

# Real Time Research of Executive Cognitive Functions of HIV/AIDS Clients: The Challenge for Social Workers



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## Preface

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# Table of Content

<b>CHAPTER 1: PROBLEM STATEMENT</b> .....	1
Historical Executive Cognitive Function Concepts .....	3
Frontal Lobe .....	5
Definition of Executive Function based on UNAIDS .....	5
Executive Cognitive Impairment .....	6
Definition and Description of HIV and AIDS .....	7
Human Immunodeficiency Virus (HIV) .....	7
Acquired Immunodeficiency Syndrome (AIDS) .....	9
Human Immunodeficiency Virus (HIV) Positive .....	9
Risk of Infection .....	9
Difference between Prevalence and Incidence Rates .....	10
Older Adults Concepts .....	11
Age Categories .....	12
Social Service/Social Delivery System Concepts .....	13

Publication Partner:

International Journal of Scientific and Research Publications (ISSN: 2250-3153)

Types of HIV and their Origins .....	17
The Research Question .....	18
<b>CHAPTER 2: REVIEW OF THE LITERATURE</b> .....	<b>19</b>
.....	
HIV/AIDS in Older Persons: Epidemiology .....	20
Risk factors for Older Adults .....	21
Medical Concerns .....	22
Psychosocial Considerations .....	23
Blending Two Theoretical Perspectives .....	24
The Social Work Geriatric Assessment Process .....	24
Assessment of Physical Functioning .....	25
Assessment of Emotions and Cognitive Functioning .....	25
Social Support .....	26
Sexual Health .....	26
Spirituality .....	27
Medications .....	28
Caregiver Health and Burden .....	28
The Concept of Social Work Assessment of Persons with HIV/AIDS.	28
Assessment of Physical Functioning .....	29

Assessment of Emotions and Cognitive Functioning .....	29
Social Support .....	30
Sexual Health .....	31
Spirituality .....	31
Overview of Cognitive Screening .....	31
Limitations of the MMSE .....	33
Rationale for Using Clock Drawing Task .....	34
Social Work’s Assessment of Executive Cognitive Functioning .....	36
Social Support and Social Work Indicators .....	38
Clock Assessment of Executive Cognitive Functioning of .....	39
Individuals Over 50	
Problem Statement Revisited .....	41
The Research Question.....	41
Conclusion .....	42
<b>CHAPTER 3: METHODOLOGY .....</b>	<b>43</b>
Research Design .....	43
Protection of Human Subjects .....	45
Sampling and Data Collection Procedures .....	46
Resources and Environment of the WINGS Clinic .....	48
Sampling .....	51

Data Collection Procedures .....	52
Variables Operationalized .....	53
The Executive Function Clock Drawing Task .....	53
Conclusion .....	57
<b>CHAPTER 4: RESULTS</b> .....	<b>59</b>
Five Specific Research Questions .....	59
Overview of Statistical Analyses .....	61
Demographics of the Sample .....	61
Clinical and Research CLOX Scoring .....	62
Cutoff Points .....	62
Sensitivity and Specificity .....	63
Truth or Consequences .....	64
<i>Question 1: What is the difference in the means of executive .....</i>	<i>66</i>
<i>cognitive function research and clinical scores (DVs)</i>	
<i>between clients known/not known to be diagnosed as having</i>	
<i>HIV/AIDS (IV)?</i>	
<i>Question 2: What is the difference in the means of executive .....</i>	<i>67</i>
<i>cognitive function research and clinical scores (DVs) by</i>	
<i>gender (IV)?</i>	
<i>Question 3: What is the difference in the means of executive .....</i>	<i>67</i>
<i>cognitive function research and clinical scores (DVs) by</i>	
<i>whether clients were served clinics that provided social</i>	
<i>services (IV)?</i>	

<i>Question 4: What is the difference in the means of executive cognitive function research and clinical scores (DVs) and clients' ages (IV)?</i>	68
Age Adjusted Prevalence Rates of Executive Cognitive Functioning	69
<i>Question 5: What are the predictors of Clinical and Research CLOX Scores of Executive Cognitive Functioning?</i>	72
Analyses of Research CLOX Scores of Executive Cognitive Functioning	75
Reliability Analyses	75
False Positive and False Negative Values	76
Results of Sensitivity and Specificity Statistical Analyses	77
Limitations of this Study	78
<b>CHAPTER 5: PRACTICE IMPLICATIONS FOR SOCIAL WORK AND FUTURE RESEARCH</b>	80
Review of Four Issues Under Study	80
The Age Issue	81
Gender Differences	81
HIV/AIDS Diagnoses	81
The Presence of Social Services	82
The Clinical CLOX/Research CLOX Conundrum	83

The Ethical and Political Dilemma .....	83
Scoring Choices .....	84
Real Time Research = Practice Based Evidence .....	85
Recommendations for Training .....	85
Implications for Social Work Practice, aka <i>So What?</i> .....	85
Future Research .....	87
<b>REFERENCES</b> .....	88
APPENDIX A: Research and Clinical CLOX (page 1) .....	101
APPENDIX B: Research and Clinical CLOX (page 2) .....	102
APPENDIX C: Population Distribution by Age, .....	103
State Data 2002- 2003, U.S. 2003	
APPENDIX D: Distribution of Cumulative AIDS Cases .....	104
all Ages by Sex	
APPENDIX E: Distribution of Cumulative AIDS Cases .....	105
all Ages by Race/Ethnicity, Reported through 2003	
APPENDIX F: Distribution of New AIDS Cases by .....	106
Race/Ethnicity, Reported through 2003	
APPENDIX G: Reported AIDS Cases and Annual (a) Rates .....	107
(per 100,000 population), by Area of Residence and Age Category, (b) Cumulative through 2003-U.S.	

APPENDIX H: Cumulative Number of AIDS Cases .....	109
all Ages, Reported through December 2003	
APPENDIX I: Cumulative Number of AIDS Cases Rank .....	110
and all Ages, Reported through December 2003	
APPENDIX J: New AIDS Cases all Ages, Reported in 2003 .....	112
APPENDIX K: New AIDS Cases all Ages, Reported in 2003 .....	113
APPENDIX L: Geographic Designations .....	115
(CDC, HIV/AIDS Surveillance Report, 2003)	

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## CHAPTER I

### PROBLEM STATEMENT

Levels of health have great effects on society as a whole, and broad social action is needed to confront health problems. Good health and access to good health care are social goals and economically essential. As the population of the developed world ages, cognitive impairment is becoming an increasingly important public health concern. The relationship between cognitive impairment and its effect on functional decline is of significant clinical and public health importance because they are common, frequently coexist, and may be treatable. The purpose of this dissertation is to learn more about executive cognitive impairment of persons receiving care in primary care clinics, especially any differences there may be between persons diagnosed (and not) with HIV/AIDS, with particular interest in older clients.

Since the start of the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) epidemic more than two decades ago, social workers, doctors, caregivers and patients themselves have observed that some people with the disease experience declines in brain function and movement skills, as well as slight or sudden shifts in behavior and mood. Two decades of research describe the high incidence of cognitive dysfunction in people with HIV/AIDS (Emlet & Berghuis, 2002). The number of older adults living with this disease is increasing, and approximately 60% of people living with HIV will develop cognitive difficulties over the course of the illness (Fernandez, Adams, & Levy, 1988). According to McArthur and others, 15% to 19% will develop cognitive problems severe enough to meet criteria for cognitive impairment in that the cognitive difficulties adversely affect their everyday work and social lives (McArthur, Hoover, & Bacellar, 2004).

Neurocognitive impairment can adversely affect independent activities of daily living (e.g., managing medications, scheduling appointments), as well as affecting quality of life. Few studies have examined whether cognitive declines in older adult populations translate into functional impairment. Surprisingly, most studies have not examined the risk factors for Executive Cognitive Function (ECF) decline in clients with depression or brain/head injuries. Neither have prior studies examined risk factors for ECF in younger vs. older clients with HIV infection.

Moreover, none of the health related research disciplines have addressed the need for social services in primary care settings for ECF impaired clients who live with HIV/AIDS. People with HIV or AIDS require a complex array of social support services. Like other vulnerable populations, people with HIV/AIDS require a network of formal and informal supports and services for optimal functioning and well-being. Many can extend their survival years and enhance the quality of their lives if they have supportive environments. These supports, however, frequently are inadequate, highly complex, and difficult to access (Gutheil & Chernesky, 1999).

The human immunodeficiency virus enters the central nervous system shortly after infection. Health care professionals predict that it moves to the subcortical brain areas where it can cause cell injury, cell dysfunction, or cell death. People with neurocognitive complications associated with HIV disease present with a complex of behavioral, cognitive, and motor symptoms. The signs and symptoms that result can be attributed to the intricate interactions between HIV (in particular, HIV-strain characteristics that increase central nervous system infection) and other factors, including (a) the person's systemic condition, (b) biological vulnerability to cognitive disorders, (c) premorbid primary psychiatric and substance abuse-

related disorders, (d) the neuropsychiatric effects of medications used to treat HIV disease and its complications, and (e) the psychological impact of a life-threatening illness.

In order to more thoroughly examine the problem, I will (a) overview the historical concepts of executive cognitive function, (b) then define and describe HIV/AIDS in ways relevant to this study, (c) discuss older adult concepts, and (d) overview social service system concepts. Executive cognitive function has been studied, but is still poorly understood in a cross disciplinary setting with HIV/AIDS, aging, and social services. The importance of examining these four elements in a collaborative way rests in detecting dementia in earlier and more treatable stages.

### ***Historical Executive Cognitive Function Concepts***

The term *executive function* is used as an umbrella for various complex cognitive processes and sub-processes. Executive Cognitive Functions (ECF) are relatively complex behaviors that include planning, active problem solving, working memory, initiation of activity, inhibition of irrelevant and inappropriate behaviors, and the capacity to monitor the effectiveness of one's own behavior (Grigsby, Kaye, Baxter, Shetterly, & Hamman, 1998). Most attempts to define executive function resort to a list of examples such as planning, task-switching, or another useful umbrella term, *working memory*, which reflects the fact that executive function is by no means a unitary concept. The neuropsychological literature converges on the view that successful performance on tests of executive function is critically dependent on the frontal cortex; indeed, the terms *executive function* and *frontal lobe function* are often used synonymously. However, recent theories have suggested that this view is simplistic and that subcortical regions may also be critically involved.

According to Royall (1998), the term *executive cognitive function* refers to cognitive processes that serve a *cybernetic* role, i.e., they *command and control* the execution of complex, goal directed behaviors (Royall & Espino, 2002). Executive function has been defined as the ability to (a) formulate goal-directed behavior, (b) sequence behavior and thought, (c) maintain goal-directed activity in the face of distraction, and (d) inhibit irrelevant behaviors, and is also involved in planning complex behavior and active problem solving (Royall, 1998). Executive functions broadly encompass a set of cognitive skills that are responsible for planning, initiating, sequencing, and monitoring complex goal-directed behavior.

Two central themes emerge from *executive functions*. The **first** associates ECF with specific higher cognitive functions such as insight, will, abstraction, and judgment, which are mostly dependent on the frontal lobes (Royall, 2002). This view implies that, like memory or language, executive cognitive functions are acquired skills that can be directly measured. ECF impairment results in the loss of these capacities. The **second** theme emphasizes the cybernetic (from the Greek *kybernetes*, meaning *pilot*) aspects of executive function. Executive functions control the execution of complex activities (Royall et al., 2002).

### ***Frontal Lobe***

The frontal lobes have been associated with higher cognitive functions. Executive *dysfunction* has been associated with certain problem behaviors, including apathy and disinhibition. Hence, a wide variety of patients' daily activities require executive functioning. Many may be of particular interest to primary health care providers, including self-management, taking medications properly, comprehending medical information and making medical decisions during the informed consent process. Historically, however, no studies to date have examined the prevalence of impaired executive function in a primary care setting.

### ***Definition of Executive Function based on UNAIDS***

According to the United Nations Programme on HIV/AIDS (UNAIDS, 2004), executive function . . .

capacities [are] involved in planning, initiat[ing], solving problems, and carrying out and monitoring purposeful behavior. Such tasks are thought to be associated with the frontal lobe. Assessing executive functions involves tests that stress evaluating, planning, and then performing some type of sequential behavior. (UNAIDS, 2004, p. 4)

### ***Executive Cognitive Impairment***

In 1994 the American Psychiatric Association added impairment of executive control functions to its list of cognitive domains that should be considered in the assessment of dementia (Royall & Mahurin, 1996). This recommendation has not been widely implemented. Nonetheless, there is growing evidence that ECF impairment is common, strongly associated with disability and functional decline and not well detected by traditional dementia screening tests (i.e., Mini-Mental Status Examination [MMSE], Folstein, 1975).

Executive functions are cognitive processes that orchestrate complex, goal directed activities. If there are deficits in this domain, they are directly related to behavioral disorganization and functional decline and ECF impairment is likely. ECF has been associated with several important causes of disabilities, including major depression, subcortical vascular disease, adult-onset diabetes mellitus, and Alzheimer's disease (Royall, 2000). Traditionally, ECF has been associated with the prefrontal cortex, which represents 30% of the brain's weight and surface area. Nonetheless, the community prevalence of ECF impairment remains unknown. While reliable screening tests are available (i.e., Clock Drawing Task), more scholars have

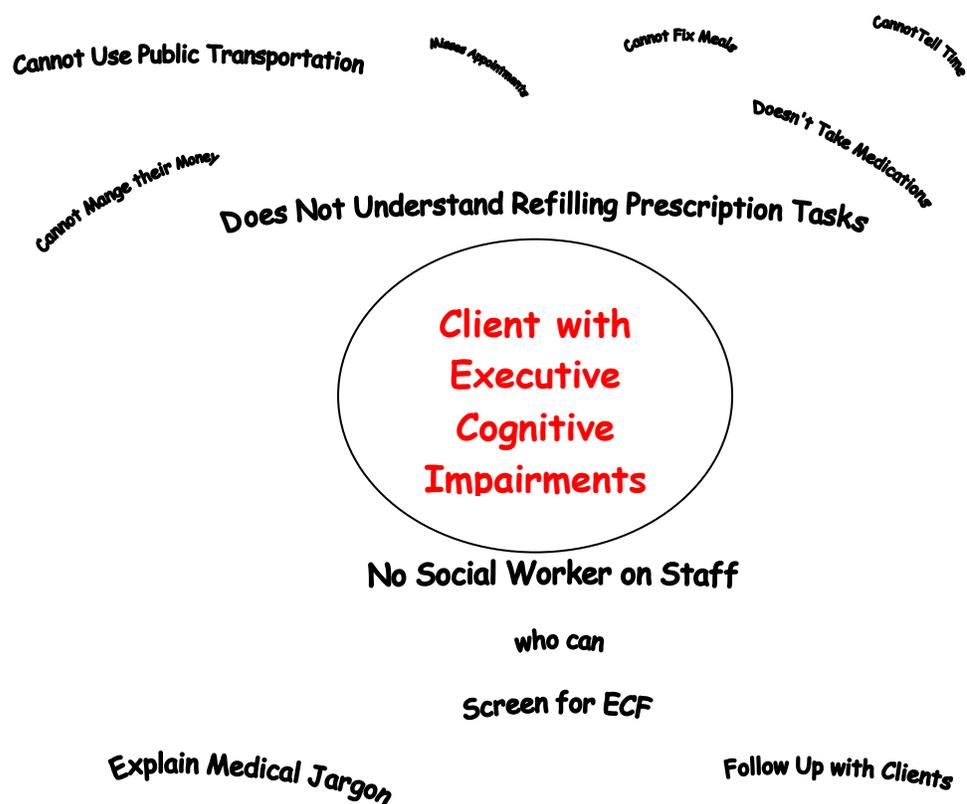
focused on dementia and fewer have examined executive cognitive functioning. These facts suggest that ECF may have important implications for the epidemiology of dementia that are not yet fully appreciated (Fogel, 1994).

Executive dysfunction has been associated with a number of different disease processes, including Alzheimer's dementia, vascular dementia, major depression (both unipolar and bipolar), diabetes mellitus, a number of neurodegenerative diseases (e.g., frontotemporal dementia, Lewy-body dementia etc.), traumatic brain injury, schizophrenia, and certain personality disorders (Royall, 2002). If patients' executive functions are impaired, they may experience impaired ability to perform self-care, manage finances and medication, comprehend important medical information, and make decisions about their care. A number of studies have demonstrated an association between the level of executive function and the number of activities of daily living a patient is able to perform (Bell-McGinty, Podell, & Franzen, 2002; Cahn-Weiner et al., 2002; Grigbsy, Kaye, & Baxter, 1998; Royall, Palmer & Chiodo, 2004) (Figure 1).

### ***Definition and Description of HIV and AIDS***

#### ***Human Immunodeficiency Virus (HIV)***

Human Immunodeficiency Virus (HIV) is the virus that causes AIDS. Once introduced into the bloodstream, HIV attacks certain cells of the immune system called the "helper-T-cells," or CD4 cells, which are responsible for helping the body fight off infections. HIV invades CD4 cells, reproducing within the infected cells, and then bursting out into the bloodstream. The immune system responds by producing antibodies to fight the virus and making more CD4 cells to replace those killed. But this immune response is ultimately ineffective. In the late stages



**Figure 1. Executive Cognitive Impairment behaviors.**

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of infection, HIV destroys increasing numbers of CD4 cells until the body's capacity to fight other viruses and bacteria gradually declines. Eventually, the immune system stops functioning, leaving the body defenseless against other infectious agents.

