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Family relationships in HIV positive individuals and their performance on the International Neurobehavioral test battery

A Research Project Report Submitted In Partial Fulfillment for the Master of Science Degree in Clinical Neuropsychology

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Declaration

I, (Lutunti Chilwesa) declare that this research project report is my own work. It is being submitted for the Masters of Science Degree in Clinical Neuropsychology in the University of Zambia, Lusaka. It has not been submitted for any degree at this or any other university.

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Lutunti Chilwesa 10th day of June, 2014

Internal examiner……..

Signature…….

Date……

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Date……..

External examiner……

Signature…….

Date…….

Head of Department (Psychiatry)…….

Signature……

Date……

Dedication

I would like to dedicate my work to my family whom in every way have patiently given me enduring support and faith, knowing I can even when it seemed impossible in my eyes, there continued trust and encouragement keep me focused on my work despite the challenges I face. I am most grateful to my husband Horace and my brothers, Peter and Andrew, whom if not for their dedication this work would not have been completed in time. I would also like to thank my little boys Sibusiso and Siyabo'nga for their patience and allowing me to do my work. To my creator Jehovah, I'm forever indebted for his guidance in trying times, his everlasting love and countless blessings are like an avalanche. I thank you all.

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Abstract

The Human Immunodeficiency Virus (HIV) pandemic was first described in the 1980's, and the first case in Zambia was reported in 1984 (Chipimo, 2011). Since then the infection rates have continued to raise with the highest rates being recorded between 1990 and 2001, however there has been a decline in the incidence rates since 2007 (CSO 2010).

This study was aimed at examining family relationships and the performance of HIV positive individuals on neuropsychological tests. It was part of a larger study looking at the effects of HIV on neuropsychological testing using tests contained in the Zambia Neurobehavioral test Battery.

The Zambia Neurobehavioral test Battery with seven domains (executive functioning, attention and working memory, recall, learning, fluency, motor and speed of information processing) was used together with a (group) questionnaire that included family relationship variables namely individual perceptions on family support, family rating, meaning of life, involvement in decision making, quality of life and living conditions. The family relationship variables were recoded from a five point scale to a three point scale hence transforming them into bipolar categorical data as positive, negative and neutral. This recoding was done by three independent raters and an inter-rater reliability of .87 was achieved. The neuropsychological tests were interpreted using the global mean t-scores and the t-scores for the seven domains which were also recoded into categorical data as either impaired or not impaired. The mean was used as a cut-off point to determine impairment.

None of the family relationship variables showed any association with any of the domains of the test battery and neither did the global family score and the test battery domains combined into the global deficit score to measure performance, reveal any relationship.

List of Tables

Table 5.1: Demographic profile 28
Table 5.2.1: classification of family relationships by participants 29
Table 5.2.2: Global family relationship scores 30
Table 5.3: Association of domains (family relationship and test battery) 31
Table 5.4: Association between global family relationship and global deficit score 33
Table 5.5: performance on test battery using global deficit score 33

List of Abbreviations

ART……..ANTIRETROVIRALTHERAPY

AIDS……ACQUIRE IMMUNO-DEFICIENCY SYNDROME

CSO……..CENTRAL STATISTICAL OFFICE ZAMBIA

HIV……HUMAN IMMUNO-DEFICIENCY VIRUS

GDS……..GLOBAL DEFICIT SCORE

UNAIDS……UNITED NATIONS AIDS REPORT

WHO……WORLD HEALTH ORGANISATI

Table of Contents

DECLARATION II

DEDICATION III

ACKNOWLEDGEMENTS IV

ABSTRACT V

LIST OF TABLES VI

LIST OF ABBREVIATIONS VII

CHAPTER ONE

INTRODUCTION……..1

BACKGROUND……..…….1

EFFECTS OF HIV……..……..……..3

JUSTIFICATION OF THE STUDY…….…….5

STATEMENT OF THE PROBLEM…….…….....5

OBJECTIVE……..…….6

HYPOTHESIS…….6

OPERATIONAL DEFINITIONS…….…….…….6

CHAPTER TWO

LITERATURE REVIEW…….…….7

THEORECTICAL FRAMEWORK…….12

CHAPTER THREE

METHODOLOGY……..……..15

STUDY DESIGN……...15

SAMPLE……15

PROCEDURE…….…….....16

DETAILED DESCRIPTION OF INSTRUMENTS…….18

ETHICAL CONSIDERATIONS……..……...25

CHAPTER FOUR

RESULTS…….….27

DATA ANALYSIS……..…….……27

CHAPTER 5

DISCUSSION OF FINDINGS…….34

CHAPTER 6

CONCLUSION AND RECOMMENDATION……37

REFERENCES……..……40

APPENDICES……..44

CHAPTER ONE

1.0 Introduction

This study aims at examining the role that types of family relationships play in influencing the performance Human Immunodeficiency Virus (HIV) positive individuals on Neuropsychological tests. It is part of a larger study looking at the effects of HIV on Neuropsychological testing using tests contained in the Zambia Neurobehavioral test battery. It focuses on the psychosocial aspect of HIV and puts the family at the center of the study.

1.1 Background

The Human Immunodeficiency Virus (HIV) pandemic was first described in the 1980's though evidence indicated that the epidemic may have started much earlier (Chipimo, 2011, Dzekedzeke & Fylkesnes 1997). Postmortems performed on people who died of a "wasting disease" shows that the virus existed as early as the 1950's (Kaplan, 2001).

The index case for HIV was believed to have been a Norwegian sailor who travelled between Europe and West Africa in the 1950's. Since then the incidence has increased steadily with the most infection nested mainly in sub-Saharan Africa. (Chipimo, 2011)

Zambia was not spared from this steady increase and a generalized HIV epidemic spread across all its population strata. The first recorded case of HIV in Zambia was in 1984. Since then the HIV infection rate had reached epidemic levels with the highest rates seen between the 1990s and 2001. However, recently evidence of a decline in incidence has been reported (CSO 2010). The prevalence rates of HIV in Zambia in 2001 were about 15% and by 2007 this rate started dropping and is currently at 13%. The prevalence rate in Zambia was considered mid-range compared to other sub Saharan African countries with Swaziland having the highest rate of 24% and Angola having the lowest rate of about 1% (UNAIDS Zambian Office Data, 2009). This decline was seen mainly among the youths, with women delaying their sexual debut and delaying child bearing. There was also evidence of safer sexual practices. The advent of anti-retroviral drugs also reduced mortality. However the scourge was far from over. The HIV prevalence rate was higher among females than males in Zambia at younger ages and significantly lower at older ages in females. This was attributed to early marriages among females and poverty (UNAIDS Zambian Office Data, 2009).

HIV affects the T-cells in the human body. It is present in blood, semen, cervical and vaginal secretions and to a lesser extent in tears, saliva and breast milk and the cerebrospinal fluid of those infected, it is

mostly transmitted through sexual intercourse and contaminated blood from one person to another (psychosocial training manual 2007). HIV progresses steadily after infection in the period 8-11 years without treatment into fully blown Acquired Immunodeficiency Syndrome (AIDS) but this progression could be slowed down by the introduction of Antiretroviral Therapy (ART).

A lot of research on HIV focused on its modes of transmission, management and improving the prognosis of the illness. Research also focused on positive living and improving the quality of life of HIV positive people. It was realized that HIV affects both the infected person and those around him or her. A common saying used to explain the effects of HIV was ‘’it’s either you are infected or affected’. The importance of the family in the management of an HIV positive person has now become an important component in research (American Psychiatric Association (APA), 2008, HIV in Canada, 2010).

The family was affected by HIV to a greater extent socially through stigmatization, economically through loss of the breadwinner or the channeling of resources to the management of the illness. Interrelations in the family became affected (APA ,HIV in Canada 2010). A lot of research had focused on how to help the family but little research particularly in Africa had addressed how family relationships could affect the quality of life of an HIV positive individual. It is against this background that this research examined family relationships as a measure of quality of life in HIV positive individuals and how this affected their performance on neuropsychological tests.

Family relationships in this study was taken to mean the kind of interaction that goes on in the family such as communication, involvement of an HIV positive individual in decision making as well as family support.

The field of neuropsychology is considered a fairly new area of study in the general profession of psychology. It has gone through a transition in the role it has played over time from diagnosing to now including treatment and rehabilitation. As with most fields of psychology, assessment lies at the core of the practice of neuropsychology. The role of assessment also has evolved in the same way that the field has grown with the way in which assessment results have been used, broadening as the field of study grows. Neuropsychological assessment is now known to be useful in diagnosis of cognitive deficits and brain related disorders, treatment planning and care of the patient as well as in research (Lezak, Howieson & Loring, 2004).

Assessment in neuropsychology guides the way in which neuropsychologists practice their field and how test batteries are used in these assessments. This means that, in order to achieve the goals of assessment, the tools being used must fit the society in which they are being used. Most tests used in

neuropsychology are made by neuropsychologists and psychometricians in various fields and are accompanied by detailed manuals providing the information to establish the validity and reliability of the tests and normative information against which test results may be compared. This is the information that allows clinicians to compare their test candidates against the scores of a normal population of similar people (Kaplan and Saccuzzo, 2001). The test battery that was used to measure performance on neuropsychological tests in this study was the Zambia Neurobehavioral Test Battery with 14 tests split into 7 neuropsychological domains. These include the following:

a) **The Visual Episodic Domain** comprising the Brief Visual Memory Test Revised – Learning and delayed recall.
b) **The Verbal Episodic Domain** comprising the Hopkins Verbal Learning Test Revised – learning and delayed recall.
c) **The Verbal Fluency Domain** comprising the Controlled Word Association Test – FAS, Category Fluency Test (Animals and Actions) and the Stroop Word.
d) **Speed of Information Processing** comprising Trail Making Test Part A, Color Trails One, WAIS Digit Symbol, WAIS Symbol Search and Stroop Color.
e) **The Executive Functioning Domain** comprising the Color Trails 2, Halstead Category Test, Wisconsin Card Sorting Test and Stroop Color – Word.
f) **The Working Memory and AttentionDomain** comprising the Paced Auditory Serial Addition Test and the Spatial Span
g) **The Motor Dexterity Domain** comprising the Grooved Pegboard Test, dominant and non-dominant hand.

1.2 Effects of HIV/AIDS.

The effects of HIV cannot be over emphasized. HIV is a global epidemic that affects every aspect of human existence in the world. It has led to the injection of billions of money in the study of HIV focusing on its modes of transmission, infection, treatment and finding a cure for the virus. A lot of work is also being done in trying to find a vaccine for the virus to control its spread. HIV has affected the economies of the world through the loss of manpower through death and inability to perform daily tasks due to neurological impairments caused by the virus (Chipimo, 2011).

HIV in its progression affects the immunity of the individual thereby causing opportunistic infections that further weaken the individual. These opportunistic infections range from simple illnesses such as flu and coughs to complicated illnesses such as meningitis, kaposis sacorma and many others. The virus has the ability to affect the brain. The neurological effects of HIV are HIV encephalopathy which is characterized by impaired cognitive functioning, delirium which can lead to HIV dementia, anxiety disorders and adjustment disorders. Simply put HIV leads to impairment of memory, concentration, attention, motor function and personality changes (Kaplan, 2001)

The above mentioned effects of HIV could be reduced by using antiretroviral therapy. The literature suggests that patients with the above mentioned HIV related complications improved greatly after being put on treatment and this improves their general level of functioning and are able to resume their normal duties. The cognitive effects of HIV also reduce as well as the progression of HIV into fully blown AIDS. Therefore it could be argued that ART improves performance of HIV positive individuals on neuropsychological tests (Carson, 2007).

This study focused on the family social support system to see whether it improves an individual's performance on the neuropsychological test battery. A disease of the immune system such as AIDS provides a great illustration of the interrelationship between stress and immune response. It could be argued that stress may not cause AIDS but it can apparently weaken further the body's already compromised immune system (Carson, 2007). It is from this angle that family relationships are being considered as contributing factors to either improving or hindering the performance on the neuropsychological test battery.

Research has shown that stress could act as a precipitating factor to an individual getting an illness. In a study conducted by Strauman etal (1993) to demonstrate the effects of stress, they deliberately exposed quarantined healthy volunteer subjects to a common cold virus and assessed the outcome in terms of actual contraction of an upper respiratory infection. Stressful life events, self perceived stress and negative emotions were all assessed before the exposure and each significantly predicted which subject would become ill with the cold. Depression could also significantly suppress the immune system. The family was greatly linked to causing stress and depression in HIV positive people through lack of proper support for the patient. People living with HIV have great emotional needs and required support in order to come to terms with their infection. They experience feelings such as shock or anger at being diagnosed, fear over how the disease will progress, and fear of isolation by family and friends and worry about infecting others (Strauman etal, 1993). It was not surprising that such a heavy emotional burden led to depression which is twice as common in people with HIV compared to the general population. Relatives

(family) and friends were also affected by what the HIV positive person was going through. The kind of family one finds oneself with also determined to what extent a person was likely to suffer from depression.

1.3 Justification of the study

The importance of this study could not be over emphasized. The literature reviewed showed a gap in the area of family relationships. Most of the studies in the literature concentrated on the transmission, progression and management of HIV. The literature also looked at the importance of social support to the HIV positive individual. It also addressed how to help the family in general to cope with a family member infected with the disease. Little has been done in the area of how family relationships affect the infected person and the impact it has on the quality of life of this individual and how this is related to performance on the neuropsychological test battery. Quality of life for HIV positive individuals has been looked at in terms of occupation, social status, ability to access treatment, cost of care and adherence. It has also focused on the cognitive variables such as uncertainty of the disease and optimism. Very little is found in the literature on family relationships as a measure of quality of life in HIV positive individuals and their performance on the neuropsychological test battery. Not much literature was found on family relationships and performance of HIV positive individuals on the neuropsychological test battery. The literature on family relationships and performance on the neuropsychological test battery did not include how type of family relationships influenced performance of HIV positive individuals. It was against this background that a decision was made to undertake this study. This study will add new information in the area of HIV, family relationships and individual performance on the Zambia Neurobehavioral Test Battery.

1.4 Statement of the problem

The study examined family relationships in HIV positive individuals and whether these relationships were related to their performance on the Zambia Neurobehavioral Test Battery. The study aimed at examining the family relationship variables of family support, family rating, meaning of life, involvement in decision making, quality of life and living conditions and how they relate to performance on the test battery.

1.5 Objective

To establish whether family relationships are related to an individual's performance using the global deficit score of the Neurobehavioral Test Battery.

1.6 Hypothesis

There is a positive association between perceived quality of family relationship and performance on the Zambia Neurobehavioral test battery.

Operational Definitions

Positive or good family relationships in this study meant individual's perceptions of:

1. Involvement in decision making that is being asked to take part in decisions such as wedding arrangements, parenting styles and any family meetings.

2. Quality of life that is the way they view their lives in general that is are they happy or not to be part of the family they belong to.

3. living conditions that is the way they view their living conditions such as number of people in the home, availability of food, access to treatment and personal space

4. Meaning of life, this refers to what they think is their value in the family and whether they see their individual contribution in the family.

5. Family support, this refers to the way they look at the support they receive from the family in terms of financial, social and emotional support.

6. Family relationship rating refers to the way they view the relationships in the family whether good or bad.

7. Global family relationship score, the above mentioned six variables were numerically combined to come up with the global family relationship score by summing all the scores in the above mentioned variables and categorizing the scores into poor or negative relationship, neutral and good or positive relationship.

8. Global deficit score(GDS) this is the combined score of all the seven domains of the test battery namely attention and working memory, executive functioning domain, learning domain, fluency domain, motor function domain, speed of information processing domain and recall domain. The global deficit score is used to show performance of an individual on the test battery that is whether it is impaired or not.

CHAPTER TWO

2.0 Literature review

This chapter examines some of the literature on family relationships in HIV positive individuals. It also looks at studies that have focused on the performance of HIV positive individuals on neuropsychological tests and whether the type of family they come from does in any way affect their performance.

The statistics about the impact of HIV/AIDS worldwide are overwhelming. Estimates of the United Nations Agency for AIDS (UNAIDS, 2001) indicates that over 40million people were living with HIV in 2001, that nearly 25 million people had died of AIDS since the disease was first discovered in the early 1980's and that more than 15.6 million children under the age of 15 had lost either their mother, father or both parents as a direct result of AIDS (UNAIDS 2001). Apart from the physical and social impact of HIV on an individual, HIV also affects the cognitive functioning. HIV enters the brain early on in the infection by crossing the blood brain barrier which serves as a protective mechanism preventing entry of foreign substances in the brain. The ability of the HIV to cross this barrier contributes to the progression of the infection (Kaplan 2001). The cognitive impairments' associated with HIV occur in the domains of Attention, Memory, Verbal fluency and Visuospatial construction. It lowers the activities of the hippocampus which affects memory. The severity of the impairment in various domains depends on whether a person is on treatment or not (Berger,JR and Avison MJ 2004). The most common neurocognitive impairment in HIV is HIV Associated Dementia (HAD) whose symptoms falls into three broad categories namely: cognitive, motor and behavioral.

Cognitive category involves problems in concentration, short attention span, and inability to do routine tasks, memory loss and a generalized slowdown in mental function. The motor category involves poor coordination, weakness in the legs, difficult maintaining balance, tendency to drop things, decline in clarity of handwriting and loss of bladder and bowel control. The behavioral category includes personality changes, increased irritability, apathy towards loved ones, mood swings, impaired judgment and sometimes psychosis. It is these symptoms that neuropsychological testing in HIV attempts to explore. These symptoms of HAD drastically improve with the provision of antiretroviral treatment (Kaplan, 2001).

Although antiretroviral therapy has been found to reduce incidence of HAD the overall prevalence of HIV associated neurocognitive disorders increase as the disease progresses. Treatment and prevention of neurocognitive disorders in HIV are becoming an increasing concern in the management strategies for cognitive impairment in patients living with HIV. Although most studies indicate that antiretroviral

therapy use results in improvements of cognitive functioning, milder symptoms still exist such as headaches, confusion, forgetfulness and behavioral changes (Kaplan 2001).

The family relationships are affected when caring for someone with neurocognitive impairment because it is very stressful. Caregivers must cope with both the practical implications of the situation such as ensuring that the patient remembers to take their medication and the loved one's fears and despair. Family members have to be gentle with the patient especially after knowing that they are losing control of themselves which might be very frightening on the part of the patient. The family also needs to keep the home environment as familiar as possible for the patient. Family members caring for patients with HIV related dementia may suffer from feelings of depression, rage despair and fear (Home Care Guide, 1997).

At a human level, the financial burden of HIV/AIDS is at least 30% greater than deaths from other causes because it affects the most productive age groups (young adults) and because the cost of medication and caring for the sick are staggering and prolonged (Nampanya, 2000). HIV leads to financial, resource and income impoverishment (Barnett and Whiteside, 2002) and puts severe strain on individuals and households. The psychological stress that was a direct consequence of the impact of HIV/AIDS on individuals and families could compromise school and work performance, family relationships and the capacity to take care of children and may also culminate into risk behaviors such as alcohol and drug abuse and unsafe sexual practices (Nampanya, 2000).

The HIV/AIDS pandemic disproportionately affects women who already carry a very heavy burden in many countries, from the physiological and medical perspectives women are at a greater risk of getting infected. In addition they are often solely responsible for the household and the children, and have less financial and material reserves to fall back on. Women also face the risk of abandonment or abuse at the hands of their partners when HIV strikes. When family members fall sick as a result of HIV, it is often the girls who are removed from school to take care of those who are sick. (Barnett & Whiteside, 2002). This increases their susceptibility to poverty and to the disease because they probably end up marrying younger and not benefiting from education.

Successful prevention programming and strategies of HIV require knowledge of the epidemic, an understanding of the socioeconomic and cultural factors facilitating its transmissions. An effective response to HIV prevention also requires governmental leadership and community activism which are important for reviewing and sustaining the response to HIV prevention (HIV in Canada, 2010). This prevention program does not address the role of the family fully as it does not state anything about how the family could contribute to the management of HIV.

HIV affects the family demographically, socially and economically. HIV has a large psychological, physical and social impact on infected individuals and their families. Stigmatization worsens this impact as it hinders the prevention and treatment of HIV and hampers social support and HIV disclosure. The families most affected by HIV are characterized by low socio economic status (Psychosocial training manual, 2007).

The risk of transmitting HIV include that of mother to child transmission which increases when people are unaware of their status or when they do not disclose their status to their families. Studies on the impact of HIV/AIDS focus mainly on the individual especially on prevention and on the strategies to cope with the disease. Little has been done on the impact of the family on HIV positive individuals (World health Organization, 2003).

Families are important caregivers that provide social and economic support for individuals or members infected with the virus, mothers and close friends being the most important care givers. Families living with individuals that are HIV positive usually face tremendous social pressure and discrimination, in Nigeria for example when one member of the family becomes HIV positive, the whole family will be called an AIDS family by other members of the community(Alubo 2002). In Thailand also when a person discloses their HIV status the whole family loses community popularity (Manopaiboon etal1998). When facing such discrimination a strong and supportive family is the first line of defense. In Zambia and other countries with family oriented social systems when patients are too sick to take care of their children, grandparents become the primary caregivers of these children by providing psychological and economic support to these children (Nampanya 2000).

