

EXAMINING THE PSYCHOSOCIAL ADJUSTMENT
AND SCHOOL PERFORMACE OF UGANDAN CHILDREN WITH HIV/AIDS

By

Rachelle A. Busman

A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

Counseling, Educational Psychology and Special Education

2010

ABSTRACT

EXAMINING THE PSYCHOSOCIAL ADJUSTMENT AND SCHOOL PERFORMANCE OF UGANDAN CHILDREN WITH HIV/AIDS

By

Rachelle A. Busman

Human immunodeficiency virus (HIV) has had a devastating impact on the children of Africa. In Uganda, over 100,000 children are infected, mostly through vertical transmission of the disease from their mother. With recent improvements in medical treatment, children are now surviving longer and reaching school age, but there is limited research examining the quality of life of these children. The current study investigated the psychosocial adjustment and school achievement of 60 Ugandan children with vertically transmitted HIV. Specific attention was given to the caregiving context and illness parameters surrounding this at-risk group of children. Results showed that being cared for by a grandmother may be a protective factor related to fewer externalizing behaviors. Cognitive functioning may also be protective, with higher scores associated with increased school performance. These findings are a first step toward understanding the protective factors associated with psychosocial adjustment and better school performance. Furthermore, these findings can serve as a basis for developing interventions that promote a better quality of life in children afflicted with HIV/AIDS in Uganda.

ACKNOWLEDGEMENTS

I would like to acknowledge several individuals who have been instrumental in my development as a researcher and who have played an integral role in facilitating the completion of my dissertation. First, I would like to thank my advisor Dr. Evelyn Oka, who also served as dissertation committee co-chair for her unwavering devotion in the execution of this research project. I would also like to thank Dr. Michael Boivin, committee co-chair, for aiding in the development of this project and making it possible for me to travel to Uganda to collect the data. This project was truly life changing. I am grateful to both of my committee chairs for their guidance and encouragement throughout the entire process. I would also like to thank the members of my dissertation committee, Drs. John Carlson and Jodene Fine for their time, flexibility, careful readings of my writing, and insightful contributions to this project. Appreciation is given to my colleagues in Uganda for their dedication to this project and their willingness to work under less than ideal conditions to complete this work. Finally, I would like to thank my family, and friends for their support and gracious tolerance of the demands associated with graduate education/training and dissertation research.

This research project was partially funded by the Michigan State University Pre-dissertation International Travel Fellowship. Additional support was provided by the Leadership Training Grant Fellowship from the U.S. Department of Education, Office of Special Education Programs.

TABLE OF CONTENTS

LIST OF TABLES	vi
LIST OF FIGURES.....	vii
CHAPTER 1	
INTRODUCTION.....	1
Resilience in the Face of HIV.....	3
The Purpose of this Study.....	5
Proposal Content.....	6
CHAPTER 2	
LITERATURE REVIEW.....	7
What is HIV?.....	7
Disease Progression.....	8
Measuring Disease Progression.....	10
Treatment (HAART Medication).....	10
Developmental Implications.....	11
Cognitive Development.....	11
Cross-Cultural Consistency.....	13
Impact of Environment on Cognitive Development.....	14
Psychosocial Development.....	14
Resiliency in the face of childhood HIV.....	17
Stress and Coping Model for Predicting Psychological Adjustment in HIV-Infected Children.....	19
Understanding Psychosocial Adjustment.....	23
Psychosocial Adjustment and Caregiving Context.....	24
Primary caregiver.....	24
Socioeconomic factors.....	26
Psychosocial Adjustment and Child Variables.....	27
Age.....	27
Gender.....	28
Academic Achievement of School Children with HIV/AIDS.....	29
Schooling within Uganda.....	31
Addressing the Needs of Children with HIV/AIDS in Uganda.....	32
Conclusions.....	33
Research Questions.....	36
CHAPTER 3	
METHODS.....	39
Research partnering with Child Health Advocacy International:	
The Larger Study.....	39
The Current Study.....	40

Participants.....	40
Variables and Instruments.....	41
Child Behavior Checklist (CBCL).....	42
Kaufman Assessment Battery for Children- Second Edition.....	43
Adaption of assessment batter into local languages and test administration.....	45
Socioeconomic Status (SES).....	45
Disease Progression.....	46
School Performance.....	47
Procedures.....	47
 CHAPTER 4	
RESULTS.....	49
Research Question 1, Caregiving Context.....	49
Research Question 2, Child Illness Parameters.....	50
Research Question 3, Psychosocail Adjustment and School Performnace.....	52
Research Question 4, Factors Contributing to Psychosocial Adjustment and School Performance.....	54
Psychosocial Adjustment.....	54
School Performance.....	55
 CHAPTER 5	
DISCUSSION.....	57
Research Question 1: Caregiving Context.....	59
Research Question 2: Child Illness Parameters.....	60
Research Question 3: Psychosocial Adjustment and School Performance.....	62
Research Question 4: Factors Contributing to Psychosocial Adjustment and School Performance.....	64
Psychosocial Adjustment.....	64
School Performance.....	65
Conclusions.....	65
Future Research.....	67
Limitations.....	68
 APPENDICES.....	94
 REFERENECES.....	116

LIST OF TABLES

Table 1.	Description of KABC-II Subtests Administered.....	71
Table 2.	Demographic Characteristics.....	73
Table 3.	Logistic Regression Predicting Likelihood of being Cared for by Mother.....	75
Table 4.	Means and Standard Deviations of KABC-II scores by Medication Status.....	76
Table 5.	Test of Between-Subjects to Assess Psychosocial Adjustment And School Performance by Gender and Age.....	78
Table 6.	Behavior Concerns by Age and Gender.....	79
Table 7.	Nominal Regression to Assess Variables Contributing to Externalizing Behaviors.....	80
Table 8.	Nominal Regression to Assess Variables Contributing to Internalizing Behaviors.....	81
Table 9.	Parameter Estimates of Variables Contributing to School Performance.....	82

LIST OF FIGURES

Figure 1.	Stress and Coping Model for Predicting Psychosocial Adjustment in HIV-infected Children.....	83
Figure 2.	Immunologic Category Definitions Based on the CD4 Count and/or Percentage.....	84
Figure 3.	Histogram of the Number of Children by Gender and Age.....	85
Figure 4.	Histogram of the Number of Children by Caregiver and Age.....	86
Figure 5.	Mean Externalizing Behavior Scores by School Performance and Gender.....	87
Figure 5.1	Scatter Plot of Externalizing Behaviors by School Performance and Gender.....	88
Figure 5.2	Boxplot of Externalizing Behaviors by School Performance and Gender.....	89
Figure 6.	Mean Internalizing Behavior Scores by School Performance and Gender.....	90
Figure 6.1	Scatter Plot of Internalizing Behaviors by School Performance and Gender.....	91
Figure 6.2	Boxplot of Internalizing Behaviors by School Performance and Gender.....	92
Figure 7.	Results: Connecting Caregiving Context, Child Illness Parameters and Child Outcomes.....	93

CHAPTER 1

Introduction

Every day, 1,100 children around the world are infected with human immunodeficiency virus (HIV), most as a result of mother-to-child transmission (MTCT) of the virus (United Nations Program on HIV/AIDS (UNAIDS), 2007). In 2007 alone, an estimated 420,000 children worldwide were newly infected almost exclusively through MTCT (UNICEF, 2008). Despite the increasing availability of medical interventions to decrease the incidence of MTCT, UNAIDS found the total number of children living with HIV had reached 2.5 million in 2007, 1 million more than was estimated in 2005. Children now make up approximately 7.5% of the 33.2 million people worldwide living with HIV/AIDS (UNAIDS, 2007). Many of these cases are in sub-Saharan Africa where the problem is compounded by the lack of resources and the presence of many other life-threatening diseases. In fact, this region of the world is responsible for 63% of the world's HIV/AIDS cases, although only 11% of the population of the world resides there (Bing & Cheng, 2008). The percentages of people with HIV/AIDS vary across the different countries that make up Sub-Saharan Africa. In urban areas of Sub-Saharan Africa rates of HIV/AIDS can be as high as 33% where 1 in 3 individuals are infected (Bing & Cheng, 2008). Although this is the extreme, many countries including Botswana, Cameroon, Lesotho, and Swaziland, Namibia, South Africa, Zambia and Zimbabwe, in sub-Saharan Africa have a HIV prevalence rate of more than 14% or approximately 1 in 7 individuals (Hodge, 2008).

In particular, HIV/AIDS has had a widespread impact on the children of Uganda, where about 1 million children are orphaned and a new child is orphaned every 14 seconds due to the AIDS epidemic (Ronald & Sande, 2005). Furthermore, over 100,000 children in Uganda are infected with HIV/AIDS (UNAIDS, 2007). There is no known cure for the virus, and being

infected means increased medical needs and decreased life-span. Thus, there is a need for research in this region of the world hardest hit by the epidemic, and the least equipped economically to take on the challenge. Fortunately, there are ways that children are beginning to receive care.

The devastating AIDS epidemic is receiving global attention and support, which has led to better pharmacological treatments that are implemented early-on in conjunction with other vital care addressing nutrition. The Ugandan government has been responsive to the epidemic by making the problem a priority and allowing for the implementation of new medical interventions and public campaigns to curb the devastation (Kirumira, 2008; Ruzindaza, 2001). Within Uganda, non-governmental organizations (NGOs) such as Child Health Advocacy International (CAI) have pioneered social programs targeted at helping to improve the lives of children and families living with HIV/AIDS. NGOs such as this have been instrumental in providing care around the world and delivering more aid to developing regions than all United Nations organizations combined (Chaplowe & Engo-Tjega, 2008). These new interventions have been successful at identifying children with the virus and prolonging life, but much more is needed to understand and ultimately improve the quality of life of children living with HIV/AIDS.

A Luganda Proverb from a tribe within Ugandan, “Akakyama anamera tekagololekeka”, is translated as, “That which is bent at the outset of its growth is almost impossible to straighten at the later age” (Kilbride & Kilbride, 1990). This proverb aptly describes the harmful effects of HIV/AIDS on the lives of children infected at birth. The developmental effects can be seen in children’s cognitive ability and psychosocial adjustment. Children may exhibit global cognitive impairments or specific deficits in attention, and/or visual-spatial functioning (Smith et al.,

2006). Numerous studies have reported the psychosocial consequences suffered by children diagnosed with HIV including externalizing and internalizing problems such as major depression, attention concerns, and anxiety disorders (Bachanas et al. 2001; Franklin, Lim & Havens, 2007; Misdrahi, et al., 2004). However, there has recently been a shift in the literature from a focus on cognitive and emotional dysfunction exhibited by children infected with HIV, to a focus on the positive outcomes demonstrated by many of these children. For example, children with HIV/AIDS have been found to exhibit normal cognitive functioning if they do not have an AIDS-defining illness such as an opportunistic infection, a disease affecting the central and peripheral nervous system, malignancies, and/or wasting syndrome (Smith et al., 2006) or if they do not experience high environmental stress (Hochhauser et al., 2008). Although children with HIV can exhibit levels of maladjustment that are elevated relative to a non-infected population, the majority of these children do not. In a study by Bachanas (2001), 75% of the infected children did not show signs of externalizing or internalizing problems suggesting an emotional resiliency despite being born with HIV/AIDS. In addition to cognitive and psychosocial resiliency, some children are also demonstrating academic success, being able to attend school and benefit from education in spite of the many barriers related to HIV/AIDS. Further research is needed to better understand the characteristics of children who face HIV/AIDS.

Resilience in the face of HIV

Resilience refers to an individual's ability to recover from, adapt, and remain strong in the face of adversity (Boyden & Mann, 2005, p. 6). Focusing on the resiliency of children amidst diverse risks and life circumstances is beneficial because it can lead to and inform action (Ungar, 2008). However, there is limited information guiding the conceptualization of risk and resiliency within resource poor regions of the world dealing with a chronic illness such as HIV.

Liebenberg and Ungar (2008) point out that the challenge of resilience researchers is that positive outcomes vary according to context and culture. This study addresses the need for more research within different cultural contexts to understand the factors associated with psychosocial adjustment.

To better understand the response to HIV in particular cultural contexts, a model of stress and coping has been useful in conceptualizing psychological adjustment in children with HIV and in identifying factors that may buffer the negative impact of the disease (Bachanas, et al., 2001). The model includes key ecological factors that contribute to the child's adjustment including: illness parameters, caregiver characteristics, demographic parameters, and child characteristics (See Figure 1). Although this model has not been used in Sub-Saharan Africa it can serve as a guide to better understand children inflicted with HIV around the world and to investigate the factors that contribute to psychosocial adjustment.

Psychosocial adjustment is a multifaceted construct that refers to an individual's mental health. According to the U.S. Surgeon General (U.S. Department of Health and Human Services, 1999) mental health can be thought of on a continuum. On one end of the continuum is mental health defined as "a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity. Mental health is indispensable to personal well-being, family and interpersonal relationships, and contribution to community or society..." (p.4). At the other end of the continuum is mental illness or maladjustment, characterized by, "alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning..." (p.5).

Psychosocial adjustment has been used to describe the adaptive functioning of individuals.

A person would be well adjusted if he or she demonstrated positive social skills, normal psychological functioning, and was able to adaptively meet the demands of the environment (Achenbach, et al., 2008). One way to conceptualize the psychosocial adjustment of children is in terms of the presence or absence of internalizing and externalizing behavioral problems. Internalizing disorders reflect “problems within the self, such as anxiety, depression, somatic complaints without know medical cause, and withdrawal from social contacts” (Achenbach & Rescorla, 2001, p.93). Externalizing behaviors on the other hand, involve conflicts with others and violations of expected behavior (Achenbach & Rescorla, 2001). This is a helpful way to identify children at risk for psychosocial maladjustment, but can be a narrow approach to mental health when examined in isolation. The stress and coping model provides a way of understanding internalizing and externalizing behaviors in context, in relation to children’s unique environmental circumstances and characteristics. It illustrates how the caregiver and the socioeconomic context in which children live play an important role in their adjustment. Children’s physical and psychological characteristics, such as their disease state and cognitive abilities, can also play a role in the development of psychosocial adjustment. There are limited data on how children’s psychosocial development within the resource poor region of Uganda are affected by the caregiving context and their psychological and physical functioning signaling the need for more research in this area.

The Purpose of this Study

The purpose of this study is to examine the psychosocial adjustment and education of Ugandan school children living with HIV/AIDS in relation to the social and cultural contextual factors that promote their resiliency. Having HIV/AIDS is associated with a plethora of negative outcomes, thus, it is important to identify the protective factors associated with

resiliency in the face of HIV. This study seeks to explore some of these protective factors related to positive developmental outcomes, guided by a model of stress and coping for children with HIV/AIDS. Although appropriate and relevant, the model has not been applied to a resource poor region, where the epidemic of HIV has had far reaching effects. Furthermore, the focus on positive outcomes and resiliency promotion is unique within the literature from resource poor regions that tend to focus on pathology and identifying dysfunction. These data can be used to identify the kinds of internalizing and externalizing behavior problems that children with HIV/AIDS experience and identify the characteristics of children who show resilience to the devastating disease in a resource poor region of Sub-Saharan Africa. Furthermore, these data can inform the development of interventions that promote the factors that contribute to resiliency. The current research seeks to: (a) to explore the caregiving context and illness parameters of children with vertically transmitted HIV/AIDS within Uganda and (b) to identify the factors that may be linked to psychosocial functioning, and school performance of these children within their unique context.

CHAPTER 2

Literature Review

This literature review aims to: (1) Provide a definition of HIV, and describe how it progresses to more advanced stages, (2) Discuss the developmental implications associated with HIV including cognitive factors and psychosocial adjustment; (3) Provide a theoretical framework for understanding the psychosocial adjustment of HIV infected children; (4) Examine the research on factors related to the psychosocial adjustment of children with HIV; (5) Discuss the academic implications for school age children with HIV/AIDS in Uganda.

What is HIV?

Being “HIV positive” indicates infection with the human immunodeficiency virus, regardless of the overt physical manifestations of disease. The virus attacks the immune system, mainly targeting the Cluster of Differentiation 4 (CD4) receptor positive cells such as CD4+ T lymphocyte (T helper cells) resulting in their eventual destruction through various mechanisms. Through this destruction the immune system is compromised, making the infected person highly susceptible to a variety of opportunistic diseases of the lungs, mouth, liver, brain, colon, genitals, and eyes (Mangione, Landau, & Pryor, 1998). An individual is classified as having AIDS when their blood reveals T helper cells/uL below 200 and/or develop an AIDS-defining illness such as an opportunistic infection, a disease affecting the central nervous system, malignancies, and/or wasting syndrome (Castro et al., 1993).

Diagnosing HIV/AIDS in children is more complex than in adults. HIV infection in children is characterized by a latency period in which the virus incubates. This period of time in which the child is asymptomatic may be shorter than in adults, however that is not always the case (Gershon, Hotez, & Katz, 2004). The CDC laid out guidelines for diagnosing children by

immunologic category based on the CD4 count and/or percentage. The categories are: No evidence of suppression, evidence of moderate suppression, and severe suppression. Placement into each category is also dependent on age, groups being: children less than 1 year, 1-5 years, and 6-12 years (See Figure 2).

There are three modes by which HIV is typically transmitted to children: perinatally from an infected mother, exposure to infected blood, and via unprotected sex with an infected person (Landau & Pryor, 1995). Nearly 90 percent of children acquire HIV through perinatal transmission (Speigel & Bonwit, 2002). Such transmission may occur in utero, intrapartum, or postnatally through breast feeding (John & Kreiss, 1996). Once infected there are two general patterns of disease progression in children. Approximately 20% develop serious disease in the first year of life with most dying by age 4, while the remaining 80% develop a slower progression of disease and do not experience serious consequences of AIDS until school age or adolescence (NIAID, 2004). The inevitable result of HIV infection is the profound immunosuppression that leaves children vulnerable to infections and neoplasms (Gershon, Hotez, & Katz, 2004). Furthermore, HIV infected children are frequently delayed in reaching important milestones in motor skills and mental development and many children develop neurological problems such as difficulty walking, poor school performance, seizures, and other symptoms of HIV encephalopathy (NIAID, 2004).

Disease Progression

Disease progression in children is complex with no clear course of the disease. For example, not all children exposed to HIV contract it and for those who do become infected, it is unclear how quickly the disease will compromise the immune system or how one's cognitive, and psychosocial functioning will be affected (Little et al. 2007). The lack of a systematic

pattern of disease progression once infected makes it difficult to predict the needs and appropriate interventions and supports. An understanding of disease progression and mortality of children with vertically transmitted HIV is vital in developing effective treatments. Unfortunately there is limited information that can speak to this, with the least amount of information in resource poor settings even though this is where the most cases of HIV/AIDS are found (Little et al., 2007). The understanding of disease progression for children with vertically transmitted HIV is in large part based on European studies. The European Collaborative Study (2001) has contributed a great deal of knowledge about survival rates of children living with HIV and impact of treatment on survival. The study followed 170 infants born between 1984 and 1999 who were identified as HIV positive as infants. Of those infants more than 15% progressed to category C or death by the age of 1 year. By 10 years of age 50% had reached the same fate (The European Collaborative Study, 2001). Other studies have reported similar results in untreated populations in which 20% of children with vertically transmitted HIV develop AIDS or die by their first birthday and 40% in advanced stages by age 6 (Gray, McIntyre, & Newell, 2000). One of the factors that seems to be correlated with a child's disease progression and death is the death of the child's mother. In southwest Uganda, child mortality risk was higher for children with mothers who died than for those with surviving mothers. This protective role of mothers was found for both children with and without vertically transmitted HIV. For those children whose mothers have died and have HIV, there is a greater risk of childhood mortality (Nakiyingi, et al., 2003). In fact pediatric HIV infection results in a mortality rate four times greater than that of the uninfected population by age 2 (Little et al., 2007). However, more research is needed to understand how the psychosocial adjustment and school performance of surviving children is affected.

Measuring Disease Progression

As seen from longitudinal studies, age is not an accurate predictor of mortality. Thus, other methods for measuring disease progression need to be used in order to get a clear picture of the impact the virus has on the child with vertically transmitted HIV. Research in this area supports the use of two different measures as predictors of mortality in developed countries as well as Sub-Saharan Africa: CD4 cell count and Viral Load. In Malawi 155 children with vertically transmitted HIV were followed from birth to understand the relationship between CD4 cell count, viral load and mortality. Researchers discovered that if the child lived past his/her first birthday, viral load or CD4 cell percentage at **any age** could be directly predictive of future survival (Taha et al., 2000; Rouet et al, 2003). Thus, these measures are accurate and useful indicators of disease progression in school age children. Disease progression is important to monitor because of the implications for drug therapy. When children's disease progresses to a certain level, medications are prescribed to slow the advancement of HIV into AIDS (Rouet et al., 2003).

Treatment (HAART medication)

Although a cure for HIV/AIDS remains elusive, continued advances in treatments including Highly Active Antiretroviral Therapy (HAART) have given new hope to those suffering from the virus. HAART has been found to slow the progression of HIV to AIDS and decrease mortality in HIV infected children and adolescents (Patel et al., 2008). In fact, children born after 1994 who were given treatment earlier and more intensively than children born before that time, showed a slowed pattern of disease progression (Gray et al., 2000). Furthermore, HAART reduces the incidence of infections and hospitalizations and some organ-specific complications of HIV (Puthanakit et al., 2007). Within Sub-Saharan Africa HAART has been

correlated with increased neurocognitive performance of individuals with HIV suggesting that medication should be provided for patients with HIV associated cognitive impairment (Sacktor et al., 2006). In Uganda where 31% of adults with HIV exhibit dementia, HAART medications were associated with improved performance on a test of executive function. However, the same medication was also associated with peripheral neurotoxicity suggesting the need for a less toxic therapy (Sacktor et al., 2009).

Less, however, is known about the impact of treatment on the cognitive functioning of children. The increasing availability of HAART along with the ability to treat associated infections, has made improved long-term survival a reality for many children with HIV/AIDS. These children, however, are now entering their school years and are exhibiting a higher incidence of neurological abnormalities than their peers (Wachsler-Felder & Golden, 2002). Given these neurologic and cognitive deficits, continued research is needed to identify the deficits and protective factors that can ensure a new generation of cognitively resilient survivors.

Developmental Implications

Cognitive Development

Children with HIV are at increased risk for developmental disabilities (Speigel & Bonwit, 2002). This is especially true for children infected via mother-to-child-transmission (MTCT), given that their central nervous systems are not fully developed when they contract the virus. Depending on the severity and progression of central nervous system involvement, children with HIV may present with impairments that are diffuse and pervasive, or impairments that are specific in nature (Armstrong, Seidel, & Swales, 1993; Knight, Mellings, Levenson, & Arpadi, 2000). Therefore, when assessing the cognitive functioning of children with HIV, it is imperative to examine both global (e.g., intelligence quotient) and specific (e.g., processing

speed, visual-spatial) domains of functioning.

In terms of language development, children with HIV tend to have difficulty with expressive language, although problems with both expressive and receptive language abilities may be present (Woodrich, Swerdlik, Chenneville, & Landau, 1999). Affected children may have decreased spontaneous and responsive vocalizations (Wachsler-Felder & Golden, 2002). More generalized language impairments center on limited verbal, emotional, and motor expression. In general, pediatric HIV compromises the acquisition of language and development of milestones. In school this may translate into the need for speech and language therapy in order to participate in and benefit from the educational setting (Papola, Alvarez, & Cohen, 1994). Further investigation is needed to identify consistent impairments that should be the target of early intervention.

Research on the cognitive functioning and academic achievement of school age children with vertically transmitted HIV has produced inconsistent results. Some studies report that by school age, IQ scores of children with HIV are in the low-average range compared to uninfected peers (Speigel & Bonwit, 2002). Papola, Alvarez, and Cohen (1994) found that over half of the school age children that they tested were in the borderline cognitively impaired range of intelligence. Furthermore, children with HIV experiencing neurological impairment and associated cognitive delays are believed to experience continued neurological deterioration into adolescence. Continued deterioration has been exhibited by the children with HIV/AIDS who have lost previously attained motor milestones (Landau & Pryor, 1995). Smith and colleagues (2006) collected data from 569 children across several demographic locations including sites within Massachusetts, New York, Texas, Puerto Rico, and Illinois. These researchers found results consistent with the previous studies reporting that children aged 3-7 years with HIV

infection scored significantly lower in all domains of cognitive development. This was only true, however, if the children had also exhibited an AIDS-defining illness. This data suggests that children are only at increased risk for poor cognitive outcomes if they have also had a severe illness associated with advanced stages of AIDS (Smith et al., 2006).

By medically treating and preventing rapid disease progression for children with vertically transmitted HIV, school age children may no longer exhibit cognitive deficits. There is still much to be learned about the resilient children with HIV who survive into school age without cognitive complications. Most of all it is important to understand cognitive functioning because of its association with quality of life and ultimately survival. In fact, cognitive impairment can substantially affect survival, with about a three-fold increased risk of death among children who are cognitively impaired (Zickler, 2009).

Cross-Cultural Consistency.

To understand the cultural and contextual impact of HIV on cognitive development some cross-cultural studies have been conducted. These studies provide important information on the cross-cultural consistency of neurocognitive development of individuals with HIV/AIDS. Similar impairments in abstraction/executive function, information processing speed, and learning have been found in China and the United States (Cysique et al., 2007). Yet in other studies including Nigerians with HIV infection, the patients exhibited a wide variety of neurological manifestations including cognitive impairment, peripheral neuropathy, and lower motor neuron facial palsy (Imam, 2007). This suggests that there are some similarities across cultures, but interestingly there are also differences. These differences in cognitive impairment may be due to other contextual factors and require further investigation. Identifying these contextual factors will allow for the appropriate supports for individuals with HIV/AIDS within

each unique cultural context.

Impact of Environmental Factors on Cognitive Development

The presence of the disease may not automatically lead to negative cognitive outcomes. Other environmental factors may play a role in the expressed cognitive ability of children with HIV/AIDS. Hochhauser and colleagues (2008), tested the hypothesis that children in conditions of high environmental risk would be at greater risk for the cognitive complications related to immunosuppression. They found that children in highly stressful environments are at particular risk for HIV-associated cognitive decline. Highly stressful environments are thought to negatively impact adherence to medication and conversely reduced environmental stressors may be neuroprotective (Hochhauser et al. 2008). Thus it is imperative to examine the cognitive abilities of school age children with HIV, and to do so in light of other environmental and contextual factors. Furthermore, identifying environmental factors that play a role in cognitive development provides a logical place to intervene. Although the ultimate goal is to prevent and eradicate HIV, when a child is infected one must also know how to intervene to prevent associated cognitive impairments through altering relevant and malleable environmental factors.

