham, S., Friedrich, J., Johnson, L., & Robinson, R. (2007, May). *HIV/AIDS research and education: A proposed model for doctoral students*. Paper presented at the Nineteenth Annual Conference on Social Work and HIV/AIDS, Albuquerque, NM.

Buckingham, S., & Stulberg, I. (1996, May). *Positively negative: Clinical themes from a support group for HIV-negative gay men*. Paper presented at roundtable session of the Eighth Annual Conference on Social Work and HIV/AIDS, Atlanta, GA.

Hinkin, C., van Gorp, W., Satz, P., Weisman, J., Freeman, D., Rogolsky, E., Hitt, R. S., & Buckingham, S. (1990, June). *Relationship between CD4 levels and neuropsychological impairment among HIV-1 sero-positive individuals*. Paper presented at the conference on Neurological and Neuropsychological Complications of HIV Infection: A Satellite Conference of the VI International AIDS Conference, Monterey, CA.

- Van Gorp, W., Hinkin, C., Freeman, D., Satz, P., Weisman, J., Rothman, P., Scarsella, A., & Buckingham, S. (1990, June). *Depressed versus non-depressed mood and its effect on neuropsychological test performance among HIV-1 seropositive individuals*. Paper presented at the conference on Neurological and Neuropsychological Complications of HIV Infection: A Satellite Conference of the VI International AIDS Conference, Monterey, CA.
- Buckingham, S. (1988, November). *AIDS dementia: Essential knowledge for social workers*. Paper presented at the National Association of Social Workers National Conference, Philadelphia, PA.
- Buckingham, S., & van Gorp, W. (1988, July). *AIDS dementia: Essential knowledge for mental health professionals*. Paper presented at the Second International Lesbian and Gay Health Conference and AIDS Forum, Boston, MA.
- Van Gorp, W., Cummings, J., Mitrushina, M., Satz, P., & Buckingham, S. (1988, June). *AIDS, Alzheimer's disease and normal aging: A comparison study*. Paper presented at the IV International Conference on AIDS, Stockholm, Sweden.
- Saunders, J., & Buckingham, S. (1988, May). *AIDS and suicide*. Paper presented at the AIDS and Mental Health Conference conducted by the University of California, San Francisco AIDS Health Project, Los Angeles, CA.
- Buckingham, S. (1988, March). *AIDS dementia: Essential knowledge for social workers*. Paper presented at the National Association of Social Workers California State Conference, Pasadena, CA.
- Buckingham, S. (1987, June). *Neuropsychiatric implications: AIDS dementia*. Paper presented at the National Association of Social Workers California Chapter Conference: The Age of AIDS, Los Angeles, CA.
- Saunders, J., & Buckingham, S. (1987, May). *AIDS and suicide: Conceptual considerations*. Paper presented at the Annual Conference of the American Association of Suicidology and the International Association for Suicide Prevention, San Francisco, CA.
- Saunders, J., & Buckingham, S. (1987, March). *AIDS and suicide: Conceptual considerations*. Paper presented at the National Lesbian and Gay Health Conference & The Fifth National AIDS Forum, Los Angeles, CA.
- Buckingham, S. (1986, November). *The HIV antibody test: Unique psychosocial issues*. Paper presented at the Challenge of AIDS Conference, Miami, FL.
- Buckingham, S., & Mancoske, R. (1986, November). *Gay adolescent identity and AIDS*. Paper presented at the Challenge of AIDS Conference, Miami, FL.

Buckingham, S., & Rehm, S. (1986, May). *AIDS: The unique issues facing patients, significant others, families, and service providers*. Paper presented at the National Association of Social Workers California State Conference, San Diego, CA.

Rehm, S., & Buckingham, S. (1986, May). *AIDS: Women at risk!* Paper presented at the National Association of Social Workers National Conference on Women's Issues, Atlanta, GA.

INVITED ADDRESSES AND WORKSHOPS

Buckingham, S., & van Gorp, W. (2008, May). *NeuroAIDS: Emerging issues and critical consideration*. Special session presented at the Twentieth Annual Conference on Social Work and HIV/AIDS, Washington, DC.

Buckingham, S., & van Gorp, W. (2007, May). *NeuroAIDS: Emerging issues and critical considerations for social workers*. Workshop presented at the Nineteenth Annual Conference on Social Work and HIV/AIDS, Albuquerque, NM.

Buckingham, S., & Conn, D. (2004, January). *Developing pastoral care groups*. Workshop presented at the All Saints' Association National Conference, Episcopal Diocese of Los Angeles, Beverly Hills, CA.