The benefits of emotional support from the family is that it buffers stress and improves adherence to HIV treatment, results in fewer symptoms of depression and improves the quality of life. Emotional support also helps the family member infected with HIV to restore their reason for existence and increases their self-esteem thereby performing their functions better. Research has also shown that the process by which caregivers (in this case, family) and people infected with HIV influence each other is reciprocal. Research has also shown that family members are more capable of coping with an HIV infected person who is actively coping with the disease, for example someone who openly talks about it and its implications rather than one that presents only with suffering(Wight etal 2003).

Family functioning describes how individual members behave in relation to one another. Family functioning can be divided into instrumental and expressive types of functioning. Instrumental functioning in a family refers to the mutuality needed to carry out the activities of daily living. Expressive

functioning refers to a family's communication patterns, problem solving abilities, family roles, power or control over one's behavior, and the intensity of relationships among family members (Haber etal 1992).

According to Rawlings, William and Beck (1993) a family can be described as functional or dysfunctional. A functional family is a family that works; it is a dynamic system where members relate to one another in order to form a unit separate from and capable of interacting with the outside world. It is characterized by open communication patterns, ability to meet physical, emotional, mental and social needs and is responsive to individual needs. A dysfunctional family on the other hand is one that fails to meet the physical, emotional and social needs of its members. It is characterized by fusion that is a lack of self-differentiation or oneness. Individual members of the family must not separate themselves from other members. This family is controlled by emotions and not intellect. There is no capacity for cohesiveness, the family lives in isolation from the rest of the world. It does not allow its members to interact with other members of society. In this family there are rigid boundaries with unclear and distorted perceptions of individual family members, high levels of both overtly expressed and suppressed methods of conflict management are impaired. Conflict is viewed as negative. In dysfunctional families individuals exist to keep the system in balance. Members need to control their interactions, feelings and personal behaviors. High levels of perfectionism and blame are present and feelings, perceptions, thoughts, wants and images are suppressed. These families deny their problems as a result most issues are not resolved.

The family may not play an important role in the causation of an illness but it plays a role in the prognosis of the illness. Prognosis can be poor as a result of expressed emotions in the family (Rawlins, William and Beck, 1993).Previous studies have demonstrated that a family member's illness impacts the whole family (Pequegnat 2001). This impact is usually shown in many different aspects such as economic hardships associated with HIV (UN General Assembly, 2005). Studies in many other countries such as China, also show that companies and indeed employers in general terminated employment for employees that tested positive (Cao, 2005)). The combination of an increasing cost of health care for HIV positive individuals and decreasing family income caused by unemployment may often hinder access to basic goods such as food, housing, medication and education for children.

Family relationships are part of the social support system which can be defined as the quality of relationships among family members and with friends, colleagues and acquaintances as well as involvement of the community (Berkman, 2000). Evidence has long demonstrated that poor family relationships and social support is associated with increased morbidity and mortality as identified by Emile Durkheim in the mid-19th century (Berkman, 2000). Social support can be measured using social isolation between socially isolated individuals and poor health outcomes have been well established in the

literature. Socially isolated individuals typically have limited access to the type of support available in social relationships (Kawachi etal, 1999). Research has also shown that socially isolated individuals lack the psychological protective effects derived from social relationships and without this protective effect, stress appears to have a longer negative impact on an individual's health (House, 2001).

Individuals that are HIV positive face many stressors which include coping with the physical aspects of the disease that is having a life threatening condition, physical ailments, regular medical checkups and strict adherence to medication (Barlette and Gallant 2001). HIV positive individuals also have to deal with psychological and social stressors associated with the disease such as fear of dying, risks of transmission of the illness to their partners, seeking and obtaining social support, initiating and maintaining close relationships and stigmatizing reactions from others. (Derlega& Barbee, 1998, Kalichman 2000).

People that are aware that their lives had been shortened by life limiting diagnosis faced enormous alterations and challenges to many aspects of their lives (Berkman, 2000). These aspects included professional, family and community and require social support in all these areas to make a difference in their quality of life and to give them an opportunity to remain in their homes and to minimize institutional admission to hospital, hospice and nursing homes (Gomes, 2004). It is important to understand patients' concept of social support which include family involvement, feelings of being supported in terms of social, physical, spiritual and emotional wellbeing (Devine& Westlake, 1995). Individuals that travel long distances to access treatment and services can experience greater disruptions of family and social life. Family distress or dysfunction can also undermine effective social support, therefore families need adequate information and support especially in the early phases of an individual's serious illness and treatment. This is because when they are not provided with information, they have greater needs, less trust and confidence in the health care system (Andershed, 2006).

House (1981) in Delgardo (2009) describes four main categories of social support namely emotional, appraisal, informational and instrumental. Emotional support generally comes from the family and close friends and this is the most recognized form of social support. It includes empathy, concern, caring, love and trust. It is this type of emotional support that is critical in this research.

Appraisal support involves transmission of information in the form of affirmation, feedback and social comparisons. This information is often evaluative and can be obtained from the family, friends, co-workers and the community. The other type of social support is informational support which includes advice, suggestions and directives that assists the person to respond to personal or situational demands.

The last form of social support is instrumental support which is the most concrete direct form of social support comprising of help in form of money, time, in-kind assistance and other explicit interventions on the individuals behalf (Delgard, 2009).

The family being the primary source of support usually goes through different stages in the process of providing support which include experiencing shame due to one member being infected, social and psychological pressure. Family support helps family members make important decisions such as taking an HIV test and enrolling themselves in HIV training programs. Involvement of families in HIV interventions has yielded great results in China (UN theme group on HIV AIDS in China 2004).

The ability to cope with physical, psychological and social aspects of HIV maybe affected by decisions made about whether, when and how to inform the family about their status(Greene, Derlega & Petronion 2003). Perceptions of social support are positively associated with whom the diagnosis has been made, these include family members, friends and significant people in the patients' life (Serovich 2000) whereas negative emotional reactions including depression and HIV related worries are inversely related to HIV disclosure (Bannettes 1999).

The negative consequences of being HIV positive include loss of employment, discrimination, rejection and isolation from the family (Fife and Wright 2000). The progression of the disease most often results in a decreasing quality of life. The world Health Organization Quality of life group (2005) defines quality of life as 'individual perception on their position in life in the context of culture, value system in which they live and in relation to their goals, expectations, standards and concerns. Daily functioning is the most significant predictor of life satisfaction. People with impaired ability to carry out daily activities have the least life satisfaction. Poverty is also directly related to lower quality of life. Antiretroviral medication does improve functional abilities thereby improving quality of life.

2.1 Theoretical framework

Behavior also defines the influence of family relationships on chronic disease. Stable, secure, and mutual family relationships enhance consistent disease management behavior by permitting a sharing of the burdens associated with disease. Such relationships enhance joint "ownership" of disease, which often includes a partitioning of disease management responsibilities among the patients and others and reduces patients' emotional and behavioral burdens. A family-focused approach is likely to maximize intervention effectiveness, whether or not family members other than the patient are directly involved (Cousins et al., 1992). This study was anchored in two theories namely the Cognitive Social learning Theory and the Social Action Theory.

Human behavior plays a central role in the maintenance of health and prevention of disease. The family is a crucial component in achieving behavior change in HIV positive individuals. Theories such as the Social Learning theory (Bandura 1997) can be used to explain how family relationships can affect HIV positive individuals. This theory proposes that reinforcements are not the sole determinants of behavior but that behavior change such as improved adherence can come from observations of others and support from the family. According to this theory the most important prerequisite for behavior modification is a person's sense of self efficacy to produce the desired outcome. People feel that they can only change their behavior if they perceive their social environment as encouraging the change. This includes the ability of the individual to accept their illness because of the way the family reacts to providing them with support, good living conditions and involvement in decision making. However if they don't believe in their own ability to change and improve their lives then their efforts will not succeed.

Substantial empirical evidence suggests that self -efficacy beliefs are reliable predictors of behaviors and that they mediate the efforts of intervention and maintaining risky behavior in illness such as HIV(Kaplan 2001). The other concept that the cognitive social learning theory brings in improving patients in cognitive testing is self- regulation that includes the will power to perform. This involves cognitive and behavioral processes such as initiation, modulation and redirection of emotions, thoughts, behavior, physiological responses and environment. This is very critical in health protective and health maintaining behaviors and managing stress. This theory has only been seen to work where family relationships are good and allow the patient to develop a self -efficacy and self -regulation (Compas etal 1999).

The other theory that can be used to explain the role of the family in HIV management is the Social Action Theory which builds on the social learning theory. It assumes that a person is influenced by the environment. This theory specifies mediating mechanisms that link the organizational structures such as the family to personal health and incorporates key concepts such as self -efficacy and expected outcomes focus on the influence of the environment on individual behavior (Ewart 1991). The social Action theory provides a framework for multilevel approaches to health promotion and illness prevention. It is a model that emphasizes the role of the environment that includes the family in encouraging individual health related behavioral change. It fosters inter-disciplinary collaboration by incorporating and coordinating epidemiological, social and behavioral perspectives (Ewart 1991).

The two theories described above show the importance of the environment which in this study looks at the family environment. The family is the cornerstone of an individual. A good family relationship allow an individual to develop a sense of self, belonging and gives individuals the will power to fight infection

and improve their quality of life. Good family relationships improve the cognitive performance of HIV positive individuals on their daily tasks and on neuropsychological tests (Baum 2000).

The good influence of supportive family relationships is widely accepted in the literature. Family relationships have greater emotional intensity than other social relationships and evidence suggests that there is a positive association between family bonds and chronic disease management and outcomes (Primomo etal 1999). It is this association that this study intends to establish between family relationships and Neuropsychological testing in HIV positive individuals.

CHAPTER 3

3.0 METHODOLOGY

This chapter outlines the methods that were used in the process of data collection as well as in the analysis of the data.

The data was collected as part of a larger project for the effects of HIV on Neuropsychological Tests contained in the Zambia Neurobehavioral Test Battery. Questions on the family relationships were formulated and incorporated in the general questionnaire for the overall study. They included questions such as: Are you happy with your family relationships? Who do you interact with the most and are you involved in making important decisions in the family? See Appendix A

3.1 Study design

This was a cross-sectional study that looked at HIV positive individuals that were on ART. The study aimed at examining whether family relationships were associated with performance of HIV positive individuals on the Zambia Neurobehavioral Test Battery by the use of Chi-square test of association.

The family relationship variables were recoded from a five point scale to a three point scale hence transforming them into bipolar categorical data as positive, negative and neutral. This recoding was done by three independent raters and an inter-rater reliability of .87 was achieved. The neuropsychological tests were interpreted using the global mean t-scores and the t-scores for the seven domains which were also recoded into categorical data as either impaired or not impaired. The mean was used as a cut-off point to determine impairment.

The sample contained only HIV positive individuals that were on antiretroviral therapy (ART).

3.2 Sample

The overall sample for the whole project comprised of 324 HIV positive individuals from chosen clinics namely Chipata, Chilenje, Kabwata, Kalingalinga, Matero main and Matero Referral clinics. This sample was shared among ten masters' students. In this study only 263 participants were used that were randomly selected from the chosen clinics using the patient registers of HIV positive individuals that attend those clinics. This was because some participants amongst the 324 in the larger project had some missing data

and therefore had to be excluded from the study. The sample consisted of HIV positive individuals aged between 20 years of age and 65 years of age with an education level of 5 years to 13+ years of schooling. This was because the Zambia Neurobehavioral Test Battery used was normed and validated on a similar sample of the population in Zambia that was HIV negative. The sample also contained an equal number of males and females and was drawn from an urban population due to limited resources.

3.3 Procedure

Inclusion-exclusion criteria

Inclusion

- HIV positive adults' status as confirmed by means of a rapid HIV-1 antibody test were carried out by a qualified health practitioner at the study site clinics.
- Educational level of between Grades 5-13+ years - obtained by means of the Demographic Questionnaire.
- Age 20-65 years and above - Demographic Questionnaire.
- HIV positive and on ART
- Ability to give consent
- Ability to speak and understand English- Assessed by means of the Wide Range Achievement Test (WRAT).

Exclusion

- Proven neurological problems that rendered a person completely nonfunctional and unable to consent. (Epilepsy, closed head injury, coma etc).
- HIV negative
- HIV positive but not on ART.
- History of Psychiatric illness that impair normal human functioning
- History of substance related disorders that impair normal human functioning
- Clinical Depression
- Inability to give consent

There were a number of stages that were followed in the recruitment of research participants. These included administration of the Zambia Achievement Test (ZAT), neuromedical evaluations and Psychiatric and Drug Abuse Assessment. Questionnaires assessing experiences of cognitive difficulties in

subjects' everyday life; any change in employment; and any decrease in the independence with which they performed instrumental activities of daily living were administered. This was so as to explore the real world effects of HIV and associated neurocognitive impairments in the population. The Academic Skills Questionnaire was also administered to assess quality of education and opportunity to use academic skills. The procedure for recruitment was staged as follows:

Stage 1: this involved recruiting individual from the urban clinics (Chipata, Chilenje, Kabwata, Kalingalinga, Matero Referral, Matero Main) with equal numbers of male and female research participants. It was done with the help of the medical personnel. They did so by asking the potential research participants if they could be willing to take part in the study. Those who were willing were asked to come back on a given date and time to meet up with the researcher.

Stage 2: As the potential research participants availed themselves, the researcher explained the terms of research participation. Those that voluntarily decided to participate were then asked to complete a demographic questionnaire and sign a written informed consent.

Stage 3: Medical screening involving neuromedical evaluations and an HIV test were done. This was so as to enable this study to have HIV positive participants on ART. Most of the medical assessments were conducted by qualified medical personnel and the results were then given to the researcher with the full consent of the research participant. Neuromedical examination involved a systematic review of past, current medical and neurological histories, history of any current or past antiretroviral therapy and their side effects as well as a brief medical and neurological exam.

Stage 4: This stage involved the completion of the following questionnaires:

Wide Range Achievement Test

Wide Range Achievement Test involved asking the participants to read and understand English words and based on their reading and understanding ability, they were graded on their ability to read and understand of English.

Psychiatric and Drug Abuse Assessment

The Psychiatric and Drug Abuse Assessment involved the Composite International Diagnostic Interview (CIDI). The CIDI provided results in terms of presence or absence of DSM/ICD10 diagnosis of present or past depression and substance disorder.

Everyday Functioning Assessment

The everyday functioning assessment included the Frontal Systems Behavior Scale (FrSBe), Independent Activities of Daily Living Scale (ADL) questionnaire, and the Patient's Assessment of Own Functioning Inventory (PAOFI). The FrSBe was a 46-item self-report behavioral scale. It was a measure of the behavioral sequelae associated with frontal systems damage. The PAOFI was a 41-item questionnaire in which the participant reported the frequency with which he or she had difficulties with memory, language and communication, use of his/her hands, sensory-perception, higher level cognitive and intellectual functions, work and recreation. This instrument focused on cognitive symptoms and was used, together with the ADL questionnaire, in the determination of neuropsychological impairments.

All those who were found to be HIV positive and were on ART were asked to volunteer their participation.

All the four stages took place in one day as the participants availed themselves. The neuropsychological testing took a maximum of three (3) hours and therefore only two (2) participants could be seen in one day. The actual data collection took thirty-five (35) days.

3.4 Detailed description of Instruments

Several instruments were used in the process of data collection. They included neuropsychological tests assessing different domains of the functioning of the brain and nervous system and questionnaires that gave demographic information, psychiatric and drug abuse history as well everyday functioning. A brief description of these items is outlined below.

3.4.1Neuropsychological Measurements

The Zambia neurobehavioral test battery was used in this study (*See Appendix D*). It is a test battery that assesses seven cognitive domains. These domains as well as the test used to assess them are as follows:

a) **Speed of information processing** – this domain included Digit Symbol & Symbol Search which are both adapted from Wechsler's Adult Intelligence Scale the two tests make up the

Processing speed index of the WAIS-III. In the Digit symbol, the participant is asked to match a symbol with a specific digit. The participant is asked to complete the task within 120 seconds without stopping or changing the answers. In the symbol search, the participant is asked to look at two symbols on the left and state whether any of them are on the right by answering "YES" or "NO" on the spaces provided. The Stroop Task being used for the current study was revised by Golden and Freshwater 2002. The colour card (C) in particular measures processing speed. The sheet consists of a series of 'X's printed in green, red and blue. The participant is asked to name the colour as quickly as possible while maintaining accuracy and the subject is given 45 seconds to complete the task. Trail making test Part A consists of encircled numbers from 1 to 25 randomly spread across a sheet of paper. The object of the test is for the subject to connect the numbers in order, beginning with 1 and ending with 25, in as little time as possible. The Trail Making Test (TMT) is a brief, easily administered tool that is widely used to measure motor speed, visual attention, and cognitive flexibility. It requires a variety of mental abilities including visual scanning, motor function, and letter and number recognition (Reitan, 2009).

The Colour trails test Part 1 is designed to minimize the influence of language so that it can be used in cross-cultural settings. The test has all odd-numbers circled pink and all even-numbers circled yellow; it shows all numbers from 1 to 25, alternating between pink and yellow circles (Strauss, Sherman & Spreen, 2006).The participant is required to move from a pink one to a yellow two, to a pink three and so on until they reach 25. The amount of time taken to complete the task is recorded.

b) Verbal Episodic Memory – it included the Hopkins Verbal Learning Test – Revised which is a test of learning ability and delayed recall on verbal information across trials. It also measures an individual's capacity to retain, reproduce and recognize information after delay (Strauss, Sherman and Spreen 2006:760). The HVLT-R to be used in the Zambia Neurobehavioral Battery is comprised of 12 nouns with four words drawn from three semantic categories i.e. four words each from four legged animals, precious stones and human dwellings. Some changes have been made to adapt the words to make the test to the Zambian situation. For instance the original items such as Emerald, Sapphire, Jade and Pearl have been replaced with Copper, Iron, Lead and Zinc respectively. (Cherner et al 2007).

c) Visual Episodic Domain - The Brief Visuospatial Memory Test – Revised (BVMT-R) measures visual learning and memory using a multiple-trial list learning paradigm. Like the

HVLT –R, it also measures immediate and delayed recall (Strauss, Sherman and Spreen, 2006). When administering the test, the participant is presented with an 8 x 11 – inch card containing six simple geometric visual designs in a 2 x 3 matrix, for 10 seconds and after that the participant is required to reproduce as many of the designs as possible on a blank sheet of paper in the same location as they appeared on the display.

d) Abstraction/executive functioning – consisted of the Wisconsin Card Sorting Test – 64 Item. The test was originally meant as a test of "abstract behaviour and shift of set". It was originally created as 60 card test with one to four symbols which are a triangle, a star, cross or circle in red, green, yellow or blue. All cards are different and there are no two identical cards. In the test the test taker is supposed to match one of the cards at the bottom to those that are shown among the four (Lezak, 2004). There are three principles in the way the cards are matched and these may be the colour, the shape or the number of items on the card e.g. four (regardless of the colour or the shape of the items). The feedback given for each response is either "right" or "wrong", indicating whether the card has been matched correctly.

The Halstead Category test (Standard Category Test) was developed by Halsted (1947) to assess the ability to conceptualise qualities such as size, shape, number, position and colour. In its original form it had 336 items with 9 subtests. Reitan in 1948 reduced the subtests to 7 with 208 items. Each subtest has a different principle which may be odd stimulus, number of objects, spatial position, a combination of different principles etc. To complete the test, the participant must rely on feedback based on correct or incorrect guesses to show what the principle in that subtest is.

The Stroop Word- Colour task CW which equally measures executive function consists of names of colours printed in an incongruent ink colour. The client is given 45 seconds to name the colour while suppressing the automatic response to read the word.

e) Verbal Fluency – this was assessed using the Controlled Oral Word Association Test - (COWAT–FAS) whose purpose is to evaluate the spontaneous production of words within a limited amount of time (Straus, Sherman, Spreen, 2006). The participant is asked orally to produce as many words as possible, beginning with a given letter in a trail of three. Examinees are allowed 60 seconds for each trial and are not allowed to generate nouns such as name of a person "Gerald" or a place "Lusaka"and the Category Fluency Test (Animals and Actions) where the test taker is asked to mention as many names of animals as they can

think of in 45 seconds and the same time is allowed for the actions where one is asked to mention as many things as possible that human beings do.