Psychosocial Development

Psychosocial adjustment is a multifaceted construct that refers to the mental health, or “a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity...” (U.S. Department of Health and Human Services, p.4, 1999). This construct has been used to understand the adaptive functioning of children. Children with HIV face many psychosocial consequences that are often exacerbated by frequent hospitalizations, poor social support, and poor performance in school. Some of the challenges faced by children with HIV include: the

loss of abilities, physical impairments, social rejection and isolation, and the fear of death (Landau & Pryor, 1995). Furthermore, there may be a connection between psychosocial adjustment and cognitive impairments. Carter et al. (2003) found that adults with HIV/AIDS who exhibited depression and medical symptoms also presented with increased cognitive complaints. Children with HIV/AIDS may exhibit this same relationship between depressive symptoms and cognitive deficits, although more research is needed to make this connection. One reason that it is important to understand this relationship is because the unique social stigma related to the disease may also lead to depression.

Given that the transmission of HIV is frequently associated with socially taboo behaviors, the disease carries a significant social stigma that evokes fear and discrimination towards these children. In Uganda where there has been an open HIV/AIDS awareness policy for over 20 years, the stigma is still high (Bateganya, Kyomuhendo, Jagwe-Wadda, & Opesen, 2008). Children and families must also deal with issues centering on disclosure of the medical condition, which can further perpetuate discrimination secondary to the disease (Wiener, Battles, & Heilman, 2000).

The cognitive, physical and social effects of HIV can contribute to infected children experiencing more subjective distress than uninfected children. This distress can manifest as dysphoria, hopelessness, preoccupation with the illness, and poor body image (Brown, Lourie, & Pao, 2000). These children can be prone to more anxiety and depression than uninfected children. Parents have also reported conduct and hyperactivity problems among infected children. In addition, children with HIV may also suffer from disruption in attention and concentration, and severe social withdrawal (Armstrong, Seidel, & Swales, 1993). In one study looking at the service needs of school-age children with HIV within the Bronx, 42% of children

were found to exhibit formal psychiatric diagnoses which included mood disorders (depression and anxiety), attention deficit hyperactivity disorder, and adjustment disorder (Papola, Alvarex, & Cohen, 1994). The authors of this study also found that as children grew older they tended to exhibit more problematic emotions and behaviors (Papola, Alvarex, & Cohen, 1994). However, these findings are not consistent throughout the literature, with many of the discrepancies explained by the population being studied. For example, one study conducted within the United States reported that children with HIV were found to be within normal limits for behavioral concerns when looked at over time, with behavior problems decreasing as the child aged (Franklin et al., 2007). Another study conducted within the United States that used care-giver reports of psychological adjustment concluded that there were no differences between the HIV and control groups with the exception of internalizing behavior problems that were actually exhibited by the control group (Bachanas et al. 2001). Within this study the variables that did make a difference when considering the psychosocial wellbeing of children with HIV/AIDS were stress, age, and coping strategies employed. Similarly, Mellins and colleagues (2003) in their study of 307 children with vertically transmitted HIV from several different geographical locations (Boston, New York, Chicago, San Juan (Puerto Rico), and Houston), did not find a link between HIV status and behavior problems. Demographic location was important in understanding behavioral problems however (Mellins et al., 2003). This finding highlights the need to consider behavior of children with HIV within the geographical context.

As evidence of the emotional impact of HIV on the Ugandan child, a study of Ugandan AIDS orphans in a rural district had higher levels of anxiety, depression, and anger than their non-orphan counterparts. Symptoms exhibited by the AIDS orphans that were indicative of clinical depressive disorder included: vegetative symptoms, feelings of hopelessness, and

suicidal ideation (Atwine, Cantor-Graae, & Bajunirwe, 2005).

Resiliency in the face of childhood HIV

The sociocultural context provides the framework for how children learn to think, speak, and behave. Thus, psychological adjustment originates through interpersonal interaction (Boyden & Mann, 2005). Boys' and girls' development can also be affected by the negative interactions that they have with their environment. Children's ability to recover in spite of these negative life circumstances has been described as "resiliency."

The term resiliency was coined in the health sciences from applied physics and engineering where it was used to simply describe the ability of materials to bounce back from stress to resume original shape and functioning. Applied in psychology it is understood to indicate an individual's ability to recover from, adapt, and remain strong in the face of adversity (Boyden & Mann, 2005, p. 6). Resiliency is a concept that changes the focus from dysfunction and disorder to a host of other contextual variables including exposure to stressful environments, individual characteristics, and social processes associated with psychosocial development (Ungar, 2008).

Joseph (1994) eloquently described resilience as,

“ the glue that keeps us functioning when we are confronted with life's misfortunes or challenges. It is the attitudes, coping behaviors, and personal strength that you see in people who manage adversity and adjust well to the changes demanded of them by their life circumstances. Resilience is the ability to bounce back from a bad or difficult situation (p. 25).”

Resiliency is thought of in terms of risk and protective factors. *Risk* refers to the variables encountered by or endured by the individual child that are associated with negative developmental outcomes and/or psychosocial maladjustment. *Protective factors* are the positive influences in a child's life that can come from within the individual or from the family, group, or society to which the child belongs. Risk and resilience are not constructed the same within all

societies. However, it is widely accepted that the development of boys and girls is dependent on the dynamic interplay between the risk and protective factors within their lives (Boyden, & Mann, 2005). It is this view of resiliency that transcends cultural and contextual differences when defining psychosocial adjustment of children living in adverse situations. Another reason the theory is useful is the natural connection that it has with intervention.

Focusing on the resiliency of children in diverse life circumstances can lead to and inform action (Ungar, 2008). The ability to identify and mitigate risk and promote protective factors in the life of a child is key to meaningful intervention (Boyden & Mann, 2005). There is a wealth of information on resilience and specifically the factors that protect children from the risks that they face. There is less information however guiding the conceptualization of children within resource poor regions of the world dealing with a chronic illness such as HIV. Liebenberg and Ungar (2008) point out that one challenge of resilience research is that positive outcomes change according to context and culture. Psychosocial adjustment in the face of an adverse condition such as HIV/AIDS can thus be thought of as the result of a “dynamic interplay of individual and social forces” (Liebenberg & Ungar, p.7, 2008). Fortunately, there has been international attention on interventions focused on the protection of children exposed to adversity (Boyden & Mann, 2005). However, there is still a need for research that carefully considers the reality of children’s lives in order to inform policy, and ultimately improve the effectiveness of interventions designed to assist them (Boyden & Mann, 2005). Some theoretical models have been developed to draw attention to important environmental factors and individual characteristics important in the conceptualization of resiliency in the face of HIV/AIDS.

Bachanas and colleagues (2001) used a model of stress and coping for predicting psychological adjustment in children with HIV. Their model was derived from the theory-driven

conceptual models developed by Thompson (1987), to guide research on children with chronic illnesses. The literature on chronic illness has recognized that increased technological ability to save lives through medical interventions has led to an increase in children living with chronic conditions (Thomas, 1987). Living with a chronic condition could have a negative impact on their psychosocial functioning, because prolonging life does not automatically mean that individuals are able to live quality lives. In fact, chronic illness can be conceptualized as a risk factor for psychological adjustment. Consequently there is a need to confront the quality of life issues faced by people living with chronic disease (Thompson & Gustafson, 1996). Ultimately we are called to better understand psychosocial adjustment and all of the dynamic factors contributing to it in order to promote resilience among children who are living with a chronic illness such as HIV/AIDS.

Stress and Coping Model for Predicting Psychological Adjustment in HIV-Infected Children

This stress and coping model was developed by Bachanas and colleagues (2001) to guide research in predicting the psychological adjustment in school-age children with HIV. The model seeks to understand all of the ecological factors that would contribute to the child's adjustment including: demographic parameters, caregiver characteristics, illness parameters, and child characteristics (See Figure 1).

The demographic parameters within Bachanas and colleagues' (2001) model of stress and coping include the child's age, gender, and family socioeconomic status. All of these measures have a direct impact on the child's adaptation process, which, in turn, influences the adjustment of the child. The importance of these parameters are set forth in the work of Bronfenbrenner (1979) and have had demonstrated continued importance within the developmental psychopathology conceptual framework (Masten, 2006). According to the framework,

demographic parameters are important to consider because throughout development children, as living systems, are continually interacting with the contexts in which they are a part. In this way typical development, and transversely, psychopathology, is due to the complex interactions between the systems that the child is a part of as well as between the child and the contexts in which the child is embedded (Masten, 2006). Consistent with Bachanas and colleagues' (2001) model, the contextual features that may play a role in the child's adjustment according to the developmental psychopathology literature include the child's age, gender, and family socioeconomic status. The child's age may determine the responsibilities and day-to-day tasks of that child, thus impacting expectations for typical development. The gender of the child, being male or female, is also a contextual variable that carries different expectations for behavior and typical adjustment. Living with a disease such as HIV/AIDS can thus have differing effects on children depending on gender. The family's resources and ability to meet the needs of the child as well as all of the family members is also important to consider as a factor impacting psychosocial adjustment. Any one of these demographic variables can serve as a risk or protective factor when considering child adjustment, and are all thought of as important pieces to consider within the larger model of stress and coping as it applies to children living with HIV.

Another variable considered important in the model of child adjustment is the caregiver. Caregiver characteristics are of key importance to the adjustment of the child. In their model of stress and coping Bachanas and colleagues (2001) focus on the caregiver adaptational process which consists of stress, coping strategies, and family functioning. These measures are important in conceptualizing the caregiver's adjustment which is thought to influence the child. The developmental psychopathology literature also stresses the importance of the caregiver. It also provides a framework for understanding how the child's adjustment is influenced by the

caregiver. According to the 'systems principal' within the developmental psychopathology literature children are thought of as social beings who are continually interacting with their families, peer groups, schools, and larger systems (Masten, 2006). Children are thought to be part of a co-dependent relationship in which they influence the regulation of others' behavior while at the same time being regulated by their relationships with others. This core principal of development also discusses the tendency to strive for consistency and the need to reorganize and transform as a result of changes to the status quo (Masten, 2006). The main point to derive from this theory is that children can influence a caregiver and then subsequently be influenced by his/her reactive behavior. Thus, the caregiver is an important variable to consider when examining child adjustment.

Within Uganda the AIDS epidemic has significantly affected the traditional caregiving system. Many children are orphaned and are then put in the care of a grandparent or alternative caregiver, which has been found to vary in quality. Research has clearly shown that positive outcomes are associated with the care of the biological mother. Thus, one important variable to consider is who the primary caregiver of the child is when trying to understand the protective qualities it can have on psychosocial adjustment.

The illness parameter is specified as the HIV status of the child. This can be defined as the presence or absence of the virus, and can also be extrapolated to mean the progression of the disease within the body. As the disease progresses there are more symptoms and difficulties experienced by the child. In fact by definition the category of disease is associated with the symptoms experienced by the child, with children in later stages presenting with more medical complications. Research on the best ways to measure disease progression supports the use of two different factors: CD4 cell count and Viral Load. These measures have been found to be the

best predictors of mortality in developed countries as well as Sub-Saharan Africa (Rouet et al., 2003). The illness is included in the model because it is thought of as a risk factor that is associated with negative outcomes. Children living with HIV, specifically those who are in advanced stages of the infection are thought to be at greatest risk for negative outcomes. Illness parameters, according to this model, are factors that may have a large impact on the overall adjustment of the child.

The final piece of the stress and coping model of child adjustment to consider is the characteristics of the child, or the personal qualities that he or she has. Child characteristics that are evaluated within Bachanas and colleagues' (2001) model are the adaptational processes including expectations and coping strategies. Expectations can be thought of as the health locus of control. This is the child's generalized expectations concerning where control over their health resides. The important coping strategies evaluated within the model are those that are palliative or adaptive. These characteristics may be dependent on the child's cognitive ability. Thus, an important child variable to consider when understanding the child's adaptational process is the child's cognitive functioning. Strong cognitive skills would aid in the coping process and be thought of as a protective factor whereas deficits in cognitive ability may be a risk for psychosocial maladjustment. This variable is an important part of the stress and coping model (Bachanas et al., 2001) and, conceptualized from the developmental psychopathology literature, exemplifies a core principal of developmental psychopathology labeled 'agency' (Masten, 2006). According to this principle, the child is an active agent in development who shows increasing independence with brain development and learning. Thus, understanding the child's ability to think and learn as they navigate their environment will be important in understanding the factors contributing to the overall psychosocial adjustment of the child.

Ultimately all of these variables feed into the outcome variable that the stress and coping model (Bachanas et al., 2001) strives to explain: child adjustment. The importance of each factor in the model is explained within the developmental psychopathology theoretical framework. Together they make clear the need to understand the psychosocial adjustment of children according to the context of which they are a part. The main components of Bachanas and colleagues' model fit into two systems of influence: the *caregiving context* composed of the caregiver and socioeconomic status, and *child illness parameters* composed of characteristics such as the disease progression and cognitive ability. These systems of influence can be used to identify contexts of psychosocial adjustment and ultimately promoting resiliency in the face of risks such and HIV/AIDS.

Understanding Psychosocial Adjustment

A child who is able to demonstrate positive social skills, psychological functioning, and is able to change to meet the demands of the environment would be considered well adjusted (Achenbach et al., 2008). Put another way, the absence of negative behaviors that are associated with negative outcomes, along with the presence of positive behaviors associated with positive outcomes would suggest psychosocial adjustment. Therefore, by understanding the child's behaviors and symptoms, one can make a judgment as to whether or not the child is well adjusted. One way to categorize the behaviors is by identifying those that would be considered internalizing versus those considered externalizing problems. Internalizing disorders reflect "problems within the self, such as anxiety, depression, somatic complaints without known medical cause, and withdrawal from social contacts" (Achenbach & Rescorla, 2007, p.93). Externalizing behaviors on the other hand are exemplified by conflicts with others and violations of expected behavior (Achenbach & Rescorla). This is a helpful way to identify children at high

risk for psychosocial maladjustment. However, understanding psychosocial adjustment according to internalizing and externalizing behaviors becomes even more meaningful when it is expressed as part of the unique environmental circumstances of the child.

Buchanas and colleagues' (2001) model of stress and coping, makes evident that child psychosocial adjustment can only be understood through the relationship that it has with other contextual/environmental factors in the child's life. There is limited data on how children within the resource poor region of Uganda are affected by all of these factors. The main contextual variables that lend themselves to be investigated in this unique context are the caregiving context and the child illness parameters. Examining these factors may provide insight on the role they play in the psychosocial development of schoolchildren in Uganda with HIV/AIDS.

Psychosocial Adjustment and The Caregiving Context

Primary caregiver. There is evidence to suggest that children infected with HIV who are living with a caregiver other than their biological mother demonstrate elevated internalizing behavior problems, presumably because of the mother's illness/death (Buchanas et al., 2001). In fact, researchers who failed to show internalizing behavior concerns or somatic complaints when using the CBCL as a measure of psychosocial well-being of children with HIV/AIDS speculated that this could be due to the fact that the children were all cared for by their biological parents (Franklin, Lim, & Havens, 2007). In other words none of the sample had lost their primary caregiver to the disease as is common in other resource poor regions such as Uganda. In a study conducted by Pelton and Forehand (2005) of 105 African American children from New Orleans age 6 to 11 years, the behavior of children whose parents were either living with HIV or had died of AIDS was observed. Relative to children who still had their parents, those who were orphaned exhibited significantly more Internalizing and Externalizing problems lasting more

than 2 years (Pelton & Forehand, 2005). Many children with HIV within the African context live with caregivers other than their parents. Within Uganda it is not uncommon for households to be headed by grandparents who have traditionally been the recipients of financial support from their adult children (Nyesigomwe, 2006). Though these alternative caregivers largely value their role in child rearing, they may not understand the importance of continued stringent medical care for the HIV infected children they are looking after (Jones, Sherman, & Varga, 2005) or may be unable to meet their needs because of advanced age and frail condition (Nyesigomwe, 2006).

Caregiving takes place within a social context and thus it cannot be appropriately studied without attention paid to the conditions of poverty that may compromise child outcomes (Dawes, Bray, & Van Der Merwe, 2007). The death of parents with HIV/AIDS and the subsequent taking-in of their children, often by grandparents, have exacerbated household poverty (Hodge, 2008) In South Africa, where the HIV/AIDS epidemic has been an ongoing struggle, caregiving has been recognized as a determining factor in psychosocial adjustment. If children receive quality care they are more likely to exhibit social and behavioral adjustment as well as intellectual achievement (Richter, Manegold, & Pather, 2004).

No matter who the primary caregiver of the child is, he/she has a role in the development and proper adjustment exhibited by the child. For example, psychological distress exhibited by the caregiver has a negative impact on the adjustment of the child, with the child exhibiting more internalizing behavior problems (Bachanas et al., 2001). This is a very important relationship to understand because, “despite real success in the fight against HIV infection, driven primarily by behavior change rather than treatment, (which remains only minimally accessible), the number of children orphaned by HIV/AIDS in Uganda is unlikely to decline until 15-20 years after the decline in HIV infections” (Hodge, 2008, p. 19). Therefore, continued examination of the

impact of the caregiver on the psychosocial resiliency of children living with HIV/AIDS is paramount.

Socioeconomic factors. One of the contextual variables that can have a large impact on the psychosocial wellbeing of children is Socioeconomic Status (SES). Researchers use SES in order to account for differences in resources between families. The measure is used to understand how people within a community compare in terms of monetary income, the ability to meet the basic needs of the family members, and the level of education. This measure is important because it is a contextual variable that has been shown to account for differences in performance, health, and overall well-being. Poverty has been established as a risk factor, associated with negative child outcomes especially for children under the age of 5 years, and those in extreme and enduring poverty (Owens & Shaw, 2003). Poverty has also been identified as one of the barriers preventing mothers from following through with care for their HIV-exposed infants in South Africa (Jones, Sherman, & Varga, 2005). Moreover, poverty has been found to impact adherence to daily drug regimens among HIV-infected children in Uganda (Bikaako-Kajura et al., 2006). Non Governmental Organizations (NGOs) in Uganda have put substantial effort into helping families improve their economic situation in the hopes that it will lead to benefits in other aspects of life. For example, loans are given to families to start farms and other businesses that can then sustain an improved quality of life. Although the benefits seem to be apparent, it is not clear what impact family SES has on the psychosocial adjustment and subsequent quality of life of a child living with HIV/AIDS. Thus, it is important to understand the SES differences within the population and how it impacts the psychosocial adjustment of children with HIV/AIDS.

Psychosocial Adjustment and Child Variables

Age. Studies looking at the correlation between age and the psychosocial wellbeing of children infected with HIV/AIDS have produced interesting results. Bachanas et al. (2001) collected measures of psychological adjustment of school age children infected with HIV through caregiver report and child-self report. In their study they found that age was a significant predictor of the children's self-reported psychological adjustment. Younger children were shown to exhibit poorer psychological adjustment, but even when the data were analyzed without the youngest children (6 and 7 years of age), age was still significantly correlated with scores of psychological adjustment (Bachanas et al., 2001).

Another study focusing on caregiver report of maladjustment found that children with vertically transmitted HIV exhibited significantly more behavioral concerns than would be expected. However, when considered over time there was a statistically significant decrease in aggressive behavior as the children grew older (Franklin, Lim, & Havens, 2005). Some hypotheses to explain this finding include: age may be a reflection of adjustment to the diagnosis of HIV, caregiver adjustment or the death of a parent, and entry into school (Franklin et al., 2005). Another hypothesis for differences in psychosocial adjustment based on age is the child's cognitive ability to cope with the stressor. Coping strategies can be seen as a function of age because as the child ages and develops more sophisticated cognitive abilities he/she is able to also employ more sophisticated forms of coping (Engel & Melamed, 2002). For example, older children are better able to manage their emotions using cognitive mediational control (Wertlieb et al., 1987). This is thought to be true because younger children are often less aware and unable to label internal emotional states. Younger children may not understand that they can regulate their

emotions and are unable to see this process modeled by others because of the internal nature of emotional regulation (Compas, Banez, Malcarne, & Worsham, 1991). Thus the experience that comes with age could lead to better coping and ultimately better psychosocial adjustment. However, further exploration is needed to understand the psychosocial adjustment of children with vertically transmitted HIV/AIDS at different ages, especially in resource poor areas.

Gender. There is limited research investigating the potential impact of gender on quality of life for individuals living with HIV/AIDS. Most of the research to date has been conducted with adults. The limited data points toward differences in quality of life between men and women with men reporting more positive feelings about their future (Chandra et al., 2008). Furthermore, men were more likely to report feeling content and having positive experiences (Chandra et al., 2008). Women living with HIV have been found to be more vulnerable to depressive symptomatology (Cook et al., 2002), show patterns of sleep impairment, and symptoms of anxiety (Junqueira, Bellucci, Rossini, & Reimao, 2008). In one large-scale study based in the United States differences in Health Related Quality of Life scores were collected throughout the course of treatment for HIV/AIDS of males and females. Females reported lower Health Related Quality of Life scores than males in all domains except social functioning at baseline, and had lower scores in all domains except overall health at 40 weeks of treatment (Mrus, Williams, Tsevat, Cohen, & Wu, 2005). However, men and women showed equivocal improvements over the course of treatment. Although it appears that men are able to adapt to the disease more readily than women, some studies have identified strengths that women demonstrate over their male counterparts when coping with HIV/AIDS. For example women have been reported to show strength in social functioning (Mrus et al., 2005), and score significantly higher than males on forgiveness scales, spirituality/religion, and personal beliefs domain (Chandra et al., 2008).

The way that males and females experience HIV infection can have implications for intervening to improve quality of life.

Moreover, inequalities in social capital in men and women may be important to consider. It is thought that social capital may influence the ability to access treatment for HIV. For example, a study in Namibia that investigated the relationship between social support networks and health found a link between social capital and greater HIV-related treatment efficacies (Smith, & Rimal, 2009). Further research is needed to see if girls and boys within resource poor nations living with HIV/AIDS are able to adjust in similar ways to their circumstances. If there are differences, they may help to identify gender as a protective factor and inform ways in which to intervene.

Academic Achievement of School Children with HIV/AIDS

One concern is that children with HIV would be too sick to attend school. This was not the case according to the research conducted by Cohen et al. (1997) in which only 3% of children with HIV/AIDS were unable to attend school due to illness. In a cohort of children from Philadelphia, two thirds of the children studied did not need to be hospitalized during the school year, however 23.5% had repeated at least one grade. (Mialky, Vegnoni, & Rutstein, 2001). This may indicate that even when children are able to attend school there are other reasons that they are having difficulty staying on track and achieving. Another way to investigate children's performance within school is to look at cognitive and academic achievement scores.

Within the United States studies have been conducted to understand if children with HIV have access to education and how they perform academically relative to their cognitive ability. Loveland et al. (2000) found that children with HIV had academic achievement scores below what would be expected based on their cognitive assessment scores. Blanchette et al. (2002)

found similar results, reporting that children with HIV had IQ scores within the average range but academic achievement scores in the low average range. More recently however Franklin et al. (2007) found that the sample of children they were working with exhibited academic achievement consistent with their cognitive ability scores. The authors hypothesized that their success could have been due to their sample of children who received antiretroviral medication and medical care in the context of their HIV program. The children in their study might have also exhibited these encouraging results due to positive parenting, the extra services that they received within school, and the focus placed on attendance and performance within school. Though encouraging, it is difficult to know if these same results can be found within the African context where resources are limited. Furthermore, it is important to try to identify some of the factors that were important in producing positive outcomes in order to provide them for more children with HIV/AIDS.

In order to better understand the deficits exhibited by HIV positive Ugandan school children, Bagenda and colleagues (2006) evaluated 28 HIV-infected children at about 8 years of age, and compared them to 37 HIV-negative children born to uninfected mothers (control children). Children were evaluated with cognitive and academic achievement tests, including the Kaufman Assessment Battery for Children (K-ABC) and the Wide Range Achievement Test-Third Edition (WRAT-3) along with measures of physical health (Bagenda et al., 2006). Results from this study showed that children with HIV had lower scores on health measures, more infections as a result of immuno-deficiency, and a greater incidence of developmental delay than unaffected children. Furthermore, the HIV positive Ugandan schoolchildren performed significantly worse on a sequential motor memory task (K-ABC Hand Movements), and had lower scores on spatial memory, though not significantly so. Finally, the HIV positive Ugandan

school-age children had significantly lower WRAT-3 reading ability scores than uninfected peers. These results though discouraging demand further investigation into the reasons for lower cognitive and reading ability scores. It could be possible that the lower scores are due to a mediating variable such as low socioeconomic status or psychosocial maladjustment.

Schooling within Uganda

Access to education and school performance can have a large influence on a child's developmental trajectory. Within Westernized societies and Uganda alike, there is a great deal of importance placed on education and school performance as a foundation for future success. Most people would agree that investing in the education of children would benefit their future, their well-being, and the success of the society as a whole. From a developmental perspective primary education is viewed as a tool that guides children's developmental trajectories toward higher education, higher paying jobs, and a higher quality of life. Within Uganda 82% of children are enrolled in primary school, making it the norm for children to receive an education (UNICEF, 2008). Unfortunately, there are some children who are unable to attend school. For many rural families, school fees, which cost around \$12 US dollars, are prohibitive (Whyte, 1998). Children with HIV/AIDS who are being raised by a caregiver other than their parent may face these same barriers to receiving an education. Many are denied education because the families that take in children/orphans cannot pay the school fees that would allow them to attend school in conjunction with the fees for their own children (Nyesigomwe, 2006).

When students are able to attend school their performance is generally very important to parents and caregivers who are frequently sent reports by the classroom teacher and head master of the school. Students' performance is numerically represented in each subject and as class rank (Whyte, 1998). The importance in Uganda placed on class rank is an example of the highly

competitive nature of their schools. Teachers believe that competition is essential in motivating students to perform, pushing intelligent and hard working students to be among the top of their class (Whyte, 1998). Thus, the teacher's appraisal of student performance in comparison to other students in the class is an important measure to look at when trying to understand if a child is participating and benefiting from education. Furthermore, this measure can logically be extrapolated to be a picture of how the child and caregiver view the student as a learner, and as a barometer of future school success.