### ***Acquired Immunodeficiency Syndrome (AIDS)***

Acquired Immunodeficiency Syndrome (AIDS) is the medical designation for a set of symptoms, opportunistic infections, and laboratory markers indicating that a person is in an advanced stage of HIV infection with an impaired immune system (Irwin, Millen, & Fallows,

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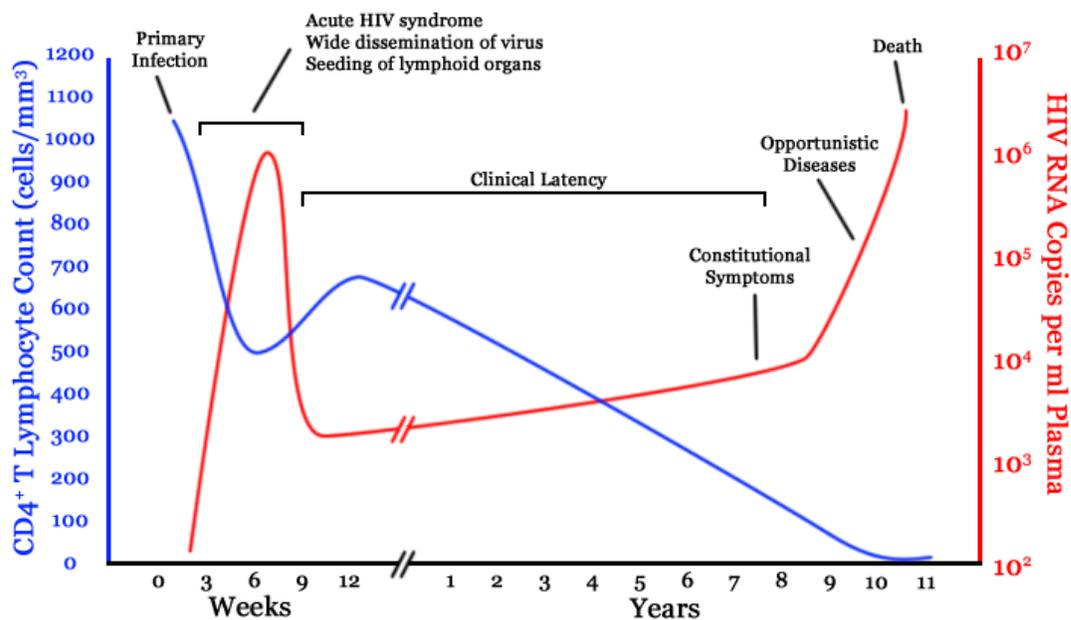
2003). Although some people may develop AIDS much sooner, it takes an average of 10 years from the time one is infected with HIV to develop clinical AIDS, regardless of whether the client is medically treated (Figure 2). As **immune functions begin to decline** (blue line in Figure 2), the body becomes an open stage to certain **opportunistic infections** (red line), so called because they are able to cause illness as a result of a weakened immune system.

### ***Human Immunodeficiency Virus (HIV) Positive***

A person who is HIV-positive (or seropositive) has been infected but does not necessarily have AIDS. Because of the long delay between the time of infection and onset of diseases, the number of HIV-positive people in a population is always much greater than the number of people with AIDS. In the absence of treatment, however, nearly everyone who is HIV-positive today will develop AIDS within the next decade.

### ***Risk of Infection***

Risk of HIV infection is defined as the probability that a person could become infected. Epidemiologists often look for risk factors, or characteristics that correlate with an increased risk of infection. Behaviors associated with the transmission of HIV, such as having multiple unprotected sexual contacts or using intravenous drugs, are some of the risk factors for HIV infection. However, looking at individual risk factors alone provides only a limited understanding of how to control the spread of HIV. Underlying socioeconomic factors including poverty, discrimination, age, and gender inequality continue to drive the pandemic.



**Figure 2. HIV copies and CD4 counts over course of HIV infection (Gilbert, 2003)**

### ***Difference between Prevalence and Incidence Rates***

*Prevalence* is the percentage of people in a population with a specific disease or condition at a given moment in time. When we talk about the prevalence of HIV infection, for example, we mean the percentage of the U.S. population that is HIV-positive. While prevalence is useful for describing the overall burden of disease to society, a low prevalence of HIV/AIDS can be falsely reassuring for two reasons. First, because prevalence is an average value, a low prevalence of HIV/AIDS in a population with widely varying risks of HIV infection can mask small high-risk groups with a high prevalence of HIV/AIDS. Secondly, countries with a low prevalence of HIV/AIDS but a very large population can have more total cases of HIV/AIDS than countries with a high prevalence but much smaller populations. Moreover, prevalence does not provide information about the trends of an epidemic over time. If we want to know about the

dynamics of an HIV/AIDS epidemic (whether it is declining, stable, or growing), we need to look at the *rates* at which new infections are occurring. This number, called the *incidence rate*, is usually expressed as the number of new HIV infections per year. By comparing the annual rates of new HIV infections, or incidences, we can learn how an epidemic or pandemic is proceeding.

### ***Older Adult Concepts***

The term *older adults* is often defined “in HIV research as those age 50 and over who are increasingly recognized as being at-risk for HIV disease.” (Fowler, 1999, p. 2.). HIV/AIDS has traditionally been seen as a disease of younger persons. Thus, older adults with HIV/AIDS have been called a “hidden population” (Emlet, 1997, p. 71). According to Emlet, “no matter the setting or primary client population, social work practitioners will probably meet and work with older persons and persons with HIV/AIDS who experience executive cognitive dysfunction.” (Emlet, 1997, p. 72). Since both aging and HIV disease are everywhere in social work practice, social workers must be prepared to provide assessment and other social work services to older persons who are infected with and cognitively impaired by HIV disease.

### ***Age Categories***

Throughout this study, I will refer to the aging and the population of older or elderly people. These terms are based, to some extent, on chronological criteria, but more importantly on individual differences in social, psychological, and biological functioning. In fact, each of us differs somewhat in the way we define old age. We may know an 80-year-old who seems youthful and a 50-year-old whom we consider elderly. Elderly people also define themselves differently. Some individuals, even in their 80s, do not want to be associated with “those old

people”, whereas others readily join age-based organizations and are proud of the years they have lived (Hooyman & Kiyak, 1988).

The Centers for Disease Control and Prevention have monitored incidence and prevalence rates of AIDS since 1982. When opportunistic infections were first reported in 1982, age breakdowns were reported in three large categories; under 25, 25 - 44, and over 44 (Centers for Disease Control and Prevention [CDC], 1982). From 1983 to 1987, the oldest age category presented in the tables was over 49. From 1988 through year-end 2001, the age categories over 49 were broken down further: 50 - 54, 55 - 59, 60 - 64, and 65 and older. In a 2003 report of AIDS cases in adolescents and adults by age, the 65 and older category is further refined to be 65 - 69 and 70 and older (CDC, 2003a).

The increased specificity of age grouping in the data has improved our ability to look at other trends in gender, race and ethnicity, and transmission route by age. The selection of age 50 as the demarcation of older adults in the population of persons with AIDS was not coincidental and certainly is not consistent with identification of “older” individuals in most contexts (Emlet, 2004). The continued use of age 50 as the lowest end of the category representing older persons is partly due to the categorical breakdowns originally reported by the CDC. People in their 50s have been seen to represent the higher end of the age range of people with HIV/AIDS and in some cases are subject to ageism in the context of the epidemic (Linsk, 2000). Although the selection of this chronological cutoff point was not arbitrary, it does lead to interesting discussions of the relative nature of terms such as *old* and *senior* (Emlet, 2004).

### ***Social Service/Social Delivery System Concepts***

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Historically, systems of care, influenced by public policy, have focused on particular needs or populations. Such focus has tended to separate issues that may be connected, such as aging and HIV issues. Older people who have HIV/AIDS face different physical and psychosocial challenges. For example, as a result of normal aging processes, older individuals with HIV are likely to have more physical, medical, cognitive, and pharmaceutical complications than younger people (Hirshhorn, 2001). Although many older adults living with HIV/AIDS have adjusted well to their illnesses, individuals who receive less social support experience barriers to services, experience HIV-related stigma, and have higher incidences of psychological symptoms (Heckman et al., 2002). Because several studies have found older individuals with AIDS more likely to live alone than their younger counterparts (Crystal & Sambamoorthi, 1999; Emlet & Berghuis, 2002; Emlet & Farkas, 2001), it is important to recognize that decreased social support can be a complicating and serious issue for older clients with HIV/AIDS.

Older persons' problems are characterized in terms of symptoms that warrant comprehensive assessment of the biological, psychological, social, and environmental structures of their lives and functioning status. The interdisciplinary comprehensive assessment integrates these several domains into a diagnostic formulation of the client's concerns. A treatment plan is then developed based on the client's diagnosis and the biopsychosocial context of the patient's current life. Personal and cultural values, family and community resources, legal precedents and restrictions, and a host of other variables are considered as part of this process. Mental health care is normally delivered in three forms of treatment: (a) biomedical interventions, such as psychotropic medications and electroconvulsive therapy, (b) interpersonal and other psychological interventions, such as individual or family therapy, and (c) socioenvironmental

interventions, such as arranging for in-home services, protective service evaluations, legal consultation, or transportation.

One of the most pressing problems for older adults as they age is maintaining independence in functioning. U.S. national statistics indicate that 20% of noninstitutionalized people who are aged 70 and older need help in performing at least one activity of daily living including bathing, dressing, eating, using the restroom, moving objects, and physical motion (Kramarow, Rooks, & Weeks, 1999). Maintaining functional independence is also important because of increasing caregiver burden and healthcare costs. Over the past decade, numerous investigations have dealt with the nature and prevalence of cognitive *dys*function in HIV-infected individuals (e.g. Szirony, 2002). There is clear agreement that cognitive impairment is more common in patients with more advanced infection (Caparros, Pecheux, Petit, DuHamel, & Petit, 1995). Although there has been considerable controversy around cognition, there is an emerging agreement that a small proportion of patients with early-stage infection may also have subtle cognitive impairment that may be sufficient to interfere with normal daily functions (White, Heaton, & Monsch, 1995).

Moreover, the most frequent neuropsychiatric complication of the HIV-Type1 infection is cognitive impairment, which may range in severity from a mild cognitive disorder to a severe dementing illness. Currently, more is known about the clinical significance of the moderate to severe cognitive *dys*function that occurs most frequently during the late stages of HIV-1 infection, than is known about the minor impairment that occurs in some individuals during the early symptomatic stages of this disease.

Older adults who have been diagnosed with HIV/AIDS or screened with an executive cognitive *dys*function may live in the intersection of two different populations (those with

HIV/AIDS, and those with HIV/AIDS *and* executive cognitive dysfunctions). Each of these groups has its own unique issues, concerns and culture. In providing assessment services when the two populations are intermingled, it is necessary to include important elements that recognize the needs of both populations and understand where complications and contradictions occur. Assessing physical functioning is of great importance, of course, in working with older adults who have been diagnosed with HIV disease. It is important to recall, however, that the changes in physical function may occur more rapidly with HIV disease than with many of the chronic diseases associated with aging.

Assessing cognitive changes in the HIV/AIDS population is further complicated by the intersection of aging and HIV. Changes in cognitive status must be considered in the context of potential disease processes commonly associated with aging, such as Alzheimer's disease, in addition to HIV associated cognitive changes. There is some evidence to suggest that HIV-dementia as an AIDS defining illness may be more common in older adults (Inungu, Mokotoff, & Kent, 2001). It is important to consider that AIDS related dementia is characterized by a rapid progression and is more often associated with general physical complaints, such as weight loss and fatigue, than the cortical dementias (Chiao, Ries, & Sande, 1999). Although we have no evidence to suggest that HIV-executive cognitive impairment is an AIDS *defining* illness, it is important to consider that AIDS related executive cognitive impairment may be associated with clients' complaints. In these circumstances the functional status may need to be screened (i.e. with the Clock-Drawing Task by Royall, Cordes, & Polk, 1998) with older adults in order to capture the more subtle symptoms associated with HIV related executive cognitive dysfunction.

### *Types of HIV and their Origins*

In 1984, 3 years after the first reports of a disease that was to become known as AIDS, researchers discovered the primary causative viral agent, the Human Immunodeficiency Virus Type 1 (HIV-1). In 1986, a second type of HIV, called HIV-2, was isolated from AIDS patients in West Africa, where it may have been present decades earlier. Studies of the natural history of HIV-2 are limited, but to date comparisons with HIV-1 show some similarities while suggesting differences (Kahn & Walker, 1998).

Two species of the virus have been recognized since 1986: *HIV-1* and *HIV-2*. They differ in their genome and infectivity, with HIV-1 being well over three times as infective as HIV-2 (Gilbert, 2003). Furthermore, it takes longer for HIV-2 infection to cause disease. HIV-2 infections are mostly found in Western Africa and, increasingly, in India; HIV-1 is endemic in the rest of the world.

Both HIV types are closely related to Simian Immunodeficiency Virus (SIV), with HIV-1 more closely related to the chimpanzee strain of SIV than to HIV-2, and HIV-2 more closely related to the Sooty Mangabey strain of SIV than to HIV-1. It is likely that HIV was introduced into humans in Africa via contact with the blood of hunted monkeys, in the first half of the 20<sup>th</sup> century (Sharp, 2001).

Both HIV-1 and HIV-2 have the same modes of transmission and are associated with similar opportunistic infections and AIDS. In persons infected with HIV-2, immunodeficiency seems to develop more slowly and to be milder. The numbers of persons with HIV-2 is increasing at a faster rate than those with HIV-1. However, compared with HIV-1, the duration

of this increase is shorter because HIV-2 patients have shorter life expectancies. HIV-1 and HIV-2 also differ in geographic patterns of infection; the United States has fewer reported cases.

Because epidemiologic data indicate that the prevalence of HIV-2 in the United States is very low, CDC (1982) does not recommend routine HIV-2 testing at U.S. HIV counseling and test sites or in settings other than blood centers. However, when HIV testing is to be performed, tests for antibodies to both HIV-1 and HIV-2 should be obtained if demographic or behavioral information suggests that HIV-2 infection might be present (CDC, 2002).

### *The Research Question*

Based on what is known and the dearth of knowledge about executive cognitive functioning, I pose the overall research question: **What is the difference in the means of executive cognitive function scores (Dependent Variable, DV) between (a) clients known/not known to be diagnosed as having HIV/AIDS (Independent Variable, IV1), (b) clients receiving services in clinics providing/not providing social services (IV2), (c) gender (IV3), and age (IV4)?**

## CHAPTER II

### REVIEW OF THE LITERATURE

Persons over age 50 with HIV/AIDS disease are often invisible or overlooked in service and research areas, even though this diagnosis is not uncommon in the 50 and older population (Chiao, Ries, & Sande, 1999). Recent estimates suggest that 11% of new AIDS cases have been identified in people 50 years of age and older (CDC, 2003a). This number will continue to increase because prevention efforts are not effectively reaching older adults with cognitive impairment. Persons with HIV/AIDS are living longer and moving into older stages of life. As a result, many are facing new and complex stressors, such as declining health and fewer resources; thus, there has been an increase in mental and psychological symptoms among older adults with HIV (CDC, 2003a).

Many of these older adults are still dealing with the shock and shame of others finding out their HIV status. At the same time, they are challenged to adjust to the various cognitive, physical, and social changes brought on by aging. The aging are not often thought to be at risk for HIV infection; therefore, a diagnosis of HIV or AIDS is often delayed. Many times the diagnosis is made only after assessment for more mainstream diseases has been negative (Szirony, 2002). HIV/AIDS symptoms might also be overlooked in an older adult, partially due to Western negative attitudes regarding the elderly. As a result, this group of older adults may not receive adequate medical or psychological treatment. Having AIDS is not what most people think of as an older adults issue, and denial about an older adult's potential to be HIV-infected is common among many health care providers, including mental health practitioners. Thus, it is essential that clinical social workers and other mental health practitioners are aware of these

issues in order to appropriately handle the unique treatment needs of their older adult clients who have been infected with HIV disease.

In this literature review I **first** focus on the epidemiology of HIV/AIDS in older persons, and **second**, I show how the blending of two theoretical perspectives perspective undergird the nature and structure of the dissertation. **Third**, I discuss the social work geriatric assessment process. **Fourth**, I offer the concept of social work assessment in HIV/AIDS, and **fifth**, I provide an overview of cognitive screening (more fully discussed in depth in Chapter 3, Methodology). **Sixth**, I review the importance of social work perspectives in assessing elders' cognitive functioning, and **seventh**, I describe the milieu of assessing cognitive functioning in persons over 50 with HIV/AIDS. The chapter closes by **eighth**, revisiting the problem and **ninth**, articulating the research question.

### ***HIV/AIDS in Older Persons: Epidemiology***

As of June 2001, “793,026 cases of AIDS were reported in the United States. Of those, 86,875, or approximately 11%, were diagnosed in people age 50 or older (CDC, 2002, report).” This figure does not include those diagnosed with AIDS at a younger age who have *aged in* with the disease, nor does it include people age 50 or older who have been diagnosed HIV positive but have not yet progressed to AIDS. According to Wooten-Bielski (1999) the figure of 11% may under-represent the actual number of cases because AIDS goes undiagnosed in older people to a larger degree than in their younger counterparts. Because of the lack of accurate diagnoses in some cases, it is possible that many infected older adults die without having been properly diagnosed (Szirony, 1999). As medical treatments extend life expectancy for those with HIV and as the population of older adults increases, the number of HIV/AIDS cases among older adults is expected to increase (Genke, 2000; Poindexter & Linsk, 2000; Wooten-Bielski, 1999).