The Stroop Word is a test that contains the words of red, green, and blue repeated randomly in a 10 X 10 matrix (Straus, Sherman, Spreen, 2006). In this task, the participant is asked to read the words as fast as they can with 45 seconds. If they finish reading before time ends, then they go to the first item and begin reading again.

f) Attention/working memory - this domain included the Paced Auditory Serial Addition Test (PASAT) as cited in (Strauss, Sherman & Spreen, 2006), the PASAT was devised by Gronwall et al. (Gronwall, 1977; Gronwall & Sampson, 1974; Gronwall & Writson, 1974 as cited in Strauss, Sherman & Spreen, 2006) to provide an estimate of speed of information processing. Paced Auditory Serial Attention Test is meant to measure attention deficits including concentration, speed of processing, mental calculation, and mental tracking. It is sensitive for diagnosing cognitive impairment in individuals 16 years old and up. The participants are given a number every 3 seconds and are asked to add the number they just heard with the number they heard before.

The Spatial Span adapted from Wechsler's Memory Scale – third edition) has 10 cubes in which the participant is required to follow a sequence of tapping the blocks both forwards and backwards. Wilde and Strauss (p323, 2002) highlight the assumptions of the Wechsler spatial span test as "(a) Spatial span is a visual analogue of the Digit Span, (b) the working memory demands of the Spatial Span backwards are greater than in the forward condition, and (c) Spatial Span is a valid measure of visual-spatial memory".

g) Motor Dexterity– this was assessed with the Grooved Pegboard Test (Dominant & Non-Dominant Hand trials. The "Grooved Pegboard (GP) task measures eye-hand coordination and motor speed" (Strauss et al., 2006:1061). This procedure measures performance speed in a fine motor task and by examining both sides of the body, it allows for inferences to be drawn regarding possible lateral brain damage (Swiercinsky, 2001).

The GP consists of a metal board with a matrix of 25 holes with randomly positioned slots. Pegs have a ridge along one side and must be rotated to match the hole before they can be inserted in the board. The participants' task is to insert the pegs in the holes as fast as they can in sequence without skipping any slot.

h) **Screening Test** – was the Hiscock Memory. The test has been designed to clinically identify an individual thought to be purposefully feigning or faking memory impairment (Prigatano & Amin, 1993). The 18-item HDMT which is a part of the Zambia Neurobehavioral test battery is a forced-choice visual memory task used clinically to detect factitious sensory or perceptual impairment and also applied to cases of claimed memory loss, on which participants view (and are asked to remember) a successive series of 5-digit numbers for 5 seconds each, which are presented singly on a 7.6 X 12.7 cm note cards attached to an easel.

3.4.2 Psychiatric and Drug Abuse assessment

3.4.2.1 Beck Depression Inventory Version 2 (BDI -II)

Depression symptoms were assessed using the Beck Depression Inventory (II) which is a 21-item self-report scale. On each item there are 4 response options of perceived severity within a period of two weeks. Administration of the BDI takes about 10 minutes.

Alcohol and Drug abuse was assessed using the Chinese Substance Use questionnaire. The questionnaire contains a list of drugs and alcohol and the participant is required to state which ones and how much they have used in the last three months. It further requires the participant to state details of the frequency of use and the quantities for each drug or alcohol stated to have been used.

3.4.2.2Everyday Functioning Assessment

The assessment of everyday functioning was done through the Activities of Daily Living Scale (ADL) questionnaire, and the Patient's Assessment of Own Functioning Inventory (PAOFI). The ADL questionnaires assesses how an individual functions in their daily lives and is mainly used in finding the effects of dementia which is both senile or as a result of HIV. The PAOFI is a 41-item questionnaire in which the participant gives information on whether the respondent has difficulty with language, memory and communication. It also considers motor skills, sensory and perceptual skill and other cognitive and intellectual functions as well as engaging in social interaction. The two instruments (ADL and PAOFI) work in complimentary fashion to assess any neuropsychological impairment that leads to disturbance in the everyday functioning of an individual.

The neurobehavioral questionnaire was also used to assess the neurological stability and to check for any cofounds that may be present in the process of assessment as well as during data interpretation.

3.5 Demographic Information

In order to obtain information on the different demographics, a questionnaire containing all the required demographic information was administered. It included information on age, education, sex, rural/urban (location), social economic status and number of languages spoken, questions on family relationship, nutrition, gender based violence (*See Appendix A*).

3.6 Quality of family relations

The measure of family relations used for data analysis in the present study was based on codings by 3 independent raters of each participant's responses to questions 1,2,3,5,8&9 in the section of the questionnaire under family relationships (see Appendix A). The inter-rater reliability was .87

3.7 Data Collection

The data was collected by 10 researchers all of whom were pursuing a Master of Science in Clinical Neuropsychology. Each researcher collected data from 36 participants making a total of 324. However, only data for 263 participants was used because they are the ones that had the complete data of all the tests and met the criteria.

Once permission was obtained from the Ministry of Health the sampled clinics were approached to recruit participants who were of a particular age and educational level as was stated in the sampling frame. The recruited participants were then screened for HIV to ensure that they were HIV negative. When the test was done, the clients were referred to the researchers for neuropsychological assessment.

Each client was assessed using the instruments stated above and the entire testing process took 3:30hrs to 4hours. Each researcher collected data at an average rate of 3 participants per day. The researcher then gave the informed consent form to the participant and once consent was obtained, they administered the ZAT tests to assess for fluency in the English language. Any clients who were not able to read either the ZAT score beyond the first line of first two items were not included in the study. They were then given the Neurobehavioral Medical Screen to assess for Neurobehavioral wellbeing and any who were found to have confounding factors such as psychiatric illness or

neurological disorders of any sort were not included in the study. Then finally the researcher administered all the tests included in the battery.

Table 1. Neuropsychological test battery.

Speed of Information Processing	*Learning and Delayed Recall (2 domains)*
WAIS-III Digit Symbol	Hopkins Verbal Learning Test, Revised-II
WAIS-III Symbol Search	Brief Visuospatial Memory Test – Revised
Trail Making Test Part A	*Language*
Attention/Working Memory	Word Sound Fluency
Paced Auditory Serial Addition Test	Category Fluency (Animals, Action)
WMS-III Spatial Span	*Motor*
Abstraction/Executive Functioning	Grooved Pegboard (Dominant and Non-dominant)
Wisconsin Card Sorting Test (64-item version)	*Screening for Effort*
Color Trails	Hiscock Memory Test
Stroop Color Word Test	Medical Screening Interview
Category Tests – computer version	Behavioral Notes Summary
	Academic Skills Questionnaire

3.8 Zambia Neurobehavioral Battery protocol

Neurocognitive Assessment: The neurocognitive assessment consisted of tests of the following ability domains: verbal fluency, abstraction/executive functions, attention/working memory, and speed of information processing, learning, delayed recall, and motor function. Specific tests were listed in Table1. These are well known NP instruments and have been widely used in neurobehavioral studies of HIV/AIDS (Carey, et al., in press; Woods, et al., in press). To explore the real world effects of family relationships in HIV+ and associated neurocognitive impairments in this population, the researcher administered brief questionnaires assessing participants' (1) experiences of cognitive difficulties in their everyday lives, as well as (2) any change in employment, and (3) any decrease in the independence with which they perform instrumental activities of daily living (see Table 2).

The Academic Skills Questionnaire had been included to assess quality of education and opportunity to use academic skills.

Table 2. Questionnaires and Psychiatric Measures

Psychiatric Measures
Composite International Diagnostic Interview (CIDI)
Beck Depression Inventory (BDI)
Brief Symptom Inventory (BSI)
Questionnaires
Patient's Assessment of Own Functioning (PAOFI)
Activities of Daily Living Scale (DLS)
General questionnaire

3.9 Ethical considerations

Research on HIV/AIDS requires a lot of ethical considerations as it hinges on the privacy and personal space of individuals with or without the virus. This study in particular looked at the individuals who had the virus and were on treatment and also focused on their families as well. This presented ethical questions such as how was the data going to be collected, analyzed and presented without causing harm to the participants? This research was also likely to affect participants psychologically as it led them to critically analyze their family relationships after being diagnosed with the virus and being on treatment. It also affected them as it was time consuming especially that they were subjected to a three hour long test battery to assess their level of cognitive functioning. The care or benefits participants received were not affected by their withdrawal from the study meaning they could withdraw from the study without losing the benefits of the study such as transport refunds and refreshments.

In order to address ethical concerns, permission to conduct the study was obtained from the ethics committee of the University of Zambia as the expected value of this research impacted on improving treatment and enriching the knowledge base of the management of HIV. Permission to conduct the study was also obtained from the Ministry of Health as well as the clinics where the sample was drawn from. Further permission was sort from would be participants after clearly explaining to them what was involved in the study. Participants were encouraged to take part on their own free will and were allowed to withdraw from the study without any consequences. The data obtained was kept under lock and key and transcribed in order to ensure anonymity. The results of this study were used only for academic

purposes and enriching the scientific knowledge base. In order to address the time factor participants were compensated for the time (with fifty thousand kwacha or fifty kwacha rebased) they committed to take part in the research and were given at least four (4) breaks during the assessment that lasted about five (5) minutes.

CHAPTER FOUR

4.0 RESULTS

4.1 INTRODUCTION

This chapter will focus on the analysis of results and will present the findings on whether family relationships do in any way relate to the performance of HIV positive individuals on neuropsychological testing.

4.2 Data analysis

The collected information was analyzed with the help of Statistical Package for Social Sciences (SPSS). The data was first analyzed using frequencies, means and percentages to explain the demographic variables and individual domains of the neuropsychological test battery. Testing for association between family relationship variables and neuropsychological tests was done using chi -squared test of association. The family relationship variables were re-coded from a five point scale in the questionnaire to a three point scale used in the analysis. This re-coding was done by three independent raters and an inter-rater reliability of .87 was achieved. The family relationship variables were transformed into bipolar categorical data as positive, negative and neutral. A complete comprehensive interpretation of neuropsychological test results was done using the Global mean tscores and the t-scores for the seven domains, the t-scores of the seven domains of the test battery were also re-coded into categorical data as either impaired or not impaired. The mean was used as a cut- off point to determine impairment. (Horton, &Wedding, 2007, quoting Heaton, et.al, 2004)

In line with my theoretical analysis, ideally positive (good) family relations were expected to be associated with higher mean scores on the Global Deficit Score (GDS) and negative (poor) family relations to be associated with lower scores. This calls for testing the following hypothesis:

There is a positive association between quality of family relationship and performance in the Zambia neurobehavioral test battery.

4.3 Demographics

The sample consisted of 263 participants that were HIV positive drawn from 6 clinics in Lusaka that underwent neuropsychological assessment using the Zambia neurobehavioral test battery and answered a questionnaire about their family relationships. The study sample composed of a mean age of 40(SD +/- 8.8). The minimum age in this sample was 21 years and the maximum age was 65. Within this sample the range was rather wide of 44, further grouping of the age shows that the majority were between 36 and 45(n=110)(41.8%). A paltry n= 18(6.8) were old people or had just passed their middle age. The gender distribution was 107 males and 156 females. Females represented 59.3% of the population. 138 were living together or married representing 52.5% while only 39 were single representing 14.8% of the sample. 126 had secondary school education level status representing 47.9% of the sample and 15.6% had primary school education level. (Table 5.1)

Table 5.1 demographic profile N=263

Characteristics	**Groups**	**Frequency**	**Percentage (%)**	**Mean**	**Standard deviation**
Age	20-35	75	28.5	40	8.8
	36-45	110	41.8		
	46-55	60	22.8		
	56-65	18	6.8		
	Total	**263**	**100**		
Marital Status	Single	39	14.8		
	Married	138	52.5		
	Widowed	62	23.6		
	Divorced	23	8.7		
	Cohabiting	1	4		
	Total	**263**	**100**		
Sex	Male	107	40.7		
	Female	156	59.3		
	Total	**263**	**100**		

In order to determine the type and level of family relationship six variables were assessed and scored categorically as negative(very poor), neutral(poor) and positive(good). The variables included individual's perception: of family support, quality of life, of living conditions, involvement in decision making, of family rating and of meaning of life.. A general overview shows that relationships were positive across all domains; this is because more than half of the respondents in each domain scored more than 50% in each domain as seen in table 5.2.1

Table 5.2.1 classification of family relationships by participants

Characteristics	Groups	Frequency	Percentage (%)
Individual Family Rating	Negative	31	11.8
	Neutral	4	1.5
	Positive	228	86.7
	Total	**263**	**100**
Individual perception Quality of Life	Negative	68	25.9
	Neutral	5	1.9
	Positive	190	72.2
	Total	**263**	**100**
Individual perception Meaning of Life	Negative	43	16.3
	Positive	30	11.4
	Positive	190	72.3
	Total	**263**	**100**
Involvement in Decision Making	Negative	89	33.8
	Neutral	7	2.7
	Positive	167	63.5
	Total	**263**	**100**
Individual perception of Living Conditions	Negative	94	35.7
	Neutral	9	3.5
	Positive	160	60.8
	Total	**263**	**100**
Individual perception of Family support	Negative	37	14.1
	Neutral	10	3.8
	Positive	216	82.1
	Total	**263**	**100**

A comprehensive examination of these family relationship variables combined to come up with the global family relationship score showed that family relationships in our sample were good or positive N=220(84%) as compared to N=43(16%)(table 5.2.2).

Table 5.2.2 global family relationships

Characteristics	**Groups**	**Frequency**	**Percentage (%)**
Global family relationship score	Good	220	84
	Poor	43	16
	Total	**263**	**100**

Chi square tests of association performed on the family relationship variables and the test battery domains revealed that there were no relationships between the family and performance on the test battery as seen in table 5.3

Table 5.3 Association of domains (family relationship domains and test battery domains)
Chi square test

P=0.05

Domains	**Questions**	**Phi**	**Chi-squared**	**Df**	**P value**
Attention/working memory	Family support	.074	1.426	2	.490
	Living conditions	.027	.196	2	.658
	Quality of life	.074	1.452	2	.484
	Decision making	.048	.593	2	.743
	Family rating	.027	.194	2	.907
	Meaning of life	.069	1.247	1	.264
Executive function	Family support	.104	2.845	2	.241
	Living conditions	.019	.098	1	.754
	Quality of life	.086	1.964	2	.375
	Decision making	.127	4.266	2	.118
	Family rating	.090	2.112	2	.348
	Meaning of life	.044	.519	1	.471
Fluency	Family support	.009	0.20	2	.990
	Living conditions	.002	.001	1	.973
	Quality of life	.038	.388	2	.824
	Decision making	.048	.601	2	.740
	Family rating	.014	.050	2	.975
	Meaning of life	.107	3.010	1	.083
Learning	Family support	.039	.406	2	.816
	Living conditions	.013	.043	1	.835
	Quality of life	.078	1.618	2	.445
	Decision making	.097	2.479	2	.290
	Family rating	.018	.089	2	.957

	Meaning of life	-.051	.677	1	.410
Motor	Family support	.044	.521	2	.774
	Living conditions	-.068	1.202	1	.273
	Quality of life	.107	3.018	2	.221
	Decision making	.034	.300	2	.861
	Family rating	.134	4.767	2	.092
	Meaning of life	.025	.166	1	.684
Recall	Family support	.102	2.706	2	.258
	Living conditions	.003	.002	1	.968
	Quality of life	.077	1.540	2	.463
	Decision making	.038	.372	2	.830
	Family rating	.003	.002	2	.999
	Meaning of life	.098	2.506	1	.113
Speed of information processing	Family support	.102	2.712	2	.258
	Living conditions	-.074	1.433	1	.231
	Quality of life	.037	.351	2	.839
	Decision making	.140	5.180	2	.075
	Family rating	.030	.234	2	.890
	Meaning of life	.023	.133	1	.715

When the family relationship variables were combined to come up with the global family relationship score were tested for a relationship with the global deficit score that measures performance on the test battery no relationship was found between family relationships and performance on the Zambia neurobehavioral test battery as can be seen by the p value of .705 as shown in table 5.4

Table 5.4. Association between global family relationship and Global deficit score.

Chi –square test.

P=0.05

		Global family relations							
		Negative	**Neutral**	**Positive**	**Total**	**phi**	**Chi squared**	**Df**	**P value**
Global deficit score	**Above mean**	19	9	42	**70**	**.052**	**.700**	**2**	**.705**
	Below mean	43	25	125	**193**				
	Total	**62**	**34**	**167**	**263**				

The global deficit score shows that there was poor performance on the test battery by the participants in this study. N=174(66%) below the mean and N= 89(34%) above the mean as seen in table 5.5

Table 5.5 Performance on the Zambia neurobehavioral test battery using the Global deficit Scores

Characteristics	Groups	Frequency	Percentage (%)	Mean	Standard deviation
Global deficit score	Below mean	174	66	46	4.3
	Above mean	89	34		
	Total	**263**	**100**		

CHAPTER FIVE

5.0 Discussion of findings

5.1 Introduction

This chapter will look at the results obtained from the study and what they mean thereby giving an interpretation of the relationship between the family and an HIV positive individual's performance on the Zambia Neurobehavioral test battery.

5.2 Demographics

This study was conducted among HIV positive individual's in Lusaka urban that attended ART clinics at the following clinics: Kabwata, Kalingalinga, Chipata, Chilenje, Matero REF and Matero main. The sample size was 263 individuals aged between 20 years of age to 65 years with at least 5 years of education. The study tried to balance the gender but this was not possible as it was observed that more females attended the clinics.

5.3 General perception of individuals on family relationships

The results showed that in general the majority of the participants assessed on perception of family relationships using the six family relationship variables incorporated in the general questionnaire rated their family relationships as positive (see table 5.2.1, 5.2.2).

5.4 Association between family relationships and performance on the international neurobehavioral test battery

The critical aspect of this study was to examine whether family relationships had an association with an HIV positive individual's performance on the test battery. Family relationships in this study were examined using six variables which included individual's perception of: family support, quality of life, living conditions, involvement in decision making, family rating and meaning of life. These variables were then numerically combined to come up with a global family relationship score, scored as very poor or negative relationship, poor or neutral relationship and good or positive relationship. Performance on the test battery was measured using the global deficit score impairment arrived at by summing up all the t-scores of the seven domains of the battery namely attention and working memory domain, executive function domain, learning domain, fluency domain, motor domain, recall domain and speed of information processing domain and then scored as either impaired or not impaired using the mean of 50 as a cut-off point.

In order to examine whether family relationships variables were related to performance on the individual domains of the test battery, Chi square test of association was done (see table 5.3) and revealed no relationships between the family relationship variables and scores on the neuropsychology test battery.

Chi square test of association was used to test for association between the family relationship using the global family relationship score and performance on the test battery using the global deficit score impairment. The results showed that there was no relationship between the two as can be seen by the p value of .700(see table 5.4.1). Therefore it can be said that on a global perspective family relationships were not related to an HIV positive individual's performance on the international neurobehavioral test battery.

5.5 Performance on the Zambia neurobehavioral test battery

The results on the performance on the test battery revealed the majority of the participants performed badly as they fell below the mean by at least one (1) standard deviation. The Global Deficit Score which was used to measure performance or impairment showed that 66% of the sample was impaired or performed poorly (table 5.5). This was not a surprising result because the test battery used is sensitive to HIV related impairments. It is a known fact that the HIV virus has the ability to affect the brain by crossing the brain blood barrier which protects the brain from infections. The neurological effects of HIV are HIV encephalopathy which is characterized by impaired cognitive functioning, HIV dementia, impairment in memory, concentration, attention, motor functioning and personality changes (Kaplan, 2001). This information is vital in that it allows us to examine the relationship between performance on the test battery and the family. It allows comparison of those that rated family relationships as positive and those that rated them as negative and how they performed on the test battery.

The literature suggests that despite the fact the family may not play a role in the causation of an illness, it plays a vital role in the prognosis of the illness. It is important to recognize that the patient's concept of social support includes family involvement that is having a sense of belonging (Devine, Westlake, 1995). Family distress or negative family relationships have the ability to undermine effective family support (Andershed, 2006)

The family relationship variables used in this study included individual perceptions on involvement in decision making, meaning of life, quality of life and family support which can be likened to what House (1981) in Delgard (2009) described when he outlined four categories of support that the family occupies namely emotional support which includes empathy, love and trust, appraisal support which includes transmission of information in the form of affirmation, feedback and social comparison. The other

category is information support which includes suggestions and involvement of individuals in decision making and the last one is instrumental support which comprises of help in form of money, time and in kind assistance. All these forms of family involvement improve family relationships and ultimately improve an individual's perception of quality of life and the meaning of life (Delgard, 2009). It can therefore be argued that our results do not give support to House's description of the importance of family relationships.

The results obtained in this study did not match any of the findings in the previous studies perhaps due to the fact that this study compared family relationships to performance on tests instead of other areas of performance such as activities of daily living where the family is directly linked. The study did administer a questionnaire on activities of daily living but this was a self- report questionnaire and therefore, not an ideal way to assess function in people that are already impaired. It could also be that the measurement of family relationships needs to be broadened in order to elicit responses that would be more directly related to performance on the test battery.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATION

6.1 SUMMARY

This study aimed at investigating the relationship between family relationships of HIV positive individuals and their performance on the Zambia Neurobehavioral Test Battery using the modified version of the WHO Quality of life questionnaire incorporated in the group's demographic questionnaire. Participants in the research were Zambian adults, drawn from urban areas of Lusaka and who were HIV positive. Family relationships were measured using six variables namely perceived family support, perceived quality of life, perceived meaning of life, perceived quality of living conditions, involvement in decision making and perceived rating of family relationships. The six family relationship variables were then numerically combined to come up with a global family relationship variable. These were then analyzed in relation to performance on the various neuropsychological domains. Chi square test of association was used to test for relationships or association between the family relationship and performance on the test battery.