Addressing the Needs of Children with HIV/AIDS in Uganda

In Uganda, about 1 million children are orphans with one or both parents dead due to HIV/AIDS. In fact, a new child is orphaned every 14 seconds in Uganda (Ronald & Sande, 2005). The number of children who are themselves infected with HIV is 110,000, most likely through MTCT (UNICEF, 2008). Fortunately, within Uganda the government has recognized pediatric HIV as a problem, and has allowed researchers and Non-Governmental Organizations (NGOs) to implement new programs addressing the needs of children inflicted with the disease. NGOs have been instrumental in providing care to resource poor regions such as Uganda. Globally, \$5 billion has been channeled through NGOs annually to areas of need including Uganda, which is more than all United Nations organizations combined have contributed (Chaplowe & Engo-Tjega, 2008). One organization that embodies a public health, ecological approach to providing services to children with HIV/AIDS is Childhealth Advocacy International. Children with HIV/AIDS and their families are provided a range of services to improve their well-being. They are provided with food if necessary, and are visited in their home once a month by a team that includes a nurse qualified in HIV counseling and trained in managing opportunistic infections in children with HIV/AIDS. The team also consists of a

medical doctor who provides medical advice, a social worker, and a nutritionist. During these monthly visits children are given treatment to prevent and treat infections, are given their antiretroviral medications (ARVs), and are counseled on adherence to the drug regimen. Counseling and Education is also provided to the caregivers (O'Hare et al., 2005), and appropriate household items like mattresses and mosquito nets are provided. Another important aspect of this organization is the importance they place on schooling for children with HIV/AIDS. All of the children enrolled in the program have their school fees paid for, and are also provided with school uniforms and books (Childhealth Advocacy International, 2008).

Evidence to date has strongly endorsed the need for this type of multidisciplinary treatment in order to facilitate comprehensive management of the medical, psychological and social needs of infected children and adolescents (Earls, Raviola, & Carlson, 2008). However, further research is needed to investigate how and if children who are being served by these organizations are exhibiting the expected positive effects. Furthermore there is a need for diligent data collection to examine the social and emotional needs of the specific population of children with HIV/AIDS. This information can inform the implementation of programs to target the risk and protective factors that promote psychosocial resilience.

Conclusions

Uganda has been hard hit by the AIDS epidemic that has spread throughout Sub-Saharan Africa. However, the heightened global awareness of the AIDS epidemic along with the willingness of the Ugandan government to openly talk about and tackle the problem has led to better medical treatment for the nearly one million afflicted individuals. NGOs have played a large role in providing medications for patients with HIV/AIDS and other accompanying illnesses (Chaplowe & Engo-Tjega, 2008). With the aid of new medications, children with

vertically transmitted HIV/AIDS are living longer. However with children surviving into the school years, the quality of life issues that they face must be examined. Theoretical models can aid in that examination. Bachanas and colleagues (2001) provide a model of stress and coping for children with vertically transmitted HIV/AIDS that helps to organize all the dynamic environmental and personal factors contributing to psychosocial adjustment. These factors fit into two systems of influence: caregiving context (the caregiver and socioeconomic conditions), and child illness parameters (the progression of the disease and the cognitive functioning of the child).

Children with HIV/AIDS may be affected by the caregiving context, and socioeconomic status of their caregiver. The caregiver's health in the first year of life can significantly predict the child's well-being (Nakiyingi et al., 2003). However, there is no research to date investigating the caregiver and socioeconomic conditions of children with HIV/AIDS within Uganda. This information is important to understanding the changing needs of children as they live longer with HIV/AIDS, and providing appropriate, time sensitive interventions.

Mixed results have been obtained on the cognitive functioning of children with vertically transmitted HIV/AIDS. Some researchers have found global and specific (ie., attention, and visual-spatial memory) cognitive deficits while others have reported typical cognitive development (Smith et al., 2006; Papola, Alvarez, & Cohen, 1994). These discrepancies seem to be the result of the populations studied, and the environmental risk factors that they face. More research is needed to understand how the cognitive functioning of children in Uganda is impacted by HIV/AIDS, and if there are factors such as socioeconomic status that are neuroprotective.

Research on the psychosocial adjustment of children with HIV/AIDS has shown that

having HIV/AIDS can be devastating, but there is also a potential for children to be well adjusted. Although some children experience major depression, attention deficit, and anxiety disorders (Misdrahi et al., 2004), other children exhibit normal psychological and social skills (Mellins et al., 2003). It is the resiliency of these children that necessitates further investigation in accord with the dynamic environmental and personal factors that may contribute. More specifically, these factors include the caregiving context (caregiver and socioeconomic status), and child illness parameters (disease progression and cognitive skills). This is an especially pertinent question in Uganda where over 100,000 children are inflicted with HIV/AIDS (UNAIDS, 2007), yet there is a lack of research to address the quality of life issues important to developing interventions.

Another variable important to quality of life is school achievement or the ability of the child to perform in school. School achievement in Uganda is thought to be essential in attaining success in later life. Teachers and caregivers place a great deal of importance on school rank, which is thought to be motivating to the students to compete for top spots in the class (Whyte, 1998). However, it is unknown how children with HIV will be able to perform in school. Some studies suggest that children may do poorly due to absence, illness, associated cognitive deficits, and attentional concerns (Mialky, Vegnoni, & Rutstein, 2001). However, it is unclear if these variables impact all children with HIV/AIDS or if there are some children who are able to overcome the barriers that they face to achieve school success.

The investigation of psychosocial adjustment and school performance will provide vital information in developing interventions to promote resiliency in the school-age children living with vertically transmitted HIV/AIDS within Uganda. In order to understand these child outcomes, the factors linked to them need to be investigated as well. Thus, in order to inform

research questions focusing on the factors contributing to psychosocial adjustment and school performance there first needs to be a better understanding of the caregiving context and child illness parameters. Thus, the following research questions are organized to first get a better understanding of the caregiving context, child illness parameters, psychosocial adjustment and school achievement, within the unique sample of Ugandan school children living with HIV/AIDS in Uganda. The answers to those research questions will then be used to inform analyses that investigate the link between the contextual factors and child outcomes.

Research Questions

1) Caregiving Context

Who is caring for children with HIV/AIDS at different ages and does SES matter?

It was hypothesized that children living with a caregiver other than their biological mother will be older and exhibit lower SES scores.

2) Child Illness Parameters

What is the effect of the illness on cognitive functioning and does SES matter?

It was hypothesized that as the disease progresses there are more cognitive deficits, so that children on medication would have significantly lower cognitive scores in all four areas (Sequential Processing, Simultaneous Processing, Learning, Planning) than children not yet taking medication. Medication status was used as a measure of disease progression with children who are on medication in the more advanced stages of the disease and children not yet on medication in a less advanced disease state. It was also hypothesized that SES played a role so that children with lower SES would exhibit lower cognitive scores.

3) Psychosocial Adjustment and School Achievement

3.1) Are there differences in psychosocial adjustment and school performance by gender or age?

It was hypothesized that female children would be less likely to have externalizing problems and that older children would be less likely to exhibit internalizing and externalizing problems than younger children.

3.2) Is there a relationship between psychosocial adjustment and school performance?

It was hypothesized that children who are better adjusted (exhibiting less internalizing and externalizing behavior concerns) would have higher school performance scores.

4) Factors contributing to Psychosocial Adjustment and School Performance

4.1) *Psychosocial Adjustment.* Do the Caregiving context and Child Illness Parameters predict psychosocial adjustment (Internalizing and Externalizing Behavior Problems) in school children with HIV/AIDS in Uganda?

It was hypothesized that both Caregiving context and Child Illness Parameters would predict psychosocial adjustment. Both Caregiver and Cognitive Scores were thought to play a role in Internalizing and Externalizing behaviors exhibited by the school children with HIV/AIDS in Uganda. It was thought that being cared for by a biological mother would be correlated with fewer Internalizing and Externalizing behaviors. It was also predicted that higher Cognitive Scores would be associated with less Internalizing and Externalizing behaviors.

4.2) *School Achievement.* Do the Caregiving context and Child Illness Parameters predict school performance in school children with HIV/AIDS in Uganda?

It was also hypothesized that both Caregiving context and Child Illness Parameters would

predict school performance. Better Cognitive Scores were hypothesized to be indicative of better school performance. Furthermore, the caregiver was also expected to be a strong predictor of how the child was performing in school. Being cared for by the biological mother was hypothesized to be correlated with higher school performance.

CHAPTER 3

Methods

This study was conducted as part of a larger research project conducted with Childhealth Advocacy International: *Cognitive Rehabilitation Training Intervention for HIV-infected Ugandan School Children*.

Research Partnering with Child Health Advocacy International: The Larger Study

The Cognitive Rehabilitation Training is an innovative program being piloted by Michael Boivin, Ph.D., from Michigan State University, and Paul Bangirana from Makerere University in Uganda, along with Dr. Bruno Giordani from the University of Michigan, and Opika Opoka and Margaret Nakakeeto who both work at Mulago Hospital in Kampala, Uganda.

The intervention attempted to directly treat cognitive deficits resulting from HIV infection in the children of sub-Saharan Africa, using computers, a technology that is becoming increasingly available. School age children with HIV are receiving cognitive rehabilitation training for an hour each week using Captain's Log® Cognitive Rehabilitation Training Program (CCRT) provided on laptop computers. CCRT is a comprehensive set of computerized programs which targets attention skills, visual motor skills, conceptual skills, and numeric concepts with memory skills (Captian's Log Brain Train, 2007). There were 60 children enrolled in the study, 30 of whom were randomly assigned to receive the treatment.

The Cognitive Rehabilitation Training Intervention in Uganda was in its piloting phase of the project and researchers monitored the effects using pre and post measures of cognitive ability. Specifically, the Kaufman Assessment Battery for Children-Second Edition (KABC-II), the CogState, and the visual and auditory versions of the Test of Variables of Attention (TOVA) were administered before the training, and at the conclusion of the 10-week training period.

Additionally, information on the socioeconomic status of the family, the child's school rank, and social emotional development were collected to examine the role of these variables. The neuropsychological and cognitive tests provide researchers with information on many different aspects of development including attention, memory, and language skills. If the children receiving the intervention make significantly more gains than their control counterparts it would enable CCRT to become an evidence-based treatment option to meet the educational needs of school-age HIV-affected children throughout Sub-Saharan Africa.

The Current Study

Participants

All of the children in the larger project were included in the current study. All data was collected prior to the implementation of the cognitive intervention. Children were recruited through Child Health Advocacy International (CAI), a non governmental organization (NGO) presently serving children with HIV and families in Kayunga District, a poor rural district about 80 km northeast of Kampala, Uganda. CAI was active in Kayunga for about 2 years before the beginning of the larger project. Recruitment in the CAI home healthcare program is done through the voluntary counseling and testing (VCT) outreach program to the communities throughout Kayunga District. CAI and the Kayunga District Hospital sponsor this free HIV testing service. School-age children with a CD4 percentage of less than 15%, or in Stage 3 with an HIV associated life-threatening illness, are eligible for HAART treatment through the HIV clinic at Kayunga Hospital. The care, however, is contingent on a caregiver who is willing to have the child commence ARV treatment and is committed to adherence to the strict regimen. Within the study 23 of the 60 children were receiving this medical support.

Children six to sixteen years of age with HIV/AIDS and enrolled in the CAI program

were eligible with parent or caregiver consent to participate in the study (See Appendix A and B). Only children who had been diagnosed in early childhood (i.e., prior to achieving sexual maturity) were eligible for enrollment, to ensure only the inclusion of children who contracted the virus from their parents. Children were excluded if they exhibited a medical history of serious birth complications, severe malnutrition, bacterial meningitis, encephalitis, cerebral malaria, or other known brain injury or disorder requiring hospitalization or continued evidence of seizure or other neurological disability. This was screened using a brief medical history questionnaire (See Appendix C), and CAI medical chart review. None of the children recruited for the study were excluded due to these criteria.

The participants consisted of 60 children (36 female and 24 male) ranging in age from 6 to 16, median age = 9.8 years. The primary caregivers varied with 17 (28%) of the children being raised by the biological mother, 24 (40%) by a grandmother, and 19 children (32%) were raised by someone else including uncles, sisters, and other distant relatives. About 40% of children 6 years and older in the CAI home healthcare program are on Antiretroviral Therapy (ART). In the study sample, 37 children (61.7%) were not on ART while 23 children (38.3%) were on the medication. Treatment was provided by the CAI home healthcare program and free medications were supplied by the Makerere University-Walter Reed Project (MUWRP) in Kayunga through support from the US-AID PEPFAR initiative (President's Emergency Plan for AIDS Relief). CAI also provides school fees for children who are enrolled in the program, but only 45 of the 60 children participating in this study were attending school.

Variables and Instruments

Measures collected include: Child Behavior Checklist (CBCL), Kaufman Assessment Battery for Children-Second Edition (KABC-2), Socioeconomic Status, Disease Progression,

School Rank, and Caregiver Information.

Child Behavior Checklist for children 6-18 years (CBCL). Social emotional wellness was measured using the CBCL 6-18 years. The Child Behavior Checklist (CBCL) is a tool by which parents/caregivers rate a child's problem behaviors and competencies. This instrument was administered through an interview format in the local language. The CBCL probes eight specific areas of functioning in order to identify syndromes including: *Anxious/Depressed, Withdrawn/Depressed, Somatic Complaints, Social Problems, Thought Problems, Attention Problems, Rule-Breaking Behavior, and Aggressive Behavior*. Three of these syndrome scales are combined to yield a composite score for a child's internalizing behaviors compared to same age peers. This internalizing score is composed of the *Anxious/Depressed, Withdrawn/Depressed, and Somatic Complaints* scales. Two scales are combined to yield a composite score for a child's Externalizing behaviors. The Externalizing score is composed of *Aggressive Behavior and Rule-Breaking Behavior* scales. An overall score for Total Behaviors combines scores for Internalizing, Externalizing, the other three syndromes (*Social Behavior Problems, Thought Problems, and Attention Problems*), and the other problems that are not on any of the scales. This score provides an indication of the overall functioning of a child compared to his or her age-mates within the standardization sample.

Extensive research on this tool has shown inter-interviewer and test-retest reliabilities to be high, with correlations of .93 to 1.00 (Achenbach & Rescorla, 2007a). Internal consistency for the empirically based problem scales ranged from alphas of .78 to .97 on the CBCL. This tool is thought to be appropriate due to the multicultural nature of the standardization, and the ability to use it with reliability across cultures (Achenbach et al., 2008). The Achenbach assessments have been translated into more than 75 languages and have been used in thousands of published

studies in over 65 societies (Berube & Achenbach, 2007). These data have been used to develop a multicultural supplement which allows users to compare children's scale scores with normative samples from various societies (Achenbach, & Rescorla, 2007b). For this study the normative data from Ethiopia (sub-Saharan Africa) is used to derive standard scores and determine if the children are in the clinical range. The CBCL has also been used in the research of medical conditions, specifically being used in HIV research (Berube & Achenbach, 2007). For this study the CBCL was translated and back-translated with the assistance of a child psychologist from Mulago Hospital in Kampala, Uganda (See Appendix D). The questions were typed for the caregiver to read along in both Luganda (Appendix B) and English (Appendix A) which was the preferred written language because English is taught within the education system in Uganda. Thus, most caregivers were more comfortable reading English than Luganda.

Kaufman Assessment Battery for Children – Second Edition (Kaufman & Kaufman, 2004).

The Kaufman Assessment Battery for Children- Second Edition (KABC-2) is based on both the Cattell-Horn-Carroll (CHC) psychometric model of broad and narrow abilities and Luria's neuropsychological theory of processing. For this study Luria's neuropsychological approach was used in order to look at Sequential Processing, Simultaneous Processing, Learning and Planning. This approach also allows for more interpretable results than the CHC approach when trying to assess brain injury from infectious disease (John, et al., 2009; Boivin et al., 1995). Furthermore, Luria's theory focuses on mental processing and deemphasizes acquired knowledge. In fact the theory considers acquired knowledge (language proficiency or general information) to lie outside the realm of mental processing (Kaufman, & Kaufman, 2004). The CHC approach was not used because Crystallized Intelligence could not easily be interpreted with the population studied and the Fluid Intelligence construct is controversial in cross-cultural

intelligence research.

Kaufman and Kaufman (2004) provide a vast amount of information on the reliability and validity of their test. Internal consistency for the core subtests ranged from .60 to .95 across age groups. Reliability coefficients for factor indexes ranged from .81 to .95. Test-retest reliability for subsets varied by age, ranging from .53 (Block Counting) to .88 (Expressive Vocabulary) for 7-12 year olds, and ranging from .60 (Hand Movements) to .92 (Expressive Vocabulary) for 13-16 year olds (Bain & Gray, 2008).

The KABC-2 was chosen for this study because it is a comprehensive assessment of cognitive ability that has been adapted and validated in other studies in diverse populations to assess the effects of infectious diseases on cognition (i.e., Bagenda et al., 2006; Boivin, 2002; Boivin et al., 1995, Boivin et al., 2007; Boivin, & Giorani, 1993). The measure has demonstrated good construct and predictive validity in these applications (Giordani et al., 1996). A recent study of 65 Ugandan children aged 7 to 16 years with a history of Cerebral Malaria was carried out to determine the construct validity of the KABC-2 in this population (Bangirana et al., 2009). The study found that the KABC-2 subtests designed to measure Learning, Simultaneous Processing, Sequential Processing and Planning did in fact measure these abilities (Bangirana et al., 2009). The authors concluded that the KABC-2 can be a valid tool for assessing cognitive function in at risk children in sub-Saharan Africa (Bangirana et al., 2009).

For this study there were 9 subtests of the KABC-2 administered to all participants. These subtests were used to look at four areas of cognitive functioning: Sequential Processing, Simultaneous Processing, Planning and Learning. Subtests used to measure sequential processing include: Number Recall, and Word Order. Simultaneous Processing was assessed using Block Counting, Rover, and Triangles. The Planning score was made up of scores from

Pattern Reasoning, and Story Completion. Finally Learning was derived from two different subtests: Atlantis, and Rebus. For a description of each subtest administered and the facet of cognitive ability that it measures please see Table 1. For this study all four of the areas of cognitive functioning were used in the analysis because SES and gender may have differing effects on Sequential Learning, Simultaneous Learning, Planning and Learning. The KABC-2 data does not have normative data for the population studied, thus it is being used as a comparative within-group measure and not a normative measure of intellectual functioning.

Adaptation of assessment battery into local languages and test administration. All assessment instructions and items were adapted to the local language with the assistance of Paul Bangirana. He was educated in Kampala and is familiar with the various groups and language we encountered in project recruitment and assessments. Tests were administered by two native Luganda speakers, one trained as a counselor and the other trained as a school teacher, who are also fluent in English. Each test administrator received intensive training in the administration of the KABC-II at Mulago Hospital as part of a research project on Cerebral Malaria, observing test administration, practicing question scoring, and becoming familiar with the manual. Before the study began test administrators completed a practice test with a child from Kayunga district that was observed and critiqued. During the research study test administration was supervised by a school psychology doctoral candidate trained in standardized test administration. Test protocols were checked over by the administrator of the test, then by the colleague not administering the test and finally by the doctoral candidate to check for accuracy and consistency of administration.

Socioeconomic Status (SES). SES takes into account an individual or family's economic and social position within a society relative to others. The measure used for this study was

developed by researchers at Mulago hospital in Kampala, Uganda who are familiar with the quality of home environments in Kayunga. The questionnaire was developed to get an idea of the resources available within the home for the child living with HIV/AIDS (see Appendix E). Specifically, the measure focused on the access to resources and asked questions to assess what type of home they live in, if they have year round access to food and if so what type, and finally what possessions, that are seen as status symbols with the district, the family owns. There are numerical values assigned to the answer for each question. The values are assigned so that possessions, ways of living, and food eaten that represent higher SES status are numerically higher. The measure allows SES to be quantified so that the higher the number a family receives (based on caregiver response to each question), the more possessions, better quality of food and everyday quality of life they would experience. The mean SES score for this population is 8.82 with a Standard Deviation of 3.4. In this sample the range is between 5 and 20.

Disease Progression. All children that were part of the study underwent a 5 ml blood draw at the local hospital, within one week of testing, in order to evaluate the child's HIV status as well as the progression of the disease. The blood draw was conducted once, at Mulago Hospital Walter Reed Project Viral Research Unit in Kampala according to previously published procedures (Kiwanuka, Laeyendecker, Robb, Kigozi, Arroyo, & McCutchan, et al., 2008). Within this study, children who are in advanced stages of the disease are on HAART, children in earlier stages according to their blood draws are not yet taking medication. Thus, in this sample of children one of the best ways to understand disease progression is by their medication status. Furthermore, children can be easily separated into two groups based on their medication status, which has been decided by doctors at Mulago Hospital based on their CD4 T-cell counts and viral load. Within the sample there were 23 children on medication (38.3%), while the other 37

children (61.9%) are not yet on the treatment.

School Performance. All of the children within the study had access to schooling because CAI paid for their school fees, uniforms and books. In Uganda, all of the children attending school are given a class rank, a number that compares their performance to the performance of their classmates as assessed by the classroom teacher. Using class rank allows researchers to see how the children are doing in school as compared to their classmates without HIV/AIDS. For the purposes of this study children were put into 4 categories of school performance based on their class rank: 1) Not attending school, 2) Below average, 3) average, 4) above average.

Procedures

Children were recruited during monthly home visits by the Childhealth Advocacy International team in Kayunga district. Caregivers who agreed to participate in the study were given a day and time to bring their child to the branch office of CAI in Kayunga. The branch office was seen as an ideal place because of the community's view of the office as a safe place to receive services and support. The office was not seen as a place where only people with HIV visited thus it did not carry the same stigma as the hospital and would not prevent families from participating. Once arriving at the office caregivers completed a consent form (see Appendix A) before assessments were completed with the child. Once consent was obtained the child was taken into a separate room to begin testing while the caregiver completed the CBCL and Socioeconomic Status form with an interviewer/test administrator. Children were seated at a table and accompanied the entire time by a test administrator. Before beginning the tests with the children they were asked if they wanted to participate in the research study by completing the testing (See Appendix F). The computerized cognitive training offered as part of the larger study was incentive for children to participate. Children were also given a questionnaire to assess if

the child was healthy enough to complete the testing, or if they needed any type of medical care at the time. If the child gave assent by signing or giving their thumb print, and was deemed healthy enough for testing, the testing procedure began. During testing children were given breaks if they appeared to be fatiguing. All of the children were also given juice and biscuits during breaks in testing or at the completion of testing. At the end of testing children were given a small toy and returned to their caregiver. The caregiver and child were reimbursed for transportation costs to and from the office in the amount of 5,000 Ugandan Shillings (approximately \$2.50 in U.S. currency), which was assessed by the CAI team to be the average cost of public transportation from most places within the district to the branch office.

Chapter 4

RESULTS

The data for the current study were collected as part of a larger project implementing a computer based program to address cognitive deficits for children with HIV/AIDS in Uganda. This study focused specifically on the quality of life issues for these children, and examined the Caregiving Context as well as the Child Illness Parameters leading to better outcomes. The demographic characteristics (age, gender, SES, and Primary caregiver) of the 60 children who participated in the study are displayed in Table 2. The number of children in the study by gender and age are represented in Figure 3 by a histogram. Sixty percent of the participants in the study were female. Most participants across the entire sample were 11 years or younger. There was a disproportionate number of females younger than 8 years of age, with far more females than males.

There were similar numbers of males and females with average and higher SES, however, there were more females than males in the lower SES group. Children with average SES were equally distributed among all types of caregivers. Among children with lower SES, the largest number were being cared for by a grandmother. Children in the highest SES group lived with a caregiver other than their mother or grandmother. Most children performing Below Average or Not Attending School exhibited lower SES.

Research Question 1, Caregiving Context: Who is caring for children with HIV/AIDS at different ages and does SES matter?

As shown in Table 2, 28% of the children are cared for by their biological mother. Most children are cared for by a grandmother (40%), followed by a relative other than their mother (32%). A similar pattern of caregivers was found for girls and boys. The caregivers for children

at different ages varied however, with children more likely to be cared for by their biological mothers at younger ages and by a grandmother or other relatives at older ages (See Figure 4). To examine if the child's age and SES predicted the likelihood of children living with either their mother or another caregiver, a direct logistic regression was employed. The full model containing both Age and SES as independent variables was not statistically significant, $\chi^2(2, N=59) = 5.06, p = .079$, indicating that the model could not distinguish between children who were cared for by their biological mother versus another caregiver (See Table 2).

Research Question 2, Child Illness Parameters: What is the effect of the illness on cognitive functioning and does SES matter?

Child Illness Parameters were investigated using a multivariate analysis of covariance (MANCOVA). It was hypothesized that as the disease progresses there are more cognitive deficits, so that children on medication would have significantly lower cognitive scores in all four areas (Sequential Processing, Simultaneous Processing, Learning, Planning) than children not yet taking medication. Medication status was used as a measure of disease progression with children who are on medication in the more advanced stages of the disease and children not yet on medication in a less advanced disease state. It was also hypothesized that SES played a role so that children with lower SES would exhibit lower cognitive scores. The Socioeconomic status of children was entered into the MANCOVA as a covariate to examine the influence of this variable on cognitive scores. KABC-II scores in all four areas of functioning were used as the continuous dependent variables within the equation. Instead of using United States norms, the raw scores for each KABC-II subtest were adjusted to account for differences in age of the participants. Specifically, raw scores were checked for normal distribution to make sure all of the assumptions in regression models were satisfied. The linear relationship between age and

each subtest was then established in order to fit a linear regression, and obtain Studentized residuals. The Studentized residuals were used because they are scaled and therefore follow a standard normal distribution when linear regression model assumptions are roughly met, and are often preferred to ordinary residuals (Kutner, Nachtsheim, Neter, Li, 2004). The resulting Studentized residuals were used to calculate the four KABC-II scale scores (Sequential Processing, Simultaneous Processing, Learning, and Planning). The Studentized residuals for the subtest that make up the scale score were added together, and the sum was then divided by the square root of the number of subtests added. Each subtest contributed equally to the scale score.

Sequential Processing= (Studentized Residual of Number Recall + Studentized Residual of Word Order) / $\sqrt{2}$

Simultaneous Processing= (Studentized Residual of Block Counting + Studentized Residual of Rover + Studentized Residual of Triangles) / $\sqrt{3}$

Learning= (Studentized Residual of Atlantis + Studentized Residual of Rebus) / $\sqrt{2}$

Planning= (Studentized Residual of Pattern Reasoning + Studentized Residual of Story Completion) / $\sqrt{2}$

For each scale score a higher score indicated higher cognitive functioning. Table 3 shows the means and standard deviations for each scale score (Sequential Processing, Simultaneous Processing, Learning, and Planning). This MANCOVA provides information on the effect of Disease Progression, and SES on Cognitive scores, and also provides information about the relationship between the independent variables.

As predicted, there was a statistically significant multivariate effect for SES, $F(4,53)=4.88, p=.002$; Wilks Lamda= .73; Partial eta squared=.27. Follow-up univariate tests

revealed a significant main effect for SES on Learning ($p < .001$), and Planning ($p = .002$), indicating that SES had an effect on children's Learning and Planning ability scales as measured with the KABC-II. However, SES did not have the same effect on Simultaneous ($p = .031$) and Sequential Processing ($p = .107$).