### ***Risk Factors for Older Adults***

Like all people, older adults are at-risk for contracting HIV/AIDS when there is a history of (a) unprotected sex with either male or female partners, (b) blood transfusions between 1977 and 1985, (c) sexual activities with prostitutes, and (d) intravenous drug use and sexual activities “with a partner who is at risk for infection” (Wooten-Bielski, 1999, p. 198). Older adults are at increased risk because the efficiency of the immune system of older adults has been reduced through age related decline (Szirony, 1999). Older women who are no longer concerned about pregnancy may not see a need for condom use. However, women who are post menopausal are actually at greater risk because their estrogen loss results in thinning “vaginal mucosa, leaving them more susceptible to tears of the vaginal walls during sexual activity” (Linsk, 2000; Szirony, 1999; Zelenetz & Epstein, 1998, p. 430). Despite their significant representation “in persons diagnosed with HIV/AIDS, there is an assumption among medical practitioners and older adults that older adults are not at risk for HIV infection and health care providers may even feel uncomfortable discussing sexual issues with their older patients” (Wooten-Bielski, 1999, p.198), or assume that older individuals are not sexually active. Thus, important questions related to sexual activity and history may be omitted from medical assessments (Johnson, Haight, Faan, & Benedict, 1998). Similarly, older adults may be reluctant to disclose behaviors they view as being socially unacceptable. This may be especially true of older gay or bisexual men who have felt a need to hide their sexual identities throughout their lives in order to protect themselves from stigma and discrimination. Such attitudes can result in older people having limited knowledge of HIV and prevention practices.

### ***Medical Concerns***

The weakened immune system in older adults that leads to greater susceptibility of HIV infection may result in a more rapid progression of the disease. Numerous studies have found shorter survival times among older persons (Ferro & Salit, 1992; Innugu, Mokotoff, & Kent, 2001) and higher rates of mortality (CDC, 2003a; Emler & Farkas, 2002). Early diagnosis, however, provides the elderly with the best chance for effective treatment and positive prognoses. Unfortunately, social workers, physicians and other health care providers continue to have low clinical suspicion for HIV in the elderly (Zelenetz & Epstein, 1998). This, combined with the fact that many AIDS related symptoms imitate medical problems that are common in older adults, may lead to delayed or misdiagnoses and thus, delayed treatment (Johnson, Haight, Faan, & Benedict, 1998).

### ***Psychosocial Considerations***

Older adults with HIV/AIDS experience many of the same psychosocial issues as their younger counterparts, such as feeling stigmatized, marginalized, and afraid (Linsk, 2000). They may fear disclosing their diagnoses and experience strained relationships with family and friends. According to Genke (2000), “they may experience lack of support from the community, and struggle with diminished financial resources and quality of life. Older people with HIV/AIDS experience difficulties specific to their age groups and may have lost multiple partner(s) and friends resulting in diminished social support. Older adults can be caught between aging and HIV services, where their HIV issues may not be addressed by aging programs and AIDS support services that are typically geared to a younger population.” (Genke, 2000, p.200). In addition to facing discrimination based on HIV status as well as sex and/or sexual identity, older adults must struggle with the effects of an ageist society. As Fowler (1999) described, “in a society that does not respect or value the aging population, older HIV infected people may confront social and professional bias regarding health care services and resources available to the AIDS community” (Fowler, 1999, p. 4).

According to a several studies, “prior research suggests that older adults with HIV experience higher levels of depression than their younger HIV positive counterparts.” (Heckman, Kochman, Sikkema, & Kalichman, 1999, p. 10). While this does not mean that HIV infected older people are incapable of adjusting to having HIV, it does mean that further research is warranted and that services must be available to support the unique needs of older HIV positive adults. Clearly, older adults face additional and different challenges regarding HIV/AIDS than their younger counterparts. As a result, it is essential that health care providers incorporate the important elements of a geriatric assessment with the elements of an HIV assessment. Such

integration will result in a more thorough understanding of the needs of HIV positive older adults.

### *Blending Two Theoretical Perspectives*

Two theoretical perspectives worked well together in this study. The **first**, the importance of the centrality of the therapeutic relationship (Leger, 2005) speaks to the Real Time Research methodology (T. P. Miles, Personal Communication, March 26, 2004). The basic tenet of this methodology is that research should intrude on the therapeutic relationship between clients and, in this case, medical care providers, as little as possible. The **second** is that of executive cognitive functioning which builds on the ideas of earlier developmentalists, i.e. Freud, Erikson, and Piaget (Huitt, 1997), a thorough review of which is beyond the scope of this study. I draw more heavily on more recent scholars, e.g. Royall and his colleagues, which I discuss later in this chapter.

### *The Social Work Geriatric Assessment Process*

Rubenstein (1987) defined geriatric assessment as a multidimensional and usually interdisciplinary process designed to quantify the elderly individual's medical, psychosocial and functional capabilities (Rubenstein, 1987). Assessment plays "a central role in the geriatric care system with regard to the integration of community programs and medical services for older persons with complex problems. Such problems are exacerbated when adding the issues associated with HIV disease to the already complicated aging process." (Rubenstein, 1987, p. 12).

### *Assessment of Physical Functioning*

According to Rubenstein, “in conducting assessments with older adults, various areas, or what I will refer to as domains, should be included. Depending upon the venue, purpose and the professional discipline of the person conducting the assessment, these domains may change slightly.” (Rubenstein, 1987, p. 14). Traditionally, assessment of physical functioning consists of the assessment of “one’s ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs)”, (Rubenstein, 1987, p. 14). The assessment of various functions provides a baseline for future comparisons, determines the need for services, and can be used as eligibility criteria for services, such as Medicaid waiver programs. Although many controversies surround measurements for the older population, a variety of measures such as the Katz Index of Independence in Activities of Daily Living, the Barthel Index and the Functional Independence Measure are commonly used (Emlet, Crabtree, Condon, & Treml, 1996; Pearson, 2000).

### ***Assessment of Emotions and Cognitive Functioning***

Assessment of emotions and cognitive function is necessary because of the prevalence of psychiatric disorders in old age; a psychosocial assessment should screen for potential cognitive and affective disorders. Mental status assessments are very important in evaluating older adults in order to detect unsuspected cognitive impairment (Gallo, Crabtree, Condon, & Treml, 1996). Traditionally, initial assessments of cognitive function include questions that assess memory, orientation and other cognitive abilities in order to identify obvious deficits consistent with dementia. The Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975) is the most commonly used instrument for screening moderate to severe dementia (Chodosh, 2000). Depression in older adults often goes unrecognized and can have serious consequences if left untreated. Self-report instruments, such as the Geriatric Depression Scale (Yesavage et al., 1983),

are common methods for initial assessments. The Center for Epidemiological Studies Depression Scale (Radloff, 1977) is another self-report assessment instrument for depression.

### ***Social Support***

“The assessment of social support networks in the lives of older persons is important for several reasons: (a) to determine whether they have the social resources (including social support and a social network) to remain living independently in the community, and (b) to identify individuals who are isolated and vulnerable (lacking social support). (Antonucci & Colleagues, 1997, p.49)” Antonucci and colleagues (1997) suggested that such an assessment will help identify others who might be available to perform critical tasks, i.e., help with medications, transportation. or personal care.

### ***Sexual Health***

Sexuality is “too often overlooked in the process of conducting health assessments with older adults because of stereotypical beliefs about aging and sexuality (that they neither need or want sex). Key components of taking a sexual history should include the older person’s normal sexual patterns, changes that have transpired due to aging or loss of partners, and possible problems with sexual functioning associated with medications.” (Gallo, Fulmer, Paveza, & Reichel, 2000, Handbook). As discussed earlier, sexual practices such as unsafe intercourse should be examined closely and not overlooked due to ageist beliefs.

### ***Spirituality***

The integration of a spiritual assessment is a key “to understanding the overall well-being of an older adult. The inclusion of spirituality and religion is important, as older people make up a large part of those who attend church or other formal religious gatherings. Religion and

spirituality have been associated with various benefits including positive outcomes in social functioning, psychological well-being and improved coping with end-of-life issues.” (Olson & Kane, 2000, p.310). Various ways of defining and assessing spirituality have been developed. “The Brief Multidimensional Measure of Religiousness and Spirituality encompasses 12 domains of religion and spirituality, including daily spiritual experiences, values/beliefs, forgiveness, private religious practices, religious and spiritual coping, religious support, religious/spiritual history, commitment, organizational religiousness, and religious preferences.” (Fetzer Institute, 1999, p.10). Recently, Hodge (2001) developed an Interpretive Anthropological Frame Work, defined as a “multidimensional framework for understanding the personal subjective reality of spirituality in clients’ lives” (p. 208). This qualitative framework examines various aspects of spirituality and includes affect, behavior, cognition, communication, conscience, and intuition.

### ***Medications***

The use of prescription and over-the-counter (OTC) medications is overrepresented in older adults. Older adults use approximately 30% of all prescription medications and 40% of OTC medications (National Council on Patient Information & Education, 2002). On average, older persons use 4.5 different prescription medications per diem in addition to OTC products, making polypharmacy a critical issue for older persons (Gallo, Fulmer, Paveza, & Reichel, 2000). Thus, a thorough inventory and evaluation of medications is an important element in the assessment of older persons.

### ***Caregiver Health and Burden***

Family caregiving is defined as providing, arranging or overseeing services that an older person needs due to functional disability or health needs (Gaugler, Kane & Langlois, 2000). Family members play key roles in helping disabled elders remain at home. Data from the Agency for Healthcare Research and Quality (2000) indicate that “79% of those who need long term care live at home or in the community rather than in institutions. Unchecked caregiver burden, however, may increase the potential for elder abuse and out-of-home placement. Since relatives and spouses commit the majority of domestic elder abuse” (National Center for Elder Abuse, 1998, p. 20), the assessment of caregiver burden is essential.

### ***The Concept of Social Work Assessment of Persons with HIV/AIDS***

When working with persons living with HIV/AIDS, a thorough assessment of needs is also necessary. Wright (2000) suggested that “through the assessment of all aspects of a person’s life social workers are better prepared to create environments that will increase a person’s understanding and, thus, strengthen their ability to adapt and cope with the complex process of HIV/AIDS.” (Wright, 2000, p. 5).

### ***Assessment of Physical Functioning***

Although the actual process of ADLs and IADLs do not differ significantly from one disease process to another, contexts change. “HIV disease, however, is different. The illness has unpredictable stages and medically affects patients in different ways; thus, determining the timing or the severity of symptoms is difficult. For example, individuals diagnosed with AIDS can quickly go from moderate dependence in ADLs to the need for 24-hour assistance” (Chian, Ries, & Sande, 1999, p. 745). Multiple factors can affect their functional dependence, including generalized weakness, opportunistic infections, AIDS related neuropsychiatric disorders (e.g.,

possibly executive cognitive dysfunction), medication side-effects or any combination of factors. Despite the advances in antiretroviral therapy, people continue to become quite ill and die from AIDS. Assessments of cognitive function, specifically executive cognitive function, in this population need to be conducted consistently and reliably (Chiao, Ries, & Sande, 1999).

### ***Assessment of Emotions and Cognitive Functioning***

Cognitive and emotional issues can significantly impact the lives of people with HIV disease. They are more likely to have preexisting mental illnesses, mental health issues arising from HIV related stressors and psychiatric/physical problems. Major depressive disorders and other forms of depression are more prevalent among HIV infected individuals than the general population (Hinkin, Castellon, Atkinson, & Goodkin, 2001). A critical component of assessment is the identification of cognitive impairment related to HIV. Cognitive impairment increases as an individual becomes more immune-compromised and symptomatic. Goodkin et al. (2001) identified two conditions: minor cognitive motor disorder and HIV-1-associated dementia. “These conditions involve information processing, speed, memory, attention, abstraction, executive function, and motor abilities. Because the most prominent feature at initial presentation is slower movements and thinking” (Buckingham, 1998, p. 30), symptoms are often missed, as HIV dementia is subcortical rather than cortical (such as with Alzheimer’s disease). Additionally, standard mental status exams do not always identify early symptoms.

### ***Social Support***

The assessment of social support for persons with HIV/AIDS is similar to that of older persons. “At the same time, however, important differences in the source of support and the function of that support have been found. Sexual orientation has been shown to alter sources of

identified social support. Beeler and colleagues (1999) found friendship networks to be among the most important sources of social support for midlife and older lesbian and gay individuals.” (Beeler et al., 1999, p. 35). She found that once an individual had a diagnosis of AIDS and needed increased care, gay men received significantly higher levels of support from their families than heterosexual men with HIV. Since family and friends are generally the chief sources of support, our notion of family must be expanded to incorporate the most important individuals as defined by clients.

### ***Sexual Health***

HIV assessment must explore clients’ values and beliefs about sexual behavior. Attitudes about HIV transmission, factors associated with risk and barriers to risk reduction, and sexual self-efficacy or self-esteem are areas that need exploration. Most health care providers suggest that questions should include information about sexual partners, types of protection used, history of forced sex and sexual activity related to substance abuse (Poindexter & Linsk, 1999). We need also to provide an extensive framework for initiating a sexual history.

### ***Spirituality***

As with older adults, spirituality is often important in the lives of people with HIV disease. “Feelings of spirituality may be long standing or may be triggered by knowledge of having a life-threatening disease. People may attempt to reconnect to religious traditions from the past or turn to philosophies or religions new to them.” (Poindexter, 2000, p. 20). Social workers and other health “professionals need to become comfortable listening to the spiritual concerns of clients. It is helpful to ask clients about their spiritual and religious beliefs, helping

them understand where to access spiritual resources that are HIV sensitive can be a great help.”  
(Poindexter, 2000, p. 19).

### ***Overview of Cognitive Screening***

A 1994 survey by the research Committee of the American Neuropsychiatric Association revealed that 58% of psychiatrists and related health care providers employed formal assessment of cognitive status; the Mini-Mental State Examination (MMSE) and neuropsychological testing were the most common techniques (Malloy, 1997). A literature review of common cognitive screening instruments revealed that the MMSE has widespread popularity, is easy to use, and a large body of research demonstrates its sensitivity to common neuropsychiatric disorders (Chodosh, 2000). Cognitive screening can also be used longitudinally to track disease progression or response to treatment.

Using standard instruments for cognitive screening is encouraged for several reasons. Cognitive impairment is often overlooked by health care professionals who do not routinely conduct formal mental status examinations. For example, mild cognitive and behavioral changes after head injury are often underdiagnosed. In addition to the MMSE, a number of widely used and well-researched cognitive screening tests are available, i.e. the Mini-Mental State Examination, Cognitive Capacities Screening Examination, and the Short Portable Mental Status Questionnaire (Pfeiffer, 1975).

A number of relatively common tests that are used to measure dementia, i.e. the Dementia Rating Scale (Matties, 1973), and the Alzheimer Disease Assessment Scale (Devenny, Hill, & Patxot, 1992), can also be considered screening tests. A number of other instruments are designed for more specific purposes. For example, the Executive Interview (Royall, Mahurin, &

Gray, 1992), the Frontal/Subcortical Assessment Battery (Rothlind & Brandt, 1993), and the Clock-Drawing Task (Royall, 1998) were designed to measure deficits commonly found in association with the frontal lobe. These instruments may be of value when used in combination with general cognitive screening instruments in certain populations.

Most of the general cognitive screening instruments used by health care professionals (a) can be administered by health care providers at all levels of training, (b) require 5 to 15 minutes to administer to most clients, (c) provide samples from all major cognitive domains including orientation, attention/concentration, executive, language, and memory functions, (d) demonstrate adequate test-retest and interrater reliability, and (e) demonstrate acceptable sensitivity to disorders commonly encountered by neuropsychiatric practitioners (Gaugler, Kane, & Langlois, 2000). It is important to remember that cognitive assessment is only one aspect of a thorough evaluation. Medical history, family report, emotional functioning, social behavior, and functioning in activities of daily living must all be included in the neuropsychiatric examination, as well as social workers' evaluations.

### ***Limitations of the MMSE***

Folstein's (1975) MMSE requires approximately 12 minutes to administer to most clients and contains items designed to assess a reasonably wide range of functions, including (a) orientation to time and place, (b) attention and concentration, (c) language functions (following a three-step command, repeating a difficult phrase, naming high-frequency items, reading and following a written command and writing a sentence), (d) construction, (e) verbal learning, and (f) short-delay recall. However, the MMSE has a number of limitations in content: (a) it does not directly assess executive or frontal lobe functions and may, therefore, be insensitive to disorders such as Pick's disease, in which other cognitive domains are frequently intact, (b) assessment of

most abilities are limited to single items with no graded scoring (for example, the relatively complex intersecting pentagon drawing is simply scored either correct or incorrect), (c) administration is not well standardized, resulting in variability across examiners, and (d) the MMSE presents relatively modest intellectual challenges and is insensitive to mild cognitive changes (Malloy et al., 1997).

### ***Rationale for Using Clock Drawing Task***

Royall (2002) held that the Clock-Drawing Test is less vulnerable to linguistic, cultural, or educational bias than traditional dementia screening instruments. Prior studies found that both CLOX 1 (an executive test that asks clients to draw a clock face showing 1:45) and CLOX 2 (a constructional test—copy a clock that shows 1:45) have good internal consistency (both Cronbach alphas 0.82). Cultural demographic variables had little effect on the clock scores. Although language had a significant effect on CLOX 1 failure rates, this was not mediated by age, education, acculturation, or income (Royall et al., 2003). The executive demands of clock-drawing are shared with independent living skills, i.e., cooking, dressing, using restroom, shopping and medical treatment compliance (making and keeping appointments, taking medications as prescribed, etc). In this sense, clock-drawing performance may mirror the performance of more functionally relevant behaviors that are also under executive control. Executive dyscontrol is associated with cortical and subcortical frontal system lesions (Royall et al., 2002).

Failure to detect cognitive impairment can result in a domino effect of medical and psychosocial problems. The Folstein MMSE (1975) is a good step in evaluating cognitive impairment, but it is designed to assess gross cognitive functioning and may not detect early dementia. It is also insensitive to impairments in executive functioning, such as planning,

organizing, abstract thinking, sequencing, and judging. Finally, it is not a good screen for individuals with less than a ninth grade education (Royall, 2000).