6.2 Conclusion

When individual family relationship variables were examined in relation to individual domains of the test battery no associations were found.

When the Global deficit score and the Global family relationship score where compared, it can be seen that there was no association between type of family relationship and performance on the Zambia Neurobehavioral test battery. The scores of the test battery were measured globally using the global deficit score and family relationships were also measured globally using the global family relationship score. Our results did not show any relationship between any of the family relationship variables and test performance on the individual domains of the neuropsychology test battery and therefore we reject our hypothesis. It can therefore be concluded that perceived quality of family relationship does not in fact relate to performance on any of the domains of the Zambia Neurobehavioral test battery.

6.3 Challenges faced during data collection

There were several challenges that were faced during the process of data collection, however, only the major ones will be highlighted:

1. In certain instances, a participant with low levels of education for example would require almost five hours before the whole process could be completed. This led to participants experiencing a lot of fatigue which may have affected their performance on the tests.

2. Another challenge was that of comprehension of the instructions as well as the questionnaires. Some of the participants even though they met the requirements for fluency in the English language, experienced difficulties understanding some of the words on the questionnaires as well as some of the instructions on the test.

3. Another challenge faced was lack of proper testing rooms in the different clinics. There were limited rooms available for the testing process and some of those which were available were not suitable for carrying out neuropsychological testing as there were noises and disturbances in some of the rooms. In some though rare cases, the researchers resorted to carrying out the testing process outside and this may have affected the validity of some of the test results.

4. The instructional booklet mostly contains American English which is not normally used in the Zambian setting. This made the understanding of the instructions difficult even for people who had high educational levels as they contained some unfamiliar words.

5. The additional questionnaires and material to be administered apart from the test battery made the administration take very long, lasting four to five hours for each participant. This caused fatigue amongst the participants and may have affected performance on certain tests particularly those at the end.

6.4 Recommendations

Based on the findings stated above, the following recommendations are proposed to help in the practice of neuropsychology in Zambia:

1. Instead of using global deficit score as a measure of performance on the test battery, individual domain scores should be used. This is because an individual can show good

performance or poor performance on the global deficit score and yet this score may be caused by only one or two domains.

2. A profile of scores in different domains is a more useful guide in counselling and rehabilitation than the global deficit score as it shows the exact areas were the client needs assistance.

3. Zambian norms on the use of the battery should be made available so as to obtain a true reflection of performance on the test battery in Zambia.

4. The instructional booklet needs to be edited to include words that are more familiar to most of the Zambian population as this will allow for easier understanding.

5. Extra instruments or questionnaires should be administered preferably on a separate day from the one being used for testing. This will reduce the amount of time spent on one client thus reducing fatigue experienced by the clients.

6. Testing rooms must be set up that are free from distracting noises and activities.

6.5 Suggestions for further research

This study is the first to be carried out in Zambia with a sample collected from selected parts of Lusaka. Therefore, it would help if the same study could be replicated to more parts of the country and with a larger sample. This would increase the confidence with which findings can be generalised to all people of Zambia.

In this study, family relationships were studied for the first time among HIV positive individuals in relation to their performance on the Zambia Neurobehavioral test battery. It would be beneficial if a similar study can be done among HIV negative individuals to establish a bench mark which such studies can be compared to.

REFERENCES

Alubo O, Zwanda A and Omudu E (2002): Acceptance and stigmatization in Nigeria AIDS care. PubMed

American Psychiatric Association (2008) Coping With AIDS and HIV.

Andershed B. (2006). Relatives in End of Life Care: A Systematic Review of the Literature the Last Five Years, Jan 1999-Feb 2004. Journal of Clinical Nursing 2006 Sep 15(9).

Bandura A(1986)Social Foundations of Thought and Action: A Social Cognitive Theory. Englewood Cliffs, New Jersey: Prentice-Hall.

Barnett T and Whiteside A (2002). AIDS in the Twenty First Century: Disease and Globalization. Macmillan, Publishers. New York

Bartlett JG and Gallant JE (2001): Medical management of HIV infection. Baltimore. John Hopkins, University press.

Baum A (2000) Behavioral and psychosocial intervention to modify pathophysiology and disease course in: Smedley BD, Syme SL, editors: Promoting Health: Intervention Strategies from Social and Behavioral Research. Institute of Medicine. Washington, DC: National Academy Press.

Bennetts A, Shaffer N, Manopaiboon C and Mock P (1999): Determinants of depression and HIV related worries among HIV positive women who have recently given birth. Bangkok. Thailand.

Berkman LE, Glass T, Brissettel I & Seeman TE (2000). From Social Integration to Health: Durkheim in the New Millennium Soc. Scie. Med. 51

Brown L, McIntyre K & Trufillo L (2003) Interventions To Reduce HIV/AIDS Stigma: What We Learned: AIDS Education And Prevention. 15 (1).

Cao XB, Pang L and Wu ZY (2005): Reasons and patterns of AIDS sigma and intervention strategies. Chinese journal of AIDS/ STD 11(3).

Carson Robert C, Butcher James N & Mineka Susan (2007). Abnormal Psychology and Modern Life.11th Ed. Pearson Publishers. New Delhi.

Central Statistical Office Zambia (2010), Census Data on HIV/AIDS. Lusaka, Zambia.

Chipimo PJ & Fylkesnes K (2011). Mental Distress in the General Population of Zambia: Impact of HIV and Social Factors. BMC Public Health. 9

Compas BE, Connor JK, Saltzman H, Thomsen AH, Wadsworth M (1999) Getting specific about coping: Effortful and involuntary responses to stress in development. In: Lewis M, Ramsay D, editors. Soothing and Stress. Mahwah, NJ: Lawrence Erlbaum Associates.

Cousins JH, Rubovits DS, Dunn JK, Reeves RS, Ramirez AG, Foreyt JP (1992): Family versus individually oriented intervention for weight loss in Mexican American women. Public Health Reports. [PubMed

Delgard OS. (2009) Social Support –Definitions and Scope: EUPHIX Euphact. Bilthoven; Rivmhttp://Www.EUPHIX.Org Euphact/Determinant of Health/ Environment/Social Support.

Derlega VJ and Barbee AP (Eds) (1998): HIV and social interaction. Thousand Oaks CA: Sage

Devine EC& Westlake SK. (1995) The Effects of Psych educational Care Provided to Adults with Cancer: Meta –Analysis of 116 Studies. Oncol Nurse Forum 1995; 22

Dzekedzeke F, Flykesnes K (1998). Reducing Uncertainties in Global HIV Prevalence Estimates: The Case of Zambia. BMC Public Health

Ewart CK (1991) Social action theory for a public health policy. American Psychologist. [PubMed]

Ewart CK(1995) Self-efficacy and recovery from heart attack: Implications for a social cognitive analysis of exercise and emotion. In: Maddux JE, et al., editors. Self-efficacy, Adaptation, and Adjustment: Theory, Research, and Application. New York: Plenum.

Fife BL and Wright ER(2000): the dimentionality of stigma : a comparison of its impact on the self of persons with HIV/AIDS and Cancer. Journal of health and social behavior.

Gomes B & Higginson D. Factors Influencing Death At Home In Terminally Ill Patients With Cancer: Systematic Literature Review. Scandiviavian Journal of Caring Sciences. June 2004; 18 (2)

Greene K, Derlega VJ, Yep GA and Petronio S (2003): Privacy and the disclosure of HIV in interpersonal relationships: A sourcebook of researchers and practitioner.

Haber J, Mcmahon AL & Sideleau BF(1992). Comprehensive Psychiatric Nursing. 4th Ed.St Louis. Mosby Year Book.

Hancock K, Clayton JM, Parker SM & Walder S. (2007). Truth Telling In Discussion Prognosis in Advanced Life Limiting Illness: A Systematic Review. Palliative Medicine. Sept 2007: 21(6)

HIV in Canada (2010) Trends and Issues That Affect HIV Prevention, Care, Treatment and Support. CATIE. Canadian AIDS Treatment Information Exchange.

House JS(2001) Social Isolation Kills but How and Why? Psychosom Med.63

Kalichman SC (2000): couples with HIV/AIDS in Schmaling KB and Goldman Sher(Ed): The psychology of couples and illness theory and practice. Washington American Psychology Association.

Kaplan RM, Ries AL, Prewitt LM, Eakin E (1994): Self-efficacy expectations predict survival for patients with chronic obstructive pulmonary disease. Health Psychology. [PubMed

Kaplan, R.M., & Saccuzzo, D.P., (2001). *PsychologicalTesting: Principles, Applications & Issues*, 4th Edition. Belmont: Wadsworth/Thomson Learning

Kawachi IK, Bruce P, & Glass R. (1999) Social Capital And Self Rated Health: A Contextual Analysis. AMJ Public Health.

Lezak, M. D., Howieson, D. B., & Loring, D. W. (2004). *Neuropsychological Assessment* (4th Ed.). New York, NY: Oxford University Press.

Li JH (2002): HIV/AIDS in Yunnan: Social economic impact of HIV/AIDS. Beijing, China.

Manopaiboon C, Shaffer N and Clark L(1998): Impact of HIV on families of HIV infected women who gave birth. Bangkok Thailand.

Nampanya Serpell N (2000). Social and Economic Risk Factors for HIV/AIDS Affected Families in Zambia. Paper Presented At AIDS And Economies Symposium In Durban South Africa.

Pequegnant W and Hoppe SK(2001): Measurement of the role of the family in prevention and adaptation to HIV/AIDS. AIDS and Behaviour 5(2) PubMed.

Primomo J, Yates BC, Woods NF (1990):Social support for women during chronic illness: The relationship among sources and types of adjustment. Research in Nursing and Health. [PubMed]

Psychosocial Training Manual(2007). Chainama College of Health Sciences. Lusaka.

Rawlings RP, William SR & Beck CK(1993). Mental Health Psychiatric Nursing. A Holistic Life Cycle Approach. St Louis. Mosby Year Book.

Rolland J(1984): Toward a psychosocial typology of chronic and life-threatening illness. Family Systems Medicine.

Serovich JM (2000): Helping HIV positive persons to negotiate the disclosure process to partners, family members and friends. Journal of marital and family therapy 26.

Strauman TJ, Lemieux AM & Coe CL (1993). Self-Discrepancy and Natural Killer Cells Activities: Immunological Consequences of Negative Self Evaluation. J. Pers. Soc.Pschol.64(6).

UN general Assembly (2005): Koffi Annan's message on international day of the family. PubMed

UN theme group on HIV/AIDS in China HIV/AIDS assessment report 2002.

UNAIDS (2001).UNAIDS Report on the Global AIDS Epidemic Geneva.

UNAIDS(2010). UNAIDS Report on the Global AIDS Epidemic Geneva.

Wight RG, Aneshensen CS & Leblanc J (2003). Stress Buffering Family Support in AIDS Caregiving. AIDS Care. 15.

World Health Organization (2003): HIV Infected Women and Their Families: Psychosocial Support and Related Issues.

World Health Organization Zambia (2005): Summary Country Profile For HIV/AIDS Treatment Scale Up

APPENDICES

APPENDIX A

THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

DEPARTMENT OF PSYCHIATRY

P. O. Box 32379, Lusaka, Zambia

NEUROPSYCHOLOGY

DATA COLLECTION QUESTIONNAIRE

FOR OFFICIAL USE ONLY

Date:……

Clinic/Centre:……
…

Examiner:……

Subject Study Number:……

INSTRUCTIONS

A. Please give/tick [√] the appropriate answer to the question.

B. All the information you will provide will be used for the purpose of this study only, therefore, provide genuine information and ensure that all questions are

For Official use only

AGE & GENDER

Q1. What is your age?

1.1. 20 – 35 [ ]

1.2. 36 – 45 [ ]

1.3. 46 – 55 [ ]

1.4. 56 and above [ ]

Q2. What is your gender?

2.1. Female [ ]

2.2. Male [ ]

Q3. What is your current status?

3.1. single ( )

3.2. married ( )

3.3. widowed ( )

3.4. divorced ( )

3.5. living with opposite sex ( )

EDUCATION

Q3. In general, what type of school did you attend?

3.1. Primary [ ]

3.1.1. Community school [ ]

3.1.2. Private school [ ]

3.1.3. Mission [ ]

3.1.4. Government school [ ]

3.2. Secondary [ ]

3.2.1. Community school [ ]

3.2.2. Private school [ ]

3.2.3. Mission [ ]

3.2.4. Government School [ ]

Q4. What were the qualifications of most (≥70%) of your teachers:

4.1. Primary

4.1.1. I do not know [ ]

4.1.2. Primary teachers' Certificate [ ]

4.1.3. Secondary teachers' diploma [ ]

4.1.4. Bachelors degree [ ]

For Official use only

4.2. Secondary

4.2.1. I do not know [ ]

4.2.2. Primary teachers' Certificate [ ]

4.2.3. Secondary teachers' diploma [ ]

4.2.4. Bachelors degree [ ]

4.2.5. Masters degree [ ]

Q5. Has your education been helpful in your execution of daily activities?

5.1. Yes [ ]

5.2. No [ ]

Q6. In what four major ways would you say your education has been helpful? (please indicate)

6.1. ..... [ ]

6.2. ..... [ ]

6.3. ..... [ ]

6.4. ..... [ ]

Q7. With your currently attained education, are you considering furthering your studies?

7.1. Yes [ ]

7.2. No [ ]

For Official use only

EMPLOYMENT, INCOME, & RESIDENCE

Q8. What are you currently doing?

8.1. Unemployed [ ]

8.2. Self-employed [ ]

8.3. Employed [ ]

8.4. Retired [ ]

Q9. What is your occupation?

9.1. Unskilled (e. g maid, farm laborer, etc) [ ]

9.2. Semi-skilled (e. g plumber, bus driver, etc) [ ]

9.3. Skilled (e. g, accountant, physician, etc) [ ]

9.4. Specialist (e. g consultant, economic analysts) [ ]

Q10. What is your income per year?

10.1. Less than K30 million [ ]

10.2. K30 million to less than K60 million [ ]

10.3. K60 million to less than K120 million [ ]

10.4. K120 million and above [ ]

Q11. Where do you currently live?

11.1. Low cost rural area (e. g village) [ ]

11.2. High cost rural area (e. g 'boma') [ ]

11.3. Low cost urban area (e. g high density area) [ ]

11.4. High cost urban area (e. g low density area) [ ]

LANGUAGE & TECHNOLOGY

Q12. What is your mother tongue?

12.1. Bemba [ ]

12.2. Nyanja [ ]

12.3. Tonga [ ]

12.4. Lozi [ ]

12.5. Kaonde [ ]

12.6. Luvale [ ]

12.7. Lunda [ ]

12.8. Other (please indicate)..... [ ]

For Official use only

Q13.How much do you use your mother tongue in communicating?

13.1. Rarely (just know and use one or two words) [ ]

13.2. Sometimes (few times at home) [ ]

13.3. Often (in home conversations) [ ]

13.4. Very often (in almost all my conversations) [ ]

Q14.Which languages would you say you fluent in and ay what age did you acquired them?

(Indicate ONLY 3 or less in the order of fluency)

	Language	Age
14.1.	.....	.....
14.2.	.....	.....
14.3.	.....	.....

Q15.How much would you say you use the English language in communicating?

15.1. Rarely (just know and use one or two words) [ ]

15.2. Sometimes (only in formal situations) [ ]

15.3. Often (at least in one conversation in a week) [ ]

15.4. Very often (in almost all my conversations) [ ]

Q16.How often do you use computers?

16.1. Not at all [ ]

16.2. Sometimes (less than 4 times in a year) [ ]

16.3. Often (at least once in a month) [ ]

16.4. Very often (at least once in a week) [

DOMESTIC VIOLENCE

Physical Abuse

1. Now I need to ask some more questions about your relationship with your (last/current) partner. Does your (last/current) partner ever:

a) Say or do something to humiliate you in front of others?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all? [ ]

b) Threaten to hurt or harm you or someone you care about?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all? [ ]

c) Insult you or make you feel bad about yourself?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all? [ ]

2. How often did this happen during the last 12 months:

Rarely [ ]

Often [ ]

Very often [ ]

Not at all? [ ]

3. Did your (last/current) partner ever do any of the following things to you:

a) Threaten or attack you with a knife, gun, or other weapon?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all? [ ]

b) Try to choke or burn you on purpose?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all? [ ]

c) Kick you, drag you, or beat you up?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all? [ ]

d) Punch you with his/her fist or with something that could hurt you?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all? [ ]

e) Push you, shake you, or throw something at you?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all? [ ]

f) Slap you?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all [ ]

g) Twist your arm or pull your hair?

Rarely [ ]

Often [ ]

Very often [ ]

Not at all [ ]

4. Did the following ever happen as a result of what your (last/current) partner did to you:

   a) You had cuts, bruises, or aches?

   Yes [ ]

   No [ ]

   b) You had eye injuries, sprains, dislocations, or burns?

   Yes [ ]

   No [ ]

   c) You had deep wounds, broken bones, broken teeth, or any other serious injury?

   Yes [ ]

   No [ ]

Sexual Abuse

5. Has your partner(husband/wife) or any person of opposite sex ever done any of the following;

   a) Force you to have sexual intercourse with him/her when you did not want to?

      Rarely [ ]

      Often [ ]

      Very often [ ]

      Not at all? [ ]

   b) Physically force you to perform any other sexual acts you did not want to?

      Rarely [ ]

      Often [ ]

      Very often [ ]

      Not at all? [ ]

   c) Threatens in any way to perform sexual acts you did not want to?

      Rarely [ ]

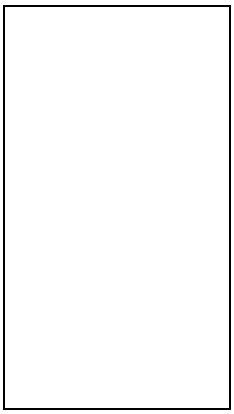
      Often [ ]

      Very often [ ]

      Not at all? [ ]

d) How long has this been happening?

Less than 6months	[ ]
6 – 12 months	[ ]
1 – 2 years	[ ]
2 – 5 years	[ ]
More than 5 years	[ ]



FAMILY RELATIONSHIPS

1. How would you rate your family relationships?
   1.1 satisfactory
   1.2 very satisfactory
   1.3 dissatisfactory
   1.4 very dissatisfactory
   1.5 neither
2. How satisfied are you with the support you get from your family?
   1.1 very satisfied
   1.2 satisfied
   1.3 dissatisfied
   1.4 very dissatisfied
   1.5 neither
3. How satisfied are you with your living conditions?
   3.1 very satisfied
   3.2 satisfied
   3.3 dissatisfied
   3.4 very dissatisfied
   3.5 neither
4. I interact the most with
   a. Mother yes/no
   b. Father yes/no
   c. Guardian yes/no
   d. Wife yes/ no
   e. Children yes/ no
   f. Siblings yes/no
   g. Friends yes/no
5. I am involved in making decisions in the family.
   5.1 Rarely
   5.2 Sometimes
   5.3 Very often

5.4 Never

6. How far do you travel to access your treatment?
   6.1 far
   6.2 very far
   6.3 near
   6.4 very near
7. How does this movement affect your family relationships?
   7.1 very much
   7.2 very little
   7.3 no much
   7.4 not at all
8. To what extent do you feel your life is meaningful?
   8.1 not at all
   8.2 a little
   8.3 moderate
   8.4 very much
9. How would you rate your quality of life?
   9.1 very satisfied
   9.2 satisfied
   9.3 dissatisfied
   9.4 very dissatisfied
   9.5 neither

NUTIRITION

Q1. Have you ever received nutritional advice since testing?

1.1. Yes [ ]
1.2 No [ ]

Q2 .Are you following the nutritional advice given to you at the health centre?

2.1 Yes [ ]
2.2 No [ ]

Q3. If not, what would be the reasons for not following the nutritional advice?

3.1 Advice is not necessary to me [ ]
3.2 Lack of money to buy the prescribed foods [ ]
3.3 Lack of time to prepare the food [ ]
3.4 Too many family members [ ]
3.5 Others reasons please indicate…….. [ ]

Q4. How many meals do you eat per day?

4.1 One meal [ ]

4.2 Two meals [ ]

4.3 Three or more meals [ ]

Q5.How would you describe the quality of food that you usually eat at each meal

5.1 Not enough [ ]

5.2 Just enough [ ]

5.3 Plenty [ ]

Q6. How much fluid (water, juice, coffee, tea, milk) do you consume per day?