Buckingham, S. (1996, November). *HIV-Associated Dementia: A clinician's guide to early detection, diagnosis, and intervention*. Paper presented at the National Association of Social Workers National Conference, Cleveland, OH.

Buckingham, S., & van Gorp, W. (1996, May). *HIV-Associated Dementia: A clinician's guide to early detection, diagnosis, and intervention*. Paper presented at the Eighth Annual Conference on Social Work and HIV/AIDS, Atlanta, GA.

Buckingham, S., & van Gorp, W. (1995, October). *HIV-Associated Dementia: A clinician's guide to early detection, diagnosis, and intervention*. Paper presented at the National Association of Social Workers National Conference, Philadelphia, PA.

Buckingham, S., & van Gorp, W. (1995, June). *HIV-Associated Dementia: A clinician's guide to early detection, diagnosis, and intervention*. Paper presented at the Seventh Annual Conference on Social Work and HIV/AIDS, Chicago, IL.

Buckingham, S., & van Gorp, W. (1994, September). *HIV-Associated Dementia: A clinician's guide*. Paper presented at the 1994 Annual Case Management/Medical Waiver Program Conference, Monterey, CA.

Buckingham, S., & van Gorp, W. (1994, June). *Neuropsychological sequelae of HIV infection*. Paper presented at the Sixth Annual Conference on Social Work and HIV/AIDS, New Orleans, LA.

- Buckingham, S. (1994, February). Conference Moderator at the National HIV Frontline Forum, Los Angeles, CA.
- Buckingham, S., & van Gorp, W. (1993, November). *Caring for patients with HIV dementia*. Paper presented at the Alzheimer's Association Conference on Practical Dilemmas: Living with Alzheimer's Disease, Los Angeles, CA.
- Buckingham, S. (1988, November). *Exploring the mental health aspects of AIDS*. Paper presented at the National Association of Social Workers National Conference, Philadelphia, PA.
- Buckingham, S. (1988, May). *Understanding the AIDS Dementia Complex: Implications for clinical practice*. Paper presented at the AIDS and Mental Health Conference conducted by the University of California, San Francisco AIDS Health Project, Los Angeles, CA.
- Buckingham, S., & van Gorp, W. (1987, November). *The neuropsychiatric and neuropsychological aspects of HIV infection: Psychosocial implications*. Address given at the National Conference on the Spectrum of Dementing Illnesses, University of South Carolina School of Medicine, Columbia, SC.
- Buckingham, S. (1987, September). *AIDS Dementia Complex: Essential knowledge for social workers*. Address given at the Southern University of New Orleans, School of Social Work, New Orleans, LA.
- Buckingham, S. (1986, June). *AIDS: Psychosocial issues*. Address given at Murray State University, Department of Sociology and Anthropology, Murray, KY.
- Rehm, S., & Buckingham, S. (1986, May). *AIDS and women at risk*. Interview with question and answers on WAOK Radio Talk Show, Atlanta, GA.
- Buckingham, S., & Rehm, S. (1986, May). *AIDS: Managing employee concerns*. Paper presented at the National Association of Hospital Admitting Managers National Conference, Los Angeles, CA.
- Buckingham, S. (1986, March). *The societal impact of AIDS and how you can help*. Address given at the Medical Media Associates Conference: AIDS: An Update for All Health Care Personnel, Los Angeles, CA.
- Buckingham, S. (1986, March). *AIDS: The psychosocial issues*. Paper presented at the Understanding Human Emotion Conference, Olive View Medical Center Los Angeles, CA.
- Buckingham, S. (1986, March). *AIDS: Psychosocial aspects*. Paper presented at the Professional Symposiums International Conference: AIDS: A Clinical Update, Los Angeles, CA.

- Buckingham, S. (1986, February). *AIDS: The Psychosocial issues*. Paper presented at the AIDS Conference: Facts versus Fallacy, American Physical Therapy Association, California Chapter, Los Angeles, CA.
- Buckingham, S. (1986, January). *AIDS: The psychosocial issues and discharge planning*. Paper presented at the Nursing Strategies in Caring for the AIDS Patient Conference, University of California, Los Angeles Medical Center, Los Angeles, CA.
- Buckingham, S. (1986, January). *Psychosocial components of caring for the AIDS patient and family*. Paper presented at the Annual Nursing Grand Rounds, UCLA Neuropsychiatric Institute, Los Angeles, CA.
- Buckingham, S. (1985, November). *AIDS: The psychosocial impact*. Keynote address given at Murray State University, Department of Social Work, Murray, KY.

REFERENCES

Professional references available upon request.