There are several ways to compensate for these weaknesses. Adding a clock drawing test to the preliminary assessment is useful because it provides basic information regarding planning and organizational skills. A number of clock drawing tests are available and scoring schemes vary widely (Royall & Espino, 2002). Royall and colleagues recommend the clock tests because they differentiate between executive and constructional impairments (Royall, Cordes, & Polk, 1998). Isolating problems with executive impairment is crucial in assessing the patient's functional capacities. Like the Folstein, however, a clock drawing test may not be as reliable with poorly educated clients. If the client is in the hospital, the hospital should be asked if a social worker or a nurse can complete ongoing daily mental status exams.

Evaluating the client at several points in the day will help determine whether cognitive status is fluctuating over time or relatively stable. It is important to remember that normal on the Folstein MMSE does not mean that they are also normal in the clock-drawing task because MMSE does not detect executive cognitive impairment. Therefore, more specific testing is needed to determine if, for example, failure on the MMSE is caused by depression, executive function impairment, dementia, or the result of a combination of any of these factors. Sometimes, there will be normal results on Folstein's (1975) MMSE and the clock drawing test, but functional assessment will continue to suggest subtle cognitive problems. When in doubt, social workers and other health care professionals should refer clients for more specific neuropsychological testing. However, in reality, the neuropsychological testing is expensive and the referral system might not be working due to the lack of awareness of executive cognitive dysfunction issues in the primary care settings. As I mentioned earlier in this chapter, we need to

work collaboratively with other health care professionals so that we can create more effective ways to detect dementia in earlier stages.

### ***Social Work's Assessment of Executive Cognitive Functioning***

When cognitive impairment is identified, the social worker and other health care professionals need to be aware of clients' functioning in their daily lives. We could ask ourselves if this client can safely (a) spend (look for evidence that finances are handled responsibly), (b) cook (ask if the client has left the stove on or the water running), (c) operate a car (ask about driving accidents and incidents), (d) take medications (check to see if medications are taken as prescribed), (e) perform everyday activities of daily living (assess safety in ambulating, dressing, toileting, and showering), and (f) make rational decisions (determine competence for safety-related decisions and judgments, Table 1).

It is important that the client have the capacity to make sound safety-related decisions, particularly in reaction to crises. For example, the client can be

**Table 1***Indicators of Executive Cognitive Functions*

<i>Safety</i>	<i>Executive Cognitive Function Indicator</i>
Spend	Look for evidence that finances are handled responsibly
Cook	Ask if the client has left the stove on or the water running
Operate a car	Consider referral for driving evaluation. Ask about driving accidents and incidents
Take medication	Check to see if medications are taken as prescribed
Perform Activities of Daily Living	Assess safety in ambulating, dressing, using restroom, and showering
Make Rational Decisions	Determine competence for safety-related decisions and judgments

asked, “What would you do if you ran out of medicine?”, “What would you do if there was fire in the house?”, or “Where is the fire extinguisher and how do you use it?” Decision-making requires judgment, executive functioning (ability to organize and follow steps), and memory. Be sure that clients responses are reasonable and reflect the level of independence necessary for their living situations. Prior studies suggest that clients with early dementia may be able to respond appropriately to these questions and learn cognitive tasks over time (McArthur, Hoover, & Bacellar, 2004). Social workers and other health care professionals should always discuss the safety concerns with family members and friends who can provide information about the client’s real functioning. Always through the lens of maximizing client autonomy, health care social workers need to make recommendations to ensure that the client is safe. When the causes of the client’s cognitive impairment are identified, it can be tempting to overlook immediate safety concerns; however, until there is evidence of normal cognitive functioning, safety should remain a primary concern (Gaugler, Kane, & Langlois, 2000).

### ***Social Support and Social Work Indicators***

Social work intervention can be multifaceted, and we can help our clients most effectively by bridging social services and services delivered to their homes. For mild executive cognitive functioning clients, a combination of in-home programs might be acceptable. For example, visiting nurses can assist with medications and personal hygiene while the family provides limited supervision. Careful assessment is always an important aspect of developing an appropriate supportive plan (Emlet, 1997). In some cases, the degree of impairment will make it unsafe for the client to be alone. When the client cannot be left alone and the family is unable to provide the needed level of supervision, nursing home placement or adult foster care may be considered. In this situation, social workers need to provide consultation to find the least restrictive environment for each client's level of functioning. Unfortunately, executive cognitive functioning issues are not seen as traditional social work interventions nor are they reactive for many other professionals' concern. However, all health care professionals need to be aware of the needs for services and support networking (Emlet, 1997).

Assistance at any level is often difficult for the client and the family to accept. For individuals accustomed to the freedom of independent living, personal losses associated with cognitive decline can be devastating. Loss of privacy, loss of control over daily routine, and loss of freedom are some painful adjustments with which clients struggle. Social workers and other health care professionals must be prepared to deal with all possible types of reactions to behavioral restrictions, including anger, grief, and a sense of betrayal. The client's feelings should be acknowledged and the reasons for the adjustment explained. One of social work's roles is to educate families about disease processes and suggest helpful coping skills (Poindexter, 2000).

### *Clock Assessment of Executive Cognitive Function in Individuals Over 50*

There is scant research on HIV/AIDS in the older adult population and their levels of executive cognitive functioning, even though the deterioration of these functions causes some of the most pressing problems for adults as they age. Executive functioning is a cognitive process that orchestrates complex, goal-directed activities (Royall, 2004). These activities include functions such as cooking, dressing, and housework. Traditionally, executive control function impairment has been associated with conditions such as major depression, Alzheimer's disease, subcortical vascular disease, adult-onset diabetes mellitus, and normal aging (Royall, 2004).

Despite the number of older adults contracting HIV, little attention has focused on how people with this disease are aging. The aging process and HIV infection each exert unique physiological effects on the nervous system that affect cognitive functioning; combined, they may be particularly damaging to both cortical and subcortical regions of the brain. Cortical regions include the outer layer of the brain such as the frontal and temporal lobes that are responsible for language and higher thought processes. Subcortical regions include structures, such as the basal ganglia and substantia nigra which are responsible for smooth motor movement and the ability to initiate and sustain action and thought (Caparros-Lefebvre, Pecheux, Petit, Duhamel, & Petit, 1995; Pugh & Lipsitz, 2002). Cortical and subcortical changes in the brain have been observed in aging persons *and* in those with HIV. Although dementia is well known for its profound impairment in cognitive ability, subtle cognitive declines associated with normal aging are also well-known in the literature (Fry & Hale, 1996; Korten et al., 1997; Schaie, 1996).

The history of executive control functioning during normal aging cannot be easily derived from the existing literature, partially because popular screening measures such as the MMSE do not pick it up. The clock drawing test, however, has been extensively used in studies

of cognitive impairment and as a companion to more conventional measures such as the MMSE (Royall et al., 1998 & 2004).

The clock drawing test is a screen for cognitive impairment. In addition to dressing, for example, executive control functions also include cognitive tasks that lead up to dressing, i.e. planning; or recognizing the need to be dressed in a certain way by a certain time; selective attention, i. e. deciding what to wear; and self monitoring the plan, or determining that the clothes are appropriate and adequate. Royall and colleagues suggested that all of these abilities are required by clock drawing (Royall, Cordes, & Polk, 1998). In addition, clock drawing tests have been found to correlate significantly with traditional cognitive measures and to discriminate healthy from demented elderly clients (Royall, Cordes, & Polk, 1997). Also, persons with impaired clock drawing skills are more likely to have problems with self-management of a complex medical regimen (T. P. Miles, Personal Communication, March 26, 2004). I will also explain this in more detail in Chapter 3.

### ***Problem Statement Revisited***

Since the start of the HIV and AIDS epidemic more than two decades ago, social workers, doctors, caregivers and patients themselves have observed that some people with the disease experience declines in brain function and movement skills. Daily living activities and quality of life are affected by neurocognitive impairment (e.g., self-management, planning, sequencing, adherence to medication, and scheduling appointments). Few studies have examined whether cognitive declines in the older adult population translate into functional impairment.

Most studies have examined the risk factors for Executive Cognitive Function (ECF) in patients with depression or brain/head injury, but not with HIV/AIDS-related illnesses (Cahn-

Weiner, Boyle, & Malloy, 2002). Since both aging and HIV disease are everywhere in social work practice, social workers will increasingly need to be prepared to provide assessment and other social work services to older persons who are infected and cognitively impaired by HIV disease. The demands of life are much more complex than the demands of the clock-drawing task screening tool. When cognitive impairment is suspected, there are important steps to take to ensure effective client care and safety.

### *The Research Question*

In the interest of the differences between executive cognitive impairment and HIV/AIDS, as well as aging and needs of social services, the following research question is posed: **What is the difference in the means of executive cognitive function scores (Dependent Variable, DV) between (a) clients known/not known to be diagnosed as having HIV/AIDS (Independent Variable, IV1), (b) clients receiving services in clinics providing/not providing social services (IV2), (c) gender (IV3), and age (IV4)?** Additionally, I am interested in comparing differences between clinical and research scoring, discussed in the methodology section.

### *Conclusion*

In conclusion, although there will be individual differences depending upon medications, coping patterns and strategies, substance abuse, and disease status, this summary of literature suggests that people aging with HIV might be vulnerable to particular cognitive declines related to functioning, such as initiation and abstraction that are associated with subcortical structures. Yet most studies of cognitive functioning of those with HIV ignore age, despite the likely associations between age and mental functioning. The manner in which such a change occurs has

implications for autonomy and quality of life for older adults with HIV, and warrants further investigation.

In this chapter I explored the epidemiology of HIV/AIDS and aging. I also proposed a rationale for appropriately using an executive cognitive function screening instrument. A detailed review of literature was followed by the research question. In the next chapter, I will describe the research methodologies used in this study.

## CHAPTER III

### METHODOLOGY

This chapter describes a new methodology, Real Time Research, and how the data were collected from a purposive sample. Sections include (a) the research design, (b) protection of human subjects, (c) sampling and data collection procedures, (d) variables under study, and (e) the clock measurements. Recall the research question: **What is the difference in the means of executive cognitive function scores (Dependent Variable, DV) between (a) clients known/not known to be diagnosed as having HIV/AIDS (Independent Variable, IV1), (b) clients receiving services in clinics providing/not providing social services (IV2), (c) gender (IV3), and age (IV4)?**

#### *Research Design*

Real-Time Research is a new methodology that is designed to collect data in a way that minimizes disruption of client care while conducting research in clinical settings (T. P. Miles, Personal Communication, March 26, 2004). Researchers have traditionally placed themselves on the outside of clinical phenomena, attempting to be more objective observers who are not involved in the events under study—somewhat like watching a movie. Real Time Researchers, on the other hand are actually *in* the movie and know what is going on every moment. Researchers present the preliminary results to the staff the very next day, much like actors and directors conferencing about a day's shooting and planning the scenes and shots for the next day.

In conducting Real Time Research, researchers may find themselves more welcome in clinical settings that have little time for additional protocols, not to mention the traditional problem of research procedures increasing the time that clients must be in treatment settings.

This method comes closer to a marriage, or at least a partnership, between researchers and clinicians, instead of the more common and somewhat adversarial relationship between clinicians and researchers. Clinicians do not want their work flow interrupted by additional research procedures, and researchers do not understand why clinicians are not 100% invested in the potential information that will help both their patients and the work flow of the clinic.

By being there, Real Time Researchers can interact with clinicians and support staff, thereby gaining a better understanding of the contexts underlying their potential findings. This is a critical point and others have spoken to the importance of contextualizing results to avoid any misrepresentation of the results (Huber, Borders, Netting, & Kautz, 2000).

Real Time Research can also be conceptualized as the other side of Participatory Action Research coin which includes participants in every phase and decision of the research, beginning with the question to be studied (Fals-Border & Rahman, 1991; Freedman, 2001; Hagner, Helm, & Butterworth, 1996; Kitchen, 2000; Lazlo, 1996; Oliver, 1992; Sample, 1996). The goal of Real Time Research, on the other hand, is to include researchers in the treatment milieu.

Juxtaposed to Participatory Action Research, Real Time Research is designed to include the researcher in the participant's clinical setting so that the researcher fully sees, hears, and understands the contexts in which data were collected, while disrupting the clinical setting as little as possible. Researchers are interacting with everyone in the client's clinical environment and observing all of the environmental elements, i.e. weather, holiday spirit, or pervasive sadness emanating from a colleague's personal crisis. It is the difference between *hearing about* an event and having *observed* the event first hand. In short, *Participatory Action Research includes subjects in the research, while Real Time Research includes researchers in practice.*

### ***Protection of Human Subjects***

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To answer the research questions, I used a quantitative cross-sectional research design. Utilizing Real Time Research and the research designs posed by Campbell and Stanley (1963), a posttest-only control research was chosen. The unit of analysis was the individual client while the main grouping variable was the HIV/AIDS clinic site. The study was approved by the Institutional Review Board in March, 2004. In the following the sections, I discuss the methodological processes that were undertaken and discuss the potential threats to internal and external validity.

### ***Sampling and Data Collection Procedures***

The Department of Family and Geriatric Medicine at the University of Louisville maintains 8 clinical sites for medial training. These sites include 4 in urban Louisville (ACB, WINGS, Iroquois, and Newburg) and 1 in a rural area. The rural site is located in Glasgow, KY at the TJ Sampson Medical Center Complex. The other three are Federally Qualified Health Clinics. Services for these clients are paid for in various ways, i.e. private insurance, Medicare, Medicaid and self-pay.

The research team collected data for four full day of clinic sessions in each of eight clinics in Louisville, Kentucky (see Appendices C – L): (a) University Hospital’s primary care clinic in the Ambulatory Care Building [ACB], (b) University Hospital’s WINGS clinic that serves HIV/AIDS clients, and six community clinics that are under University Hospital’s primary care clinics, Department of Family and Geriatric Medicine: (c) Glasgow, (d) Iroquois, (e) Newburg, (f) Park DuValle, (g) the Family Health Center, and (h) the Women’s Clinic. Table 2 provides a brief explanation of each of these sites.<sup>1</sup> The process of collecting data was discussed

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<sup>1</sup> Throughout the rest of the dissertation these clinics will be referred to by pseudonyms of Kentucky Derby winners. However, e.g., Smarty Jones will refer to the same clinic throughout.

and shaped by all parties in each clinic prior to beginning the study. Preliminary findings were discussed during a regular staff meeting the next day when all health care providers and support staff in the clinic were present (doctors, social workers when on staff, nurses, nursing assistants, pharmacists, and the receptionist). Results were discussed and decisions were made about the next steps.

**Table 2**

***The Clinics where Clients were Interviewed***

1	<b>War Emblem, n = 90.</b> All of the clients in the War Emblem Clinic are HIV/AIDS and there is a strong social service component. The clinic is located on the 2 <sup>nd</sup> floor of the Funny Cide building (#6) and staffed by Family Medicine and Internal Medicine Infectious disease specialists. War Emblem has 9 exam rooms and serves an average of 15 - 20 patients daily. All labs are done at the University of Louisville hospital. Patients seen at this clinic come from Louisville and the 6 surrounding counties. Staff includes 3 MDs, 2 Nurse Practitioners, 2 Administrative support staff, 1 Social Worker, and 1 or 2 Pharmacy students.
2	<b>Monarchos, n = 153.</b> Also has a strong social service component and a majority of the population is African American—many more than any other clinic. The clinic is a free standing in a 40,000 square foot, 2-story building which includes a lab. Staff consists of 9 MDs, 12 Nurse Practitioners 30 Administrative support staff, and 1 Social Worker. There are 21 exam rooms and an average of 40 – 70 patients are seen per day.
3	<b>Real Quiet, n = 133.</b> This clinic has no social worker on staff, but has a strong educational component, even hosting medical student interns.
4	<b>Fusaichi Pegasus, n = 113.</b> This clinic is outstanding in its organizational skills and good transportation services, and is seen as an ideal clinic setting. It is located about 5 miles southeast of the Health Science Center campus in a 2-story building that houses several other medical offices. Staff includes 4 MDs, 12 Residents, and 8 Administrative support staff. They have 12 exam rooms and serve an average of 40 - 60 patients daily.
5	<b>Silver Charm, n = 103.</b> This clinic is the only clinic of the University of Louisville's Department of Family and Geriatric Medicine that is in a rural area. Although there are no social services, patients have strong family support systems. The clinic serves a population of about 200,000 in a 6000 square foot, hospital-based clinic. All labs are done on site. Staff is 2 MDs; 1 Nurse Practitioner; 4 Medical Students; 2 Nursing Students; 12 Residents; 5 Administrative support staff.
6	<b>Funny Cide, n = 95.</b> This clinic is part of the University of Louisville hospital system and operates in a 3-story building that houses the other primary care clinics and a full-range of specialty clinics for the University of Louisville. The clinic itself is small and has insufficient workers to adequately serve the highest numbers in the study. The staff cannot do any follow-up, and this system is designated as the

	<p>one in the city that must serve indigent citizens. Residents and faculty see patients 5 days a week, It primarily those who are under-insured and indigent. The staff consists of 5 MDs, 6 residents, 1 nurse practitioner, 1 Physician Assistant, and 10 administrative support staff. There are 8 exam rooms and the staff sees an average of 20 – 45 patients per day.</p>
7	<p><b>Smarty Jones, <math>n = 53</math>.</b> The highest percentage of older persons are served here, space is extremely limited, and it has the lowest ratio of workers to clients. Many clients struggle with English as a second language. Although one worker speaks Russian, the client population is very diverse and language is a problem. The clinic is in a 2-story building that houses a lab and one other family medicine practice (Smarty Jones Medical Group). It has 8 exam rooms and is about 5 miles south of the Health Science Center campus. The staff consists of 4 MDs, 6 Residents, and 6 administrative support staff who see an average of 32 – 35 patients per day.</p>
8	<p><b>Charismatic, <math>n = 46</math>.</b> This clinic has no Social Worker on staff but provides prenatal and parenting education for this youngest population in the study. Most of the women are between 18 and 35.</p>

### ***Resource and Environment of the War Emblem Clinic***

The War Emblem Clinic is the only 1 of the 8 clinics that solely serves HIV/AIDS clients, and *all* of the HIV/AIDS clients are served in the War Emblem Clinic. I later recode this variable, clinic, into a dichotomy were 1 = War Emblem clients (or those with HIV/AIDS), and 1 = information from clients served by the other seven clinics. As an independent variable, therefore, I will explain a little more about the War Emblem Clinic.