6.1 Less than one cup/ glass [ ]

6.2 Three to five cups/glasses [ ]

6.3 More than 5 cups/glasses [ ]

TIME TABLE

Activity	**Date**
Presentation to Graduate Forum	February 2012
Proposal submission	February 2012
Proposal approval	April 2012
Data collection	May 2012—July 2012
Data Analysis	September 2012
Presentation to Graduate Forum	November 2012
Report write up	October 2012—December 2012

BUDGET

Item	Unit cost	Quantity	Amount ZMK
Participants transport	30 000	32	960 000
Participants refreshment	20 000	32	640,000
Recruitment fee	20 000	32	640 000
Transport for Researcher	2 500 000	1	2 500 000
Accommodation for Researcher	250 000	25	6 250 000
Food	150 000	25	3 750 000
Stationery			-
Colour photocopying	7 000	230	1 610 000
Photocopying	500	3 500	1 750 000
Reams of Paper	35 000	8	280 000
Memory Stick	200 000	1	200 000
Communication	200 000	1	200 000
Ethics Committee fees	250 000	1	250 000
Typing and Printing	5 000	100	500 000
pencils, pens and stop watch	30 000	1	30 000
stationery bag	100 000	10	1 000 000
Binding	50 000	4	1 000 000
			20 130 000
Contingency @ 10%			**2 316 000**
Total			**25 476 000**
Photocopying = 90 copies for each of us that includes the questionnaires or extra			

instruments			
Reams of paper = 3 for each of us			
Memory sticks 2 for each of us			
Transport is for 25 days (the local transport may not be so costly so even if we are in the field for 35 days			
The transport money should be enough.			
Accommodation is for 20 days			
N.B. I put photocopying at 300 for a better quality			

Study No. | Visit No. | Date | Staff I.D. | Data Entry Only

ZAMBIA NEUROBEHAVIORAL BATTERY

_____ Handout: Beck Depression Inventory-II (CH3) _____ Handout: Patient's Assessment of Own Functioning (NP6) _____ Handout: Activities of Daily Living (NC2) _____ Handout: Substance Use (CH13A) _____ Handout: Substance Use History (CH13D) _____ Handout: Use of Academic Skills Questionnaire (CN18)

_____ Neurobehavioral Medical Screen (CH42) _____ Behavioral Notes (NP31) _____ Hiscock Digit Memory Test (NC3) _____ Hopkins Verbal Learning Test - Revised Record Form A (TB15Z) _____ Brief Visuospatial Memory Test - Revised (TB16) _____ WAIS-III Digit Symbol (ND16) _____ WAIS-III Symbol Search (ND18) _____ Grooved Pegboard Test (TB31) _____ Hopkins Verbal Learning Test - Revised Record Form A (TB15A) *-20 min delay* **_____ Brief Visuospatial Memory Test - Revised (TB16)** *-25 min delay* **_____ Trail Making Test A (NP19A) _____ Color Trails 1 (NP41A) _____ Color Trails 2(NP41B) _____ WMS-III Spatial Span (ND30) _____ Wisconsin Card Sorting Test - Computerized 64 Items _____ Controlled Oral Word Association Test - FAS (NP23A) _____ Category Fluency Test (NP27) _____ Paced Auditory Serial Addition Task (NP17B) _____ Stroop Color and Word Test (NC6-N) _____ Halstead Category Test (NP12)**

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Study No. | Visit No. | Date | Staff I.D. | Data Entry Only

BECK DEPRESSION INVENTORY-II FS BECK

SCORE: TOTAL:

INSTRUCTIONS TO PARTICIPANT: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the past two weeks, including today. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group.

1. **Sadness** I do not feel sad..... 0 I feel sad much of the time ..... 1 I am sad all the time. ..... 2 I am so sad or unhappy that I can't stand it..... 3

2. **Pessimism** I am not discouraged about my future..... 0 I feel more discouraged about my future than I used to be ..... 1 I do not expect things to work out for me ..... 2 I feel my future is hopeless and will only get worse 3

3. **Past Failure** I do not feel like a failure..... 0 I have failed more than I should have..... 1 As I look back, I see a lot of failures..... 2 I feel I am a total failure as a person 3

4. **Loss of Pleasure** I get as much as I ever did from the things I enjoy ..... 0 I don't enjoy things as much as I used to ..... 1 I get very little pleasure from the things I used to enjoy ..... 2 I can’t get any pleasure from the things I used to enjoy 3

5. **Guilty Feelings** I don't feel particularly guilty..... 0 I feel guilty over many things I have done or should have done..... 1 I feel quite guilty most of the time..... 2 I feel guilty all of the time..... 3

6. **Punishment Feelings** I don't feel I am being punished..... 0 I feel I may be punished ..... 1 I expect to be punished ..... 2 I feel I am being punished 3

7. **Self-Dislike** I feel the same about myself as ever..... 0 I have lost confidence in myself..... 1 I am disappointed in myself..... 2 I dislike myself 3

8. **Self-Criticalness** I don't criticize or blame myself more than usual.....0 I am more critical of myself than I used to be .....1 I criticize myself for all my faults.....2 I blame myself for everything bad that happens 3

9. **Suicidal Thoughts or Wishes** I don't have any thoughts of killing myself.....0 I have thoughts of killing myself, but I would not carry them out.....1 I would like to kill myself.....2 I would kill myself if I had the chance 3

10. **Crying** I don't cry any more than I used to .....0 I cry more than I used to.....1 I cry over every little thing .....2 I feel like crying, but I can't.....3

11. **Agitation** I am no more restless or wound up than usual.....0 I feel more restless or wound up than usual.....1 I am so restless or agitated that it's hard to stay still .....2 I am so restless or agitated that I have to keep moving or doing something.....3

12. **Loss of Interest** I have not lost interest in other people or activities.....0 I am less interested in other people or things than before.....1 I have lost most of my interest in other people or things.....2 It's hard to get interested in anything.....3

13. **Indecisiveness** I make decisions about as well as ever .....0 I find it more difficult to make decisions than usual .....1 I have much greater difficulty in making decisions than I used to.....2 I have trouble making any decisions.....3

14. **Worthlessness** I do not feel that I am worthless.....0 I don't consider myself as worthwhile and useful as I used to.....1 I feel more worthless as compared to other people.....2 I feel utterly worthless.....3

15. **Loss of Energy** I have as much energy as ever.....0 I have less energy than I used to have .....1 I don't have enough energy to do very much.....2 I don't have enough energy to do anything.....3

16. **Changes in Sleeping Pattern** I have not experienced any change in my sleeping pattern.....0 I sleep somewhat more than usual.....1a I sleep somewhat less than usual.....1b I sleep a lot more than usual.....2a I sleep a lot less than usual .....2b I sleep most of the day.....3a I wake up 1-2 hours early and can't get back to sleep.....3b

Study No. | Visit No. | Data Entry Only

17. Irritability I am no more irritable than usual..... 0 I am more irritable than usual..... 1 I am much more irritable than usual..... 2 I am irritable all the time 3

18. Changes in Appetite I have not experienced any change in my appetite ..... 0 My appetite is somewhat less than usual..... 1a My appetite is somewhat greater than usual..... 1b My appetite is much less than before..... 2a My appetite is much greater than usual ..... 2b I have no appetite at all ..... 3a I crave food all the time 3b

19. Concentration Difficulty I can concentrate as well as ever ..... 0 I can't concentrate as well as usual..... 1 It's very hard to keep my mind on anything for very long ..... 2 I find I can't concentrate on anything..... 3

20. Tiredness or Fatigue I am no more tired or fatigued than usual..... 0 I get more tired or fatigued more easily than usual ..... 1 I am too tired or fatigued to do a lot of the things I used to do ..... 2 I am too tired or fatigued to do most of the things I used to do 3

21. Loss of Interest in Sex I have not noticed any recent change in my interest in sex..... 0 I am less interested in sex than I used to be..... 1 I am much less interested in sex now ..... 2 I have lost interest in sex completely..... 3

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Study No. | Visit No. | Date | Staff I.D.

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PATIENT'S ASSESSMENT OF OWN FUNCTIONING

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never

INSTRUCTIONS TO PARTICIPANTS: Please answer each of the following questions by circling the number that best describes your response to each of the following statements. There is no right or wrong answer. Express how you have been feeling lately. It will tell us more about your daily functioning and any problems you might

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
2. How often do you forget events which have occurred in the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
3. How often do you forget people whom you met in the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
4. How often do you forget things that you knew a year or more ago?	**1**	**2**	**3**	**4**	**5**	**6**
5. How often do you forget people whom you knew or met a year or more ago?	**1**	**2**	**3**	**4**	**5**	**6**
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	**1**	**2**	**3**	**4**	**5**	**6**
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	**1**	**2**	**3**	**4**	**5**	**6**
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	**1**	**2**	**3**	**4**	**5**	**6**
9. How often do you lose things or have trouble remembering where they are?	**1**	**2**	**3**	**4**	**5**	**6**
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	**1**	**2**	**3**	**4**	**5**	**6**
	Almost Always	**Very Often**	**Fairly Often**	**Once In A While**	**Very Infrequent y**	**Almost Never**
11. How often do you have difficulties understanding what is said to you?	**1**	**2**	**3**	**4**	**5**	**6**
12. How often do you have difficulties recognizing or						

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
2. How often do you forget events which have occurred in the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
3. How often do you forget people whom you met in the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
4. How often do you forget things that you knew a year or more ago?	**1**	**2**	**3**	**4**	**5**	**6**
5. How often do you forget people whom you knew or met a year or more ago?	**1**	**2**	**3**	**4**	**5**	**6**
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	**1**	**2**	**3**	**4**	**5**	**6**
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	**1**	**2**	**3**	**4**	**5**	**6**
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	**1**	**2**	**3**	**4**	**5**	**6**
9. How often do you lose things or have trouble remembering where they are?	**1**	**2**	**3**	**4**	**5**	**6**
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	**1**	**2**	**3**	**4**	**5**	**6**

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**

SCALE II: LANGUAGE AND COMMUNICATION

SCALE III: USE OF HANDS

SCALE IV: SENSORY-PERCEPTUAL

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [ ] Items read by examiner.] Examiner marked answers given verbally.

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
2. How often do you forget events which have	**1**	**2**	**3**	**4**	**5**	**6**

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

SCALE V: HIGHER LEVEL COGNITIVE AND INTELLECTUAL FUNCTIONS

be having in your daily living.

Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	1	2	3	4	5	6
2. How often do you forget events which have occurred in the last day or two?	1	2	3	4	5	6
3. How often do you forget people whom you met in the last day or two?	1	2	3	4	5	6
4. How often do you forget things that you knew a year or more ago?	1	2	3	4	5	6
5. How often do you forget people whom you knew or met a year or more ago?	1	2	3	4	5	6
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	1	2	3	4	5	6
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	1	2	3	4	5	6
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	1	2	3	4	5	6
9. How often do you lose things or have trouble remembering where they are?	1	2	3	4	5	6
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	1	2	3	4	5	6
	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never

34. Do you think you are as "bright" now as you were before your accident or present illness?

Yes 1
No ..... 2 I don't know..... 3

SCALE VI: WORK

35. Are you presently holding a job?

Yes, Full-time ..... 1 Yes, Part-time..... 2
No.....**SKIP TO QUESTION 39** 3

36. What kind of job do you have, and briefly describe your duties:

37. What is your salary per month:

_____

38. On your job how much supervision is being given to you now?

I am closely observed and supervised in almost everything I do..... 1 There is a supervisor around most of the time, but supervision is not really constant. .....2 I receive only occasional supervision, though there may be more when a new job is given or after a job is completed. ..... 3 I usually receive supervision only when being given a new job to do, or after a job has been completed. ..... 4 I function very much on my own at work..... 5 I am self-employed..... 6

39. Are you a student?

Yes, Full-time ..... 1 Yes, Part-time..... 2
No.....**SKIP QUESTIONS 40 & 41** 3

40. Are you currently taking regular academic courses or special education courses?

All special education courses ..... 1 Mostly special education courses.....2 About an equal number

of each type of course ..... 3 Mostly regular academic courses ..... 4 All regular academic courses..... 5

41. What is your approximate grade point average in regular academic courses only (i.e., leaving out grades in special education courses)?

Better than 3.7 (A) ..... 1 3.0 to 3.6 (B to A minus)..... 2 2.0 to 2.9 (C to B minus)..... 3 1.0 to 1.9 (D to C minus)..... 4 Less than 1.0 (F)..... 5

Study No. | Visit No. | Date | Staff I.D. | Data Entry Only

ACTIVITIES OF DAILY LIVING

INSTRUCTIONS TO PARTICIPANT: We are interested in knowing how well you are able to perform common tasks.

- **Please circle the number under the "NOW" column that most accurately indicates your current ability level.**
- **Then circle the number under the "BEST" column that most accurately indicates your highest ability level (this would be the time in your life when you were functioning at your best).**

Please add any comments that you feel will help clarify your responses (e.g., when you started having difficulties and what you think are the causes of the problem).

1. Housekeeping **Now Best**

I maintain my house/apartment by myself or only need occasional help for larger jobs.....0 0 I
only perform light daily tasks (wash dishes, make bed) .....1 1 I
perform some light tasks, but have difficulty keeping my place clean.....2 2 I
need help with all housekeeping tasks.....3 3 I
am fully able to do housekeeping, but choose not to do so 8 8

Comments_____
_

2. Managing finances **Now Best**

I manage all of my finances (check cashing, banking, handling money) by myself .....0 0 I
manage routine small purchases, but need help with banking, checking and balancing accounts.....1 1 I
am not able to handle money accurately.....2 2 I
am able to handle my own finances, but someone else does them for me.....8 8

Comments_____
_

3. Buying Groceries **Now Best**

I create my own grocery list and do my own shopping.....0 0 I
need occasional assistance in buying groceries.....1 1 I
need someone else to do my grocery shopping for me .....2 2 I
am able to create my own grocery list and do my own shopping, but someone else does it for me.....8 8

Comments_____
_

4. Cooking **Now Best**

I plan, prepare, and serve many of my own meals.....0 0 I
prepare meals if someone else provides me with the right ingredients.....1 1 I
heat and serve meals provided by others .....2 2 I
need to have meals prepared and served to me.....3 3 I
am able to plan, prepare, and serve my own meals but someone else does it for me.....8 8

Comments_____

5. Planning social activities **Now Best** I frequently initiate and plan social activities (e.g., going out, having a party)..... 1 1 I rarely initiate and plan social activities..... 2 2 I do not plan and initiate social activities..... 3 3

Comments_____
_

6. Understanding reading materials/TV **Now Best** I understand reading materials (e.g., novels, newspaper) and TV (plots, etc.) without difficulty ..... 0 0 I have occasional difficulty understanding reading materials or TV ..... 1 1 I have frequent difficulty understanding reading materials or TV..... 2 2 I am unable to understand reading materials or TV..... 3 3

Comments_____
_

7. Transportation **Now Best** I drive my own car or take public transportation on my own (if you do not own a car)..... 0 0 I arrange my own travel using taxis, but do not drive or use public transportation ..... 1 1 I can travel on public transportation or use taxis if I am assisted by another..... 2 2 I do not travel at all..... 3 3

Comments_____
_

8. Using the telephone **Now Best** I handle using the telephone without difficulty (looking up and dialing new numbers, etc.)..... 0 0 I only dial a few well-known numbers ..... 1 1 I answer the telephone, but do not dial ..... 2 2 I do not use the telephone at all..... 3 3 I do not have access to a telephone 8 8

9. Home repairs **Now Best** I handle most minor home repairs (plumbing, gardening) .....0 0 I need assistance with most minor home repairs..... 1 1 I am unable to do most repairs by myself ..... 2 2 I am capable of making minor repairs but choose not to 8 8

Comments_____
_

10. Bathing **Now Best** I handle all of my bathing needs by myself..... 0 0 I need occasional assistance with bathing (getting in and out of the tub/shower, etc.) ..... 1 1 I always need help from others when bathing..... 2 2

Comments_____
_

11. Dressing **Now Best** I am able to dress myself and pick out my own clothes..... 0 0 I dress myself, but someone else must pick out my clothes for me ..... 1 1 I need occasional assistance getting dressed or frequently make mistakes in choosing clothes..... 2 2 I need frequent assistance in getting dressed

..... 3 3

Comments_____
_

Study No. | Visit No. | Data Entry Only

12. Shopping (e.g., clothes, other non-food goods) Now Best

I take care of all of my shopping needs.....0 0 I
only make small purchases.....1 1 I
need someone to go with me on any shopping trip.....2 2 I
am unable to shop.....3 3 I
am able to shop, but choose to have someone else do my shopping for me.....8 8

Comments_____

_

13. Laundry Now Best

I do all of my own laundry .....0 0 I
need occasional help in doing the laundry.....1 1 I
launder only small items (e.g., rinse socks, stockings, etc.).....2 2 All
laundry must be done by others.....3 3 I am
able to do my own laundry, but choose to have others do it for me.....8 8

Comments_____

_

14. Taking/keeping track of medication Now Best

I take sole responsibility for taking medications in correct dosages at the correct time.....0 0 I
take medications that are prepared in individual doses by someone else .....1 1 I
am unable to track my own medications .....2 2 I
am able to take care of my own medications, but choose to have someone else do it for me.....8 8

Comments_____

_

15. Child Care Now Best

I am fully able to handle child care.....0 0 I
need occasional assistance in caring for my children .....1 1 I
need constant assistance in caring for my children.....2 2 I do
not have children.....8 8

Comments_____

_

16. Work Now Best

I am efficient at work .....0 0 I
am not very efficient at work and have difficulty maintaining attention or finishing tasks.....1 1 I
am having a great deal of difficulty in maintaining attention or finishing tasks at work .....2 2 I
am no longer able to work.....8 8

Comments_____

_

17. Please tell us of any other areas in which you are having difficulty:

18. What do you think are your major areas of difficulty at this time?

19. I feel that the difficulties that I am having on the above tasks, if any, are due to: Now Primarily cognitive problems (e.g., thinking, memory, paying attention) ..... 1 Primarily physical problems (e.g., fatigue, feeling sick) ..... 2 Equally cognitive and physical problems ..... 3 I am not having any difficulties on the previous tasks..... 8

Comments_____
_

20. If you are having more difficulty than you used to with the above tasks, approximately when did the difficulties begin? Within the last month ..... 1 1 to 6 months ago.....2 6 months to 2 years ago ..... 3 2 to 5 years ago ..... 4 More than 5 years ago..... 5 I am not having any difficulties..... 8

Study No. | Visit No. | Date | Staff I.D.

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SUBSTANCE USE

INSTRUCTIONS TO CLINICIAN: Ask the participant if he/she has used or even tried any substances from the following categories listed below EVER (if Cross-Sectional visit) or SINCE THE LAST VISIT (if longitudinal visit). Provide examples of substances from each substance category. (This list does not encompass all illicit substances; these are just a few examples. Refer to your reference manual for a longer list.) Circle the number that corresponds best to the participant's response.

Code "1" if the participant has used the substance 5 or more times in the period of interest. Code "2" if the participant has used the substance 4 or less times in the period of interest.

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	1	2	3	4	5	6
2. How often do you forget events which have occurred in the last day or two?	1	2	3	4	5	6
3. How often do you forget people whom you met in the last day or two?	1	2	3	4	5	6
4. How often do you forget things that you knew a year or more ago?	1	2	3	4	5	6
5. How often do you forget people whom you knew or met a year or more ago?	1	2	3	4	5	6
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	1	2	3	4	5	6
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	1	2	3	4	5	6
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	1	2	3	4	5	6
9. How often do you lose things or have trouble remembering where they are?	1	2	3	4	5	6
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	1	2	3	4	5	6

For each substance coded "1," complete the Substance Use History (CH13B or ND25) for that substance.

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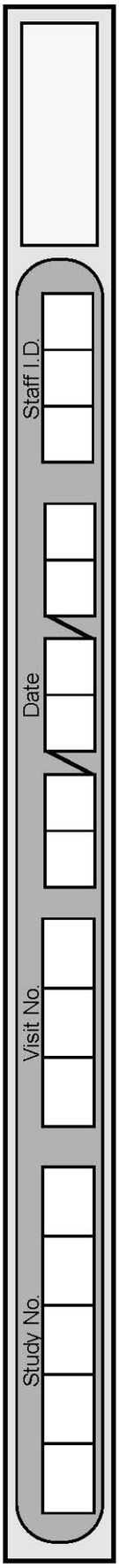
CHQUSUBCH13D

CHINESE SUBSTANCE USE HISTORY



INSTRUCTIONS TO CLINICIAN: Refer to detailed instruction cards on substance c

at eg or ie s.

st Use:

Hours ago.....1

Days ago.....2

Weeks ago.....3

Months ago.....4

Years

Su bs ta nc e: 1. 2. La

Age Of 1st Use: 4.

1 unit = 1 drink = 1 cigarette = 1 pill = 1 tab = 1 dose

Current Age: 3.