Contrary to prediction, the multivariate main effect for medication group was not significant, $F(4,53) = .461$, $p = .764$; Wilks Lambda = .97; Partial eta squared = .034. There was no difference in cognitive scores based on the child's disease progression as measured by medication use.

Research Question 3, Psychosocial Adjustment and School Performance: Are there differences in psychosocial adjustment and school performance by gender or age, and is there a relationship between psychosocial adjustment and school performance?

The psychosocial adjustment was calculated using the Ethiopian (sub-Saharan) norms provided within the multicultural supplement to the Manual for the Child Behavior Checklist (Achenbach & Rescorla, 2007b). A MANCOVA was used to assess the differences in internalizing, and externalizing problems from the Child Behavior Checklist (checking first for multicollinearity of these variables) and school performance by gender and age, and to understand the relationship between psychosocial adjustment and school performance. Gender (2) and School Performance (4) were entered in the model as factors. Age was a covariate in the model. The dependent variables were internalizing and externalizing behavior problems. Preliminary checks were conducted to ensure that there was no violation of the assumptions of normality, linearity, homogeneity of variance, homogeneity of regression of slopes, and reliable measurement of the covariate.

There were no notable differences in respondents across the School Performance groups. There were equal numbers of grandmothers across groups. Mothers made up half of the caregivers within the below average group. There were only 2 mothers reporting in the group of children not attending school, and in the above average group. Within the group of children not attending school the largest group of reporters were Other Caregivers. Other Caregivers were represented in all other School Performance Groups.

None of the main effects for externalizing behaviors were significant with the following results: School Performance: $F(3,49)=1.59$, $p=.204$; Gender: $F(1,49)=.105$, $p=.747$. As seen in Table 4, after adjusting for age there was a significant interaction effect (School performance and Gender) for externalizing behaviors: $F(1,49)=4.38$, $p=.008$, using a Bonferroni adjusted alpha level of .017, (partial eta squared=.21). These results suggest that males and females have different externalizing behavior scores based on their school performance (see Figure 5, Figure 5.1, and Figure 5.2). Males who are not in school tend to have higher externalizing problems than those who are performing in the below average or average range. For males attending school, there is a trend for externalizing behavior problems to be higher than those performing at lower levels in school. Males with above average school performance had the highest average externalizing behavior problems, which was in the borderline range. Conversely, externalizing behavior problems among females tended to decrease with higher levels of performance in school. Females in the above average performance group had the lowest average externalizing behavior concerns.

Contrary to predictions, none of the main effects for internalizing behaviors were significant, School Performance: $F(3,49)=1.67$, $p=.185$; Gender: $F(1,49)=2.815$, $p=.1$; Age: $F(1,49)=.045$, $p=.833$. The interaction effect for internalizing behaviors did not reach

significance using a Bonferroni adjusted alpha level of .017, $F(3,49)= 2.978$, $p=.04$ (See Figure 6, Figure 6.1, and Figure 6.2).

Research Question 4, Factors Contributing to Psychosocial Adjustment and School

Performance: Do Caregiving context and Child Illness Parameters predict Psychosocial Adjustment (Internalizing and Externalizing Behavior Problems) and School Performance in school children with HIV/AIDS in Uganda?

Psychosocial Adjustment. The CBCL was completed for 58 children in the study. Data were missing for two children, but appeared to be random. Using the CBCL multicultural norms for sub-Saharan Africa resulted in eight children (14%) scoring in the borderline range for Internalizing behaviors, 5 males and 3 females. Eleven (19%) of the children, 5 males and 6 females, scored in the clinical range for Internalizing behaviors (See Table 4). Four children (7%), equal numbers of boys and girls, were in the borderline range, for Externalizing behaviors. Eleven children (19%) were in the clinical range, including 4 males and 7 females. As seen in Table 5, on the Total Behavior Problems Scale, 14% of the children obtained scores in the borderline range (2 males and 6 females) and 14% in the clinical range (3 males and 5 females).

In order to understand what factors were contributing to psychosocial adjustment 2 separate multiple regressions were conducted, one for internalizing behaviors and another for externalizing behaviors. Cognitive functioning was deemed an important factor to include as a predictor variable from the analyses on child illness parameters. It is thought to be an important indicator of the child's disease state, and was more sensitive than medication in previous analyses. A total cognitive score served as the predictor variable representing an important aspect of child illness parameters. The other predictor variable is the Caregiver, representing an important aspect of the caregiving context. Age was not added into the equation because it was

found to be the strongest predictor of caregiver. Similarly, SES was not included due to its relationship with cognitive outcomes as found in the analyses on child illness parameters. Using these variables (cognitive score and caregiver) preliminary checks for multicollinearity revealed that the assumption was met, and there were no other violations in assumptions detected using the Normal Probability of the Regression Standardized Residual and a Scatter plot of the data. Mahalanobis distance was checked using a critical value based on the number of independent variables, and did not detect outliers within the data. The multiple regression for externalizing behaviors revealed that the overall model was not statistically significant: $F(2, 55) = 2.85, p = .067$ (See Table 6).

The model for internalizing behaviors was significant $(2,55) F = 3.12, p = .048$. Caregiver and Cognitive Score explained 10% of the variance in internalizing behaviors. Cognitive score explained the largest amount of variance, $\beta = .318, p = .016$. Using the semipartial correlation coefficients almost all (10%) of the total variance in internalizing behaviors was uniquely explained by cognitive score. Caregiver only accounted for .4% of the variance in the model (See Table 7). Thus, the child's cognitive score had a significant unique contribution to the prediction of internalizing behaviors. Children with higher cognitive functioning had fewer internalizing behavior problems.

School Performance. School Performance was first examined by transforming class rank into a percentile rank. Percentile rank was then split into four categories of analysis: 1) not attending school ($n=15$); 2) below average, a percentile rank of 1 to 40 ($n=18$); 3) average, a percentile rank of 41 to 60 ($n=14$); 4) above average, a percentile rank of 61 to 100 ($n=13$). The four categories were formed in order to include the group of children who are not attending school. Most children who were not attending school were less than 8 years of age. Children

ages 9-14 were more likely to be attending school than their younger or older counterparts. Only 50% of the 15 and 16 year olds were attending school.

A logistic regression with a multinomial set of procedures was then used. The dependent variable was School Rank, and the predictor variables were Caregiver and Cognitive Scores. The model was significant, $\chi^2 (9, n=60) = 22.63, p=.007$, thus the null hypothesis was rejected and at least one of the predictors was significantly related to the school performance. The model as a whole explained between 31.4% (Cox and Snell) and 33.6% (Nagelkerke R squared) of the variance in School Performance. The likelihood ratio test of individual parameters show that Caregiver was not a significant factor in the model, $\chi^2 (6, n=60)=7.68, p=.263$, however, Cognitive Score was a significant factor, $\chi^2 (3, n=60)= 14.75, p=.002$. Using children in the ‘above average’ group as a reference, Cognitive Scores were significant for the group of children not attending school ($p=.002$), and for those in the below average performance group ($p = .015$). The odds ratio for cognitive scores of children not attending school is .427 (See Table 7). This indicates that as the Cognitive Score of children decreases by one, the odds of being in the *not attending school group* increases by a factor of .427. Similarly, for children in the below average group, as the Cognitive Score decreases by 1 point the odds of being in the below average group rather than in the above average group changes by a factor of .542 (See Table 8). Thus, as cognitive scores increase the probability of not attending school or being in the below average performance group decreased.

Chapter 5

DISCUSSION

The purpose of this study was to examine the nature and predictors of the quality of life of children with vertically transmitted HIV/AIDS in Uganda. It is important to first understand the characteristics and developmental context of children with HIV/AIDS. Of note is the resilience of children who are surviving well beyond the point of transmission. In this sample of children 6–16 years of age there was a decrease in children 12 years and older participating in the research with the fewest participants in the 14-16 year age range. These data are challenging to interpret because length of life may not reflect disease progression, but instead reflect the quality of care they have received in the community throughout their lives. At the time of the study CAI had been involved in the region for about 2 years, meaning that none of the children in the study had received care in the critical first few years of their lives. Thus, this group of children may be a robust group of survivors. Furthermore, the numbers of children in each age group may reflect access to and enrollment in CAI (where they would receive medical care and emotional support) rather than being indicative of the age to which children are surviving.

Although there is not a clear reason for the disparity in gender, the majority of children in the study were female. It may be that more females were identified to participate or more females survive to age 6 than males. The discrepancy may just be representative of the children within the region studied, and may mean that there is an imbalance in children who have contracted the disease. More research is needed to confirm these hypotheses. In order to understand the population studied, progression of the virus was also examined.

The child disease progression revealed that the disease had not progressed to critical levels in most of the children. The majority, 62% of the children within the sample were not yet

on medication due to sufficient CD4 cell count and low Viral Load. This is a surprising finding as these children are at least 6 years old and have had the HIV virus since birth. These results suggest a certain degree of resilience characterizing these children, who are literally, survivors, successfully living with HIV/AIDS and sufficiently healthy to not require medication. Though medically resilient, a psychosocial measure was also administered to understand adjustment.

Using the sub-Saharan norms on the CBCL (Achenbach, & Rescorla, 2007b) one third of children in the sample demonstrated internalizing behavior problems (either in the borderline or clinical range as compared to same age peers). These findings were consistent with a study of Ugandan AIDS orphans in a rural district that also exhibited high levels of anxiety, depression, and anger (Atwine, Cantor-Graae, & Bajunirwe, 2005). Over a quarter (26%) of children exhibited problematic externalizing behavior concerns. Total behavior problems were of concern in 28% of the population. These findings are lower than the 42% of children with psychiatric dysfunction found by Papola, Alvares, and Cohen (1994) in a study of children with HIV in the Bronx, however, these findings also demonstrate that a large portion of children were exhibiting behaviors of concern that confirms the need for further investigation.

Schooling also plays an important role in childhood quality of life, and thus this aspect of the developmental context was investigated further. The majority of children with HIV/AIDS in the study attended school. Although school fees were paid for, 25% of children did not attend school. Previously it was thought that cost was one of the largest barriers to attending school for children with HIV/AIDS in Uganda (Nyesigomwe, 2006; Whyte, 1998). This substantial proportion of children not attending school without the burden of school fees suggests that there are other reasons why they are unable to benefit from an education. Of the students who attend

school, 45% are performing in the average to above average range. Outside of school, the caregiving context also affects the child.

An examination of the caregiving context revealed that the large majority of children (72%) were cared for by a relative other than their mother. There were only 17 children (28%) who were cared for by their biological mother. Most of the children with HIV in this region of Uganda were cared for by a grandmother (40%). Within the African context it has become common for households to be headed by grandparents (Nyesigomwe, 2006). None of the children within the sample were without a caregiver during the data collection. The results of the logistical regression provided partial support for the hypothesis that the younger the children were, the more likely they were to be living with their biological mother, controlling for SES. As they grew older, they were more likely to be living with another relative. Contrary to the hypothesis, SES was not significantly related to the caretaker. This change in caregiver may be due to the length of time their mother has lived with HIV/AIDS, with those who have had the disease the longest succumbing to the virus. The older children will have been more likely to have lost their mother to the disease and will thus need to be taken in and cared for by another caregiver. Including younger children (prior to age 6) may have made this trend more apparent.

Research Question 1: Caregiving Context

In trying to understand the caregiving context it was hypothesized that children would be older and have lower SES when living with a caregiver besides their biological mother. This was only partially substantiated with the data. There was not a difference between those children being cared for by their mother or another caregiver (grandmother or other). However, within the model, age was the strongest predictor of caregiver. The older children were, the longer their mother has had HIV/AIDS and thus the likelihood of her passing away or being too ill to care for

her children is increased. Contrary to prediction SES did not decrease as children aged. These socioeconomic results are reassuring because they demonstrate that children within the sample were not worse off financially once their mother is no longer able to take care of them. It has long been documented that the taking-in of children has exacerbated household poverty (Hodge, 2008), and that poverty has been found to impact adherence to daily drug regimens among HIV-infected children in Uganda (Bikaako-Kajura, et al., 2006). Within our sample children are not facing worse financial hardship once they are placed with another caretaker. The financial stability of families in the study may also be due to the involvement of CAI. The extra assistance that the program is able to provide may boost the family's SES and thus there is not a disparity as was expected.

Research Question 2: Child Illness Parameters

It is important to understand the effect of SES and disease progression on the cognitive functioning of children within the sample. In the sample of children studied those who were on medication, and in a more advanced disease state did not exhibit lower cognitive functioning in any of the domains examined (Sequential Processing, Simultaneous Processing, Planning and Learning). These results support the importance of medications, and the potentially neuroprotective role that they may play in children. Several adult studies within sub-Saharan Africa found that the use of medications was correlated with increased neurocognitive performance, and improved performance on a test of executive function (Sacktor et al., 2006; Sacktor et al., 2009). The results from this sample of children demonstrate that medications may contribute to cognitive resiliency, as well as their medical well-being. However, many studies gauging the neuropsychological benefit of medications found that medication alone is not sufficient to reverse the inevitable neurocognitive decline that accompanies HIV/AIDS

(Koekkoek, de Sonnevle, Wolfs, Licht, & Greelen, 2008; Shanbhag et al., 2005). Thus, another explanation for the cognitive resilience of children in more advanced disease states is that they are a robust survivor group. Because medical intervention was only provided through CAI within the two years before the collection of this data, the children studied may also represent those with a less aggressive form of the disease. Another explanation for the stability in cognitive function may be the measure used for disease progression. Although being on medication represents a CD4 count and Viral Load that is more advanced, using the actual numbers from the blood draws may have produced more accurate results.

As hypothesized, SES did have an effect on the cognitive functioning (Planning, Learning, Simultaneous processing, and Sequential processing) of children, accounting for 27% of the variance. Children with HIV are at increased risk for developmental disabilities (Speigel & Bonwit, 2002), and those who have fewer resources (lower SES) may be in even greater jeopardy of exhibiting cognitive deficits. These results are consistent with the research of Hochhauser and colleagues (2008), in which they found that children in highly stressful environments are at particular risk for HIV-associated cognitive decline. Conversely, focusing on the children with the highest cognitive functioning revealed that higher SES may contribute to their cognitive resiliency.

Of the domains examined, there were two domains of cognitive functioning significantly associated with SES: Learning and Planning. Learning was measured with the Atlantis and Rebus subtests on the KABC-2. These subtests assess the ability to learn new information. The learning construct emphasizes attention and concentration, the coding and storage of information and requires participants to generate strategies to learn and retain new information (Kaufman, & Kaufman, 2004). The Planning construct was measured using Pattern Reasoning and Story

Completion. These subtests look at nonverbal reasoning and planning skills as well as hypothesis testing. As a domain Planning is thought to assess high-level decision making and executive functioning processes (Kaufman, & Kaufman, 2004). Both Learning and Planning are extremely important to the children's everyday functioning, and children who have higher SES are performing better than their peers who have fewer resources. As all of the children within the study were involved with Child Health Advocacy International and were receiving some resources, the effect of SES may be even more profound within the general population. Thus, interventions need to be focused on improving children's access to resources.

Research Question 3: Psychosocial Adjustment and School Achievement

The results show that there is not a clear relationship between internalizing behavior problems, externalizing behavior problems and School Performance, Gender or Age. Thus, females are not less likely to have externalizing problems nor are older children less likely to exhibit internalizing and externalizing problems, as was hypothesized, but this was qualified by an interaction between School Performance and Gender as noted below. This is departs from the results found by Bachanas et al. (2001) in which age was a significant predictor of the children's self-reported psychological adjustment. These results also disconfirms the hypothesis that age may be a reflection of adjustment to the diagnosis of HIV, caregiver adjustment or the death of a parent, and entry into school (Franklin, Lim, & Havens, 2005).

According to these results the hypothesis that differences in psychosocial adjustment correspond to age was not supported. It has been postulated that with increased age comes increased cognitive ability which allows children to employ more sophisticated forms of coping as he or she ages (Engel & Melamed, 2002; Franklin et al., 2005). Instead there may be a more complicated relationship between psychosocial adjustment and within child factors. Although

age is not correlated with internalizing or externalizing behaviors, perhaps cognitive ability is the mediating variable that needs to be looked at in closer detail.

The results do not support previous conclusions that females with HIV are more vulnerable to depressive symptomatology (Cook et al., 2002), or show symptoms of anxiety (Junqueira, Bellucci, Roccini, & Reimao, 2008). In fact, there was no significant difference between males and females in internalizing or externalizing behaviors. These results may suggest that males and females are equally capable of coping with the disease. The data also exemplifies the complexity of the relationship between these factors, showing that males and females have different externalizing behavior scores based on their school performance. More specifically, males who are not in school tended to have higher externalizing behavior problems than those who are performing in the below average or average range at school. It is unclear why these males are not attending school, however it could be related to the behavior difficulties that they are exhibiting or the lack of socialization may exacerbate negative behaviors. Surprisingly, there is a trend for the externalizing behaviors of males to increase with their performance in school. Males who performed in the above average group exhibited more problems than any other group. In fact males in the above average performance group were in the borderline range for externalizing behavior problems. Females showed a much different pattern of externalizing behavior problems. There was very little difference in the externalizing behavior concerns of females not attending school, those in the lowest performance group and those in the average performance group, however, females in the highest performance group exhibited the least externalizing behavior concerns. The differences in externalizing behaviors for males and females may be due to gender expectations. It may be more socially acceptable for males to exhibit externalizing behaviors, with the smartest and perhaps most popular boys exhibiting the

most behaviors. The opposite trend may be true for females, and those that are the performing well in school also know that socially it would be unacceptable for them to exhibit the kind of externalizing behaviors measured by the CBCL.

Research Question 4: Factors Contributing to Psychosocial Adjustment and School Achievement

Psychosocial Adjustment. Externalizing and Internalizing behaviors were considered separately in the analyses and revealed differing results. Cognitive Scores did not significantly contribute to the externalizing behaviors exhibited by the children with HIV/AIDS in Uganda. However, the caregiver did make a statistically significant unique contribution to the equation. Thus, children who were being cared for by their mothers versus a grandmother or other caregiver had different externalizing behavior scores. Children being raised by someone other than a grandmother or mother had the highest externalizing behavior scores, followed by those being cared for by their mother. Children being cared for by their grandmothers had the lowest average externalizing behavior concerns. These results were unexpected and show the complexity of the caregiving context. Children who were still with their biological mother had been predicted to show the fewest externalizing behavioral concerns, however if their mother was sick and unable to provide adequate care, the children may be acting out more. Furthermore, the group of children with their grandmothers exhibited the fewest behavior concerns. This may be due to the grandmother's involvement from the time the child was young, leading to a more secure attachment with their caregiver. It will take further investigation to understand the benefits of having a grandmother as the primary caregiver, but it can be thought of as a protective factor leading to desirable outcomes.

The model for understanding predictors of internalizing behavior revealed that caregiver and cognitive scores were associated with these problems. Children's cognitive scores were the best predictor of internalizing behavior problems. These results may be showing that when children have the ability to employ more sophisticated coping strategies based on their cognitive capabilities, they demonstrate fewer internalizing behavior concerns. These results are consistent with theorists who postulate that psychosocial adjustment is based on the child's cognitive ability to cope with the stressor (Engel, & Melamed, 2002; Wertlieb et al., 1987).

School Performance. The school performance of children within the sample of children with HIV living in Uganda was correlated with their cognitive scores as measured by the KABC-2. Children with higher cognitive scores were more likely to be doing well in school. Conversely, there was a distinct difference in the cognitive ability of those children who were not attending school and those in the lowest performance group as compared to those children in the above average performance group. Regardless of who was caring for the child, the child's cognitive ability score was the greatest predictor of school performance. These results are consistent with those found by Franklin et al. (2007) in which children with HIV/AIDS exhibited academic achievement in line with their cognitive ability scores.

Conclusions

In Uganda the AIDS epidemic has infected over 100,000 children (UNAIDS, 2007), yet there is a lack of research studying their quality of life and factors important in the development of meaningful interventions. The aim of this study was to examine the psychosocial and academic outcomes of those children with vertically transmitted HIV/AIDS surviving into the school years within Uganda. Bachanas and colleagues (2001) model of stress and coping for children with HIV/AIDS helped to organize the dynamic environmental and personal factors

contributing to child outcomes. Specifically the Caregiving Context and Child Illness Parameters were examined to better understand internalizing and externalizing behavior problems, as well as school performance.

Prior to this study, there was no research investigating the caregiver and socioeconomic conditions of children with HIV/AIDS in Uganda. This study revealed that there was not a clear relationship between age, SES and Caregiver. When looking at the child illness parameters, it was discovered that as children's SES increased so did their cognitive scores regardless of whether or not their infection had progressed to a stage where they needed to take medication. Although more investigation is necessary, socioeconomic status may be neuroprotective, or a protective factor for children with HIV/AIDS in Uganda. Furthermore, because there was no difference in cognitive performance for children on medication and those not yet in need of medication. The medication itself may be playing an important role in curbing the detrimental effects of the virus on the brain. Another explanation however is that this sample of children are robust survivors who may have a less aggressive form of the disease.

The majority of children exhibited positive psychosocial adjustment with about half performing in the average to above average range in school as compared to their same age typically developing peers. Cognitive functioning was found to be related to Internalizing behaviors and School Performance, with higher cognitive functioning associated with fewer internalizing behaviors and higher school performance. Socioeconomic status was found to be associated with Cognitive functioning. Thus, there is an intricate interweaving of factors from the caregiving context and child illness parameters contributing to these outcomes. Socioeconomic status is correlated with Cognitive Functioning, and higher Cognitive Functioning is related to fewer internalizing behavior problems and better school outcomes.

School performance, externalizing behaviors and gender have a complex relationship in which gender may mediate the relationship between Externalizing behaviors and School Performance. The caregiving context may influence externalizing behaviors. Although only a trend within the data, caregiver was the strongest predictor of externalizing behavior problems. All of the outcome variables researched are influenced by both the caregiving context and child illness parameters. Specifically, SES was found to have an effect on cognitive functioning. Cognitive functioning as well as caregiver had an effect on the outcome variables: child psychosocial adjustment and school performance (See Figure 7.). In planning for meaningful intervention for children with HIV/AIDS within Uganda, both caregiving context (SES and Caregiver) and child illness parameters (cognitive functioning) need to be taken into consideration. Medication has long been the focus of intervention, and results show that there may be some benefit to taking medication once CD4 Cell Count and Viral Load indicate their use. However more focus needs to be given to cognitive performance, which played a large role in the child outcome measures of interest. Thus, when targeting the well-being of children in Uganda living with HIV/AIDS organizations need to look beyond medical intervention and include social programs that focus on the Caregiver and Cognitive Functioning of the child.

Future Research

Results from this study support the evidence to date which strongly endorses multidisciplinary treatment to facilitate comprehensive management of the medical, psychological and social needs of infected children and adolescents (Earls, Raviola, & Carlson, 2008). However, more research is needed to understand the relationships found in this study. Research using path analyses to understand the intricate connections found in this research will be important to clarify the causal relationships between these variables. Future research should

also aim to collect more information about the wellbeing and health of the primary caregiver, the coping strategies used by caregivers, and the quality of the relationship with the caregiver. In this research, although it is clear that the primary caregiver is important to the child's well-being it is not clear why there are differences among caregivers. Understanding these caregiver characteristics may inform the intervention, as most of the time placement of the child is beyond the control of the helping organization.

Future research should also focus on developing cognitive skills, like the research being done by Boivin and colleagues (2010), that seeks to produce neuropsychological benefits for Ugandan children with HIV using a computerized cognitive rehabilitation. Because of the effect that cognitive skills have shown to have on important outcome measures such as internalizing behaviors and school performance, interventions that are feasible and beneficial to children's cognition need to be one focus of future research and intervention.

Limitations

One of the most important limitations of the study is the recognition that these findings reflect a particular cultural context in Uganda and this research was conducted from a Western perspective. The research questions and methods for answering them were developed by a student who is not part of Ugandan culture. To address this, individuals who were a part of the culture were involved in the design of the study. Although cultural awareness was an important aspect of study design, there is a risk that the results will not be accurate due to different cultural expectations and interpretations.

Another limitation of this study is the number of children for whom data were collected. A larger sample of children would provide more statistical power, and allow for more robust conclusions. Furthermore the study would have been stronger if there had been a control group.

Children matched for demographic characteristics, perhaps a sibling from the same home environment without HIV/AIDS would allow for the identification of characteristics unique to the population of school age children with HIV/AIDS. Without having a control group of typically developing children within the region, it is not possible to draw conclusions about the effects of HIV/AIDS. It may be that all children in the region are exhibiting the same difficulties due to other contextual factors. Furthermore, because the same children may have been a robust sample of survivors it is difficult to understand if and how the virus was impacting their lives.

One other limitation of the assessment measures was the use of only the CBCL to measure psychosocial adjustment. Although used in many different cultures, the CBCL has not been standardized with the unique population of children from Kayunga, Uganda for which it is being utilized in this study. Another limitation is that it relied on the caregiver's perception of the child's behavior, which may be different from the child's perception. The caregiver may also have a different perception of the child based on the relationship with the child. Future studies should aim to collect data from multiple informants including the child, and the classroom teacher.

Another limitation to recognize is the potential difference in treatment throughout the life of the child. The oldest children would have needed care before Child Health Advocacy International was present in Kayunga. Thus, some children may have received excellent medical treatment, whereas others who could not afford to go to the hospital would have gone without treatment. For the past few years that the NGO has operated out of Kayunga the care that children received has been consistent and equitable. However, there most likely has been some variation in medical treatment between children at earlier stages in their life. The study is limited because researchers are unable to control for differences in medical interventions from

the time of birth, which may have had an impact on the overall health of the child.

This study is also limited in that the data are from one point in time. Data from one time point can provide a good snapshot of child adjustment and cognitive functioning, however it is just a static and single picture. Future longitudinal studies, collecting data over multiple points of time will be important to truly understand the developmental trajectories of schoolchildren with vertically transmitted HIV/AIDS within Uganda.

Research such as this on the quality of life of schoolchildren with HIV/AIDS will continue to be important. Identifying the risk and protective factors is just the first step in helping to improve the care provided to thousands of children in this resource poor region of sub-Saharan Africa. Focusing on the caregiving context has the potential to drastically improve the adjustment of children living with HIV/AIDS. Furthermore, cognitive resiliency should also be a goal of intervention for nations and organizations that continue to address this epidemic.