War Emblem operates with federal funding from the Ryan White CARE Act, providing comprehensive medical care for individuals infected with HIV/AIDS and support services for clients and their families. Below is a list of services the clinic offers and other programs to which clients are referred.

1. ***Family support:*** family support is available to families of women and youth (ages 13 - 24) and children infected with HIV. Services include meal tickets during clinical appointments, diapers, food boxes, and prevention/intervention services, HIV testing, safer sex presentations, client-centered support groups, consumer advisory group, and referrals to community support services.
2. ***Dental*** services to clients are provided by the University of Louisville School of Dentistry. Services include dental screening, cleaning, oral surgery and dentures as appropriate. All War Emblem clients are referred to the Dental School, conveniently located community-based clinics, or to their private dentists for routine care.
3. ***Mental Health*** services are provided by a board certified psychiatrist available by appointment in the War Emblem Clinic. The clinic, also, have a therapist available for

counseling. These services are free of charge. The clients may also be referred to other counseling agencies throughout the Metro Louisville area.

4. ***Social Services*** are provided by a full-time Social Worker who can assist with various needs Monday through Friday from 7:30 am to 4:00 pm. The Social Worker provides information or resources for (a) financial assistance, (b) support groups, (c) transportation, (d) disabilities, (e) assistance with obtaining medications, (f) pregnancy, (g) sexually transmitted diseases and safe sex, and (h) food or housing. The social worker also provides clients with literature about HIV/AIDS and other topics. If the client's partner or loved one (over age 13) would like to be tested for HIV, the client may also call the Social Worker to ask for a confidential HIV test using a mouth swab.
5. ***Legal Services*** are available by phone or appointment to ensure that low income individuals have access to civil legal services such as bankruptcy, will preparation, and divorce, regardless of the ability to pay. Such services include issues of insurance, discrimination, access to care, testing and confidentiality issues, housing, and disability applications. The clinic, however, does not provide legal assistance with criminal cases.
6. ***AIDS Interfaith Ministries of Kentuckiana***: AIDS Interfaith Ministries of Kentuckiana is a group of clergy, laity, and community professionals and volunteers of all faith perspectives who are committed to offering practical emotional and spiritual support and counseling to individuals and families living with HIV/AIDS.
7. ***House of Ruth***: This stand alone agency provides a compassionate, listening presence, free of judgment and discrimination to HIV positive persons and families who come for assistance, and its staff members serve as connectors to other community resources. The

House of Ruth also provides emergency financial assistance when possible, and medical support in understanding HIV/AIDS, spiritual care and wellness retreats. The Housing Program for individuals and their families provides case management and support while clients enter a rental assistance program and stabilize their housing. Participants receive a percentage of their rent from one of three programs: Section 8, Housing Opportunities for Persons with Aids (HOPWA), or Shelter Plus Care.

8. **Substance Abuse** counseling is available in War Emblem for the clinic's clients through the Volunteers of America. Federal funding guidelines suggest that all clients who have used beer or alcohol in the past six months, or who use or have used marijuana, cocaine or other recreational substances, are referred to a substance abuse counselor for assessment. A wide variety of treatment programs including outpatient, residential and half-way house services are available with War Emblem clinic funding when private funds are lacking.
9. **Pharmacist:** A War Emblem pharmacist is available to assist clients with understanding their illness and the medications needed to fight the virus. The pharmacist can educate the client on the necessity of taking clients' HIV medications every day and help with designing a plan to fit the individual's lifestyle. If the client is experiencing side effects from their medications or any problems with dosing, the client may contact the War Emblem Clinic to schedule an appointment.
10. **Clinical Trials:** the War Emblem clinic has access to the newest medication and diagnostic tests for HIV and related diseases through clinical research studies. The client may be referred to the study nurse in the clinic by the client's medical provider.

### ***Sampling***

Samples should closely represent the population of interest—in this case, clients with HIV/AIDS. Thus we drew a purposive sample by accessing HIV/AIDS clients served by the university's War Emblem clinic as the treatment group, and used data from the other seven clinics for a comparison group. All clients in the War Emblem clinic have HIV or AIDS diagnoses, and none of the clients in the other clinics have these diagnoses.

By approaching clients who were served by each of the eight clinics on the day the researchers were on site, there is no known bias at the onset ( $n = 786$ ). All respondents gave written, informed consent using an English protocol approved by the University of Louisville Institutional Review Board. Participants included 90 HIV-positive adults (55 men and 35 women—two of the independent variables, HIV/not, and gender), and 696 from the other seven sites shown in Table 2.

### ***Data Collection Procedures***

Real Time Research means that clients are invited to participate in research only when they are present for routine services, and efforts were made to make the research as unintrusive as possible—not requiring significantly more time or energy commitments from either clients or staff. Clinic clients who agreed to participate were interviewed by trained research team members from two different disciplines from the following group: the Principal Investigator who holds an MD and a Ph.D., a Nurse, a Medical student, and a Social Work doctoral student.

Clients were approached in examination rooms after nurses had taken their vital signs and while they were waiting on physicians to examine them. This provided the privacy and lack of distraction necessary to follow instructions. Participants were told that this was not a mandatory

test and that refusal to participate would not influence the care they would receive. After obtaining consent, clients were given a form and asked to draw a clock showing 1:45, drawing the hands and numbers on the face so that even a child could read them (Royall, 1998). The task usually took no more than 5 minutes to administer. After clients had drawn in the face of the clock, the examiner thanked them and told them that their physicians would be in shortly, and left the room. Researchers were trained not to comment on the quality or meaning of any individual clock and there were no adverse events resulting from poorly drawn clocks.

Data were collected in this manner by a University of Louisville, Department of Family and Geriatric Medicine research team. Clock drawings that assessed executive cognitive functioning were collected from every consenting client 18 and older who presented for services on the days that the research team was in each clinic. In this study, I choose to not to include copy CLOX due to not related with executive cognitive functional level.

### ***Variables Operationalized***

There are several independent variables: (a) age, (b) recoded age groups, (c) gender, (d) clinic, or site, (e) whether social services are present, and (f) whether there is an HIV/AIDS diagnosis. The primary dependent variable is the score from the CLOX test (drawing in the face of the clock). The variables are operationalized in Table 3.

### ***The Executive Function Clock Drawing Task***

The clock drawing procedure was administered in one way (draw a clock that says 1:45), but scored two different ways, one that produces an acknowledged clinical score (Borson, Scanlan, Brush, Vitaliano, & Dokmak, 2000), and one that is research based (Royall, 1998).

**Clinical CLOX** scoring ranges from 0 to 4 with lower scores reflecting greater impairment (Table 4). For example, if clients drew closed circles but could not place numbers in their proper positions or place the hands properly, their scores would be 1 (Royall, 1998). The rating items are shown in Table 4.

**Research CLOX** scoring ranges from 0 to 14 (Table 5). As with the clinical scoring, lower scores reflect greater impairment. For example, if clients' clinical drawings accomplish only the first three tasks in Table 5 but no more, their scores would be only 3. Clearly, the *research* scoring system is more discrete than *clinical* scoring (Royall, 1998).

**Table 3**

***Operationalization of Data Variables***

Variable		Operationalization	Data Level
<b>Independent Variables</b>			
1	Age	Actual age	Ratio
2	Age Groups	0 = 18-49 1 = 50-older	Nominal
3	Gender	0 = Female 1 = Male	Nominal
4	Clinic	0 = Funny Cide 1 = War Emblem 2 = Smarty Jones 3 = Monarchos 4 = Fusaichi Pegasus 5 = Silver Charm 6 = Family Health Center 7 = Charismatic	Nominal

5	SocServ: Whether receiving social services	Recoded from Clinic variable: Only the War Emblem and Monarchos clinics provide social services; thus  1 = Yes, receiving SS  0 = No, Not receiving SS	Nominal
6	HIVAIDS: Whether client has HIV/AIDS diagnosis	Recoded from Clinic variable: All HIV/AIDS clients are referred to the War Emblem clinic; thus  1 = HIV/AIDS  0 = Not HIV/AIDS	Nominal
<b>Primary Dependent Variables</b>			
7	Clinical CLOX		Computed by summing scoring points: Ratio
8	Research (draw)		Computed by summing scoring points: Ratio

**Table 4*****Clinical CLOX Scoring***

	<b>Organizational Elements</b>	<b>Points</b>
1	Draw closed circle	1
2	Placed numbers in correct position	1
3	Includes all 12 correct numbers	1
4	Places hands in correct	1
	Highest possible score	<b>4</b>

**Table 5*****Research CLOX Scoring (adapted from Royall, 1998)***

<b>Scoring the Research CLOX</b>		
Have the subject draw a clock at the bottom of the form. Instruct him or her to “Draw a clock that says 1:45. Set the hands and numbers on the face so that a child could read them.” Repeat the instructions until they are clearly understood. Once the subject begins to draw no further assistance is allowed. Rate this clock. The score may range from 0 to 14, with lower scores indicating less impairment.		
<b>Organizational Elements</b>		<b>Points</b>
1	Figure resembles a clock	1
2	There is an outer circle	1
3	Diameter > 1 inch	1
4	All numbers inside the circle	1
5	Spacing Intact (Symmetry on either side of the 12-6 axis) If yes, skip next (#6).	2
6	If spacing errors are present, there are signs of correction or erasure	1
7	Only Arabic numerals used	1
8	Only Arabic numbers 1-12 are used	1
9	Sequence 1-12 intact (No omissions or intrusions)	1
10	Only two hands are present	1
11	All hands represented by arrows	1
12	Hour hand is between 1 and 2 o'clock	1

13	Minute hand is longer than the hour hand	1
14	None of the following are present:	1
	1) Hand pointing to 4 or 5 o' clock	
	2) 1:45	
	3) Intrusion of <i>hands</i> or <i>faces</i> (actually drew human hands or faces)	
	4) Any letters, words or pictures	
	5) Any intrusion from the circle below	
	Highest possible score	14

Item 2, 8, 9, and 12 are clinical scale items in scale (shaded). Note that if #5 is intact, #6 is skipped.

The Research CLOX instructions can be repeated until they are clearly understood, but once the subject begins to draw no further assistance is allowed. The participant is presented only with a blank surface and no further guidance regarding the task. The Research CLOX reflects performance in various ways. Clients are responsible for choosing the clock's overall form (a digital or analog face, alarm clock, wrist watch, or wall clock, etc.), its size, position on the paper, elements (hands, numbers, date, indicators), and the forms of these elements (hands as arrows, relative lengths, Roman versus Arabic numerals, etc.).

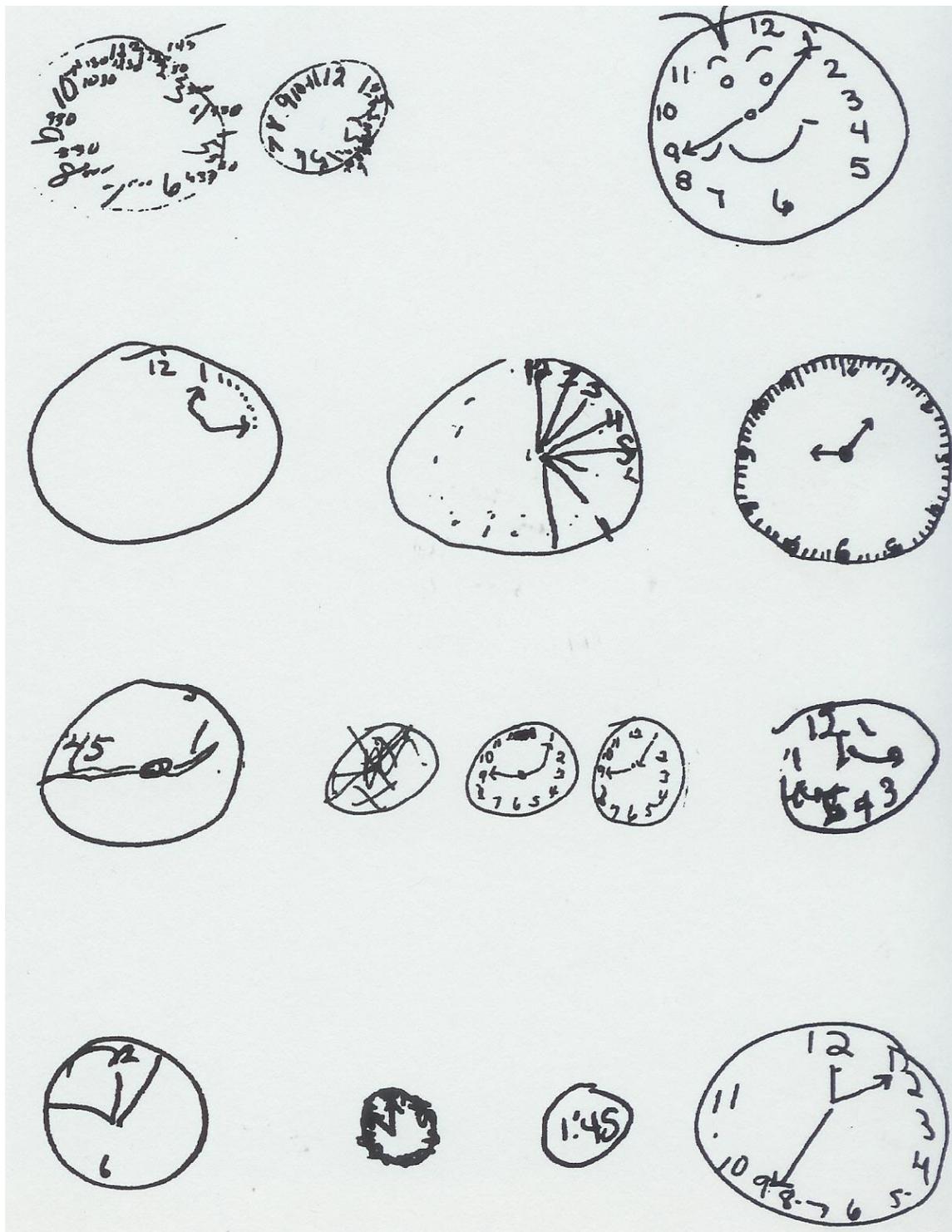
Furthermore, the subject must also initiate and persist in clock drawing through a sequence of constructional actions (usually drawing the outer circle, followed by placing the numbers, followed by setting the time).

Finally, the Clock form and its verbal instructions have been designed to distract the subject with strongly associated but irrelevant cues. The survey instructions use the words *hand* and *face* because they are more strongly associated with body parts than clock elements and may trigger semantic intrusions from their more common meanings. Moreover, the number *45* does not appear on a typical clock face and may intrude into the client's construction in the form of a digital image (1:45) or hands pointing to the four or five o'clock positions.

Figure 3 shows examples of clock faces drawn by cognitively impaired individuals with various medical complications: a 35 year old male with HIV/AIDS, a 24 year old pregnant female, a 39 year old female with high blood pressure, a 51 year old male living by himself, a 34 year old male with depression, and a 36 year old male with HIV/AIDS.

### ***Conclusion***

The research questions are answered in the next chapter and formulae are provided for Sensitivity and Specificity, and Age Adjusted Prevalence rates. In Chapter 5 I discuss political and ethical issues that boil around the issue of how people are categorized by their level of executive cognitive impairment and the implications of resulting decisions on social work practice.



**Figure 3.** Examples of clock faces drawn by clients with varying degrees of executive cognitive impairment.

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## CHAPTER IV

### RESULTS

Recall the research question: **What is the difference in the means of executive cognitive function scores (DV) between the independent variables (a) clients known/not known to be diagnosed as having HIV/AIDS, (b) clients receiving services in clinics providing/not providing social services, (c) gender, and (d) age?** Table 6 separates these questions and shows how the answers were found.

In this chapter I (a) separate the five specific research questions, (b) overview different statistical analyses used, and (c) briefly provide demographics. I then discuss (d) Clinical and Research CLOX scoring, and (e) present and answer research questions. Question 4 is answered in three different ways, one of which introduces (f) the concept of age adjusted prevalence rates.

#### *Five Specific Research Questions*

Table 6 shows five specific research questions to be answered in this chapter. Together, the answers provide a complex picture of the dance between executive cognitive functioning in individuals, analyzed by HIV/AIDS, age, and other compounding variables.