VERSION: 2.0ED Page 1 of 1

be having in your daily living.
Manner of Inventory Administration: |
read and answered items independen
read items, and marked verbal given a

SCALE I: MEMORY

1. How often do you forget something tha told to you within the last day or two?	
2. How often do you forget events which occurred in the last day or two?	
3. How often do you forget people whom the last day or two?	
4. How often do you forget things that yo or more ago?	
5. How often do you forget people whom met a year or more ago?	
6. How often do you lose track of time, or either earlier or later than they are usually are supposed to be done?	
7. How often do you fail to finish somethi because you forgot that you were doing i such things as forgetting to put out cigarettes, turning off the stove, etc.)	
8. How often do you fail to complete a tas start because you have forgotten how to more aspects of it?	
9. How often do you lose things or have t remembering where they are?	
10. How often do you forget things that y supposed to do or have agreed to do (su gas in the car, paying bills, taking care of errands, etc.)?	
	5
11. How often do you have difficulties un what is said to you?	
12. How often do you have difficulties rec identifying printed words?	
13. How often do you have difficulty unde reading material which at one time you c understood?	
14. Is it easier to have people show you t is to have them tell you about things?	
15a.When you speak, are your words indi improperly pronounced?	
15b.If this happens, how often do people difficulty understanding what words you trying to say?	
16. How often do you have difficulty think names of things?	
17. How often do you have difficulty think words (other than names) for what you w say?	
18. When you write things, how often do difficulty forming the letters correctly?	
19. Do you have more difficulty spelling, errors in spelling, than you used to?	
20. How often do you have difficulty perf	

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Study No. | Visit No. | Date | Staff I.D.

Data Entry Only

USE OF ACADEMIC SKILLS QUESTIONNAIRE

1. How often do you read in your everyday life:

Never.....**SKIP TO QUESTION 7**.....1
Rarely (less than once per day) 2
Sometimes (at least once per day, but less than 3 times/day) 3
Often (3 times per day or more) 4

If participants reads in everyday life, does he/she always or almost always understand (for each item code "yes", "no" or "not applicable/ does not attempt to read).

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.
SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
2. How often do you forget events which have occurred in the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**

7. How often do you write in your everyday life?

Never.....1
Rarely (less than once per day) 2
Sometimes (at least once per day, but less than 3 times/day) 3
Often (3 times per day or more) 4

8. How often do you use addition or subtraction?

Never.....1
Rarely (less than once per day) 2
Sometimes (at least once per day, but less than 3 times/day) 3
Often (3 times per day or more) 4

[ ] Number of people

9. During a typical day, how many non-family people do you talk with?

10. During all years you attended school, how often did you skip or miss classes except for sick time or sick leave?

Never missed classes except sick leave 1
On average, missed less than one week per year 2
On average, missed one week or more, but less than one month per year.....3 On average, missed on month or more, but less than 3 months per year.....4 On average, missed three months or more, but less than 6 months per year.....5 On average, missed 6 months or more per year (missed more than half of the classes) 6

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Study No. | Visit No. | Date | Staff I.D.

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NEUROBEHAVIORAL MEDICAL SCREEN

Date of Birth: _____ MM/DD/YY Age: _____

INSTRUCTIONS TO EXAMINER: Ask the subject the following questions. If "Yes" is circled for any of the items below, write a summary of the incident in the space provided. Also, list any aftereffects (e.g., changes in vision, headaches, nausea, vomiting, amnesia, dizziness) or related events (e.g., artificial resuscitation, hospitalization).

1. In your lifetime, have you ever...

a. Had an open or closed head injury? Yes / No

b. Had a CHI with a loss of consciousness? Yes / No

c. Been in a coma? Yes / No

d. Had a blackout from alcohol and/or drugs? Yes / No

e. Passed out from alcohol and/or drugs? Yes / No

f. Been unconscious for any other reason (exclude surgery)? Yes / No

g. Had a seizure? Yes / No

h. Had a heart attack? Yes / No

i. Had a stroke? Yes / No

j. Fainted for any reason? Yes / No

k. Overdosed on alcohol, drugs or medication? Yes / No

1 **Is there a history of neurologic illness in your family such as Parkinson's Disease, Alzheimer's Disease, Huntington's Chorea, Multiple Sclerosis, Epilepsy, etc.? If so, who and was this from maternal or paternal side of the family?**

2 **Did you ever have any difficulty in school learning basic academic skills (i.e., problems in math or problems with reading). If so, were you in special classes or require tutoring?**

3 **Were you ever diagnosed as having a learning disability, dyslexia, attention deficit disorder or attention-deficit hyperactivity disorder? Who diagnosed you? How old were you when diagnosed?**

4 **Were you ever held back or skipped a grade in school? Why?**

5 **How many years of education have you completed? (Tester: List specific degrees or units/semesters completed and <u>when</u> and <u>where</u>.)**

High school diploma or GED? **If GED, what was the last grade completed?** _ | | |

If degree(s) earned, please list college and degree obtained

_

If no college degree, college and number of classes/units completed

_

Total years of education:

1 **How much sleep did you get last night? Is this more or less sleep than usual? Was it restless or restful?**

2 **Are you currently employed? If so, what is your occupation? If not, how long has it been since you last worked? What was highest position you ever held? How long did you have this position? (Indicate dates)**

3 **What medications are you currently taking? When did you last take them? (Tester: only list non-HIV medications.)**

Name of Medication When did you last take it? What is it for?

Study No. | Visit No. | Date | Staff I.D.

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BEHAVIORAL NOTES

EDUCATION: AGE:

1. Confounds: **(LIST REASON(S) FOR CONFOUND(S) IN ITEM #28)** **NO YES**

Alcohol .....0 1 Drug .....0 1 Language .....0 1 Education .....0 1 CHI with LOC .....0 1 Medical.....0 1 Psychiatric.....0 1

☐ **SEE ITEM #28**

2. Gender at Birth:

Male .....1 Female 2

☐ **SEE ITEM #28**

3. Handedness:

Right.....1 Left 2

☐ **SEE ITEM #28**

1. **Ethnicity and Code:**

2. **Language Tested: Spanish / English** ☐ ☐ **(CIRCLE ONE)**

3. **First Language:** _____

4. **Transportation:** _____

5. **Employment:** _____

☐ **SEE ITEM #28**

9. Affect:

Euthymic.....1 Dysthymic.....2 Dysphoric 3

10. Appropriateness

Appropriate.....1 Inappropriate 2

☐ **SEE ITEM #28** **NO YES**

11. Demeanor:

Friendly.....0 1 Cheerful.....0 1 Anxious .....0 1 Humorous.....0 1 Defensive 0 1

☐ **SEE ITEM #28**

12. Rapport:

Good .....1 Fair 2
Poor.....3

☐SEE ITEM #28

13. Cooperation:

Excellent.....1 Good 2
Adequate.....3 Fair 4
Poor.....5

☐SEE ITEM #28

14. Effort:

Excellent.....1 Good 2
Adequate.....3 Fair 4
Poor.....5

☐SEE ITEM #28

15. Gait Disturbance:

Severe.....1 Moderate.....2
Moderate/Mild .....3 Mild.....4
None.....5

☐SEE ITEM #28

16. Impaired Use of Hands:

Severe.....1 Moderate.....2
Moderate/Mild .....3 Mild.....4
None.....5

☐SEE ITEM #28 **NO YES**

17. Speech:

Rapid.....0 1 Average.....0 1 Slow .....0 1 Slurred.....0 1
Pressured.....0 1 Stuttering.....0 1

☐SEE ITEM #28

18. Sensory - Auditory:

Adequate.....1 Poor.....2

SEE ITEM #28

19. Sensory - Visual:

Adequate ..... 1 Poor 2

SEE ITEM #28

20. Attention Concentration:

Good..... 1
Fair..... 2 Poor 3

SEE ITEM #28

21. Distractibility:

Low 1
Moderate..... 2 High 3

SEE ITEM #28

22. Understanding of Instructions:

Very Good.....1
Good..... 2
Adequate 3
Fair..... 4 Poor 5

28. Examiner's Observations:

SEE ITEM #28

23. Memory:

	NO	YES
Intact.....	0	1
Impaired: Poor - Recent.....	0	1
Impaired: Poor - Remote.....	0	1

SEE ITEM #28

24. Frustration Tolerance:

Very Good..... 1
Good..... 2 Adequate 3
Fair..... 4 Poor 5

SEE ITEM #28

25. Nonstandard or Invalid Test:

None..... 1 Yes - See Comments Below 2

26. Step Down:

No ..... 1 Yes - Explain Below 2

SEE ITEM #28

27. Reliabilty:

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HISCOCK DIGIT MEMORY TEST

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O

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almo Neve
1. How often do you forget something that has been told to you within the last day or two?	1	2	3	4	5	6
2. How often do you forget events which have occurred in the last day or two?	1	2	3	4	5	6
3. How often do you forget people whom you met in the last day or two?	1	2	3	4	5	6
4. How often do you forget things that you knew a year or more ago?	1	2	3	4	5	6
5. How often do you forget people whom you knew or met a year or more ago?	1	2	3	4	5	6
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	1	2	3	4	5	6
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	1	2	3	4	5	6
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	1	2	3	4	5	6
9. How often do you lose things or have trouble remembering where they are?	1	2	3	4	5	6
10. How often do you forget things that you are						

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Study No. | Visit No. | Date | Staff I.D.

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Z

HOPKINS VERBAL LEARNING TEST REVISED - RECORD FORM

Time Trial 3 Completed: _____ Time Delay Recall Complete: _____ Delay Interval (20 min.): _____ TRIALS 1-3

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers.
SCALE I: MEMORY

& DELAY:

Trial 1 Total:

	Almost Always	Very Often	Fairly Often
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**
2. How often do you forget events which have occurred in the last day or two?	**1**	**2**	**3**
3. How often do you forget people whom you met in the last day or two?	**1**	**2**	**3**
4. How often do you forget things that you knew a year or more ago?	**1**	**2**	**3**
5. How often do you forget people whom you knew or met a year or more ago?	**1**	**2**	**3**
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	**1**	**2**	**3**
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	**1**	**2**	**3**
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	**1**	**2**	**3**
9. How often do you lose things or have trouble remembering where they are?	**1**	**2**	**3**

Trial 2 Total:

Trial 3 Total:

Delay Total:

True Positives:

False Positives:

TRIAL RECOGNITION:

VERSION: 3.1IE

be having in your daily living.
Manner of Inventory Administration: [ ] P
read and answered items independently.
read items, and marked verbal given ans

SCALE I: MEMORY

1. How often do you forget something that ha told to you within the last day or two?
2. How often do you forget events which have occurred in the last day or two?
3. How often do you forget people whom you the last day or two?
4. How often do you forget things that you kn or more ago?
5. How often do you forget people whom you met a year or more ago?
6. How often do you lose track of time, or do either earlier or later than they are usually do are supposed to be done?
7. How often do you fail to finish something y because you forgot that you were doing it? (I such things as forgetting to put out cigarettes, turning off the stove, etc.)
8. How often do you fail to complete a task th start because you have forgotten how to do c more aspects of it?
9. How often do you lose things or have troub remembering where they are?
10. How often do you forget things that you a supposed to do or have agreed to do (such a gas in the car, paying bills, taking care of errands, etc.)?

11. How often do you have difficulties unders what is said to you?
12. How often do you have difficulties recogn identifying printed words?
13. How often do you have difficulty understa reading material which at one time you could understood?
14. Is it easier to have people show you thing is to have them tell you about things?
15a.When you speak, are your words indistin improperly pronounced?
15b.If this happens, how often do people hav difficulty understanding what words you are trying to say?
16. How often do you have difficulty thinking names of things?
17. How often do you have difficulty thinking words (other than names) for what you want say?
18. When you write things, how often do you difficulty forming the letters correctly?
19. Do you have more difficulty spelling, or m errors in spelling, than you used to?

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BRIEF VISUOSPATIAL MEMORY TEST - REVISED

Time Trial 3 Completed: _____ Time Delay Recall Completed: _____ Delay Interval (25 min.): _____ Form Administered: 1 2 3 4 5 6 (circle one)

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [ ] Items read by examiner marked answers given ve

Normative

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Infi
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**	**4**	
2. How often do you forget events which have occurred in the last day or two?	**1**	**2**	**3**	**4**	
3. How often do you forget people whom you met in the last day or two?	**1**	**2**	**3**	**4**	
4. How often do you forget things that you knew a year or more ago?	**1**	**2**	**3**	**4**	
5. How often do you forget people whom you knew or met a year or more ago?	**1**	**2**	**3**	**4**	
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	**1**	**2**	**3**	**4**	
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include	**1**	**2**	**3**	**4**	

table/comparison group_____

[1] Total Recall = (Trial 1 raw score + Trial 2 raw score + Trial 3 raw score). [2] Percent Retained = [Delayed recall raw score/(higher value of Trial 2 raw score or Trial 3 raw score)] x 100. [3] Recognition Discrimination Index = Recognition Hits raw score - Recognition False Alarms raw score.

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Recognition Trial Scoring

Response Bias Look-up Table

False Alarms

Worksheet

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[
SCALE I: MEMORY

	Almost Always
1. How often do you forget something that has been told to you within the last day or two?	**1**
2. How often do you forget events which have occurred in the last day or two?	**1**
3. How often do you forget people whom you met in the last day or two?	**1**
4. How often do you forget things that you knew a year or more ago?	**1**
5. How often do you forget people whom you knew or met a year or more ago?	**1**
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	**1**
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	**1**
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	**1**
9. How often do you lose things or have trouble remembering where they are?	**1**
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	**1**

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[
SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**
2. How often do you forget events which have occurred in the last day or two?	**1**	**2**	**3**
3. How often do you forget people whom you met in the last day or two?	**1**	**2**	**3**
4. How often do you forget things that you knew a year			

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WAIS-III DIGIT SYMBOL

TOTAL is 133

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner [[ ] Items read by examiner.] Examiner read items, and marked verbal given answers. marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequently	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	1	2	3	4	5	6
2. How often do you forget events which have occurred in the last day or two?	1	2	3	4	5	6
3. How often do you forget people whom you met in the last day or two?	1	2	3	4	5	6
4. How often do you forget things that you knew a year or more ago?	1	2	3	4	5	6
5. How often do you forget people whom you knew or met a year or more ago?	1	2	3	4	5	6
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	1	2	3	4	5	6
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	1	2	3	4	5	6
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	1	2	3	4	5	6
9. How often do you lose things or have trouble remembering where they are?	1	2	3	4	5	6
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	1	2	3	4	5	6

) maximum Score

0

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WAIS-III SYMBOL SEARCH TOTAL:

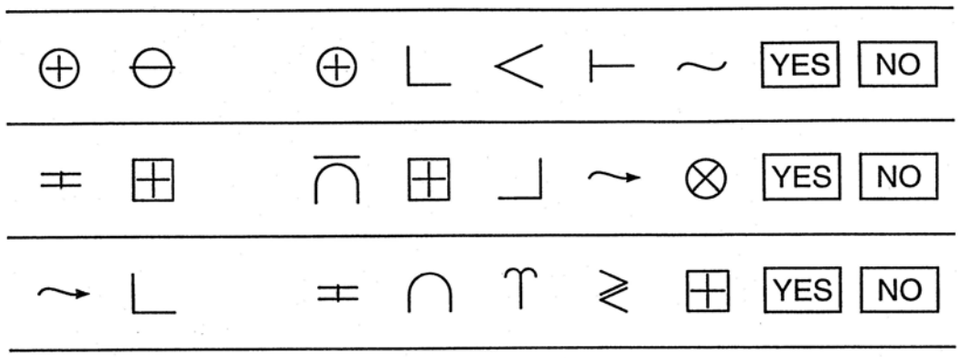
(Maximum 60)

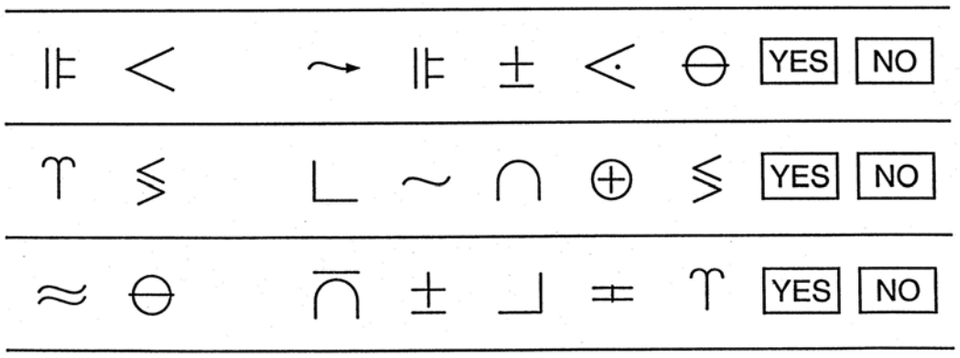
INSTRUCTIONS TO EXAMINER: Discontinue after 120 seconds.

Sample Items

Practice Items

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner] Items read by e
read items, and marked verbal given answers [[marked answers





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VERSION: 1.0E

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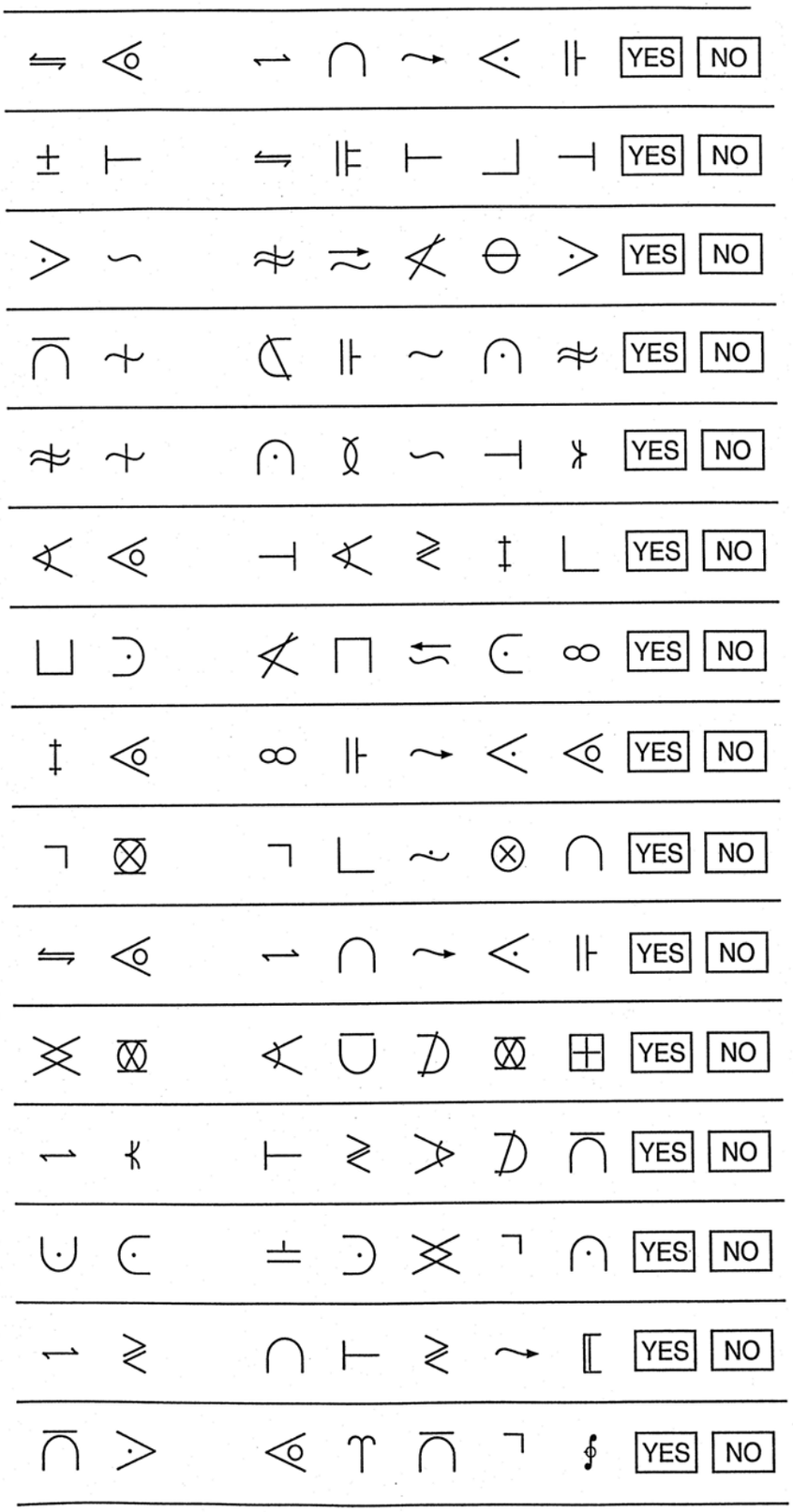