Table 1. *Description of KABC-II subtests administered*

Scale	Subtest	Description /What it measures
Sequential Processing	Number Recall	Child repeats a series of numbers in the same sequence the examiner said them. Measures sequential processing and short-term memory.
	Word Order	The child touches a series of silhouettes of common objects in the same order as the examiner said the names of the objects. Measures sequential processing and short-term memory.
Simultaneous Processing	Block Counting	The child counts the exact number of blocks in various pictures of stacks of blocks. The stacks are configured such that one or more blocks is hidden or partially hidden from view. Measures visualization of objects in 3-dimensions.
	Rover	The child moves a toy dog to a bone on a checkerboard-like grid that contains obstacles (rocks and weeds) and tries to find the quickest path i.e. the one that takes the fewest moves. Measures visual processing
	Triangles	For most items, the child assembles several identical foam triangles (blue on one side, yellow on the other) to match a picture of an abstract design. For easier items, the child assembles a set of colorful plastic shapes to match a model constructed by the examiner or shown on the easel. Measures visual ability and spatial relationships.
Planning	Pattern Reasoning	The child is shown a series of stimuli that form a logical, linear pattern, but one stimulus is missing. The child completes the pattern by selecting the correct stimulus from an array of 4 to 6 options at the bottom of the page. Measures nonverbal reasoning skills and hypothesis testing.
	Story Completion	The child is shown a row of pictures that tell a story, but some of the pictures are missing. The child is given a set of pictures, selects only the ones that are needed to complete the story and places the missing pictures in their correct locations. Measures nonverbal planning or reasoning skills.

Table 1 (Cont'd). *Description of KABC-II subtests administered*

Learning	Atlantis	The examiner teaches the child nonsense names for fanciful pictures of fish, plants and shells. The child demonstrates learning by pointing to each picture (out of an array of pictures) when it is named. Measures the ability to learn new information, specifically the association between pictures and nonsense names.
	Rebus	The examiner teaches the child the word or concept associated with each particular rebus (drawing) and the child then “reads” aloud phrases and sentences composed of these rebuses. Measures ability to learn new information.

Table 2. *Demographic Characteristics*

<i>Age in Years</i>	<i>Gender</i>		<i>Disease Progression</i>		<i>Caregiver</i>		
	Male	Female	On ART	Not on ART	Other	Mother	Grand-mother
6-8	5	17	8	14	7	9	6
9-11	11	10	8	13	4	6	11
12-14	6	7	5	8	6	2	5
15-16	2	2	2	2	2	0	2
Total(60)	24(40%)	36(60%)	23(38%)	37(62%)	19(32%)	17(28%)	24 (40%)
SES Groups							
Low	14	24	13	25	9	12	17
Med	9	9	7	11	6	5	7
High	1	2	3	0	3	0	0
Total(59)	24(40%)	35(60%)	23(38%)	36(62%)	18(30%)	17(29%)	24(41%)

Table 2 (cont'd). *Demographic Characteristics*

	<i>School Performance</i>			
<i>Age in Years</i>	<i>Above Average</i>	<i>Average</i>	<i>Below</i>	<i>Not Attending</i>
6-8	2	3	6	11
9-11	6	8	6	1
12-14	4	3	5	1
15-16	1	0	1	2
Total(60)	13(22%)	14(23%)	18(30%)	15 (25%)
<i>SES Groups</i>				
Low	9	5	13	11
Med	2	8	5	3
High	2	1	0	0
Total(59)	13(22%)	14(24%)	18(30%)	14(24%)

Represented in Number of Children per Group

Table 3. *Logistic Regression Predicting Likelihood of being Cared for by Mother*

							95% C.I. for EXP(B)	
	B	S.E	Wald	Df	Sig.	Exp(B)	Lower	Upper
Age	-.246	.123	3.967	1	.046	.782	.614	.996
SES	-.004	.102	.002	1	.966	.996	.815	1.216
Constant	1.465	1.229	1.421	1	.233	4.328		

Table 4. Means and Standard Deviations of KABC-II scores by Medication Status

Medication Status			Statistic
Learning	Not on Medication	Mean	.0092
		Std. Deviation	1.25767
		Minimum	-3.30
		Maximum	3.72
		Range	7.02
	On Medication	Mean	-.0226
		Std. Deviation	1.43201
		Minimum	-2.01
		Maximum	3.00
		Range	5.02
Planning	Not on Medication	Mean	.0538
		Std. Deviation	1.29297
		Minimum	-2.46
		Maximum	5.08
		Range	7.54
	On Medication	Mean	-.0872
		Std. Deviation	1.00917
		Minimum	-1.56
		Maximum	2.16
		Range	3.71
Sequential Processing	Not on Medication	Mean	-.0515
		Std. Deviation	1.34146
		Minimum	-3.97
		Maximum	3.15
		Range	7.12
	On Medication	Mean	.0738
		Std. Deviation	1.04730
		Minimum	-2.43
		Maximum	1.64
		Range	4.07

Table 4 (cont'd). *Means and Standard Deviations of KABC-II scores by Medication Status*

Simultaneous Processing	Not on Medication	Mean	-0.0205
		Std. Deviation	1.49412
		Minimum	-4.54
		Maximum	3.85
		Range	8.39
	On Medication	Mean	.0238
		Std. Deviation	1.55540
		Minimum	-3.18
		Maximum	3.21
		Range	6.39

Table 5. *Test of Between-Subjects Effects to assess psychosocial adjustment and school performance by gender and age*

	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	Internal	1211.36	8	151.42	2.23	.041	.267
	External	960.35	8	120.04	2.06	.058	.252
Intercept	Internal	11023.58	1	11023.58	162.4	.000	.768
	External	10778.47	1	10778.47	184.97	.000	.791
Age	Internal	3.05	1	3.05	.045	.833	.001
	External	4.58	1	4.58	.079	.780	.002
School Group	Internal	340.68	3	113.56	1.63	.185	.093
	External	277.89	3	92.63	1.59	.204	.089
Gender	Internal	191.09	1	191.09	2.82	.100	.054
	External	6.11	1	6.11	.105	.747	.002
SchoolPerform * Gender	Internal	606.17	3	202.06	2.98	.040	.154
	External	765.6	3	255.2	4.38	.008	.211
Error	Internal	3326.23	49	67.88			
	External	2855.05	49	58.27			
Total	Internal	181752	58				
	External	176963	58				
Corrected Total	Internal	4537.57	57				
	External	3815.4	57				

Table 6. Behavior Concerns by Age and Gender

	Internalizing Behaviors			Externalizing Behaviors		
AGE	Normal	Borderline	Clinical	Normal	Borderline	Clinical
6-8	16	2	2	13	1	6
9-11	10	5	6	17	1	3
12-14	10	1	2	10	1	2
15-16	3	0	1	3	1	0
Gender						
Male	14	5	5	17	2	4
Female	25	3	6	26	2	7

	Total Problem Behaviors		
AGE	Normal	Borderline	Clinical
6-8	15	3	2
9-11	14	3	4
12-14	10	2	1
15-16	3	0	1
Gender			
Male	18	2	3
Female	24	6	5

Table 7. *Nominal Regression to Assess Variables Contributing to Externalizing Behaviors*

Model	Standardized Coefficients	t	Sig.
	Beta		
Constant		34.078	.000
Caregiver	-.305	-2.372	.021
SRTotalCog1	-.027	-.207	.837

Table 8. *Nominal Regression to Assess Variables Contributing to Internalizing Behaviors*

Model	Standardized Coefficients	t	Sig.
	Beta		
Constant		30.462	.000
Caregiver	-.066	-.520	.605
Cognitive Score	.318	2.488	.016

Table 9. *Parameter Estimates of Variables Contributing to School Performance with the Above Average Performance Group as the Reference Category*

School Performance Group*		B	Std. Error	Wald	df	Sig.	Exp(B)
Not Attending School	Intercept	.088	.613	.021	1	.886	
	CogScore	-.851	.280	9.229	1	.002	.427
	Mother	.611	.973	.394	1	.530	1.842
	Grandmother	.228	1.316	.030	1	.863	1.256
	Other	0**			0		
Below Average School Performance	Intercept	.147	.600	.060	1	.806	
	CogScore	-.613	.252	5.920	1	.015	.542
	Mother	-.023	1.022	.000	1	.982	.978
	Grandmother	1.858	1.119	2.758	1	.097	6.413
	Other	0**			0		
Average School Performance	Intercept	.146	.593	.061	1	.805	
	CogScore	-.405	.236	2.933	1	.087	.667
	Mother	.232	.953	.060	1	.807	1.262
	Grandmother	1.092	1.153	.898	1	.343	2.982
	Other	0**			0		

*The reference group is Above Average School Performance

**This parameter is set to zero because it is redundant

Figure 1. *Stress and Coping model for predicting psychosocial adjustment in HIV-infected children (Buchanas et al., 2001).*

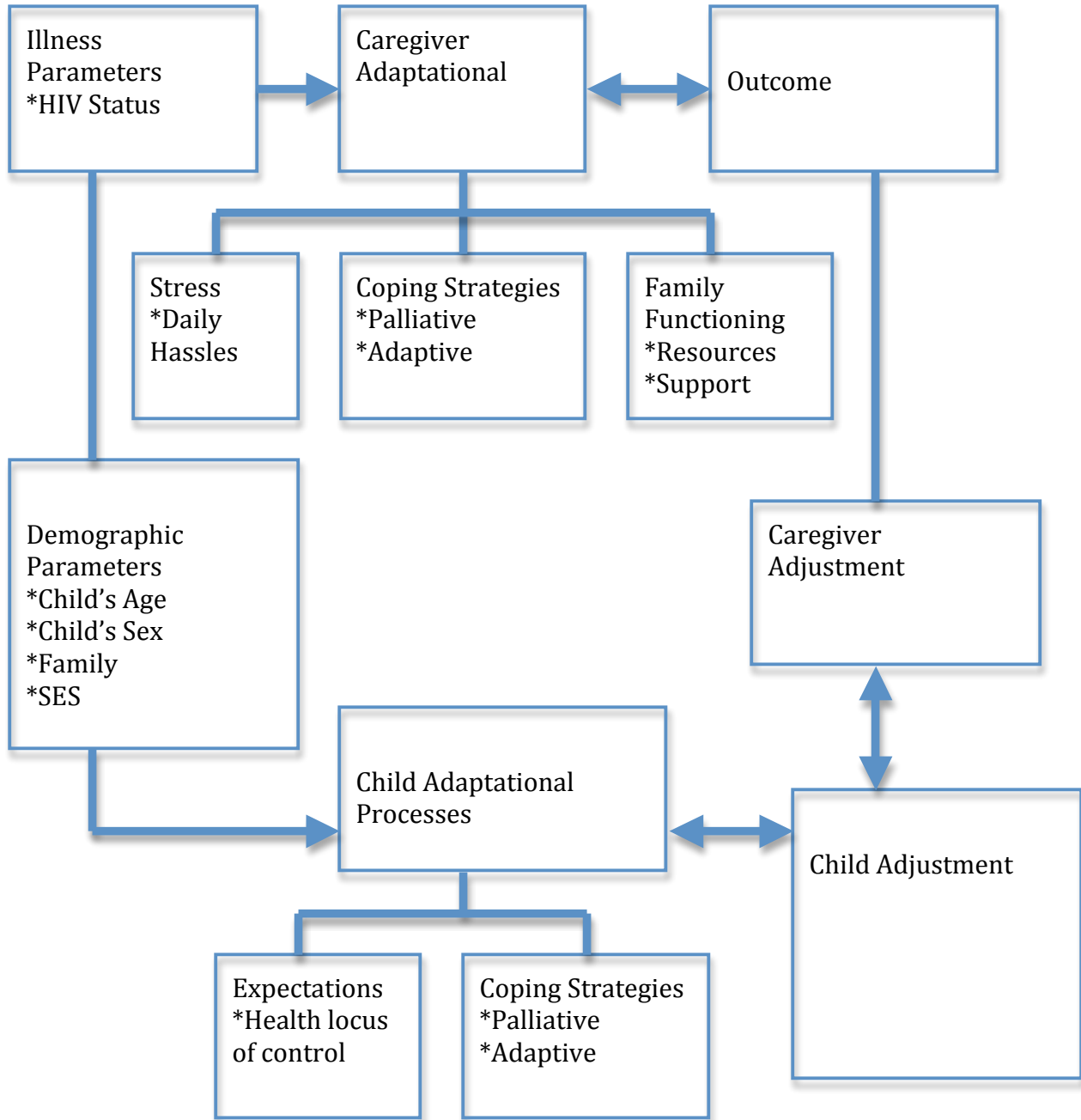


Figure 2. *Immunologic Category Definitions Based on the CD4 count and/or percentage*

	Age of Child					
	<12 months		1-5 years		6-12 years	
Immunologic Category	μ L	(%)	μ L	(%)	μ L	(%)
1) No evidence of suppression	\geq 1,500	(\geq 25)	\geq 1,000	(\geq 25)	\geq 500	(\geq 25)
2) Evidence of moderate suppression	750-1,499	(15-24)	500-999	(15-24)	200-499	(15-24)
3) Severe Suppression	<750	(<15)	<500	(<15)	<200	(<15)

*If the CD4+ percent indicate different classification categories, the child should be classified into the more severe category.

Figure 3. *Histogram of Children by Gender and Age*

For interpretation of the references to color in this and all other figures, the reader is referred to the electronic version of this dissertation.

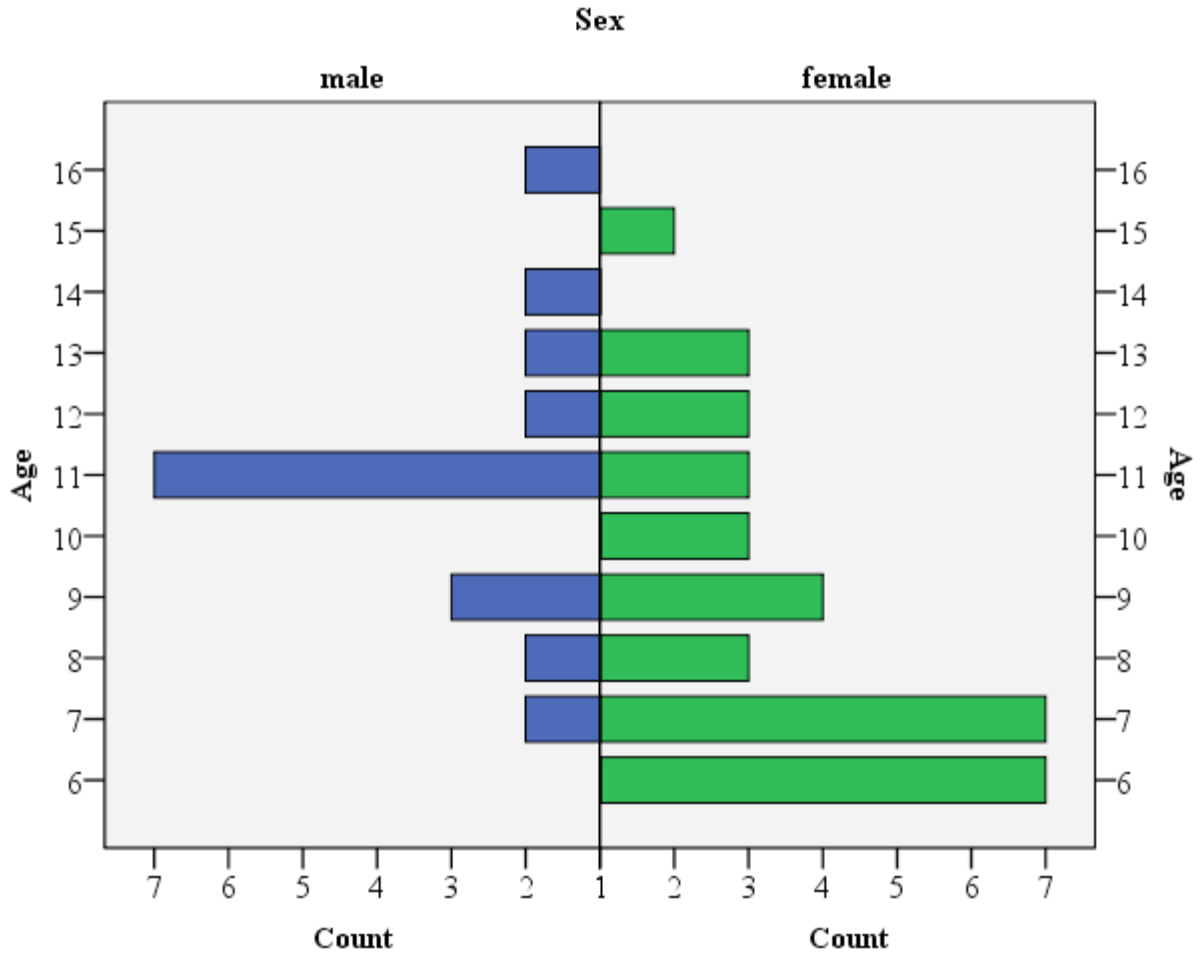


Figure 4. Histogram of the Number of Children by Caregiver and Age

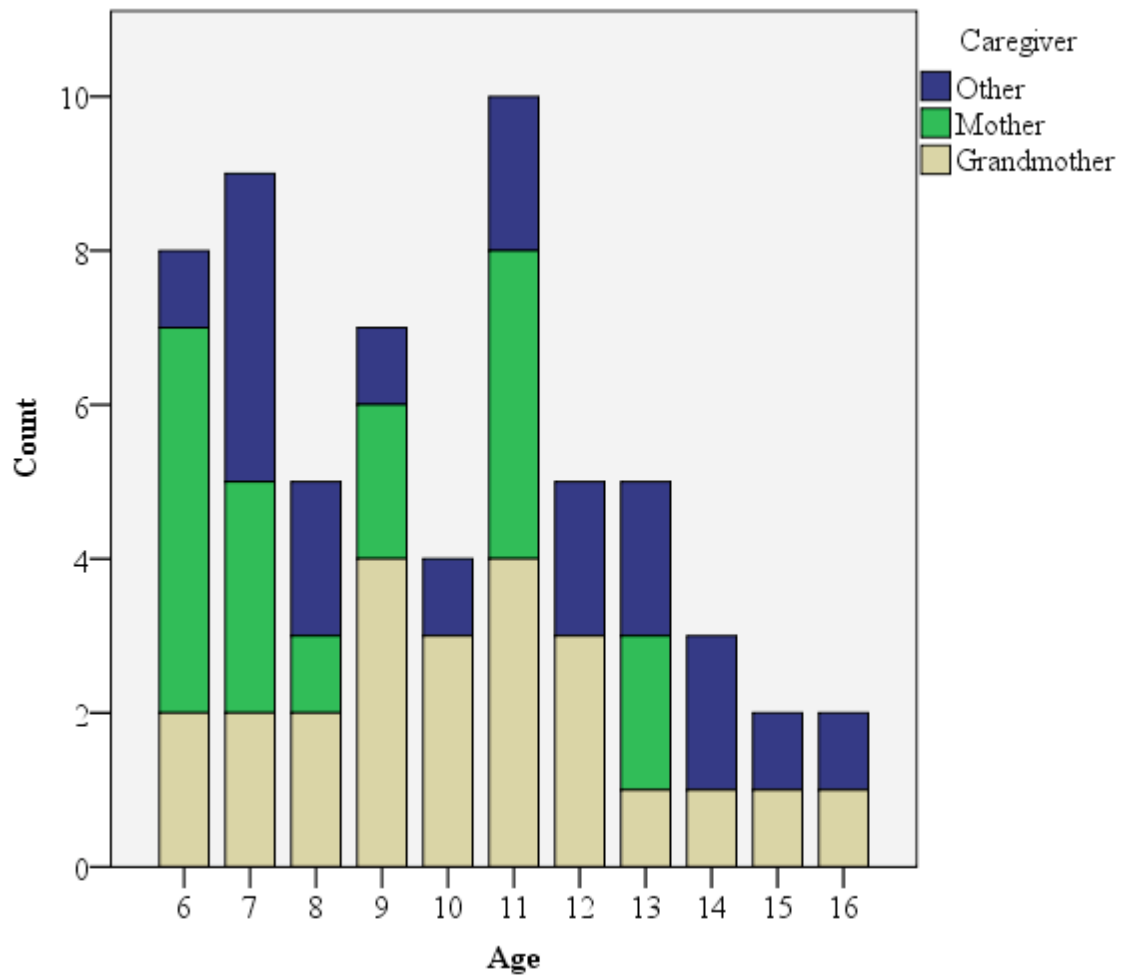


Figure 5. Mean Externalizing Behavior Scores by School Performance and Gender

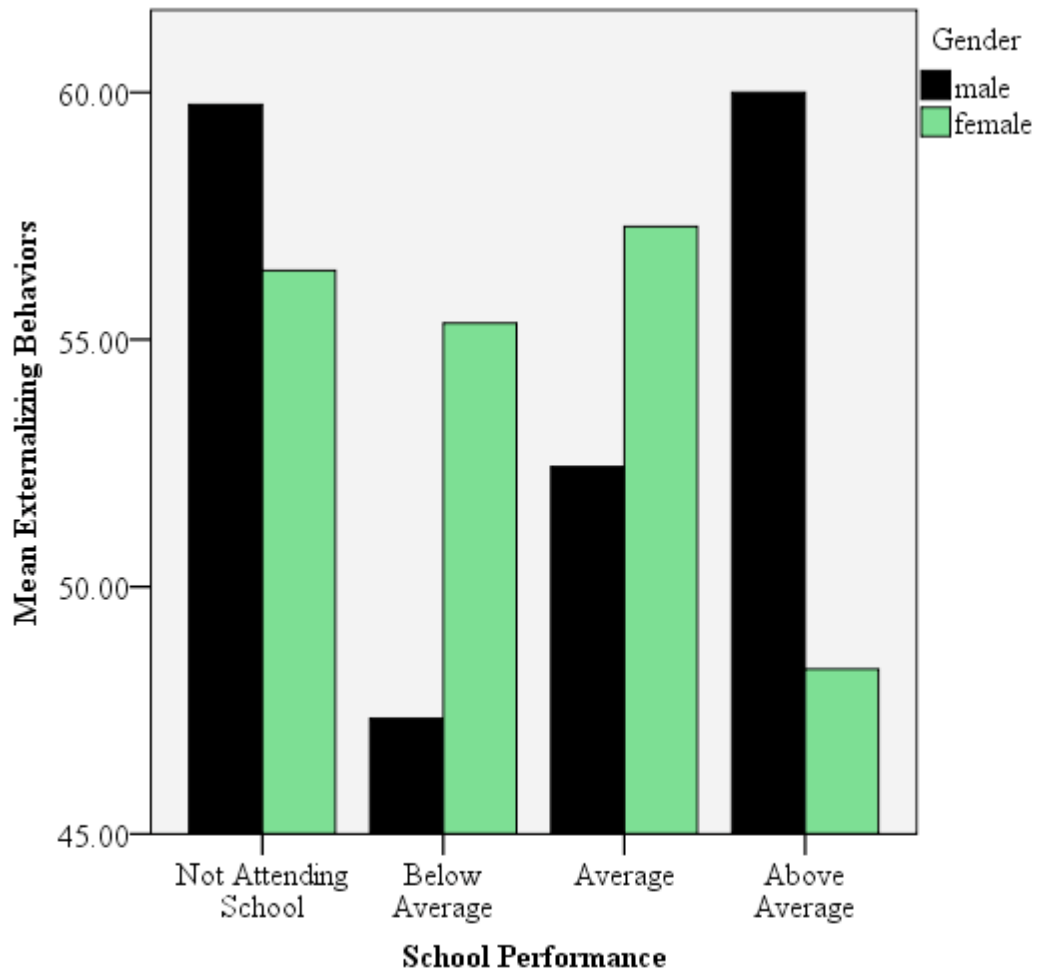


Figure 5.1. Scatter Plot of Externalizing Behaviors by School Performance and Gender

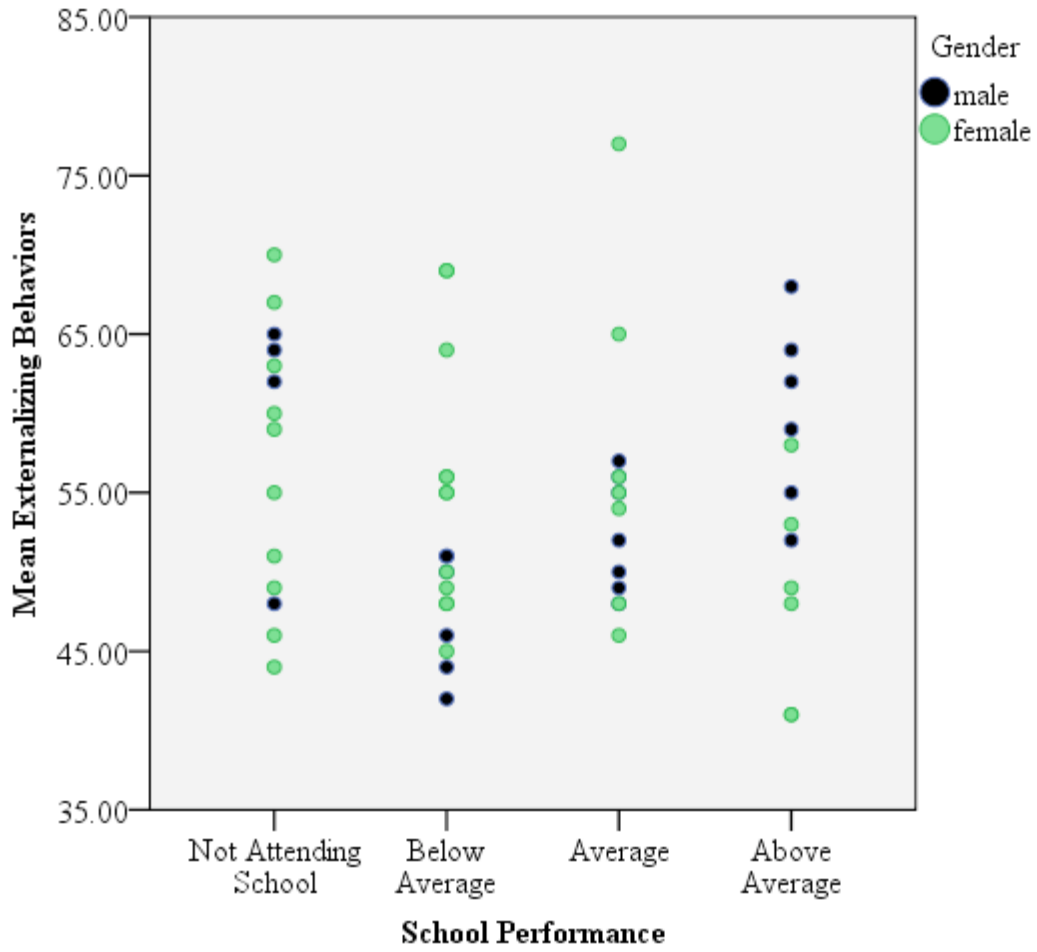


Figure 5.2. *Boxplot of Externalizing Behaviors by School Performance and Gender*