**Table 6***Analysis of Research Questions*

<b>Research Questions</b>		<b>Data Transformations and Analyses</b>
1	What is the difference in the means of executive cognitive function research and clinical scores (DVs) between clients known/not known to be diagnosed as having HIV/AIDS (IV).	<ul style="list-style-type: none"> <li>a. Recoded Site into a dichotomous variable where 0 = HIV/AIDS clients from the War Emblem clinic, and 1 = non-HIV/AIDS clients from all other sites.</li> <li>b. Summed Clinical and Research CLOX scores.</li> <li>c. Conducted independent t-test with the scores as the testing variables, or DVs, and HIV/AIDS (Yes/No) as the IV.</li> </ul>
2	What is the difference in the means of executive cognitive function research and clinical scores (DVs) by gender (IV).	Conducted independent t-tests with the scores as DV, and gender as the IV.
3	What is the difference in the means of executive cognitive function research and clinical scores (DVs) by whether clients were served in a clinic that provided social services (IV).	<ul style="list-style-type: none"> <li>a. Recoded site into a dichotomous variable, i.e. SocServ, where 0 = Clients from War Emblem, Monarchos, Real Quiet, and Charismatic, and 1 = Clients from all other sites.</li> <li>b. Conducted independent <i>t</i>-tests with the scores as the testing variables, or DVs, and Social Services (Yes/No) as the IV.</li> </ul>
4	What is the difference in the means of executive cognitive function research and clinical scores (DVs) and clients' ages (IV)?	<ul style="list-style-type: none"> <li>a. Conducted Pearson correlation using both research and clinical scores (DVs) with actual age (IV).</li> <li>b. Conducted Oneway Analysis of Variance with Research and Clinical scores (DVs) with the three age categories (IV).</li> <li>c. Age adjusted prevalence rates by clinic.</li> </ul>
5	What are the predictors of Clinical and Research scores of Executive Cognitive Functioning?	Regression analyses were conducted.

### ***Overview of Statistical Analyses***

Independent samples *t*- tests were conducted because the dependent variables (Research and Clinical scores) are continuous variables. Although originally nominal, they were summed and treated as ratio because I treated as scale which is its continuous variable (Rubin & Babbie, 1997; Schutt, 2001; Tabachnick & Fidell, 2001). Independent variables that can be used in tests include diagnosis (HIV/AIDS yes/no), gender, age, and social services present (yes/no).

Conducting six *t*-tests increases the danger of making Type 1 errors (inappropriately claiming statistical significance) with an alpha of .05. Therefore a Bonferroni correction is necessary which brings the acceptable level to assert a statistically significant finding at .008 ( $.05/6 = .008$ ). This correction, however, made no difference in the results reported below. Next, a Pearson correlation was used for age and CLOX scores, and chi-square cross-tabulations between nominal variables (a) HIV/AIDS status, (b) gender, and (c) social services (received or not). Finally, One-way ANOVA test was conducted for age categories (18-35, 36-50, and 51-Older) and CLOX scores.

### ***Demographics***

Data from 786 interviews in 8 clinics in Louisville, KY in 2004 and 2005 were available for statistical analysis; 70% of those were women, and 12% of the 786 were diagnosed with HIV/AIDS. Thirty percent were between ages 18 and 35, 38% were between 36 and 50, 32% were 51 and older, and 54% were receiving social services in their treatment clinics.

### ***Clinical and Research CLOX Scoring***

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Clinical and Research CLOX scores are indicators of executive cognitive functioning (e.g., Royall, 1998). I measured executive cognitive functioning by using the Research and Clinical CLOX scores. The CLOX is not a diagnostic tool, but rather a screening instrument that can discriminate between those who have/do not have executive cognitive impairment (Simonds, Brown, Thea, Orloff, Steketee, Lee, Palumbo, & Kalish, 1998).

### ***Cut-Off Points***

The following analysis discussion is based on predetermined cut-off points. The cutoff point for the Clinical CLOX is  $\leq 1$  on the 4-item scale. As Table 4 showed, the highest possible score was 4. If clients had scores of 0 or 1, they were determined to be cognitively impaired on the Clinical CLOX. If they score  $\geq 2$ , they were deemed to be higher functioning and not cognitively impaired. The implications, politics, and economics of establishing cutoff points are discussed more fully in the last chapter because establishing the cutoff points can be hotly debated as the decision affects how clients are viewed and whether they are appropriately treated, and the decision can be manipulated based on economic factors.

Recall also Table 5 which described the Research CLOX scoring protocol with the highest possible score of 14. If individuals scored  $\leq 9$  on the Research CLOX they were seen as cognitively impaired, and if they scored  $\geq 10$  they were not (Royall, 2004). For six *t*-test analyses, a *p* value of .008 (0.05/6; family-wise alpha) to guard against the inflated probability of a Type I error was used to determine statistical significance. I also a *p* value of .05 was used to determine statistical significance.

### ***Sensitivity and Specificity Statistical Analysis***

The *sensitivity* is the proportion or percentage of true cases (people with executive cognitive impairment) correctly identified as having executive cognitive *dys*function by the instrument/test/variable; and *specificity* is the proportion of true non-cases (healthy people) correctly identified as being healthy. In other words, *sensitivity* analysis captures *inclusion* criteria, and *specificity* analysis filters for *exclusionary* criteria.

The *sensitivity* of a test can be determined by counting the number of true positive cases, and dividing that by the true positives + false negatives, and multiplying that result by 100 to make it a percentage. When the false negatives are a small number relative to the true positives, sensitivity approaches 100%.

The *specificity* of a test can also be determined by counting the number of true negatives, and dividing it by true negatives + false positives, and again multiplying by 100 to obtain a percentage. When the false positive is a small number relative to the true negatives, specificity approaches 100%. Ideally, an executive cognitive function screening test should have 100% sensitivity and 100% specificity. In other words, the test always correctly identifies the impairment state of the people tested (Halperin & Baker, 1992). In this manner, true and false positives, and true and false negatives can be identified and analyzed to determine the comparative effectiveness of the two scoring methods. (Unfortunately, the terminology here follows the medical model so that positive means that individuals tested positive for problems, i.e. cancer or being cognitively impaired in executive level brain functions, which further complicates understanding these complex analyses.)

### ***Truth or Consequences***

At the root of the True/ False issue is the Clinical CLOX score, with *True* or *False* determined by whether the Research CLOX scores agree with the Clinical CLOX scores. For example, if individuals scored low (most impaired) according to the Clinical CLOX and the Research CLOX score confirmed that indeed, they were cognitively impaired, that would be a True Positive (Cell A in Table 7). In other words, the Clinical CLOX found positive for impairment, and so did the Research CLOX. In this manner, the more discrete Research CLOX serves as the gold standard against which the simplified Clinical CLOX is measured.

On the other hand, if individuals were found to be severely impaired by the Clinical CLOX but the Research CLOX score found no impairment, the Clinical CLOX would be seen as a False Positive: the Clinical CLOX found them impaired (positive test result for impairment) but the more discrete Research CLOX score did not agree (Yellow Cell C in Table 7). The *True Negatives* are those who are not cognitively impaired (both CLOX scores agree, Cell D in Table 7), and *False Negatives* represents those who were found to be negative for impairment by the Clinical CLOX, but the Research CLOX score did not confirm (Yellow Cell B in Table 7).

The *Predictive Positive Value* of a screening test is the probability that a person is impaired when a positive test result is observed. In practice, predictive values should only be calculated from the study cohort that legitimately reflects the number of people in the population (i.e. a representative random sample) with the characteristic of interest. The *Predictive Negative Value* of a screening test is the probability that a person is *not* impaired when a negative test result is observed (Table 7).

## **Table 7**

### ***Analysis using Sensitivity and Specificity Statistical Analysis***

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Research Scoring of Executive Cognitive Function	Clinical Scoring of Executive Cognitive <i>Impairment</i>		
	<i>Impaired</i>	<i>Not Impaired</i>	Formulae
Positive (Impaired)	True Positive A	False Negative B	A + B
Negative (Not Impaired)	False Positive C	True Negative D	C + D
Formulae	A + C	B + D	Total

$$\text{Sensitivity} = A / (A + C)$$

$$\text{Predictive Value Positive} = A / (A + B)$$

$$\text{Specificity} = D / (D + B)$$

$$\text{Predictive Value Negative} = D / (D + C)$$

***Question 1: What is the difference in the means of executive cognitive function research and clinical scores (DV<sub>s</sub>) between clients known/not known to be diagnosed as having HIV/AIDS (IV)?***

The main focus of this study was to show if there is a significant difference in CLOX scores between clients who were diagnosed with HIV/AIDS and those who were not. In other words, we attempted to identify whether HIV/AIDS clients were more likely to be cognitively impaired. An independent samples *t*-tests was conducted. The differences between clients with and without HIV/AIDS was nil: both groups scored means of 11/14 on the Research CLOX. Neither were there statistically significant differences on the Clinical CLOX scores between those with/not with HIV/AIDS (Table 8). The Bonferroni correction (0.05/6; family-wise alpha = .008) to guard against the inflated probability of a Type I error was not relevant to this finding.

**Table 8**

***Results of t-tests of the Means of Clinical and Research CLOX Scores by Whether Clients had HIV/AIDS (n = 786)***

Test	Means		<i>t</i>	<i>df</i>	SD	<i>p</i>
	HIV/AIDS	Not HIV/AIDS				
Clinical CLOX Scores 0-4 scale	3.3	3.34	.572	785	1.081	.568
Research CLOX Scores 0-14 scale	10.6	10.99	-1.720	785	2.114	.086

df: Degrees of freedom

SD: Standard Deviation

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**Question 2: What is the difference in the means of executive cognitive function research and clinical scores (DVs) by gender (IV)?**

Independent *t*-tests were also conducted to identify differences in means in both the Clinical and Research CLOX by gender. The results of this *t*-test remain significant after application of the Bonferroni correction (0.05/6; family-wise alpha=.008). The difference between men and women on both CLOX scores were statistically significant ( $p .001$ ) (Table 9).

**Table 9**

***Results of t-tests of the Means of Clinical and Research CLOX Scores by Clients Gender (n = 786)***

Test	Women, $n = 551$		Men, $n = 235$		$t$	$df$	$p$
	Means	SD	Means	SD			
Clinical CLOX Scores	3.45	.954	3.07	1.198	4.289	784	< .001
Research CLOX Scores	11.17	1.907	10.40	2.370	4.409	784	< .001

df: Degrees of Freedom

SD: Standard Deviation

**Question 3: What is the difference in the means of executive cognitive function research and clinical scores (DVs) by whether clients were served clinics that provided social services (IV)?**

Independent samples *t*-tests were conducted to identify differences in means in Clinical and Research CLOX scores by whether clients were served in clinic that provided social services (War Emblem, Monarchos, Real Quiet, and Charismatic). A *t*-test for equality of variances was

not statistically significant on the Clinical CLOX so equal variance was assumed. Equal variance on the Research CLOX, however, was statistically significant ( $p = .008$ ) (Table 10). There were virtually no differences in the CLOX scores by whether social services were present in the clinics. Again, the Bonferroni correction ( $0.05/6$ ; family-wise alpha =  $.008$ ) to guard against the inflated probability of a Type I error was not relevant to this finding. As with the *t-tests* of differences by HIV/AIDS and the presence of social supports, the result did not approach the statistical significance level of the Bonferroni corrected alpha of  $.008$ .

**Table 10**

***Results of t-tests of the Means of Clinical and Research CLOX Scores by Whether Clients were Receiving Services in Clinics that Provided Social Services (n = 786)***

Test	Social Services <i>n</i> = 422		No Social Services <i>n</i> = 364		<i>t</i>	<i>df</i>	<i>p</i>
	Means	SD	Means	SD			
Clinical CLOX Scores	3.36	1.022	3.31	1.075	.733	784	.464
Research CLOX Scores	10.93	1.977	10.96	2.206	-.183	784	.855

df: Degrees of Freedom

SD: Standard Deviation

***Question 4: What is the difference in the means of executive cognitive function research and clinical scores (DVs) and clients' ages (IV)?***

I **first** conducted a Pearson correlation using both Research and Clinical scores (DVs) with actual age (IV). There is a high positive correlation and a marked relationship (Craft, 1990) between the Clinical and Research CLOX scores ( $r .720, p <.008$ ).

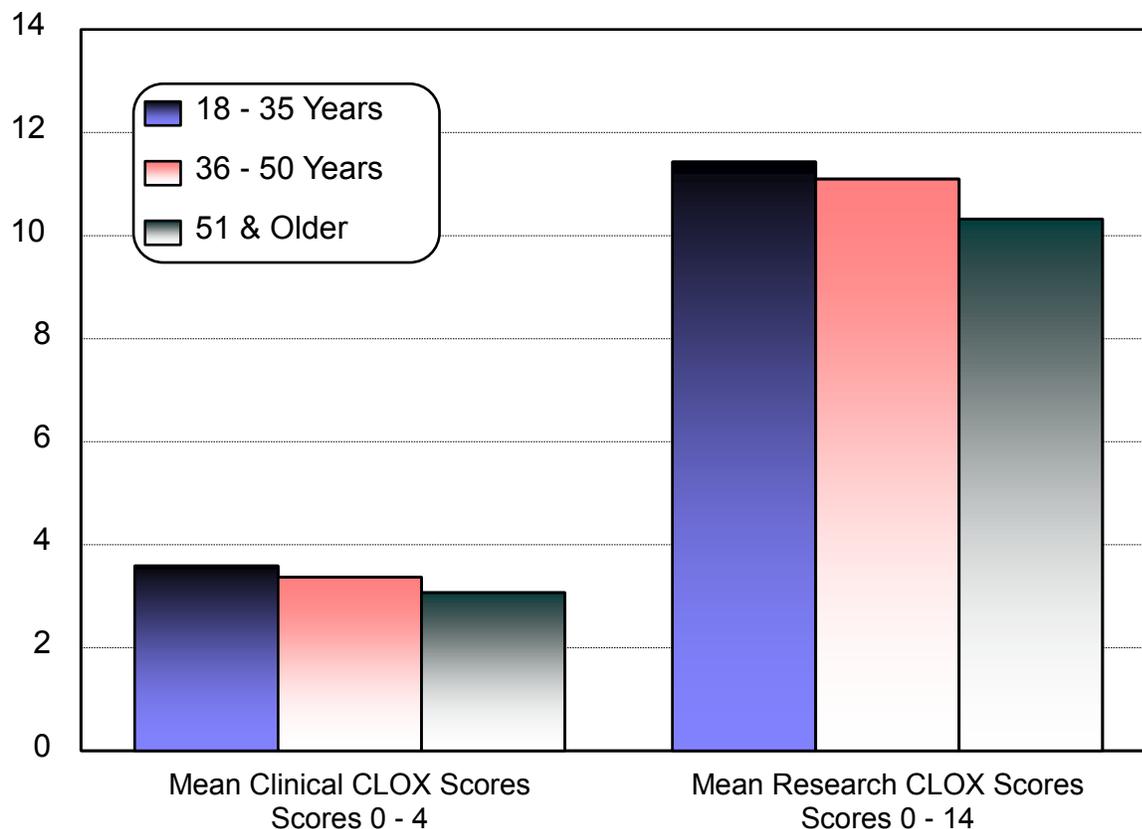
The negative relationship between both CLOX scores and age was not as strong (Clinical CLOX  $-.241$ ; Research CLOX  $-.285$ ). These are slight but definite relationships (both  $p <.008$ ). Older people appear to sustain more impairment in executive cognitive functions than younger people. The results of this  $t$ -test remain significant after application of the Bonferroni correction (family-wise  $\alpha = .008$ ) to address possible inflation of  $\alpha$  due to multiple  $t$ -tests.

**Second**, in concert with the CDC age categories for AIDS prevalence rates explained earlier, I recoded actual age into CDC's categories of under 25, 25 - 44, and over 44 (CDC, 1982) and conducted a Oneway Analysis of Variance with the Clinical and Research CLOX scores (DVs) with the these age categories as the IV. Again we see the means of both the Clinical and Research CLOX scores decrease as age progresses ( $p <.008$  level, Figure 4). The **third** way that I analyzed the CLOX scores by age was via age adjusted prevalence rates, explained in the next section.

### ***Age Adjusted Prevalence Rates of Executive Cognitive Functioning***

Age adjustment is used to compare the risks of two or more populations at one point in time as in this study, or one population at two or more points in time. Age-adjusted rates should be viewed as relative indices rather than actual measures of risk. Age-adjustment is not an analysis, but rather a different way to look at the data—a way to look at age distribution across all of the clinics that really have very different age distributions—or gain a standardized age distribution so that it makes sense to compare ages across different age distributions in the

different sites (CDC, 2005). “Age-adjusting a rate is a way to make fairer comparisons between groups with different age distributions” (*Missouri Monthly Statistics*, 2000, p 1).



**Figure 4. Means of Clinical and Research CLOX scores by age groups.**

The age adjustment process begins by first looking at the actual, or crude rates, for example, of impaired individuals by clinic and age groups (Table 11). Unadjusted, the last column in Table 11 shows, e.g., that 22% of the WAR EMBLEM clients who were interviewed and tested for this study had some executive cognitive impairment.

The first step in the age adjustment procedure is to sum the totals for each age group in Table 11 (Ages 18–35: **233** + 36–50: **299** + 51 & Older: **254** = **786**). The next step is to multiply the percentage of impairment for each age group and clinic by the total for that age group, i.e.

233 for the 18-35 age group in the WAR EMBLEM Clinic. For example, for the WAR EMBLEM Clinic alone:

For the 18 - 35 age group:  $233 \times .13 = 30$

For the 36 - 50 age group:  $233 \times .28 = 84$

For the 51 & older age group:  $233 \times .14 = \underline{36}$

150

**Table 11**

*Total Number of Clients, and Number and Percentage of Those Impaired, and Crude Rate by Clinic*

Clinic Specific		18-35			36-50			51 & Older			Totals		Crude Rate
		Ttl	Imp	%	Ttl	Imp	%	Ttl	Imp	%	#	Imp	
1	War Emblem	23	3	13	53	15	28	14	2	14	90	20	22%
2	Monarchos	53	3	6	46	4	9	54	17	31	153	24	16%
3	Real Quiet	36	1	3	58	6	10	39	13	15	133	20	10%
4	Fusaichi Pegasus	29	3	10	37	2	5	47	9	19	113	14	12%
5	Silver Charm	35	1	3	41	3	7	27	6	22	103	10	10%
6	Funny Cide	12	2	17	36	5	14	47	19	40	95	26	27%
7	Smarty Jones	7	0	0	22	6	27	24	9	38	53	15	28%
8	Charismatic	38	5	13	6	0	0	2	0	0	46	5	11%
<b>Totals</b>		<b>233</b>			<b>299</b>			<b>254</b>			<b>786</b>		

Ttl = Total; Imp = Impaired; % = % Impaired

The sum of these totals, 150, is the age adjusted total number of people from the War Emblem Clinic (in parentheses after the name of each clinic in Table 12). The final steps to arrive at an age adjusted impairment prevalence rate are to divide that figure (e.g., 150 for the War Emblem Clinic) by the total population (786), and multiply by 100 = .19, the impairment prevalence rate for the War Emblem Clinic. Thus the formula for each clinic is

Age adjusted total number of people x 100 = Age adjusted prevalence rate

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Total population number or  $150 / 786 \times 100 = 19\%$ .