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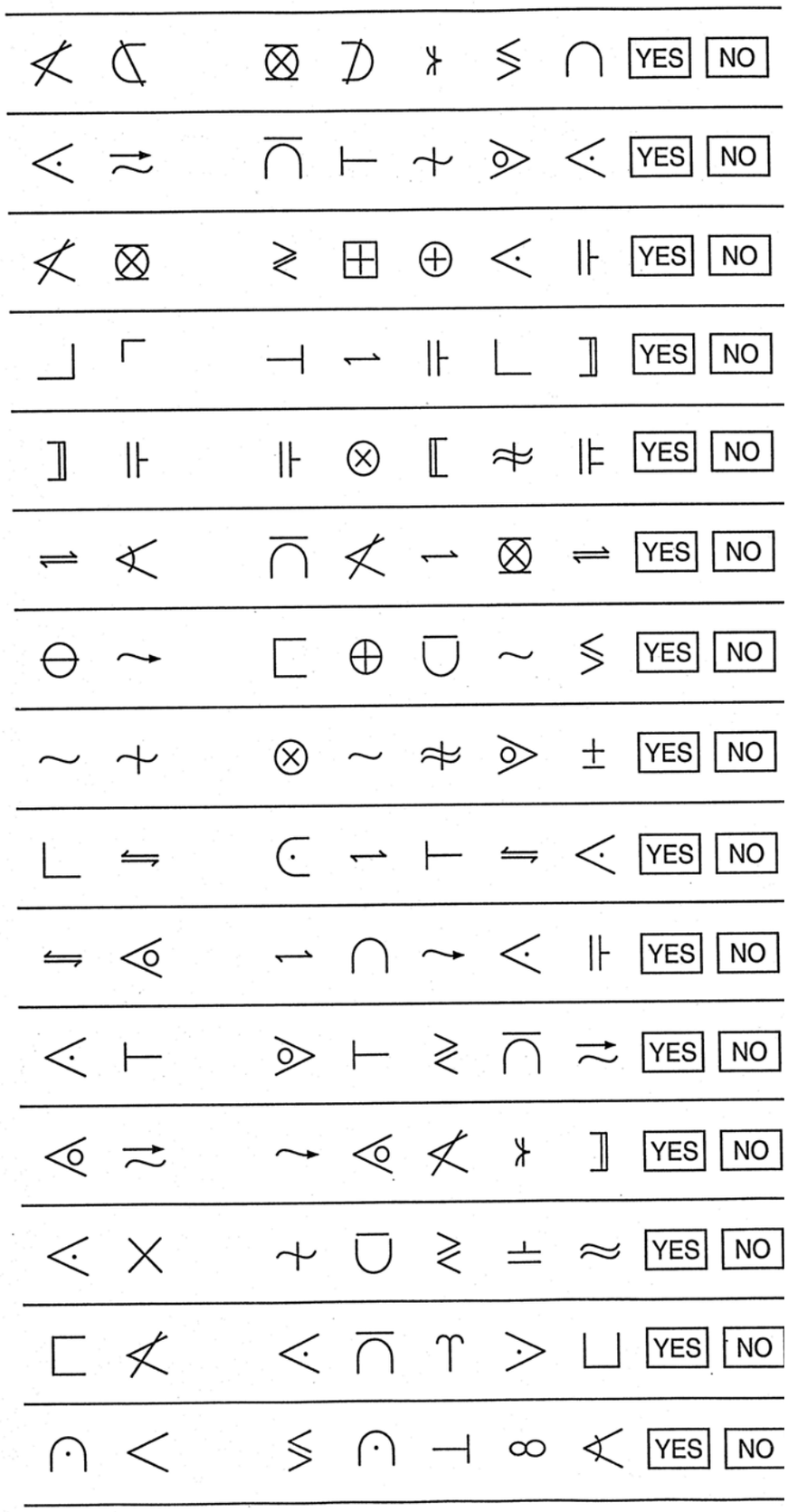
VERSION: 1.0E



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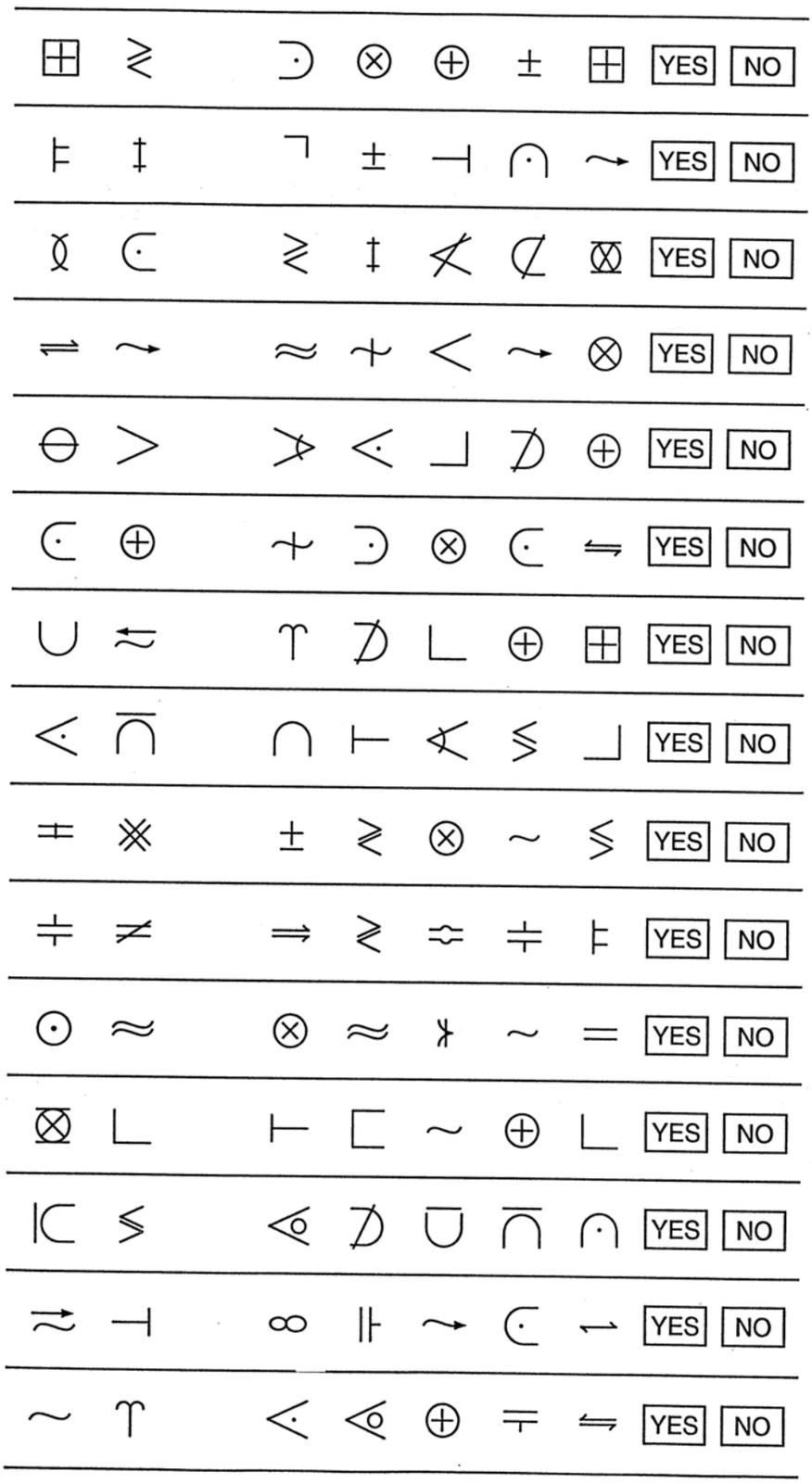

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GROOVED PEGBOARD TEST SUMMARY SHEET

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
2. How often do you forget events which have occurred in the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
3. How often do you forget people whom you met in the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
4. How often do you forget things that you knew a year or more ago?	**1**	**2**	**3**	**4**	**5**	**6**

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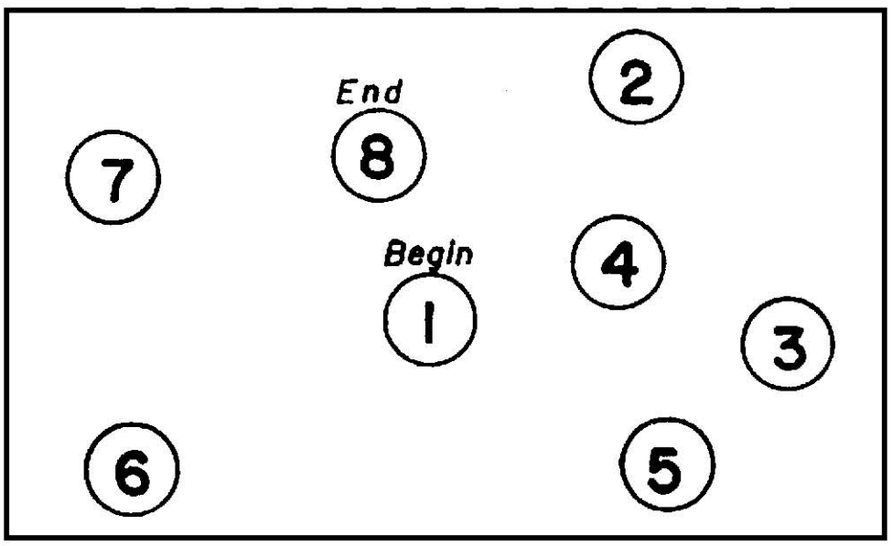
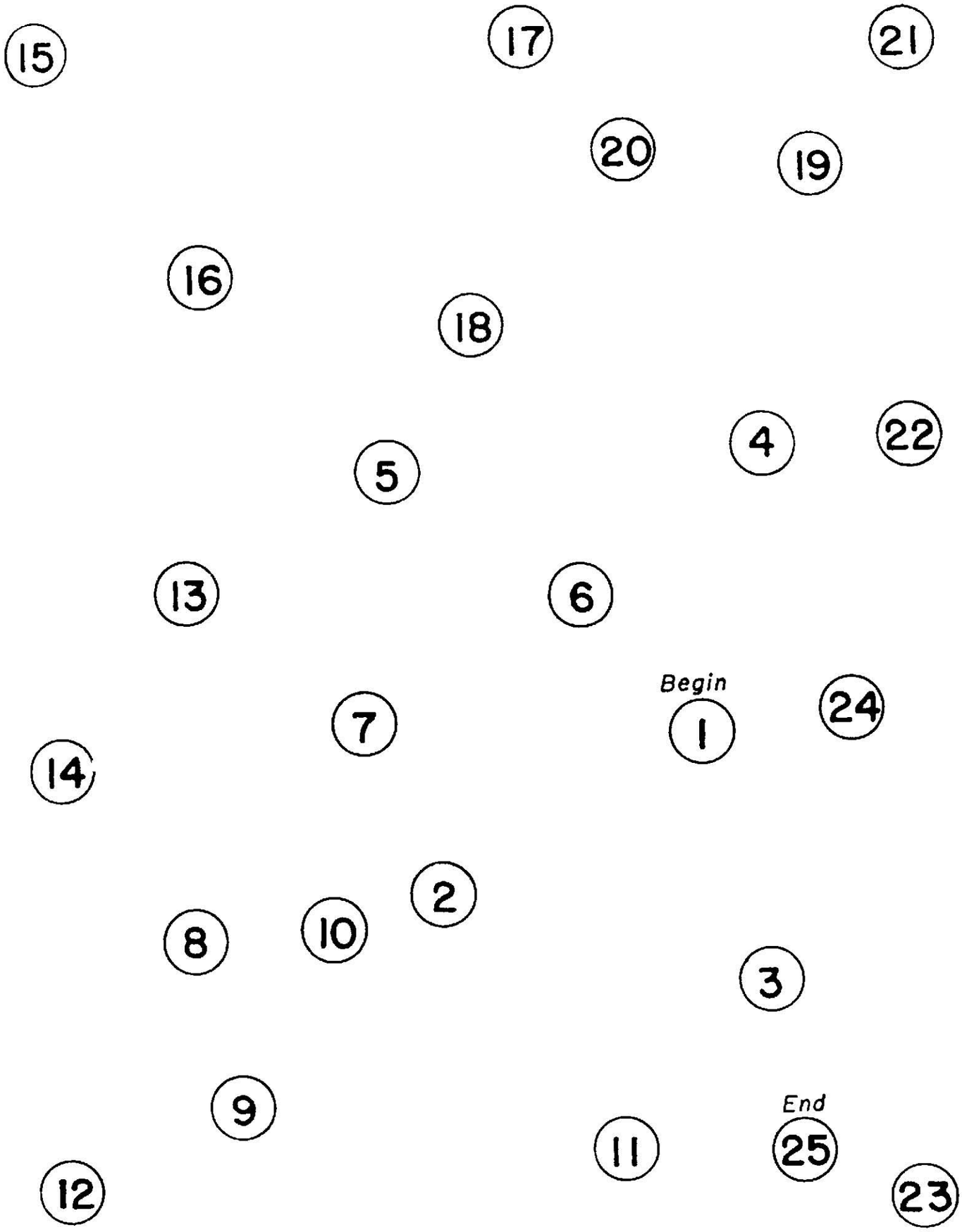
TRAIL MAKING TEST - PART A SAMPLE **PART-A PART-A**

SAMPLE



TIME: TIME: **ERRORS:**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Study No. | Visit No. | Date | Staff I.D.

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COLOR TRAILS 1 - FORM A SAMPLE **TRAILS 1 TRAILS 1**

ERRORS:

TIME: TIME:

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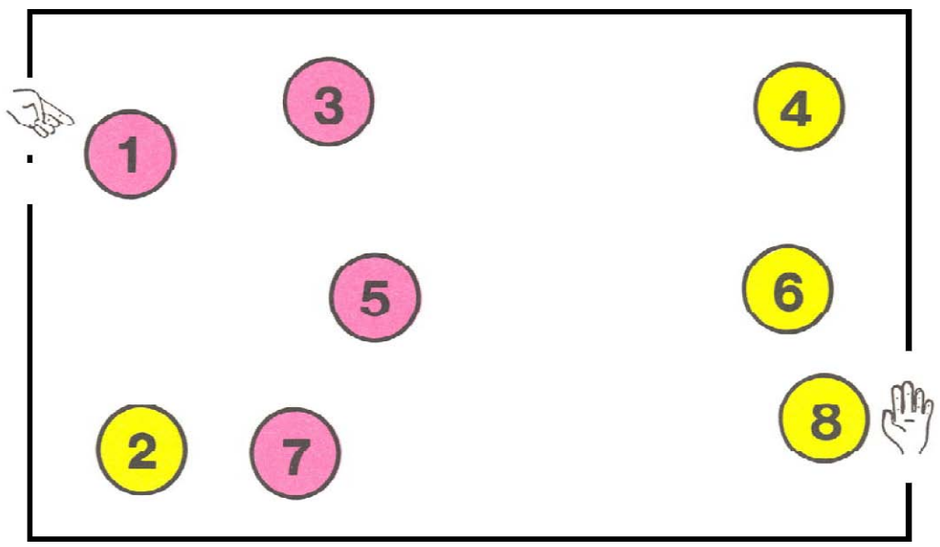

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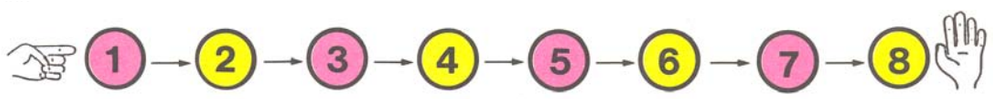

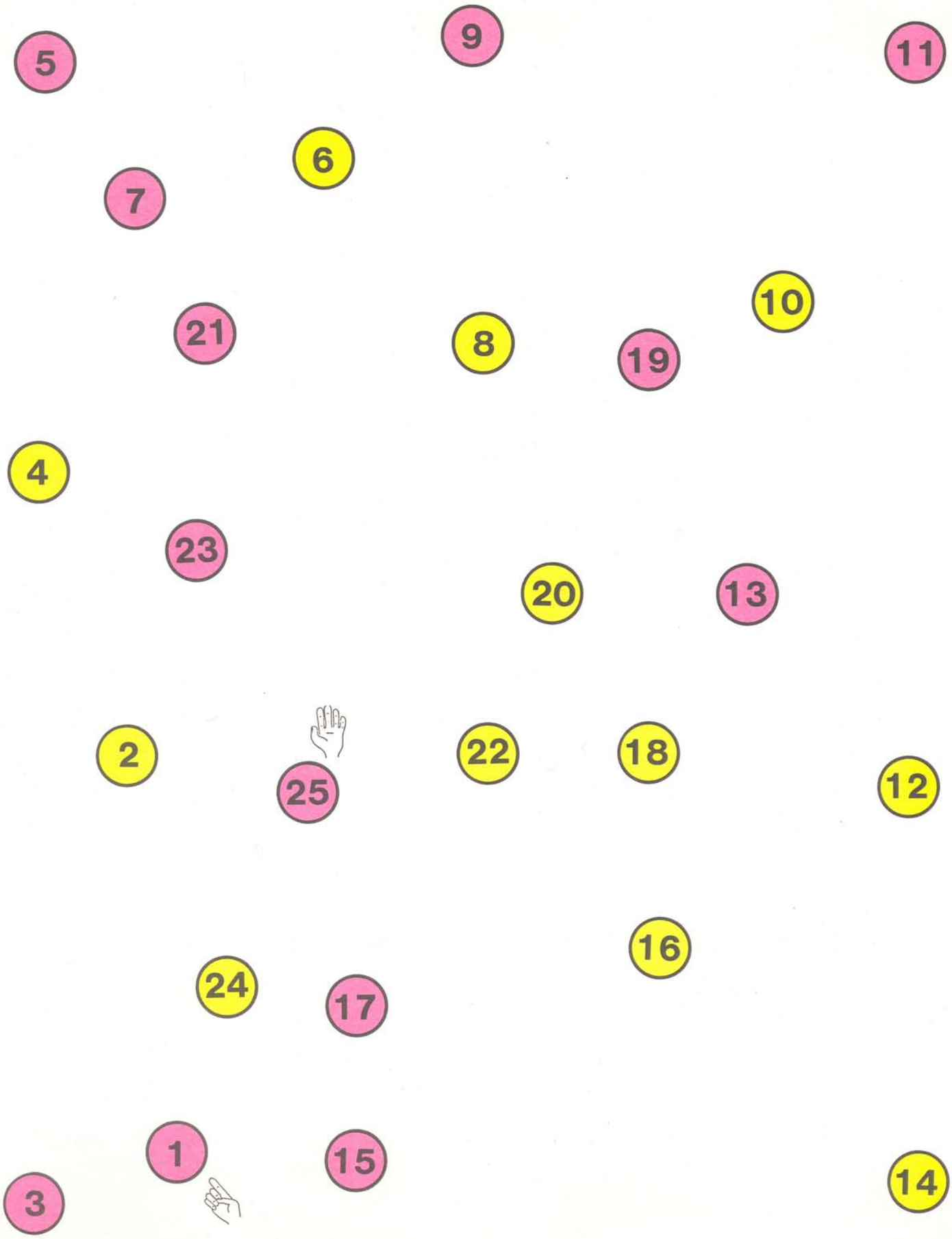
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Study No. | Visit No. | Date | Staff I.D.