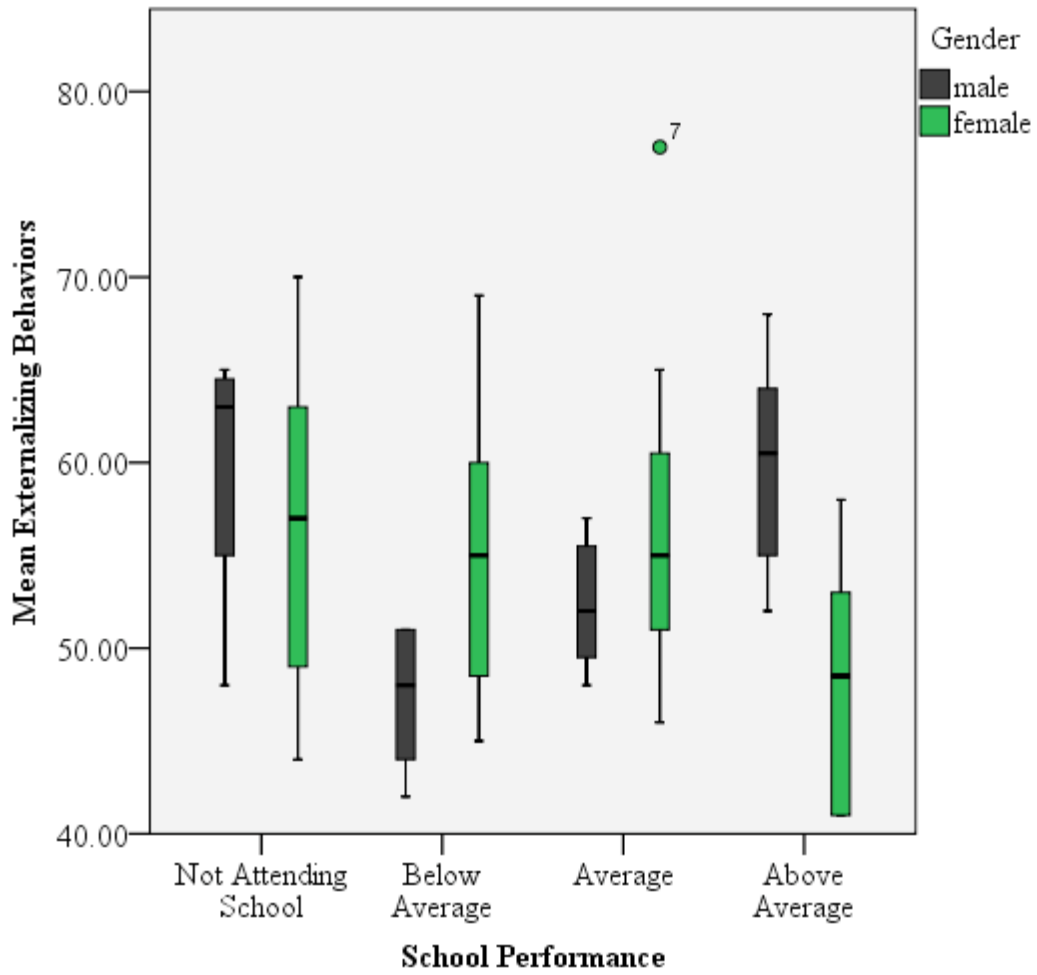


Figure 6. Mean Internalizing Behavior Scores by School Performance and Gender

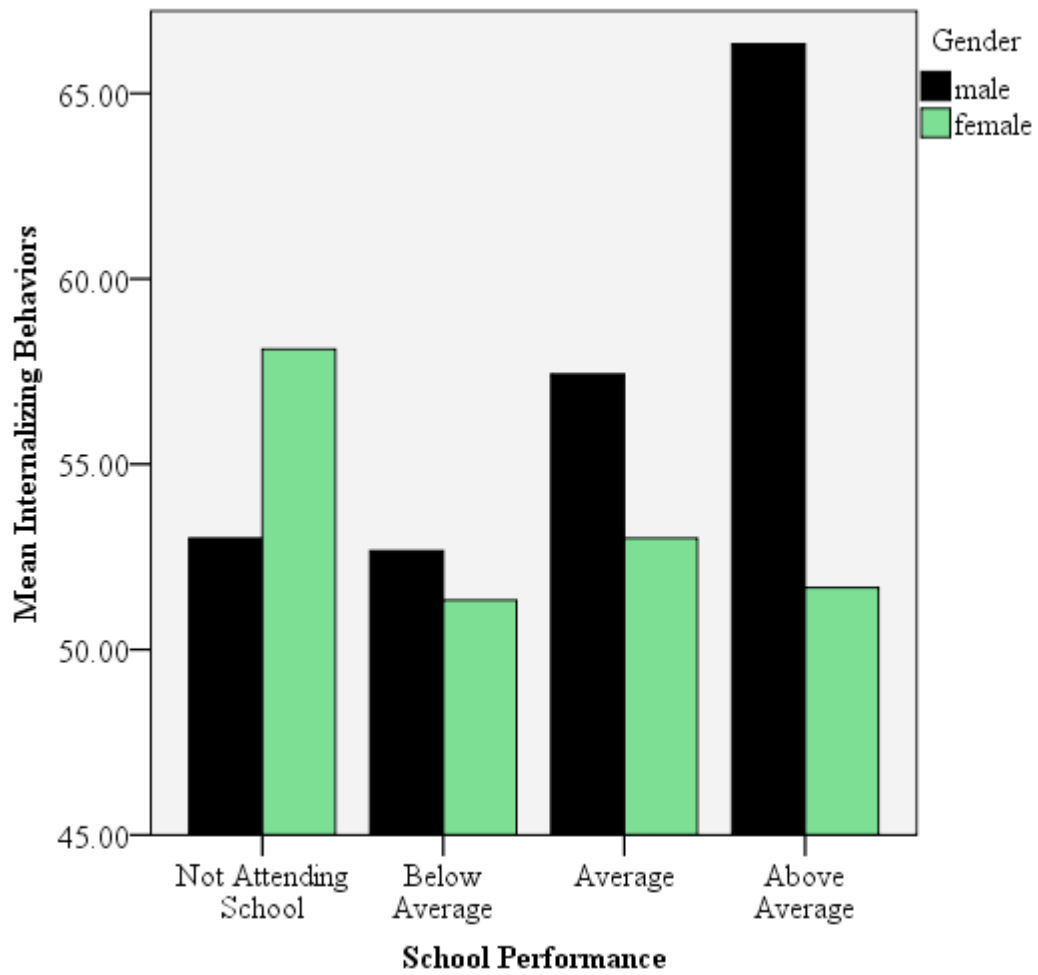


Figure 6.1. Scatter Plot of Internalizing Behaviors by School Performance and Gender

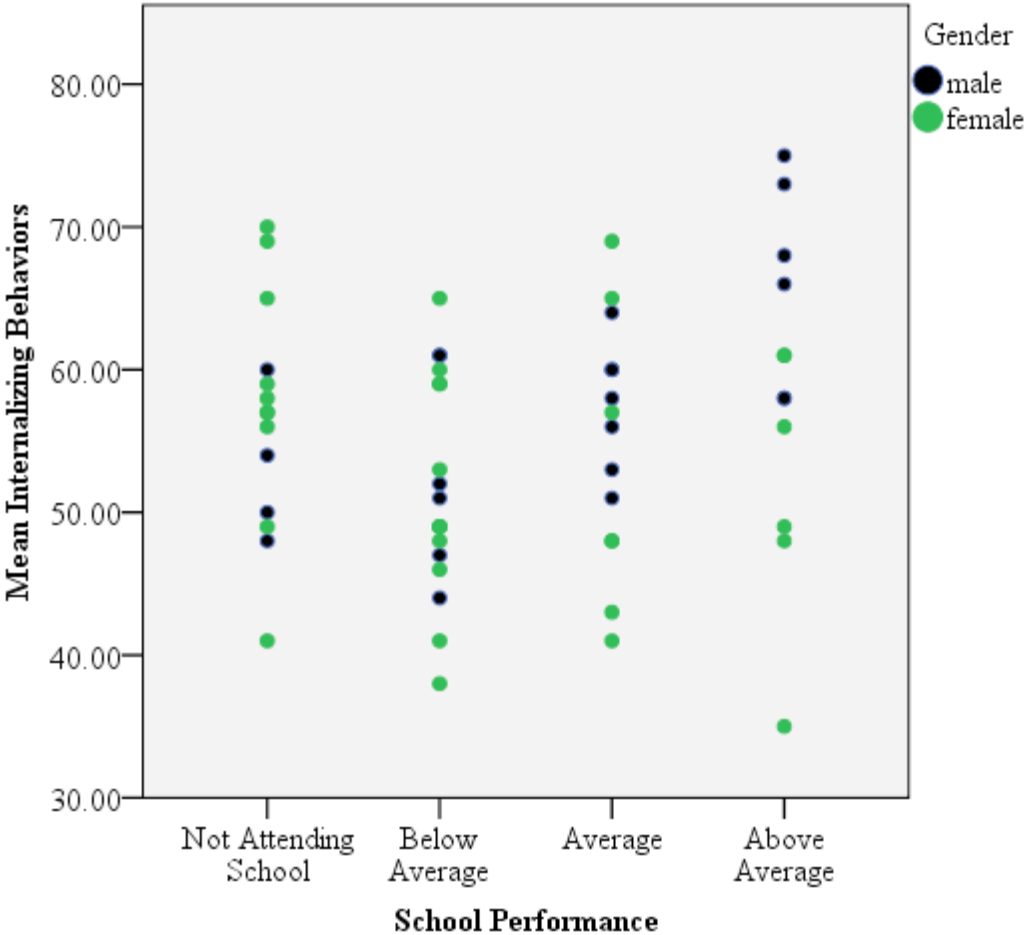


Figure 6.2. *Boxplot of Internalizing Behaviors by School Performance and Gender*

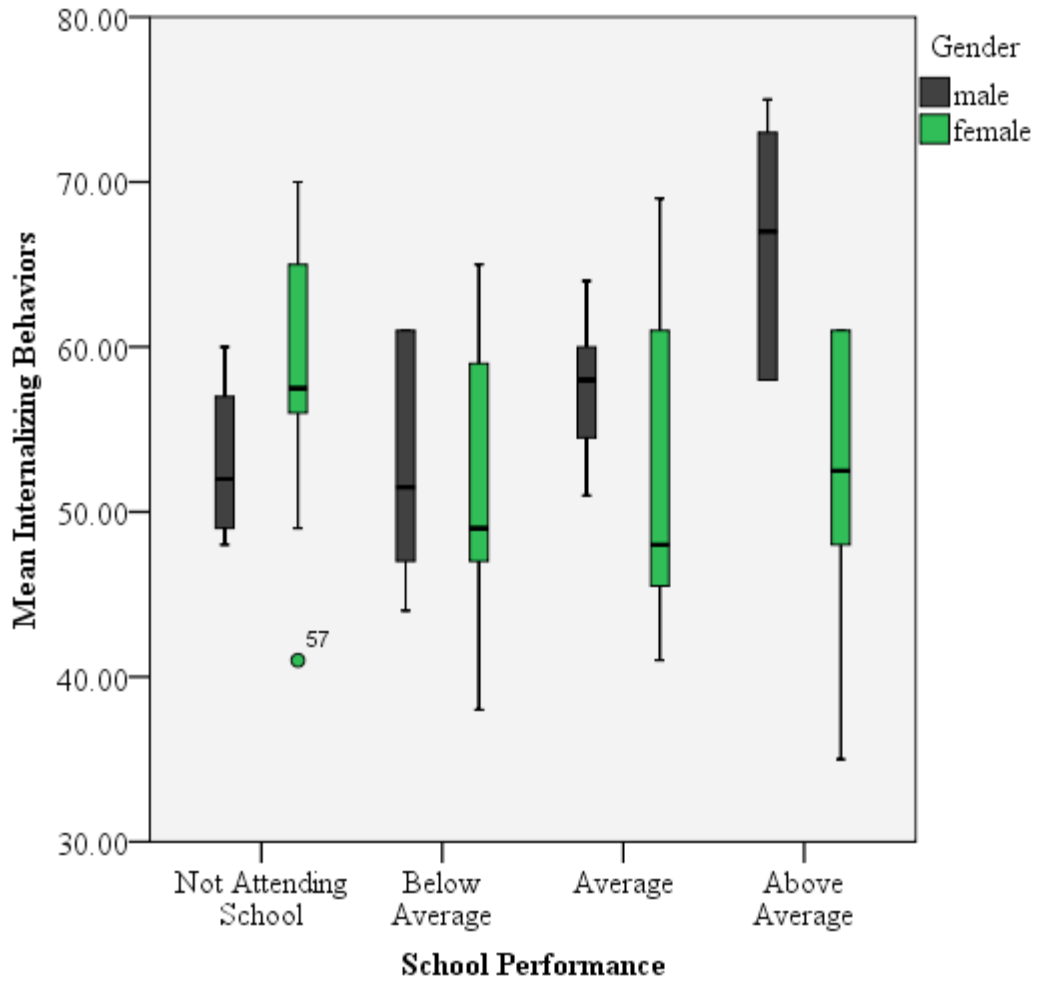
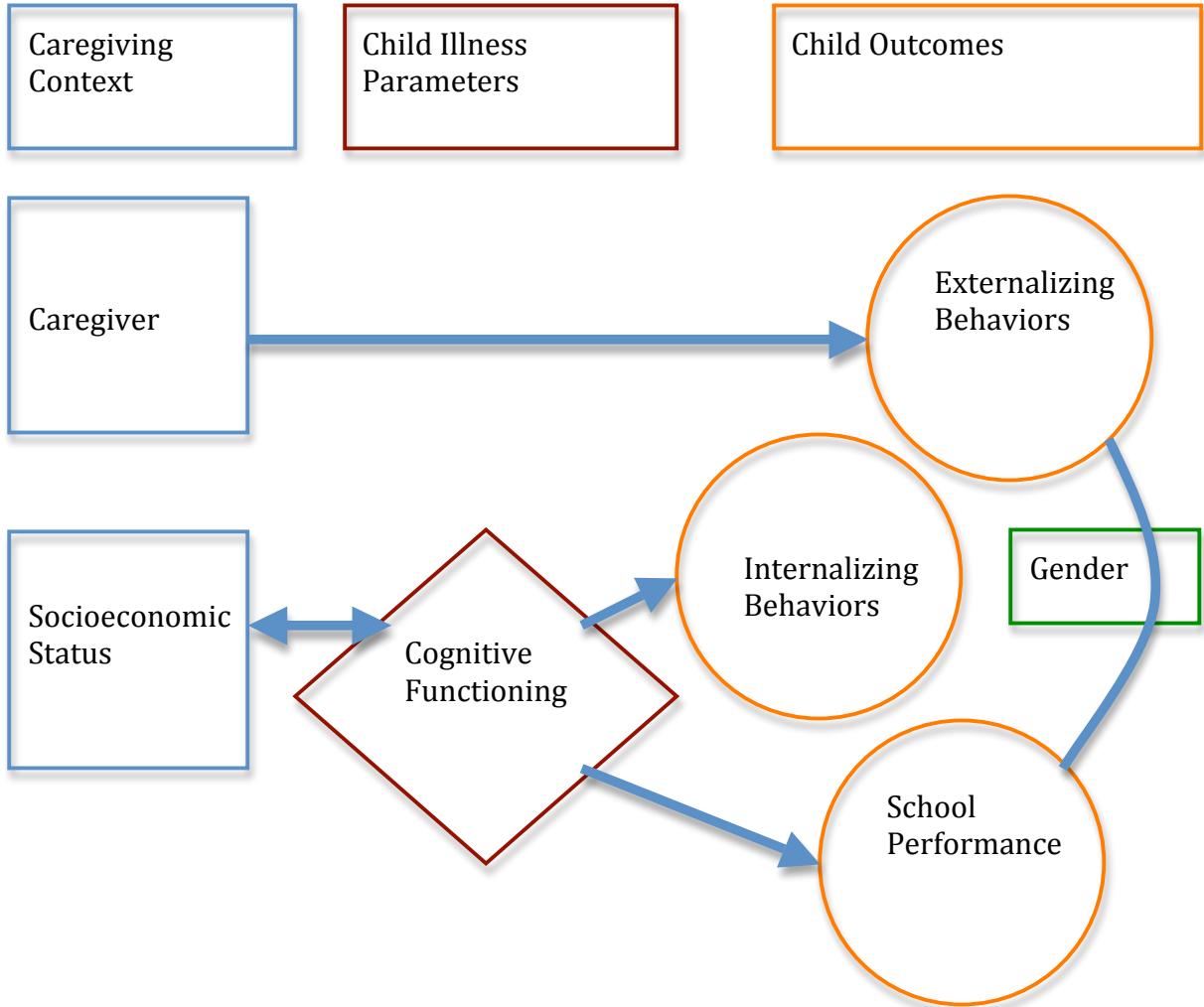


Figure 7. Results: Connecting the Caregiving Context, Child Illness Parameters, and Child Outcomes



APPENDICES

Study number: _____

CONSENT FORM

A. Introduction: We request that you let your child be in our study looking at whether cognitive effects of HIV/AIDS in children can be treated. The AIDS virus may affect the child's brain resulting in poor memory, attention, language and learning. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by **Paul Bangirana** from Makerere University, **Michael J. Boivin**, Michigan State University, **Bruno Giordani**, University of Michigan, and others from Mulago Hospital.

B. Study Purpose: The purpose of this study is to determine whether a computerised brain training program improves memory, attention, language and learning in children who have the HIV/AIDS virus. This study will also look at whether this training improves academic performance. A new computerised assessment of memory, attention and learning will also be tested in this study.

C. Study Procedures:

If you agree to participate in this study, we will ask you to do the following:

1. To let us ask a few questions about the medical condition of the child and allow us to do careful physical examination of the child.
2. If he/she is healthy, we will then perform an assessment on your child of his/her memory, attention, language, reasoning and academic skills. Some of these tests will be done using a new computerised assessment that is being used for the first time in this setting. All these assessments will take about 2 hours to complete. If your child gets tired, he/she will be given time to rest before proceeding with the tests.
3. A blood draw of 5ml (about one teaspoon) will be drawn at the end of these tests. This blood sample will be used to test how well your child's body fights infection.
4. In order to see whether this training improves memory, attention, learning and language, we will randomly assign your child to either a group receiving computerized brain training exercises to improve attention, learning, language and memory or a group that receives no training. If your child is assigned to the group receiving brain training, he/she will receive a training session once a week for two months. These training sessions will be done from home, school or from our study office if that is convenient for you and will start a week after mental ability tests. These exercises last between 45 and 60 minutes. If your child is assigned to the group that does not receive this training, he/she will not do these brain training exercises.
5. All the children will be assessed again at the end of training (two months later) using the new computerized assessment and the performance of the two groups compared.

6. At the end of these assessments, a final blood draw of another 5 ml will be drawn to see whether your child's body's ability to fight infection affects the potential gains from the brain training exercises.

D. Risks of Study Participation

The study has minimal risks. The risks of having blood drawn are bleeding at the site, pain at the site for a time, bruising and infection. We are drawing a small amount of blood that should not affect your child's blood volume. However, we have not had any case in our previous studies where such a blood draw led to any infection. In a study like this, there is a risk that study questions or tests could embarrass a child. We shall try not to ask questions or perform tests that will embarrass you or your child, if however you feel that a particular question or test is embarrassing, there is no requirement that your child answers questions or performs such a test.

There is very little risk of the release of information from your child's health or study records because they will be kept safe and not shared with anyone else. Reports about this research will not reveal the identity of your child.

E. Benefits of Study Participation

1. Basing on evidence from other studies, we hope that the brain training exercises could be of benefit to school-age children who are infected and who struggle with attention, memory, language, and other cognitive skills as a result of the disease. Your child therefore stands a chance to benefit from these brain training exercises. If your child is not in the group receiving the training and is found to have severe problems in the areas tested, you will be invited to receive this training if it's found to be effective.
2. Basing on our assessments, we shall also make appropriate referrals if we believe your child may require other specialist help which we can't provide.

F. Alternatives to Study Participation

Brain training exercises have been tested in other countries with other types of brain injury but to our knowledge have never been tested with African children affected by infectious diseases affecting the CNS such as HIV, cerebral malaria or meningitis. We are not aware of any appropriate alternative assessment tests in Uganda to measure the types of learning we are assessing (memory, attention and learning) that can be done besides the ones that we are going to perform on you child.

G. Study Costs/Compensation You will not incur any costs in participating in this study, a transport refund of 5000/= will be given to you.

H. Research Related Injury There are no potential risks of injury, as no invasive procedure will be performed on your child. If you or your child experiences physical injury or illness as a result of participating in this research study, contact **Dr. Opika Opoka Robert** or **Mr. Paul Bangirana** at 0772996164 or 0772673831 respectively.

I. Voluntary Nature of the Study Participation in this study is voluntary. Your decision whether or not to participate in this study will not affect your current or future relations with Kayunga Hospital or Childhealth Advocacy International. If you decide to participate,

you are free to withdraw at any time without affecting those relationships. Refusing to participate will not alter your/your child's usual health care or involve any penalty or loss of benefits to which you or your child are otherwise entitled.

J. Confidentiality The records of this study will be kept private. In any publications or presentations, we will not include any information that will make it possible to identify you or your child as a subject. Your child's record for the study may, however, be reviewed by the Faculty of Medicine, Mulago Hospital and University of Michigan who have authorized this study. No study information will be recorded in the child's hospital record. Any study data that is to be transmitted via the Internet will be encrypted with secure passwords known to the sender and recipient(s) only. There is a possibility that your participation in this study may be known by your neighbors as we come to visit your home or give your child the brain training exercises. We shall minimize this risk by being inconspicuous and parking far from your home.

K. Contacts and Questions If you have any questions about this study, please contact the responsible investigator **Mr Paul Bangirana**, Department of Psychiatry, P. O. Box 7072, Kampala; Telephone 0772-673831; Email pbangirana@yahoo.com and **Dr. Robert Opika Opoka** 0772996164.

L. Participant rights

If you have any questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you are encouraged to contact the Makerere University Faculty of Medicine Institutional Review Board on 041530020. If you have any questions or concerns regarding your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact - anonymously, if you wish - Dr Charles Ibingira, Chairman of the Makerere University Faculty of Medicine Institutional Review Board, on phone on 041530020. You will be given a copy of this form to keep for your records.

M. Consent

A copy of this consent form will be given to you if you wish.

The consent form has been explained to me and I give consent for my child to take part in the study. I understand that I am free to choose for my child to be in this study. I understand that by signing this consent form, I do not waive any of my legal rights. Signing this consent form does not relieve the investigators of responsibility for adverse events as a result of my participation in this study. Signing this consent form indicates that I have been informed about the research study in which I am voluntarily agreeing to participate. I will be given a copy of this form for my records.

Name of Parent/Guardian 1

Name of Parent/Guardian 2

Appendix B. Consent form in Luganda

Nnamba y'okunonyereza_____

FOOMU EKKIRIZA OKUNONYEREZA

A. Enyanjula

Tukusaba okirize omwana wo yetabe mu kunoonyereza kwaffe okulaba oba obuvune mu kutegera obuletebwa akawuka ka siliimu busobola okujanjabibwa mu baana. Akawuka ka siliimu kayinza okukosa obwongo bw'omwana nekimuletera obunafu mu kujukira, okufaayo, olulimi n'okuyiga. **Tukusaba osome foomu eno era obuuze ekibuzo kyona kyewandyagadde nga tonaba kukiriza kwetaba mu kunonyereza kuno.**

Okunonyereza kuno kukolebwa **Paul Bangirana** okuva e Makerere University awamu ne **Michael J. Boivin**, Michigan State University; **Bruno Giordani**, University of Michigan, n'abalala okuva e Mulago Hospital.

B. Ebigendererwa

Ebigendererwa ky'okunonyereza kuno kwe kumanya oba emisomo ku kompyuta egiwagala obwongo giyamba okujukira, okufaayo, olulimi, n'okuyiga mu baana abalina akawuka ka siliimu. Okunonyereza kuno era kujja kulaba oba emisomo gino giyamba enkola y'omwana muby'okusoma. Enkola empya eya kompyuta egezesesha okujukira, okufaayo, n'okuyiga nayo egenda kuba egezesebwa mukunonyereza kuno.

C. Okunonyereza kujja genda bwekuti:

Bw'onokiriza okwetaba mu kunonyereza kuno, tujja kusaba okiriza tukole bino:

1. Okirize tukubuzeyo ebibuuzo bitono ebikwata ku mbeera y'obulamu bw'omwana era otukirize okwekebejja n'obwegendereza omubiri gw'omwanawo mungeri ey'ekisawo.
2. Singa omwana tukizula nti mulamu bulungi, tujja kugezesesha okujukira kwe, okufaayo, olulimi, okulowooza n'enkola ye muby'okusoma. Okugezesebwa okumu kujja kweyambisa enkola empya eya kompyuta, egenda okukozesebwa omulundi ogusooka mu ngeri ng'eno. Okugesebwa kwona awamu kujja kumala essawa nga bbiri. Singa omwana akowa, ajja kuwebwa akaseera awumulemu, alyoke agende maaso.
3. Oluvanyuma lw'okuzesebwa, omwana tujja kumugyako omusaayi akagiko ka sukaali nga kamu (5ml). Omusaayi guno tujja kugweyambisa okukebera engeri omubiri gw'omwanawo gyegulwanyisamu obulwadde.
4. Okusobola okumanya oba emisomo gino giyamba okujukira, okufaayo, okuyiga n'olulimi, Omwanawo ajja kutekebwa mu kimu ku bibinja bino: ekibinja ekifuna emisomo gya kompyuta egiwagala obwongo okuyamba okufaayo, okuyiga, olulimi n'okujukira oba ekibinja ekitagenda kuwebwa misomo. Singa omwana wo atekkebwa mu kibinja ekifuna emisomo, ajja kusomesebwa omulundi gumu mu wiiki okumala emyezi ebiri. Okusomesebwa kujja kutandiika wiiki emu oluvanyuma

lw'ebigezo mukutegera era kuyinza okukolebwa eka, kusomero oba mu offisi yaffe, bwekiba tekibakalubiriza. Emisomo gino gitwala eddakiika ana mu ttano (45) oba essaawa emu. Omwanawo singa atekebwa mukinja ekirala, tajja kufuna misomo gino.