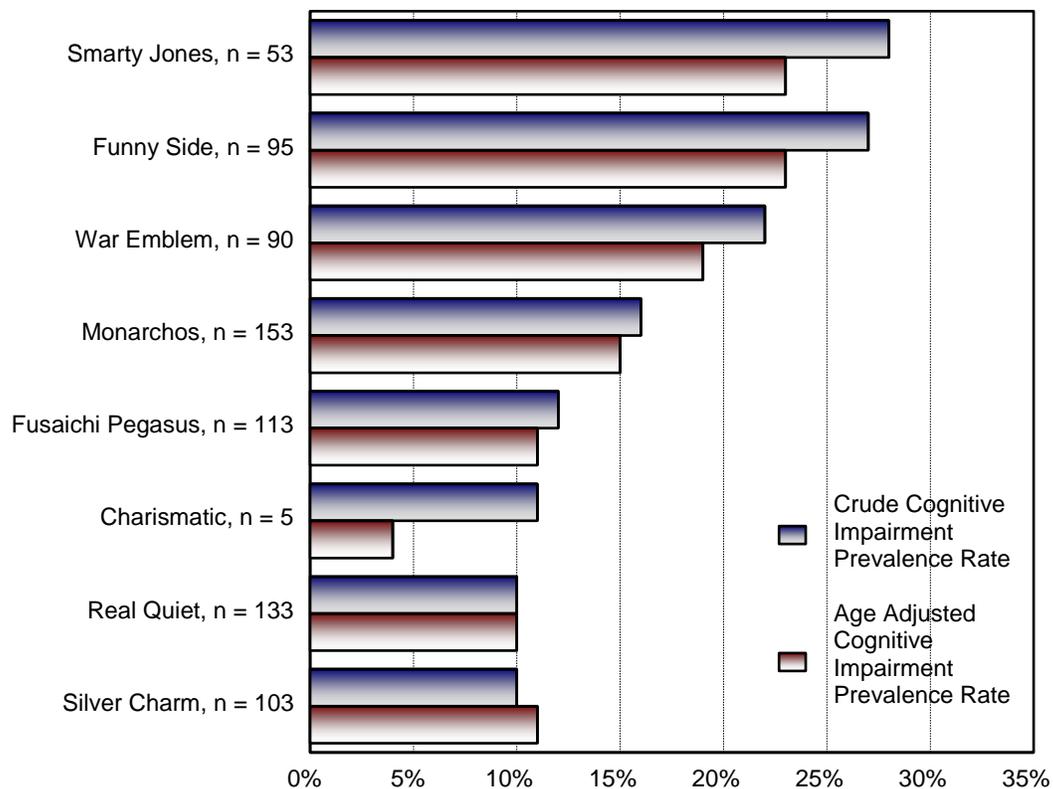
In other words Table 12 tells us that if the populations served by all of the clinics were more age homogenous, the Funny Cide and Smarty Jones Clinics would have the highest percentages of clients who were cognitively impaired in executive functions (each at 23%) and Charismatic the smallest percentage (4%). Figure 5 shows (a) the crude cognitive impairment prevalence rate (top blue bars), and (b) the age adjusted cognitive impairment prevalence rates by clinic.

**Table 12**

*Age Adjusted Prevalence Rates by Age Categories and Clinic*

Clinic Specific	18-35 %	36-50 %	51 & Over %	Age Unadjusted Prevalence Rate	Age Adjustment Prevalence Rate
Smarty Jones (177)	0	27	38	28%	23%
Funny Cide (183)	17	14	40	27%	23%
War Emblem (150)	13	28	14	22%	19%
Monarchos (119)	6	9	31	16%	15%
Fusaichi Pegasus (89)	10	5	19	12%	11%
Charismatic (31)	13	0	0	11%	4%
Real Quiet (77)	3	10	15	10%	10%
Silver Charm (85)	3	7	22	10%	11%

Tables 13 and 14 show the above process repeated when the WAR EMBLEM Clinic is dichotomized vs. the other seven clinics combined. Table 13 shows actual, or crude prevalence of cognitive impairment rates, and Table 14 shows the age adjusted prevalence rates (Figure 6).



**Figure 5. Crude (actual) and age adjusted prevalence rates of executive cognitive impairment, by clinic.**

**Table 13**

**Totals of Clients, Number and Percentage Impaired, and Crude Rate by War Emblem versus Other Clinics Combined**

Clinic	18-35			36-50			51 & Older			Totals		Crude Rate
	Ttl	Imp	%	Ttl	Imp	%	Ttl	Imp	%	#	Imp	
1 War Emblem	23	3	13	53	15	28	14	2	14	90	20	22%
2 Monarchos, Real Quiet, Fusaichi Pegasus, Silver Charm, Funny Cide, Smarty Jones, & Charismatic	210	15	7	246	26	11	240	73	30	696	114	16%

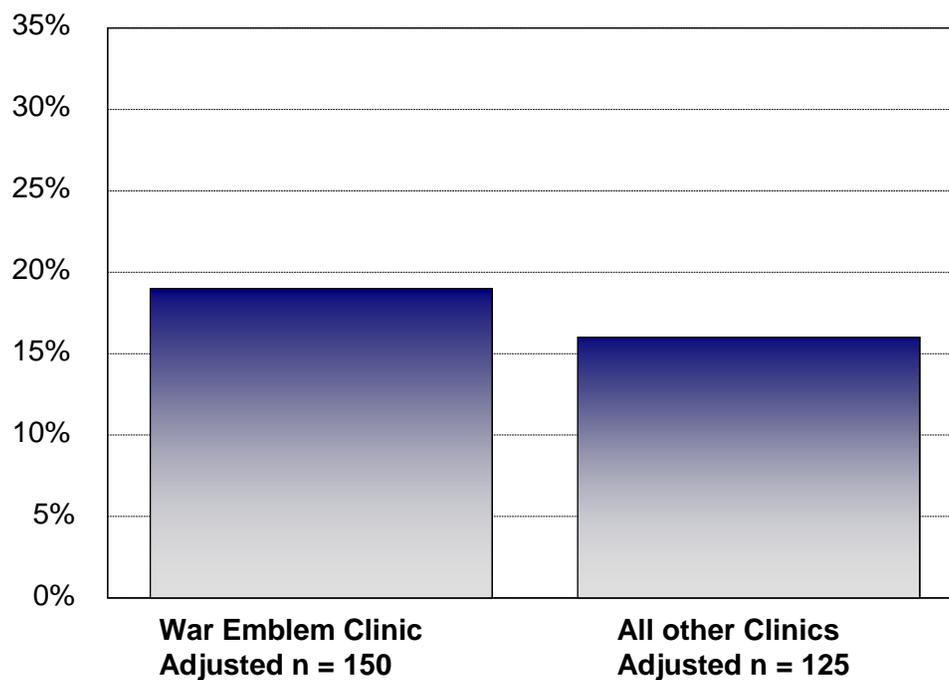
Ttl: Total, Imp: Impaired, %: % Impaired

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**Table 14***Age Adjusted Prevalence Rates by War Emblem versus Other Clinics Combined*

	<b>Clinic</b>	18-35	36-50	51 & Over	<b>Ages Adjusted Total</b>	<b>Age Adjustment Prevalence Rate</b>
1	War Emblem	30	84	36	150	19%
2	Monarchos, Real Quiet, Fusaichi Pegasus, Glasgow, Funny Cide, Smarty Jones, & Charismatic	16	33	76	125	16%



**Figure 6.** Percentage of adjusted impairment prevalence rates for War Emblem vs. all other clinics.

***Question 5: What are the predictors of Clinical and Research CLOX Scores of Executive Cognitive Functioning?***

Three multiple regression models were developed to identify whether there were any significant interaction effects between HIV/AIDS status, social services, gender, and age (IVs) and the Clinical and Research CLOX scores (DVs). **The first model** regressed age and gender on both the Clinical and Research CLOX. These two factors, age and gender, accounted for a small, but statistically significant proportion of the variance in the Clinical ( $R^2 = .081$ ) and Research CLOX ( $R^2 = .107$ ), with both  $p$  values  $<.001$ .

**The second multiple regression model** examined the effect of the interactions of (a) social services and age, (b) HIV and social services, (c) HIV and gender, and (d) HIV and age, on both Clinical and Research CLOX scores. The ability of this model to predict the CLOX scores did not change appreciably; the  $R^2$  for the Clinical CLOX changed from .081 to .087, and the  $R^2$  for the Research CLOX changed from .107 to .108.

**The third was a Backward regression model** in which I looked to see how much of the variance in, e.g. War Emblem's CLOX scores, could be predicted by the interactions of age and gender in all of the other clinics combined. Again, this model did not improve the predictability a great deal although from the first model to this model the Clinical  $R^2$  changed from .081 to .098, and the Research CLOX from .107 to .120 (both  $p <.05$ ). However, the interactions of age and gender in three clinics (Funnny Cide,  $p .022$ ; Silver Charm,  $p .046$ ; and Smarty Jones,  $p .049$ ) appear to be stronger than the interactions in the other five, which calls for further future exploration.

### ***Analyses of Research CLOX Scores of Executive Cognitive Functioning***

I will first provide (a) the reliability estimates of the Clinical and Research CLOX scores which is followed by (b) an analysis of the sensitivity and specificity of CLOX scores. I then close with (c) limitations of this study.

#### ***Reliability Analyses***

For the Clinical CLOX score, a 4-item scale, a reliability analysis yielded a reliability coefficient of  $\alpha = .526$ . By eliminating Item 4 (place hands in the correct places on the clock), however, the alpha increased to  $.593$ . Although this reliability coefficient of alpha level is still low it is representing factors from research items impact alpha. Even though by eliminating item 4 increases alpha, however the item is critique in order to measure the executive cognitive impairment (i.e., self-correcting, problem-solving, planning, and organizing skills).

According to Carmines and Zeller, a 10-item scale should be required to reach a reliability of  $.60$  (Carmines & Zeller, 1979). Based on Royall's previous reliability tests, the internal consistency of the Research CLOX was high (Chronbach's  $\alpha = 0.82$ ; Royall, 1998). The Research CLOX score reliability analyses, however, indicated that by eliminating the fifth item from the scale (Spacing Intact: Symmetry on either side of the 12-6 axis on the clock face) the reliability increased considerably. Graders were more likely to have differences of opinions regarding the scoring on item 5. Supported by the data, when item-5 was excluded from the scale, the reliability coefficient increased from  $\alpha = .659$  to  $\alpha = .745$  on the Research CLOX.

#### ***False Positive and False Negative Values***

Halperin and Baker (1992) provided a formula to determine False Positive and Negative values. As stated above, the Clinical CLOX (alpha .526) and Research CLOX (alpha .359) are two different ways of scoring the same clock drawing test.

Individuals who fell into the False Positive cell, therefore, are the 14 (15%) in the Yellow Cell C in Table 15 who were deemed to be cognitively impaired by the Clinical CLOX, but were found negative for cognitive impairment by the stronger Research CLOX. In other words, the Clinical CLOX found clients impaired, but the Research CLOX found them *not* to be impaired, making the Clinical CLOX score a False Positive.

Conversely, the Yellow Cell B in Table 15 represents the 56 (8%) of clients whom the Clinical CLOX found negative for cognitive impairment, but the Research CLOX indicated that they *were* impaired. Thus the Clinical CLOX's negative score for these 56 individuals is seen as a False Negative.

### ***Results of Sensitivity and Specificity Statistical Analyses***

Recall from the discussion above that *sensitivity* refers to the number of times clients' scores indicated impairment ( $\leq 1$ ) on the Clinical CLOX. *Specificity*, on the other hand, identifies when clients' scores were  $\geq 2$  on the Clinical CLOX. Using Halperin and Baker's (1992) formula shown in Tables 15 and 16, the

**Table 15*****Clinical and Research CLOX: True and False, Positive and Negative Results***

<b>Research CLOX Scores of Executive Cognitive Impairment</b>	<b>Clinical CLOX Scores of Executive Cognitive Impairment</b>		
	<b><i>Impaired</i></b> $\leq 1$	<b><i>Not Impaired</i></b> $\geq 2$	Formulae
<b>Positive (Impaired)</b> $\leq 9$	79 (84.9%) True Positive A	56 (8.1%) False Negative B	135 A + B
<b>Negative (Not Impaired)</b> $\geq 10$	14 (15.1%) False Positive C	637 (91.9%) True Negative D	651 C + D
Formulae	93 A + C	693 B + D	786 Total

Clinical CLOX is sensitive enough to pick up 85% of clients' impairment. Conversely, it is 92% accurate in discerning those who were not impaired (Table 16).

In application, when I see a client scoring  $\leq 1$  on the Clinical CLOX, I am 85% confident that this client is cognitively impaired. In evaluating another client who presents a Clinical CLOX score  $\geq 2$ , I am 93% confident that this client is probably not cognitively impaired. Thus, clinicians who are not as research

**Table 16**

***Sensitivity and Specificity Rates for the Clinical CLOX***

<p><b>Sensitivity:</b> The number and percentage of times the Clinical CLOX picked up clients' impairment.</p> <p><b>Specificity:</b> The number and percentage of times the Clinical CLOX identified no impairment.</p>	<p><b>Sensitivity</b> A/ (A + C) 79/93</p>	<p><b>Specificity</b> D/ (D + B) 637/693</p>
<b>Total</b>	<b>84.9%</b>	<b>91.9%</b>

inclined, have the option of using the Clinical CLOX with a fairly high degree of confidence in its ability to identify cognitive impairment.

***Limitations of this Study***

This study had several limitations. First, clients were interviewed as they appeared in eight local primary clinics; therefore, results cannot be generalized beyond those who participated. Second, there was no pretest so any decrease or increase in executive cognitive functioning cannot be determined, nor can strong causal statements be made on the findings. Third, the professionals providing services in the eight clinics had little/no knowledge of the problem of executive cognitive functioning and its relation to their physical conditions. And finally, most of the clients in this study fall in the lower socioeconomic ranges who cannot afford personal primary physicians. It's interesting to note that a higher percentage of clients served in the Funny Cide and Monarchos clinics managed sample size and the fact that it was conducted in only eight primary care clinics in Kentucky region. Although the sample is local level, a rich portrayal of each clinic has been achieved by many different types of data obtained through our primary care clinic. Because the number s of older HIV/AIDS and

unknown diagnosis HIV/AIDS clients receiving primary care services is continuing to rise, further research with these clients will become increasingly important.

## CHAPTER V

### PRACTICE IMPLICATIONS FOR SOCIAL WORK AND FUTURE RESEARCH

In this chapter I attempt to pull together the research while focusing on the more broad dilemmas surrounding the heretofore silent problem of executive cognitive impairment of clients, especially older men who have very limited resources and social support, and are being treated in the less attractive clinics around Louisville. Doing so, however, holds some weighty issues up to glaring lights. Following brief sections about the results as they involve age, gender, diagnosis, and availability of social services, I will discuss the elephant in the clinic—how to detect and measure people the executive cognitive impairment—even though there is, as yet, any indication that treatment is on the horizon: the *so what*.

#### *Review of Four Issues Under Study*

One of purposes of this study was to identify key issues for future research addressing the needs of social service with older HIV/AIDS clients' executive cognitive functions. We identified four issues: (a) age, (b) gender, (c) known or unknown HIV/AIDS diagnosis status, and (d) whether clients were receiving social services in their clinics.

#### *The Age Issue*

Consistent with Royall (2000) I found that elderly clients required a greater number and broader scope of resources to meet their needs. Moreover, older HIV/AIDS clients' complex needs challenge most health care providers in primary health care clinics who typically have little preparation in caring clients with executive cognitive *dys*functions.

Age was the strongest predictor of executive cognitive impairment, although even that R<sup>2</sup> was not as strong. The decline in cognitive functioning is graphically gradual as seen in Figure 3,

regardless of whether measured with the Clinical or Research CLOX. One wonders whether a deceleration line on Figure 3 would show a continual downward trend toward cognitive impairment.

### ***Gender Differences***

Analyses show that men and older people are more vulnerable to executive cognitive impairment ( $p < .001$ ). In a circular pattern, clients' "cognitive impairment can prevent their families and health care professionals from understanding the problems that arise from executive cognitive impairment. Although there are individual differences depending on medications, coping patterns and strategies, and disease status, current data suggest that aging people, especially men, might be vulnerable to particular declines related to visual-spatial praxis functioning" (Royall, Cordes, & Polk, 1998, p.590).

### ***HIV/AIDS Diagnosis***

The health care providers in primary care clinics tended to underestimate known and unknown HIV/AIDS clients' executive cognitive dysfunctional signs, and not take advantage of family members' involvement. Although the differences in CLOX scores by diagnosis were small, health care professionals failed to identify executive cognitive *dys*function reported by both clients and family members, except for those working in the clinics that provided social services. Better strategies for executive cognitive *dys*function assessment need to be developed and tested, with attention given to identifying the symptoms of cognitive problems that are characteristic of HIV/AIDS clients, e.g., their ability to plan, initiate, sequence, monitor, and inhibit complex goal directed behaviors.