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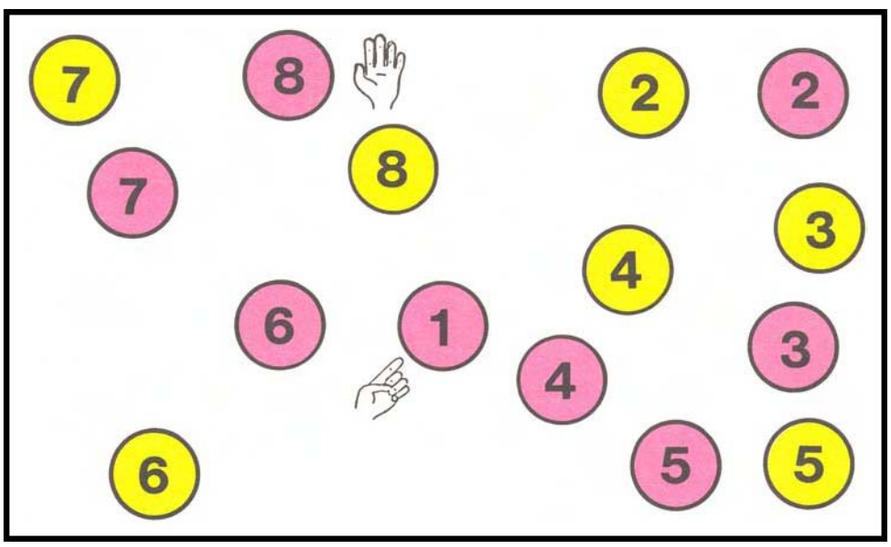
COLOR TRAILS 2 - FORM A SAMPLE **TRAILS 2 TRAILS 2**

ERRORS:

TIME: TIME:

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



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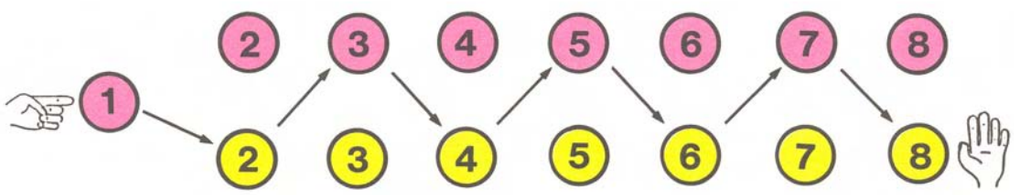

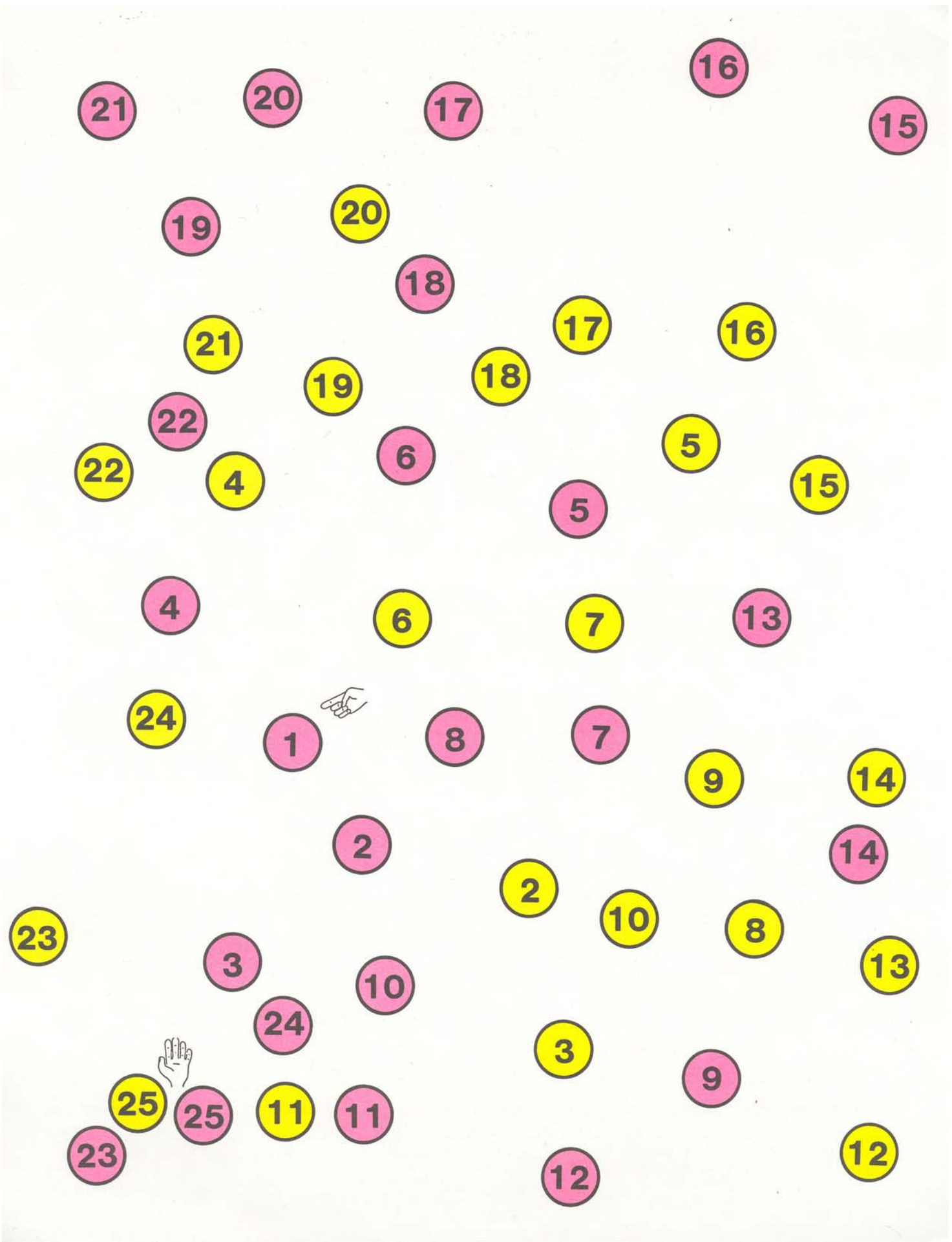
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Study No. | Visit No. | Date | Staff I.D. | Data Entry Only

WMS-III SPATIAL SPAN

TOTAL SCORE:

o

INSTRUCTIONS TO EXAMINER: Administer both trials of each item, even if examinee passes first trial. Discontinue after failure on both trials of any item. Maximum score for both trials is 32.

SPATIAL SPAN FORWARD

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	1	2	3	4	5	6
2. How often do you forget events which have occurred in the last day or two?	1	2	3	4	5	6
3. How often do you forget people whom you met in the last day or two?	1	2	3	4	5	6
4. How often do you forget things that you knew a year or more ago?	1	2	3	4	5	6
5. How often do you forget people whom you knew or met a year or more ago?	1	2	3	4	5	6
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	1	2	3	4	5	6
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	1	2	3	4	5	6
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	1	2	3	4	5	6
9. How often do you lose things or have trouble remembering where they are?	1	2	3	4	5	6
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of	1	2	3	4	5	6

Forward Total Score

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
2. How often do you forget events which have occurred in the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
3. How often do you forget people whom you met in the last day or two?	**1**	**2**	**3**	**4**	**5**	**6**
4. How often do you forget things that you knew a year or more ago?	**1**	**2**	**3**	**4**	**5**	**6**
5. How often do you forget people whom you knew or met a year or more ago?	**1**	**2**	**3**	**4**	**5**	**6**
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	**1**	**2**	**3**	**4**	**5**	**6**
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	**1**	**2**	**3**	**4**	**5**	**6**
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	**1**	**2**	**3**	**4**	**5**	**6**
9. How often do you lose things or have trouble remembering where they are?	**1**	**2**	**3**	**4**	**5**	**6**
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	**1**	**2**	**3**	**4**	**5**	**6**
	Almost Always	**Very Often**	**Fairly Often**	**Once In A While**	**Very Infrequent y**	**Almost Never**
11. How often do you have difficulties understanding what is said to you?	**1**	**2**	**3**	**4**	**5**	**6**
12. How often do you have difficulties recognizing or identifying printed words?	**1**	**2**	**3**	**4**	**5**	**6**
13. How often do you have difficulty understanding reading material which at one time you could have	**1**	**2**	**3**	**4**	**5**	**6**

SPATIAL SPAN BACKWARD

BACKWARD TOTAL SCORE:

Study No. | Visit No. | Date | Staff I.D. | Data Entry Only

CONTROLLED ORAL WORD ASSOCIATION TEST - FAS

be having in your daily living.

"F"Trial
"A"Trial
"S"Trial

Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

Correct Words:

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	1	2	3	4	5	6
2. How often do you forget events which have occurred in the last day or two?	1	2	3	4	5	6
3. How often do you forget people whom you met in the last day or two?	1	2	3	4	5	6
4. How often do you forget things that you knew a year or more ago?	1	2	3	4	5	6
5. How often do you forget people whom you knew or met a year or more ago?	1	2	3	4	5	6
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	1	2	3	4	5	6
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	1	2	3	4	5	6
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	1	2	3	4	5	6
9. How often do you lose things or have trouble remembering where they are?	1	2	3	4	5	6
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	1	2	3	4	5	6
	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent	Almost Never

Perseverations:

Intrusions:

Variants:

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Study No. | Visit No. | Date | Staff I.D.

Data Entry Only

CATEGORY FLUENCY TEST

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [ ] Items read by ex marked answers g

"Actions

Correct

Intrusions:

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Onc A Wl
1. How often do you forget something that has been told to you within the last day or two?	**1**	**2**	**3**	**4**
2. How often do you forget events which have occurred in the last day or two?	**1**	**2**	**3**	**4**
3. How often do you forget people whom you met in the last day or two?	**1**	**2**	**3**	**4**
4. How often do you forget things that you knew a year or more ago?	**1**	**2**	**3**	**4**
5. How often do you forget people whom you knew or met a year or more ago?	**1**	**2**	**3**	**4**
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	**1**	**2**	**3**	**4**
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	**1**	**2**	**3**	**4**
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	**1**	**2**	**3**	**4**
9. How often do you lose things or have trouble remembering where they are?	**1**	**2**	**3**	**4**
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	**1**	**2**	**3**	**4**
	Almost Alwavs	Very Often	Fairly Often	Onc A Wl

"Animals" Trial

Trial"

Words:

Perseverations:

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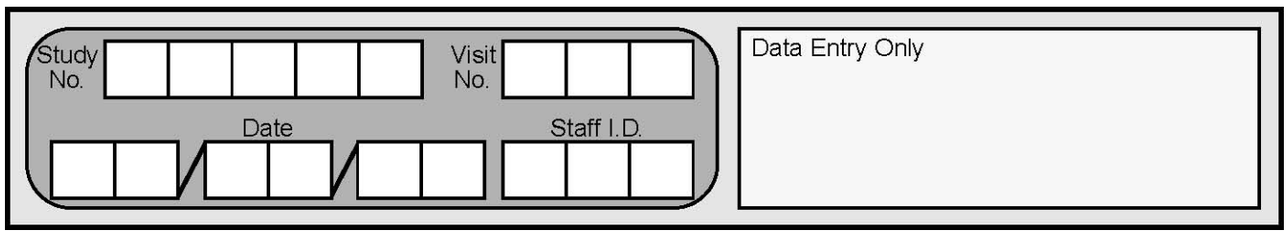

PACED AUDITORY SERIAL ADDITION TASK - 1 CHANNEL Channel 1

Correct Response

1. 9.....---____ ____ ____ ____
2. 1.....10 ____ ____ ____ ____
3. 4.....5 ____ ____ ____ ____
4. 2.....6 ____ ____ ____ ____
5. 8.....10 ____ ____ ____ ____
6. 6.....14 ____ ____ ____ ____
7. 5.....11 ____ ____ ____ ____
8. 3.....8 ____ ____ ____ ____
9. 4.....7 ____ ____ ____ ____ 10 9.....13 ____ ____ ____ ____

1. 1.....10 ____ ____ ____ ____
2. 3.....4 ____ ____ ____ ____
3. 6.....9 ____ ____ ____ ____
4. 8.....14 ____ ____ ____ ____
5. 2.....10 ____ ____ ____ ____
6. 5.....7 ____ ____ ____ ____
7. 1.....6 ____ ____ ____ ____
8. 8.....9 ____ ____ ____ ____
9. 6.....14 ____ ____ ____ ____
10. 9.....15 ____ ____ ____ ____
11. 2.....11 ____ ____ ____ ____
12. 4.....6 ____ ____ ____ ____
13. 3.....7 ____ ____ ____ ____
14. 5.....8 ____ ____ ____ ____
15. 6.....11 ____ ____ ____ ____
16. 5.....11 ____ ____ ____ ____
17. 8.....13 ____ ____ ____ ____
18. 9.....17 ____ ____ ____ ____
19. 4.....13 ____ ____ ____ ____
20. 3.....7 ____ ____ ____ ____
21. 1.....4 ____ ____ ____ ____
22. 2.....3 ____ ____ ____ ____
23. 6.....8 ____ ____ ____ ____
24. 3.....9 ____ ____ ____ ____
25. 4.....7 ____ ____ ____ ____
26. 8.....12 ____ ____ ____ ____
27. 9.....17 ____ ____ ____ ____
28. 5.....14 ____ ____ ____ ____
29. 1.....6 ____ ____ ____ ____
30. 2.....3 ____ ____ ____ ____
31. 8.....10 ____ ____ ____ ____
32. 1.....9 ____ ____ ____ ____
33. 2.....3 ____ ____ ____ ____
34. 5.....7 ____ ____ ____ ____
35. 3.....8 ____ ____ ____ ____
36. 9.....12 ____ ____ ____ ____
37. 6.....15 ____ ____ ____ ____
38. 4.....10 ____ ____ ____ ____
39. 3.....7 ____ ____ ____ ____

.....9 ____ ____ ____ ____ **#Attempted: #Correct:**

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Study No.		Visit No.		Data Entry Only
Date		Staff I.D.		

STROOP TEST

INSTRUCTIONS TO THE EXAMINER: Begin by instructing the participant: (Page with word in black ink.) ***"This is a test of how fast you can read the words on this page. After I say "BEGIN", read down the columns starting with the first one (point to the leftmost column) until you complete it (run hand down the leftmost column) and then continue without stopping down the remaining columns in order (run your hand down the second column, then third, etc.). If you finish all the columns before I say "STOP", then return to the first column and begin again (point to the first column). Remember, do not stop reading until I say "STOP" and read out loud as quickly as you can. If you make a mistake, I will say, "NO" to you. Correct your error and continue without stopping. Are there any questions?"*** **Instructions may be repeated or paraphrased as often as necessary until the subject understands what is to be done. "*Ready?....Then begin.*" As the subject starts, begin timing. After 45 seconds, say: "STOP". Circle the item they are on.**

WORDS:

Word Total:

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almo Neve
1. How often do you forget something that has been told to you within the last day or two?	1	2	3	4	5	6
2. How often do you forget events which have occurred in the last day or two?	1	2	3	4	5	6
3. How often do you forget people whom you met in the last day or two?	1	2	3	4	5	6
4. How often do you forget things that you knew a year or more ago?	1	2	3	4	5	6
5. How often do you forget people whom you knew or met a year or more ago?	1	2	3	4	5	6
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	1	2	3	4	5	6
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	1	2	3	4	5	6
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	1	2	3	4	5	6
9. How often do you lose things or have trouble remembering where they are?	1	2	3	4	5	6
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	1	2	3	4	5	6
	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almo Neve
11. How often do you have difficulties understanding						

INSTRUCTIONS TO THE EXAMINER: (Page with colored X's.) ***"This is a test of how fast you can name the colors on this page. You will complete this page just as you did the previous page, starting with this first column. Remember to name the colors out loud as quickly as you can. Are there any questions?"*** **If the subject has had any trouble following the instructions, they should be repeated in their entirety. As with Page 1, the subject should be allowed 45 seconds.**

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
1. How often do you forget something that has been told to you within the last day or two?	1	2	3	4	5	6
2. How often do you forget events which have occurred in the last day or two?	1	2	3	4	5	6
3. How often do you forget people whom you met in the last day or two?	1	2	3	4	5	6
4. How often do you forget things that you knew a year or more ago?	1	2	3	4	5	6
5. How often do you forget people whom you knew or met a year or more ago?	1	2	3	4	5	6
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	1	2	3	4	5	6
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	1	2	3	4	5	6
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	1	2	3	4	5	6
9. How often do you lose things or have trouble remembering where they are?	1	2	3	4	5	6
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	1	2	3	4	5	6
	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almost Never
11. How often do you have difficulties understanding						

COLORS:

Color Total:

Study No. | Visit No. | Data Entry Only

INSTRUCTIONS TO THE EXAMINER: **(Page with colors and words.)** ***"This page is like the page you just finished. I want you to name the color of the ink the words are printed in, ignoring the word that is printed in each item. For example, (point to the first item of the first column), this is the first item: what would you say?"*** **If the subject is correct, go on with the instructions. If incorrect, say:** ***"No, that is the word that is spelled there. I want you to say the color of the ink the word is printed in. Now (pointing to the same item) what would you say to this item? That's correct (point to the second item), what would the response be to this item?"*** **If correct, proceed; if incorrect, repeat above as many items as necessary until the subject understand or it becomes clear that it is impossible to go on.** ***"Good.You will do this page just like the others, starting with the first column (pointing) and then going on to as many columns as you can. Remember, if you make a mistake, just correct it and go on. Are there any questions?"*** **(As with the other two pages, the instructions can be repeated or paraphrased as often as necessary.) "Ready? ...Begin!" After 45 seconds, say: Stop; Record on the form how many correct responses**

COLORS -WORDS:

Color/Word Total:

be having in your daily living.
Manner of Inventory Administration: [ ] Participant read and answered items independently. [ ] Examiner read items, and marked verbal given answers. [[ ] Items read by examiner.] Examiner marked answers given verbally.

SCALE I: MEMORY

	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almo Neve
1. How often do you forget something that has been told to you within the last day or two?	1	2	3	4	5	6
2. How often do you forget events which have occurred in the last day or two?	1	2	3	4	5	6
3. How often do you forget people whom you met in the last day or two?	1	2	3	4	5	6
4. How often do you forget things that you knew a year or more ago?	1	2	3	4	5	6
5. How often do you forget people whom you knew or met a year or more ago?	1	2	3	4	5	6
6. How often do you lose track of time, or do things either earlier or later than they are usually done or are supposed to be done?	1	2	3	4	5	6
7. How often do you fail to finish something you start because you forgot that you were doing it? (Include such things as forgetting to put out cigarettes, turning off the stove, etc.)	1	2	3	4	5	6
8. How often do you fail to complete a task that you start because you have forgotten how to do one or more aspects of it?	1	2	3	4	5	6
9. How often do you lose things or have trouble remembering where they are?	1	2	3	4	5	6
10. How often do you forget things that you are supposed to do or have agreed to do (such as putting gas in the car, paying bills, taking care of errands, etc.)?	1	2	3	4	5	6
	Almost Always	Very Often	Fairly Often	Once In A While	Very Infrequent y	Almo Neve
11. How often do you have difficulties understanding						

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Study No. | Visit No. | Date | Staff I.D.

Data Entry Only

HALSTEAD CATEGORY TEST RECORD FORM

ERRORS TOTAL:

INSTRUCTIONS TO EXAMINER: The right-hand column is used to check correct responses and the left-hand incorrect.

	SUBTEST I	SUBTEST II	SUBTEST III	SUBTEST IV	SUBTEST V	SUBTEST VI	SUBTEST VII
1.	1	1	1	1	1	1	1
2.	3	3	3	3	3	3	3
3.	1	1	1	1	1	1	1
4.	4	4	4	4	4	4	4
5.	2	2	2	2	2	2	2
6.	4	4	4	4	4	4	4
7.	1	1	1	1	1	1	1
8.	2	2	2	2	2	2	2
9.		3	3	3	3	3	3
10.		2	2	2	2	2	2
11.		3	3	3	3	3	3
12.		1	1	1	1	1	1
13.		4	4	4	4	4	4
14.		3	3	3	3	3	3
15.		4	4	4	4	4	4
16.		2	2	2	2	2	2
17.		1	1	1	1	1	1
18.		4	4	4	4	4	4
19.		1	1	1	1	1	1
20.		3	3	3	3	3	3
21.			2	2	2	2	
22.			1	1	1	1	
23.			2	2	2	2	
24.			4	4	4	4	
25.			3	3	3	3	
26.			2	2	2	2	
27.			4	4	4	4	
28.			3	3	3	3	
29.			1	1	1	1	
30.			4	4	4	4	
31.			2	2	2	2	
32.			1	1	1	1	
33.			3	3	3	3	
34.			1	1	1	1	
35.			3	3	3	3	
36.			2	2	2	2	
37.			4	4	4	4	
38.			3	3	3	3	
39.			4	4	4	4	
40.			2	2	2	2	

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APPENDICES

Appendix A

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm
Assurance No. FWA00000338
IRB00001131 of IORG0000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

25th September, 2012.

Your Ref: 005-05-12.

Ms Chilwesa Lutunti,
School of Medicine,
Department of Psychiatry,
PO Box 50110,
Lusaka.

Dear Ms. Lutunti,

RE: RE-SUBMITTED RESEARCH PROPOSAL: **"FAMILY RELATIONSHIPS IN HIV POSITIVE PEOPLE AND PERFORMANCE ON THE INTERNATIONAL NEUROPSYCHOLOGICAL TEST BATTERY IN LUSAKA PROVINCE"**

The above mentioned research proposal was re-submitted to the Biomedical Research Ethics Committee with recommended changes on 13th July, 2012. The proposal is approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a final copy of the results is submitted to this Committee.**

Yours sincerely,

Dr. J.C Munthali
CHAIRPERSON

Date of approval: 25 September, 2012 **Date of expiry:** 24 September, 2013

Appendix B

P.O. Box 50827
Lusaka
Tel: +260-211-235554
Fax: +260-211-236429

In reply please quote

No.....

Republic of Zambia

MINISTRY OF HEALTH
LUSAKA DISTRICT HEALTH MANAGEMENT TEAM

Thursday, July 19, 2012.

Professor MPS Ngoma
Associates Professor
Paeadiatrics and Child Health
University Teaching Hospital
LUSAKA.

Dear Dr. Ngoma,

RE: PERSMISSION TO CONDUCT RESEARCH AT LUSAKA DISTRICT CLINICS: MASTERS IN CLINICAL NEUROPSYCHOLOGY.

The District Health Office is in receipt of your letter dated 16th July, 2012 on the above subject.

Approval has been granted for the ten named students to conduct research in the Lusaka District Clinics.

However, the research should only commence upon production of a copy of UNZA REC approval.

You will also be required to furnish the DHO with a summary of your research findings at the completion of the study.

Yours sincerely,

DR. M. M. CHIKO
ACTING PRINCIPAL CLINICAL CARE OFFICER
For/ACTING DISTRICT MEDICAL OFFICER.

c.c.: Health Centre in-charges.