5. Emisomo nga giwedde (oluvanyuma lw'emyezi ebbiri), abaana bonna bajja kuddamu bagezesebwe nga tukozesa enkola empya eya kompyuta, oluvanyuma tugerageranye enkola y'abaana mubibinja byombi.
6. Oluvanyuma lw'okugezesebwa, omwana tujja kumugyako omusaayi ogusembayo, akagiko ka sukaali nga kamu (5ml). Guno tujja kugukozesa okulaba oba obusobozi bw'omubiri gw'omwanawo okulwanyisa obulwadde bwekusa ku kuganyulwa omwana kwayinza okufuna mu misomo egiwagala obwongo.

D. Ebizibu.

Okunonyereza kuno kulimu obubenje butono ddala. Obuzibu obuli mu kugyako omusaayi buli nti omwana ayinza okulumwa ng'afumitiddwa akayiso akaggyako omusaayi oluusi n'avaamu omusaayi awafumitiddwa okumala akaseera oba n'afuna akawundu akatono oba obuvune. Tujja kugyako omusaayi mutono ddala era tekigya kendeza musaayi gwa mwanawo, Mukunonyereza kwaffe okw'emabega, tewali mwana yafuna buvune olw'okugyibwako omusaayi. Mukunonyereza nga kono, wabawo okuttya nti ebibuuzo ebimu biyinda okukuswaza oba omwanawo. Tetujja kukaka mwana kuddamu bibuuzo oba kukola kukeberegwa okuyinza okuswaza omwanawo oba gwe. Ebinabuzibwa omwanawo ngabikwata ku bulamu bwe bijja kuterekebwa bulungi ddala era tebijja kumanyisibwa muntu mulala yenna.. Ebinawandiikibwa ebikwata ku kunonyereza kuno tebijja kwatukiriza mwanawo.

E. Okuganyulwa.

1. Okusinzira kukunonyereza okulala, tusubira emisomo gya kompyuta egiwagala obwongo giyinda okuyamba abaana b'emyaka egisoma abalina akawuka ka siliimu era nga batawana mukufaayo, okujukira, olulimi n'okutegera oluvanyuma lw'okulwala. N'olwekyo omwanawo afuna omukisa okuganyulwa mu misomo gino. Singa omwana wo abeera mu kibinja ekitafula misomo naye nazulibwa ng'alina obuzibu obw'amanyi mu okufaayo, okuyiga, olulimi oba okujukira, tujja kumuyita aweebwe emisomo gino singa kizulibwa nti giyamba.
2. Nga tusinzira ku kukeberegwa kwaffe, singa tukakasa nti omwana wo yetaga obuyambi obw'ekikugu bwetutasobola kumuwa, tujja kumuwereza awasanidde.

F. Engeri endala singa tewetaba mu kunonyereza

Emisomo egiwagala obwongo gigezesebwa muni endala ku bika by'obuvune ku bwongo ebirala naye tumanyi nti wano mu Africa teginagezesebwako mu baana abalwala endwadde ezikosa obwongo, gamba nga siliimu, omusujja gw'okubwongo, oba mulalama. Tetumanyi ngeri ndala zonna zisobola kukozebwa wano mu Uganda, okukebera engeri omwana gyayigamu (okujukira, okufaayo, olulimi) ng'ogyeko ezo zetugenda okukozesa ku mwanawo.

G. Ensimbi ezinasasanyizibwa/ Okuliyirira

Tojja kusasanya nsimbi zo zonna ngawetabye mukunoonyereza kuno. Ojja kudizibwa enkumi ttaano (5000/=) kulw'entambula.

H. Obulumi obwekuusa kukunonyereza

Olwokuba nti teri kufumitibwa kwona kunakolebwa, okunonyereza kuno tekulimu kabenje konna. Singa omwana wo afuna obuzibu ku mubiri gwe oba obulwadde obulowozebwa nti bwajja olw'okwetaba mu kunonyereza kuno, tegeza **Dr. Opika Opoka Robert** ku ssimu 07729960164 **Mr. Paul Bangirana** ku ssimu 0772673 831.

I. Okukiriza kwa kyeyagalire

Okukiriza okwetaba mu kunoonyereza kuno kwa kyeyagalire. Bwosalawo obutetaba mukunoonyereza kuno tekijja kukosa nkolagana yo, kakati oba mu maaso, ne'ddwaliro lye Kayunga oba Child Health Advocacy International. Era bwosalawo okwetaba mukunoonyereza kuno, osigala oli waddembe okuva mu kunonyereza essaawa yonna era nga tekikoseza nkolaganayo n'ebitongole ebyo. Okugaana okwetaba mu kunonyereza kuno, tekukyusa ndabirila esanidde ey'obulamu bwo oba obw'omwana wo, oba okubakugira okufuna ebyo ebibagwanidde.

J. Ebyama

Ebiwandiiiko ebikwata kunoonyereza kuno byonna byakuterekebwa mu kyama. Ebinawandikibwa mu butabo oba mumpapula zonna ez'okuyigiriza, tebijja kukwatukiriza newankubade omwana wo, era tekijja kusoboka kubategeera, wabula ebifa ku mwana wo biyinja okulabibwa abakulu mu tendekero ly'abasawo mu yunivasite ye'Makerere, Mulago Hospital oba University ye Michigan abatukiriza okukola okunonyereza kuno. Tewali kikwata kumwana wo kijja kuwandikibwa mu fayiro ya ddwaliro. Ebinawerezebwa ku mpewo za komputa bijja kusibwako enyukuta eze'kyama ezitakiriza muntu yenna kubisoma okujako oyo abiwereza ne gwebabiwereza. Okwetaba kwo mu kunonyereza kuno kuyinza okumanyibwa baliranwa bo olw'okukyala kwaffe ewaka wo oba olw'okugezesa omwana wo. Tujja kukendeza obuzibu buno nga tetwelambika nnyo gyebali era emotooka tujja kugireka wala n'eka wo.

K. Endagiriro za'bokwebuzaako

Bwoba olina ekibuuzo kyona ekikwata kukunonyereza kuno, tukirira omunonyerezi gwekikwatako, **Mr. Paul Bangirana**, P. O. Box 7062, Kampala; Telephone 0772673831; Email pbangirana@yahoo.com oba **Dr. Robert Opika Opoka** ssimu 0772996164.

L. Eddembe ly'abaneetaba mu

Bwoba olina ekibuuzo oba okwemulugunya okukwata kukunoonyereza kuno naye nga wandiyagadde webuuzo awalala awatali kubanonyerezi bano, kubira Makerere University Faculty of Medicine Institutional Review Board Essimu 0414 530020.

Bwoba olina ekibuuzo oba okwemulugunya okukwata ku ddembe lyo ng'eyetabye mukunonyereza, oba ng'olina obutali bumativu kunsonga yonna ekwata kukunonyereza kuno, tegeza – Dr Charles Ibingira, ssentebe wa Makerere University Faculty of Medicine Institutional Review Board, ssimu: 0414-530020. Ojja kuwebwa kkopi ya foomu eno ojitereke.

M. Okukkiriza

Ojja kufuna kkopi ya ffoomu eno ey'olukusa bwoba ogyetaaze.

Ebintu byonna ebiri mu ffoomu y'olukusa eno binyinyonnyoddwa bulungi ne mbitegeera era nzikiriza omwana wange okwetaba mu kunoonyereza kuno nga tewali ankase oba okunsalirawo. Ntegera nti ndi waaddembe okusalirawo omwana wange okwetaba mu kunonyereza kuno. Okussa omukono ku ndagaano eno tekingigyaako ddembe lyange lya bwebange ery'okwewozaako nga wabaddewo ekisobye mu mateeka. Okussa omukono ku ndagaano era tekuggyaawo buvunaanyizibwa bw'abaddukanya okunoonyereza kuno singa wabawo obuzibu bwonna obw'amaanyi obuyinza okugwaawo olw'okwetaba mu kunoonyereza kuno. Okussaako omukono kitegeeza nti ntegeezeddwa ebikwata ku kunoonyereza era nenesalirawo nzekka okukwetabamu nga tewali kukakibwa. Njakuweebwaako kkopi ku ffoomu eno ey'olukusa njitereke.

Erinnya ly'omuzadde / Alabirira omwana.1

Erinnya ly'omuzadde / Alabirira omwana. 2

Omukono oba ekinkumu ky'omuzadde / Alabirira omwana.

1

Ennaku z'omwezi

Omukono oba ekinkumu ky'omuzadde / Alabirira omwana.

2

Ennaku z'omwezi

Akoze ku ffoomu y'olukusa lw'okunoonyereza eno.

Omukono gw'akoze ku ffoomu eno.
z'omwezi

Ennaku

- Omwana anoonyerezebwaako oba mukadde we bw'abeera tamanyi kusoma na kuwandiika walina okubaawo omujulizi nga bannyonnyolwa ebikwata ku kuwa olukusa. Oluvannyuma lw'okunnyonnyolwa ne bakkiriza omujulizi ono assaako omukono okukasa nti abantu abo ebintu bye bataddeko ekinkumu babinyonnyoddwa bulungi mu bigambo ne babitegeera bulungi nti era babikkiriza ku lwabwe nga tewali abawaliriza oba okubasalirawo.

Erinnya ly'omujulizi (mu nnukuta ennene)

Omukono gw'omujulizi.

Ennaku z'omwezi

Omukono gw'anonyereza

Ennaku z'omwezi

Appendix C. Medical History and Physical Examination Form

MU-MSU collaborative study

Neuropsychological benefits of cognitive training for Ugandan HIV children - Kayunga

Medical History and Physical examination Form

Patient Name: _____ **Study ID#** _____

Complete this medical history and physical examination form at the enrolment of study participants.

PARTICULARS

Study No.	Names:	Age:
Sex: Male [] Female []	Date today:	Date of birth:
Child's care giver:	Relationship with child:	Village:
Sub county:	District:	Contact phone #s:

PRESENT HEALTH HISTORY

Is the patient currently ill with any of the following symptoms:
 Fever, vomiting, severe diarrhea, active convulsions, difficulty breathing, severe cough?
 Y N

If Y, send to Medical staff of Kayunga Hospital for evaluation and have child return when symptom-free

If N, continue with enrolment

HIV HISTORY

Is the child currently on HAART? Y N
 If Yes, combination
 If Y, stating date

Is the child on O.I prophylaxis? Y N
 If Y, list medications

PAST MEDICAL HISTORY

Has the child:		
Any other medical condition apart from HIV If yes list condition	Y	N
<i>Been hospitalized for malnutrition?</i>	Y	N
<i>Been hospitalized with coma?</i>	Y	N
<i>Been hospitalized meningitis?</i>	Y	N
<i>Been hospitalized with head injury?</i>	Y	N
If Yes for any of the above conditions, exclude from the study.		
Been hospitalised for reasons other than those listed above? If yes, reason for the hospitalization	Y	N

PHYSICAL EXAMINATION

Temp ____ . ____ ° C Wgt. ____ . ____ kg Hgt. ____ cm.
 MUAC ____ cm

Is the child acutely ill by screening exam? Y N
 If yes, describe:

If acutely ill, stop enrolment and refer to staff of Kayunga Hospital for evaluation and treatment and ask to return for testing after recovery.

GENERAL ASSESSMENT OF THE CHILD

General exam normal? Y N
 If no, describe
 Respiratory system normal? Y N
 If no, describe;
 Cardiovascular system normal? Y N
 If no, describe;
 GIT system normal? Y N
 If no, describe;
 CNS examination normal? Y N
 If no, describe;
 Other findings Y N
 If yes, describe:

Done by _____ **Sign and Date** _____

Appendix D. Child Behavior Checklist Translated in Luganda

STUDY ID _____ **NAME** _____

Child Behavior Checklist for Ages 6- 18

Child's Last Full name		First	Middle	Omulumu gw'omuzadde ogwabulijjo, wadde kati nga takola okugeza makanika, musomesa, musubuzi etc						
Child's gender Boy <input type="checkbox"/> Girl <input type="checkbox"/>		Child's age <input type="checkbox"/>	Child's Ethnic group or race		Omulumu gwa taata _____ Omulumu gwa maama _____					
Today's date Mo _____ Yr _____		Child's birthdate Mo _____ Yr _____		Erinya ly'akoze ku foomu <input type="checkbox"/>						
Grade in School _____ Tasoma	Juzza foomu eno okulaga ky'olowooza ku neyisa y'omwana wadde nga abalala tebakiriziganya nawe. Ddamu ebibuuzo byonna			Your gender <input type="checkbox"/> Male <input type="checkbox"/> Female Oluganda lwo n'omwana Biological parent <input type="checkbox"/> Step Parent <input type="checkbox"/> Grand parent <input type="checkbox"/> Adoptive parent <input type="checkbox"/> Foster Parent <input type="checkbox"/> Other (specify) _____						
I. Menya emizanyo omwana gyasinga okwagala okwetabamu. Okugeza okuwuga, okuvuga eggaali etc Tewali <input type="checkbox"/>			Omwana ng'omugerageranyiza ku bane ab'emyaka gyegimu, biseera ki byawa buli muzanyo?				Omwana ng'omugerageranyiza ku bane ab'emyaka gyegimu, akola atya mu buli muzanyo?			
			Bitono	Byakigero	Bingi	Simanyi	Bubi	Agezako	Bulungi	Simanyi
			a.							
			b.							
			c.							
II. Menya ebintu omwanawo byanyumirwa okwenyigiramu Okugeza okusoma obutabo, eby'emikono, okuyimba etc (Ng'ogyeko Radio ne TV)			Omwana ng'omugerageranyiza ku bane ab'emyaka gyegimu, biseera ki byawa buli kimu?				Omwana ng'omugerageranyiza ku bane ab'emyaka gyegimu, akola atya mu buli kimu?			
			Bitono	Byakigero	Bingi	Simanyi	Bubi	Agezako	Bulungi	Simanyi

) Tewali <input type="checkbox"/>									n y i
a.									
b.									
c.									
III. Menya ebibiina, tiimu oba obubinja omwanawo mw'ali Tewali <input type="checkbox"/>	Omwana ng'omugerageranyiza ku bane ab'emyaka gyegimu,,obujumbize bwe buli butya mu buli kimu?								
	Tajumbira	Agezako	Ajumbira nnyo	Simanyi					
a.									
b.									
c.									
IV. Menya emirimu omwana gy'akola awaka. Okugeza okukima amazzi, okweera olugya, okulera omwana etc (Tekako egisasula n'egitasasula wamu negy'akola awaka) Tewali <input type="checkbox"/>	Omwana ng'omugerageranyiza ku bane ab'emyaka gyegimu,,akola atya emirimu gino?								
	Bubi	Agezako	Bulungi	Si m a n y i					
a.									
b.									
c.									
V. 1. Omwana wo alina mikwano gye ennyo ng'emeka? (Ng'ogyeko baganda be ne bannyina) <input type="checkbox"/> Talina <input type="checkbox"/> 1 <input type="checkbox"/> 2 oba 3 <input type="checkbox"/> 4 oba okusingawo 2. Emirundi ng'emeka mu wiiki omwana gyaberako nemikwano gye ng'ogyeko ebiseera by'okusomero? (Ng'ogyeko baganda be ne bannyina) <input type="checkbox"/> Tewali <input type="checkbox"/> 1 oba 2 <input type="checkbox"/> 3 n'okusingawo									
VI. Omwana ng'omugerageranyiza ku bane ab'emyaka gyegimu,,:	Bubi	Kigero	Bulungi						
a. Akolagana atya ne bagandabe?					Talin a baga nda be				
b. Akolagana atya n'abaana abalala									
c. Yeyisa atya ne bazaddebe?									
d. Okuzanya n'okukola yekka kuli									

kutya?								
VII. 1. Enkola ye mu masomo		Tasoma olw'ensonga						
Saaza ku masomo omwan g'atwala		Munafu nnyo	Afuba	Agezak o	Mulung i			
a. Okusoma, Oluzungu oba olulimi								
b. Ebyafaayo oba social studies								
c. Okubala								
d. Science								
e.								
f.								
g.								
2. Omwana wo afuna okuyigirizibwa okwenjawulo oba okusomesebwa okutali kwa bulijjo oba asoma me ssomero lyanjawulo? <input type="checkbox"/> Nedda <input type="checkbox"/> Yee (Kiki enkyenjawulo)								
3. Omwana wo yali azeko mukibiina? <input type="checkbox"/> Nedda <input type="checkbox"/> Yee- Kibiina ki era lwaki?								
4. Omwanawo yali afunye obuzibu mu kuyiga kwe oba ku ssomero? <input type="checkbox"/> Nedda <input type="checkbox"/> Yee- Nnyonyola Obuzibu buno bwatandiika ddi? Obuzibu buno bwagwawo? <input type="checkbox"/> Nedda <input type="checkbox"/> Yee- Ddi?								
Omwana alina obulwadde bwonna oba obulemu (ku mubiri oba ku bwongo)? Nedda Yee- Nnyonyola								
Kiki ekisinga okukweralikiriza ku mwanawo ?								

Wammanga waliwo ebintu ebinnyonyola abaana n'abavubuka. Ku buli kintu ekiraga omwanawo bwali kati oba bwabadde emyezi mukaaga egiyise, saza ku nnamba 2 singa kituufu ku mwanawo. Saaza ku nnamba 1 singa ekintu oluusi kutuukirira ku mwanawo. Ekitali kitufu ku mwanawo saza ku zero.

0= Si kitufu		1= Olusi kitukirira oba kitufumu		2= Kitufu nnyo	
oba emirundi mingi kitukirira					
0	1. Eneyisa ye yakito okusinzira ku myaka gye	0	32. Awulira alina kukola bulungi nnyo oba bitufu byoka	1	
1		1		2	
2		2			
0	2. Anywa omwenge ng'abazadde be tebamukiriza. Nyonyola	0	33. Awulira tewali amwagala	1	
1		1		2	
2		2			
0	3. Awakana nnyo	0	34. Awulira nga abalala baagala kumulumya	1	
1		1			

2		2	
0 1 2	4. Alemwa okumaliriza ebibtu by'atandikako	0 1 2	35. Awulira nga talina mugaso/ muwendo
0 1 2	5. Ebibtu bitono ebimunyumira	0 1 2	36. Anyiga mangu, alabika okugwa me bubenje
0 1 2	6. Yeyamba ebweru wa kabuyonjo	0 1 2	37. Yenyigira mu ntalo nnyingi
0 1 2	7. Yemanyi	0 1 2	38. Asekererwa nnyo
0 1 2	8. Tasobola kusayo mwoyo kumala kiseera kiwanvu	0 1 2	39. Abeera nyo na'abantu abatava mu buzibu
0 1 2	9. Tasobola kujja birowoozo bye kubintu ebimu, (Nnyonyola)	0 1 2	40. Awulira amaloboozi agataliwo (Nnyonyola)
0 1 2	10. Tasobola kutula ntende, amaguka,	0 1 2	41. Apakuka oba akola ebintu nga tasose kulowooza
0 1 2	11. Yesiba ku bantu abakulu, teyetongola	0 1 2	42. Anyumirwa okubeera yekka okusinga okubera n'abantu
0 1 2	12. Ekiwubaalo kimuluma	0 1 2	43. Alimba, abinkanya
0 1 2	13. Atabusetabuse oba ali mu nsi ye	0 1 2	44. Aluma enjjala
0 1 2	14. Akaaba nnyo	0 1 2	45. Amameeme gamukubba
0 1 2	15. Mukambwe eri ebisolo	0 1 2	46. Atiitira era akankana olw'okutya (Nnyonyola)
0 1 2	16. Mukambwe,, atawanya, talina kisa oba mukodo	0 1 2	47. Afuna agalooto agatiisa
0 1 2	17. Aloota nga teyebase oba abulira mu birowoozo bye	0 1 2	48. Tayagalibwa baana balala
0 1	18. Yekola ko obulabe oba okugezako okwetta	0 1	49. Olubuto lumwesibye, tafuluma

2		2	
0 1 2	19. Ayagala okumufako	0 1 2	50. Atya, yeralikirira nnyo
0 1 2	20. Ayonona ebintu bye	0 1 2	51. Awulira kamunguluze
0 1 2	21. Ayonona ebintu by'awaka oba eby'abalala	0 1 2	52. Awulira okulumirizibwa ensobi ze
0 1 2	22. Munyomi ewaka	0 1 2	53. Alya nnyo
0 1 2	23. Munyomi ku ssomero	0 1 2	54. Akowa nga talina kyakoze
0 1 2	24. Talya bulungi	0 1 2	55. Munene / azitowa nnyo
0 1 2	25. Takolagana bulungi n'abaana balala		56. Alina ebirwadde ebitamanyiddwa kibileeta:
0 1 2	26. Talaga kulumirizibwa oba nsonyi oluvanyuma lw'okweyisa obubi	0 1 2	a. Okulumizibwa (nga si mutwe oba lubuto)
0 1 2	27. Akwatiibwa obuggya	0 1 2	b. Okulumwa omutwe
0 1 2	28. Amennya amateeka awaka, ku ssomero nabuli wamu	0 1 2	c. Okusindikirirwa emeeme
0 1 2	29. Atya ensolo, embeera oba ebifo ebimu ng'ogyeko ku ssomero (Nnyonyola)	0 1 2	d. Obuzibu ku maaso (Obutasobola kuterezebwa galubindi) (Nnyonyola)
0 1 2	30. Atya okugenda ku ssomero	0 1 2	e. Okubutuka oba obuzibu obulala ku lususu
0 1 2	31. Yelaliikirira nti ajja kulowooza oba okukola ekikyamu	0 1 2	f. Okulumwa olubuto
		0 1 2	g. Okusesema

	0 1 2	h. Ekirala (Nnyonyola)
--	-------------	------------------------

0= Si kitufu oba emirundi mingi kitukirira		1= Olusi kitukirira oba kitufumu	2= Kitufu nnyo
0 1 2	57. Alumba / akuba abantu	0 1 2	86. Mulalu , anyiiga mangu
0 1 2	58. Yeekwata mu nnyindo, n'ebitundu by'omubiri ebirala (Nnyonyola)	0 1 2	87. Embeera ze zikyukakyuka
0 1 2	59. Azanyisa ebitundu bye eby'ekyama mu bantu	0 1 2	88. Akola nnyo entondo
0 1 2	60. Azanyisa nyo ebitundu bye eby'ekyama	0 1 2	89. Yekengera
0 1 2	61. Akola bubi ku ssomero	0 1 2	90. Alayira, akozesa ebigambo ebitasana mu bantu
0 1 2	62. Musamaavu	0 1 2	91. Ayogera ku kwetta
0 1 2	63. Ayagala kubeera n'abana abamusinga obukulu	0 1 2	92. Ayogera oba atambula nga yeebase (Nnyonyola)
0 1 2	64. Ayagala kubeera n'abana abamusinga obuto	0 1 2	93. Ayogera nnyo
0 1 2	65. Agaana okwogera	0 1 2	94. Asaaga nnyo
0 1 2	66. Waliwo ebikolwa by'adingana (Nnyonyola)	0 1 2	95. Alaga mangu obusungu
0 1 2	67. Adduka awaka	0 1 2	96. Alowooza nyo ku by'okwegatta
0 1 2	68. Awoggana nnyo	0 1 2	97. Atiisatiisa abantu
0 1	69. Teyeyabiza Bantu, yekumira ebyama bye	0 1	98. Anuuna engalo ensajja

2		2	
0 1 2	70. Alaba ebintu ebitaliwo (nnyonyola)	0 1 2	99. Anywa sigala
0 1 2	71. Yetya, aswala mangu	0 1 2	100. Obuzibu okwebaka (nnyonyola)
0 1 2	72. Akoleza emiriro	0 1 2	101. Atoloka ku ssomero, ayosa
0 1 2	73. Ebizibu by'okwegatta (Nnyonyola)	0 1 2	102. Walulembe, asooba,
0 1 2	74. Yelaga	0 1 2	103. Munyikavu
0 1 2	75. Alina ensonyi	0 1 2	104. Aleekana ekiteetagisa
0 1 2	76. Yeebaka kitono ku baana abasinga	0 1 2	105. Akozesa amadaggala nga si mulwadde (ng'ogyeko taaba n'omwenge) Nnyonyola
0 1 2	77. Yeebaka nnyo ekiro oba emisana okusinga abaana abalala (nnyonyola)	0 1 2	106. Ayonoona ebintu by'abalala
0 1 2	78. Tassaayo mwoyo oba kyangu okumugya ku ky'aliko	0 1 2	107. Yefukira emisana
0 1 2	79. Obuzibu mu kwogera (nnyonyola)	0 1 2	108. Afuka ku buliri
0 1 2	80. Atunula enkaliriza awatali ky'alaba	0 1 2	109. Yemulugunnya nnyo
0 1 2	81. Abba awaka	0 1 2	110. Yeegomba okuba ow'ekikula ekilala (musajja oba mukazi)
0 1 2	82. Abba wabweru w'eka	0 1 2	111. Teyewa bantu
0 1 2	83. Atereka ebintu bingi by'atetaga (Nnyonyola)	0 1 2	112. Yeelalikirila

0 1 2	84. Enn'eyisa ezitali za bulijjo (Nnonyola)		113. Wandika ekizibu kyona omwanawo ky'alina ekitamenyebwa
0 1 2	85. Ebirowooza ebitali bya bulijjo (Nnyonyola)	0 1 2	
		0 1 2	

Appendix E. Education, Socioeconomic Status and Migration Questionnaire

**KAYUNGA HOSPITAL/MU-MSU HIV PROJECT
EDUCATION, SOCIOECONOMIC STATUS AND MIGRATION QUESTIONNAIRE**

Circle the numbers or letters of all correct answers.

EDUCATION

1. Is the child currently in school? 1. Y 2. N
2. If child is in school, what level? 1 2 3 4 5 6 7
3. If N, was child ever in school? 1. Y 2. N
4. If Y, what was the highest level of education the child reached? 1 2 3 4 5 6 7
5. Is child's mother able to read and write? 1 Y 2N
6. What was the highest level of education for the child's mother?
1 2 3 4 5 6 7 8 (Secondary) 9 (Tertiary)
7. Is child's father able to read and write? 1 Y 2N
8. What was the highest level of education for the child's father?
1 2 3 4 5 6 7 8 (Secondary) 9 (Tertiary)

SE STATUS

1. How many brothers and sisters does this child have?
0 1 2 3 4 5 6 7 8 9 10 11 12 >12
2. How many people live under the same roof as this child?
0 1 2 3 4 5 6 7 8 9 10 11 12 >12
3. What type of roof do you have?
1. Other 2. Thatch 3. Iron sheets 4. Tile
4. What kind of water supply do you have?
1. Carried in jerry can to home 2. Water source near home 3. Running water
5. What kind of cooking fuel do you use?
1. Firewood 2. Charcoal 3. Paraffin 4. Gas/Electricity
6. Does the family eat meat at least once a week? 1 Y 2 N
7. Does the family have food all year round? 1 Y 2 N
8. Which of the following items are owned by you or found in your home?