### ***The Presence of Social Services***

Given the different perspectives of primary health care providers and social workers' assessments, social workers' client self-assessments should be routinely included in a primary care clinic. Although statistical analyses did not provide a definitive answer to the relationship between CLOX scores for those who received services in their clinics and those who did not, the most severe cognitive impairment, adjusted for age, was seen in clients who were served in two of the clinics that provide no social services, are overcrowded, are understaffed, and have overall poor environments (Figure 4). The clients in these clinics are also the most ethnically diverse and most economically disadvantaged. For executive cognitive disabilities of older HIV/AIDS clients, who may have a poor social support and a lack of social services, culturally and educationally appropriate executive cognitive function assessment instruments may need to be developed.

### ***The Clinical CLOX / Research CLOX Conundrum***

There are at least four threads to this conundrum: (a) the ethical/political dilemma, (b) scoring choices, (c) recommendations for training, and (d) practice based evidence (Hall, J. C., Personal Communication, March 6, 2005).

### ***The Ethical/Political Dilemma***

Establishing the cutoff points can be hotly debated as this decision affects how clients are viewed and whether they are appropriately treated, and the decision can be manipulated based on economic factors. For example, if a clinic is short-staffed and short-funded, they can move the cutoff point down (lower functioning) so that only those with the most severe cognitive impairment (i.e. zero scores) are treated. On the other hand, if the clinic is overstaffed or not reaching the population stipulated by their funding sources, the cut point (to treat/not) can be

moved up so that those with even the slightest impairment would be identified as executive cognitively impaired and served. On paper, therefore, the latter scenario could look as though such a clinic was serving large numbers of cognitively impaired people, when in reality, the clinic down the street may have moved their cut point in the other direction and actually be serving individuals with much more severe impairment.

Another conundrum is the ethical push/pull between erring, on one hand, on the side of ethical caution, establishing cutoff points very high to be sure that if there is any cognitive impairment, you identify it and provide appropriate services. The other side of that coin, however, is that with limited resources, you may need to ration them to serve only the most severely impaired clients, knowing that you simply do not have staff or funds to serve those with lesser problems. This dilemma is similar to the western (American? Liberal?) tradition of preferring to let 10 criminals go free rather than incarcerate 1 innocent person. In other words, in the hearts of social workers probably lies the desire to lean in this direction: do our best to identify even the earliest indication of impairment and provide services. We typically do not like to take the position on the other side of the coin: limit services to only the most severely impaired.

### ***Scoring Choices***

Perhaps the most useful result of this work is seeing and understanding the performance of both the Clinical and Research CLOX. Recall that these two scores are based on one very simple-to-use-and-score procedure: simply ask clients to *draw a clock that says 1:45. Put the numbers and hands on the face so that even a child can read it* (Royall, 1998). If implementing this protocol in a clinic or practice setting, the Real Time Research methodology can be

employed, in which the drawing is simply a part of the practice experience, even while the client is waiting to be seen.

The more serious researcher type of practitioner, not to mention hard core researchers, will want to use the scoring protocol from the 14-item Research CLOX which demonstrated a reliability of .745. Perhaps more importantly, however, it yielded a sensitivity rating of .85, a specificity of .92, a positive predictive value of .59, and a negative predictive value of .97. If, on the other hand, the social worker's time is extremely limited and the only interest is in getting a handle on the client's level of executive cognitive impairment, the 4-item Clinical CLOX may be more appealing (reliability .59). Either way, practitioners will have some indication of whether their clients see clocks as most of us do, or as those in Figure 2, and can immediately adjust treatment and referrals; hence Real Time Research.

### ***Real Time Research = Practice Based Evidence (Hall, 2005)***

While the cry for *evidence based practice* become more intense with the appearance of many social work journals, Real Time Research is more in keeping with Hall's (2005) revision of the idea to *practice based evidence*. In other words, perhaps another approach would be to base the evidence on that which is learned in the practice setting, and Real Time Research accomplishes just that.

### ***Recommendations for Training***

Training practitioners to implement the clock drawing task is incredibly easy, as described earlier. This is not a technique that requires multiple degrees or research and statistical expertise, yet the results are conceptually and statistically sound. We need not remain in the dark

regarding clients' cognitive capabilities, wondering why they do not always follow through on recommendations, medication regimens, or referrals.

### ***Implications for Social Work Practice, aka So What?***

Executive cognitive impairment is an important risk factor that must be assessed in primary care multidisciplinary and interdisciplinary settings. If we continue to be blind to this issue we may be harming individuals, families, and communities as well as society. Social workers and other professionals must be aware of this phenomenon. The strong associations observed between executive cognitive function impairment, age, and gender suggests that interventions to counter executive cognitive dysfunction may be fruitful. However, the low values of both  $R^2$  coefficients clearly show that other factors than HIV/AIDS status account for the variation in the Clinical and Research CLOX scores distributions. Further studies are needed to identify what other factors could cause the onset of cognitive impairment.

Older HIV/AIDS clients with executive cognitive *dysfunctional* clients might be better physically and emotionally if their families and social service providers were more involved in both their primary care clinics and daily lives. The role of family as advocates for residents needs further examination. Interventions designed to improve communication between family and staff members would be helpful. Research is needed to identify ways of educating family members about the relationship between executive cognitive functioning and HIV/AIDS.

Interventions that are sensitive to age, gender, and individual diagnoses are needed for health care providers' use in helping elderly clients with executive cognitive impairment, especially those with HIV/AIDS, deal with family obstacles. The benefits of an HIV/AIDS program for older clients with executive cognitive dysfunction *without* family members should

also be evaluated. One *disadvantage* for *dys*function of executive cognition is the lack of exciting community programs targeted to meet their needs.

Linkages also need to be fostered with the community, and particularly with the community health care centers and churches. Because older adults have a shorter survival time following AIDS diagnosis than younger individuals, they and their families are more likely to confront issues related to dying. Generally, those who received services in clinics with stronger social service programs appeared to be stronger physically, mentally, and emotionally.

### ***Future Research***

Future research must focus on what to do once clients are identified as having executive cognitive impairments. I suggest that social work practitioners use the clock drawing test and whichever scoring model they prefer, then move the knowledge base to the next level by learning how to treat clients with such impairments. Surely our clients deserve no less.

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## APPENDIX A

### *Research and Clinical CLOX*

## APPENDIX B

### *Research and Clinical CLOX*

## APPENDIX C

### *Population Distribution by Age, State Data 2002-2003, U.S. 2003*

*(Kaiser State Health Facts, 2003)*

Age Categories	United States/ Percent	Kentucky/Percent
Children 18 and under	27 %	26 %
Adults 19-64	61 %	61 %
65+	12 %	13 %
65-74	6 %	7 %
75+	6 %	6 %

### *Population Distribution by Gender, State Data 2002-2003, U.S. 2003*

*(Kaiser State Health Facts, 2003)*

Gender	United States/ Percent	Kentucky/Percent
Female	52 %	51 %
Male	48 %	49 %

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\* Reporting Delays: Reporting delays (time between diagnosis of HIV infection or AIDS and report to CDC) may differ among exposure, geographic, racial/ethnic, age, sex, and vital status categories; for some AIDS cases, delays have been as long as several years.

## APPENDIX D

*Distribution of Cumulative AIDS Cases all Ages by Sex, Reported Through 2003 (Kaiser State Health Facts, 2003)*

Gender	United States/ Percent	Kentucky/Percent
<b>Female</b>	18.4%	14.0%
<b>Male</b>	81.6%	86.0%

*Distribution of New AIDS Cases all Ages by Sex, 2003*

*(Kaiser State Health Facts, 2003)*

Gender	United States/ Percent	Kentucky/Percent
<b>Female</b>	25.8%	18.3%
<b>Male</b>	74.2%	81.7%

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## APPENDIX E

### *Distribution of Cumulative AIDS Cases all Ages by Race/Ethnicity, Reported Through 2003*

*(Kaiser State Health Facts, 2003)*

Race/Ethnicity Categories	United States/ Percent	Kentucky/Percent
<b>White</b>	42.0%	67.8%
<b>Black</b>	40.6%	29.3%
<b>Hispanic</b>	15.9%	2.4%
<b>Asian/Pacific Islander</b>	0.8%	0.3%
<b>American Indian</b>	0.3%	0%
<b>Unknown</b>	0.2%	0.1%

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## APPENDIX F

### *Distribution of New AIDS Cases all Ages by Race/Ethnicity, Reported 2003*

*(Kaiser State Health Facts, 2003)*

Race/Ethnicity Categories	United States/ Percent	Kentucky/Percent
<b>White</b>	31.1%	60.7%
<b>Black</b>	48.2%	31.5%
<b>Hispanic</b>	18.5%	5.5%
<b>Asian/Pacific Islander</b>	1.3%	1.4%
<b>American Indian</b>	0.5%	0%
<b>Unknown</b>	0.5%	0.9%

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## APPENDIX G

*Reported AIDS Cases and Annual (a) Rates per 100,000 Population by State of Residence and Age Category, (b) Cumulative Through 2003-U.S.*

*(CDC, HIV/AIDS Surveillance Report, Vol. 15, 2003)*

States	2002		2003		Cumulative Through 2003a		
	No.	Rate	No.	Rate	Adult/ Adolescent	Child (<13 yrs)	Total
Alabama	433	9.7	472	10.5	7,531	76	7,607
Alaska	35	5.5	23	3.5	559	6	565
Arizona	633	11.6	614	11.0	9,166	42	9,208
Arkansas	239	8.8	188	6.9	3,543	38	3,581
California	4,228	12.1	5,903	16.6	132,650	642	133,292
Colorado	326	7.2	366	8.0	8,042	31	8,073
Connecticut	611	17.7	736	21.1	13,284	180	13,464
Delaware	193	23.9	213	26.1	3,206	25	3,231
D.C.	926	162.7	961	170.6	15,660	181	15,841
Florida	4,979	29.8	4,666	27.4	93,235	1,490	94,725
Georgia	1,471	17.2	1,907	22.0	27,697	218	27,915
Hawaii	131	10.6	110	8.7	2,816	17	2,833
Idaho	31	2.3	26	1.9	569	3	572
Illinois	2,111	16.8	1,730	13.7	29,857	282	30,139
Indiana	491	8.0	507	8.2	7,450	54	7,504
Iowa	90	3.1	77	2.6	1,554	13	1,567
Kansas	71	2.6	116	4.3	2,647	12	2,659
Kentucky	304	7.4	219	5.3	4,162	30	4,192
Louisiana	1,163	26.0	1,041	23.2	15,519	134	15,653
Maine	28	2.2	52	4.0	1,075	9	1,084
Maryland	1,848	33.9	1,570	28.5	26,606	312	26,918
Massachusetts	808	12.6	757	11.8	18,311	214	18,525

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Michigan	795	7.9	680	6.7	13,215	111	13,326
Minnesota	162	3.2	177	3.5	4,225	27	4,252
Mississippi	436	15.2	508	17.6	5,742	57	5,799
Missouri	388	6.8	403	7.1	10,346	60	10,406
Montana	17	1.9	7	0.8	363	3	366
Nebraska	71	4.1	59	3.4	1,286	10	1,296
Nevada	313	14.4	277	12.4	5,209	28	5,237
New Hampshire	39	3.1	37	2.9	985	10	995

States	2002		2003		Cumulative Through 2003a		
	No.	Rate	No.	Rate	Adult/ Adolescent	Child (<13 yrs)	Total
New Jersey	1,456	17.0	1,516	17.5	45,936	767	46,703
New Mexico	86	4.6	109	5.8	2,381	8	2,389
New York	6,741	35.2	6,684	34.8	160,109	2,337	162,446
North Carolina	1,045	12.6	1,083	12.9	13,335	121	13,456
North Dakota	3	0.5	3	0.5	114	1	115
Ohio	773	6.8	775	6.8	13,373	129	13,502
Oklahoma	205	5.9	213	6.1	4,414	27	4,441
Oregon	300	8.5	242	6.8	5,580	19	5,599
Pennsylvania	1,789	14.5	1,895	15.3	29,639	349	29,988
Rhode Island	107	10.0	102	9.5	2,337	26	2,363
South Carolina	822	20.0	774	18.7	11,724	94	11,818
South Dakota	11	1.4	13	1.7	214	4	218
Tennessee	772	13.3	837	14.3	10,686	54	10,740
Texas	3,076	14.2	3,379	15.3	62,592	391	62,983
Utah	68	2.9	73	3.1	2,156	20	2,176
Vermont	12	1.9	16	2.6	451	6	457
Virginia	948	13.0	777	10.5	15,544	179	15,723
Washington	471	7.8	525	8.6	10,953	34	10,987
West Virginia	82	4.5	94	5.2	1,341	11	1,352
Wisconsin	187	3.4	184	3.4	4,103	33	4,136
Wyoming	11	2.2	8	1.6	210	2	212
Subtotal	42,336	14.7	43,704	15.0	863,702	8,927	872,629
<b>U.S. Dependencies, Possessions, and Associated Nations</b>							
Guam	2	1.2	6	3.7	64	1	65
Pacific Islands, U.S.	0	0.0	1	0.7	2	0	2
Puerto Rico	1,135	29.4	1,065	27.5	27,903	398	28,301
Virgin Islands	54	49.6	34	31.2	585	18	603
Total b	43,578	14.9	44,963	15.2	892,875	9,348	902,223

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1. Rates (a): Rates per 100,000 population were calculated for the numbers of AIDS cases in 2003, as well as for persons living with HIV infection (not AIDS) at the end of 2003.
2. Cumulative (b): A “cumulative” gives a total number, from the time that recording of data first began, until a specified date.
3. Includes persons with a diagnosis of AIDS, reported from the beginning of the epidemic through 2003.
4. Includes persons whose state or area of residence is unknown. Cumulative total includes 620 persons whose state or area of residence is unknown.



## APPENDIX I

### *Cumulative Number of AIDS Cases Rank and all Ages, Reported through December 2003*

*(Kaiser State Health Facts, 2003)*

Rank		Cumulative AIDS Cases All Ages
	<b>United States</b>	<b>902,223</b>
1	New York	162,446
2	California	133,292
3	Florida	94,725
4	Texas	62,983
5	New Jersey	46,703
6	Illinois	30,139
7	Pennsylvania	29,988
8	Georgia	27,915
9	Maryland	26,918
10	Massachusetts	18,525
11	District of Columbia	15,841
12	Virginia	15,723
13	Louisiana	15,653
14	Ohio	13,502
15	Connecticut	13,464
16	North Carolina	13,456
17	Michigan	13,326
18	South Carolina	11,818
19	Washington	10,987
20	Tennessee	10,740
21	Missouri	10,406
22	Arizona	9,208
23	Colorado	8,073
24	Alabama	7,607

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25	Indiana	7,504
26	Mississippi	5,799
27	Oregon	5,599
28	Nevada	5,237
29	Oklahoma	4,441
30	Minnesota	4,252
31	Kentucky	4,192
32	Wisconsin	4,136
33	Arkansas	3,581
34	Delaware	3,231
35	Hawaii	2,833
36	Kansas	2,659
37	New Mexico	2,389
38	Rhode Island	2,363
39	Utah	2,176
40	Iowa	1,567
41	West Virginia	1,352
42	Nebraska	1,296
43	Main	1,084
44	New Hampshire	995
45	Idaho	572
46	Alaska	565
47	Vermont	457
48	Montana	366
49	South Dakota	218
50	Wyoming	212
51	North Dakota	115
	Puerto Rico	28,301
	Virgin Islands	603
	Guam	65

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## APPENDIX K

### *New AIDS Cases all Ages, Reported in 2003*

*(Kaiser State Health Facts, 2003)*

Rank	United States	New AIDS Cases All Ages
		<b>44,963</b>
1	New York	6,684
2	California	5,903
3	Florida	4,666
4	Texas	3,379
5	Georgia	1,907
6	Pennsylvania	1,895
7	Illinois	1,730
8	Maryland	1,570
9	New Jersey	1,516
10	North Carolina	1,083
11	Louisiana	1,041
12	District of Columbia	961
13	Tennessee	837
14	Virginia	777
15	Ohio	775
16	South Carolina	774
17	Massachusetts	757
18	Connecticut	736
19	Michigan	680
20	Arizona	614
21	Washington	525

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22	Mississippi	508
23	Indiana	507
24	Alabama	472
25	Missouri	403
26	Colorado	366
27	Nevada	277
28	Oregon	242
29	Kentucky	219
30	Delaware	213
31	Oklahoma	213
32	Arkansas	188
33	Wisconsin	184
34	Minnesota	177
35	Kansas	116
36	Hawaii	110
37	New Mexico	109
38	Rhode Island	102
39	West Virginia	94
40	Iowa	77
41	Utah	73
42	Nebraska	59
43	Maine	52
44	New Hampshire	37
45	Idaho	26
46	Alaska	23
47	Vermont	16
48	South Dakota	13
49	Wyoming	8
50	Montana	7
51	North Dakota	3
	Puerto Rico	1,065

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	Virgin Islands	34
	Guam	6

## APPENDIX L

### *Geographic Designations (CDC, HIV/AIDS Surveillance Report, 2003)*

<b>Geographic and Regions of Residence</b>
<b>North East</b>
Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont
<b>Mid West</b>
Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin
<b>South</b>
Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina Tennessee, Texas, Virginia, West Virginia
<b>West</b>
Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, Wyoming
<b>U.S. Dependencies, Possessions, and Associated Nations</b>
Guam, Puerto Rico, the U.S. Pacific Islands, the U.S. Virgin Islands