Circle the number if the family has the item; put an X through if not.

Add circled values for total.

Item	Score	Item	Score
Electricity	3	Bicycle	1
Shoes for subject	1	Motorcycle	2
Radio	1	Motor vehicle	3
Television	2	Cows (>2)	2
TOTAL			

MIGRATION

Village/Town District

In which village/town was the subject born?

In which village/town has the child lived for most of his/her life?

In which village/town did the subject usually live for the past 12 months

Appendix F. Child Assent Form

Study number: _____

Foomu y'okukiriza kw'omwana

Today's date	<input type="text"/>	Hospital	
Child's first name		Child's surname	Father's surname

Anonyereza ajja kusomera omwana foomu eno ku lunaku omwana lw'anasooka okulabibwa mu kunonyereza ku ddwaliro lya ChildHealth Advocacy International e Kayunga.

Tuli mukukola okunonyereza mu baana abagya ku ddwaliro lino. Abamu ku baana bano balina obuzibu mu kujukira, okufaayo, n'okuyiga. Twagala wetabe mu kunonyereza kwaffe n'abaana abalala abagya ku ddwaliro lino, tweyongere okuzuula ebikwata ku busobozi bwo okujukira, okusayo omwoyo, n'okuyiga. Twagala n'okugezesa emizannyo egiwagala obwongo tulabe oba giyamba okujukira, okufaayo, n'okuyiga mu baana. Okuzuula ebintu bino, abaana abamu tujja kubazanyisa emizanyo, abalala tetujja. Oluvanyuma tujja kugerageranya obusobozi bwabwe tulabe oba waliwo enjawulo wakati w'abaana abazanye emizanyo n'abatazanye.

Tokakibwa kubeera mu kunoonyereza kuno singa toyagala. Wadde nga toli mu kunonyereza kuno, oja kusobola okufuna obuyambi nga bulijjo. Tetugya kunyigira oba okubonereza singa toyagala kuzannya mizannyo gino. Bwonoba okiriza okwetaba mu kunonyereza kuno, omusawo ajja kukebera okulaba embeera mw'oli. Oluvanyuma ojja kuzannya emizannyo egigezesa embeera y'okujukira kwo, okufaayo n'okuyiga mu ssomero. Oluvanyuma lw'emizannyo gino, ojja kutekebwa mu kibinja ekifuna emizannyo egiwagala obwongo oba ekitafuna. Singa oggwa mu kibinja ekizannya emizannyo, ojja kugizannya buli wiiki, naye oli waddembe okutegeza omusawo singa owulira nga toyagala kugenda maaso na mizannyo gino. Singa oggwa mu kibinja ekirala, tojja kuzannya mizannyo gino egyabuli wiiki.

Ekituzaamu emizanyo gino kwekulaba embeera y'obusobozi bw'okujukira kwo, okufaayo, n'okuyiga bweri oluvanyuma lw'emyezi ebiri. Byonna byetunakola tojja kulumizibwa ate n'ebibuuzo tebiringa bya ku ssomero nti oyita oba ogwa. Tetugya kubulira muntu yenna bwewakoze.

Tumaze okwogera n'abazadde bo ku kunoonyereza kuno. Nawe osobola okwogera nabo olabe kyebaloozoza.

Ojja kuganyulwa mu kunonyereza kuno kubanga emizannyo gy'ogenda okuzannya giyinda okuyamba okujukira, okufaayo n'okuyiga, obulungi. Ojja kuyingira mu kunonyereza kuno singa osaza ku ka bokisi akaliko 'yee' wamanga.

Study number _____

Okiriza okwetaba mu kunonyereza kwaffe?

Yee (YES)

Needa (NO)

Simanyi (Not Sure)

Ngumikirizako (Need more time)

Singa oyagala okubeera mu kunoonyereza kwaffe, wandiika erinya lyo wansi wano.

Erinya ly'omwana (Nnukuta enene)

Ennaku z'omwezi

Erinya ly'omwana (omukono oba akabonero k'okukiriza)

Erinya ly'akoze ku foomu

Omukono gw'akoze ku foomu

Ennaku z'omwezi

To be signed by witness:

Omwana ebiwandiikibwa waggulu bimusomeddwa era n'akiriza okwetaba mukunonyereza kuno

Erinya ly'omujulizi

Omukono gw'omujulizi

Ennaku z'omwezi

Erinya ly'anoonyereza

Omukono gw'anoonyereza

Ennaku z'omwezi

REFERENCES

References

- Achenbach, T. M., Becher, A., Dopfner, M., Heiervang, E., Roessner, V., Steinhausen, H. C., et al. (2008). Multicultural assessment of child and adolescent psychopathology with ASEBA and SDQ instruments: research findings, applications, and future directions. *Journal of Child Psychology and Psychiatry, 49*, 251-275.
- Achenbach, T. M., & Rescorla, L. A. (2001). Manual for the ASEBA School-Age Forms & Profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.
- Achenbach, T. M., & Rescorla, L. A. (2007a). Multicultural Guide for the ASEBA School-Age Forms & Profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.
- Achenbach, T. M., & Rescorla, L. A. (2007b). Multicultural Supplement to the Manual for the ASEBA School-Age Forms & Profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.
- Armstrong, F. D., Seidel, J. F., & Swales, T. P. (1993). Pediatric HIV infection: A neuropsychological and educational challenge. *Journal of Learning Disabilities, 26*, 92-103.
- Atwine, B., Cantor-Graae, E., & Bajunirwe, F. (2005). Psychological distress among AIDS orphans in rural Uganda. *Social Science Medicine, 61*, 555-564.
- Bachanas, P. J., Kullgren, K. A., Suzman Schwarz, K., Lanier, B., McDaniel, S., Smith J., et al. (2001). Predictors of psychological adjustment in school-age children infected with HIV. *Journal of Pediatric Psychology, 26*, 343-352.
- Bagenda, D., Nassali, A., Kalyesubula, I., Sherman, B., Drotar, D., Boivin, M. J., et al. (2006). Health, neurologic, and cognitive status of HIV-infected, long-surviving, and antiretroviral-naive Ugandan children. *Pediatrics, 117*, 729-740.
- Bain, S. K., & Gray, R. (2008). Test Reviews: Kaufman, A. S., & Kaufman, N. L. (2004). Kaufman Assessment Battery for Children, Second edition. Circle Pines, MN: AGS. *Journal of Psychoeducational Assessment, 26*, 92-101.
- Bangirana, P., Musisi, S., Allebeck, P., Giordani, B., John, C. C., Opoka, R. O., et al. (2009). A preliminary examination of the construct validity of the KABC-II in Ugandan children with a history of cerebral malaria. *African Health Sciences, 19*, 186-192.
- Bateganya, F. H., Kyomuhendo, S., Jagwe-Wadda, G., & Opesen, C. C. (2008). Male involvement in Uganda: Challenges and opportunities. In Foller, M. L., & Thorn, Hakan (Eds.). *The politics of AIDS: Globalization, the state and civil society (pp. 123-138)*. New York, NY: Palgrave Macmillan.

- Berube, R. L., & Achenbach, T. M. (2007). *Bibliography of published studies using the Achenbach System of Empirically Based Assessment (ASEBA): 2007 edition*. Burlington, VT: University of Vermont, Research Center for Children, Youths, and Families.
- Bikaako-Kajura, W., Luyirika, E., Purcell, D. W., Downing, J., Kaharuzza, F., & Mermin, J., et al. (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV infected children in Uganda. *AIDS and Behavior, 10*, s85-s93.
- Bing, E. G., & Cheng, K. G. (2008). HIV/AIDS in sub-Saharan Africa: Using a comprehensive approach to tackle an epidemic. In Omwami, E. M., Commins, S., & Keller, E. J. (Eds.). *HIV/AIDS in Africa: Challenges and impact* (pp. 53-74). Trenton, NJ: Africa World Press, Inc.
- Blanchette, N., Smith, M. L., King, S., Fernandes-Penney, A., & Reed, S. (2002). Cognitive development in school age children with vertically transmitted HIV infection. *Developmental Neuropsychology, 21*, 223-241.
- Boivin, M. J. (2002). Effects of early cerebral malaria on cognitive ability in Senegalese children. *Journal of Developmental Behavioral Pediatrics, 23*, 353-364.
- Boivin, M. J., Bangirana, P., Byarugaba, J., Opoka, R. O., Idro, R., Jurek, A. M. et al. (2007). Cognitive impairment after cerebral malaria in children: A prospective study. *Pediatrics, 119*, e360-366.
- Boivin, M. J., Busman, R. A., Parikh, S. M., Page, C. F., Opoka, R. O., & Giordani, B. (2010). A pilot study of the neuropsychological benefits of computerized cognitive rehabilitation in Ugandan children with HIV. *Neuropsychology, 24*, 667-673.
- Boivin, M. J. & Giordani, B. (1993). Improvements in cognitive performance for schoolchildren in Zaire, Africa, following an iron supplement and treatment for intestinal parasites. *Journal of Pediatric Psychology, 18*, 249-264.
- Boivin, M. J., Giordani, B., & Bornefeld, B. (1995). Use of the Tactual Performance Test for cognitive ability testing with African children. *Neuropsychology, 9*, 409-417.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Brown, L. K., Lourie, K. J., & Pao, M. (2000). Children and adolescents living with HIV and AIDS: A review. *Journal of Child Psychology and Psychiatry, 41*, 81-96.
- Boyden, J., & Mann, G. (2005). Children's risk, resilience, and coping in extreme situations. In Ungar, M. (Ed.) *Handbook for working with children and youth: Pathways to resilience across cultures and contexts*. (pp. 247-262). Thousand Oaks, California: Sage Publications, Inc.

- Captain's Log Brain Train. (2007). Retrieved May 24, 2007 from http://www.braintrain.com/professionals/captains_log/captainslog_pro.htm
- Carter, S. L., Rourke, S. B., Murji, S., Shore, D., & Rourke, B. P. (2003). Cognitive complaints, depression, medical symptoms, and their association with neuropsychological functioning in HIV infection: A structural equation model analysis. *Neuropsychology, 17*, 410-419.
- Castro, K.G., Ward, J.W., Slutsker, L., Buehler, J.W., Jaffe, H.W., Berkelman, R.L. (1992). 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. *Morbidity and Mortality Weekly Report, 41*, RR-17.
- Chandra, P. S., Satyanarayana, V. A., Satishchandra, P., Satish, K. S., & Kumar, M. (2009). Do men and women with HIV differ in their quality of life? A study from South India. *AIDS and Behavior, 13*, 110-117.
- Chaplowe, S. G., & Engo-Tjega, R. B. (2008). The role of communities & civil society organizations in response to sub-Saharan Africa's AIDS epidemic. In Omwami, E. M., Commins, S., & Keller, E. J. (Eds.). *HIV/AIDS in Africa: Challenges and impact* (pp. 97-144). Trenton, NJ: Africa World Press, Inc.
- Childhealth Advocacy International: Improving maternal and child healthcare worldwide. Projects Uganda. Retrieved September 12 2008, from <http://www.childadvocacyinternational.co.uk/projects/uganda.htm>
- Cohen, J., Reddington, C., Jacobs, D., Meade, R., Picard, D., Singleton, K., et al. (1997). School-related issues among HIV-infected children. *Pediatrics, 100*, e8.
- Compas, B. E., Banez, G. A., Malcarne, V., & Worsham, N. (1991). Perceived control and coping with stress: A developmental perspective. *Journal of Social Issues, 47*, 23-34.
- Cook, J., Cohen, M., Burke, J., Grey, D., Anastos, K., Kirstein, L., et al. (2002). Effects of depressive symptoms and mental health quality of life on use of highly active antirviral therapy among HIV-seropositive women. *Journal of Acquired Immune Deficiency Syndromes, 30*, 401-409.
- Cook, P., & Toit, L. D. (2005). Overcoming adversity with children affected by HIV/AIDS in the indigenous south African cultural context. In Ungar, M. (Ed.) *Handbook for working with children and youth: Pathways to resilience across cultures and contexts*. (pp. 247-262). Thousand Oaks, California: Sage Publications, Inc.
- Cysique, L. A., Jin, H., Franklin, J., Morgan, E. E., Shi, C., Yu, X., et al., (2007). Neurobehavioral effects of HIV-1 infection in China and the United States: A pilot study. *Journal of the International Neuropsychological Society, 13*, 781-790.

- Dawes, A., Bray, R., VanDerMerwe, R. B., & VanDerMerwe, A. (Eds.). (2007). *Monitoring child well-being: A south African rights-based approach*. Cape Town, South Africa: HSRC Press.
- Earls, F., Raviola, G. J., & Carlson, M. (2008). Promoting child and adolescent mental health in the context of the HIV/AIDS pandemic with a focus on sub-Saharan Africa. *Journal of Child Psychology and Psychiatry*, *49*, 295-312.
- Engel, R. G., & Melamed, B., G. (2002). Stress and Coping in Children at Risk for Medical Problems. In Hayman, L., L., Mahon, M., M., Turner, J., R. (Eds.), *Chronic Illness in Children: An Evidence-Based Approach* (pp. 171-198). New York, NY: Springer Publishing Company, Inc.
- Franklin, S., Lim, H. J., & Havens, P. L. (2007). Longitudinal Behavioral and Academic Adjustment in Children with HIV Infection. *Journal of Clinical Psychology in Medical Settings*, *14*, 335-343.
- Gershon, A., A., Hotez, P., J., & Katz, S., L. (Eds.). (2004). *Krugman's Infectious Diseases of Children (11th Edition)*. Philadelphia, Pennsylvania: Mosby.
- Giordani, B., Boivin, M. J., Opel, B., Dia Nseyila, D. N., & Lauer, R. E. (1996). Use of the K-ABC with children in Zaire, Africa: An evaluation of the sequential-simultaneous processing distinction within an intercultural context. *International Journal of Disability, Development and Education*, *43*, 5-24.
- Gray, G., McIntyre, J., Newell, M. L. (2000). HIV-1 infection. In Newell, M. L., & McIntyre, J. (Eds.). *Congenital and perinatal infections: Prevention, diagnosis, and treatment* (pp. 232-257). Cambridge, UK: Cambridge University Press.
- Hochhauser, C. J., Gaur, S., Marone, R., & Lewis, M. (2008). The impact of environmental risk factors on HIV-associated cognitive decline in children. *AIDS Care*, *20*, 692-699.
- Hodge, M. (2008). HIV/AIDS, demographics and economic development. In Omwami, E. M., Commins, S., & Keller, E. J. (Eds.). *HIV/AIDS in Africa: Challenges and impact* (pp. 7-26). Trenton, NJ: Africa World Press, Inc.
- Imam, I., (2007). Neuological manifestation of HIV infection in Nigerians. *African Journal of AIDS Research*, *6*, 187-192.
- John, G. C., & Kreiss, J. (1996). Mother-to-child transmission of human immunodeficiency virus type 1. *Epidemiologic Reviews*, *18*, 149-157.
- Jones, S. A., Sherman, G. G., & Varga, C.A. (2005). Exploring socio-economic conditions and poor follow-up rates of HIV-exposed infants in Johannesburg, South Africa. *AIDS Care*, *17*, 466-470.

- Joseph, J. M. (1994). *The resilient child: Preparing today's youth for tomorrow's world*. New York, NY: Plenum Press.
- Junqueira, P., Bellucci, S., Rossini, S., Reimao, R. (2008). Women living with HIV/AIDS: Sleep impairment, anxiety and depression symptoms. *Arquivos de Neuro-Psiquiatria*, 66, 817-820.
- Kaufman, A. S., & Kaufman, N. L. (2004). *Kaufman Assessment Battery for Children, Second edition*. Circle Pines, MN: AGS.
- Kilbride, P. L., & Kilbride, J. C. (1990). *Changing family life in East Africa: Women and children at risk*. University Park, PA: Pennsylvania State University Press.
- Kirumira, E. (2008). Multi-sectoral response to HIV/AIDS in the context of global funding: Experiences from Uganda. In Foller, M. L., & Thorn, Hakan (Eds.). *The politics of AIDS: Globalization, the state and civil society* (pp. 87-96). New York, NY: Palgrave Macmillan.
- Kiwanuka, N., Laeyendecker, O., Robb, M., Kigozi, G., Arroyo, M., & McCutchan, F., et al. (2008). Effect of human immunodeficiency virus type 1 (HIV-1) subtype on disease progression in persons from Rakai, Uganda, with incident HIV-1 Infection. *Journal of Infectious Diseases*, 197, 707-713.
- Knight, W.G., Mellins, C.A., Levenson, R.L., Jr., Arpadi, S.M., & Kairam, R. (2000). Brief report: Effects of pediatric HIV infection on mental and psychomotor development. *Journal of Pediatric Psychology*, 25, 583-587.
- Koekkoek, S., de Sonnevile, L. M. J., Wolfs, T. F. W., Licht, R., & Greenen, S. P. M. (2008). Neurocognitive function profile in HIV-infected school-age children. *European Journal of Paediatric Neurology*, 12, 290-297.
- Kutner, M. H., Nachtsheim, C. J., Neter, J., and Li, W. (2004). *Applied Linear Statistical Models*. McGraw-Hill/Irwin, 5th edition.
- Landau, S., & Pryor, J.B. (1995). Pediatric HIV: School-based sequelae and curricular interventions for infection prevention and social acceptance. *School Psychology Review*, 24, 213-230.
- Liebenberg, L., & Ungar, M. (Eds.). (2008). *Resilience in action: Working with youth across cultures and contexts*. Toronto, Canada: University of Toronto Press.
- Little, K. Thorne, C., Luo, C., Bunders, M., Ngongo, N., McDermott, P., et al. (2007). Disease progression in children with vertically-acquired HIV infection in sub-Saharan Africa: Reviewing the need for HIV treatment. *Current HIV Research*, 5, 139-153.
- Loveland, K. A., Stenhhens, J. A., Mahoney, E. M., Sirois, P. A., Nichols, S., Bourdeaux, J. D., et al. (2000). Declining immune function in children and adolescents with hemophilia

and HIV infection: Effects on neuropsychological performance. *Journal of Pediatric Psychology*, 25, 309-322.

- Mangione, C., Landau, S. & Pryor, J. B. (1998). HIV and AIDS (pediatric and adolescent). In L. Phelps (Ed.), *Health-related disorders in children and adolescents. A guidebook for understanding and educating* (pp. 328-336). Washington, DC: American Psychological Association.
- Masten, A. (2006). Developmental psychopathology: pathways to the future. *International Journal of Behavioral Development*, 30, 47-54.
- McArthur, J. C., Brew, B. J., Nath, A. (2005). Neurological complications of HIV infection. *Lancet Neurology*, 4, 543-555.
- Mellins, C. A., Smith, R., O'Driscoll, P., Lawrence, M. S., Brouwers, P., & Chase, C., et al. (2003). High rates of behavioral problems in perinatally HIV-infected children are not linked to HIV disease. *Pediatrics*, 111, 384-393.
- Melrose, R. J., Tinaz, S., Castelo, J. M. B., Courtney, M. G., Stern, C. E., (2008). Compromised fronto-striatal functioning in HIV: An fMRI investigation of semantic event sequencing. *Behavioural Brain Research*, 188, 337-347.
- Mialky, E., Bagnoni, J., & Rutstein, R. (2001). School-age children with perinatally acquired HIV infection: Medical and psychosocial issues in a Philadelphia cohort. *AIDS Patient Care and STDs*, 15, 575-579.
- Misdrahi, D., Vila, G., Funk-Brentano, I., Tardieu, M., Blanche, S., & Mouren-Simeoni, M. C. (2004). DSM-IV mental disorders and neurological complications in children and adolescents with human immunodeficiency virus type 1 infection (HiV-1). *European Psychiatry*, 19, 182-184.
- Mrus, J. M., Williams, P. L., Tsevat, J., Cohen, S. E., & Wu A. W. (2005). Gender differences in health-related quality of life in patients with HIV/AIDS. *Quality of Life Research*, 14, 479-491.
- Nakiyingi, J. S., Bracher, M. Whitworth, J. A. G., Ruberantwari, A., Busingye, J., Mbulaiteye, S. M., et al. (2003). Child survival in relation to mother's HIV infection and survival: evidence form a Ugandan cohort study. *AIDS*, 17, 1827-1834.
- NIAID (2004). HIV infection in infants and children. Retrieved April 26, 2008 from <http://www.niaid.nih.gov/factsheets/hivchildren.htm>
- Nyesigomwe, L. (2006). Strengthening the capacity of grandparents in providing care to young children affected by HIV/AIDS. *Journal of Intergenerational Relationships*, 4, 55-63.
- O'Hare, B. A. M., Venables, J., Nalubeg, F., Nakakeeto, M., Kibirige, M., & Southall, D.

- P. (2005). Home-based care for orphaned children infected with HIV/AIDS in Uganda. *AIDS Care*, *17*, 443-450.
- Owens, E. B., & Shaw, D. S. (2003). Poverty and early childhood adjustment. In Luthar, S. S. (Eds.), *Resilience and vulnerability: Adaptation in the context of childhood adversities* (pp.267-292). New York, NY: Cambridge University Press.
- Papola, P., Alvarez, M., & Cohen, H. J. (1994). Developmental and service needs of school-age children with human immunodeficiency virus infection: A descriptive study. *Pediatrics*, *94*, 914-918.
- Patel, K., Herman, M. A., Williams, P. L., Seeger, J. D., McIntosh, K., Vandyke, R. B., et al., (2008). Pediatric AIDS clinical trials group 219/219C Study Team. *Clinical Infectious Disease*, *46*, 507-515.
- Pelton, J., & Forehand, R., (2005). Orphans of the AIDS epidemic: An examination of clinical level problems in children. *Journal of American Academy of Child & Adolescent Psychiatry*, *44*, 585-591.
- Puthanakit, T., Aурpibul, L., Oberdorfer, P., Akarathum, N., Kanjananit, S., Wannarit, P., et al. (2007). Hospitalization and mortality among HIV infected children after receiving highly active antiretroviral therapy. *Clinical Infectious Disease*, *44*, 599-604.
- Richter, L. M., Manegold, J., & Pather, R. (2004). *Family and community interventions for children affected by AIDS*. Cape Town: HSRC Press.
- Ronald A. R., & Sande M. A. (2005). HIV/AIDS care in Africa today. *Clinical Infectious Disease*, *40*, 1045-1048.
- Rouet, G., Sakarovitch, C., Msellati, P., Elenga, N., Montcho, C., Viho, I., et al. (2003). Pediatric viral human immunodeficiency virus type 1 RNA levels, timing of infection, and disease progression in children. *Pediatrics*, *112*, e289-e297.
- Ruzindaza, C. (2001). *Living positively with AIDS: An African experience*. Nairobi, Kenya: Paulines Publications Africa.
- Sacktor, N., Naasujja, N., Skolasky, R. L., Robertson, K., Musisi, S., Ronald, A., et al. (2009). Benefits and risks of stavudine therapy for HIV-associated neurologic complications in Uganda. *Neurology*, *72*, 165-170.
- Sacktor, N., Nakasujja, N., Skolasky, R., Robertson, K., Wong, M., Musisi, S., et al. (2006). Antiretroviral therapy improves cognitive impairments in HIV+ individuals in sub-Saharan Africa. *Neurology*, *67*, 311-314.
- Shanbhag, M. C., Rutstein, R. M., Zaoutis, T., Zhao, H., Chao, D., & Radcliffe, J. (2005). Neurocognitive functioning in pediatric human immunodeficiency virus infection: Effects

- of combined therapy. *Archives of Pediatric and Adolescent Medicine*, 159, 651-656.
- Smith, R., Malee, K., Leighty, R., Brouwers, P., Mellins, C., Hittelman, J., et al. (2006). Effects of perinatal HIV infection and associated risk factors on cognitive development among young children. *Pediatrics*, 117, 851-862.
- Smith, R., A., & Rimal, R., (2009). The impact of social capital on HIV-related actions as mediated by personal and proxy efficacies in Namibia. *AIDS and Behavior*, 13, 133- 144.
- Speigel, H. M. L., & Bonwit, A. M. (2002). HIV infection in children. In M. Batshaw (Ed.), *Children with disabilities*, 5th ed. (123-139). Baltimore, MD: Brookes.
- Taha, T. E., Kumwenda, N. I., Hoover, D. R., Biggar, R. J, Broadhead, R. L., Cassol, S., et al. (2000). Association of HIV-1 load and CD4 lymphocyte count with mortality among untreated African children over one year of age. *AIDS*, 14, 453-459.
- The European Collaborative Study (2001). Fluctuations in symptoms in human immunodeficiency virus-infected children: The first 10 years of life. *Pediatrics*, 108,116-122.
- Thomas, R. B. (1987). Introduction and conceptual framework. In Rose, M. H., & Thomas, R. B. (Eds.) *Children with chronic conditions: Nursing in a family and community context*. (p. 3-12). Orlando, Florida: Grune & Stratton, Inc.
- Thompson, R. J., & Gustafson, K. E. (1996). *Adaptation to chronic childhood illness*. Washington, DC: American Psychological Association.
- UNAIDS (2007). Report on the global AIDS epidemic: Joint United Nations programmes on HIV/AIDS.
- Ungar, M. (2008). Putting resilience theory into action: Five principles for intervention. In Liebenberg, L., & Ungar M. (Eds.) *Resilience in action: Working with youth across cultures and contexts* (pp. 17-36). Toronto, Canada: University of Toronto Press.
- UNICEF (2008). Children and HIV/AIDS. Retrieved April 26, 2008 from <http://www.unicef.org/aids/>
- U. S. Department of Health and Human Services. (1999). *Mental health: A report of the Surgeon General*, Rockville, MD: Author.
- Wachsler-Felder, J. L., & Golden, C. J. (2002). Neuropsychological consequences of HIV in children. A review of current literature. *Clinical Psychology Review*, 22, 441-462.
- Wertlieb, D., Weigel, C., & Feldstein, M. (1987). Measuring children's coping. *American Journal of Orthopsychiatry*, 57, 548-560.

- Whyte, S. R. (1998). Slow cookers and madmen: competence of heart and head in rural Uganda. In Jenkins, R. (Ed). *Questions of competence: Culture, classification and intellectual disability*. Cambridge: Cambridge University Press.
- Wiener, L. S., Battles, H. B., & Heilman, N. (2000). Public disclosure of a child's HIV infection: Impact on children and families. *AIDS patient care and STDs*, 14, 485-497.
- Woodrich, D. L., Swerdlik, M. E., Chenneville, T., & Landau, S. (1999). HIV/AIDS among children and adolescents: Implications for the changing roles of school psychologists. *School Psychology Review*, 28, 228-241.
- Zickler, P. (2009). When the body suffers, the mind suffers. *Monitor on Psychology*, 40, 31-34.